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The Residential Information Systems Project (RISP)

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University of Minnesota

Mary Sowers
National Association of
State Directors of
Developmental
Disabilities Services
(NASDDDS)

Brittany Taylor, MSSW
Human Services Research Institute
Residential Information Systems Project (RISP)
An Administration on Community Living
Data Project of National Significance

Funded under the DD Act of 1988 and subsequent reauthorizations to inform Congressional decisions about funding supports and services for people with IDD.
RISP Purpose

- Track status and trends in long-term supports and services (LTSS) for people with intellectual or developmental disabilities (IDD)
  - Nationally
  - State-by-state
- Provide research evidence used by federal and state policy makers, advocates and other stakeholders to:
  - Describe national and state trends in LTSS for people with IDD
  - Compare a state’s performance to the nation or other states
  - Inform legislation, litigation and policy decisions
  - Advocate for systems change
  - Evaluate impact of policy decisions
- Inform and provide a context for research and training
  - Describe state variations in service utilization and expenditures
  - Provide context for public discourse (in the media, by advocates)
RISP Topics

- Conduct annual surveys of IDD agencies in 50 states and the District of Columbia
- Collect longitudinal data on
  - Medicaid- and State-funded Long-Term Supports and Services (LTSS) for people with Intellectual or Developmental Disabilities (IDD) since 1977
  - Residential IDD Institutions since 1880
- Report Status and Trends in
  - Living arrangements (Own home, family home, congregate settings)
  - Supports for families
  - Congregate setting sizes
  - Medicaid rebalancing and deinstitutionalization
  - State-operated residential services
  - Medicaid utilization and expenditures
  - Age of LTSS recipients
- Monitor the impact of legislation, policy and litigation on services for people with IDD

risp.umn.edu
Long-Term Supports and Services

- Supported or competitive employment
- Adult day care
- Environmental Modifications and Technology
- Supports for families
- Habilitation (skill development)
- Behavior Supports
Long-Term Supports and Services

- Personal Care: ADLs
- Residential and In-home Services: IADLs
- Respite
- In-Home Therapies and Medical Supports
- Participant Directed Supports
- Transportation
## Long-Term Supports and Services Dimensions

<table>
<thead>
<tr>
<th>Operating Entity</th>
<th>Setting Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>(State vs Nonstate)</td>
<td>(Own home, family home, host/foster home, group residence, institution)</td>
</tr>
<tr>
<td>The proportion of LTSS recipients living in non-state settings increased from 37% in 1977 to 93% in 2014</td>
<td>57% of LTSS recipients lived in the home of a family member</td>
</tr>
</tbody>
</table>

### Funding Authority

<table>
<thead>
<tr>
<th>(Medicaid State Plan, Waiver, ICF/IID; State only)</th>
</tr>
</thead>
<tbody>
<tr>
<td>91% of 826,350 Medicaid ICF/IID plus waiver recipients received Medicaid Waiver funding.</td>
</tr>
</tbody>
</table>

### Setting Size

<table>
<thead>
<tr>
<th>(1-3, 4-6, 7-15, 16+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Of 483,784 LTSS recipients not living with a family member</td>
</tr>
<tr>
<td>53% lived in settings of 1 to 3 people</td>
</tr>
<tr>
<td>26% lived in settings of 4 to 6 people</td>
</tr>
</tbody>
</table>

### Age

<table>
<thead>
<tr>
<th>61% of LTSS recipients were 22 years +</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range: 34% (AZ) to 95% (DC)</td>
</tr>
</tbody>
</table>
Prevalence of Intellectual and Developmental Disabilities

How many people in the U.S. have an IDD?
How many receive supports and services?
1.17 million received long-term supports or services through state IDD agencies.
State IDD Agency Caseloads per 100,000

431 per 100,000 people in the United States are known to state IDD agencies (on their caseload).
LTSS Policy
Milestones

1965 Medicaid Program
1971 Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities
1975 PL 94-142 Individuals with Disabilities Education Act
1981 Home and Community Based Services Waiver
1990 Americans with Disabilities Act
1999 Supreme Court Olmstead Decision
2014 Home and Community Based Services Rule
Federal and State Funding Authorities

Medicaid Waivers
- 1115 Demonstration waivers
- 1915(a) Voluntary managed care
- 1915(b) Managed care
- 1915(b/c) Managed care
- 1915 (c) HCBS Waivers
  - Comprehensive Waivers
  - Capped Supports Waivers
  - Model Waivers for people with
    - Special healthcare needs
    - Autism

Medicaid State Plan
- Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/IID)
- 1915(i) State plan HCBS
- 1915(j) Self-Directed Personal Assistance Services
- 1915(k) Community First Choice
- Other state plan
- Other Medicaid Authority

Non-Medicaid
- State IDD Agency
- Other state or local funding
### Use of LTSS Funding Authorities for People with IDD

*(Number of States Using in FY 2014)*

<table>
<thead>
<tr>
<th>Authority</th>
<th>States Using</th>
</tr>
</thead>
<tbody>
<tr>
<td>1915 (c) Waiver</td>
<td>47</td>
</tr>
<tr>
<td>1115 Demonstration Waiver</td>
<td>7</td>
</tr>
<tr>
<td>1915(a), (b), or (b/c) Managed Care Waiver</td>
<td>6</td>
</tr>
<tr>
<td>ICF/IID State Plan</td>
<td>45</td>
</tr>
<tr>
<td>1915 (i) State Plan HCBS</td>
<td>10</td>
</tr>
<tr>
<td>1915 (k) Community First Choice</td>
<td>5</td>
</tr>
<tr>
<td>Non-Medicaid</td>
<td>45</td>
</tr>
</tbody>
</table>

Number of reporting states:
- 1915(c) – 51
- 1915(i) – 49
- All other funding authorities - 50
2014 Medicaid Home and Community Based Services (HCBS) Rule

**HCBS services must**
- Support for full access to the greater community
- Be selected by the individual
- Privacy, dignity and respect, and freedom from coercion and restraint.
- Initiative, autonomy, and independence in making life choices
- Choice regarding services and supports

**Key Provisions**
- Conflict of interest provision
- Requires Person centered planning
- Settings rule
  - Rights of LTSS recipients living in provider-owned housing
People in Large State Operated IDD Facilities (16+ people)
1950 to 2014

- Medicaid
- IDEA (PL94-142)
- Medicaid Home and Community Based Services Waiver
- ADA
- Olmstead Decision
Rebalancing Medicaid LTSS Settings for People with IDD

Recipients (Waiver surpassed ICF/IID in 1994)

Expenditures (in millions) (2000)

Average annual per person expenditures

* Truven data used for 5 states, Eiken et al., (2016)
Closures of State IDD Facilities with 16+ People

327 Facilities in 1977; 151 in 2014
Trends

- Expansion of Medicaid funding authorities
- Growth of Medicaid LTSS Managed Care
- Availability of Medicaid-funded supports for people living in the home of a family member
- Continued deinstitutionalization as individualized HCBS services are developed
What’s Next

- Significant cuts to the Medicaid program, including LTSS, have been the focus of intense public debate in Congress.
- Future funding levels for Medicaid remain unknown, but demand for services continues to rise.
- States are still negotiating their transition plans with CMS for implementing the 2014 HCBS rules. Significant changes will be needed to comply with the new standards.
RISP Highlights

What is the status of the long-term supports and services states are providing to people with Intellectual and Developmental Disabilities?
LTSS Recipients with IDD by Funding Authority

FY 2014
Includes duplicate counts. Medicaid state plan and Non-Medicaid state funds can be combined with other funding authorities
Annual Per Person Medicaid Waiver and ICF/IID Expenditures by Age and Living Arrangement

- **Waiver (Family Home)**
  - 21 years or younger: $12,978
  - 22 years or older: $23,865
  - All ages: $28,843

- **Waiver (Non-Family)**
  - 21 years or younger: $46,046
  - 22 years or older: $58,839
  - All ages: $52,792

- **Waiver (all)**
  - 21 years or younger: $18,541
  - 22 years or older: $50,727
  - All ages: $69,268

- **ICF/IID**
  - 21 years or younger: $118,540
  - 22 years or older: $128,251
  - All ages: $133,582

RISP FY 2014

University of Minnesota
Annual HCBS Expenditures per Recipient with IDD
National Average $43,154

FY 2014

University of Minnesota
Age of Service Recipients with IDD

An estimated 1.4 million people with IDD were known to or served by state IDD agencies on June 30, 2014. Of these:

61% WERE 22 YEARS OR OLDER

39% WERE BIRTH TO 21 YEARS OLD
Where did LTSS Recipients with IDD Live?

- Family Home, 57%
- Own Home 1-3, 11%
- Host/Foster Family 1-3, 5%
- IDD Group 7 - 15, 5%
- IDD Group 4 - 6, 11%
- IDD Group 1-3, 6%
- IDD Group 16+, 4%
- Nursing Home, Psychiatric, 2%

FY 2014
Percent Living in Home of a Family Member by State

FY 2014

Est. US

MD  CT  WA  WI  WV  OR  NY  LA  HI  NV  FL  OH  SC  CA  AZ  AZ  CA  SC  OH  FL  NY  HI  LA  NY  OR  WI  WI  WA  WA  Est. US
People With IDD Receiving or Waiting for Medicaid HCBS Funded Supports 1996 to 2014

% increase needed to serve people living with a family member or in a home of their own who are waiting for HCBS funded supports

<table>
<thead>
<tr>
<th>Year</th>
<th>Waiver Recipients</th>
<th>Waiting for HCBS waiver</th>
<th>All LTSS Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>87,187</td>
<td>291,255</td>
<td>914,103</td>
</tr>
<tr>
<td>2000</td>
<td>71,922</td>
<td>291,255</td>
<td>762,226</td>
</tr>
<tr>
<td>2005</td>
<td>115,059</td>
<td>443,606</td>
<td>946,141</td>
</tr>
<tr>
<td>2010</td>
<td>592,070</td>
<td>1,040,279</td>
<td>1,040,279</td>
</tr>
<tr>
<td>2014</td>
<td>748,585</td>
<td>1,170,190</td>
<td>1,170,190</td>
</tr>
</tbody>
</table>
Using RISP Data to Inform Policy and Practice
National Association of State Directors of Developmental Disabilities Services (NASDDDS)

- NASDDDS represents the nation's agencies in 50 states and the District of Columbia providing services to children and adults with IDD and their families.

- We promote and assist state agencies in developing effective, efficient service delivery systems that furnish high-quality supports to people with IDD.
NASDDDS Continued…

- NASDDDS provides both broad-based membership resources as well as state-specific detailed technical assistance.
- RISP is an essential tool in all efforts.
- RISP data show state’s longitudinal progress on settings and expenditures, as well as a national vantage point of emerging and effective supports and service models.
Our members use RISP data to illustrate key issues for state leadership and legislators, as well as other key partners and stakeholders.

For example, several states have used the RISP data to support efforts to grow and expand more individualized service models, such as shared living and supports to families.
Human Services Research Institute (HSRI)

- As policy consultants for LTSS systems for people with I/DD, HSRI uses RISP data to observe trends in service populations and expenditures.
- Utilizing RISP data allows for quick comparison between states and a national average to use as a benchmark on a number of data points.
- RISP data allows us to show states comparable systems by finer grain--such as by similar service populations by age, numbers served per 100,000, funding authority, or others.
HSRI Continued…

- We see huge variability in what states spend per person—from over $100,000 per person in some states, to $30,000 or less in many others.

- However, we don’t find that support needs differ greatly between states—so why do costs?
  - How much is enough?
  - What are states that serve many but spend little doing differently than those that serve few but spend a lot?
University of Minnesota Research and Training

- Characteristics of state IDD programs are used to explain variability in National Core Indicators outcome findings over and above variability that can be explained by individual characteristics or types of service settings.
- Context for research proposals, journal articles and presentations on the LTSS system for people with IDD
- ICI core certificate program course for graduate students
Using Research Data to Inform the Media

1 Person 1 Home

University of Minnesota Technical Assistance

- Media Inquiries: Deinstitutionalization stories
- State and Federal agencies – data to compare outcomes or policy impacts over time or across states (e.g., Medicaid HCBS)
- Protection and Advocacy and litigators – status and trends in a state or comparing one state to another
- Families and people with IDD – What state should I move to if I want xx type of services?
Resources

**RISP.UMN.EDU**
- RISP Annual Report (2000-Present)
- Build a Report: Compare States on Waiver and ICF/IID Recipients and Expenditures
- State Profiles
- Infographics
- Presentation Slides

**FISP.UMN.EDU**
- FISP Annual Report (2012-2014)
- Special Reports
- State Profiles
- Infographics
- Presentations
- Research Data Briefs
- Impact feature issue

Contact us at risp@umn.edu for technical assistance to interpret or customize reports
Table 1: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Individualized Settings</td>
<td>Own Home</td>
<td>46,908</td>
<td>73,147</td>
<td>101,143</td>
<td>127,455</td>
<td>133,584</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>590,180</td>
<td>391,859</td>
<td>533,048</td>
<td>592,180</td>
<td>661,442</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Host Home</td>
<td>24,675</td>
<td>37,167</td>
<td>35,288</td>
<td>40,060</td>
<td>56,146</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 to 3</td>
<td>15,702</td>
<td>33,380</td>
<td>49,037</td>
<td>62,584</td>
<td>68,637</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congregate Settings by size and type</td>
<td>4 to 6</td>
<td>17,486</td>
<td>67,146</td>
<td>107,573</td>
<td>105,290</td>
<td>123,793</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 to 5</td>
<td>20,400</td>
<td>33,188</td>
<td>69,933</td>
<td>108,479</td>
<td>124,499</td>
<td>156,010</td>
<td>167,874</td>
<td>182,430</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7 to 15</td>
<td>20,024</td>
<td>30,515</td>
<td>48,637</td>
<td>53,475</td>
<td>56,389</td>
<td>52,802</td>
<td>52,888</td>
<td>55,882</td>
<td>55,960</td>
</tr>
<tr>
<td></td>
<td>16+ Nonstate</td>
<td>51,638</td>
<td>55,786</td>
<td>42,081</td>
<td>48,001</td>
<td>37,016</td>
<td>35,253</td>
<td>27,005</td>
<td>25,927</td>
<td>18,248</td>
</tr>
<tr>
<td></td>
<td>16+ State</td>
<td>156,716</td>
<td>121,180</td>
<td>95,052</td>
<td>79,407</td>
<td>58,320</td>
<td>47,329</td>
<td>40,061</td>
<td>31,101</td>
<td>21,600</td>
</tr>
<tr>
<td></td>
<td>16+ Total</td>
<td>207,356</td>
<td>180,146</td>
<td>137,103</td>
<td>127,408</td>
<td>95,336</td>
<td>82,582</td>
<td>67,066</td>
<td>57,028</td>
<td>43,560</td>
</tr>
<tr>
<td></td>
<td>State Psychiatric Facility</td>
<td>15,524</td>
<td>7,865</td>
<td>2,520</td>
<td>121</td>
<td>1,269</td>
<td>488</td>
<td>362</td>
<td>873</td>
<td>2,613</td>
</tr>
<tr>
<td>People with IDD in the Sys.</td>
<td>Waiting list</td>
<td>87,187</td>
<td>71,922</td>
<td>73,028</td>
<td>115,059</td>
<td>209,267</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Estimated Total</td>
<td>247,780</td>
<td>243,849</td>
<td>256,673</td>
<td>289,382</td>
<td>914,103</td>
<td>762,226</td>
<td>946,141</td>
<td>1,040,279</td>
<td>1,168,658</td>
</tr>
<tr>
<td>Medicaid Recipients and Expenditures</td>
<td>Waiver Expenditures per Person</td>
<td>0</td>
<td>901</td>
<td>12,955</td>
<td>22,319</td>
<td>24,783</td>
<td>33,142</td>
<td>38,679</td>
<td>44,396</td>
<td>43,183</td>
</tr>
<tr>
<td></td>
<td>Waiver Recipients per 100,000</td>
<td>0</td>
<td>6</td>
<td>94</td>
<td>20</td>
<td>72</td>
<td>103</td>
<td>150</td>
<td>192</td>
<td>235</td>
</tr>
<tr>
<td></td>
<td>ICF/IID Expenditures per Person *</td>
<td>5,758</td>
<td>14,868</td>
<td>24,826</td>
<td>56,036</td>
<td>73,926</td>
<td>85,040</td>
<td>119,162</td>
<td>149,099</td>
<td>135,447</td>
</tr>
<tr>
<td></td>
<td>ICF/IID per 100,000 *</td>
<td>48</td>
<td>61</td>
<td>60</td>
<td>58</td>
<td>49</td>
<td>41</td>
<td>34</td>
<td>28</td>
<td>24</td>
</tr>
</tbody>
</table>

*Data for FY 2014 may be from an outside source for these data elements. For ICF/IID expenditures and number of people, the source would be Eiken et al (2016). For Nursing Facilities, the source would be AHCA (2014a, 2014b, or 2014c).
What are the ages of people who receive home and community-based services in their family homes?

- In fiscal year 2013, about 55% of people with IDD known to state agencies receive HCBS-funded long-term supports and services. This is about 11% of all the people believed to have an intellectual or developmental disability living in the United States.

- More Medicaid dollars are now spent on Home and Community Based Services and supports than on institutional services such as large group homes for people with disabilities.

- Because children are in school and often receive supports through schools, there are age differences in both the proportion of children receiving Medicaid funded supports and in the cost of providing these supports.

This data is for FY 2013.
Contact Information

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HSRI: Val Bradley, John Agosta, Brittany Taylor, Yoshi Kardell, Alexandra Bonardi
NASDDDS: Mary Lee Fay, Mary Sowers, Mary Lou Bourne, Barbara Brent
Discussion

- Your comments and questions
- How do the status and trends in LTSS for people with IDD compare with other HCBS populations?
  - Living arrangements
  - Rebalancing progress
- Why is it important to monitor trends in Medicaid LTSS utilization and expenditures?
- Why do states vary so widely?
## Medicaid LTSS Utilization and Waiting Lists FY 2014

<table>
<thead>
<tr>
<th>Service</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting Targeted Case Management While Waiting</td>
<td>27,932</td>
</tr>
<tr>
<td>Waiting to move from family home</td>
<td>95,999</td>
</tr>
<tr>
<td>Waiting for Medicaid Waiver LTSS</td>
<td>209,267</td>
</tr>
</tbody>
</table>

**ICF/IID Plus Waiver Recipients:** 836,889