

# THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES PROJECT

**KU** THE UNIVERSITY OF  
**KANSAS**



**STATE OF THE STATES**  
IN INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES

CA DS Taskforce  
October 6, 2022

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Principal Investigator  
Research Associate Professor  
Life Span Institute  
University of Kansas

# Land Acknowledgement

At the University of Kansas, we acknowledge that our institution occupies land that has long been cared for by Indigenous peoples and work to reflect on the history of genocide and the forced removal of people and communities.

At KU we are also taking the time to understand and acknowledge the history that has brought our institution to occupy this space and to understand our institutions' place within that history. Native American and Indigenous peoples are still here as our students, staff, faculty, and partners, and continue to thrive despite ongoing colonialism and oppression.

So, with this acknowledgment:

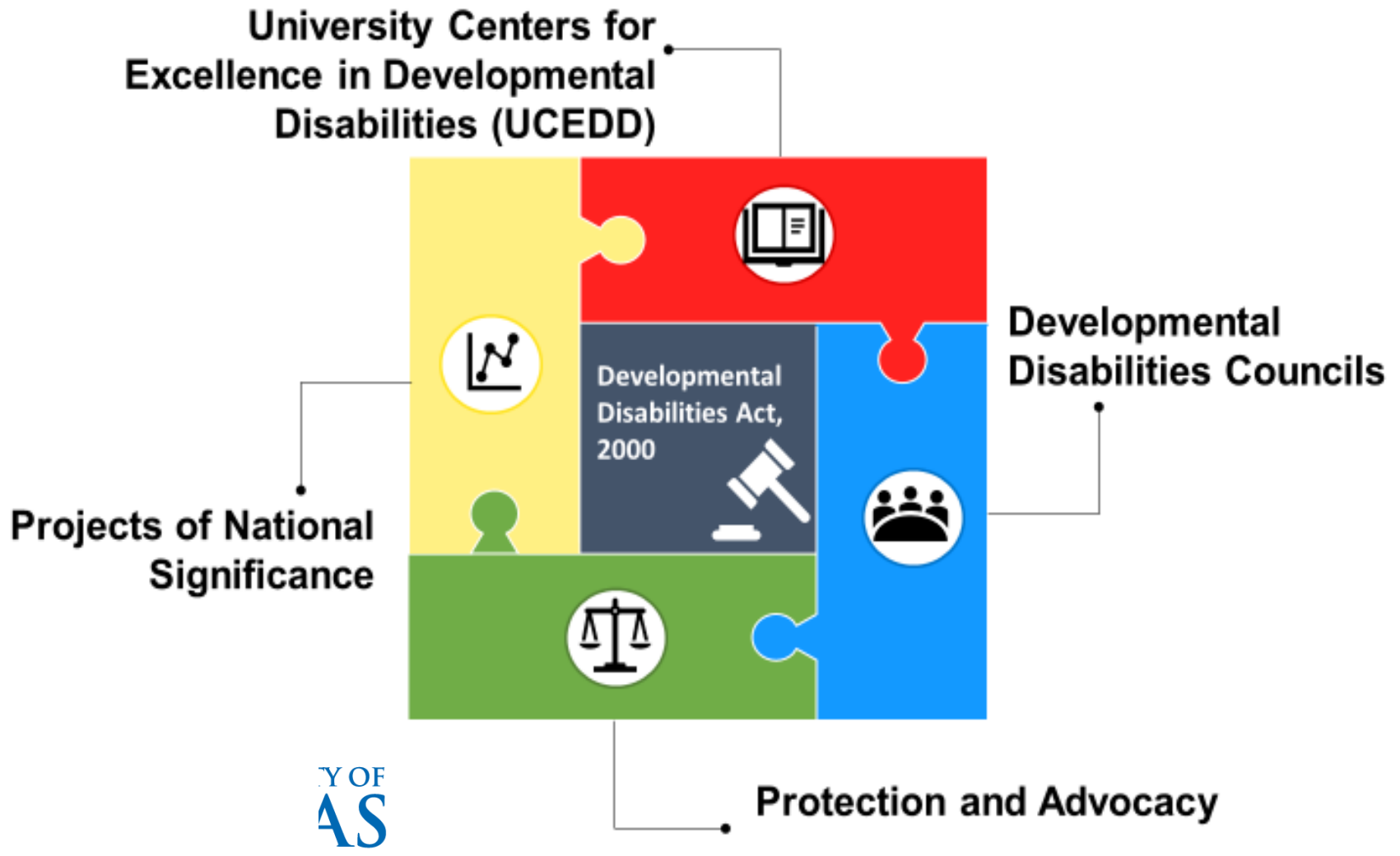
- We affirm sovereignty of the 574 federally recognized tribal nations in the US, 4 of which have reservations in Kansas, the 63 state recognized tribes and the many more tribes who seek recognition.
- And we continue our commitment to support our Native American community and recognize the dynamic contributions Indigenous people make at KU and at our sister institution Haskell Indian Nations University, as well as in our local communities, the state of Kansas, and our country.

# STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (SoS)



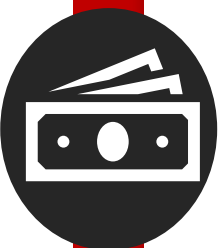
**STATE OF THE STATES**  
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# Developmental Disabilities Assistance and Bill of Rights Act of 2000



Source: Tanis et al., (2022). State of the States in Intellectual and Developmental Disabilities, University of Kansas

# Longitudinal Data Projects and Linkages



State of  
the  
States

Longitudinal trends  
in public spending  
for services and  
supports for people  
with IDD and their  
families

University of  
Kansas



RISP

Longitudinal trends  
in living  
arrangements for  
people with IDD

University of  
Minnesota



StateData.  
info

Longitudinal data on  
day and  
employment  
services

University of  
Massachusetts  
Boston



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Overlapping Data



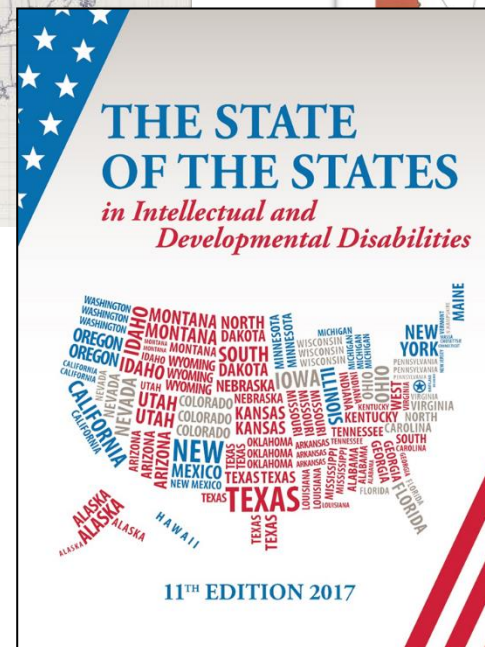
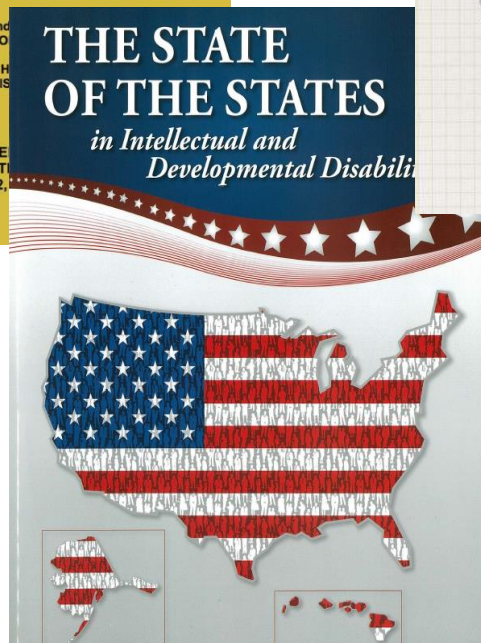
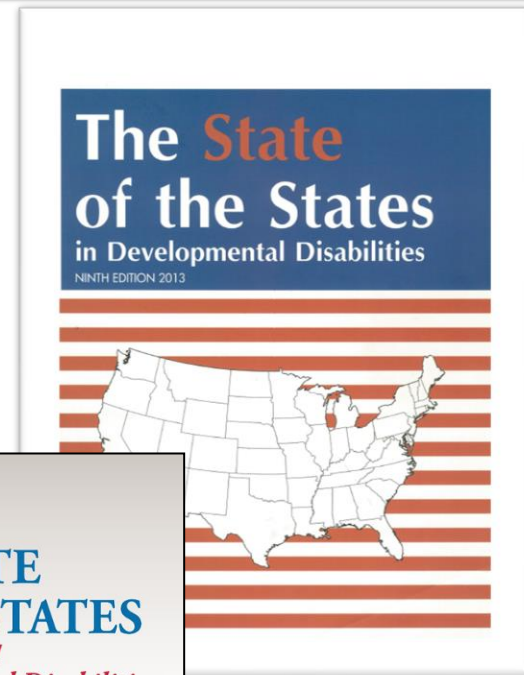
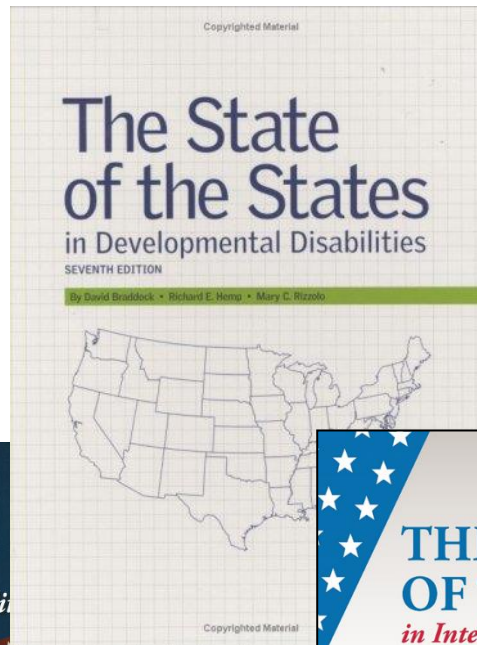
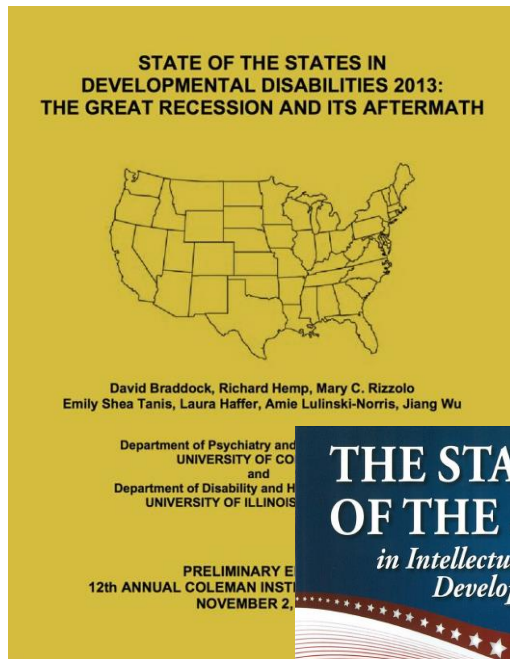
# *30 Years of Community Living*

A joint publication of national data trends in community living over the last 30 years from the Longitudinal Data Projects of National Significance.

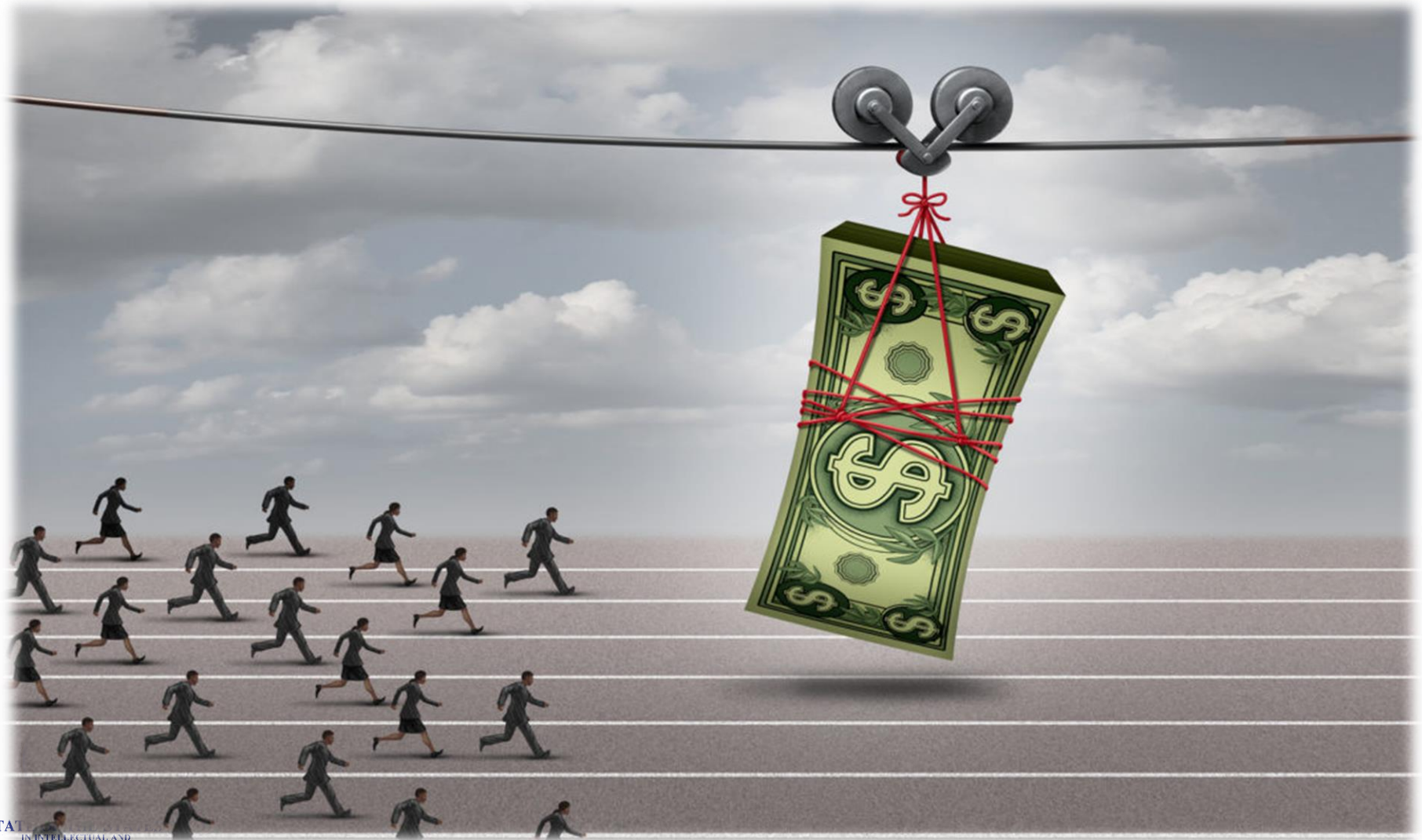
<https://acl.gov/30years>



# Financial and Programmatic Trends in Supports and Services for People with ID/DD



# Key Point: We Follow the Money!

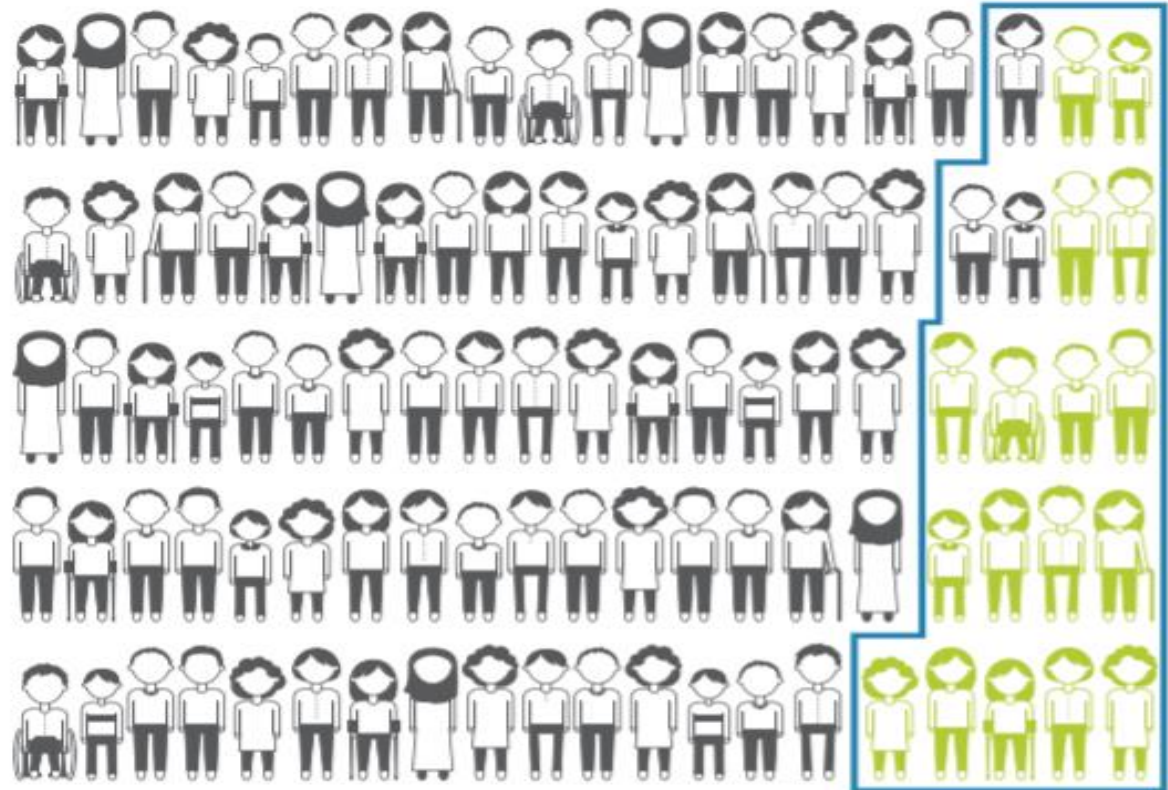




# 20% of People with ID/DD are Known by State ID/DD Agencies



**7.37** million people in the United States had Intellectual or Developmental Disabilities (IDD) in 2016



**20%** 1.49 million people with IDD were known to or served by state IDD agencies

**17%** 1.23 million people with IDD received long-term supports or services through state IDD agencies



# Key Program and Participant Categories in State of the States



## Institutional Settings (16+)

Public & Private ICF/ID  
Nursing Facilities  
Other



## Community and Residential Settings (7-15)

Public & Private ICF/ID  
Other Residential



## Community and Residential Settings (1-6)

Public & Private ICF/ID  
Supported Living  
Personal Assistance  
Family Support  
Other Residential



## Day / Work Program

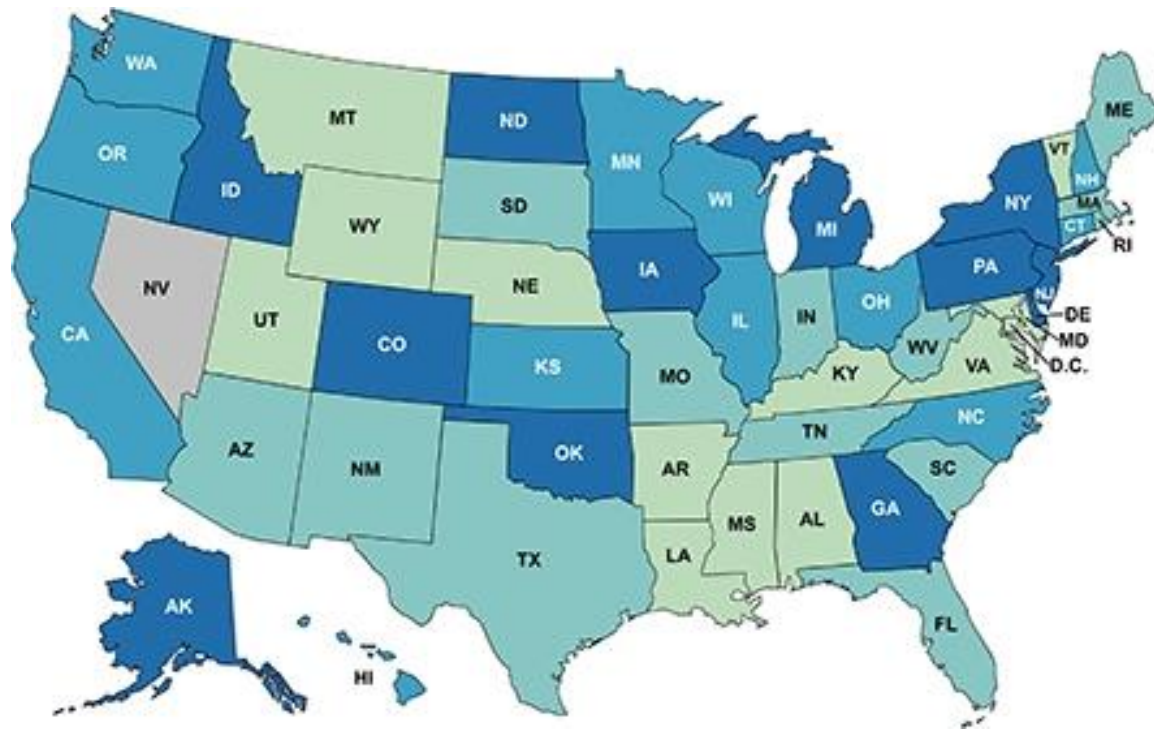
Sheltered Employment/Work Activity  
Day Habilitation  
Supported Employment



## Technology

Smart Homes  
Individual Support Technology  
Remote Supports

# Data Sources



United States<sup>™</sup>  
**Census**  
Bureau



STATE OF THE STATES  
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Source: Tanis et al., (2022). State of the States in Intellectual and Developmental Disabilities, University of Kansas

# Data Cycles

Data collection occurs on biennial basis

Some delays due to COVID

2020-2021 data collection to be in 2022



**Year 2  
Data Dissemination**

Source: Tanis et al., (2022). State of the States in Intellectual and Developmental Disabilities, University of Kansas



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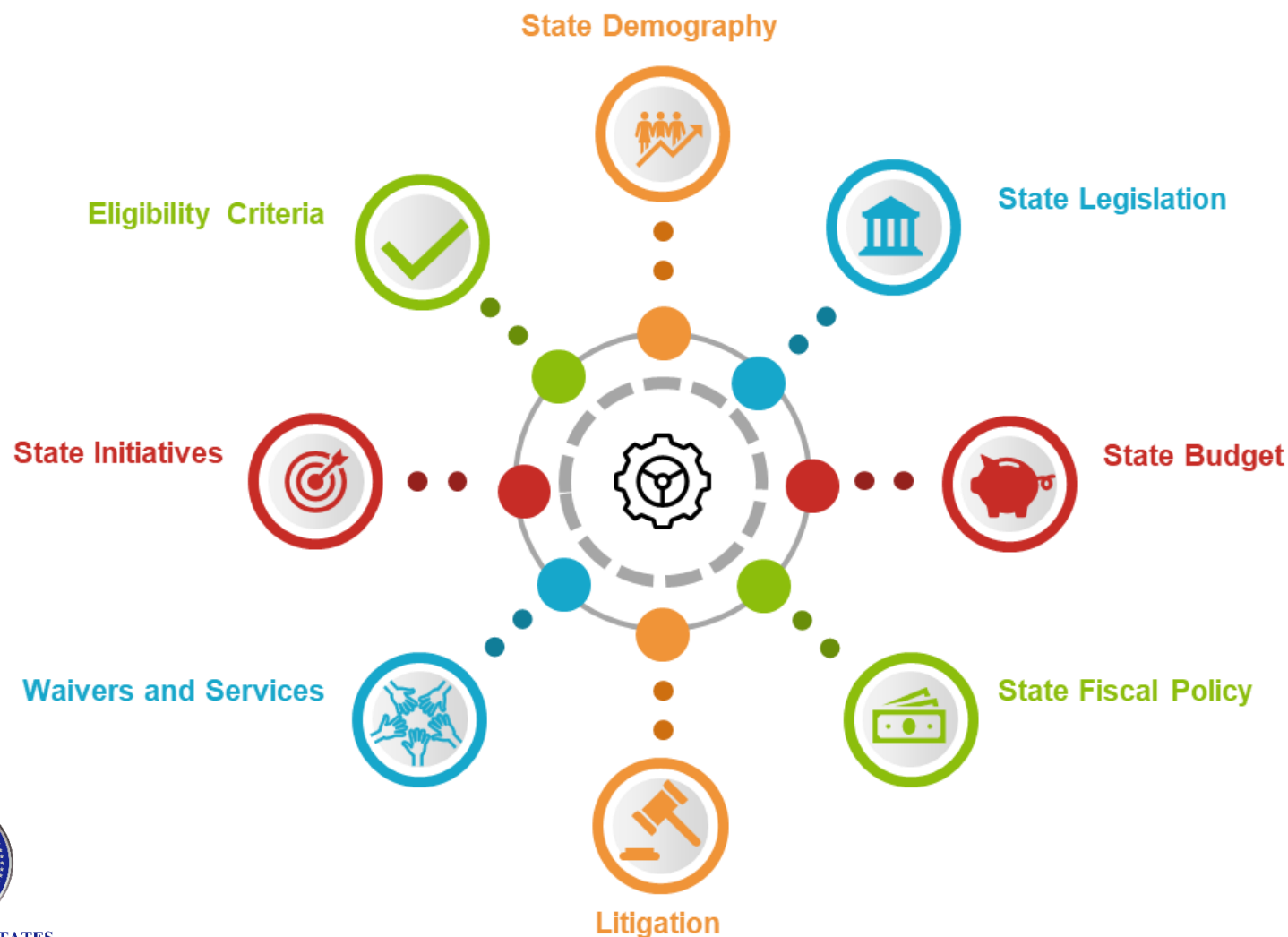
# Limitations of the Data



- Due to the data collection cycle, reporting of *actual* expenditures, and secondary data sources reporting is generally on a 2-year lag
- Statewide data may not be representative of the activities in select areas or programs in a state
- Analyses are only as good as the data systems and reporting
- Difficult to rank and compare states due to diversity and complexity of state political, fiscal, and programmatic variations



# Constellation of State Variables



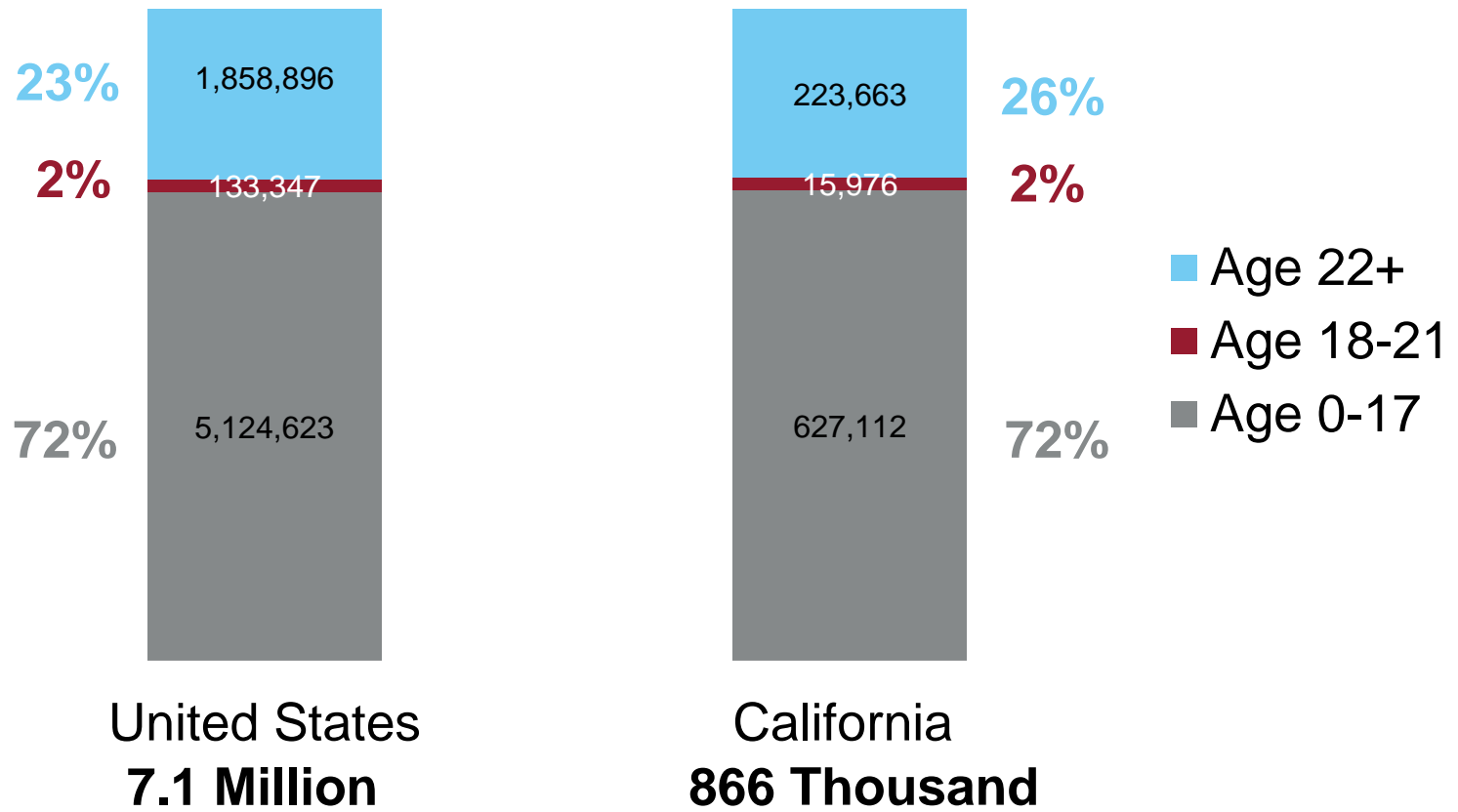
# Presented Data

California  
2018 – 2019

National  
2018 – 2019

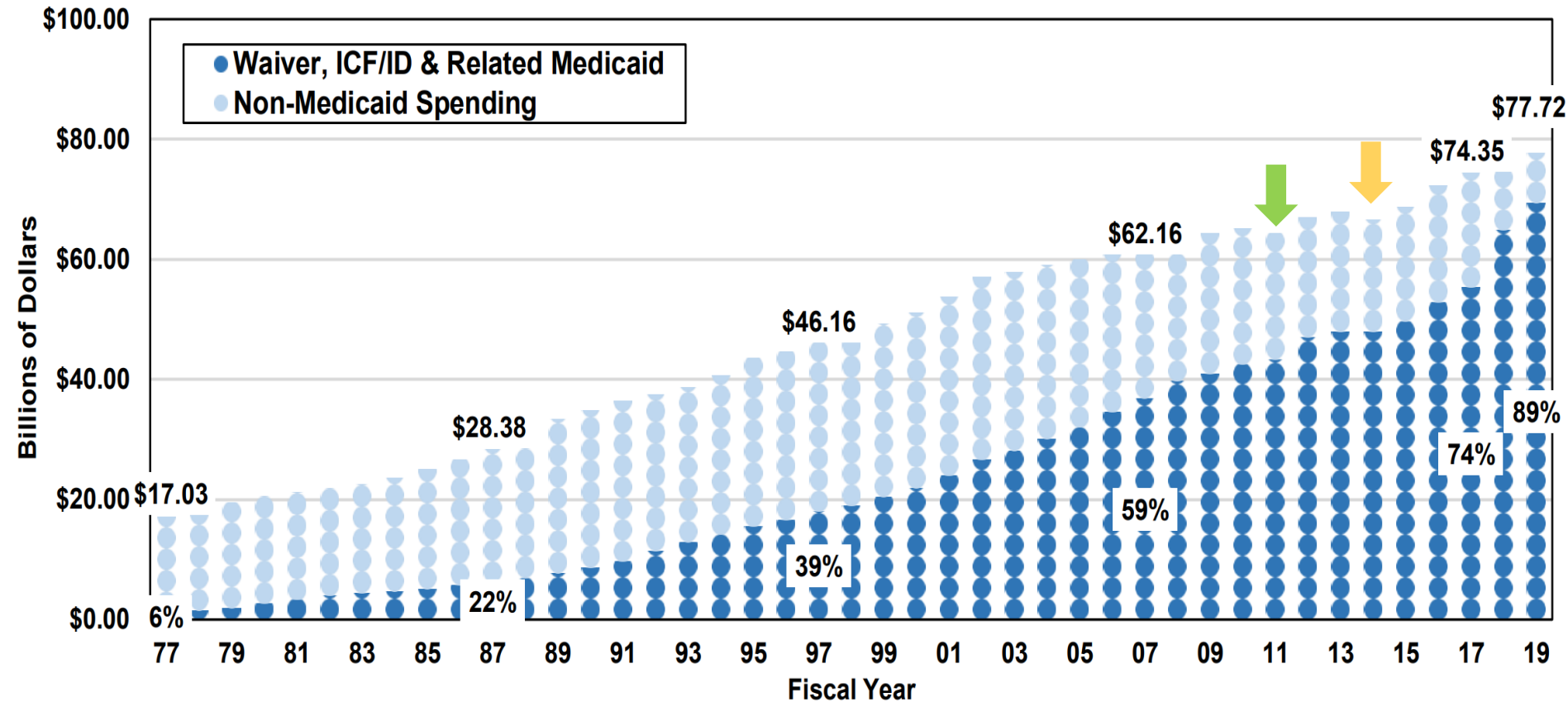


# Prevalence of Intellectual and Developmental Disabilities in California

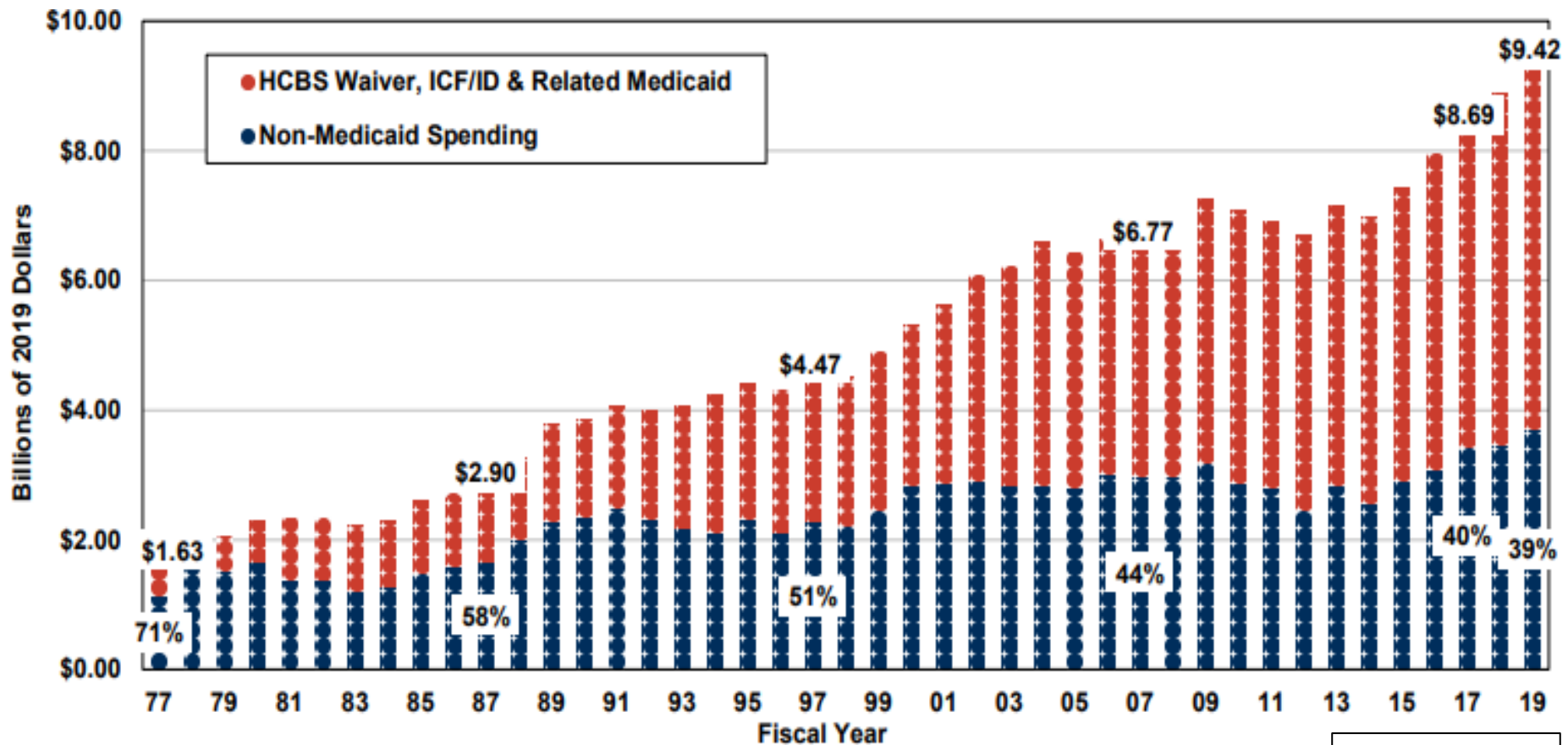




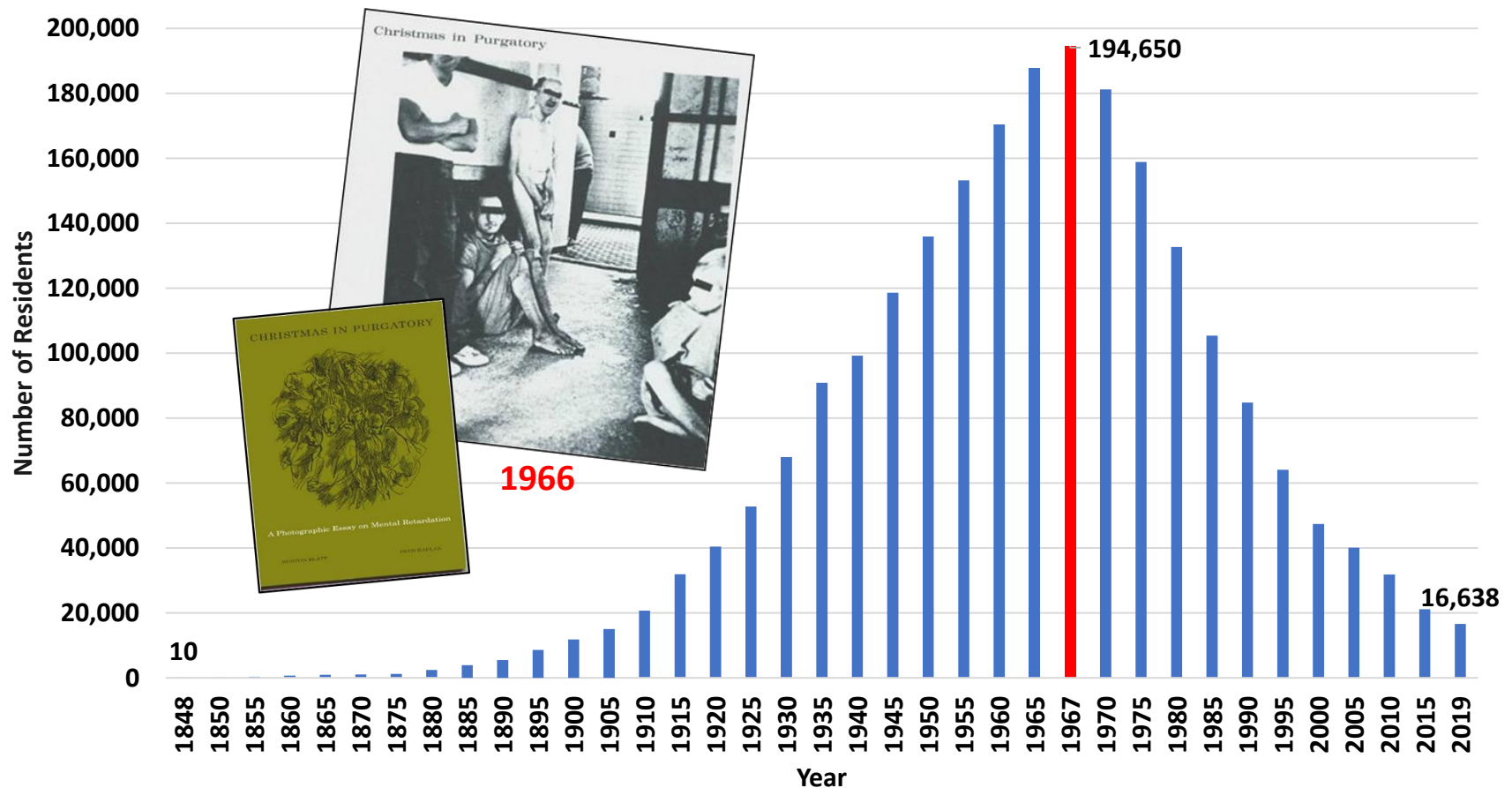
# Total Public ID/DD Spending in the U.S. FYs 1977 – 2019



# Total Public ID/DD Spending in California FYs 1977 – 2019



# Number of People in ICF/ID Institutions in the **U.S.** by Year FYs 1848 – 2019



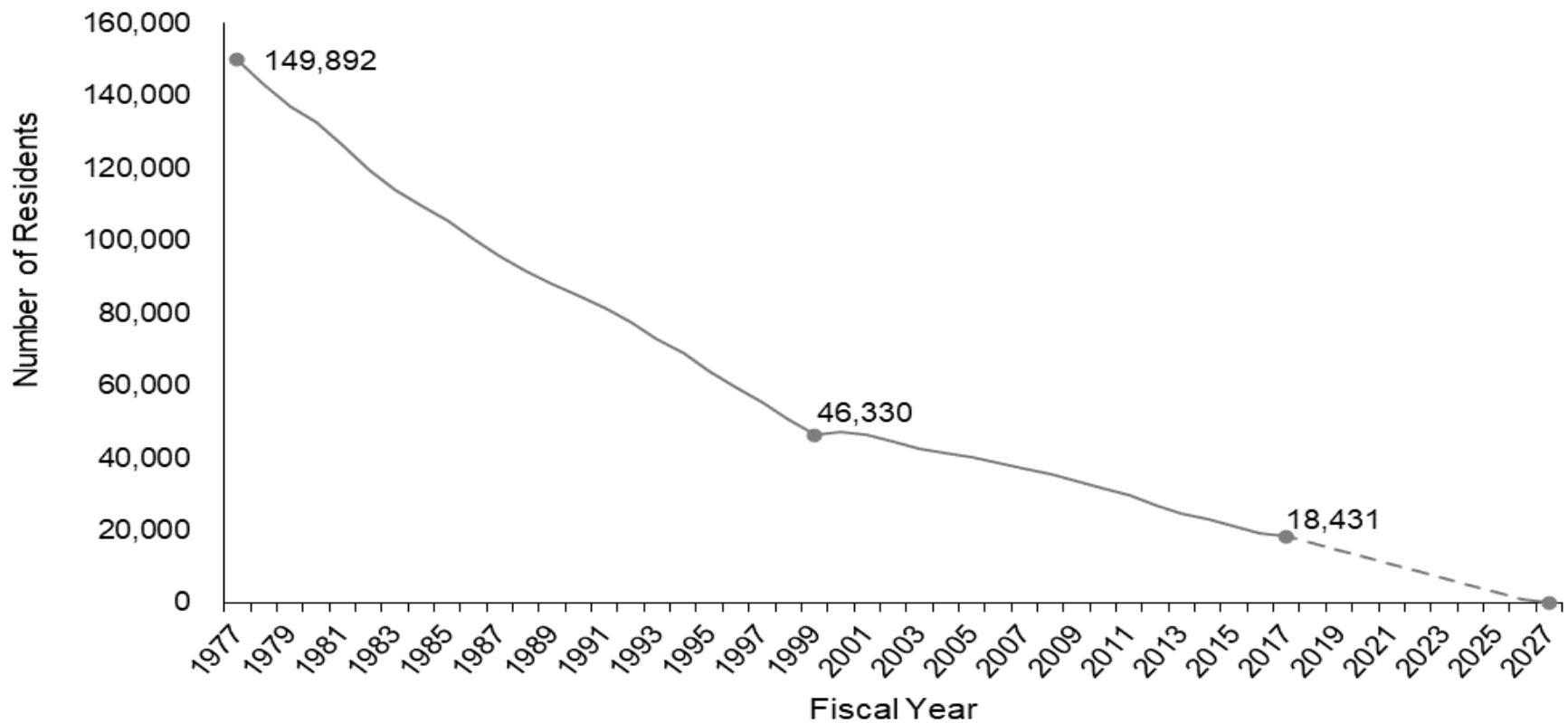
# Smallest ID/DD Public State Institutional Census FY 2019

- 
- #1 Tennessee (10)
  - #2 Idaho (17)
  - #3 Nevada (40)
  - #4 Delaware (49)
  - #5 Oklahoma (50)
  - #6 Wyoming (55)
  - #7 North Dakota (67)
  - #8 Arizona (78)
  - #9 Maryland (93)
  - #10 South Dakota (103)

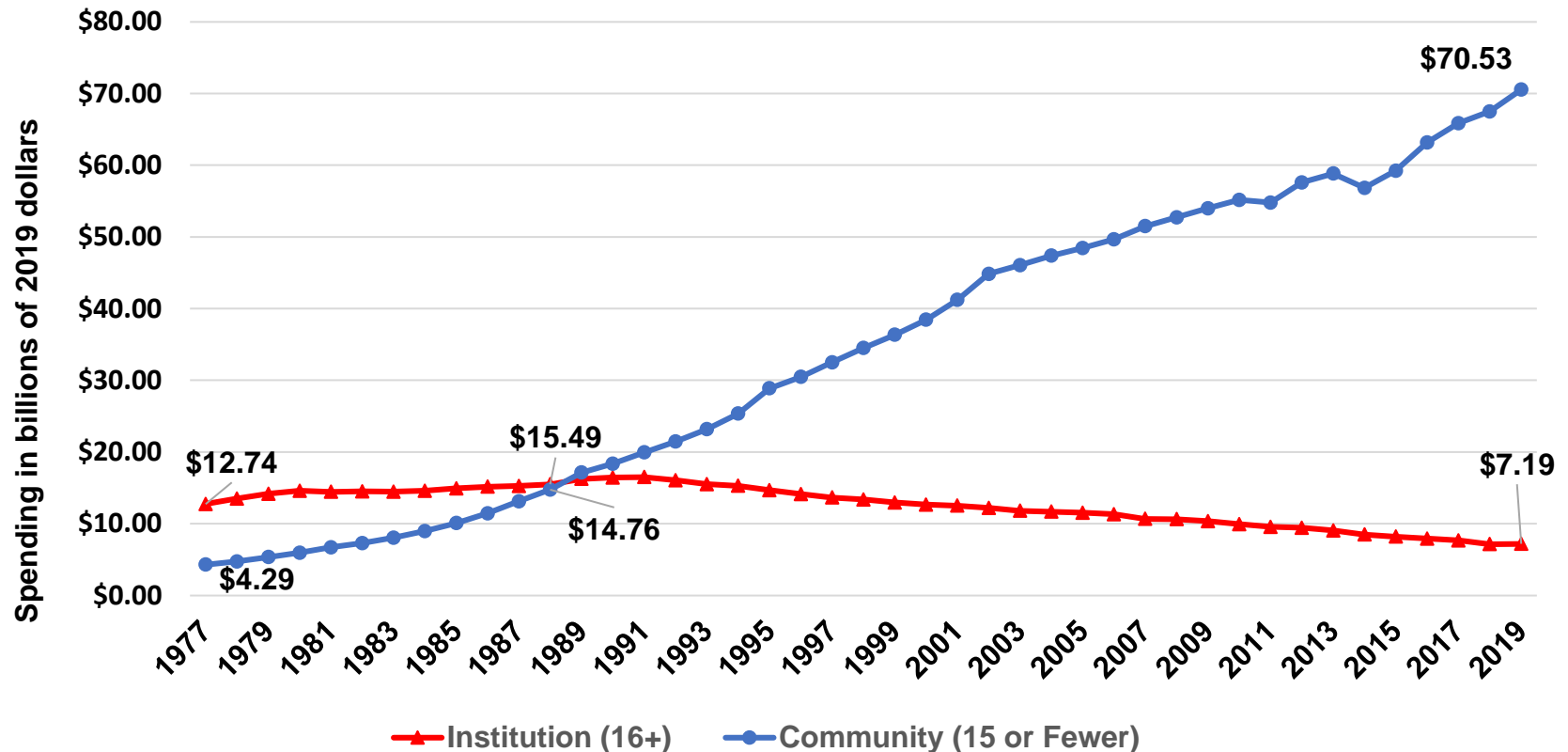




# Forecasted Final Institutional Closure Date in the U.S.



# U.S. Institutional and Community Spending in the U.S. FYs 1977 – 2019



# Out-of-Home Placements in the U.S. FYs 2009 – 2019

	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
<b>TOTAL</b>	<b>571,117</b>	<b>593,192</b>	<b>608,010</b>	<b>621,961</b>	<b>622,721</b>	<b>660,866</b>	<b>669,796</b>	<b>683,600</b>	<b>698,541</b>	<b>715,770</b>	<b>728,565</b>
<b>16+ PERSONS</b>	<b>91,059</b>	<b>86,632</b>	<b>83,836</b>	<b>83,804</b>	<b>76,649</b>	<b>74,409</b>	<b>75,085</b>	<b>72,997</b>	<b>68,387</b>	<b>64,837</b>	<b>62,773</b>
Nursing Facilities	32,164	31,341	31,248	33,418	29,486	29,755	30,595	32,295	29,736	27,977	27,099
State Institutions	33,451	31,494	29,325	26,908	24,392	22,709	20,854	19,580	18,425	17,380	16,638
Private ICF/ID	18,812	18,266	17,770	18,456	18,027	17,585	19,622	18,004	17,439	16,376	16,030
Other Residential	6,631	5,531	5,494	5,022	4,744	4,360	4,015	3,118	2,788	3,104	3,006
<b>7-15 PERSONS</b>	<b>57,389</b>	<b>53,209</b>	<b>53,564</b>	<b>54,201</b>	<b>53,442</b>	<b>52,448</b>	<b>50,008</b>	<b>50,657</b>	<b>50,295</b>	<b>44,835</b>	<b>43,974</b>
Public ICF/ID	1,435	1,407	1,392	1,363	1,337	1,308	1,265	1,354	1,308	1,291	1,241
Private ICF/ID	19,169	19,180	19,351	18,973	18,777	18,079	15,497	15,564	15,333	14,049	13,620
Other Residential	36,785	32,622	32,821	33,865	33,327	33,061	33,246	33,739	33,654	29,495	29,113
<b>≤6 PERSONS</b>	<b>422,670</b>	<b>453,351</b>	<b>470,610</b>	<b>483,956</b>	<b>492,631</b>	<b>534,009</b>	<b>544,703</b>	<b>559,946</b>	<b>579,859</b>	<b>606,098</b>	<b>621,818</b>
Public ICF/ID	350	221	194	211	238	252	266	342	334	296	284
Private ICF/ID	20,063	23,356	22,988	22,833	22,846	23,097	23,112	22,634	23,505	22,882	22,727
Supported Living	238,534	260,289	273,466	273,126	282,950	320,994	333,613	337,352	352,761	367,960	381,333
Other Residential	163,723	169,485	173,961	187,786	186,597	189,666	187,712	199,618	203,259	214,960	217,474



# Out-of-Home Placements in California

## FYs 2009 – 2019

	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
<b>TOTAL</b>	<b>56,686</b>	<b>55,294</b>	<b>55,713</b>	<b>59,379</b>	<b>59,616</b>	<b>60,366</b>	<b>60,899</b>	<b>61,524</b>	<b>61,296</b>	<b>60,428</b>	<b>60,167</b>
<b>16+ PERSONS</b>	<b>5,978</b>	<b>5,501</b>	<b>5,107</b>	<b>5,914</b>	<b>5,397</b>	<b>5,108</b>	<b>4,988</b>	<b>4,972</b>	<b>4,338</b>	<b>3,253</b>	<b>3,020</b>
Nursing Facilities	1,408	1,312	1,241	2,379	2,194	2,225	2,248	2,329	1,943	1,160	1,146
State Institutions	2,194	1,970	1,774	1,584	1,348	1,148	1,011	963	787	512	329
Private ICF/ID	894	804	766	749	771	759	764	744	709	679	660
Other Residential	1,482	1,415	1,326	1,202	1,084	976	965	936	899	902	885
<b>7-15 PERSONS</b>	<b>1,743</b>	<b>1,679</b>	<b>1,632</b>	<b>1,606</b>	<b>1,572</b>	<b>1,607</b>	<b>1,561</b>	<b>1,542</b>	<b>1,504</b>	<b>1,419</b>	<b>1,382</b>
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	412	369	362	363	376	360	342	363	351	357	370
Other Residential	1,331	1,310	1,270	1,243	1,196	1,247	1,219	1,179	1,153	1,062	1,012
<b>≤6 PERSONS</b>	<b>48,965</b>	<b>48,114</b>	<b>48,974</b>	<b>51,859</b>	<b>52,647</b>	<b>53,651</b>	<b>54,350</b>	<b>55,010</b>	<b>55,454</b>	<b>55,756</b>	<b>55,765</b>
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	6,086	6,201	6,211	6,246	6,254	6,280	6,262	6,258	6,213	6,129	5,940
Supported Living	20,521	21,459	22,126	22,797	23,547	24,304	25,004	25,626	26,074	26,489	26,782
Other Residential	22,358	20,454	20,637	22,816	22,846	23,067	23,084	23,126	23,167	23,138	23,043





# Estimated Distribution of People with ID/DD by Living Arrangement in U.S. FY 2019

## PERCENTAGE OF INDIVIDUALS WITH IDD BY LIVING ARRANGEMENT: FY 2019



# Estimated Distribution of People with ID/DD by Living Arrangement in CA FY 2019

## PERCENTAGE OF INDIVIDUALS WITH IDD BY LIVING ARRANGEMENT: FY 2019

Supervised  
Residential Setting

7%



Alone or  
with Roommate

19%



With Family  
Caregiver

74%

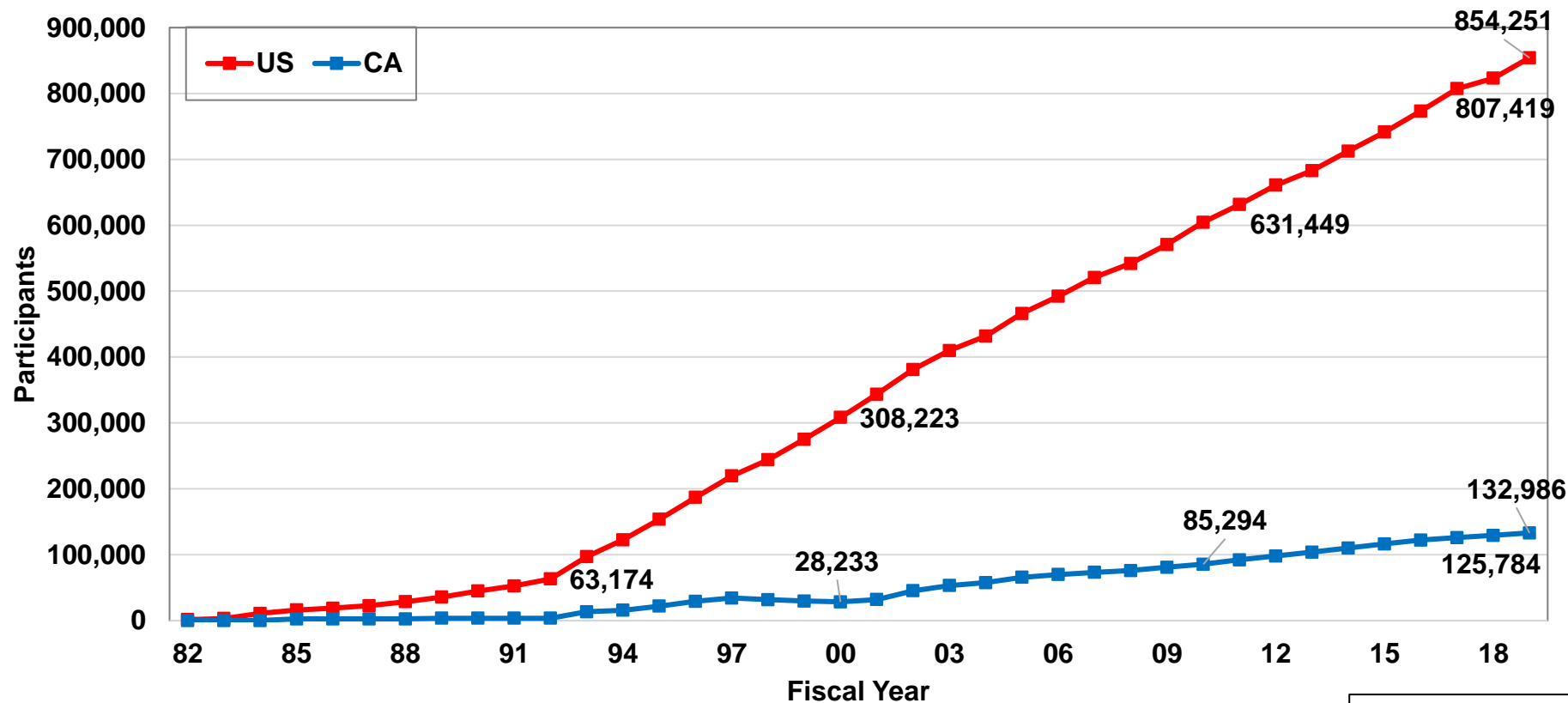


# Growth of the Home and Community-Based Services Waiver

HCBS waivers “waive” certain Medicaid requirements applied to Medicaid nursing or other facilities, thereby making Medicaid funding eligible to those living in home-like and family settings.

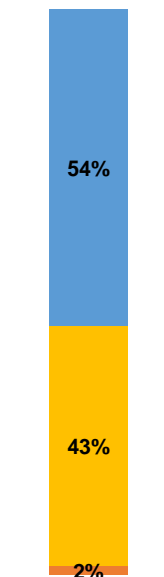


# HCBS Waiver Participants with ID/DD in California and the U.S. FY 1983 - 2019



# Total Public ID/DD Spending By Revenue Source in the U.S. FY 2019

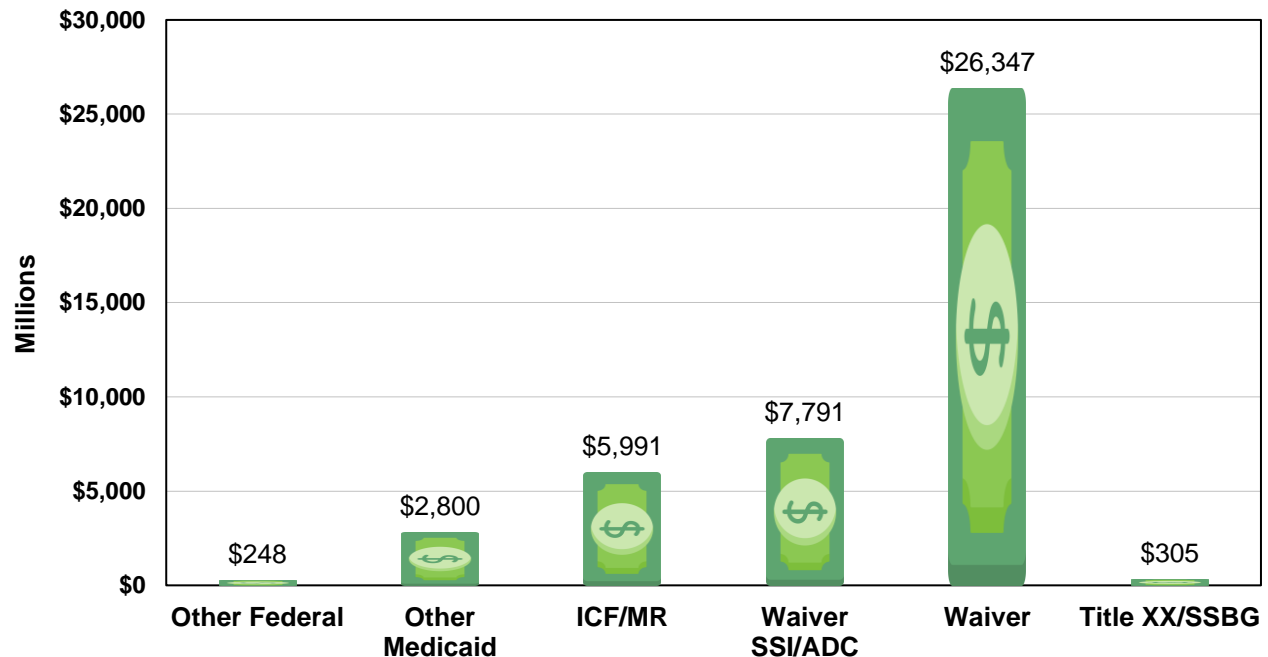
Local Funds  
State Funds  
Federal Funds



Total \$77.72 Billion

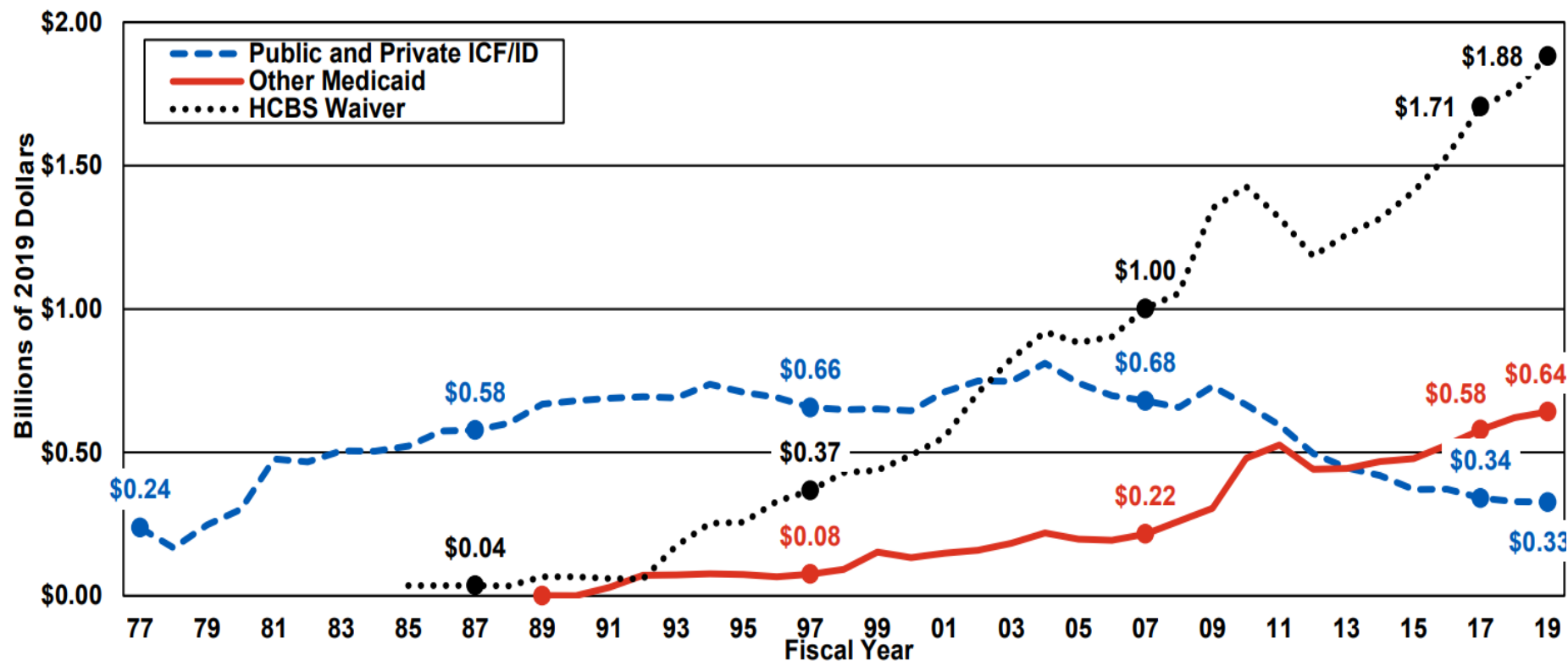
## Public IDD Spending by Revenue Source: FY 2019

### Federal Breakdown





# Federal ID/DD Medicaid Spending by Revenue Source in **California** FYs 1977 – 2019



# Fiscal Effort

- **Fiscal Effort** is a measure of how much a state spends on IDD LTSS per \$1,000 of statewide personal income.
- ...in other words, **how much does your state spend after you control for state wealth** – this allows you to compare your state to any other state regardless of state wealth.

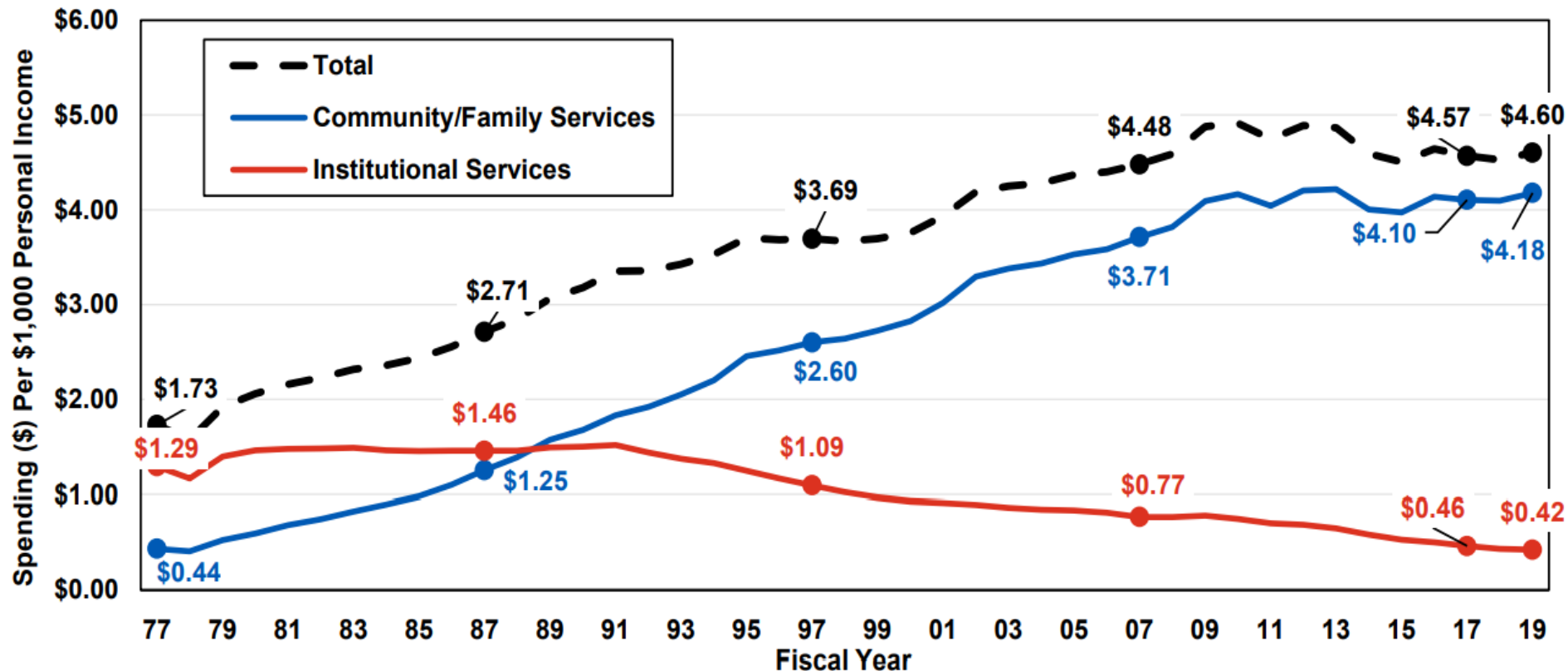


U.S. Total Fiscal Effort: \$4.60

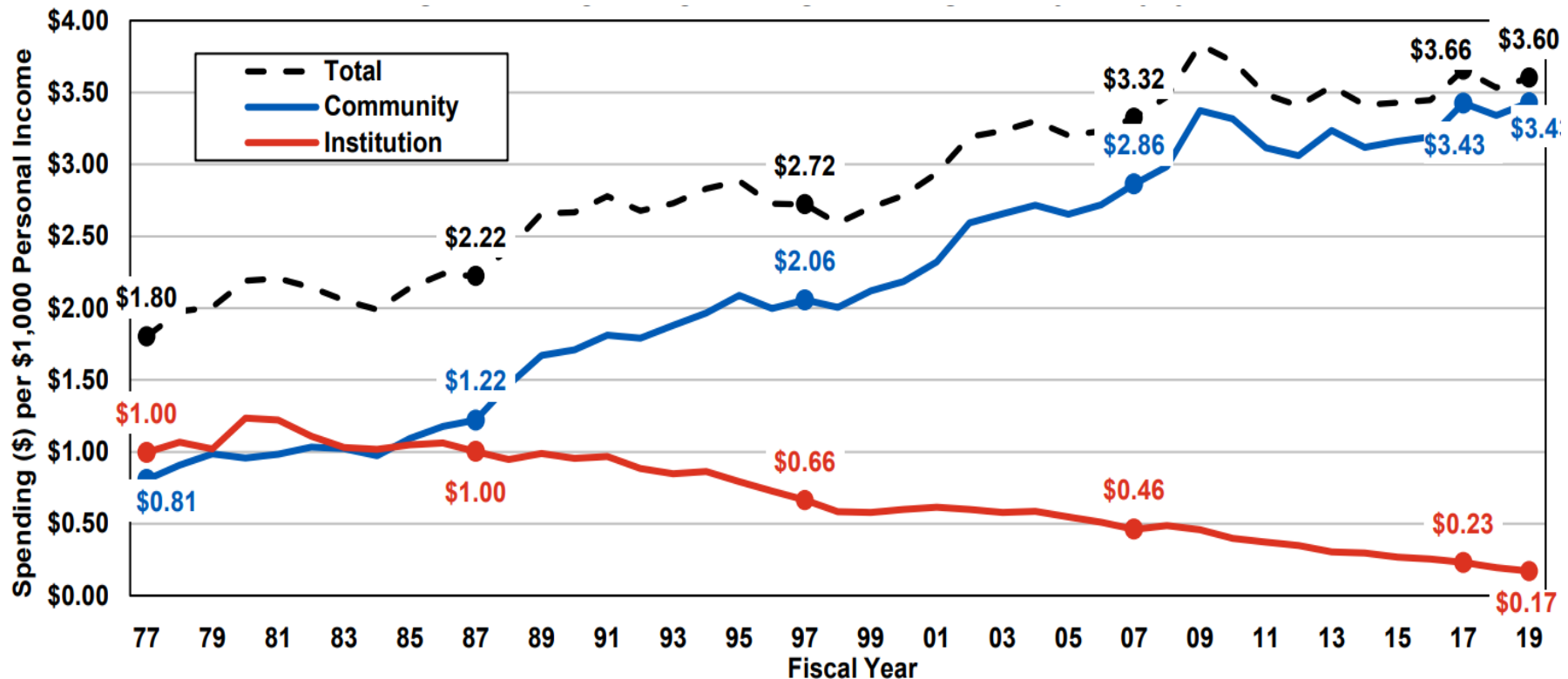
U.S. Community Fiscal Effort: \$4.18



# Fiscal Effort for ID/DD Services and Support in the U.S. FYs 1977-2019



# Fiscal Effort for ID/DD Services and Support in California in FYs 1977-2019



# Comparison and Ranking



- Rank with caution
- In fiscal effort we rank according to how much change between years (ex. CA rank 26<sup>th</sup> in percent change in fiscal effort between 2017-2019)
- Colorado will always have a low fiscal effort investment (\$2.29) due to TABOR legislation





# Programmatic Trends in Spending

Family  
Support

Supported  
Employment

Technology



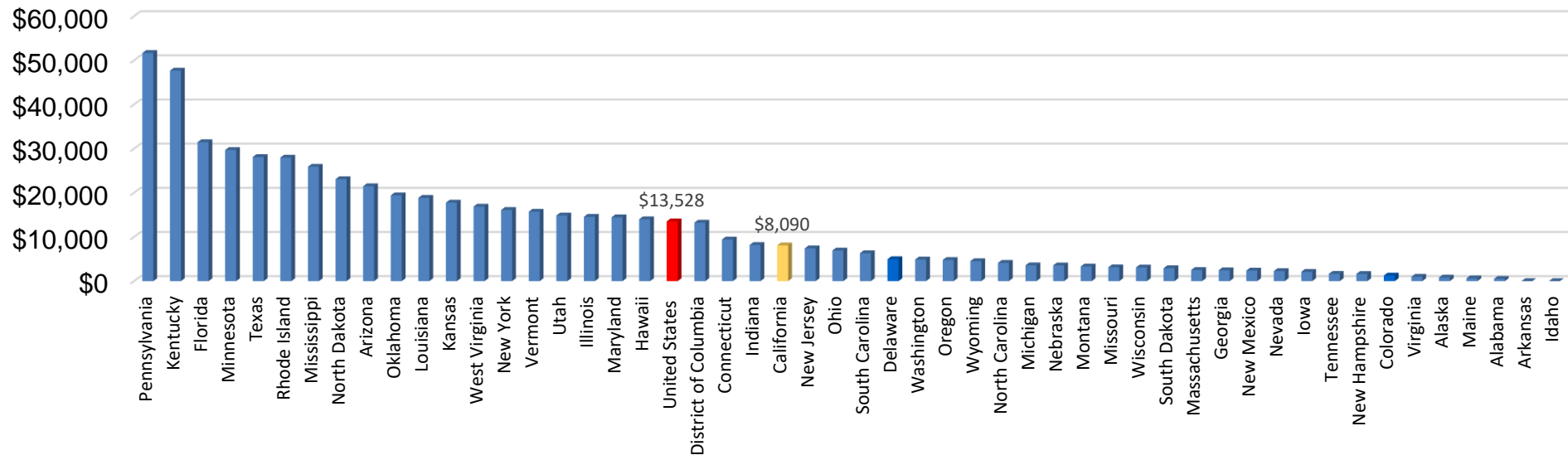
# Family Support Definition

**Family supports** are community-based services are provided to families for children or adults with IDD living in the family home.

- Services range from service coordination on an episodic basis to a full array of respite care and in-home supports provided on a daily, weekly or monthly basis.
- There are two categories of Family Support:
  1. Financial subsidy/cash payments to families; and
  2. General family support payments (non-subsidy) including respite care, family counseling, equipment, architectural adaptation of the home, parent education and training, behavior management training, or **other state-designated categories of family support**.
- The state IDD agency **may** provide vouchers, direct cash payments to families, reimbursement, or direct payments to service providers, which that state agency identifies as family support.



# Family Support Spending Per Family in the U.S. FY 2019



# Family Supports in California

- An estimated 74% of Californians with ID/DD live with their families in FY 2019
- Approximately 18% of those families receive formal support from the state
- Approximately 10% of families nationally receiving formal family supports in the U.S.



# Employment

In 2018:

- 12% of people with IDD served in integrated employment
- 87.7% were in facility-based non-work settings
  - 7% were in facility-based work
  - 80% were in community-based non-work



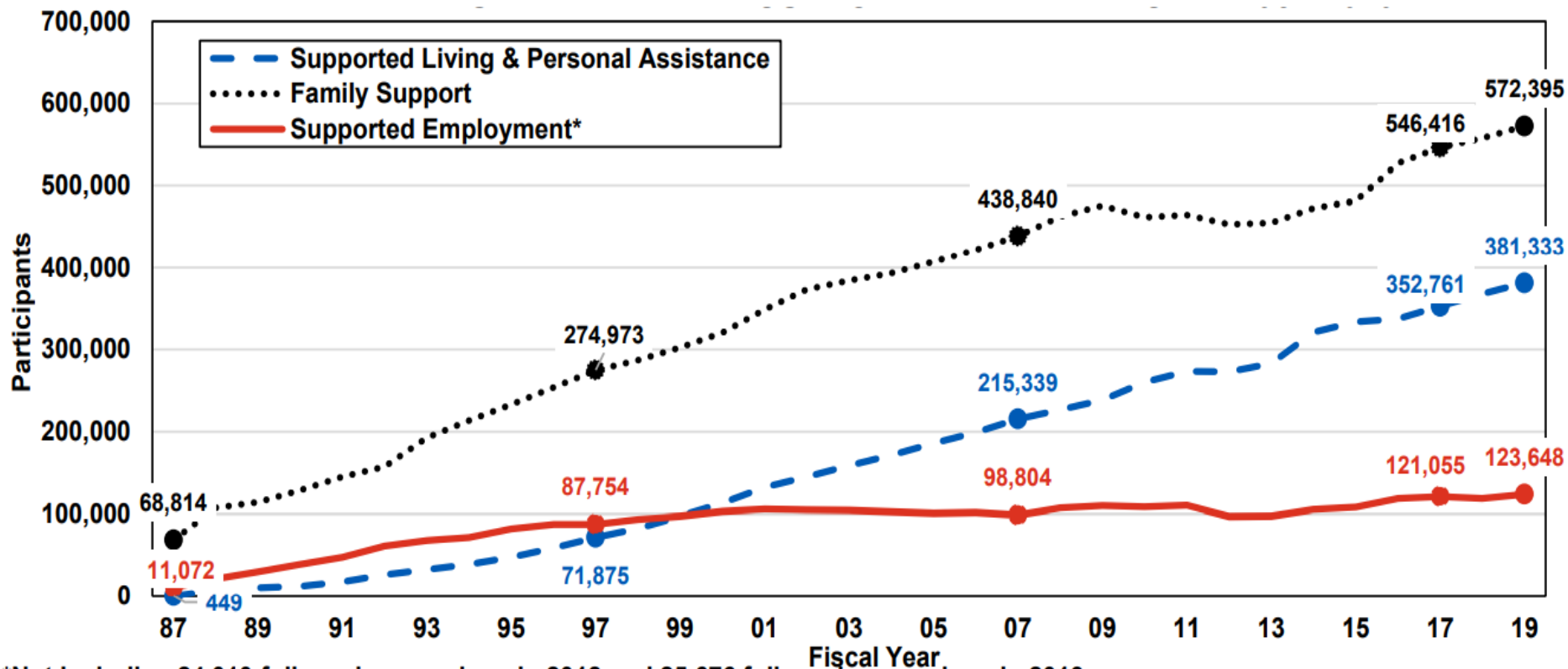
Source: StateData: The National Report on Employment Services and Outcomes Through 2018.

[www.statedata.info](http://www.statedata.info)





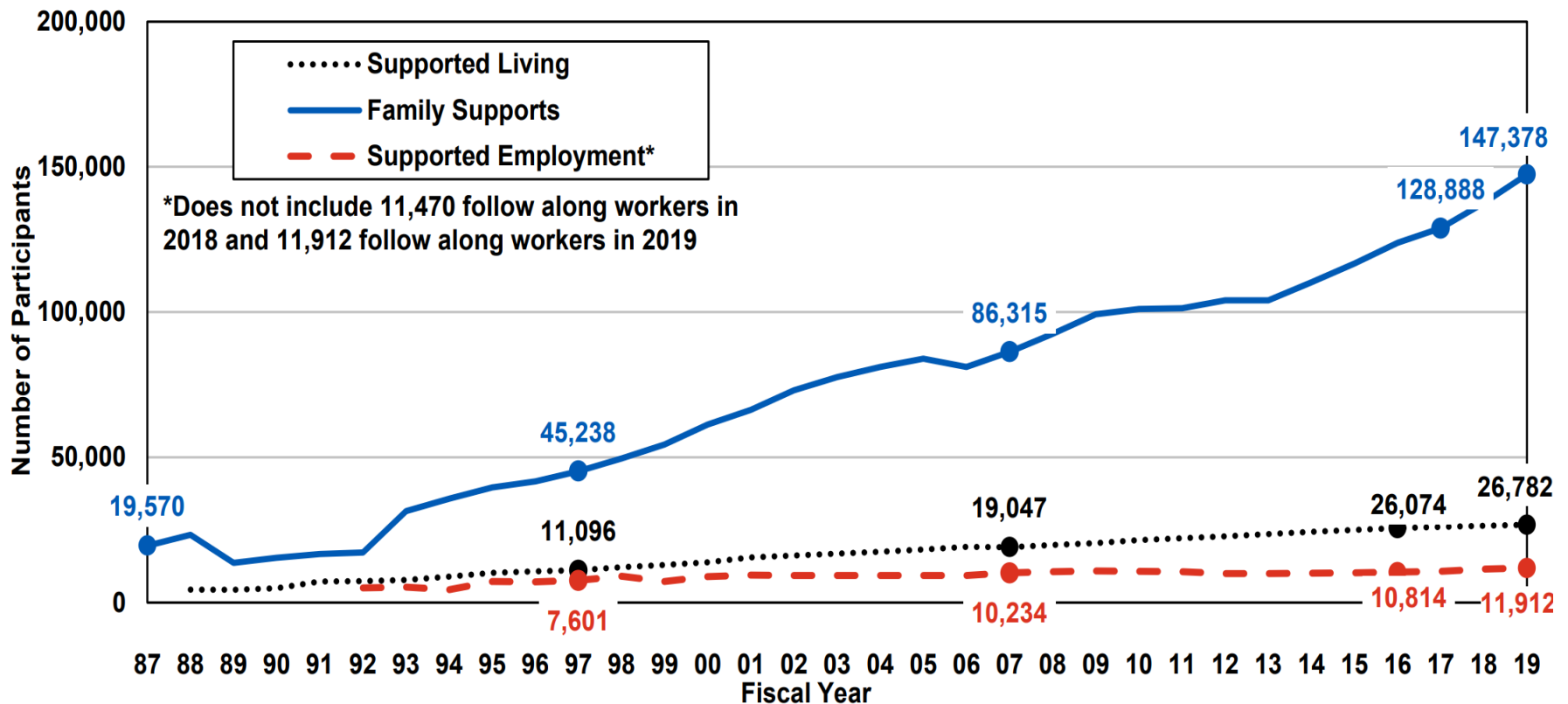
# Individual and Family Support Participants in the U.S. FY 1987-2019



\*Not including 24,010 follow-along workers in 2018 and 25,676 follow-along workers in 2019.



# Individual and Family Support Participants in California FYs 1987 – 2019

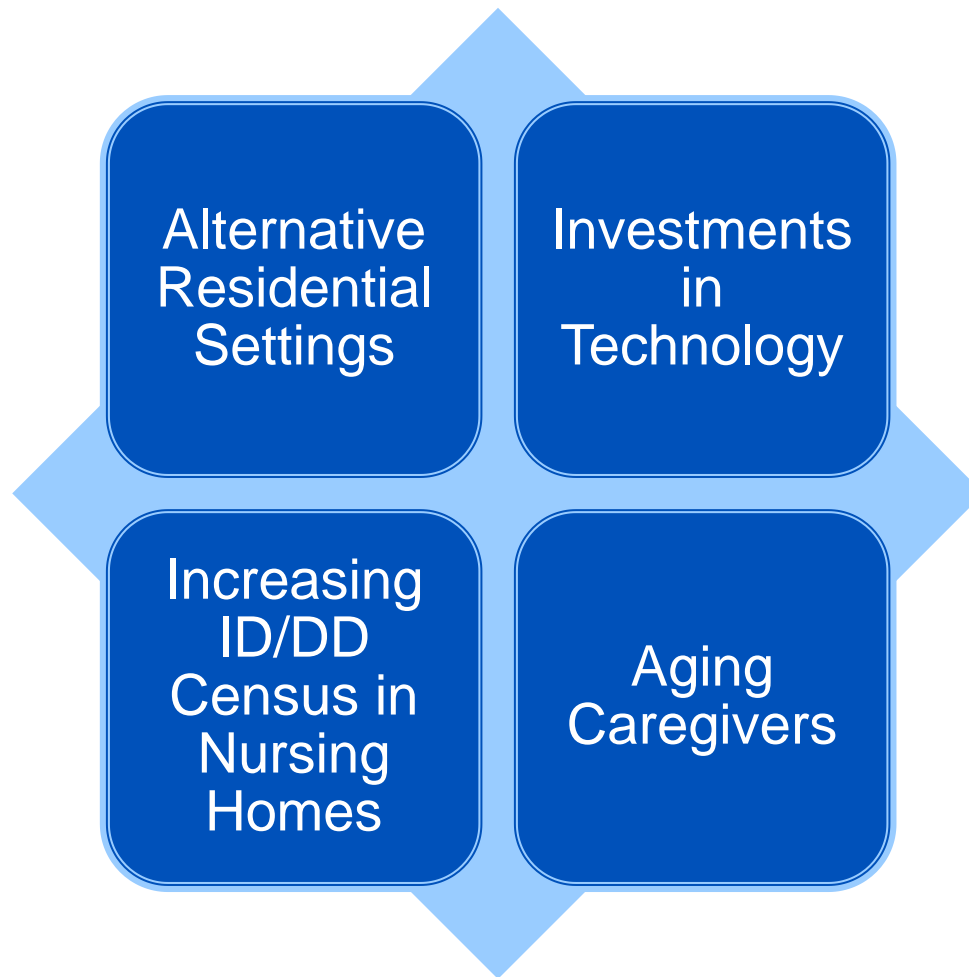


# Examples of Data Analyses Not Presented Today

- Cost of Care by Setting
- Cost Per Participant in HCBS Waivers
- Spending for Supported Living
- California in Relation to Regional States
- Federal-State Medicaid Breakdown



# Emerging Trends Across the U.S.



# How Do People Use Data For Systems Change?

**“If you can’t measure it,  
you can’t improve it.”**

- Developing measurable goals for mobilization
- Evaluating state policy and progress
- Identifying trends
- Demonstrating inequity
- Identifying innovation





# Frequently Asked Questions (FAQ's)



How does CA compare to other states?



How has COVID impacted financial investments in people with ID/DD and families?



Can you break down your data by race/ethnicity?



# Acknowledgements

Special thanks to the U.S. Administration on Disabilities (AoD), Administration for Community Living for supporting the Longitudinal Data Projects of National Significance.

[WWW.ACL.GOV](http://WWW.ACL.GOV)



Administration for Community Living



# Stay in Touch



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