

# Deinstitutionalization in Two States: The Impact of Advocacy, Policy, and Other Social Forces on Services for People with Disabilities

Based on the work of

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# Overview

This presentation is drawn from a paper\* which explores the findings of a qualitative study of the factors that led two states, Illinois and Michigan, to enact or fail to enact policy changes facilitating the movement of persons with developmental disabilities from institutional settings to community care settings

\*Parish, S.L. (2005). Deinstitutionalization in Two States: The Impact of Advocacy, Policy, and Other Social Forces on Services for People with Developmental Disabilities. *Research & Practice for Persons with Severe Disabilities*, 30(4), 1-13.

# General Trends Catalyzing Deinstitutionalization

- Parents of persons with developmental disabilities becoming politically organized
- Growing normalization of disabilities
- Increasing awareness of dehumanizing conditions in institutions

# Current Status of Deinstitutionalization

- Current proportion of persons with developmental disabilities in institutions varies by state
  - Many states have dual residential service systems (combination of institutional and community placements)
- 44,000 persons with developmental disabilities currently in an institutional setting
  - Compared to 1967 zenith of 195,000 (Braddock, 2002)

# Benefits of Deinstitutionalization

- Established by four decades of research
- Improved behavioral outcomes (e.g., Apgar, Cook, & Lerman, 1998; Klein & Strully, 2000; Larson & Lakin, 1991)
  - Applies equally to more and less severe disabilities (Kim, Larson, & Lakin, 1999)
- Enhanced life satisfaction
- Greater levels of competence in activities of daily living

# Preference for Deinstitutionalization

- Smaller settings are preferred by
  - Self-advocates (e.g., Nelis & Ward, 1995)
  - Others with developmental disabilities (Kennedy, Killius, & Olson, 1987; LoConto & Dodder, 1997)
  - Researchers (Klein & Strully, 2000; Racino & Taylor, 1993)

# Method

- Qualitative comparative case study of polarized deinstitutionalization outcomes in Illinois and Michigan
- Interviews and comprehensive archival document review
- Illinois and Michigan shared many similarities
  - Demographic characteristics
  - Political characteristics
  - Socioeconomic characteristics
  - Histories of large institutional systems providing care to persons with developmental disabilities

# Data Collection

- Review of archived documents
  - 7 archival sites (e.g. the Arc of both states, Michigan state library, Illinois state library)
- Interviews with key informants
  - Leaders of public and private developmental disability (DD) organizations between 1970-90
    - All interviewees had participated in their state's service system for at least five years
  - Snowball sampling
  - 31 completed for Illinois; 21 for Michigan
  - Average duration 108 minutes
  - Semi-structured, open-ended

# Interview Topic Areas

- Four domains established by political science and DD policy research to be salient to state policy development
  - Legislation
  - Leadership
  - Litigation
  - Sociopolitical context

# Analysis

- Atlas/ti software used to code and analyze themes
- Codes dichotomized into factors facilitating or barring deinstitutionalization
- Member checks found a general concurrence that findings were accurate
- Four national experts (from states other than Michigan and Illinois) in dd research generally concurred with findings

# Facilitating Factors in Michigan (1970-1990): Leadership

- Convergence of leadership
- Leader's use of single-issue coalitions to build political/advocacy power
- Commitment to a human rights movement with common vision
- Efforts of Macomb-Oakland Regional Center (MORC) of Department of Mental Health (DMH) in early 1970's
  - Developed group homes for persons with severe developmental disabilities—unprecedented at the time
  - Fought zoning battles
  - Piloted numerous Michigan programs

# Facilitating Factors in Michigan- Leadership (cont.)

- DMH and Community Mental Health (CMH) Boards
  - CMH Board authorized in 1974 to assume responsibility for DD services
- The Arc
  - Secured passage of mandatory special education in 1971
  - Consistent advocacy in Michigan House Committee on Mental Health throughout the 1970s and 1980s
  - Appointed to coordinate Protection and Advocacy (P&A) organizations in 1975 amendment to federal DD act
  - Filed federal lawsuit against DMH because of abusive conditions at the Plymouth Center
- Support of certain state legislators collaborating with advocates and DMH staff
- Support from other individuals and organizations

# Facilitating Factors in Michigan: Role of the Court

- 1976 zoning laws prohibited discrimination against group homes
  - 120 cases of neighborhoods opposing group home development
    - Zoning statute supported in all but 3 cases; these 3 were overturned on appeal
- 1985 rulings ended zoning challenges by upholding rights of persons with developmental disabilities to group homes
  - *City of Livonia v. Department of Social Services*
  - *Green Trees Civic Association v. Pignatiello*

# Facilitating Factors in Michigan: *Detroit Free Press*

- Advocated for community homes through editorials
- Broke story of abuse and cover-up at Plymouth Center in 1978

# Facilitating Factors in Michigan: Federal Funding

- Medicaid funds made available through Intermediate Care Facility for the Mentally Retarded (ICF/MR) in 1971
  - Federal reimbursements for facilities that met ICF/MR regulations
  - Forced states to reduce their institutional populations in order to comply with ICF/MR's minimum staffing and square footage requirements

# Facilitating Factors in Michigan: Economic Recession

- 1980s recession especially difficult in Michigan
- Move to community settings promised financial savings
  - Utilized as selling point by advocates

# Facilitating Factors in Michigan: Politics

- Legislative power was dispersed among legislators (not concentrated among a few)
  - Favored innovative policies
  - Required coalitions and cooperation to get any new policies enacted
- Individual legislators had considerable independence

# Facilitating Factors in Illinois (1970-1990)

- Illinois DMH sought accreditation of its institutions in the 1960's
  - Moved residents from two major institutions to nursing homes or boarding homes
- Need to obtain ICF/MR funds spurred (limited) deinstitutionalization
- Enhanced reimbursement rates offered for nursing home operators converting facilities to ICFs/DD
  - By 1980, ICFs/DD overtook nursing homes as the primary noninstitutional form of care
- Regional administrative structure to oversee community placement

# Barriers in Michigan (1970-1990)

- Neighborhoods attempted to keep group homes out through
  - Zoning laws
  - Deed restriction definitions of family
  - Guerrilla tactics (threats, incidents of firebombing homes, shooting out windows)
- 1985 unsuccessful attempt of three legislators to stop further group home construction through population restrictions
- Michigan's early construction of specialized nursing homes for persons with developmental disabilities diverted state resources away from community homes
- Institutional superintendents and unions of state institutional workers opposed deinstitutionalization
  - Most respondents characterized their efforts as poorly organized and ineffective

# Barriers in Illinois (1970-1990)- Lack of Arc Leadership

- Commonly cited as major barrier by respondents
  - Lack of advocacy perceived to be a function of Arc's atypical role in Illinois as a service provider
- Heated conflicts within the Arc between parents of children in institutions and parents of children living at home
- Unlike many other states, Illinois Arc did not pursue litigation to support deinstitutionalization
  - In one instance, even sued to keep an institution open after its closure (Dixon ARC v. Thompson, 1982)

# Barriers in Illinois: DMH

- DMH used psychiatric hospitals as long-term residential facilities for persons with developmental disabilities
- Lack of DMH leadership for community homes
- Institutions developed in spite of evidence that many parents opposed institutional care

# Barriers in Illinois-Scandals

- Many of the most dramatic scandals occurred in what were considered community settings (even though they were usually large private institutions)
  - Increased fear and opposition to community placements from parents
    - Muddied distinction in Illinois between community and institutional settings
      - “Community”=all private facilities regardless of size
      - “Institutional”=state-operated

# Barriers in Illinois: Scandals (cont.)

- Legislature examined three fatalities in nursing homes of patients with developmental disabilities that involved mysterious or abusive circumstances
- Accounts of inadequate care in newspapers
- Due to rate negotiation difficulties with DMH, one institution gave 24 hour notice of intent to close
  - 500 persons with developmental disabilities were bused to three state institutions in one day (Phillips v. Thompson, 1983)
    - Resulted in a dramatic and traumatizing situation

# Barriers in Illinois: Institutional Parents and Unions

- Parents of institutionalized children were politically organized and active
  - This was easier for them, because the co-location of their children gave greater opportunities to be together (as contrasted with parents of children living at home)
- Unions organized with some effectiveness
  - The American Federation of State, County and Municipal Employees (AFSCME) represented institutional workers

# Barriers in Illinois: Political System

- Legislative structure and campaign finance laws contributed to maintenance of the status quo
- Power in the legislature concentrated among the leadership because of their control of campaign finances
- Patronage created a system of interdependence between officials and institutions
  - Elected officials rewarded supporters with state jobs at institutions

# Barriers in Illinois: Other

- Size and financial resources of large private residential providers increased their political influence in advocating to DMH for retention of large-scale facilities
- Illinois Constitution facilitated the use of zoning boards by municipalities to exclude group homes

# Overview of Findings

- Presence or absence of leadership was leading factor of difference between Michigan and Illinois
- Sociopolitical issues also important

# Findings in Best Practice Context

- Understanding of disability issues and how to address them has deepened since the era studied
- Deinstitutionalization was a first step towards more effective and humane practice
- Current best practice standard entails:
  - Individualized supports
  - Self-determination
  - Positive behavior supports
- Persons with disabilities should be consulted and their desires incorporated into policy development
  - This did not occur in either state studied
- Far-reaching public policy initiatives will be more effective than individual programs in improving services
  - Institutions still exist in most states
  - Inclusive education not universally available

# Advocacy Lessons for States with Receptive Political Cultures

- Open political structures
  - Harness potential of coalitions
  - Work with the media
- Progressive political structures
  - Educate policy makers about benefits of individualized supports
  - Work with policy makers to create self-determination policies

# Advocacy Lessons for States with Conservative Political Cultures

- Strategically focused approaches to work through resistance to change
  - Target change from multiple vantage points
  - Seek incremental and sweeping change
    - Incremental: more easily and rapidly attainable, which creates momentum
    - Large scale shifts usually take more time and resources

# Statewide Cross-Organizational Collaboration

- Developing collaborations that draw from the breadth of organizations in the state is an effective approach
- Existing DD orgs like the Arc and TASH are likely leaders
- Efforts should be made to involve persons with developmental disabilities in the movement
- University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) can offer technical expertise in policy development, building advocacy capacity, and facilitating coalitions

# Limitations of Findings

- Not all leaders participated
  - Analysis of early years relied more heavily on archival documents than interviews given lack of respondents available
- Recall bias
  - But respondents were prompted with key events and dates as necessary

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