

A Critical Analysis of the Emerging Crisis in Long-Term Care for People with Developmental Disabilities

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Overview

There is an impending crisis in long-term care for people with developmental disabilities. The demand for care will likely outpace the supply for decades to come. Factors such as limited existing long-term care resources, increased life expectancy for people with developmental disabilities, changing family demographics, legal actions, and competition for resources with the elderly are driving the crisis. Virtually every domain of social work practice will face challenges in this area. This presentation is drawn from a paper* that argued for an immediate response from the social work community in several areas. The profession needs to provide social workers with expanded training in family-centered approaches to working with people with developmental disabilities, develop new interventions, create new organizational supports, and practice assertive advocacy.

*SL Parish & ZE Lutwick (2005). A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work*, 50, 345-354.

Defining Developmental Disabilities

- ◆ Chronic intellectual, cognitive and often physical impairments with onset before age 22 that are likely to continue indefinitely
- ◆ Substantial functional limitations in at least three of these areas:
 - ◆ Self-care
 - ◆ Language
 - ◆ Learning
 - ◆ Mobility
 - ◆ Potential for independent living
 - ◆ Potential for economic independence

Perceptions of People with DD

- ◆ People with developmental disabilities historically viewed as being a menace requiring lifelong segregation & sterilization
- ◆ Ongoing civil rights struggle to fully realize the human rights and dignity of people with developmental disabilities Shift from segregation to normalization
- ◆ Society's views of people with developmental disabilities are shifting from fear and mistrust; full community participation and "normalized" lives are now more the norm

History of Care

- ◆ Before 1960s, care provided depended on bricks and mortar – institutions – services received depended on what was available at the facility
- ◆ Care has subsequently shifted from institutions to a network of smaller community-based residential programs (apartments, group homes)
- ◆ This transition to community began in the late 1960's and is ongoing

History of Litigation

- ◆ Federal class action litigation fought against states and their institutions
- ◆ Based on human rights violations inhumane conditions, inadequate treatment
- ◆ Advocates for people with developmental disabilities: the Arc (formerly the Association for Retarded Citizens)
- ◆ These lawsuits catalyzed the move towards community-based long-term care services

Current Service System

- ◆ Services include
 - Long-term care (institutions, group homes, etc)
 - Employment
 - Family support
 - Therapies
 - Case management
- ◆ Network of services funded by
 - Federal government
 - State government
 - Local government (minimal \$)
 - Private resources (family contributions)

Medicaid: Primary Funding Source

- ◆ Federal government provides Medicaid funding
- ◆ States must comply with regulations to receive federal reimbursements
- ◆ States determine types of care and allocation of funds
- ◆ Two Medicaid programs are the primary means
 - Intermediate Care Facilities/Mentally Retarded (ICF/MR) for medical aspect
 - Home and Community Based Services (HCBS) Waiver program allows states to increase community supports by foregoing certain regulations

Prevalence and Needs

- ◆ Approximately 1.49% of civilian population has developmental disabilities (Larson et al., 2001)
- ◆ Long-term needs entail planning for the person after their caretakers can no longer care for them
 - Living arrangements
 - Guardianship
 - Financial advising
 - Employment
 - Health care
- ◆ Need for long-term care exceeds current availability
 - Evidenced by wait list records

Unmet Long-Term Care Needs

- ◆ Long-term care
 - Majority of spending related to people with developmental disabilities is spent on long-term care
 - Long-term care still provided only to minority (15%) of people with developmental disabilities (Fujiura, 1998)
- ◆ Most states have service shortages

Long-term Care Settings

- ◆ Large-scale institutions
 - Nursing homes
 - Private facilities operated by corporations or non-profits
 - Public state or county facilities
- ◆ Smaller community settings (15 or fewer individuals)
 - Group homes
 - Foster care
 - Supervised apartments
 - Supportive living
 - Personal assistance

Advantages of Community Settings

- ◆ Better psychosocial and behavioral outcomes for people living in community settings (Apgar, Lerman, & Jordan, 2003; Larson & Lakin, 1989, 1991; Racino & Taylor, 1993)
- ◆ Preferred by people with developmental disabilities themselves (Nelis & Ward, 1995; *People First of Tennessee v. Arlington Developmental Ctr.*, 1992)

Difficulty Attaining Long-Term Care

- ◆ Lack of services available
- ◆ Long waiting lists
- ◆ Complex state bureaucracies
- ◆ Aging of baby boomers will increase service needs

Family Caregiving

- ◆ Families are the largest group of care providers for people with developmental disabilities
- ◆ Family support services provided by state and local agencies
 - Respite
 - Environmental adaptations
 - Assisting devices
 - Personal assistance
 - Mental health care
 - Crisis intervention
 - Behavior management
- ◆ Family support services allows families to care for their relatives with developmental disabilities at home instead of having to seek costly out-of-home residential care

Meeting Families' Support Needs

- ◆ Needs for family support services increase as parents and children age (Freedman, Griffiths, Krauss, & Seltzer, 1999; Seltzer & Krauss, 2001)
- ◆ \$1 billion spent on family support compared to \$29 billion for entire DD service system (Parish, Pomeranz-Essley, & Braddock, 2003)
- ◆ Unmet needs a strong predictor of family seeking out-of-home placement (Essex, Seltzer, & Krauss, 1997)
- ◆ Difficulties for those who receive services
 - Lack of flexibility in types and frequency of services
 - Services often unavailable when most needed (Freedman & Boyer, 2000)

Demography of U.S. Families

- ◆ Demographic changes are reducing the availability of unpaid, informal supports
 - Women's increasing labor market participation
 - Families are becoming smaller and fewer adults are available to care for people with developmental disabilities
 - Increased family mobility
 - ◆ Extended families less likely to live in close proximity (Hooyman & Gonyea, 1995)

Aging of People with DD

- ◆ Increased life expectancy
 - Age of death for people with developmental disabilities now generally matches age for nondisabled people (Roizen & Patterson, 2003)
 - ◆ Services needed for longer periods of time which further strains the service system
- ◆ People with DD commonly outliving caregivers for the first time in U.S. history
 - Need to develop comprehensive care plan for the period after parent-caregivers are no longer able to care for their (adult) children, whether due to death or incapacity

Aging of General U.S. Population

- ◆ Senior boom will occur in next 25 years (Hooyman & Gonyea, 1995)
 - 20% of all Americans will be over 65 by 2030 (U.S. Census Bureau, 2000)
- ◆ DD service system will compete with elderly care system for paid caregivers – labor pool will continue to shrink

Staff and Quality of Care

- ◆ Staff in long-term care
 - Are significantly underpaid (Braddock & Mitchell, 1992)
 - Lack sufficient training (Minnesota Technical College Task Force, 1993)
 - ◆ These factors increase turnover
 - Negatively affects quality of care for persons with a d.d. (Larson, Lakin, & Bruininks, 1998)

Litigation

- ◆ Class action lawsuits brought by families in the 1970's to improve conditions and expand long-term care
 - Institutional conditions had been horrific
 - ◆ widespread neglect, inadequate supervision, insufficient treatment, use of restraints
 - Families championed the closure of these institutional facilities across the U.S.

Litigation: *Olmstead v. L.C. and E.W.*

- ◆ Supreme Court case related to the Americans with Disabilities Act (ADA)
- ◆ Two women in institutions were denied community services, even though their treatment plan called for such services
- ◆ State of Georgia argued against community services because of inability to pay for these services
- ◆ Supreme Court decided states have some responsibility to provide community care
- ◆ Implementation continues to be spotty
 - many states are noncompliant

Impact of Olmstead v. L.C. and E.W.

- ◆ Case could be used to support community-based alternatives to institutions
- ◆ Has been used by families on waitlists
- ◆ Has been used to order states to expand long-term care and increase system funding
- ◆ As of 2003, only 21 states have developed compliance plans (Fox-Grage, Folkemer, & Lewis, 2003)
- ◆ HHS has limited power to force compliance

Makin et al. v. State of Hawaii et al.

- ◆ Federal class action lawsuit
- ◆ Resulted in increase in number of people receiving Waiver services by 700 in three-year period (Smith, 2005)
- ◆ Targets still not reached

Challenges of Litigation

- ◆ Slow, long-term solution to situations needing immediate attention
- ◆ Additional expensive court intervention required to obtain settlement agreement objectives (Hayden, 1997)

Deinstitutionalization

- ◆ Increased frequency of people with developmental disabilities interacting with agencies not specializing in servicing their needs (e.g., generic social welfare organizations)
- ◆ Increased incarceration rates for people with developmental disabilities (Davis, n.d.; Denkowski & Denkowski, 1985)
- ◆ Increased psychiatric hospitalization for people with developmental disabilities (Prouty et al., 2003)

What is Needed

- ◆ Political advocacy
- ◆ Organizational development
- ◆ Inclusive, family-centered practice in non-specialized agencies

Political Advocacy

- ◆ Social work organizations (e.g. NASW) could partner with organizations in the DD field (e.g. the Arc, TASH, AAMR)
- ◆ Coalition building
 - Strengthen services for people with developmental disabilities and the general elderly population
 - ◆ Social work perfectly suited to this role

Organizational Development

- ◆ Implement and interpret requirements of the Americans with Disabilities Act of 1990
- ◆ Integrate services across organizations
 - Social workers' knowledge of organizational change and community development could be utilized

Inclusive, Family-Centered Practice

- ◆ Take contextual view of person to develop appropriate services
 - Consistent with social work's person-in-environment focus

Recommendations for Teaching

- ◆ Social work education should provide core competencies for working with people with developmental disabilities, addressing these topics
 - Heterogeneity of the population and their needs
 - Lobbying to obtain family and individual services
 - Supporting families across the lifespan
 - Relevant policy

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