Ensuring Quality in Rapidly Changing Times

Residential Information Systems Project & Supporting Individuals and Families Information Systems Project

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# Change in Residence Size and Type

<table>
<thead>
<tr>
<th>Year</th>
<th>People with IDD</th>
</tr>
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<tbody>
<tr>
<td>1998</td>
<td>62,669</td>
</tr>
<tr>
<td>1999</td>
<td>65,006</td>
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<tr>
<td>2000</td>
<td>73,147</td>
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<td>2001</td>
<td>80,242</td>
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<td>2002</td>
<td>86,694</td>
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<td>2003</td>
<td>90,597</td>
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<td>2004</td>
<td>107,157</td>
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<td>2005</td>
<td>101,143</td>
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<td>2006</td>
<td>104,386</td>
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<td>2007</td>
<td>113,659</td>
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<td>2008</td>
<td>113,873</td>
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<tr>
<td>2009</td>
<td>122,088</td>
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<td>2010</td>
<td>127,455</td>
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<tr>
<td>2011</td>
<td>126,998</td>
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<tr>
<td>2012</td>
<td>122,665</td>
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People Waiting for In-Home or Residential LTSS 1999 to 2012

<table>
<thead>
<tr>
<th>Year</th>
<th>Value</th>
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<tbody>
<tr>
<td>1999</td>
<td>66,246</td>
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<tr>
<td>2000</td>
<td>71,922</td>
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<td>2001</td>
<td>69,787</td>
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<td>2002</td>
<td>59,818</td>
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<td>2003</td>
<td>75,288</td>
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<td>2004</td>
<td>88,841</td>
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<td>2005</td>
<td>83,828</td>
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<td>2006</td>
<td>84,523</td>
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<td>2007</td>
<td>88,349</td>
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<td>2008</td>
<td>114,916</td>
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<tr>
<td>2009</td>
<td>123,249</td>
</tr>
<tr>
<td>2010</td>
<td>115,059</td>
</tr>
<tr>
<td>2011</td>
<td>76,677</td>
</tr>
<tr>
<td>2012</td>
<td>77,353</td>
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</table>
% Living in the Home of a Family Member
Living in a home with 3 or fewer (other than with a family member)
Dimensions of Change in LTSS

Operating Entity
(State vs Non-state)

Setting Type
(Individualized vs Congregate)

Funding Authority
ICF-IDD, HCBS, State Plan, Non-Medicaid

Setting Size
(1-3, 4-6, 7-15, 16+)

Age
0-21 vs 22+
Funding Authority

**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 For People with IDD Known to State IDD Agencies

- HCBS Waiver, 680,610
- Other or None, 371,511
Medicaid LTSS Recipients By Age and Funding Authority

- **ICF/IID**: 72,038 (22 years +), 5,011 (Birth to 21 years)
- **HCBS Family**: 143,623 (22 years +), 115,394 (Birth to 21 years)
- **HCBS Non-Family**: 196,935 (22 years +), 14,586 (Birth to 21 years)
- **HCBS Total**: 402,768 (22 years +), 142,958 (Birth to 21 years)
- **Combined Total**: 445,274 (22 years +), 145,444 (Birth to 21 years)
HCBS Annual Per Person Expenditures By Age and Setting

- Birth to 21 years: $17,671
- 22 years+: $49,466

Other Residence Type: $65,125

Family Home: $54,988
A View Out the Back Window (Large State Facilities)
Average Annual Institution Closures in 5-Year Intervals
Large State Facilities (16+)

- Fewer and smaller
- New admissions
  - Younger
  - More like to have mild or no ID
- Current residents
  - Older
  - Profound ID
- Short-term admissions (churning)
- 1,257 of 26,503 Criminal Justice Involvement
Self-Advocacy On-Line

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
Contact Information

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NASDDDS: Mary Sower, Nancy Thayler, Mary Lee Fay
Setting Type

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
Admissions, Discharges and Current Residents by Level of Intellectual Disability

Admissions

Discharges

Current Residents

Mild + None
Moderate
Severe
Profound
Admissions, Discharges and Current Residents by Age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Discharged</th>
<th>Admitted</th>
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<tbody>
<tr>
<td>0 - 18 YRS</td>
<td>69</td>
<td>117</td>
</tr>
<tr>
<td>19 - 21 YRS</td>
<td>57</td>
<td>97</td>
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<tr>
<td>22 - 39 YRS</td>
<td>374</td>
<td>311</td>
</tr>
<tr>
<td>40 - 54 YRS</td>
<td>98</td>
<td>43</td>
</tr>
<tr>
<td>55 - 62 YRS</td>
<td>156</td>
<td>118</td>
</tr>
<tr>
<td>63+ YRS</td>
<td>287</td>
<td>336</td>
</tr>
</tbody>
</table>

Series1:
- 287
- 336
- 3,208
- 6,287
- 3,800
- 2,827

Data Source: University of Minnesota
Setting Size

- **Individualized**
  - 3 or fewer people with IDD sharing a home
  - Includes own home, family home and host/foster family home

- **Congregate**
  - 4 to 6 people with IDD
  - 7 to 15 people with IDD
  - 16 or more people with IDD
  - 16 or more people any diagnosis
Large State Facility Admissions, Discharges and Deaths

Year
- 1950
- 1955
- 1960
- 1965
- 1970
- 1975
- 1980
- 1986
- 1990
- 1995
- 2000
- 2005
- 2010
- 2012

Residents
- 0
- 2,000
- 4,000
- 6,000
- 8,000
- 10,000
- 12,000
- 14,000
- 16,000
- 18,000
- 20,000

Admissions
Discharges
Deaths

University of Minnesota
Large State Facilities June 2012
26,503 people

- Conditions
  - Alzheimer’s (3%)
  - Autism (17%)
  - Cerebral Palsy (19%)
  - Behavior Disorder (52%)
  - Psychiatric Disorder (54%)

- Communication - Cannot
  - Express self verbally (57%)
  - Understand simple verbal requests (31%)

- Needs Assistance With
  - Dressing (65%)
  - Eating (60%)
  - Using Toilet (56%)
  - Walking (43%)

- Criminal Justice
  - In system (1,247)
  - Court ordered for competency (144)
  - Incompetent to stand trial (1,338)
  - Under parole supervision (100)
  - Other (446)
Large State 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%