Building Your Advocacy Case with Data

Disability Policy Seminar
April 24, 2018
Washington, DC

Amie Lulinski, PhD
Wanda P. Felty
David Braddock, PhD
Emily Shea Tanis, PhD
Richard Hemp, MA
“Don’t tell me what you value, show me your budget, and I’ll tell you what you value.”

~Joe Biden, 47th Vice President of the United States
1. 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/MR match)  
      c. Other State Funds (not including state ICF/MR 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)
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
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

State protocol

Selected examples

- Review of:
  - Published budget documents
  - Conversations with state IDD agency personnel

- Data collection tool
  - Excel spreadsheets
    - Revenue and expenditure data
    - Number of participants
    - Spending, revenue, and participant data on specific support categories
  - Accompanied by an instruction guide and definitions
National data sources

United States Census Bureau

Social Security Administration

National Governors Association

CENTERS for MEDICARE & MEDICAID SERVICES

State of the States in Intellectual and Developmental Disabilities
US IDD institutional census (1848-2015)
<table>
<thead>
<tr>
<th>State</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>District of Columbia</td>
<td>1991</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>1991</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>1994</td>
</tr>
<tr>
<td>Vermont</td>
<td>1995</td>
</tr>
<tr>
<td>Alaska</td>
<td>1997</td>
</tr>
<tr>
<td>New Mexico</td>
<td>1997</td>
</tr>
<tr>
<td>West Virginia</td>
<td>1998</td>
</tr>
<tr>
<td>Hawaii</td>
<td>1999</td>
</tr>
<tr>
<td>Maine</td>
<td>1999</td>
</tr>
<tr>
<td>Minnesota</td>
<td>2000</td>
</tr>
<tr>
<td>Indiana</td>
<td>2007</td>
</tr>
<tr>
<td>Michigan</td>
<td>2009</td>
</tr>
<tr>
<td>Oregon</td>
<td>2009</td>
</tr>
<tr>
<td>Alabama</td>
<td>2012</td>
</tr>
</tbody>
</table>

Projected institutional closures through 2020
Projected Trend in Public Institutional Census: 1977 - 2030

Thousands of Residents

- 150,207
- 21,103 (2015)
## Who’s next? Smallest IDD institutional censuses

<table>
<thead>
<tr>
<th>State</th>
<th>FY2015 census</th>
<th>FY2017 census</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Idaho</td>
<td>23</td>
<td>25</td>
<td>9%</td>
</tr>
<tr>
<td>2. Nevada</td>
<td>47</td>
<td>48</td>
<td>2%</td>
</tr>
<tr>
<td>3. Delaware</td>
<td>54</td>
<td>48</td>
<td>-11%</td>
</tr>
<tr>
<td>4. Montana</td>
<td>55</td>
<td>21</td>
<td>-62%</td>
</tr>
<tr>
<td>5. Oklahoma</td>
<td>66</td>
<td>50</td>
<td>-24%</td>
</tr>
<tr>
<td>6. Wyoming</td>
<td>70</td>
<td>64</td>
<td>-9%</td>
</tr>
<tr>
<td>7. North Dakota</td>
<td>82</td>
<td>74</td>
<td>-10%</td>
</tr>
<tr>
<td>8. Arizona</td>
<td>93</td>
<td>83</td>
<td>-11%</td>
</tr>
<tr>
<td>9. Nebraska</td>
<td>116</td>
<td>111</td>
<td>-5%</td>
</tr>
<tr>
<td>10. Maryland</td>
<td>122</td>
<td>92</td>
<td>-25%</td>
</tr>
</tbody>
</table>

Source: Braddock, et al.(2018). *Preliminary Data from The State of the States in Intellectual and Developmental Disabilities*
## Ten largest IDD institutional censuses

<table>
<thead>
<tr>
<th>State</th>
<th>FY2015 census</th>
<th>FY2017 census*</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Texas</td>
<td>3,541</td>
<td>Not yet reported</td>
<td>n/a</td>
</tr>
<tr>
<td>2. Illinois</td>
<td>1,724</td>
<td>1,656</td>
<td>-4%</td>
</tr>
<tr>
<td>3. New Jersey</td>
<td>1,701</td>
<td>1,437</td>
<td>-15%</td>
</tr>
<tr>
<td>4. North Carolina</td>
<td>1,194</td>
<td>1,125</td>
<td>-6%</td>
</tr>
<tr>
<td>5. Mississippi</td>
<td>1,063</td>
<td>938</td>
<td>-12%</td>
</tr>
<tr>
<td>6. California</td>
<td>1,011</td>
<td>787</td>
<td>-22%</td>
</tr>
<tr>
<td>7. Pennsylvania</td>
<td>971</td>
<td>880</td>
<td>-9%</td>
</tr>
<tr>
<td>8. Ohio</td>
<td>923</td>
<td>702</td>
<td>-24%</td>
</tr>
<tr>
<td>9. Arkansas</td>
<td>918</td>
<td>907</td>
<td>-1%</td>
</tr>
<tr>
<td>10. Florida</td>
<td>774</td>
<td>774</td>
<td>0</td>
</tr>
</tbody>
</table>

Sustained growth of IDD service spending: 1977-2015

One reduction: -0.8% in 2011
Federal, state, and local Medicaid spending in FY 2015

TOTAL IDD SPENDING: $65.21 BILLION

*TOTAL FEDERAL-STATE MEDICAID: $49.4 BILLION
  a) HCBS WAIVER (70%)
  b) PUBLIC & PRIVATE ICFs/ID (22%)
  c) STATE PLAN MEDICAID (8%)
Estimated distribution of people with IDD by living arrangement (FY 2015)

- **SUPERVISED RESIDENTIAL SETTING**: 683,290 (13.5%)
- **WITH FAMILY CAREGIVER**: 3,590,998 (70.9%)
- **ALONE OR WITH ROOMATE**: 793,615 (15.7%)

**TOTAL: 5,067,903 PERSONS**

*Source:* Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2016, based on Fujiura (2015).
Out-of-home placements

PRIVATE 16+ INSTITUTIONS 48,454
STATE 16+ INSTITUTIONS 21,103
7-15 PERSONS 52,122

SUPPORTED LIVING 337,264 PERSONS
Group, foster, host homes, apartments 221,908 Persons

TOTAL: 680,851 PERSONS

*82% ARE IN 6/FEWER SETTINGS*
Use of IDD residential settings for six or fewer are growing

Thousands of Persons

- **6 or Fewer Person Settings**
  - 1980: 259,909
  - 2000: 441,101
  - 2020: 680,851
  - 2030: 880,226

- **7-15 Person Settings**
  - 1980: 321,552
  - 2000: 594,389
  - 2020: 737,950

- **Public and Private 16 + Person Settings**

**STATE OF THE STATES**
INTELLECTUAL AND
developmental disabilities
Estimated distribution of people with IDD by living arrangement, FY 2015

TOTAL: 5,067,903 PERSONS

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2016, based on Fujiura (2015).
Estimated number of individuals with IDD living with family caregiver by age group, FY 2015

Total: 3,590,998 Caregivers

Largest Growth is in Individual and Family Support

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017
17% of caregiving families received formal IDD agency supports
Projected aging of America

US Population 65 Years and Older

- 16.7 million in 1960
- 25.5 million in 1980
- 34.9 million in 2000
- 41.4 million in 2011
- 47.7 million in 2015
- 56.0 million in 2020
- 72.8 million in 2030
- 79.7 million in 2040
- 83.7 million in 2050
- 92.0 million in 2060

% of Total US Population: 25.0%

Source: US Census Bureau
Supported employment

Supported Employment Spending
(FY1985 - 2015)

IFS & SEP spending

![Graph showing Individual Support, Family Support & Supported Employment Spending (FY1995-2015). The graph indicates an increasing trend in spending over the years, with notable amounts of spending at various fiscal years.

Technology spending

Technology Spending by State IDD Agencies (FY2008 - 2017*)

*FY 2016 – 2017 data is preliminary with 40 states obtained; 15 reporting technology spending
DSP Workforce – Projected demand

Home Health Aides and Personal Care Aides
Percent change in employment, projected 2016-26

- Home health aides: 47%
- Home health aides and personal care aides: 41%
- Personal care aides: 39%
- Total, all occupations: 7%

Note: All Occupations includes all occupations in the U.S. Economy.
DSP Workforce – comparative pay

Home Health Aides and Personal Care Aides
Median annual wages, May 2016

- Total, all occupations: $37,040
- Home health aides: $22,600
- Home health aides and personal care aides: $22,170
- Personal care aides: $21,920

Note: All Occupations includes all occupations in the U.S. Economy.
Untapped resources

TOTAL IDD SPENDING:
MATCHED AND UNMATCHED FUNDS*

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017.
Note: Total Spending in 2016 and 2017 based on 3% adjusted annual growth FY 2009-15;
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](http://www.stateofthestates.org)
Create-a-chart  www.StateoftheStates.org

The State of the States in Developmental Disabilities
University of Colorado
Boulder | Colorado Springs | Denver | Anschutz Medical Campus

Creating Charts for Fiscal Year 2015
You can create two types of charts:

A) to compare all or some subset of states or regions; you can quickly compare up to four 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 or all regions, or other selected groups of states/regions.

B) for a chart of multiple states or regions:

1. 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.
Create-a-chart (state)
www.stateofthestates.org

Choose your variables
Choose your state(s)

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

1. Total Fiscal Effort for IDD 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 IDD services, per $1,000 of personal income.

Copyright © 2017, The State of the States in Developmental Disabilities Project
Create-a-chart (region)
www.stateofthestates.org

Choose your variables

De-Select all states

Choose your region & then your states
Chose table or chart. 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>GREAT LAKES REGION</td>
<td>$4.91</td>
</tr>
<tr>
<td>Illinois</td>
<td>$2.72</td>
</tr>
<tr>
<td>Indiana</td>
<td>$5.60</td>
</tr>
<tr>
<td>Michigan</td>
<td>$3.71</td>
</tr>
<tr>
<td>Minnesota</td>
<td>$6.95</td>
</tr>
<tr>
<td>Ohio</td>
<td>$6.77</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>$5.73</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
Using SOS data for advocacy

- Advocacy organizations
  - State budget hearings
  - Advocacy efforts
  - Strategic planning

- DD Councils
  - Five year plan
  - Advocacy
  - Make the case for services/supports
“Don’t tell me what you value, show me your budget, and I’ll tell you what you value.”

~Joe Biden, 47th Vice President of the United States
Keep in Touch!

@SOS_in_DD
Shea.Tanis@cu.edu
Rick.Hemp@cu.edu
Amie.Lulinski@cu.edu

Wanda P. Felty
http://www.ouhsc.edu/thecenter
Wanda-Felty@ouhsc.edu