Using Data on Long-Term Supports and Services For People With IDD to Influence Change

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Profile of Developmental Disabilities Services in the States

Financial Commitments and Programmatic Trends

Residential Services and Supports

Employment Services and Supports

http://www.acl.gov/Data_Outcomes/Index.aspx#Data_and_Statistics
2015 U.S. Territories Report

SERVICES FOR PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES IN THE U.S. TERRITORIES
Supporting Individuals and Families Information Systems Project (FISP)

- From Facilities to Family Homes
  - From facility-based program models to flexible person-centered, in-home support strategies
  - Most people with IDD have always lived with family but to get supports the had to leave the family home.
  - Now most receiving Medicaid funded supports live with family members.

- Providing accurate, timely data on the nature and costs of:
  - Where people with IDD live, what services they get, and what funding mechanisms pay for those services
  - Supports received by people with disabilities and their families

FISP.UMN.EDU
Residential Information Systems Project (RISP)

- Tracking the status and trends of Medicaid funded long-term supports and services for people with intellectual and developmental disabilities since 1977
  - Nationally
  - State-by-state
  - And now U.S. Territories
- Funded by the DHHS, Administration on Community Living, Administration on IDD
- Annual reports describe
  - National and state longitudinal trends
  - Current status of LTSS for people with IDD
- Data used to tell the story of IDD systems and LTSS available to individuals and families.
  - States and federal agencies
  - Congress and state legislatures, courts
  - Advocates, researcher, families

RISP.UMN.EDU
What are Long-Term Services and Supports?

Lifelong paid or unpaid supports that help a person with

- Daily activities such as dressing, bathing and eating
- Household tasks such as shopping, preparing meals, and doing household chores
- Finding and keeping a job
- Participating in family and community activities
- Maintaining health, managing chronic health conditions

Slides by the RISP and FISP
Projects at the U of MN's RTC on Community Living
Residential Services Settings

Individualized

- Own home (Person with IDD owns or leases the home in which he/she lives)
- Family home – Person with IDD lives in the home of a related family member
- Host home/Foster Family (Host or Foster family owns or leases home)
- Group settings with 3 or fewer unrelated individuals with IDD living together (Agency owns or leases)

Congregate

- Group IDD 4 or more people with IDD living together in an IDD setting owned, rented or managed by a provider
  - ICF-ID
  - Not ICF-ID funded
- Nursing home (Skilled nursing facility, rehabilitation facility)
- Psychiatric facility (Institutions for mental disease)
Where did people with IDD live in 2013?

- US Total 4,710,320
- No IDD services
  - 432,628 own home or with spouse
  - 3,651,561 family home

Congregate settings:
- IDD facilities
- Group homes
- Nursing homes
- Psychiatric facilities
% of Service Recipients with IDD Living in the Home of a Family Member June 2012 by State

[Bar chart showing percentages for each state]
% Living in a home with 3 or fewer people with IDD (Not with a family member) by State 2012
Key Public Policies Shaping Places People Live and Services they get

- 1965 Medicaid
- 1971 Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID),
- 1975 PL 94-142 Individuals with Disabilities Education Act,
- 1981 Medicaid Home and Community Based Services Waiver
- 1990 Americans with Disabilities Act
- 1999 Supreme Court’s Olmstead Decision,
- 2014 Medicaid Home and Community Based Settings (HCBS) rule
A View Out the Back Window: Children and Adults in State IDD Facilities 1950-2012
PRF Facility/Unit Closures in 5-Year Intervals 1960 to 2024
Changes in PRF Census and Costs ($2012)
Age of Current, New and Discharged PRF Residents 2012

- **0 to 21 years**
  - Admissions: ~200
  - Discharges: ~100
  - Current Residents: ~250

- **22-39 years**
  - Admissions: ~300
  - Discharges: ~350
  - Current Residents: ~100

- **40-54 years**
  - Admissions: ~150
  - Discharges: ~100
  - Current Residents: ~250

- **55-62 years**
  - Admissions: ~50
  - Discharges: ~50
  - Current Residents: ~200

- **63+ years**
  - Admissions: ~10
  - Discharges: ~10
  - Current Residents: ~10

The graph shows the distribution of admissions, discharges, and current residents for different age groups in 2012.
Level of Intellectual Disability of PRF Residents FY 2012

Current Residents
- Profound: 58%
- Severe: 16%
- Moderate: 13%
- Mild or None: 12%
- Unknown: 1%

Admissions and Readmissions
- Profound: 13%
- Severe: 11%
- Moderate: 26%
- Mild or None: 47%
- Unknown: 3%
Who has better outcomes?

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Best</th>
<th>Worst</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Satisfaction</td>
<td>Family home, small community setting</td>
<td>Institution</td>
</tr>
<tr>
<td>Choice</td>
<td>Small settings</td>
<td>Institution</td>
</tr>
<tr>
<td>Skills</td>
<td>Small community settings</td>
<td>Institutions</td>
</tr>
<tr>
<td>Cost per person</td>
<td>Family home</td>
<td>Institutions</td>
</tr>
<tr>
<td>Individual Satisfaction</td>
<td>Family home</td>
<td>All others</td>
</tr>
<tr>
<td>Access to Doctors and Dentists</td>
<td>Institution</td>
<td>Family home</td>
</tr>
<tr>
<td>Healthy Weight*</td>
<td>Institution</td>
<td>Own Home</td>
</tr>
</tbody>
</table>

*Likely due to differences in choice and restricted access to food
The ADA Generation

- 2015 Marks the 25th Anniversary of the Americans with Disabilities Act
- People with IDD finishing high school now have been included in schools and communities as they grew up.
- New expectations
  - A job for pay NOT segregated day activity or workshop
  - A home alone or with family or friends NOT a group home
  - Meaningful participation in preferred activities NOT group visits to “The community”
  - Spending time with friends NOT special programs and separate activities
Key Features of the 2014 HCBS Rule

- Residential settings are community based only if:
  - the setting has all of the qualities specified in the person’s individual plan;
  - the person chose the setting from among several options;
  - the living unit is physically accessible,
  - each person owns or has a legally enforceable lease or similar agreement; and the person has
    - privacy in sleeping and living unit spaces,
    - freedom and support to control their own schedules, activities, and access to food, and
  - access to visitors of their choosing at any time.

- Additional guidelines describe the types of supports and services that qualify for funding.
Funding (Flavors of Waivers)

**Medicaid HCBS Waiver**
- 1115 Demonstration waivers
- 1915(a) – Voluntary managed care
- 1915(b) – Managed care
- 1915(b/c) – Managed care
- 1915 (c) Waivers
  - 1915(c) Comprehensive Waivers
  - 1915(c) Capped Supports Waivers
  - 1915(c) Model Waivers (e.g., for people with special healthcare needs)
  - 1915 (c) Autism waivers
- Other Medicaid Waiver Authorities

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

**Non-Medicaid funded**
- Long-term supports and services offered under the auspices of the state IDD Division or Director
Funding Long-Term Supports and Services 2012

- HCBS Waiver, 680,610
- ICF/IID, 86,000
- Other or None, 371,511
HCBS Annual Per Person Expenditures by Age and Living Arrangement FY 2012

- Birth to 21:
  - Family: $17,671
  - Other: $55,446

- 22 years +:
  - Family: $49,466
  - Other: $69,715
Using RISP and FISP Data

- Tracking deinstitutionalization and community residential supports and services
  - Nationally
  - State-by-state
  - And now U.S. Territories

- Used by federal and state policy makers, and advocates to
  - Present national and state trends in LTSS to Congress, State Legislatures, Courts and other stakeholders (78%)
  - Compare a state’s performance to the nation or other states (73%)
  - Prepare reports (71%)
  - Advocate for systems change (70%)

- Enhances ongoing programs of research
  - Provides state level data to help explain variability in outcomes
  - Provides a local context for proposed changes
**Technical Assistance Examples**

- Explained differences in expenditures between institutions and community services to a national news reporter
- Provided data to a state for court proceedings
- Provided waiting list analysis to advocacy group
- Provided resources on DSW workforce to a grant writer
- Assisted a state DD Council to prepare a report for a legislative hearing regarding institutional costs
- Provided data to support deinstitutionalization (outcome studies, state examples, progress to date)
# RISP and FISP Data Resources

## Families/Self-Advocates
- Webinar for communities of practice states,
- Template for sharing info with policy makers,
- Brief Reports
- Self-Advocacy Online
- State Profiles

## Other Policy Stakeholders
- Technical Report
- Journal Articles
- Presentations
  - Conferences
  - State specific
- Customized Chart Gallery
- Presentation slides
Using Data to Influence Policy

- Developing your story
- Your elevator speech
- Data customized to your state and topic
This is what caregivers said about supports

listen

7 out of 10 families can’t find the help they need.

Can’t find support

Can find support
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