Residential Services in the U.S.

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Americans with DD by Living Arrangement (thousands): 2000

- With Spouse: 661 (15%)
- Own Household: 584 (14%)

- Resid Setting: 434 (10%)

Total Persons with DD: 4.32 million

Family Caregiver: 2.6 million
Overview of U.S. Residential Services

- No federal law (unlike education) mandates residential services – there is no entitlement
- States (sometimes local government) generally license & fund services
- Administration is usually coordinated through states’ MR/DD agencies
- Medicaid is largest source of funding for residential services in U.S.
- Ongoing trend: Downsizing of large facilities; Expansion of individual-scale services
- Enormous unmet needs (>87,000 in 1998)
Americans with DD by Support Received: 2000

- No LTC (3.5 million, 77%)
- Residential (433,799, 13%)
- Family Supp (385,414, 10%)

Total Persons with DD: 4.32 million
Critical Issues

- Housing type
- Home ownership
- Financing strategies
- Support services & management
- Quality assurance
- Waiting lists
Housing & Home Ownership

- Separation of housing from services
- Housing types: group homes, apartments, supported living, foster care
- Except for foster care, housing type does not have to dictate services
- Common Funding Sources: ICF/MR, SSI, HUD, low-income tax credits, parent donations, other donated housing stock
- Home ownership: service recipients, parents, non-profits, for-profits investors, etc.
Residential Recipients with DD, by Setting Type (thousands): 1998

- Public Institutions (16+): 52.8
- Community ICFs/MR (4-15): 44.5
- Foster Care (1-6): 26.2
- Group Homes (1-6): 80.8
- Supported Living: 80.1
- Apartments (1-6): 20.6
- Other (1-15): 38.7
- Private Institutions (16+): 36.3

Total Residential Recipients: 417,819
Financing: Medicaid & Social Security

- States receive federal reimbursement 50-80% of expenditures, depending on state wealth
- 2 central programs: ICF/MR & HCBS Waiver
- Reimbursable programs vary by state, include residential, day programs, case management, etc.
- Pro: Allows state to leverage own resources & obtain federal funds
- Con: Federal regulations often perceived as burdensome
- Social Security: SSI, DI
Financing: ICFs/MR

- Optional Medicaid service (all states participate to some extent)
- Characterized by regulations & medical services
- “Active Treatment” requirements
- $3.2 billion spent in 2000 for public & private institutions
- $1.1 billion spent in 2000 for facilities serving 4-15 people
- Not considered best practice – services are not individualized; high regulatory demands
Financing: HCBS Waiver

- Part of Medicaid; federal reimbursement for allowable services (everything except room/board)
- Allows states, with federal approval, to “waive” certain Medicaid requirements, (statewideness and choice of provider)
- $4.1 billion spent in 2000 on Waiver services for people with DD
Benefits of the HCBS Waiver

- Flexibility: states can pick & choose service elements
- Individualization of services is mandated
- Leverage state resources to obtain federal reimbursement
- States with strong Waiver programs have the greatest financial commitment for community-based services
Support Services

- Staff supports can be continuous or intermittent
- Supports can be individually tailored, or program-driven
- Service providers can be religious or secular non-profits, for-profit corporations, parent groups
- Best practice: separation of housing control from support service delivery
- Financing: SSI, HCBS Waiver, ICF/MR
Quality Assurance

- Best practices combine monitoring shared by parents, service providers, state authorities
- Best practices monitor quality of services received, don’t just prevent abuse or neglect
- Different structures exist; sometimes state laws
- Meaningful sanctions are necessary
- Abuses occur in community settings & institutions: ongoing, committed oversight is critical
Unmet Needs & Waiting Lists

- U of Minn researchers estimated >87,000 people waiting for residential services in 1998 across U.S.
- U.S. Residential service system supported 433,000 people in 2000
- Between 1995-2000, community placements expanded by 12,000 people (3%) annually
- Great state variability – some states don’t keep waiting lists
- Urgency of need; planning for future
17 class action lawsuits across country attempting to force states to expand

Watershed 1998 Florida decision: Medicaid law doesn’t allow states to indefinitely wait list individuals for ICF/MR services

Illinois case dismissed (February 2002)

Settlements: FL, HI, WA, MA, VA, OR, WV

The true scope of need is unknown; many families aren’t on waiting lists

Families are reluctant to plan
Comparing the States (2000)

- Top 5, residential services: IA, ND, SD, MN, WI
- Bottom 5, residential services: TX, AZ, KY, GA, NV
- Top 5, overall DD spending: ND, RI, NY, ME, CT
- Bottom 5, overall spending: AL, GA, FL, HI, NV
- Top 5 expanding (#): NC, WA, GA, AL, MS
- Bottom 5 expanding (#): CA, ND, WY, HI, AR
- Top 5 expanding ($): ID, TN, AK, AZ, UT
- Bottom 5 expanding ($): SD, NH, WY, IN, HI
How do I get services for my daughter in 5-10 years?

- Make your needs known to the “authorities”
- Join waiting lists if they exist in your state
- Network with other families to learn the service provider system
- Connect with family supports
- Learn about the types of services that would be best for your daughter
- Learn the language of the service system
- Lay a foundation for advocacy: network with your state representatives, state agency personnel, service providers, other families
How do I get services for my daughter in 5 years?

- Pressure your state or local DD agency personnel for placement (letters, phone calls)
- Become a priority to your state representative
- Be a very squeaky wheel
- Actively monitor waiting list status
- Continue networking with service providers
- Have your daughter found Medicaid eligible
- File a lawsuit
- Join with other parents/professionals & devise your own program
How do I construct a program?

- Team up with families of people with whom you’d like to see your daughter live
- Consider partnering with a provider
- Raise funds for housing & start-up costs
- Present a complete package to your local representative & get endorsement
- Sell endorsed package to state DD agency
What to seek in a provider

- Meaningful parent advising and/or control of the agency
- Demonstrated track record of quality (accreditation, etc.)
- Policies that encourage family participation
- Policies that encourage family leadership
- Respectful of family knowledge
- Resources to meet changing times
- Experience serving people with medical challenges
Advocacy Strategies/Venues

- Target separate strategies for different audiences: newspaper editorial staff, elected officials, state agency personnel
- What can you offer these targets in return for what they deliver for you? (Legislative breakfasts, “Meet the candidate” party,
- Focus on the costs of care – institutionalization is generally more expensive than community care
A savvy and successful parent...

- Is not intimidated by state DD agency personnel
- Believes that her daughter is just as deserving and entitled to services as current recipients
- Knows that he is the expert in his daughter’s care needs
- Learns how “the system’s” red tape can be cut
- Learns to effectively work in the state’s political culture