Panelists

- Jennifer Johnson, PhD, Deputy Director, Administration on Intellectual and Developmental Disabilities, Administration for Community Living, USDHHS
- Andrew Morris, MPH, Policy Analyst, Administration for Community Living, USDHHS
- Kristen Robinson, PhD, Senior Research Scientist, Administration for Community Living, USDHHS
- John Butterworth, PhD, Institute for Community Inclusion, University of Massachusetts Boston
- Heidi Eschenbacher, PhD, Researcher, Institute on Community Integration, University of Minnesota
- Amie Lulinski, PhD, FAAIDD, Research and Development Coordinator, Coleman Institute for Cognitive Disabilities, University of Colorado
Administration for Community Living (ACL)

ACL brings together the programs and achievements of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, the HHS Office on Disability, and various other programs to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan.

Mission

Maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

Vision

All people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society.
The Administration on Disabilities is headed by a Commissioner, who reports directly to the Administrator, and a Deputy Commissioner/Director of Independent Living. In this dual role, the Deputy Commissioner/Director of Independent Living serves as a member of the Administrator’s senior leadership and reports directly to the Administrator in carrying out the functions of the Director of Independent Living consistent with Section 701A of the Rehabilitation Act.
Administration on Disabilities (AOD)

The Administration on Disabilities (AoD) is the coordinating body that oversees the administration of several programs within the

• Administration on Intellectual and Developmental Disabilities (AIDD)
• Independent Living Administration (ILA)
Administration on Intellectual and Developmental Disabilities

- Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) Programs
- Help America Vote Act (HAVA) Disability Provisions
- Assistive Technology Act Protection and Advocacy provisions
- The Traumatic Brain Injury Act Protection and Advocacy provisions
- President’s Committee for People with Intellectual Disabilities (PCPID)
Principles of the AoD Authorizing Statutes

• Independence, Self-determination: Choice & Control

• Rights, Responsibilities: Equal Access & Participation

• Community Integration, Active Participation: Inclusion & Support

• Productivity & Economic Well Being: Contributing to Household & Community
AIDD PROGRAMS
Projects of National Significance (PNS)

• Create and enhance opportunities for individuals with developmental disabilities to contribute to, and participate in, all facets of community life

• Grants and contracts are awarded to projects that focus on the most pressing issues affecting individuals with developmental disabilities and their families and promote and increase the independence, productivity, inclusion and integration in the community
In recent years PNS has supported projects within the DD Network as well as states agencies and entities that provide supports to individuals with I/DD in the following areas:

- Employment
- Self-Advocacy
- Family Support
- Community Living
- Diversity
- Transportation
- Supported Decision Making
- Business Acumen
- Data Collection
Connecting People to Resources

- **Longitudinal Data Collection Projects**: AIDD has supported 3 data collection studies for over 20 years which keeps our Networks strengthened with information on the States services and trends in the DD field.

  - **The State of the States in Developmental Disabilities** is a comparative nationwide longitudinal study of public financial commitments and programmatic trends in developmental disabilities services and supports.

  - **The National Residential Information System Project (RISP)** is a longitudinal study of annual state-by-state and national statistics on residential services and supports for people with intellectual and developmental disabilities.

  - **Access to Integrated Employment** is a National Data Collection on Day and Employment Services for Citizens with Developmental Disabilities project is a longitudinal study describing day and employment services nationwide for individuals with developmental disabilities.

- **External Assessment of the Data Collection Projects**: the purpose of the assessment was to understand the contributions of the projects and make recommendations to consider during the next funding cycle.
Impact of PNS Initiatives

Longitudinal Data Collection – The data collection projects have made an impact in several areas:

- AIDD grantees use the information for future planning and setting goals
- People with I/DD and family members use the information to compare their states with others regarding DD services
- The information is used to prepare testimony before the U.S. Congress and state legislatures
- Policymakers use the information as background to change law
- Journalists use the information to write in-depth stories
Office of Performance and Evaluation (OPE)

- Part of ACL’s Center for Policy and Evaluation
- Oversees the OAA performance data system, responds to congressional and departmental requests for data, and manages program evaluation
- Compiles, analyzes, publishes, and disseminates data on the health, social, and economic status of older persons and persons with disabilities
Access to Data and Information

www.acl.gov

• Program Evaluations
• Performance of Older Americans Act Programs
• Statistical Reports
• AGing Integrated Database (AGID) website, on-line query system
Background of Profile

• Annual report produced by the Administration for Community Living/HHS

• Data are primarily from the U.S. Census Bureau and National Center for Health Statistics

• Unique report in that it combines the most recent data from several different Federal data sources
Administration on Aging: AGing Integrated Database (AGID)

The AGing Integrated Database (AGID) is an on-line query system based on ACL-related data files and surveys, and includes population characteristics from the Census Bureau for comparison purposes. The four options or paths through AGID provide different levels of focus and aggregation of the data – from individual data elements within Data-at-a-Glance to full database access within Data Files.

Before you begin your query, please review AGID's Resources section with an "About AGID" overview, descriptions of data sources, and frequently asked questions (FAQs). Even experienced AGID users may find the Resources documentation helpful. At any time, you may select from one of the four options below and follow the system prompts. If you need additional assistance, please complete an AGID Support request from the link found at the bottom left of every AGID screen.
Data Sources in AGID

- State Program Reports
- National Survey of Older Americans Act Participants
- American Community Survey Special Tabulation
- National Ombudsman Reporting System
- Title VI Services by Tribal Organization
- Population Estimates
- Census 2010
State Program Reports (SPR)

- Counts and general characteristics (including disability status) of clients served under the OAA
- Service units provided
- Caregiver and grandparent information
- Program utilization and expenditures profiles
- Staffing profiles of SUAs and AAAs
- Focal points and senior centers
- Legal assistance and abuse prevention
Disability Measures in SPR

ADLs - The inability to perform one or more of six activities of daily living without personal assistance, stand-by assistance, supervision or cues:

• Eating
• Dressing
• Bathing
• Toileting
• Transferring in and out of bed/Chair
• Walking
Disability Measures in SPR (cont’d)

IADLs - The inability to perform one or more instrumental activities of daily living without personal assistance, or stand-by assistance, supervision or cues:

- Preparing meals
- Shopping for personal items
- Medication management
- Managing money
- Using telephone
- Doing heavy housework
- Doing light housework
- Transportation ability
Percentage of people age 60+ receiving home-delivered nutrition who have 3+ ADLs

<table>
<thead>
<tr>
<th>Year</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>48</td>
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<td>2007</td>
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<tr>
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<tr>
<td>2014</td>
<td>56</td>
</tr>
<tr>
<td>2015</td>
<td>57</td>
</tr>
<tr>
<td>2016</td>
<td>56</td>
</tr>
</tbody>
</table>

Source: State Program Reports
Percentage of people age 60+ receiving home-delivered nutrition who live below poverty

Sources: State Program Reports and American Community Survey Special Tabulation
National Survey of Older Americans Act Participants (NSOAAP)

Survey of older adults who receive the following services:

• Homemaker services
• Home-delivered nutrition
• Congregate nutrition
• Assisted transportation services
• Case management services
• Caregiver support services
Disability Measures in NSOAAP

- Difficulties/need help with Activities of Daily Living (ADLs)
- Difficulties/need help with Instrumental Activities of Daily Living (IADLs)
- Short form 12 (SF-12) Health Survey
- Medical Conditions
Percentage of people age 60+ who have 3+ ADLs by service type

Source: National Survey of Older Americans Act Participants
American Community Survey
Special Tabulation
• Ongoing national survey that collects data on a sample of the U.S. population to produce detailed population and housing estimates each year
• Designed to produce critical information that had previously come from the Decennial Census long form questionnaire
• Data are available in 1-year and 5-year data files
• Data are available at low levels of geography
Need for ACS Special Tabulation

• Specific geographic needs
  – Planning and Service Areas

• Unique age group served
  – 60 and over
Examples of how ACS Special Tabulation data are used

- Serving as a component in OAA allocation formulas
- Planning programs and services for older adults
- Comparing populations within and across state boundaries
ACS Disability Measures

1. Is this person deaf or have serious difficulty hearing?
2. Is this person blind or have serious difficulty seeing?
3. Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering or making decisions?
4. Does this person have serious difficulty walking or climbing stairs?
5. Does this person have difficulty dressing or bathing?
6. Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor’s office or shopping?
ACS Disability Tables in AGID

- Sex by Age by Disability Status
- Age by Number of Disabilities
- Sex by Age by Hearing Difficulty
- Sex by Age by Vision Difficulty
- Sex by Age by Hearing and Vision Difficulties
- Sex by Age by Cognitive Difficulty
- Sex by Age by Ambulatory Difficulty
- Sex by Age by Self-Care Difficulty
- Sex by Age by Independent Living Difficulty
- Sex by Age by Self-Care/Independent Living Difficulties
- Age by Disability Status by Poverty Status
- Disability Status by Age by Types of Health Insurance Coverage
Percentage of women age 85+ with 3+ disabilities by selected counties

- Suffolk County (Long Island): 33%
- Nassau County (Long Island): 36%
- Richmond County (Staten Island): 38%
- Queens County: 39%
- Bronx County: 41%
- New York County (Manhattan): 43%
- Kings County (Brooklyn): 51%

Source: American Community Survey Special Tabulation, 2011-2015
What do we need?

- Comparable measures of physical, mental, and emotional conditions across data collection efforts
- Better ways to measure mental disorders and cognitive impairment among older adults
- Longitudinal data to better understand the use of HCBS over time
- Nationally representative data to know how many people are using HCBS at any given point in time
Status and Trends in Financing Supports and Services for People with IDD

National Home & Community Based Services Conference
August 30, 2018
Baltimore, MD

Amie Lulinski, PhD, FAAIDD
David Braddock, PhD
Emily Shea Tanis, PhD, FAAIDD
Richard Hemp, MA
Financial and Programmatic Trends Through FY 2015

Published by

American Association on Intellectual and Developmental Disabilities
Follow the money

I. INSTITUTIONAL SERVICES FINANCIAL DATA
(16 or more persons)

A. PUBLIC 16+ INSTITUTIONAL SERVICES FUNDS
1. State Funds
   a. ICF/ID Medicaid Match
   b. General Funds (not including state ICF/ID match)
   c. Other State Funds (not including state ICF/ID match)
   d. Local Funds in Excess of Match
2. Federal Funds
   a. Federal ICF/ID
   b. Title XX/Social Services Block Grant
   c. Other Federal Funds

B. PRIVATE 16+ INSTITUTIONAL SERVICES FUNDS
1. State Funds
   a. ICF/ID Medicaid Match
   b. General Funds (not including state ICF/ID match)
   c. Other State Funds (not including state ICF/ID match)
   d. Local Funds in Excess of Match
2. Federal Funds
   a. Federal ICF/ID
   b. Other Federal Funds

Sources: Braddock et. al. (1981-2017)
What data do we collect? (continued)

II. COMMUNITY SERVICES FINANCIAL DATA
(15 or fewer persons)

A. COMMUNITY SERVICES FUNDS FOR 15 OR FEWER PERSONS
1. State Funds
   a. ICF/ID Medicaid Match
   b. General Funds (not including state ICF/ID match)
   c. Other State Funds (not including state ICF/ID match)
   d. Local/County Funds in Excess of Match
   e. SSI State Supplement Funds

2. Federal Funds
   a. Public ICF/ID (<16)
   b. Private ICF/ID (<16)
   c. HCBS Waiver
   d. Other Medicaid Services
      1. Rehabilitation Services
      2. Clinic Services
      3. Targeted Case Management
      4. Personal Care Services
      5. Other Medicaid Services
   e. Title XX/Social Services Block Grant
   f. Other Federal Funds
   g. SSI and Adults Disabled in Childhood (ADC) benefits – HCBS Waiver participants
What data do we collect? (continued)

I. COMMUNITY RESIDENTIAL SETTINGS (1-6 PERSONS)
   A. Public ICFs/ID
   B. Private ICFs/ID
   C. Supported Living
   D. Personal Assistance
   E. Other residential settings
      (Group homes, apartments, foster, host homes)

II. COMMUNITY RESIDENTIAL SETTINGS (7-15 PERSONS)
   A. Public ICFs/ID
   B. Private ICFs/ID
   C. Other residential settings for 7-15 persons

III. DAY/WORK PROGRAM PARTICIPANTS
   A. Sheltered employment/work activity
   B. Day habilitation ("day training")
   C. Supported/competitive employment

IV. HCBS WAIVER PARTICIPANTS

V. PUBLIC & PRIVATE INSTITUTIONAL SETTINGS (16+ PERSONS)
   A. State-operated institutions
   B. Private ICFs/ID
   C. Other private residential facilities
   D. Nursing facility residents with I/DD

Data Note

- Preliminary FY 2016-17 data
  - Subject to additional analysis

Sustained growth of IDD services spending: FYs 1977 – 2017

One reduction in 2011

Federal, State, and Local Medicaid Spending in FY 2017

- Federal-State-Local Medicaid: 75.7%
- General fund, special tax levies, lottery, other state & local funds: 19.0%
- SSI/ADC, Title XX/SSBG, other federal funds: 13.1%

Total spending: $71.4 billion

Medicaid Spending FY2017

Total federal-state Medicaid: $48.5 billion

Institutional and community spending

Fiscal effort for IDD services in the US: FYs 1977-2017

Spending ($) Per $1,000 Personal Income

Fiscal Year

Total IDD spending by category in US (FY 2017)

- 6 or less residential & related community services: 55%
- Supported living: 16%
- Family support: 9%
- ICF-ID (6 or less): 6%
- 7-15 Person settings: 3%
- Public Institution (16+): 7%
- Private Institution (16+): 3%
- Supported employment: 1%

TOTAL: $71.7 B
Growth between 1993 – 2017:
- Supported Living/Personal Assistance: **1746%**
- Family Supports: **889%**
- Supported employment: **74%**

**Source:** Braddock, D. et al. (2018). *The State of the States in Intellectual Disabilities*
Caregiving families

IDD caregiving families and families supported by state IDD agencies: FY 1988-2017

- Families supported by state IDD agencies
- Total IDD caregiving families

State IDD Agency Technology Spending

Access to data

- Online
  - www.stateofthestates.org
- Hard copy
  - www.aaidd.org
- Technical Assistance
- State-specific briefs and presentations

Personalize a Chart for your State or Region

http://www.StateoftheStates.org/

Creating Charts for Fiscal Year 2015

You can create two types of charts:

A) to compare all or some subset of states or regions; or B) to quickly compare up to four states or regions.

For a chart of multiple states or regions:
1. First select the type of data to compare,
2. Then choose whether to sort alphabetically, from low to high, or from high to low.
3. Complete the selection by choosing all states and all regions or other selected groups of states/regions.

Create Chart

For the second type of chart, first select the type of data to display. Then select up to four states or regions.

Create Chart

Right click on the chart to print.

NOTE: Seven states that no longer finance 16+ person state-operated institutions do, however, finance 16+ private facilities (IN, ME, MI, MN, NH, RI, and WV).

If you need any assistance, contact us at stateofthestates@cu.edu.
State profile www.stateofthestates.org
The State of the States in Developmental Disabilities
University of Colorado
Boulder | Colorado Springs | Denver | Anschutz Medical Campus

Welcome to the website for the State of the States in Developmental Disabilities Project, administered by the University of Colorado. The Project is funded by the Administration on Intellectual and Developmental Disabilities, U.S. Department of Health and Human Services, and by the University of Colorado School of Medicine, Department of Psychiatry.

You can access nationwide longitudinal financial and programmatic trends in intellectual and developmental disabilities services by clicking on State Profiles and Create a Chart.

Creating Charts for Fiscal Year 2015
You can create two types of charts:
A) to compare all or some subset of states or regions (B) to quickly compare up to four states or regions.

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If you need any assistance, contact us at stateofthestates@cu.edu.
Choose a chart (state or region)
www.stateofthestates.org
Create-a-chart, continued

Print to PDF & paste into documents and presentations (don’t forget to cite!)

1. Total Fiscal Effort for I/DD Services: 2015

<table>
<thead>
<tr>
<th>State/Region</th>
<th>$s per $1,000 of personal income</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maryland</td>
<td>$3.35</td>
</tr>
</tbody>
</table>

Total community and institutional spending for I/DD services, per $1,000 of personal income.

Copyright © 2017, The State of the States in Developmental Disabilities Project
The State of the States in Intellectual and Developmental Disabilities

Data Brief 2018 (1)

USE OF STATE INSTITUTIONS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN THE UNITED STATES

Arnie Lutinske & Emily Shea Tans, State of the States in Intellectual and Developmental Disabilities Project, Coleman Institute for Cognitive Disabilities, University of Colorado
Tia Niles, Self Advocates Becoming Empowered

The use of state-operated institutions to provide residential supports to people with intellectual and developmental disabilities (IDD) was highest in 1967. That year, almost 165,000 people with IDD lived in an institution. In 2015, that number dropped to just over 21,000. If people continue to move out of institutions at the same rate, there will be zero people living in them by the year 2030.

Number of People Living in IDD Institutions in the US by Year (1848 - 2016)

Rebalancing of Long-Term Supports and Services for Individuals with Intellectual and Developmental Disabilities in the United States

Arnie Lutinske, PhD, Nicole T. Jorvick, JD, Emily Shea Tans, PhD, & David Braddock, PhD

Background

In 1965, Medicaid was created to finance health care for the aging population, people with disabilities, and the poor. A federal-state partnership in which costs are shared between the federal government and states, the federal government matches state financial investments in Medicaid services based on a formula called Federal Medical Assistance Percentages (FMAP), which takes into account state wealth. All 50 states and the District of Columbia have a Medicaid program.

While Medicaid is a federally administered program, states retain authority and flexibility in providing services to targeted populations on condition that they meet basic Medicaid requirements. Medicaid funds both mandatory services, which states are required to provide under federal law, and optional services that states may opt to cover. Mandatory services include skilled nursing facilities, ICF-MRs, and physician services. Optional services include dental services, transportation, and home and community-based waiver services (HCBS), such as personal care attendants, speech therapy, employment supports, and other services that allow individuals to live in the community.

HCBS is funded through the Medicaid waiver program that waives certain provisions of the Social Security Act to allow for the provision of services outside of institutional settings. The HCBS program waiver began in 1981 as a means to correct the "institutional bias" of Medicaid funding by offering an alternative to institutional services. The vast majority (76%) of the supports and services that individuals with IDD use to...
Like us on FaceBook
Follow us on Twitter@SOS_in_DD
Email us:
Shea.Tanis@cu.edu
Amie.Lulinski@cu.edu

To learn more about the Coleman Institute visit
www.ColemanInstitute.org

For more information about State of the States visit:
http://www.StateoftheStates.org

Financial support for this project was obtained from the U.S. Administration on Intellectual and Developmental Disabilities and the Coleman Institute for Cognitive Disabilities, University of Colorado.
Community Inclusion and the Residential Information Systems Project (RISP)

risp.umn.edu    risp@umn.edu

HCBS Conference 2018
Heidi Eschenbacher hje@umn.edu


Preparation of this presentation was supported, in part, by cooperative agreements (90DN0297, 90DN0291, and 90RT5019-01-00) from the US Health and Human Services, Administration on Community Living. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore necessarily represent official AIDD policy.
People with IDD in the US in 2016

2% of the U.S. population

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
Where did LTSS Recipients with IDD live?

- Family Home: 58%
- Own Home: 12%
- Host/Foster Family: 5%
- IDD Group 1-3: 7%
- IDD Group 4-6: 11%
- IDD Group 7: 4%
- IDD Group 16+: 3%
- Nursing home and Psychiatric Facility: 1,228,700 LTSS

Residents often do not receive LTSS through IDD Agencies.
Average Number of LTSS Recipients with IDD Per Setting as of June 30, 2016

- **State ICF/IID**: 68.8
- **Nonstate ICF/IID**: 18.6
- **Nonstate Group Home**: 9.2
- **Host/Foster Family Home**: 5.2
- **Nonstate ICF/IID**: 3.4
- **Host/Foster Family Home**: 2.2

This figure does not include LTSS recipients living in the home of a family member.

An average of **2.2 people** lived in each non-family IDD setting.

- **2.1 people** per setting in nonstate settings
- **14.0 people** per setting for state-operated settings
Historic Trends: RISP tracks LTSS for people with IDD (e.g., deinstitutionalization)

Number of people in State-Operated Facilities with 16 or more people with IDD

- 1880, 2,429
- 1910, 19,499
- 1939, 101,396
- 1967, 194,650
- 1987, 95,886
- 2016, 19,502

Average Daily Population
Historic Trends: State IDD Agencies are serving more people, particularly in community settings.
Settings Rule Implications:
Percent of LTSS Recipients who lived with 3 or fewer and 6 or fewer people with IDD on June 30, 2016

* Imputed values for 1-3 and 4-6 proportions based on national estimates.

Percentages among people who receive LTSS who do not live with family members.
Number of People Receiving Waiver-Funded Supports per 100,000 of the Population

250 people with IDD per 100,000 of the population received Medicaid Waiver-funded supports

[Map showing the number of people receiving waiver-funded supports per 100,000 of the population across the United States.]
Age and Spending for Waiver Recipients Settings in 2016

Of the 807,462 Medicaid Waiver recipients with IDD:

- 25% were 21 years or younger
- 75% were 22 years or older

Annual per person Medicaid Waiver expenditures:

- 21 years and younger: $17,404
- 22 years and older: $52,918
Number of People in ICF/IID Settings per 100,000 of the Population

23.2 people with IDD per 100,000 of the population lived in an ICF/IID

Map showing the distribution of people in ICF/IID settings across the United States.
Age and Spending for People Living in ICF/IID Settings in 2016

Of the 74,614 people living in ICF/IID settings:

- 7% were 21 years or younger
- 93% were 22 years or older

Annual per person ICF/IID expenditures

- 21 years and younger: $117,714
- 22 years and older: $142,499
Number of Individuals by Medicaid Funding Authority and Residence Type with Average Per Person Expenditure FY 2016

**People**
- Waiver (Family Home): 173,363
- Waiver (Other Setting): 254,547
- Waiver (all settings): 348,509
- ICF/IID: 603,056

**Cost Per Person**
- Birth to 21 years: $13,831, $37,360, $72,224
- 22 years or more: $26,486, $17,404, $52,918
- ICF/IID: $117,714, $142,499

Caution: Data may not sum to totals due to rounding.
What’s available online

- State Profiles
- Interactive Visualizations
- Reports
- Infographic pages

Maryland
Living Arrangements of LTSS Recipients by Fiscal Year over Time

The number of Long-Term Supports and Services Recipients is for the IDD Agency in the state. Group settings (1-6, 7-15, and 16+) include ICF/IID, group homes, and other congregate settings.
Contact Us with questions or for technical assistance

Heidi Eschenbacher hje@umn.edu
Sheryl Larson, Ph.D. Principal Investigator

RISP MN: Amy Hewitt (ICI Director), Sheryl Larson (Principal Investigator), Heidi Eschenbacher, Lynda Anderson, Sandy Pettingell, Kristin Dean, Jonathan Walz, Shawn Lawler, John Westerman, Sarah Hollerich

HSRI: Brittany Taylor, Yoshi Kardell, John Agosta

NASDDDS: Mary Lee Fay, Mary Sowers, Mary Lou Bourne

Research and Training Center on Community Living
Institute on Community Integration (UCEDD)
University of Minnesota, Twin Cities
214 Pattee Hall, 150 Pillsbury Drive SE
Minneapolis, MN 55455

For general questions: risp@umn.edu
Access to Integrated Employment
National Data Collection on Day and Employment Services

StateData.info

ThinkWork!
Core Activities

- National Survey on Day and Employment Services
  State IDD Agencies

- VR services and outcomes
  RSA 911

- National Core Indicators

- American Community Survey
  Employment participation and outcomes

- Social Security Administration
  Work incentive use, work participation

- Workforce development
  Number of customers, entry into employment
Core Activities

- Promising Practices
  IDD Agency, Community Providers, Community Life Engagement

- National Survey of Community Rehabilitation Providers

- Employment first case studies

- Young Adult Outcomes and Services Report

- Real People Real Jobs
  www.realworkstories.org

www.ThinkWork.org
Number in Employment and Day Services

Source: ICI National Survey of State IDD Agencies
Participation in integrated employment services varies widely

Source: ICI National Survey of State IDD Agencies 2015
StateData: The National Report on Employment Services and Outcomes


Download the PDF here*

Download the report narrative, no tables (Accessible PDF)

Download Your State:

- Choose -

View state summary

Build a Chart

Our chart-building tool offers descriptive information on state characteristics and services drawn from several national databases. View a single state trend, or compare several states and national data.

Data Updates
- According to WIOA data, there has been a
Individuals may be working or be on a pathway to employment.

<table>
<thead>
<tr>
<th></th>
<th>Massachusetts 2015</th>
<th>Nation 2015</th>
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<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td>Total in day and employment services</td>
<td>16,217</td>
<td></td>
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<tr>
<td>Total in integrated employment services</td>
<td>6,222</td>
<td>38%</td>
</tr>
<tr>
<td>Total funding for day and employment services</td>
<td>$125,858,386.00</td>
<td></td>
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<tr>
<td>Total funding for integrated employment services</td>
<td>$49,328,917.00</td>
<td>39.2%</td>
</tr>
</tbody>
</table>

* = Data not available

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**How many people are working for pay in an integrated job?**

Source: National Core Indicators Project Adult Consumer Survey (http://www.nationalcoreindicators.org)

Who: Individuals who receive any service other than/in addition to case management from the state IDD agency. Inclusion criteria varies by state.

What: Individuals who are reported as working for pay in an integrated job.

<table>
<thead>
<tr>
<th></th>
<th>Massachusetts 2015/2016</th>
<th>Mean hours worked in 2 weeks</th>
<th>Mean wages earned in 2 weeks</th>
<th>Nation 2015/2016</th>
<th>Mean hours worked in 2 weeks</th>
<th>Mean wages earned in 2 weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percent</td>
<td></td>
<td></td>
<td>Percent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In an integrated job</td>
<td>individual supported job + group supported employment + competitive job</td>
<td>30%</td>
<td>*</td>
<td>19%</td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

---

*individual supported job + group supported employment + competitive job*
## Works in integrated employment

**Mean Hours and Wages per 2 weeks**

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>Hours worked</th>
<th>Gross Wages</th>
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</thead>
<tbody>
<tr>
<td>In an integrated job</td>
<td>20%</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>In an individual job</td>
<td>12%</td>
<td>*</td>
<td>*</td>
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<tr>
<td>Individual job with funded supports</td>
<td>5.6</td>
<td>25</td>
<td>$212</td>
</tr>
<tr>
<td>Individual job without funded supports</td>
<td>6.4%</td>
<td>29</td>
<td>$258</td>
</tr>
<tr>
<td>In a group supported job</td>
<td>5.5%</td>
<td>30</td>
<td>$174</td>
</tr>
<tr>
<td>Not specified</td>
<td>2.8%</td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

Source: National Core Indicators Project 2017-2017
Build a chart

- Population Data from the American Community Survey (Post 2007)
- Social Security Administration
- State Demographics
- State IDD Agencies
- State Mental Health Agency Data
- State Vocational Rehabilitation (VR) Agency Data
- Wagner Peyser job Seeker Data
- Workforce Development, Adults
- Workforce Development, Dislocated Workers

Select additional states for comparison

- U.S. Total
- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia

Select a variable *

- Total served
- Integrated employment, number
VR trends: Nation
Number of closures: Persons with ID

Source: RSA 911
Use of work incentives:
Impairment Related Work Expenses

Source: SSA
Pro tip #1: Select all states to see a state by state table

Select Data Source
Population Data from the American Community Survey (Post 2007)

Select a state
U.S. Total

Select additional states for comparison
U.S. Total
Alabama
Alaska
Arizona
Arkansas
California
Colorado
Connecticut
Delaware
District of Columbia

Select a category
Cognitive Disability

Select a variable *
Pro tip 2:

<table>
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<tr>
<th>State</th>
<th>31.83</th>
<th>34.57</th>
<th>29.76</th>
<th>32.19</th>
<th>33.64</th>
<th>34.91</th>
<th>34.32</th>
<th>34.71</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Virginia</td>
<td>37.41</td>
<td>40.40</td>
<td>41.61</td>
<td>40.80</td>
<td>38.53</td>
<td>36.27</td>
<td>43.29</td>
<td>36.50</td>
</tr>
<tr>
<td>Wyoming</td>
<td>22.98</td>
<td>30.15</td>
<td>27.50</td>
<td>25.37</td>
<td>32.62</td>
<td>23.92</td>
<td>24.35</td>
<td>13.00</td>
</tr>
</tbody>
</table>

Download the table above as a CSV file (for use in Excel) | Email chart

Download the table

Email the chart
John Butterworth
john.butterworth@umb.edu
Jean Winsor
Jean.winsor@umb.edu

www.ThinkWork.org

www.RealWorkStories.org
The Who & What

- The Administration on Intellectual and Developmental Disabilities (AIDD) at the Administration for Community Living (ACL) has been leading an effort within the United States Department of Health and Human Services (USDHHS) to:
  - Update national prevalence data
  - Gain better understanding of health and health status of people with IDD
  - Look at best practices for the collection of state data
What does the data tell us to do?

We only have bad data on this.

Does the bad data suggest we should do what we wanted to do anyway?

Well, yes.

That's called "good data."
The Why

• To improve standardization and utilization of state data about health status and factors that influence health of individuals with ID/DD.

• Need for better information that influences federal and state agencies:
  – Solid Fiscal policy
  – Solid program policy
  – Performance evaluation
Brief History

2015:
- Initial exploratory discussions with ASPE, NCHS, CDC/NCBDDD and ACL colleagues

2016:
- Continued discussions

2017:
- Expanded the group to include CMS and OMH
- Held meeting of federal partners and external researchers and subject matter experts to discuss and identify next steps (November).
Brief History

2018:
• Formed two workgroups of federal and non-federal experts to develop recommendations on:
  – Workgroup 1: Identifying Prevalence of the Population of Individuals With Intellectual and Developmental Disabilities
Health Surveillance for People with Intellectual and Developmental Disabilities
Overview

• Why knowing about health of people with intellectual and developmental disabilities is important

• Surveillance as context for understanding other data

• Inter-agency meeting organized by AIDD, Nov 2-3, 2017
Need for Health Data about People with IDD

• HHS agencies need data for projections and planning

• AIDD need for prevalence data

• High need for services → Cost
PREVALENCE OF INTELLECTUAL DISABILITY AND DEVELOPMENTAL DISABILITIES
Estimated Prevalence of Child and Adult ID and DD (%)
PREVIOUS WORK ON HEALTH SURVEILLANCE OF PEOPLE WITH INTELLECTUAL & DEVELOPMENTAL DISABILITIES
Recognizing the Need for Health Surveillance

• Surgeon General’s Listening Session and Report, 2001

• Special Olympics Healthy Athletes; National Core Indicators data sets

• Numerous papers, including IASSID reports

• CDC/AUCD/ADD meetings—(2009, 2010, 2012)
  – Five-stage plan (2010)
<table>
<thead>
<tr>
<th>Plan to Advance Health Surveillance and IDD*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Define ID conceptually and operationally</td>
</tr>
<tr>
<td>(Bonardi, Lauer, Mitra, Bershadsky, Taub, Noblett, 2011)</td>
</tr>
<tr>
<td>2. Compile and synthesize a knowledge base</td>
</tr>
<tr>
<td>(Bonardi, Lauer, Noblett, Taub, Bershadsky, 2011)</td>
</tr>
<tr>
<td>3. Extend past analyses of existing data</td>
</tr>
<tr>
<td>Manitoba Data Repository; SC Data Cube; NCI; Healthy Athletes</td>
</tr>
<tr>
<td>4. Pilot state or regional demonstrations</td>
</tr>
<tr>
<td>(McDermott, Royer, Cope, Lindgren, et al, 2018)</td>
</tr>
<tr>
<td>5. Expand surveillance nationally</td>
</tr>
<tr>
<td>Where we are NOW</td>
</tr>
</tbody>
</table>

*Krahn, Fox, Campbell, Ramon & Jesien, 2010; Fox, Bonardi & Krahn, 2016*
Charges to Workgroups

Overall Charge:
“To prioritize and address the need for better data to understand the prevalence, health status and health determinants of people with intellectual and developmental disabilities.”

Surveillance Workgroup:
To develop survey questions/domains/constructs that could be used in national surveys to get an updated prevalence of individuals with IDD.

State and Local Administrative Data:
Look for and describe best practices that could lead to better standardization and utilization of state data regarding health status and other factors for people with IDD.
Identifying Persons with Intellectual and Developmental Disabilities in National Population Surveys
Process and Product

1. Workgroup met February to July 2018 to discuss the IDD construct and how to best identify people with IDD in survey research
2. White paper that provides historical context and alternative conceptualizations that underlie measurement approaches
3. Defines ID and DD
4. Describes currently available IDD prevalence estimates
5. Identifies gaps in current surveillance efforts
6. Proposes strategies for national survey programs
7. Identifies key constructs that must be measured
   1. Minimal questions needed to identify for health research
   2. Additional domains needed for incidence and prevalence
8. Methodological considerations
9. Anticipated next steps
<table>
<thead>
<tr>
<th>Life Activity</th>
<th>ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning</td>
<td>✓</td>
</tr>
<tr>
<td>Conceptual Skills</td>
<td>✓</td>
</tr>
<tr>
<td>Self-Care</td>
<td>✓</td>
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<tr>
<td>Social skills</td>
<td>✓</td>
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<tr>
<td>Communication</td>
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<tr>
<td>Mobility</td>
<td></td>
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<tr>
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<tr>
<td>Economic self-sufficiency</td>
<td></td>
</tr>
<tr>
<td>Other Criteria</td>
<td></td>
</tr>
<tr>
<td>Age of onset</td>
<td>✓ (18)</td>
</tr>
<tr>
<td>Severity</td>
<td>✓</td>
</tr>
<tr>
<td>Duration</td>
<td></td>
</tr>
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</table>

**Intellectual Disability**  
(Schalock et al, 2010)

significant limitations in both intellectual functioning and in adaptive behavior, which originates before the age of 18
### Life Activity

<table>
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<tr>
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<tbody>
<tr>
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**DD Act of 2000**

severe, chronic disability that is
• attributable to a mental or physical impairment, is
• manifested before age 22,
• is likely to continue indefinitely,
• results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive or expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency;
• and reflects the individual’s need for a combination and sequence of services and supports
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<td></td>
<td>✓</td>
</tr>
</tbody>
</table>
Methodological Considerations

- Benchmarking—benchmark estimates of the number of people with IDD in the US vary by source
  - Public health surveillance
  - Administrative data
  - Nationally representative surveys
  - Which segments of the population are included and excluded from the survey (e.g., age, type of disability)
  - Three years of survey data will be needed to benchmark an updated prevalence rate.
Methodological Considerations

• Item development and testing: NHCS lab conducts extensive testing on all items included in the NHIS
  – learning and self-direction have been difficult to measure in cognitive testing
• Ensuring inclusion of diverse populations
  – culturally sensitive survey design includes a sampling frame must contain diverse populations and oversamples for underrepresented groups
  – attend to cultural and linguistic differences
Anticipated Next Steps

1. AIDD has entered into an interagency agreement with NCHS to construct and cognitively test survey questions to identify adults with IDD

2. Continue to build collaboration and awareness of the need to implement national prevalence and health surveillance practices that allow regular and timely updating of the population with IDD

3. Explore how to have questions included in future iterations of the NHIS to meet benchmarking requirements
State and Local Data to Inform Surveillance of the Population with Intellectual and Developmental Disabilities
Previous efforts have described potential data at the state level. ¹

– Administrative data from state service systems
– Health insurance (payor) claims
– State level (population-level) surveys.
Limitations in using state-level data for surveillance:

– Administrative data (collected to administer a program, service, or pay for a program or service)
– Shifts in policy (e.g. to Managed Care) can modify how and who is responsible for data collection.
– Survey data (collected from a sample to learn about the characteristics of a population). [workgroup 1 can talk a lot about this! ]

– Purpose of the data collection (e.g. for eligibility, billing, health information...) drives data collection elements (and accuracy)
Unlocking the potential of state level data

1. Intra-state. Establish effective approaches for population identification, along with priority measures **within a state**.

2. Across states. Ability to interpret state level data at a national level requires data collection and population identification with a view to combining **across multiple states**.
Potential for use of data within states

Data sources considered for using administrative data to examine health and other outcomes for people with IDD.

- State DD service agencies
- Education / Transition programs
- Medicaid and other Health Care claims data
- Social Security Administration
- State level surveys (National Core Indicators, HCBS-CAHPS, BRFSS)
- Registries
Data collection in the US Territories

- Keep in mind – data is not as robust as in states and District of Columbia
- All territories participate in census but not ACS
- USVI has HeadStart data, including numbers of children with developmental delay, disability
- No territories participate in Medicaid ICF/ID or HCBS (administrative data not available)

- Takeaway – additional challenges in population level data collection in territories.
HIGHLIGHTING STATES USING AVAILABLE DATA
Washington

• State tracks people receiving closely, can produce detailed reports about services received.

• Outreach to people beyond those deemed ‘eligible for IDD services’. Families-informing families directed outreach (tools, info, culture-specific info.) http://informingfamilies.org

• Presently, transition to behavioral health services through managed care, possibly raising issue of availability of data going forward.
Ohio

- Department of Developmental Disabilities (DODD) used a matching methodology to link Medicaid records to active recipients from DD state agency.
- Allows for robust analysis of targeted health services utilization.
- Made possible by ensuring adequate analysis capacity within DODD, with knowledge of state Medicaid data.
- Other states have demonstrated data linkages with state IDD agency, but a minority do this routinely
South Carolina

• Partnership between University of South Carolina and state repository of numerous datasets allowed for creation of “Disability Cube”.

• Ongoing linkage allows for multiple analyses.

Recent publication:
California

- Launched initiative to monitor, publicly report service data by race, ethnicity, language spoken, among other personal characteristics.
- Examination of access and outcomes and potential disparities.
- Race/ethnicity in general population in regional center’s catchment area compared to demographics of population receiving services.
- Legislative action encouraged monitoring and public reporting of data – included an appropriation of $11M annually in targeted funding to work with communities to ensure equitable access.
CDC seven state Cooperative Agreement

- AK, IA, MA, NH, MY, OR, SC funded to implement Medicaid analyses across states

Multiple publications have resulted, most recently:

- Large, multi-state dataset and standardized case-identification algorithm in Medicaid data
- Includes only Medicaid members – identified with IDD
- Variation in Medicaid eligibility rules, data coding procedures across states
Strategies and opportunities to enhance available data

- Expanding electronic data systems (e.g. T-MSIS)
- Linkages (e.g. SC, OH)
- Data harmonization (e.g. 7 state Medicaid project)
- ‘Indirect estimation’ (e.g. CMS Office of Minority Health project with RAND Corporation to enhance quality of race, ethnicity, language data).
- Proposed: Capture/Recapture methodology
Capacity Building

• Encourage federal and state partners to include measures of race, ethnicity, primary language

• Learning collaborative comprised of state and federal agencies that collect data on the people with intellectual and developmental disabilities to develop and test system changes that can be implemented on a broader level.

• Identify and disseminate successful strategies states are using to collect data, merge files, share findings.
Expanded data collection to fill enduring challenges with state-level data.

Studies proposed to fill gaps:

- Longitudinal study
- Qualitative and quantitative studies to allow for exploration of disparities at intersection of race, ethnicity and disability
- Promote data collection efforts that include categories of ID, DD, mental health/behavioral health diagnoses
Next Steps Workgroup One:

1. AIDD has entered into an interagency agreement with NCHS to construct and cognitively test survey questions to identify adults with IDD

2. Continue to build collaboration and awareness of the need to implement national prevalence and health surveillance practices that allow regular and timely updating of the population with IDD

3. Explore how to have questions included in future iterations of the NHIS to meet benchmarking requirements
Next Steps Workgroup Two:

- Work collaboratively with internal federal partners and stakeholders to review work group recommendations.
- Consider federal/state; public/private; federal/federal partnerships to fund recommendations
How Long???

• 1 to 5 year goal:
  • Jan 2020: Complete survey questions
  • 2020/2021: NHIS Year 1 survey
  • 2022/2023: NHIS Year 2 survey
  • Begin learning collaborative, community of practice, and/or demonstrations to improve data collection at the state level

• 5 to 10 year goal:
  • 2025/26: NHIS Year 3 survey
  • 2027: Benchmark New IDD Prevalence
  • Data from state data projects becomes available

• 10 + year goal:
  • Regular updates of IDD prevalence
  • 50% of states have improved state level data for individuals with IDD
THANK YOU