WHAT IS THE STATE OF THE STATES AND HOW CAN I USE THE DATA?

ITACC/NACDD Training Series
Session 1
January 30, 2024

THE UNIVERSITY OF KANSAS
KU CENTER ON DEVELOPMENTAL DISABILITIES

State of the States
In Intellectual and Developmental Disabilities

WELCOME

State of the States
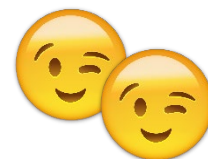In Intellectual and Developmental Disabilities

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas

Thank You!

Thank you for completing the survey.

If you have not had the chance to complete the survey you still can 😉🙂

Link to Survey: https://kusurvey.ca1.qualtrics.com/jfe/form/SV_cYNdTeLqrxXatIW

State of the States Team Members

Shea Tanis, Ph.D.
Principal Investigator and
Associate Research
Professor

Gloria Gantt
Research Assistant and
Data Ambassador
Program Lead

NACDD/ITACC and State of the States Partnership

OUTCOME

DISABILITY ORGANIZATIONS, PEOPLE WITH I/DD, AND FAMILIES REPORT ACQUISITION AND USE OF PROJECT DATA

OUTCOME

INCREASED UTILIZATION OF STATE OF THE STATES DATA IN THE DEVELOPMENT OF UCEDD AND DD COUNCIL 5-YEAR PLANS AND ADVOACY

Training Session Agenda

1   **What is the State of the States?**

2   **What data is available?**

3   **How can I use the data?**

4   **What is next in the training series?**

Session Logistics

- **Session Materials**
  - Posted on the State of the States Website under "Presentations" after the training (access code emailed)
- **Participation**
  - Please place comments and questions in the chat or email Tanis@ku.edu
    - We will respond to questions following the session
    - Open consultation session will be held on May 7th
- **Accessibility**
  - Presentation will be recorded
  - Live-automated closed captioning can be turned on through the zoom navigation
    - [Enabling automated captions - Zoom Support](#)
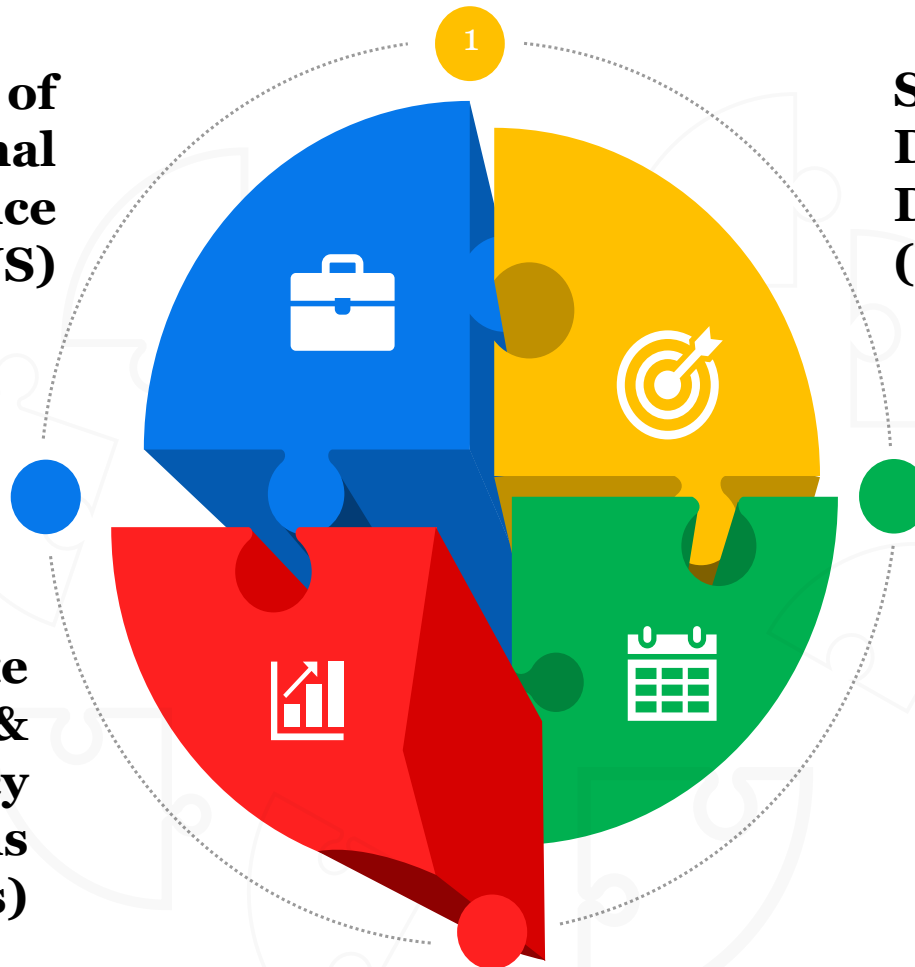
WHAT IS THE STATE OF THE STATES?

Developmental Disabilities Assistance and Bill of Rights Act of 2000
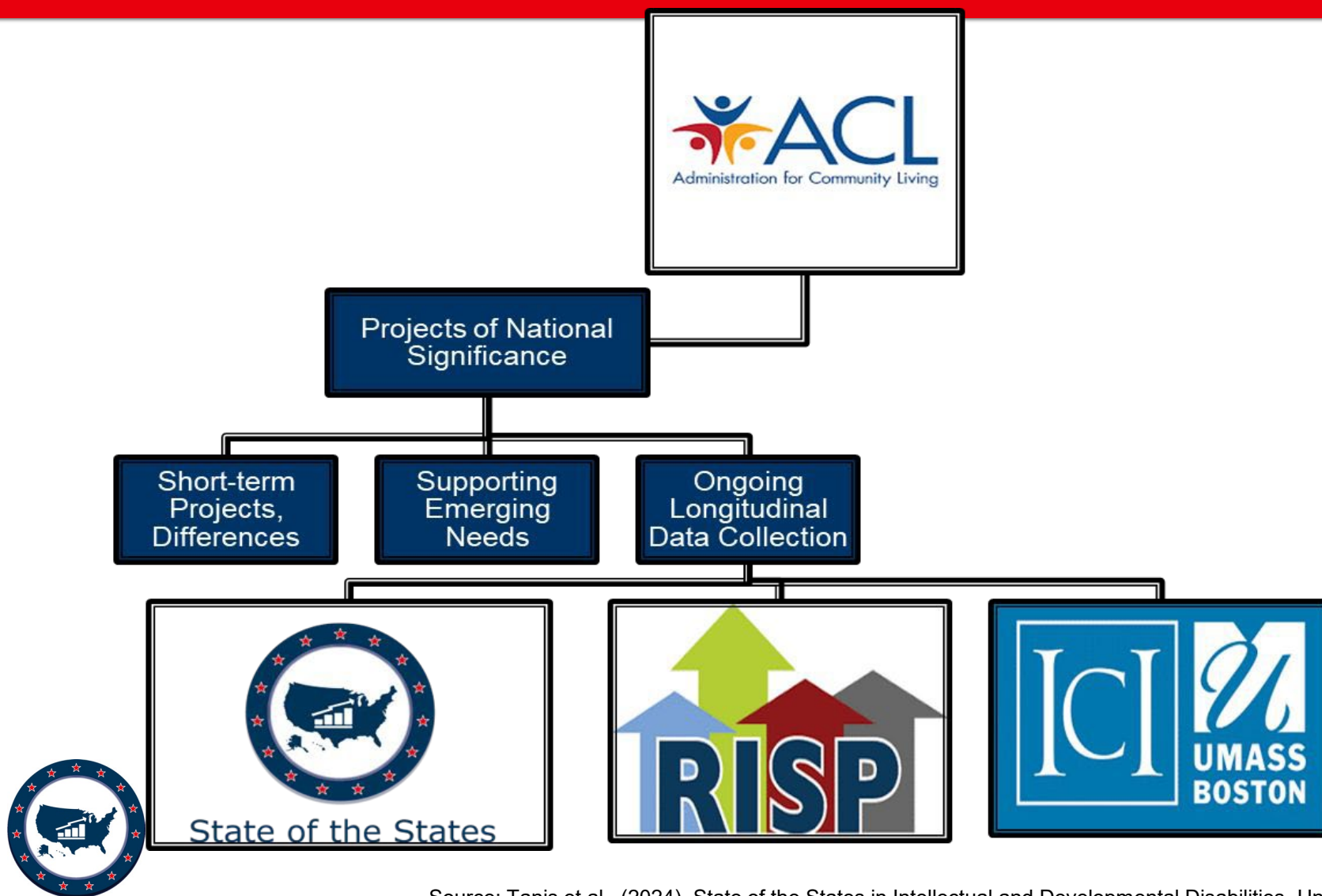
*Projects of National Significance (PNS)

State Councils on Developmental Disabilities (Councils)
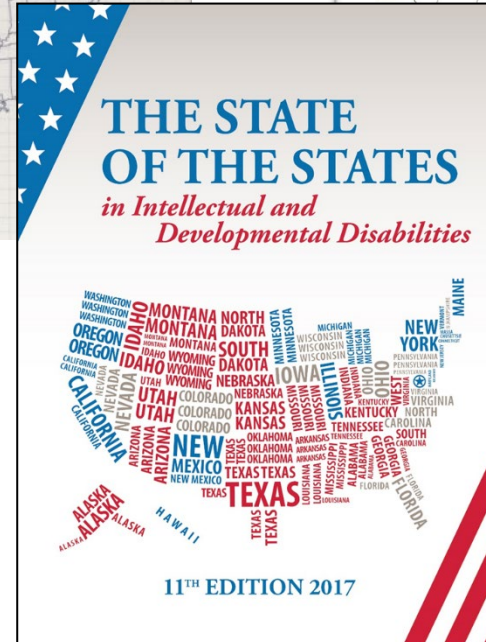
State Protection & Advocacy Systems (P&As)

University Centers for Excellence in Developmental Disabilities Education, Research, & Service (UCEDD)

Projects of National Significance (PNS)

Financial and Programmatic Trends in Supports and Services for People with I/DD
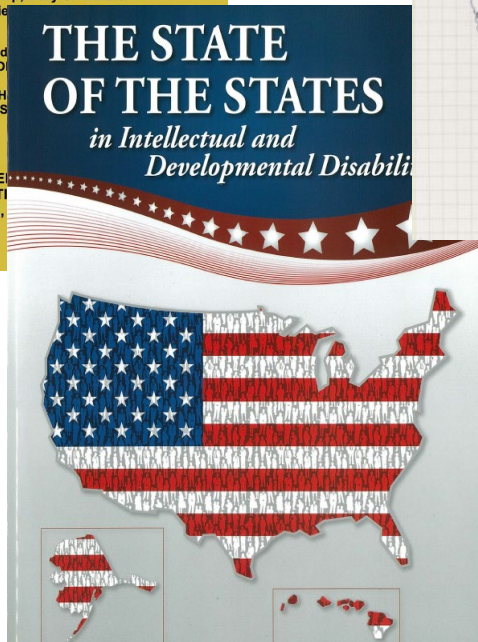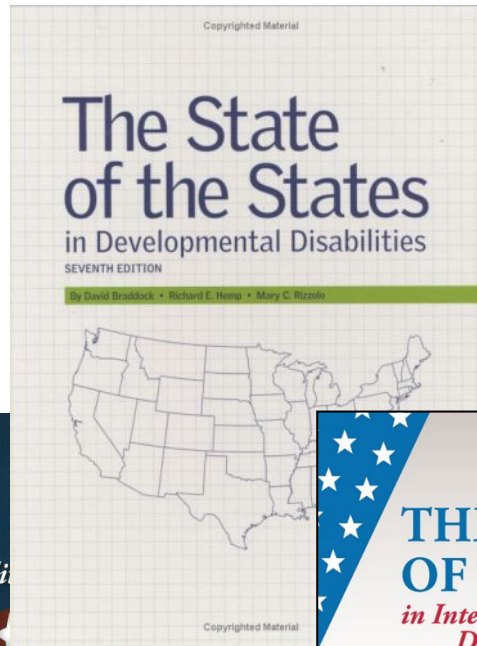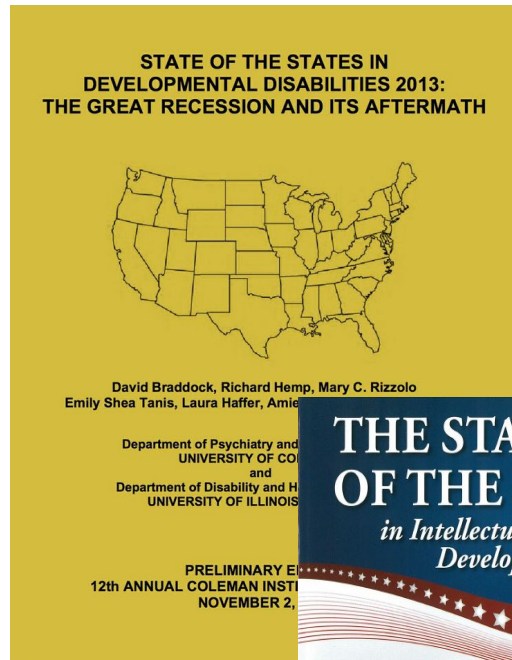
Longitudinal Data Projects and Linkages
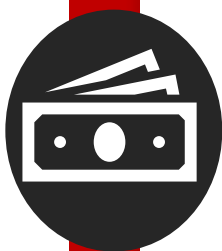
State of the States

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

Overlapping Data

Select Data Sources

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas

Data Cycle

Data collection occurs on biennial basis

Fiscal years 2022-2023 data collection spring 2024

States have opportunities to revise data

Year 1
Data Collection

2. Analyses

1. Collect from State

3. State Confirmation

2 Years

Year 2
Data Dissemination

Core Data Collection

- Reliable and robust data collection
  - Training of all state data contacts
- Data mining, cleaning, analytics
- Data checks with states for reliability
- Data dissemination
- Technical Assistance
  - State studies – 3 state special studies in the past year
  - Topical presentations – Technology First Systems Change and Technology Solutions, Cognitive Accessibility
  - Legislative support – Communications, Video, Technology, Accessibility Act (CVTA) – Sen. Markey (D-MA)
  - Federal Agency Data Collection Methodologies and Support – CDC and Census Bureau

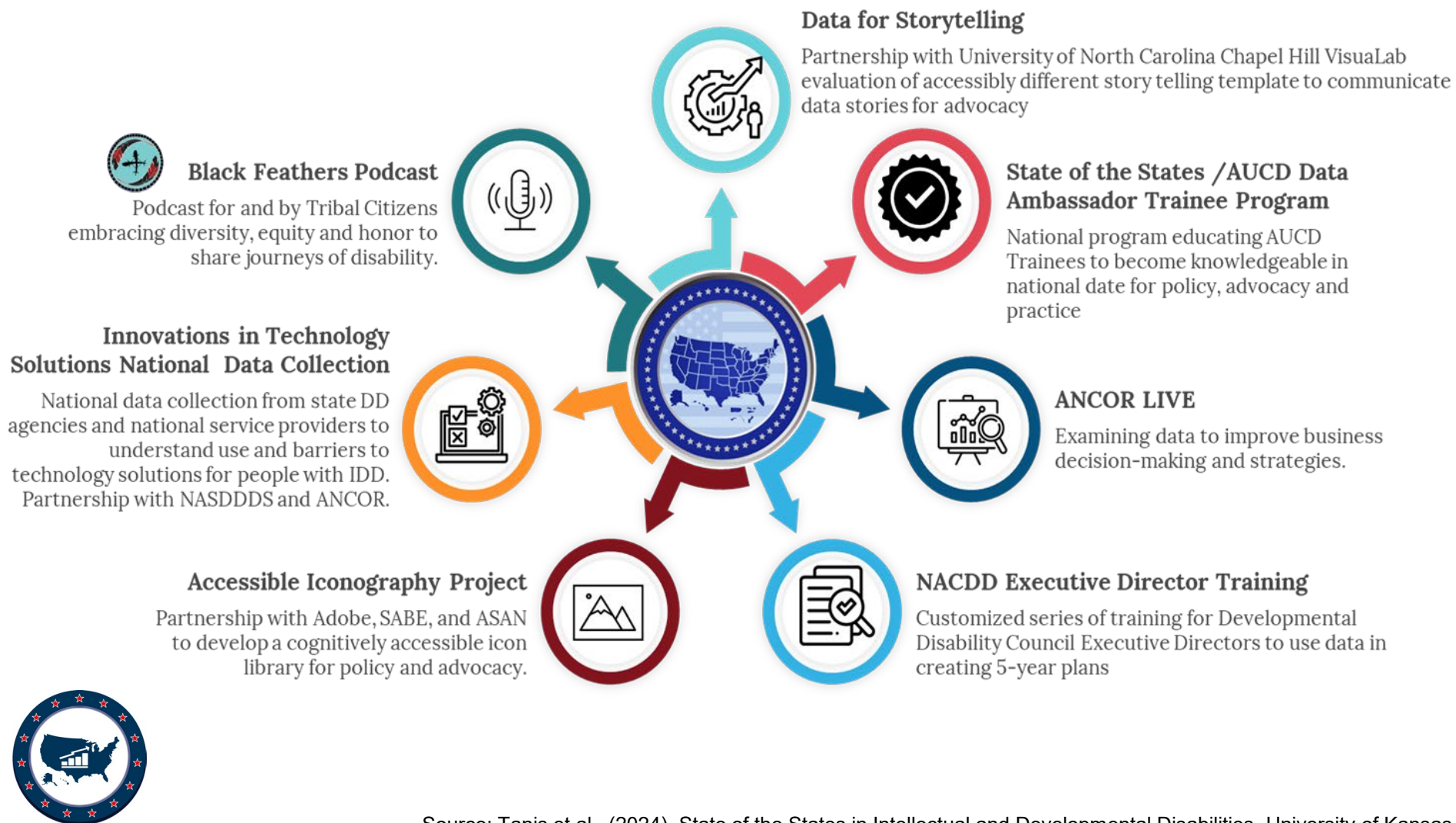# Complexity of Tracking Expenditures in States

- Braided and blended funding
- Emergency relief funding
- State agency organizational structure changes
- Software and data infrastructure changes
- Policy changes
- Proprietary data
- Professional turnover rate
- Content knowledge of data contacts
- Variation across states

Special Studies and Other Activities

Data for Storytelling

Partnership with University of North Carolina Chapel Hill VisuaLab evaluation of accessibly different story telling template to communicate data stories for advocacy

Black Feathers Podcast

Podcast for and by Tribal Citizens embracing diversity, equity and honor to share journeys of disability.

State of the States /AUCD Data Ambassador Trainee Program

National program educating AUCD Trainees to become knowledgeable in national date for policy, advocacy and practice

Innovations in Technology Solutions National Data Collection

National data collection from state DD agencies and national service providers to understand use and barriers to technology solutions for people with IDD. Partnership with NASDDDS and ANCOR.

ANCOR LIVE

Examining data to improve business decision-making and strategies.

Accessible Iconography Project

Partnership with Adobe, SABE, and ASAN to develop a cognitively accessible icon library for policy and advocacy.

NACDD Executive Director Training

Customized series of training for Developmental Disability Council Executive Directors to use data in creating 5-year plans

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas
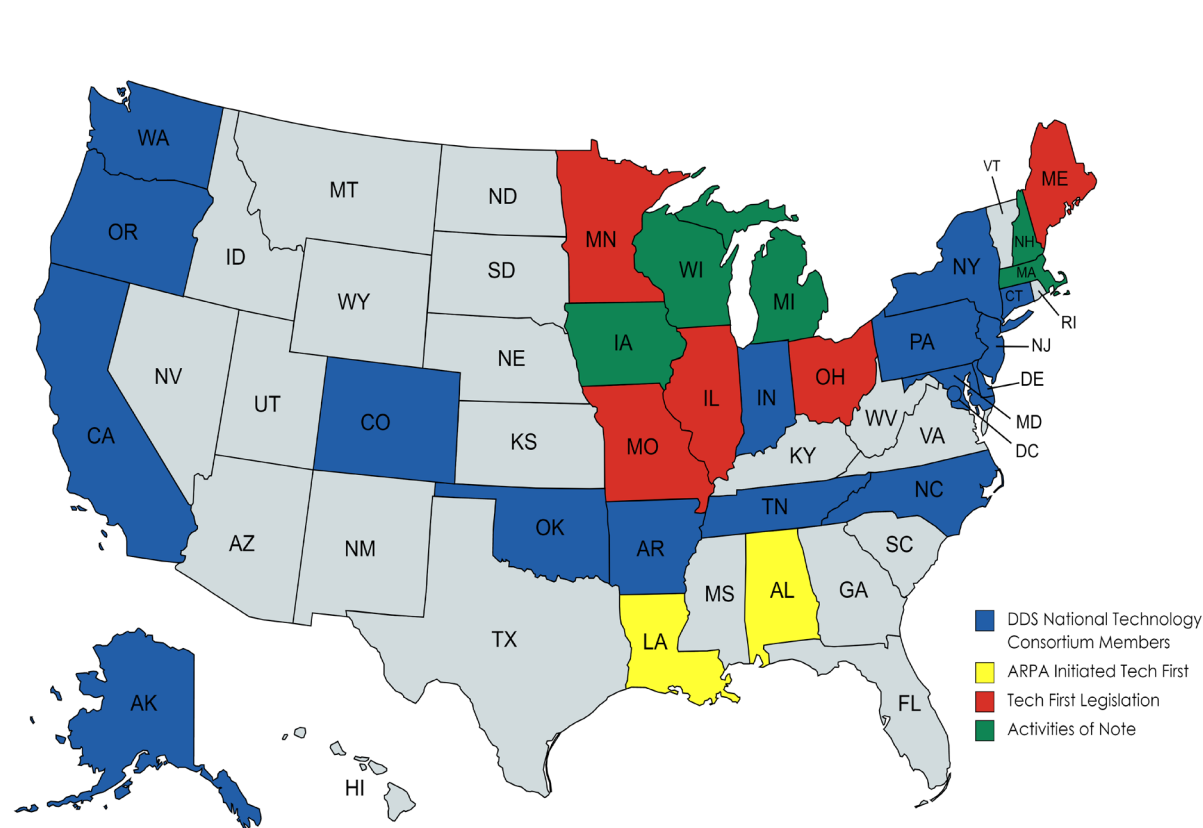
Data Ambassador Program

- ***Partner with the AUCD network to establish regional cohorts of UCEDD/LEND Trainee Data Ambassadors knowledgeable in administrative and national I/DD data and data accessibility to advance leadership in policy, education, and practice.***
- Cohort 1 : Alabama, Colorado, Kansas, Ohio, Oklahoma, Oregon, New Jersey, Puerto Rico, and Wyoming
- Work with DD Network Partners

Technology First Systems Change

Map legend:
- Blue: DDS National Technology Consortium Members
- Yellow: ARPA Initiated Tech First
- Red: Tech First Legislation
- Green: Activities of Note

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas

WHAT DATA IS AVAILABLE?

State of the States
In Intellectual and Developmental Disabilities

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
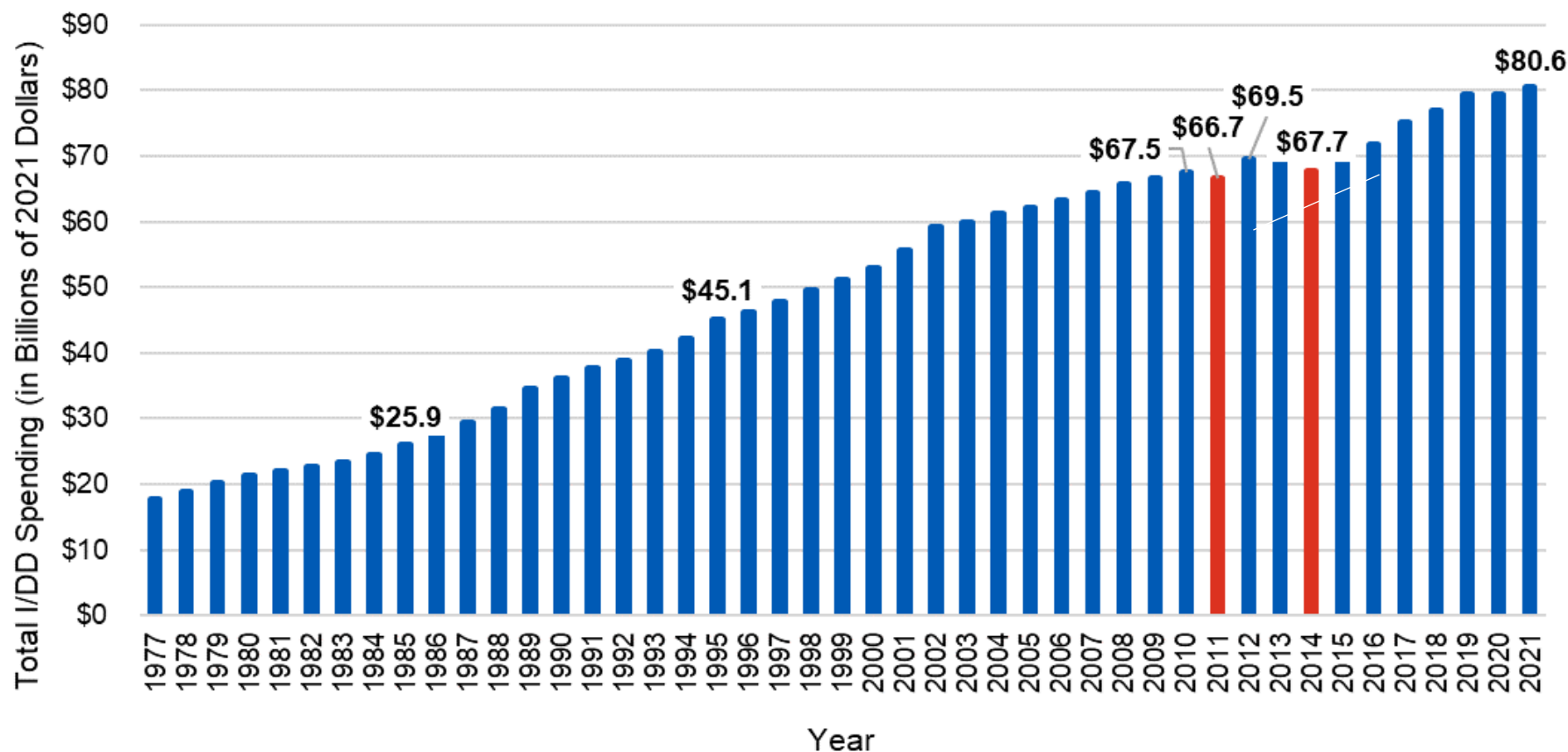Family Support
Other Residential

Day / Work Program

Sheltered Employment/Work Activity
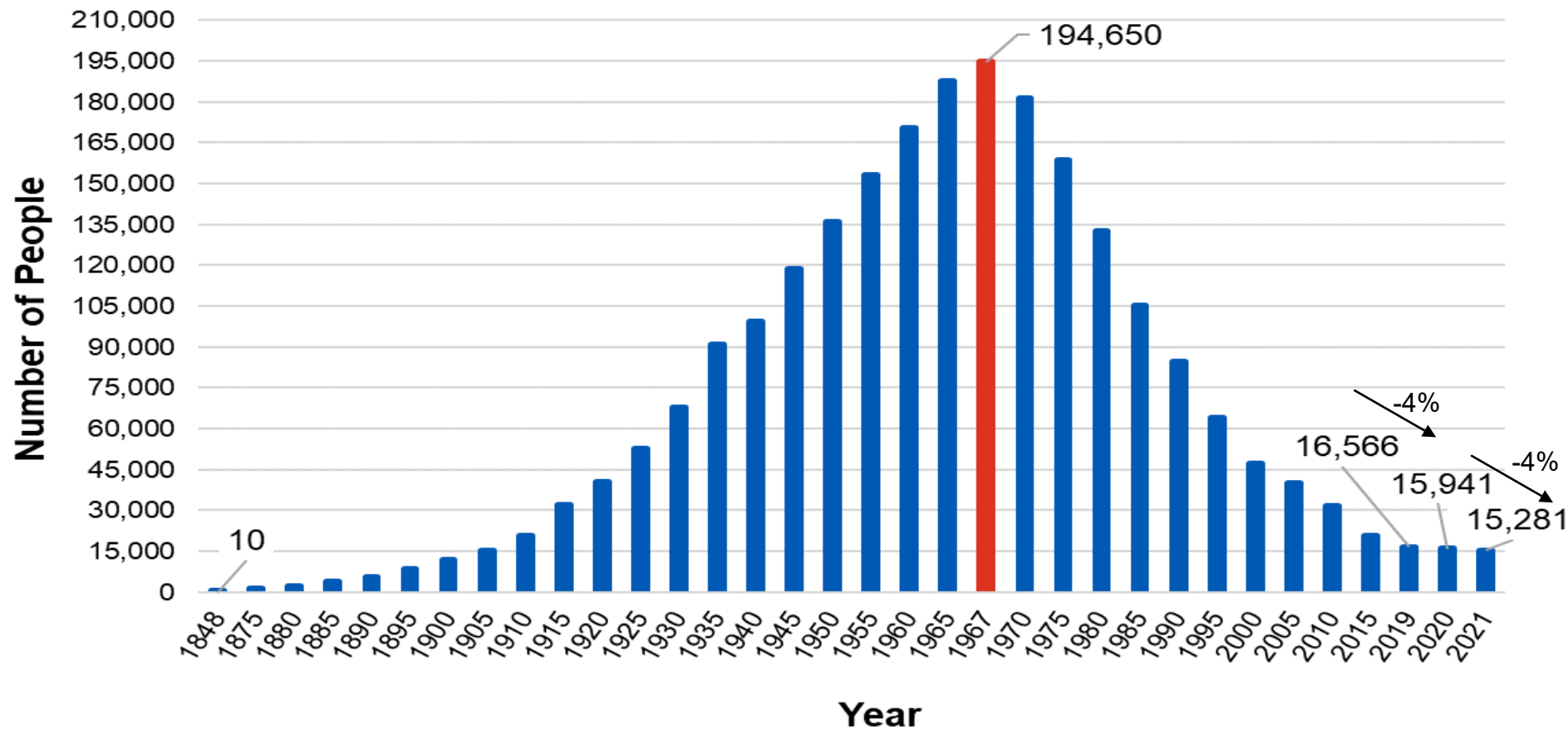Day Habilitation
Supported Employment

Technology

Smart Homes
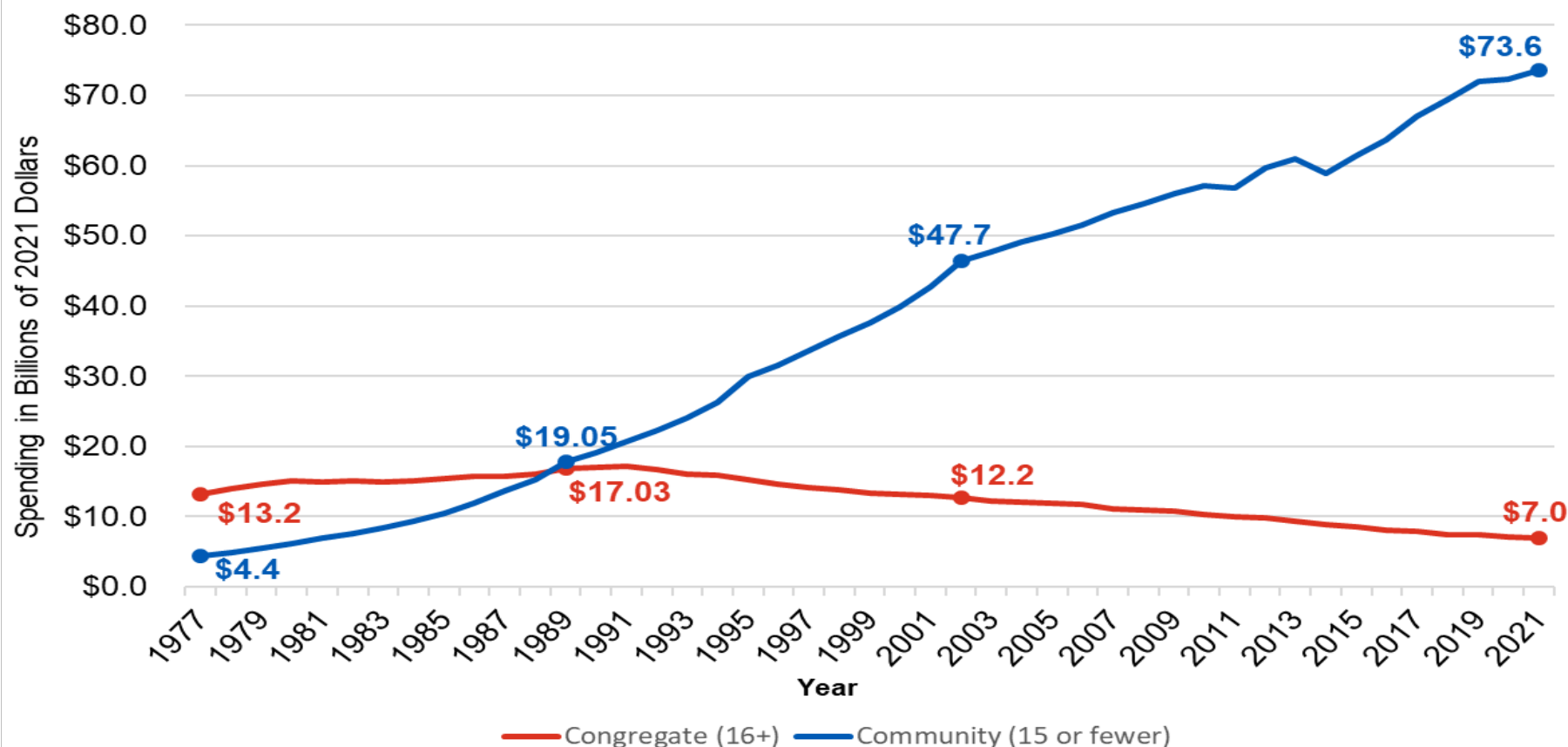Individual Support Technology
Remote Supports

Total Public I/DD Spending in the U.S. FYs 1977 – 2021

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas

Number of People in ICF/ID Institutions in the U.S. by Year (FYs 1848 – 2021)

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas

U.S. Institutional and Community Spending FYs 1977 – 2021

Institutional Census in Colorado FY 1990-2021

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas
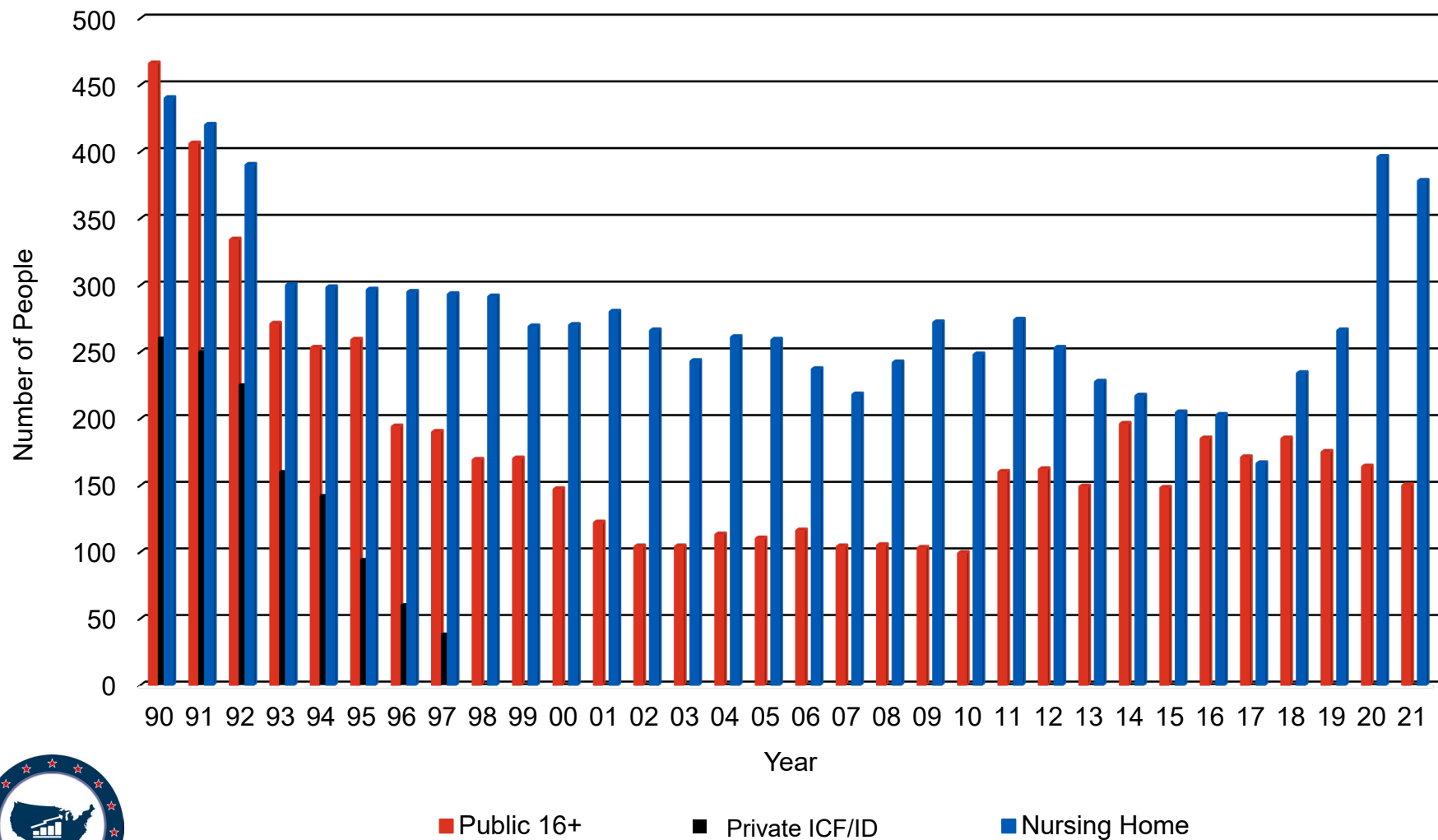
Federal-State Medicaid Provided 89% of Total I/DD Spending FY 2021

Other Federal, 10.92%
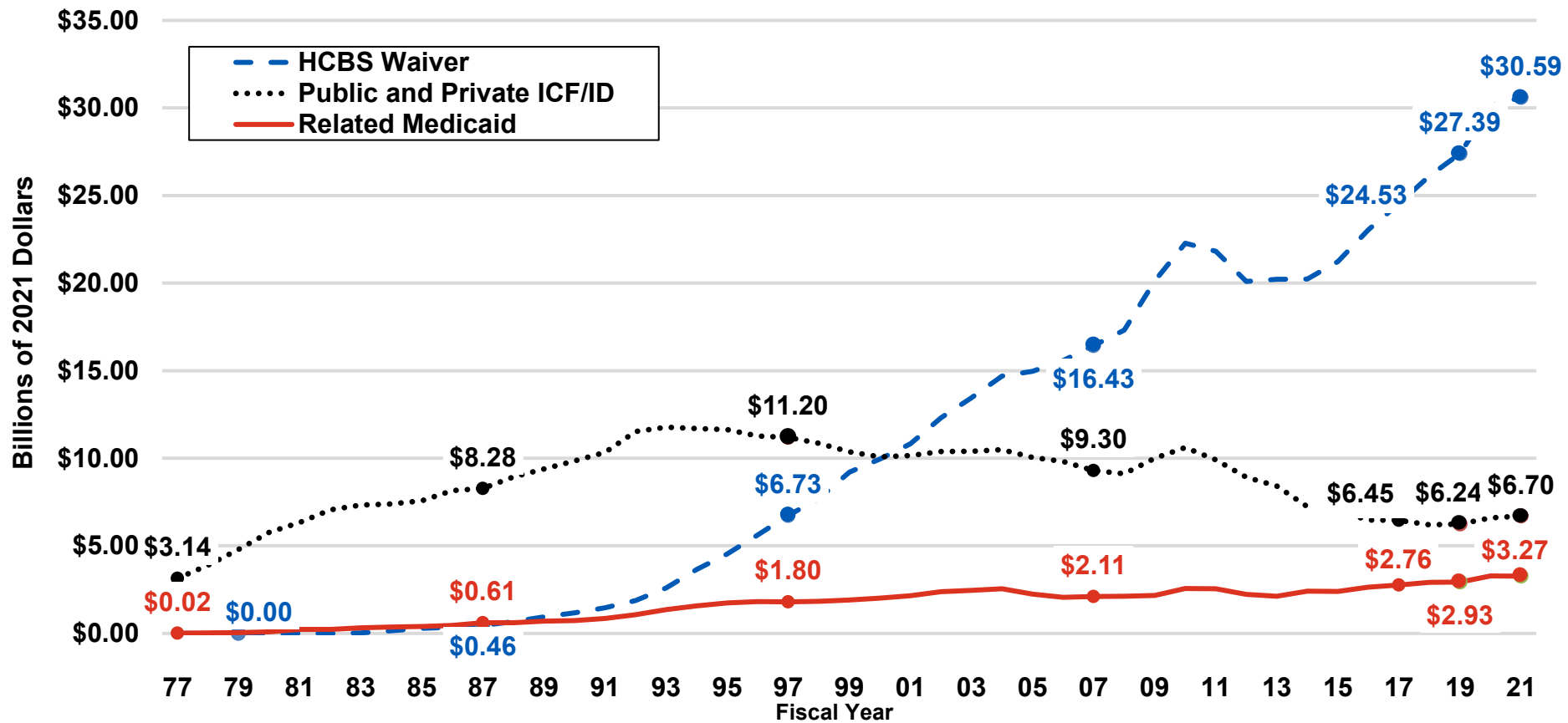
Other State, 0.12%

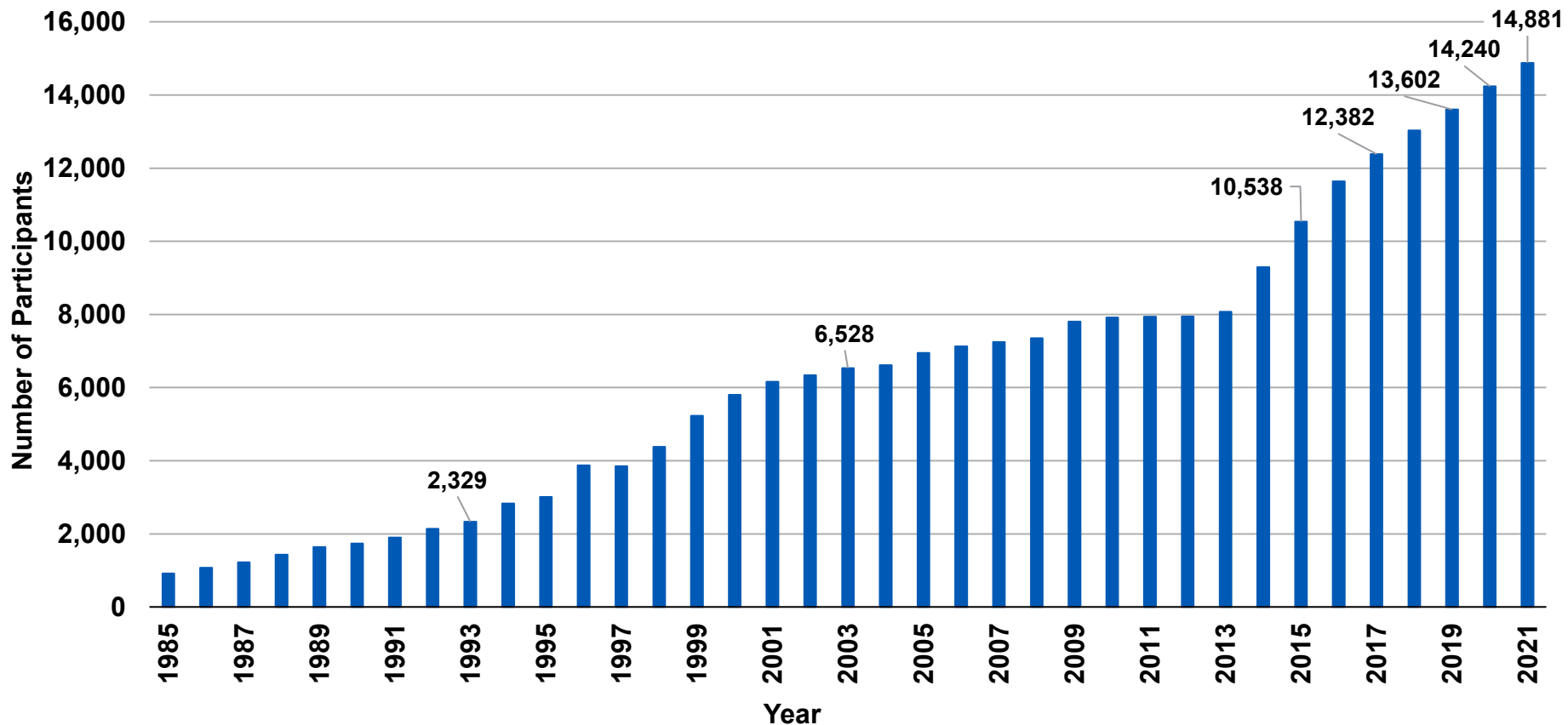Federal-State Medicaid, 88.96%

a)

b)

c)
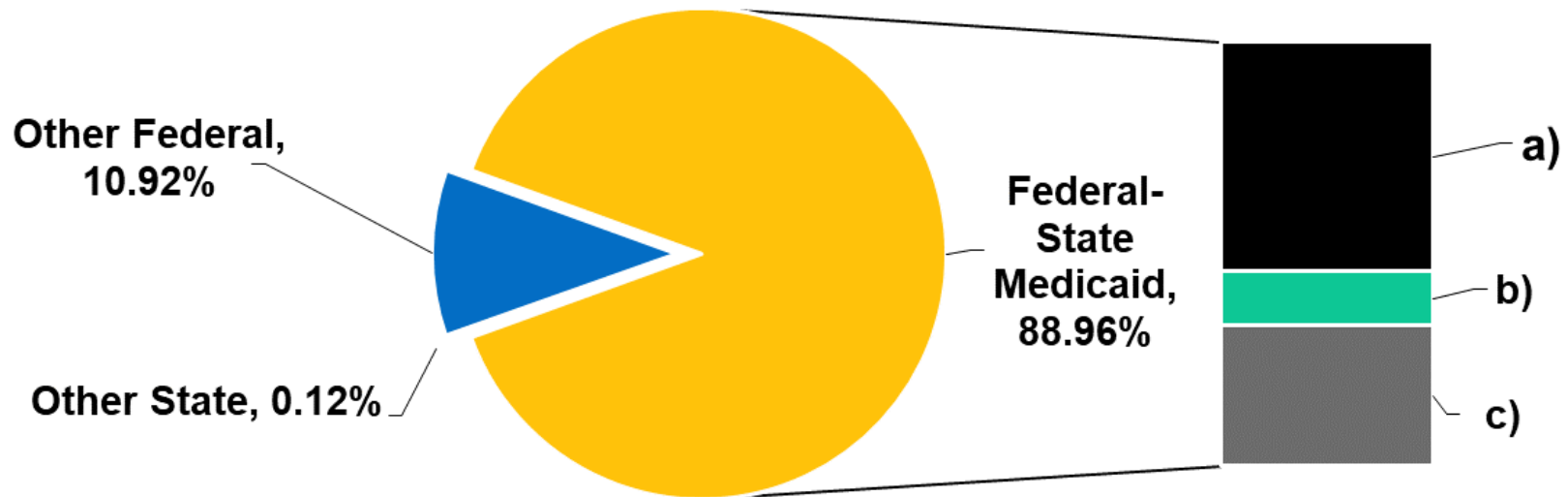
Total I/DD Spending: $80.61 Billion

* Total Federal-State Medicaid: $71.7 Billion
a) HCBS Waiver (54.2%);
b) Public and Private ICF/ID (12.7%); and
c) State Plan Medicaid (33.1%)

Federal I/DD Medicaid Spending by Revenue Source in the U.S. FYs 1977 – 2021

Source: Tanis et al., (2023). State of the States in Intellectual and Developmental Disabilities, University of Kansas
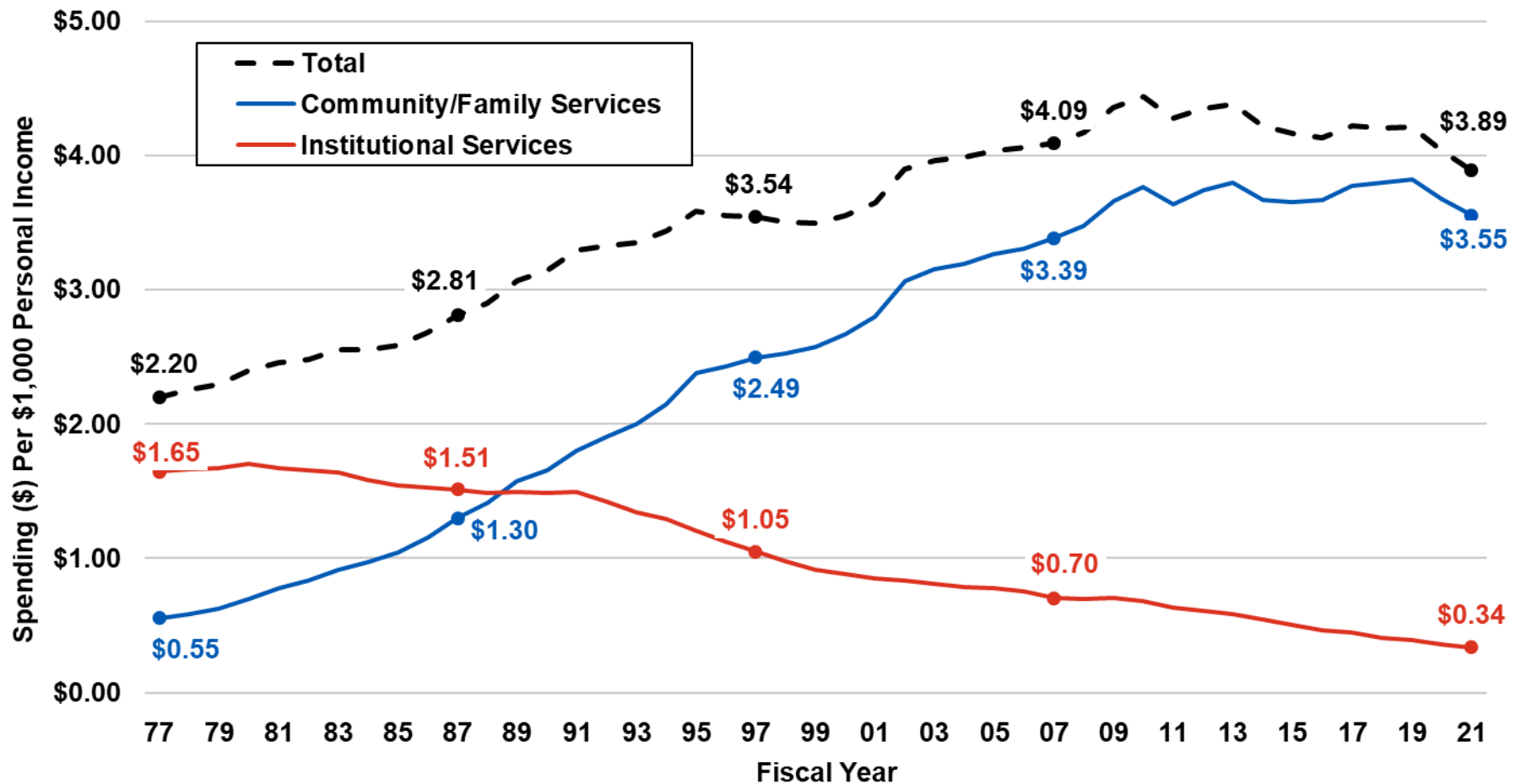
Fiscal Effort – FY 2021

- **Fiscal Effort** is a measure of how much a state spends on I/DD LTSS <u>per $1,000 of statewide personal income</u>.

- …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.

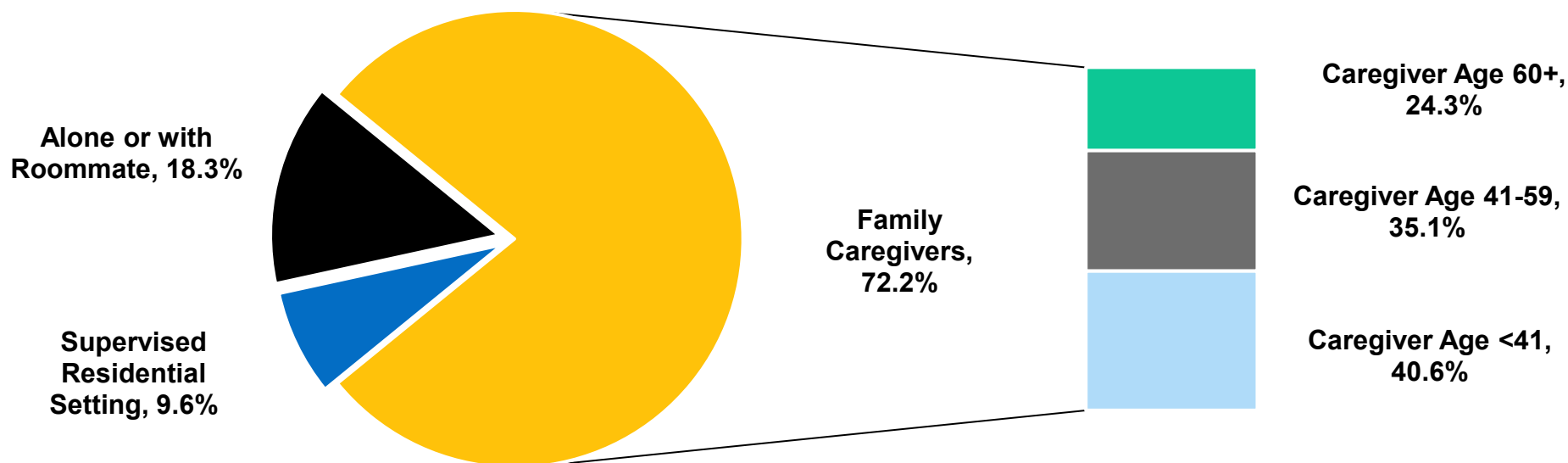U.S. Total Fiscal Effort: $3.89

U.S. Community Fiscal Effort: $3.55

Total Fiscal Effort for I/DD Services in the U.S. FY 1977 - 2021

Estimated Distribution of People With I/DD By Living Arrangement in U.S. (FY 2021)

Alone or with Roommate, 18.3%

Supervised Residential Setting, 9.6%

Family Caregivers, 72.2%

Caregiver Age 60+, 24.3%

Caregiver Age 41-59, 35.1%

Caregiver Age <41, 40.6%

Family Support Spending Per Family FY 1986-2021 Colorado

Source: Tanis et al., (2023). State of the States in Intellectual and Developmental Disabilities, University of Kansas
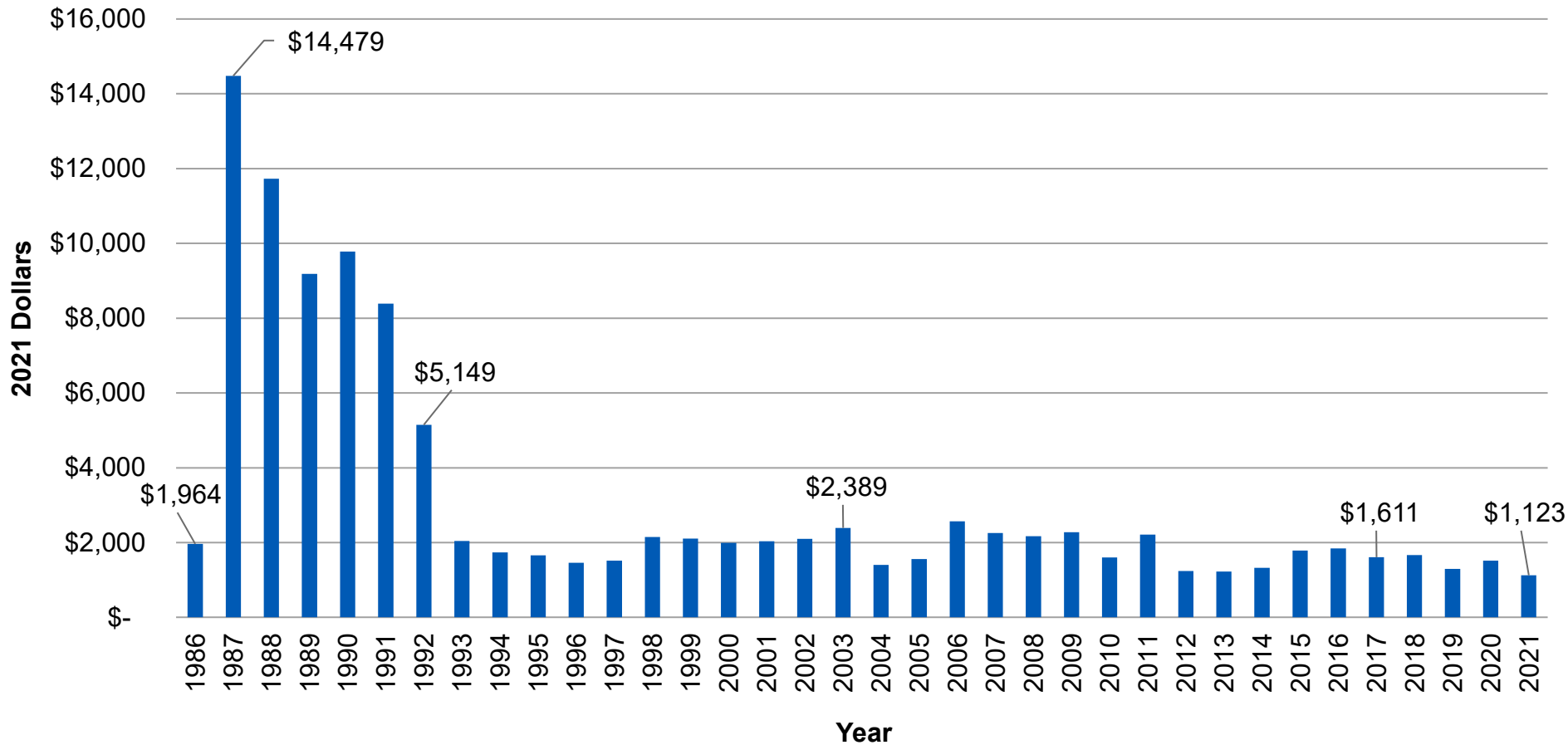
Total Day/Work and Supported Employment Participants FYs 1987 – 2021 Colorado

Source: Tanis et al., (2023). State of the States in Intellectual and Developmental Disabilities, University of Kansas
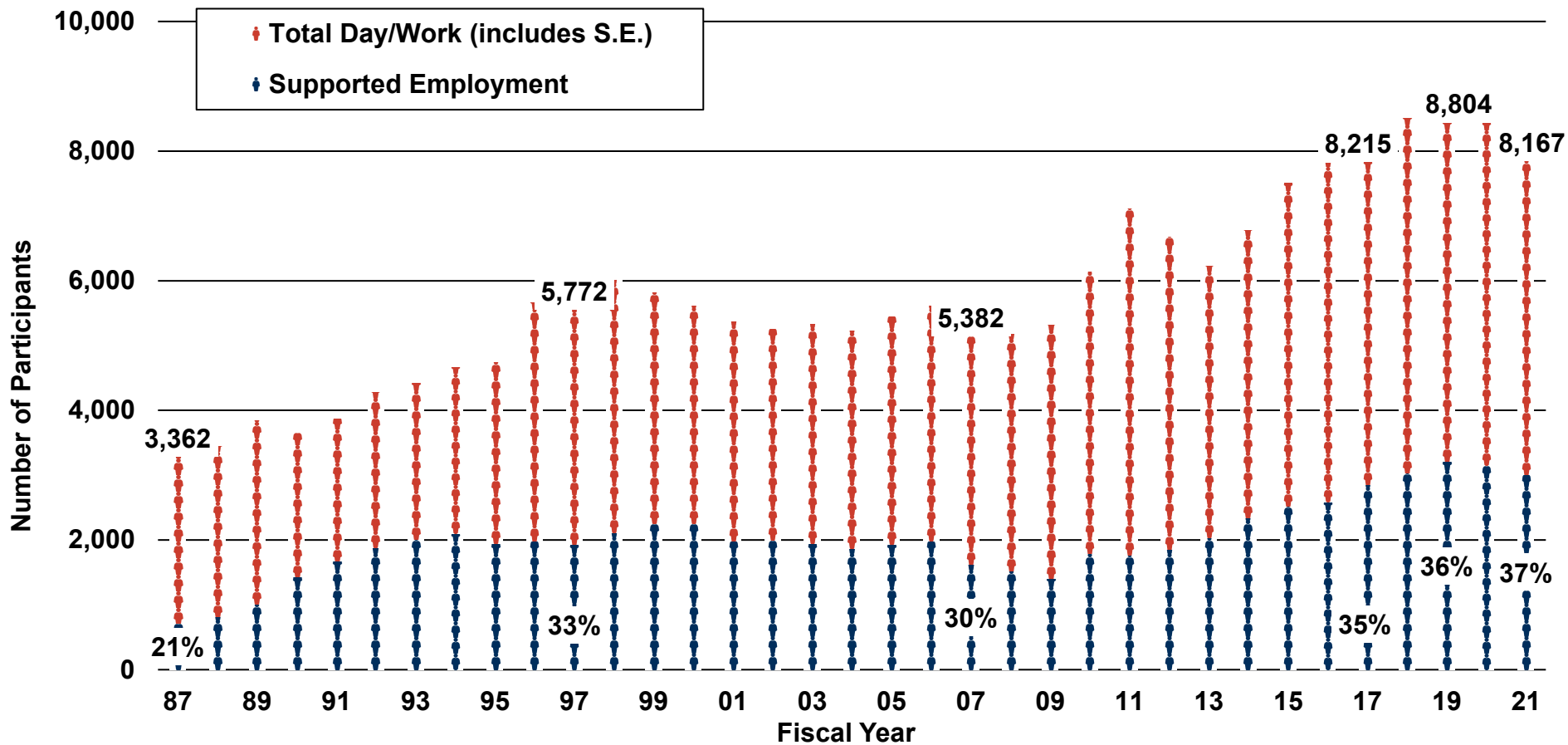
Technology Investments in the U.S. FY 2021

Source: Tanis et al., (2023). State of the States in Intellectual and Developmental Disabilities, University of Kansas
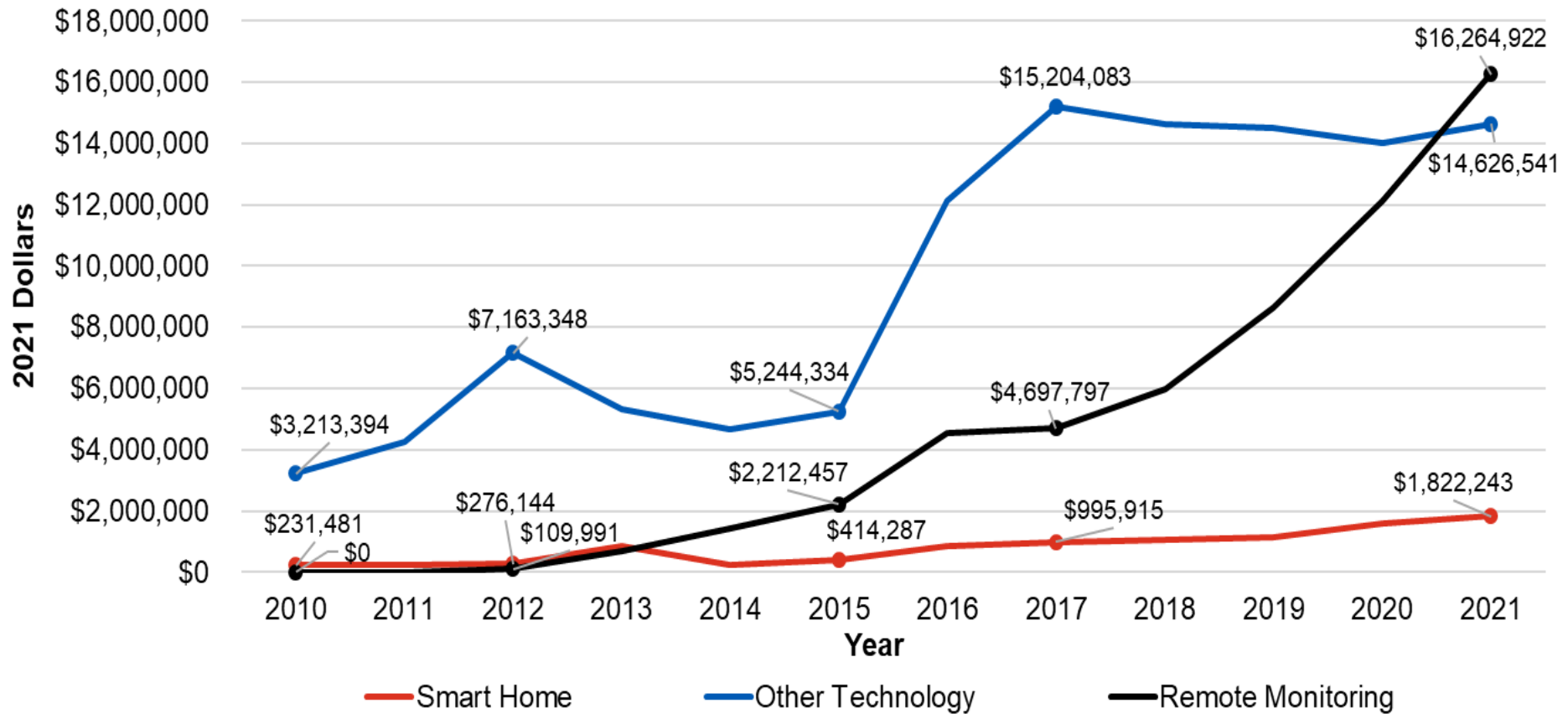
Examples of Data Analyses Not Presented Today

- Cost of Care by Setting
- Cost Per Participant in HCBS Waivers
- Supported Living
- Individual State Raking Compared to Other States
- Federal-State Medicaid Breakdown
- Etc.

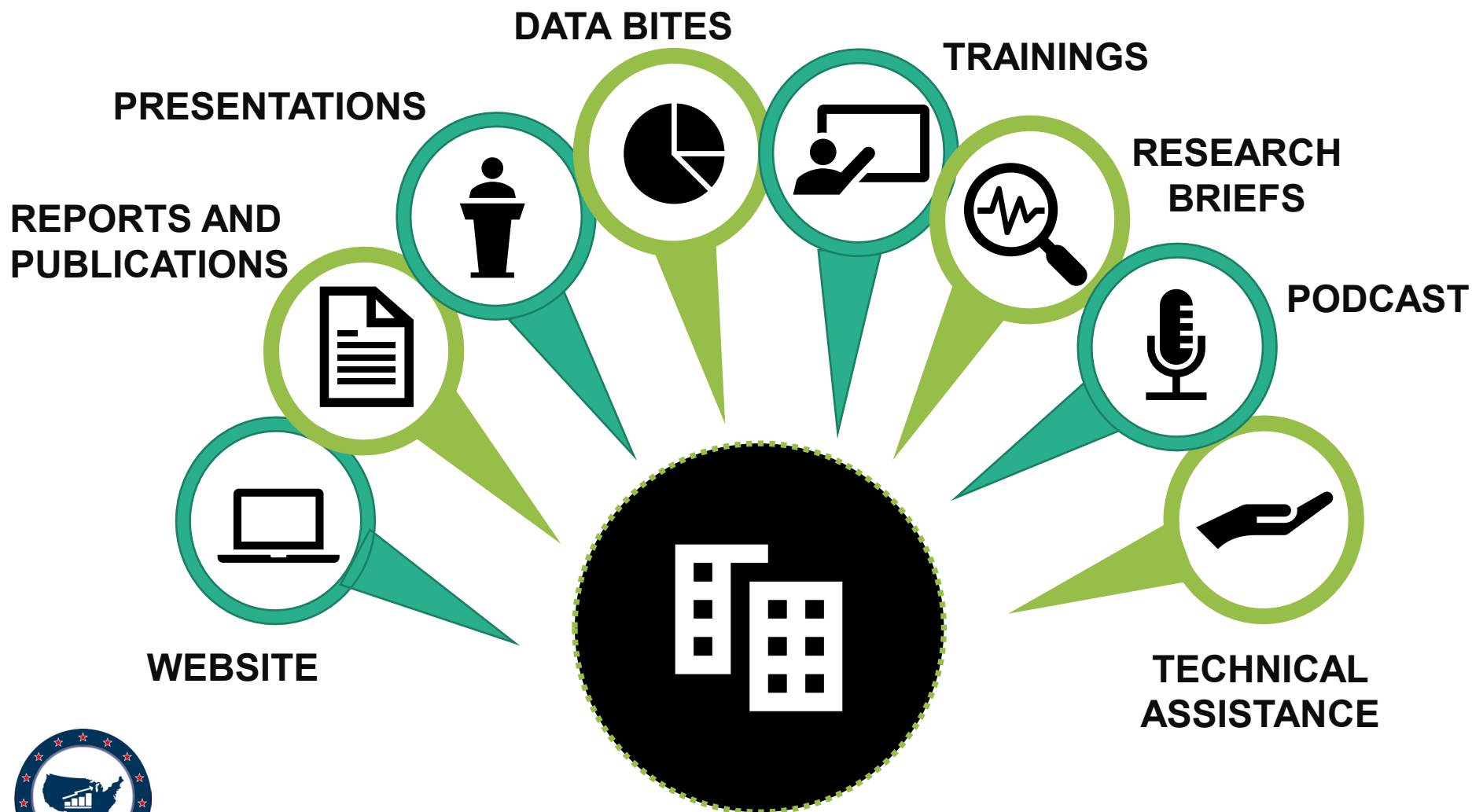# How Do I Get Data From The Project?

HOW CAN I USE THE DATA?

State of the States
In Intellectual and Developmental Disabilities

Applications of Data

- Policy advocacy and systems change
- Annual reporting
- Develop or inform your 5-year plan
- Inform decision-making
- Educating Council members
- Support grantees
- Integration into a *data strategy*

Content Analysis of 5-Year Plans

Themes in DD Council 5-Year Plans

Employment ✓
Focus on competitive integrated employment.

Self-Advocacy Support
Statewide organizational support and leadership training

Supports and Services ✓
Navigation of supports and services

Education
Early intervention, transition, postsecondary and meaningful inclusion

Housing ✓
Affordable, equitable housing options

Transportation
Affordable, accessible and varied options

Awareness and Community Inclusion ✓
Educating the community about issues important to people with IDD and their families

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas

Creating a Comprehensive Data Strategy

- A data strategy is a roadmap for data acquisition, analysis, and management to be applied in achieving organizational goals. A data management system is a system that collects, organizes, protects, and stores the organization's data

37.93%

62.07%

Yes | No | I do not know

Source: Tanis et al., (2024). State of the States in Intellectual and Developmental Disabilities, University of Kansas
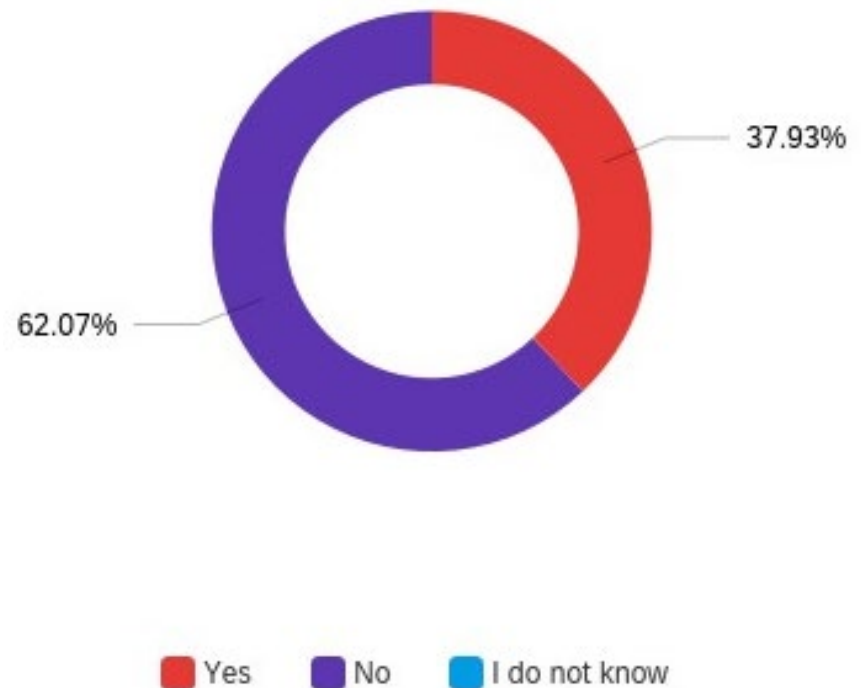
WHAT IS NEXT IN THE TRAINING SERIES?

State of the States
In Intellectual and Developmental Disabilities

NEXT MEETING

WEDNESDAY

📅 MARCH 27, 2024

🕐 1:00 PM - 2:00 PM EST

👤 OPEN TO DD COUNCIL STAFF

SESSION 2

WHAT IS THE DATA SET AND WHAT CAN IT DO FOR ME?

Acknowledgements

Administration for Community Living for supporting the Ongoing Longitudinal Data Projects of National Significance.

WWW.ACL.GOV

Stay in Touch

Email us:

Tanis@ku.edu

Stateofthestates@ku.edu

New Cognitively Accessible Website
www.Stateofthestates.ku.edu