Deinstitutionalization of Adults with Developmental Disabilities: A report on critical incidents

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Objective:

Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities at the level of the state.

Identify advances in clinical assessment and management of selected healthcare issues related to persons with developmental disabilities.

Notes:
Deinstitutionalization of Adults with Developmental Disabilities

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Historical Background

- <1970s Asylums
- 1972 Public Law 92-223, Nixon
- 1981 Medicaid 1915(c) Waiver
- 1986 Consolidated Omnibus Budget Reconciliation Act
- 1990 Americans with Disabilities Act, Bush
- In 1990s Executive Order, Clinton
- 1996 Olmstead vs. L.C. & E.W.
- 1999 Consolidated Omnibus Budget Reconciliation Act
- 2005 Deficit Reduction Act, Obama

Change Movement

- Moved from a medical model to a social model
- Change driven by:
  - Social policies
  - Economic perspectives
  - Health professionals
  - Advocates
  - Scholars
- Major forces:
  - Federal funding (Medicaid specifically)
  - Integration of person-centered services
  - Externalized service delivery by NGOs
Then Now

Prevalence of adults with ID/DD in the U.S.

<table>
<thead>
<tr>
<th>Then</th>
<th>Now</th>
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<tbody>
<tr>
<td>–</td>
<td>3.1% (Y2001)</td>
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U.S. Institutional Population (≥ 16 adults with ID/DD)

<table>
<thead>
<tr>
<th>Then</th>
<th>Now</th>
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<tbody>
<tr>
<td>194,650 (Y1976)</td>
<td>36,650 (Y2009)</td>
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U.S. Community Settings (≤ 6 adults with ID/DD)

<table>
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<tr>
<th>Then</th>
<th>Now</th>
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<tbody>
<tr>
<td>20,400 (Y1977)</td>
<td>353,213 (Y2010)</td>
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Average spending on community services

<table>
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<tr>
<th>Then</th>
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<tbody>
<tr>
<td>29% (National)</td>
<td>42.7% (National)</td>
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<tr>
<td>6.4% (State)</td>
<td>13.9% (State)</td>
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Segregation is still present today.

Disparities exist across states in the number of individuals who receive community supports.

In 1967, 9,800 persons with ID/DD were living in state institutions.

Seven state-operated developmental centers in Illinois (n = 1,603 (Y2015) adults with ID/DD)

SODC population declined since 2005 (n = 2,783)

Approximately 250 ICF/DDs (≤ 16 individuals)

Persons served: 18,355 in ICF/DDs and 8,344 in HCBS (Y2012)

Persons living in 1-6 bed out-of-home residential settings was 3,818 (Y2008) and 4,172 people received services in their own home (Y2008).

Average cost per person $82,468 in ICF/DDs and $32,223 in HCBS.

Ligas Lawsuit: By 6/15/2017 all class members living in ICF/DDs who request community services will transition to community settings.

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Improvements</th>
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<tr>
<td>State budget constraints</td>
<td>Adaptive behavior</td>
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<tr>
<td>Lack of skilled caregiver workforce</td>
<td>Competition &amp; personal growth</td>
</tr>
<tr>
<td>Accessible, affordable housing</td>
<td>Community participation</td>
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<tr>
<td>Politically powerful institutional care providers stonewall legislation</td>
<td>Engagement in meaningful activities</td>
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<tr>
<td>Unmet healthcare needs (i.e., undiagnosed or unmanaged health problems)</td>
<td>Staff support</td>
</tr>
<tr>
<td>Challenging behavior (i.e., aggression)</td>
<td>Satisfaction</td>
</tr>
<tr>
<td></td>
<td>Family relationships</td>
</tr>
<tr>
<td></td>
<td>Social networks &amp; friendships</td>
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<tr>
<td></td>
<td>Self-determination &amp; choice</td>
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<td></td>
<td>Quality of life</td>
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Money Follows the Person (MFP)\textsuperscript{1,17,18}

- Grant funding for states to overcome institutional bias and promote community living in the most integrated setting
- Develop systems that are person-centered, effective and accountable, sustainable and efficient, coordination and transparency, and culturally competent
- Benchmarks:
  - Equality of opportunity
  - Full participation
  - Independent living
  - Economic self-sufficiency
- Support Services:
  - Personal assistant
  - Public accommodations (i.e., transportation)
  - Employment (i.e., supported employment)
  - Housing
  - Assistive technology (i.e., iPad)

MFP – Goals\textsuperscript{1,17}

- Rebalancing - Increase the use of Home and Community Based Services (HCBS) and reduce the use of Institutional services
- Individual Choice - Eliminate state barriers that prevent the use of Medicaid funds to enable individuals to receive care in the settings of their choice
- Transfer of funds - Eliminate state barriers that prevent the use of Medicaid funds to enable individuals to receive care in the settings of their choice
- Continuity of Service - Strengthen the ability of Medicaid programs to assure continued provision of HCBS
- Quality Assurance - Ensure procedures are in place to provide quality assurance and continued quality improvement

MFP – Transition Program Success\textsuperscript{4}

- Medicaid expenditures decreased by 20% in regards to transitioning persons with ID/DD from institutional care to the community
- By participating in MFP, persons received more HCBS than other transitioners, and their post-transition institutional care expenditure appear to be lower
- These additional HCBS services may decrease acute care episodes
Population Characteristics

- Increasing lifespan (shorter than the general population)
- Greater risk for health problems
- Higher rates of morbidity and premature mortality
- Morbidity of chronic conditions expected to account for up to 80% of healthcare expenditures by 2020

Common Health Conditions

Individual

- Behavioral/ Mental Health Disorders: SIB, Aggression
- GI Disorders: Constipation, Ulcers
- Infectious Diseases: Hepatitis, Tuberculosis, H. Pylori
- Cataracts, Gingivitis

- Neuronal Disorders: Epilepsy
- Congenital and Chromosomal Disorders
- Cardiovascular Disease: Myocardial Infarction
- Respiratory Disorders: Asthma, Chronic Bronchitis, Pneumonia
- Arthritis, Osteoporosis, Fractures
- GI Disorders: Constipation, Ulcers
- Cataracts, Gingivitis

Health Disparities in ID/DD

- Definition: Population specific differences in health indicators
- Higher rates of premature mortality (i.e., cardiovascular disease, intestinal obstructions, pneumonia, trauma)
- Higher rates of morbidity (i.e., epilepsy, behavioral/mental health problems, fractures, skin conditions, poor oral health, asthma, diabetes)
- Differences in environment, access to health care services, and provision of care
Cascade of Disparities

Experience lower rates of preventative care and health promotion activities including physical activity, oral health, screening and immunization.

Unhealthy eating habits, sedentary lifestyles, and smoking are common in community settings.

Six most neglected activities:
- Health protection (i.e., vaccination, regular checks, smoking cessation)
- Referral to an optician for sight testing, glaucoma, and cataracts
- Hematological testing, medication levels, blood sugar screening
- Weight management
- ENT services (i.e., wax removal, hearing assessments)
- Gynecological and other women’s health concerns

Health Promotion

Experience higher rates of emergency room visits and hospitalizations along with longer hospital stays (for ambulatory sensitive conditions than the general population).

Frequent admission diagnoses:
- Psychoses
- Seizure Disorder
- Septicemia
- Respiratory Infections
- Pneumonia

Influencing variables include demographics, degree of intellectual disability, polypharmacy, tracheostomy presence, feeding tube presence, hearing and visual impairment, higher BMI, and adaptive status.

Service Utilization
SODC Transition Characteristics

- Between 2001-2008 (n=1,480) transitioned from 10 SODCs in Illinois
  - 66.8% male
  - 47 years old (mean age)
  - 47.6% diagnosed with a psychiatric diagnosis (out of this sample 15% were diagnosed with more than one)
    - Top three psychiatric diagnoses were mood disorder (33.9%), psychotic disorder (25.8%), and impulse disorder (17.7%)
  - 44.8% diagnosed with profound intellectual disability
  - 44.5% (n=658) moved into a CILA, 10.6% (n=157) moved into an ICF/DD, 5.2% (n=77) moved in with a family member, and 1.8% (n=26) moved into an intermittent CILA (the rest moved into non-community settings)

Reinstitutionalization After Transition

- A year after transition,
  - 51.4% (n=338) remained in the CILA
  - 64.3% (n=101) remained in an ICF/DD
  - 53.2% (n=41) remained with family
  - 76.9% (n=20) remained in an intermittent CILA
- Three top reasons for re-institutionalization included behavioral issues, medical issues, and combination of behavioral and medical issues
- Challenges of preventing costly hospital re-admissions and re-institutionalization, in addition to preventing new community settings from becoming smaller institutions
  - Be cognizant. Is the bed location the only thing that has changed?
  - In the community, individuals may still experience institutional practices and attitudes that devoid them of choice, independence or inclusion.

Practice Strategies to Reduce Re-Admissions

- Areas of improvement in care within residential settings:
  - Develop specific protocols
  - Conduct staff training
  - Staff attitudes and knowledge
  - Service provision
  - Increase interagency and interdisciplinary coordination of care and services
  - Communication and information sharing
  - Safe physical environments including a culture of respect, choice, independence, and skill acquisition
  - Develop person-centered, individualized service plans
**Chronic Care Model**

- A guide for effective chronic care management
- Involves essential components of care coordination:
  - A collaborative, interdisciplinary team
  - Longitudinal care coordination with the individual/caregiver
  - Implementation of the care coordination process
  - Individual/caregiver empowerment and self-management
  - Effective transitional care
  - Identification and management of care-related barriers and facilitators
  - Use of information technology
  - Consistent, systematic use of evaluation strategies

**Transitional Care Model**

- Developed by Dr. Mary Naylor and a multidisciplinary team at the University of Pennsylvania
- More research is needed on using this model in the ID/DD community, primarily focused on older adults
- The model emphasizes establishing person-centered goals, coordination and continuity of care throughout acute care episodes, streamlining plan of care, and preparing caregivers for implementing plan of care.
- Outcomes include:
  - Reductions in preventable hospital readmissions for both primary and co-existing health conditions
  - Improvements in health outcomes
  - Enhancement in patient satisfaction
  - Reduction in total health care costs

**Health Care Strategies to Reduce Re-Admissions**

- Areas of improvement in health care for persons with ID/DD:
  - Deliver quality health care
  - Develop and incorporate curriculum on how to care for persons with ID/DD into health professionals’ academic programs
  - Improve methods of communication between persons with ID/DD and health care providers
  - Develop standards of care and best practices specific to persons with ID/DD
  - Conduct frequent medication reviews at primary care provider visits
Future Research

- Develop systems to improve data collection methods
- Examine the impact of caregiver relationship and CILA culture on the health outcomes of persons with ID/DD
- Examine the impact of exercise on challenging behavior
- Investigate the type, severity and duration of the particular behaviors
- Examination of accessibility, delivery, and effectiveness of related community-based behavioral supports
- Compare health outcomes of MFP participants to non-MFP transitions including acute care utilization (i.e., emergency room visits, inpatient admissions), critical incidents and reinstitutionalization
- Explore the use of the Transitional Care Model in persons with ID/DD
- Explore other care management models to prevent reinstitutionalization for persons with ID/DD

Conclusion

- Deinstitutionalization movement continues
- Be weary of new, smaller institutions forming
- Focus on the most effective approaches and supports for persons with ID/DD transitioning from institutional care into the community
- Continue to fight for the freedom, dignity and independence for persons with ID/DD

Questions
References


References


