Residential Information Systems Project:
Survey of Public Residential Facilities

APDDA Conference 2015
San Antonio

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FY 2012 Annual Reports

Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends Through FY 2012

In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2012

Research and Training Center on Community Living
Institute on Community Integration/UCEDD

University of Minnesota
Driven to Discover™
Supporting Individuals and Families Information Systems Project (FISP)

- A changing paradigm
  - 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 the majority receiving Medicaid funded supports live with family members.

- States (and stakeholders) need 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
% Living in the Home of a Family Member June 2012
People Waiting for In-Home or Residential LTSS 1999 to 2012 (Rev.)

![Bar chart showing the number of people waiting for in-home or residential LTSS from 1999 to 2012. The chart indicates a significant increase in the number of people waiting in 2008 and 2009.](chart.png)
Residential Information Systems Project

- 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 and
  - 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
  - Advocates, researcher, families and courts
Where do People with IDD Live?

**Individualized (1 to 3 people)**
- 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 (4+ people)**
- 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)
- Other group setting 4 or more people on the same property/ same address
  - May include people with other diagnoses or other target populations
  - Excludes hospitals, correctional facilities and educational settings.
Residence Type for People Supported by State IDD Agencies

- Family Home: 56%
- Own Home 1 to 3: 10%
- IDD Group 1 to 3: 6%
- Host Family/ Family Foster 1 to 3: 5%
- State IDD 16+: 2%
- Nursing Home, Psychiatric: 3%
- All other 4+: 18%
- Own Home 1 to 3: 10%
% Living in a home with 3 or fewer people with IDD (Other than with a family member)
PRF Movement Patterns 1950-2012

- Residents
- Admissions
- Discharges
- Deaths


Graph showing the trends of admissions, discharges, and deaths from 1950 to 2012.
Changes in Congregate Settings

- Nonstate 16+
- State 16+
- All, 1-6 People
- All, 7-15 People

<table>
<thead>
<tr>
<th>Year</th>
<th>Nonstate 16+</th>
<th>State 16+</th>
<th>All, 1-6 People</th>
<th>All, 7-15 People</th>
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<td>2007</td>
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<td>2012</td>
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PRF Facility/ IDD Unit Closures in 5-Year Intervals 1960 to 2014
Support Needs and Conditions: Percent of Residents 2012

- Understand verbal requests: 31%
- Express needs verbally: 57%
- Dressing: 65%
- Eating: 60%
- Toileting: 56%
- Walking: 43%
- Psychiatric Disorder: 54%
- Behavior Disorder: 52%
- Epilepsy: 45%
- Cerebral Palsy: 19%
- Autism Spectrum Disorder: 17%
- Alzheimer's Disease: 3%

Cannot... Needs help... Has...
Estimated US PRF Census Changes and Characteristics FY 2012

- Deaths: 747
- Discharges: 2,436
- Admissions/Readmissions: 1,141
- Respite: 823
- Evaluation: 617
- Crisis Housing: 26
- Found Incompetent to Stand Trial: 1,338
- Behavior Led to Criminal Justice Involvement: 1,247
- Other Criminal Court Jurisdiction: 446
- Charged and Court Ordered for Competency Training: 144
- Under Parole Supervision: 100
Level of Intellectual Disability

Residents on June 30, 2012

- 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%
A clash of cultures: Incoming vs. Current PRF Residents

Level of ID

- Mild or None
- Moderate
- Severe
- Profound

(Re)Admit Discharged Current Resident

Age

- 0-14 years
- 15-18 years
- 19-21 years
- 22-29 years
- 40-54 years
- 55-62 years
- 63+ years
- Age Unknown

Admitted Discharged Current Resident
FY 2012 Admissions/Discharges by Previous/New Setting

(Re)Admissions
Discharge
Where did the leavers go? 1985-2012

- Family, Foster or Own Home
- Group Home 1-15 residents
- Facility with 16 or more people
Large State IDD Facility Staff

- Total number 80,734
- Direct Support 47,342 (59% of total)
- Personnel Costs 82% of total budget
- Average DSP wage $14.67
- DSP turnover rate 33%
- Average supervisor salary $38,062
- Supervisor turnover rate 14%
Concerns of PRF Administrators

- Direct care staff turnover: 54% in 2002, 52% in 2012
- Finding qualified direct care staff: 52% in 2002, 54% in 2012
- Morale problems: 37% in 2002, 37% in 2012
- Direct care staff wages/benefits: 31% in 2002, 31% in 2012
- Direct care staff training and development: 37% in 2002, 29% in 2012
- Direct care staff motivation: 35% in 2002, 25% in 2012
- New hires quit during the first 6 months: 31% in 2002, 13% in 2012
- Coworkers do not get along: 11% in 2002, 6% in 2012
- Direct care staff are dissatisfied with supervisors: 7% in 2002, 6% in 2012
- None of the above: 4% in 2002, 6% in 2012
Change in DSP Turnover and Vacancies

DSP Turnover Rates (%)

2002: 28
2004: 29
2006: 27
2008: 30
2010: 24
2012: 24

DSP Vacancy Rates (%)

DSP Turnover Rates (2002 - 2012):
- 2002: 5.6%
- 2004: 5.8%
- 2006: 6.7%
- 2008: 6.9%
- 2010: 6.3%
- 2012: 6.9%

The graph shows an increase in DSP turnover rates from 2002 to 2010, reaching a peak of 6.9% in 2008. After 2010, the rates start to decrease, stabilizing at 24% in 2012.
Public Residential Facilities: Services Offered to Non-Residents

- Behavioral assessment and intervention (33%)
- Dental services (32%)
- Crisis support services (25%)
- Respite (23%)
- Vocational training (21%)
Funding For People with IDD Known to State IDD Agencies

- Other or None, 371,511
- HCBS Waiver, 680,610
- ICF/IID, 86,000
Funding Authority (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
Medicaid LTSS Recipients By Age and Funding Authority

- **ICF/IID**
  - 22 years +: 72,038
  - Birth to 21 years: 5,011

- **HCBS Family**
  - 22 years +: 143,623
  - Birth to 21 years: 115,394

- **HCBS Non-Family**
  - 22 years +: 196,935
  - Birth to 21 years: 14,586

- **HCBS Total**
  - 22 years +: 402,768
  - Birth to 21 years: 142,958

- **Combined Total**
  - 22 years +: 145,274
  - Birth to 21 years: 145,444
Annual Per Person Costs FY 2012

State Operated

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<th>Age Group</th>
<th>Waiver</th>
<th>ICF/IID</th>
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<td>1 to 6</td>
<td>$181,207</td>
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<td>$210,589</td>
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<td>16 +</td>
<td>$150,364</td>
<td>$237,149</td>
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Waiver by Size and Setting

- Birth to 21 years
  - Family Home: $17,671
  - All Other Settings: $54,988
- 22 years +
  - Family Home: $49,466
  - All Other Settings: $65,125

Overall

- Waiver: $44,160
- ICF/IID: $142,118
Changes in PRF Census and Costs ($2012)
### Table RP1

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<td>1 to 3</td>
<td>Own Home</td>
<td>48,809</td>
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<td>Family</td>
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<td>Host Home</td>
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<td>1 to 3 Group Home</td>
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<td>16+ Private</td>
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<td>16+</td>
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<td><strong>Recipients and Expenditures by</strong></td>
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Upcoming Dates

- Webinar FY 2014 Long-Form Survey - March 2015
- FY 2014 Surveys due June 15, 2015
- FY 2015 Short Form Survey – First quarter of 2016
- Ongoing – Let us know if a closure date has been announced
Project Websites

- PDF copies of all annual reports since 1988
- New interactive graphics summarize key findings
- Access your surveys
- View/download resources
  - https://risp.umn.edu/
  - https://fisp.umn.edu/
Questions

- Track Race/Ethnicity
- Reduce number of questions related to staffing
- Other changes?
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