National Data on People with Intellectual and Developmental Disabilities (IDD) Living with Family Members

March 22nd, 2016
2:00 pm – 3:30 pm (Eastern)

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Agenda

- Why?
- Project Overview
- Data Collection
  - Methods
  - Challenges
  - 2013 FISP Highlights
- Products
  - Reports
  - Interactive Website (www.fisp.umn.edu)
  - Special Studies & Research Briefs
Why?
Importance of Data

- National longitudinal data show how intellectual and developmental disabilities (IDD) service systems change over time
- Adapting service systems to meet the needs of future generations of people with IDD and their families
- Understanding the big picture can aid advocacy efforts
Supporting Individuals and Families Information Systems Project (FISP)
Project Overview

Supporting Individuals and Families Information Systems Project (FISP) was funded in 2011 by the Administration on Intellectual and Developmental Disabilities (AIDD) to better understand and promote effective supports for families and individuals with IDD who direct their own support.
Project Overview, cont.

Project Goal

To collect, report, and disseminate essential information on in-home supports and services provided to individuals with IDD (including services directed by the individual), and on services and supports designed to benefit the families of those individuals (including services that are directed by family members).
Investigates

- How many people in a state are using publicly-funded services while living in the home of a family member?
- How many people in a state have requested publicly-funded services but are currently waiting?
- How do states compare in dollars spent per person by age?
- How do states compare in dollars spent per person living in the family home versus other settings?
Advisory Committee

- Consists of families of people with IDD and other stakeholders who are interested in and familiar with reviewing data
- Meets quarterly by webinar
- Reviews draft reports and web material, and provides feedback on the presentation and usability
- Input is utilized by project staff to share results with families and other stakeholders in the most user-friendly way
Data Collection
Data Collection

Methods

- Annual survey of State Directors of Developmental Disabilities Services
- Data is collected in conjunction with the Residential Information Systems Project (RISP – risp.umn.edu)
- Data collection started in 1979 with new questions added as supports and services have changed
Challenges

- State data systems are not always compatible with survey categories
  - Missing data
  - Different kinds of supports available with differing names across states
- Information is only available about those known to the service system
Data Highlights from FY2013

People Known to State Intellectual or Developmental Disabilities Agencies by Age

- 501,203 (39%) Birth - 21
- 796,175 (61%) 22+ years
Waiting to move from the home of a family member: 108,665
Getting Targeted Case Management While Waiting: 42,662
Waiting for Medicaid Residential or In-Home LTSS: 233,724

Status of Individuals on State Intellectual/Developmental Disability Agency Waiting Lists on June 30, 2013
Living Arrangement of People with Intellectual or Developmental Disabilities Receiving Long-term Supports and Services FY 2013

- Own Home: 127,664
- Family Home: 370,372
- Other Setting: 630,367

Family Home: 630,367
Average Annual Per Person Medicaid Waiver Expenditures by Age and Living Arrangement FY 2013 for People with Intellectual or Developmental Disabilities

- **Birth to 21 years**
  - Family Home: $14,950
  - Other Settings: $19,310
  - Total All Settings: $44,775

- **22 years or older**
  - Family Home: $24,515
  - Other Settings: $43,493
  - Total All Settings: $57,075
People with IDD Receiving LTSS while Living in the Home of a Family Member or in their Own Home With or Without Medicaid Waiver Funding 1998 to 2013
Using FISP Data

- Assess state performance and inform policy and practice
  - View trends related to numbers of individuals served while living in the home a family member
  - Review numbers of people served and expenditures by age group and settings
  - Support individuals and families toward a positive life trajectory
- Compare data across states
  - States with similar circumstances
STATE A

State Profile 1: 2013 Waiver Recipients by Age and Living Setting

- Family Home 0-21: 1,548
- Family Home 22+: 3,699
- Other Setting 0-21: 649
- Other Setting 22+: 6,251

State Profile 2: 2013 Per Person Expenditures by Age and Living Setting

- Family Expenditure 0-21: $8,873
- Family Expenditure 22+: $15,048
- Other Expenditure 0-21: $86,390
- Other Expenditure 22+: $77,524
### State Profile 1: 2013 Waiver Recipients by Age and Living Setting

<table>
<thead>
<tr>
<th>Setting</th>
<th>0-21</th>
<th>22+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Home</td>
<td>1,396</td>
<td>8,687</td>
</tr>
<tr>
<td>Other Setting</td>
<td>283</td>
<td>9,934</td>
</tr>
</tbody>
</table>

### State Profile 2: 2013 Per Person Expenditures by Age and Living Setting

<table>
<thead>
<tr>
<th>Setting</th>
<th>0-21</th>
<th>22+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Expenditure</td>
<td>$12,679</td>
<td>$16,519</td>
</tr>
<tr>
<td>Other Expenditure</td>
<td>$45,470</td>
<td>$81,979</td>
</tr>
</tbody>
</table>

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Comparison

Examples of comparisons in spending

- State B serves more adults in the family home than State A, but spends about the same per person in that type of setting ($16,519 vs. $15,048)

- State B serves more adults in all other settings, but spends significantly less per person in that type of setting ($45,470 vs. $77,524)

- In both states, the category with the highest cost per person is youth (birth to 21 years) living in a setting other than the family home

- There are multiple factors to explore that might contribute to the variance in number served and spending
STATE A

State Profile 3:
2013 Total LTSS Recipients by Living Setting

<table>
<thead>
<tr>
<th>Living Setting</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Home</td>
<td>3,104</td>
<td>3,065</td>
<td>3,269</td>
<td>3,424</td>
<td>3,363</td>
<td>4,366</td>
<td>4,553</td>
<td>5,194</td>
</tr>
<tr>
<td>Own Home</td>
<td>8,183</td>
<td>8,396</td>
<td>8,729</td>
<td>8,766</td>
<td>9,105</td>
<td>10,215</td>
<td>11,041</td>
<td>12,147</td>
</tr>
</tbody>
</table>

State Profile 4:
2013 Waiver Recipients – Total and Living in Family Home

- Total Waiver Recipients
- Waiver Recipients in Family Home
STATE B

State Profile 3: 2013 Total LTSS Recipients by Living Setting

<table>
<thead>
<tr>
<th>Living Setting</th>
<th>2013 Total LTSS Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Home</td>
<td>10,416</td>
</tr>
<tr>
<td>Own Home</td>
<td>767</td>
</tr>
</tbody>
</table>

State Profile 4: 2013 Waiver Recipients – Total and Living in Family Home

<table>
<thead>
<tr>
<th>Year</th>
<th>Waiver Recipients in Family Home</th>
<th>Total Waiver Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>4,162</td>
<td>12,409</td>
</tr>
<tr>
<td>2007</td>
<td>4,299</td>
<td>12,800</td>
</tr>
<tr>
<td>2008</td>
<td>5,206</td>
<td>14,496</td>
</tr>
<tr>
<td>2009</td>
<td>5,817</td>
<td>15,302</td>
</tr>
<tr>
<td>2010</td>
<td>5,698</td>
<td>16,954</td>
</tr>
<tr>
<td>2011</td>
<td>6,937</td>
<td>18,108</td>
</tr>
<tr>
<td>2012</td>
<td>18,355</td>
<td></td>
</tr>
<tr>
<td>2013</td>
<td>20,300</td>
<td></td>
</tr>
</tbody>
</table>
Comparison

- Example of a comparison in residential service use
  - State A serves more people while living in their own home than State B. State A may have policies or practices, or other circumstances that promote the availability of this service option.
Products
FISP Reports

- 2012 & 2013 FISP reports
- Available on the FISP website
- Limited hard copies available
- FY 2014 report will be out this spring
FISP/RISP website

risp.umn.edu  fisp.umn.edu
Infographics

Who gets services from State IDD agencies?

4.7 million
people in the U.S. had intellectual or developmental disabilities in 2013

An estimated 1.3 million people with IDD were known to or served by state IDD agencies on June 30, 2013. Of these:

61% were 22 years or older

39% were birth to 21 years old

Estimated as of June 2013

Supporting Individuals and Families: Status and Trends through 2013
Research Briefs
Special Study

- Collecting information from selected states on the type of Medicaid Home and Community Based Services (HCBS) that people receive while living in the home of a family member

- Service Categories
  - Family Caregiver Support
  - Behavior Supports
  - Respite
  - Medical Supports
  - Personal Care Supports
  - Participant Directed Supports
  - Day Services
  - Environmental Modifications & Technology
Collaboration with National Core Indicators (NCI)

- National Core Indicators (www.nationalcoreindicators.org) is a voluntary effort by public developmental disabilities agencies to measure and track their own performance
- Uses standard measures across states to assess outcomes of services provided to individuals and families
2012-2013 Adult Family and Child Family NCI Surveys

- Adult family Survey – 13 states, 5010 responses
- Child Family Survey – 10 states, 4,322 responses
- Topic Areas:
  - Demographic information about family member and respondent
  - Information and planning
  - Access and Service Delivery
  - Choice and control
  - Community Connections
  - Satisfaction with services and service outcomes
Types of Disabilities of Adults and Children Living with Family Members

- Intellectual Disability
- Seizure/Neurological Disorder
- Cerebral Palsy
- Autism Spectrum Disorder
- Down Syndrome
- Other or Don't Know
- More Than One Diagnosis

Adult  Child

More Than One Diagnosis
Social Connections of Adults and Children

- **Spends Time with Children without Disabilities**
  - Yes: 86%
  - No: 14%

- **Has Friends Other Than Family or Support Workers**
  - Yes: 75%
  - No: 25%
Concluding Remarks