Ensuring Quality in Rapidly Changing Times

Residential Information Systems Project
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Preparation of this presentation was supported, in part, by a cooperative agreement from the Administration on Intellectual and Developmental Disabilities, Administration for Children and Families, U.S. Department of Health and Human Services and a grant (#H133B080005) from the National Institute on Disability and Rehabilitation Research (NIDRR). Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore necessarily represent official AIDD or NIDRR policy.
Living Arrangements FY 2012

- Family home: 634,988
- Own home: 1 to 3, 118,575
- Congregate: 68,781
- Host Family /Foster 1 to 3: 54,755
- IDD Group 1 to 3: 68,781
- Not IDD (Nursing Home, Psychiatric): 29,203
- IDD Group 4+ (ICF/IDD): 85,384
People Waiting for In-Home or Residential LTSS 1999 to 2012 (Rev.)

Year | Number of People Waiting
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1999 | 66,246
2000 | 71,922
2001 | 69,787
2002 | 59,818
2003 | 75,288
2004 | 88,841
2005 | 83,828
2006 | 84,523
2007 | 88,349
2008 | 114,916
2009 | 123,249
2010 | 115,059
2011 | 95,934
2012 | 110,039
% Living in the Home of a Family Member June 2012

[Bar chart showing percentage of individuals living in the home of a family member across different states and the US average.]
% Living in a home with 3 or fewer people with IDD (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
(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
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
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
Funding For People with IDD Known to State IDD Agencies

Other or None, 371,511

ICF/IID, 86,000

HCBS Waiver, 680,610
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+: 445,274
  - Birth to 21 years: 145,444
HCBS Annual Per Person Expenditures By Age and Setting
(23 reporting states for FY 2012)

- Family Home: $17,671
- Other Residence Type: $54,988

- Family Home: $49,466
- Other Residence Type: $65,125

Birth to 21 years vs. 22 years +
This is what caregivers said about supports

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

Can’t find support

Can find support
A View Out the Back Window (Large State Facilities)
Average Institution Closures Per Year in 5-Year Intervals
Changing Large State Facilities (16+)

- Fewer and smaller facilities
- New admissions
  - Younger
  - More like to have mild or no ID
- Current residents
  - Older
  - Most have Profound ID
- Short-term admissions (churning)
  - 1,257 of 26,503 Criminal Justice Involvement
Admissions, Discharges and Current Residents by Level of Intellectual Disability
Admissions, Discharges and Current Residents by Age FY 2012
Characteristics of People with IDD Living in Large State Facilities June 2012
(26,503 total 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 IDD Facility Staff FY 2012

- 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%
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