

# **SEGREGATION OR COMMUNITY INTEGRATION:**

## **Ensuring the Civil Rights of People with Developmental Disabilities in Illinois**

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# **INTRODUCTION**

## **The State of the State: Illinois**

National studies indicate a trend over the past three decades that shows a significant decrease in the number of individuals with mental retardation and developmental disabilities (MR/DD) residing in large state residential facilities. There has also been a concomitant shift of resources and people to the community; a decline in the number of state-operated institutional facilities; and an increasing average institutional cost of care.<sup>1</sup> Despite this national trend toward serving people with developmental disabilities in community settings, nine state-operated institutions remain open across Illinois. No institution was closed in the 1990s, and even institutional downsizing was limited during this time period.

Prior efforts to close Illinois state-operated facilities were met with significant opposition. In 1995, the Illinois Department of Mental Health and Developmental Disabilities (now the Department of Human Services) announced the closure of Kiley Developmental Center. In response to pressure, mainly from a strong local political constituency and the Kiley Parents' Association, a five-year transition plan was developed to forestall the date of closure. To date, Kiley has decreased its census but has not closed. Another attempt to close a state-operated institution, the Lincoln Developmental Center, occurred after the Federal Government decertified it in 2001 due to a pattern of egregious incidents of abuse and neglect.<sup>2</sup> Although Lincoln was eventually closed in 2002, the process was hindered because of pressures from the surrounding community, union, and some families of Lincoln residents.

A summary profile of Illinois reinforces the conclusion of a recent study by the National Council on Disability that "Illinois is a heavily institutionalized state which ranks higher than all but five other states in its rate of institutionalization of persons with developmental disabilities in public and private facilities."<sup>3</sup>

Given the lack of movement to make any headway in significantly improving this profile, several key advocacy groups in Illinois are now considering litigation as the only viable remedy to promote community integration for people with developmental disabilities.

## **Research Methods**

To confront the reality of Illinois' record in providing services to people with developmental disabilities in the community setting, Equip for Equality (EFE) responded to a "call for investment" from the Illinois Council on Developmental Disabilities (ICDD). EFE was awarded the contract in 2002 to conduct a 50-state study of deinstitutionalization and community integration of people with developmental disabilities, referred to as the Community Integration Policy Project (CIPP).

Research methods included survey interviews with at least two individuals from every state; a review of relevant written documents from these states; site visits to Minnesota, New York, and Wisconsin;<sup>5</sup> and, an analysis of key litigation strategies that have been used to promote community integration. This involved having in-depth discussions with principal attorneys involved in several states' lawsuits, in order to evaluate the long-term impact of the litigation. The content of the survey interviews and auxiliary materials is presented in a compilation of 50 State Profiles that provide concise summaries of each state's past and present activities and also serve as experiential guideposts for recommending what should be done to promote community integration in Illinois.

## FINDINGS

There has been a strong and consistent national movement toward institutional downsizing, closing institutions, and increasing community integration. In most states, this process began with litigation, the result of which was recognition of the rights of people with disabilities to live in environments less restrictive than institutions. Invariably, there was strong opposition to closure, particularly among parents of those in institutions and unions whose members work in institutions. In addition, legislators representing districts where institutions are situated were protective of the economic and other benefits they felt derived from the institutions.

What we learned from these states is that it is possible to address the concerns of parents of institutional residents, unions, and political representatives without reneging on the state's responsibilities to people with disabilities and their right to live in the least restrictive setting. Common strategies for overcoming opposition to community living included having parents and guardians of family members in the institutions meet with parents whose children have successfully transitioned into the community. Additionally, parents and guardians were sometimes apprised of the many longitudinal studies that show that, despite initial opposition to deinstitutionalization, parents of individuals in institutions had come to view the experiences of their family members in the community as positive, affording a better quality of life than the institution. In the case of unions, their concerns have often been addressed by finding jobs for their members in state-operated community residences or elsewhere in state government.

The key factor that was emphasized repeatedly in those states that succeeded in integrating their citizens with developmental disabilities into the community was the will and determination of state political and departmental leaders to recognize that anyone can live *successfully* in the community, and then making the controversial political choices to make this happen. The three site visits revealed community and employment settings that offered a high quality of life to the people living there. In short, what is revealed by the interviews, literature, and site visits of this project, is that, once state leaders set their sight on the goals of inclusion, the battle is half-won.

Those states that have been successful in deinstitutionalization and community integration have these common threads:

The following is a composite of **FINDINGS** compiled from the 50 State Profiles:

### Institutional Closure

- Litigation has played a role in almost all the states where deinstitutionalization has occurred, often providing the initial impetus for closing or downsizing institutions.
- An important factor in the successful closing/downsizing of institutions is a governor's commitment to take a strong, sometimes unpopular, stand to implement the process, and legislators' willingness to provide fiscal support.
- The continued determination, commitment, and continuity of the state department responsible for providing services to people with developmental disabilities has been key to ensuring sustained success of institutional downsizing and community integration.
- Many states have ceased admitting people to their existing state-operated institutions.
- Articles in local newspapers, particularly those that put a "human face" on the issues, have spurred discussion about conditions in both institutional and community

settings, as well as educated the public about individuals with developmental disabilities living in the community.

- A lively debate continues in academic journals comparing factors such as safety and cost of residing in institutions and in the community.
- Alternative uses for closed institutions include their conversion for use by correctional facilities, day programs, other state agencies, and private developments.

### **Opposition to Closure**

- There is often a generational difference in attitudes among parents of offspring with developmental disabilities with regard to residential placement. In general, younger parents, who currently mainstream or integrate their children into the school system and the broader community, expect that their children will continue to live in the community upon reaching adulthood. Older parents, who placed a child in an institution when there was no other viable alternative, are generally more skeptical about placing a family member in the community.
- In addition to opposition from some parents/guardians of individuals living in institutions, the opposition to institutional closure has come most often from employees (both union and non-union), community business interests, politicians, and legislators representing districts where institutions are located. Parent and advocacy groups committed to community integration have been mobilized to counterbalance this opposition.
- One common method used to allay fears about the community has been to hold meetings of parents who have experienced successful transitioning of their family members with parents and guardians of those residing in institutions.
- Longitudinal studies conducted in some states that have closed institutions substantiate that a large percentage of parents who were initially opposed to closure became satisfied with community living and believed their family members to be happier in the community.
- The main reason why state employees oppose closure is that their salaries and benefits are superior to direct care workers who are employed in the community.
- Where state employees are unionized, a major barrier to institutional closure has been the opposition of the unions, in particular AFSCME, which has often been allied with institutional parents in lobbying the legislature and governor against closure. On the other hand, there are indications that the State Employees International Union (SEIU) is willing to collaborate in efforts to realize community integration.
- Included among the successful methods used to gain union support for closure has been creating state-operated community-based residences and prioritizing other state jobs for staff leaving the institutions.

### **Community Integration**

- Studies on outcomes of deinstitutionalization of people with developmental disabilities have concluded that most who have moved from institutions into community environments have made significant gains in adaptive behaviors and have decreased more challenging behaviors.
- The aging of caregivers and the increasing longevity of people with developmental disabilities continue to increase demand for community services.
- Individuals who present the greatest challenge to being served in the community are people with severe behavioral disorders and those with dual diagnoses of mental

illness and mental retardation. Nonetheless, many such individuals have been successfully integrated into the community.

- Dental care, psychiatric care, and transportation, particularly in rural communities, are noted as the most difficult services to provide.
- There is a trend toward “person-centered planning” to prepare individuals and families for transitioning into the community. Support has grown for programmatic changes that give people with developmental disabilities and their families control over the choice of services and service providers to meet their needs.
- In some states, institutional staff moved with their clients, often being retrained for employment in the community setting.
- Strong quality assurance programs are essential to ensure consistent delivery of community-based services.
- Comparative cost of community vs. institutional care varies, depending on short- and long-term factors, including transition costs and individual needs.
- “Money Follows the Person” programs are used in many states to ensure that people live in settings of their choice and have flexibility and control over available resources for long-term community supports.
- States successful in community integration have aggressively utilized all or most Medicaid options. In some cases, budgetary limitations have constricted states’ capacities to increase their matching funds, with the result that some states are not fully maximizing their Medicaid dollars.
- In a few states a process of reinstitutionalization of individuals is taking place, by either transferring people to nursing homes or gradually enlarging community group homes into “mini-institutions.”
- Litigation continues to be among the strategies used to require states to cease alleged violations of federal Medicaid law, the ADA, Section 504 of the Rehabilitation Act, and the U.S. Constitution. Litigation has been successful in improving access to Medicaid home and community services, decreasing waiting lists for community placement for institutionalized people, downsizing institutions, and challenging restrictions on the scope of services so that individuals with developmental disabilities can live in the most integrated settings.

## **RECOMMENDATIONS**

Community integration pertains to the civil and human rights of individuals with developmental disabilities. The legal consensus that people have a fundamental right to live in the least restrictive environment that meets their needs is consistent with data showing that individuals with developmental disabilities are successful in community settings. The current administration in Illinois has the opportunity to show leadership by joining the national trend of steadily downsizing state-operated facilities and increasing services in the community. Illinois needs to adopt a policy of refusing to admit people to existing institutions, so that, combined with a plan for downsizing, there will be a natural attrition that shifts the balance of services and funding to the community.

There are successful models for Illinois to emulate. States with similar demographics and political realities have succeeded in placing themselves on a track of institutional downsizing and community integration. A comparative study of Illinois and

the neighboring state of Michigan revealed innovations in deinstitutionalization and increased community-based services in the latter that failed to evolve in Illinois.<sup>6</sup> Thus, bringing about community integration in Illinois requires the state's political leaders, Department of Human Services, advocacy organizations, unions, parents, and consumers to recognize that individuals have a right to community living and then to develop a strong community system. How this can be accomplished in Illinois in an efficient and cost-effective manner has been highlighted in a recently published study by the National Association of State Directors of Developmental Disabilities Service, Inc. (NASDDDS).<sup>7</sup>

In order to promote the civil rights of people with disabilities in Illinois, Equip for Equality calls on the governor and leaders of the General Assembly to immediately take a series of actions to bring Illinois into compliance with the ADA's "community integration mandate," otherwise known as the U.S. Supreme Court's decision in *L.C. v. Olmstead*, with which all states are required to comply.

I. An Executive Order should be issued by the governor to reflect this Administration's commitment to community integration of people with disabilities. The Order should:

- Recognize that community living is a civil right of people with disabilities.
- Introduce and support a comprehensive package of reforms to develop a strong, coordinated in-home and community-based service system.
- Seek significant expansion of Medicaid funding for home and community-based services by following the recommendations made in the NASDDDS report. Require the Departments of Public Aid, Public Health, and Human Services each to submit an annual progress report of Medicaid-funded in-home and community-based services. Included in these reports should be a description of the oversight process in the areas of abuse and neglect.

II. Further steps to ensure that individuals with developmental disabilities can become integrated into the community should:

- Establish a statutory right of people with developmental disabilities and other disabilities to receive in-home and community-based services necessary for successful community living.
- Prohibit the development of new residential programs for more than four people and to forbid new admissions into state-operated institutions for people with developmental disabilities.
- Create an effective monitoring system, addressing the reasonable concerns of parents about the well-being and safety of their family members.
- Lay out a statutory timetable for downsizing and closure of state-operated institutions for people with developmental disabilities.
- Require that any financial savings from downsizing or closing an institution be used for expanding home and community-based services.
- Fund and fill all of the federally approved HCBS Medicaid waiver slots.
- Develop a plan for moving people out of state-operated developmental centers and large ICFs-DD into the community.
- Expand funding for People First and Centers for Independent Living to assist people in institutions who want to transition to the community, and provide funding to legal

advocacy groups to represent individuals referred by these entities for additional advocacy services.

- Contract for independently conducted client and family satisfaction surveys of all individuals who leave institutions for community living and release these results to the governor, relevant state agencies and elected officials, and the public.
- Require a study of the state's statutory and regulatory quality assurance and oversight system for in-home and community-based services and the performance of existing enforcement mechanisms. Recommendations for reform should be submitted to the governor and relevant state agencies for consideration.
- Develop the capacity for crisis intervention for people living in the community by establishing interim housing with clinical support that leads to an individual's timely reintegration to a community residence.
- Strengthen the state's oversight systems by requiring a coordinated comprehensive review of providers from a programmatic, environmental, and fiscal perspective.
- Ensure effective transition into the community for people with developmental disabilities once the decision has been made to close or downsize an institution.

## **FINAL NOTE: REPORT CONTENTS**

The full report, available online at [www.equipforequality.org](http://www.equipforequality.org), is divided into five sections: Section I presents the 50 State Profiles. Section II consists of the summaries of site visits to Minnesota, New York, and Wisconsin. Section III consists of an overview of Litigation Strategies that have had an impact throughout the country on delivery of services for individuals with developmental disabilities. Section IV, the general Findings of the Community Integration Policy Project, presents a composite picture of national trends, based on information from Sections I-III, as well as additional material from the interviews and other material that was collected during the research. Finally, Section V presents a series of concrete Recommendations for implementing plans for community integration in Illinois. As addenda, there are a Glossary of General Abbreviations and Acronyms and a Selected Bibliography chosen from materials used as references for the State Profiles, for those readers interested in further examining particular aspects of state or national policy on community integration.

## **FOOTNOTES**

1. Braddock, David, ed. *Disability at the Dawn of the 21st Century and the State of the States*. Washington, D.C.: American Association on Mental Retardation, 2002. Prouty, Robert W. et al., ed. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001*. Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, 2002.
2. See: Abuse Investigation Unit at Equip for Equality. *Lincoln Developmental Center— The Politics of Closing a State Institution: Vulnerable People Fall Victim to Special Interests*, 2003.
3. National Council on Disability. *Olmstead: Reclaiming Institutionalized Lives*, [www.ncd.gov/newsroom/publications/reclaimabridged.html](http://www.ncd.gov/newsroom/publications/reclaimabridged.html), 2003. The National Council on Disability is an independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities. This report was published after completion of this study.

4. Data from Tables in Rizzolo, Mary et al. *The State of the State in Developmental Disabilities*. Washington, D.C.: American Association on Mental Retardation, 2004. [www.cu.edu/ColemanInstitute/stateofthestates](http://www.cu.edu/ColemanInstitute/stateofthestates). Because research for this study was concluded in 2003, information in the State Profiles of the full report was based on the 2002 report (footnote 1). For purposes of this summary, however, 2004 tables are used.
5. These states were chosen because, taken together, it was deemed that their experiences with deinstitutionalization and community integration provide a range of challenges that must be addressed and overcome as Illinois begins to develop strategies to increase community integration.
6. Parish, Susan L. "Forces Shaping Developmental Disabilities Services in the States: A Comparative Study," in David Braddock, *supra* note 1, at 353.
7. Gettings, Robert M. et al. *Financing Services to Individuals with Developmental Disabilities in the State of Illinois*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services, Inc., 2003. Also commissioned by the Illinois Council on Developmental Disabilities, the time frame for research for this in-depth study of financing of the Illinois developmental disabilities services coincided with that of this study. Significantly, its conclusions complement those of this 50-state qualitative study.

## **AUTHORS' BIOGRAPHIES**

**E.G. Enbar, M.S.**, is policy analyst at Equip for Equality. She has served as assistant manager of the Guardianship Reform Project, co-manager of the Community Integration Policy Project and project manager for the Outreach, Education, and Policy Review Initiative for private psychiatric hospitals. She has worked as an advocate and consultant for agencies that provide services to people with disabilities for over 20 years, as well as an advocate for patients in healthcare settings.

**Morris A. Fred, J.D., Ph.D.**, is senior policy analyst at Equip for Equality. He served as co-manager of the Community Integration Policy Project and before that, as manager of Equip for Equality's Guardianship Reform Project initiative. In addition to his work at EFE, he is currently professorial lecturer in the Graduate Division of the University of Chicago and Research Associate in the Department of Anthropology. Before coming to Chicago, he conducted research in Taiwan and in Sweden, where he taught at Stockholm University and served as a consultant for the Swedish National Board of Health and Welfare on immigration and refugee policy.

**Laura J. Miller, J.D.**, is Equip for Equality's managing attorney, responsible for supervising the legal work of the attorneys and advocates in the agency's three offices – Chicago, Rock Island, and Springfield. She has extensive litigation experience in private practice, as well as at the New York legal aid society and Northwestern Law School's legal clinic, where she taught and litigated several major cases, including *Corey H. v. The Chicago Board of Education*, which challenged the segregation of children with disabilities in the Chicago Public Schools. Prior to taking her position at Equip for Equality, she worked as senior civil rights attorney at Access Living, Chicago's center for independent living.

**Zena Naiditch, M.A.**, is the founder, president and chief executive officer of Equip for Equality since its inception in 1985. Prior to entering the private sector, she served as the director of the governor's Long-Term Care Policy Project, a special one-year initiative aimed at ensuring that Medicaid-funded in-home services and supports were available to older people to prevent their unnecessary institutionalization. She also served as a staff associate with the Commission on Mental Health and Developmental Disabilities, a bi-partisan legislative body which advised the state legislature on disability policy issues.