

# **A NATIONWIDE STUDY OF DEINSTITUTIONALIZATION & COMMUNITY INTEGRATION**

**A SPECIAL REPORT OF THE PUBLIC POLICY & LEGAL  
ADVOCACY PROGRAMS**

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## SECTION I: INTRODUCTION<sup>1</sup>

### **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>2</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>3</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>4</sup>

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<sup>1</sup> The authors would like to express their appreciation to the following colleagues at Equip for Equality who have contributed to the teamwork that has made this ambitious project possible: Marsha Koelliker, Program Director of Public Policy; Barry Taylor, Legal Advocacy Director; Deborah Kennedy, Abuse Investigation Unit Director; Mary Jo Kern and Karen Kirby-Hall, Senior Investigators; Peter Grosz, Corporation & Foundation Relations Manager; Brenda Lane, Human Resources Manager; Hugh Smith, Director of Operations; and Paris Tillery, Executive Assistant.

<sup>2</sup> Braddock, David, ed. *Disability at the Dawn of the 21<sup>st</sup> 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.

<sup>3</sup> 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.

<sup>4</sup> 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.

## ILLINOIS PROFILE<sup>4</sup>

- Approximately 19,000 people with DD/MR receive residential services. 8,200 live in facilities with a population of 16 or more people.
- 3,089 people live in state-operated institutions; 3,311 people live in Intermediate Care Facilities for Developmental Disabilities (ICFs-DD).
- Illinois ranks
  - 5<sup>th</sup> in total personal income (Bureau of Economic Analysis 2001)
  - 40<sup>th</sup> in the nation in total spending on developmental disabilities
  - 47<sup>th</sup> in the percentage of people residing in publicly funded residences for 1-6 people
  - 47<sup>th</sup> in the percentage of MR/DD spending allocated for community services
  - 42<sup>nd</sup> in fiscal effort for community spending; 8<sup>th</sup> in fiscal effort for institutional spending (“Fiscal effort” is spending for services per \$1,000 of aggregate statewide personal income.)
  - 46<sup>th</sup> in per capita spending for the Home and Community Based Services (HCBS) Waiver

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). Two researchers from the Public Policy Program of Equip for Equality (EFE) were devoted to conducting the 50-state survey, with the research on litigation strategies carried out by a member of EFE’s Legal Program.

Research methods included in-depth telephone interviews with at least two individuals from every state, collecting and reviewing relevant written documents from the states, site visits to three states, and analysis of key litigation strategies used to promote community integration. The first step was to create a questionnaire that would become the prime tool for gathering information on the 50 states’ experiences with deinstitutionalization and community integration. Though the questionnaire was quite detailed, many of the questions were open-ended. The result was that the typical telephone exchange became an extended conversation of up to two hours, with some interviewees feeling comfortable interjecting ideas at will.

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<sup>5</sup> 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 of the length of the interview schedule, it was determined that the two researchers would each take 25 states and interview at least two individuals from different organizations in each state: This would generally be one person from the state's department responsible for individuals with developmental disabilities and the other from an advocacy organization. Providing a quality overview of a state's experience with community integration often required that additional written materials be reviewed to supplement the interviews. The information collected in each interview represents the particular individual's perspective on what has happened and why. In those cases in which views have differed, every effort has been made to present a balanced account.

The content of the interviews and auxiliary materials is presented in this report in a compilation of 50 State Profiles. These profiles are meant to provide concise summaries of each state's past and present activities, and also to serve as experiential guideposts for recommendations to promote community integration in Illinois. Each profile has been based on information from the interviews and relevant materials provided primarily by those interviewed, from websites, and from other reference sources. Once completed, the profile was sent to the interviewees for their feedback, including verification and clarification. Interviewees' responses were reviewed and necessary corrections were made. Finally, it should be noted that the profiles do not purport to cover all of a state's activities. In some states, changes have already occurred since the state profiles were written and reviewed.

The second key feature of the research process was the site-visit conducted in three states. The final choices regarding which states to visit were decided at the completion of all the interviews. Narrowing the choice to three states was a challenge, but the final selection of Minnesota, New York, and Wisconsin was made because, taken together, these states' 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. Minnesota's accomplishments in the community integration field were noted by other states as representing a model to emulate. New York, with a diverse demographic similar to Illinois, has had a long history of overcoming barriers to deinstitutionalization and maximizing Medicaid to build community resources. Finally, Wisconsin offers the opportunity to observe the dynamic process of the first planned significant downsizing of a state-operated institution in that state.

During the site visits, which took place in April and May 2003, representatives from the state departments responsible for individuals with developmental disabilities, advocates, self-advocates, and service providers were included in the groups of those interviewed. In addition to providing insights into community integration and the various state programs for individuals with developmental disabilities, these representatives also made recommendations on how to support initiatives for community integration. Staff also visited group homes, day programs, employment sites, and in the case of Wisconsin, the facility designated for closure. In addition to a separate section describing each site visit, relevant information gathered from these visits has been incorporated into the respective State Profiles.

The third and final methodological component is the analysis of the main legal strategies that have been used to require states to initiate or increase community integration. In almost all of the states, litigation at some stage has played a role in the downsizing or closure of institutions. Litigation has also challenged policies that limit access to Medicaid home and community services, and/or securing community services in the most integrated settings.<sup>6</sup> In addition to gathering material on these strategies, several states' lawsuits have been chosen for in-depth analysis, including interviews with the principal attorneys, to evaluate the long-term impact of the litigation.

### **Contents of the Report**

The report is divided into five key sections:

- **Section I** presents the 50 **State Profiles**. Each profile may differ in types of information presented, since not all the same issues were considered equally relevant in every state. It was possible, however, to provide some consistency by grouping that information into the broad categories that encompass the range of data gathered. The last category, *Interviewee Reflections*, presents a selection of additional comments that the interviewees considered as important lessons or reflections for guiding any future plans for community integration.
- **Section II** consists of summaries of site visits to Minnesota, New York, and Wisconsin.
- **Section III** presents in-depth **Legal Case Studies** of three states, analyzing the litigation strategies used and the roles that litigation served in shaping systemic changes.
- **Section IV** presents the **Findings** of the Community Integration Policy Project, a composite picture of national trends based on information from the two prior sections, as well as additional material from the interviews and other material that was collected during the research.
- **Section V** presents a series of concrete **Recommendations** to key state officials for realizing the goal of 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.

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<sup>6</sup> Human Services Research Institute publishes a continuously updated report, which is posted on its website at <http://www.hsri.org/index.asp?id=news>. Scroll to Status Report: Litigation Concerning Home and Community Services for People with Disabilities.

## **Final Note**

During the interview process, our mentioning the fact that we were conducting a 50-state qualitative study to be completed in six months (later extended two months) often elicited surprise from those experts and stakeholders who understood the complexities of the problems we were undertaking to analyze. Our interactions with the majority of those people interviewed were gratifying. They were both gracious with their time and patient during the lengthy conversations. Although opinions varied about the strengths, weaknesses, and degrees of success of different strategies used by the states, one thing became apparent to us: No matter where individuals placed themselves in terms of their position on the institution/community continuum, the dedication and care of these people provide a ray of hope for ultimately finding a common ground that will benefit people with developmental disabilities in our state.

## SECTION I: STATE PROFILES

### ALABAMA

**# State-Operated Institutions Remaining: 4**      **Approximate Census: 400**  
**# State-Operated Institutions Closed: 1**      **Closed Since 1993: 1**

#### **Service System:**

The Division of Mental Retardation (DMR), of the Alabama Department of Mental Health and Mental Retardation (DMH/MR), provides a comprehensive service system that is managed through five geographic regions. Services in the community are contracted through a variety of local providers.

#### **Alternative Use(s) for Closed Institution(s):**

No usage is being made of the Glen Ireland property since the closure in 1996.

#### **Institutional Closure Information:**

- The landmark class action lawsuit, *Wyatt v. Stickney*, filed in 1970, is the longest running suit having to do with the right to treatment for persons involuntarily committed to a state institution. In 1972, the judge's ruling established minimum standards for providing treatment and habilitation in state mental health and mental retardation facilities. The Settlement Agreement signed in 2000 requires implementation of a three-year plan to downsize state-operated psychiatric hospitals and developmental centers and significantly expand community-based options.
- Glen Ireland was closed in two months' time with no advance public announcement, as the DMR did not want groups to build an alliance to oppose the closure. There were approximately 50 residents living at Glen Ireland at the time the closure was announced.
- The Governor approved the closure. There was no legislation about closure; however, legislators were informed before the press.
- The DMR was responsible for bringing about the closure. There was also an internal Advocacy Division within the DMR that worked closely with families.
- There is now a plan, put forth by the Commissioner of the DMH/MR, to consolidate three of the four remaining facilities incrementally throughout the next fiscal year. Hearings are occurring statewide, and efforts are being made to keep everyone informed.

#### **Opposition:**

- Two months prior to the Glen Ireland closure, the DMR informed the consumers, families, and employees of the institution. The families were worked with one by one. The DMR said to a family member, "Let's not worry about these buildings; let's find out the best things for Michael." The emphasis was on planning for the individual.

- Friends of Glen Ireland (a parent/guardian organization), the union, and the State Employees Association were all opposed, but the closure plans were too far along to have any impact.
- When the announcement was made, the DMR offered other state employment to union workers. Of those employees laid off, there were eighty who could not find other jobs. Some workers followed residents to private providers in the community, where the salaries are comparable, but the employee benefits are not.

### **Transition and Community Living:**

- The Glen Ireland staff did a lot of training with community providers that was very individualized and based on person-centered planning. Additionally, the DMR worked with providers to find the best match for residents.
- Most of the residents moved to group homes of three people or less. Some residents moved to a smaller type of community-supported living arrangement or lived with staff in a foster care setting. Fewer than five of the 200+ persons moved to another state facility.
- The size of residence depended on the individual. Consideration was also given to physical disability issues and geographic proximity to one's family. People made several visits before finally moving to their community residence.
- Individuals with challenging behaviors have been difficult to serve in the community, as there are not enough resources or expertise.
- Dental services and transportation were identified as hard services or needs to fill. The transportation issue impacts on community integration.
- The Office of Continuous Quality Improvement (CQI) monitors and coordinates the statewide Mental Retardation CQI System for developmental centers and community service.
- The state Advocacy Division does routine monitoring to ensure that people's rights are not violated.
- Case management, support services, residential services, and day services are contracted through a variety of local providers. These services are purchased through the DMR.

### **Economics:**

- Economics did not play a major role in determining the type of community services that were offered to replace Glen Ireland.
- 97% of the state money is being used for the federal Medicaid match.
- State funds, Medicaid waiver federal funds, Part C federal funds from the U.S. Department of Education, and other funding sources provide major resources in the delivery of community services.

### **Noteworthy:**

- Three of the four remaining institutions have diminished in population to approximately 60-70 residents each.
- Each developmental center dedicates five beds to be used for community respite services.

- In April 2003, Governor Bob Riley was quoted saying that “the state could save \$40 million or more by closing half a dozen state mental health facilities and caring for patients in other ways.” The DMH/MR Commissioner has recommended closing three of the four existing developmental centers and giving residents a choice of either moving to the remaining open facility or to a residential setting in the community. The Commissioner said that she would begin meeting with families, employees, and legislators to describe the consolidation plan she said will be implemented next year. She also asserted that employees at affected centers would be offered jobs or training assistance. (*Tuscaloosa News*, April 23, 2003)

**Interviewee Reflections:**

- Providers tend to develop programs by buying properties. Zoning ordinances are a problem. It’s better for people to be served in a smaller apartment or their own home, but there’s not much choice offered. It’s usually a two- to three-person home in a neighborhood, and there are sometimes issues related to “Not in my backyard....”
- Every facility has to be approached differently. It’s best to get to know staff and families to develop a strategy. Documentation should be done of the transition process, the stories of what was happening to people, and consumer satisfaction. Gradually downsize!

## ALASKA

**# State-Operated Institutions Remaining: 0**

**# State-Operated Institutions Closed: 1**

**Closed Since 1993: 0**

### **Service System:**

The Developmental Disability Program is now part of the Division of Mental Health and Developmental Disabilities of the Department of Health and Human Services; in July 2003, it will however become part of the Division of Senior and Disability Services. It administers Medicaid waivers and DD Community Grants for services delivered by 36 community organizations in over 100 different communities across the state.

### **Alternative Use(s) for Closed Institution(s):**

Harborview, located in Valdez, is still a state building and is used to house different state organizations.

### **Institutional Closure Information:**

- There were no admissions to Harborview after 1988, and by 1994, it was felt that anyone could be served in the community. A few people, with complicated service needs, did not leave until 1997 in order to have the time to build appropriate assisted-living homes.
- There was a gradual elimination of the institutional budget. The time frame for closure was approximately two years.
- By the time of the final closure, there had been six years to demonstrate that people could live in the community. Because Alaska is 75% rural and over 50% Native American, it was important to serve people in the communities where they live.
- Alaska has no community ICFs-MR, no institutions, and sends no one out of state, even though the waiver requires them to offer the alternative of going to an institution. A few individuals have been sent out of state for short-term treatment when such treatment is not available in the state.

### **Opposition:**

- A few families remained fearful of transitioning their relatives into the community. A few neighbors also expressed opposition to having assisted living nearby. But, in general, there was minimal opposition to closure.
- Unions had previously been active in trying to work with Harborview employees, who had expressed dissatisfaction with the working conditions. By the time the decision was made to close Harborview, the union was no longer strongly adversarial.
- No one lost a job because of the closure. There were special retirement incentives and relocation packages offered by the state. People who transferred into another state job were allowed to retain seniority, sometimes even bumping others from potential jobs.
- Many people working in the institution were transient workers who merely left once their jobs were eliminated; others were married to people with good jobs,

and so they stayed in Valdez. Only about 20% of the employees took advantage of benefits and early retirement incentives.

### **Transition and Community Living:**

- Families met with providers at “fairs” to evaluate what was available and how it could satisfy the needs of their family members. Individuals were allowed to move anywhere in the state; however, they often ended up in the Anchorage area because of inadequate services in their community of first choice.
- Many at Harborview were incapable of participating fully in the planning process, so family advocates participated. In the absence of family, state and institutional staff, together with the resident, determined what was in the individual’s best interest. During this transitioning process, out-of-state guardians could transfer guardianship to the Office of Public Advocacy (state guardian).
- The Department of Health and Social Service made a concession that everyone could be served in community settings, which was often a two-person apartment/home or one’s own home, but could include up to five people.
- Initially, the state sought to have the community staff visit Harborview. It was subsequently decided that because of the “institutional” mindset of many facility personnel, this might have a negative influence in causing future community staff to underestimate individuals’ abilities to adapt to the community. Nonetheless, the Harborview staff spent a week with receiving staff in the community to help when the individual moved out.
- There was an improvement in the functional capacity of some of those transitioned into the community.
- In 1991, the DD Program initiated “individualized” services tailored to meet the unique needs of each individual and family. This approach allowed funds to follow an individual so he or she could choose different providers, thus enhancing the person’s capacity for independence as providers attempted to deliver services in his hometown.
- There are care coordinators to develop a comprehensive planning team for selecting needed services. Sometimes the care coordinator works within an agency. However, there are proposed regulations to require that the care coordinator work outside the agency to prevent any conflict of interest and provide the consumer with greater flexibility to choose a new agency when displeased with services.
- There has been a concerted effort to train families, who had been previously detached from the process, on how to request and evaluate the quality of services.
- There is a centralized Waiting List in the state for assessing the relative needs of individuals who seek services.

### **Economics:**

- When Harborview closed, the state initially saved several million dollars with the conversion to waiver funds. The 60% federal match was applied to residential habilitation, environmental modifications, respite care, specialized medical equipment, and supported employment. The waiver program has since grown

- exponentially, with over 1,200 individuals on waivers and an additional 2,500 on Community Developmental Disability grants.
- When closure occurred, even though families were allowed to spend as much in the community as had been spent for the family member at Harborview, most did not ask for the full amount allowed when they were given choices of how to best meet the needs of the individual. However, because of the subsequent increase in administrative costs paid to the agencies, the state is now considering self-determination waivers with which the consumer can buy services directly without using agencies as intermediaries. In preparation for adopting these self-determination waivers, a study has been conducted to evaluate the average cost of each category. A subsequent study is planned on cost methodology for developing a process by which this average will be tied to individuals' needs.

**Noteworthy:**

- A video, *Road Maps*, presents the process of dismantling the state's ICFs-MR and the subsequent successful integration of individuals with a wide range of disabilities into the community.

**Interviewee Reflections:**

- Anyone with an eligible diagnosis, whatever the level of disability, can be served in the community.
- The openness of the transitional process, involving individual and family, was the key to the success of deinstitutionalization.
- The only way to guarantee lower rates in the community is to either offer families choice and set individual service categories or have capped waiver amounts that cannot be exceeded.
- At this point, the state staff only monitors plans of care, levels of care, and funding services at Certified agencies through waiver and/or Community DD grants. However, the state has considered either taking back the case management role or contracting it out, in order to ensure a high-quality service delivery system.
- There is a need to modify the statutory definition of developmental disability. For example, one category, "Other Mental Retardation," is too broad and often leads to including those with learning disabilities, mild FAS/FAE, TBI, and PDD, who would be better served through other programs. One result has been that some children who should be integrated into the existing school service system are instead categorized inappropriately into the DD system.

## ARIZONA

**# State-Operated Institutions Remaining: 1**

**Approximate Census: 150**

**# State-Operated Institutions Closed: 2**

**Closed Since 1993: 1**

### **Service System:**

The state's Department of Economic Security, Division of Developmental Disabilities (DDD) funds the system through Regional Offices of six planning districts, which are either single county, in the case of the two largest counties, or several counties that have been combined into one region.

### **Alternative Use(s) for Closed Institution(s):**

- Tucson: Community Resource Center (outreach services) for staff; offices for other community agencies such as Senior Nutrition/ Meals on Wheels, which use the facility's kitchen; and the KARE Center, which provides support to grandparents for children who otherwise would be in foster care.
- Phoenix: Developed for commercial use. The money received by the state from the sale was placed in a special trust fund used to award funds to individual consumers based upon an application to meet specific needs.

### **Institutional Closure Information:**

- Problems with the closure of the Tucson facility were alleviated because there was no closure deadline and a great amount of time was used to prepare families. Initially, DDD worked with only those parents who were open to the idea of moving their children into the community.
- From 1977-87, the state went from a high of 2,000 in institutions to approximately 350.
- The Phoenix experience indicated that there is about a two-year period when costs go up because of the need for a closure manager and transition planners, and for essentially funding a dual system of institutional and community supports.
- Outside of DDD, there was initially little support for closure in the community. Together with a lawsuit and lobbying from the provider group association, support for deinstitutionalization grew. In the 1970s, three events occurred that together resulted in greater movement towards deinstitutionalization:
  - In 1975, there was a new state director who, because he had been part of a group in Nebraska that had worked with Wolf Wolfensberger (a key figure in reform of the developmental disability system in that state), focused on community integration;
  - In 1976, the Arc of Arizona filed suit against the state (*Griswald v. Riley*). The Department signed a consent decree leading to more community placements and better individual planning.
  - A Joint Legislative Committee held hearings on how people with developmental disabilities could best be served. This led to a 1977 statute that focused on least restrictive environments and provided a plan for downsizing, from which developed a five-year plan that estimated the

costs of implementing the legislation and developing a community-based service system.

### **Opposition:**

- There have been five different attempts to close the last institution, in Coolidge, but all have been defeated by an alliance of elected officials, parents, chambers of commerce, and the employees union (although relatively weak, the union gained strength by allying itself with a parents' group). In 2002, the Legislature once again considered closing Coolidge, after having conducted a cost-benefit analysis that indicated savings would occur with closure.
- During the legislative process for closing the Phoenix facility, families successfully lobbied the legislature to create three ICFs-MR that were larger than group homes.
- There is an option for the state to operate group homes that has been proposed as one way to overcome some opposition to closing Coolidge.

### **Transition and Community Living:**

- The transition process is now guided by person-centered planning, which focuses on the total person, his or her personal goals, and what he or she needs to live in the community. (See Smull and Harrison's *Essential Lifestyle Planning* and O'Brien and Mount's *Personal Futures Planning*). Even though this takes more time (up to six months), it is the most effective approach.
- The support coordinator (case manager) reviews the personal plan within 30 days of transitioning and subsequently every six months. Evaluations are used to check if overall objectives have been met and if proper medication and staffing are available for the individual. There is also a twice-a-year review of residential settings by program monitors within the DDD.
- As a result of the *Griswald* agreement, the Arc was given the authority to monitor individuals in community settings. Evaluation surveys of clients have been conducted by both consumers and family members.
- The Core Indicator Project from HSRI does regular interviews with family members about satisfaction with community living and supports.

### **Economics:**

- Medicaid/matching funds (35/65) is the mainstay of the system. There is also a small general fund for those who are not Medicaid eligible. Arizona is the only state in the country with no Medicaid cap. It costs the state about \$10 million/year in matching funds to keep up with growth.
- To alleviate some of the financial pressure, the Medicaid program is a statewide demonstration project that seeks to contain costs through a managed care system.

### **Noteworthy:**

- The 1977 statute also included a Bill of Rights for people with developmental disabilities.
- In 2001, with a federal grant, DDD established the Arizona Coalition for Family Support, Self-Determination and Disability. This council consists primarily of

individuals served by DDD. Its purpose is to review, comment, make recommendations, and give input on Division policy, procedures, and rules that directly affect the services and supports of customers.

- DDD is moving toward a model of consumer control over the purchase and selection of services and providers. DDD's new role will be to facilitate consumer choice and to assist qualified vendors to effectively make their program plans known to consumers.
- The Arizona Coalition for Family Support, Self-Determination and Disability, in collaboration with the Northern Arizona University/ Institute for Human Development, presented a policy study with recommendations for person-centered planning to the Governor's Council on Developmental Disabilities.
- The state participates in the NASDDDS Core Indicators Project that aims to support state authorities in developing and implementing performance/outcome indicators that will enable them to measure service delivery system performance.

**Interviewee Reflections:**

- Consumer involvement, choice, and self-determination flow from a person-centered planning process. If this is not effective, the result will be re-institutionalization.
- There is still a problem with the quality of services being offered, and, despite the goal of person-centered planning, there is often a "cookie-cutter" approach that hinders individualization and effective person-centered planning.

## ARKANSAS

# State-Operated Institutions Remaining: 6

Approximate Census: 1,160

# State-Operated Institutions Closed: 0

### Service System:

- The Division of Developmental Disabilities Services (DDS) of the Arkansas Department of Human Services is responsible for the overall coordination of services for people with developmental disabilities in the state.
- DDS contracts with about 100 providers who provide a variety of services, including day programming, respite care, family support, case management, integrated supports, and community integration companions.

### Institutional Closure Information:

- There is little discussion about closure of the six Human Development Centers, although there is a pattern of decreasing population in all centers.
- The decreasing institutional population is due to two factors:
  - Diversion, in which consumers, parents, and others have learned about the success of waiver programs and therefore choose community services over institutional services; and,
  - Transition, in which individuals, with the support of their family members, move to the community. This happens most often when institution superintendents and staff take an active role in encouraging the development of transitional services.
- Work is proceeding on a comprehensive plan for community integration. Five town hall meetings were held in 2002 to get public input on the draft of the state's Olmstead Plan in Arkansas.

### Opposition:

- There is a strong Voice of the Retarded (VOR) organization in the state.
- There is concern about job loss of state employment, with accompanying benefits, in Booneville and Warren, where the state ICF-MR employs a large number of people.
- To bridge differences among groups about community integration strategies and provide a framework to maintain civility in debates about community services and institutions, a "Common Threads" program was initiated by the P&A in collaboration with the Governor's Council on Developmental Disabilities. This group, comprising representatives with diverse viewpoints, such as VOR and the P&A, has tried to develop common goals, such as quality of care and funding for clients.

### Transition and Community Living:

- Most individuals living in institutions are transitioned using a "fast track" program, so they are not placed on a waiting list. There is a process for interim services (90 days). Once a plan is fully developed, it is sent back to the state for

- review. The case manager, consumer, family members, and providers all participate in the planning process.
- Monitoring by the state includes utilizing a waiver staff to ensure that an individual is securing appropriate services and a licensing staff to review compliance by the waiver provider, as well as making unannounced visits. Nonetheless, not enough resources have been allotted for sufficient monitoring.
  - There is a choice of providers that have been designated to serve in particular counties.
  - Guardians/families/consumers often visit providers before making a final choice.
  - Several new federal grants have been made available to the state for recruiting and training direct support staff, developing a family support program, improving the transition process, and building self-advocacy among those with disabilities.

**Economics:**

Main funding is provided in the following ways:

- There is a 27.2% state to 72.8% federal match in FY02.
- The main funding for DD services comes from the HCBS and ICF-MR waivers.
- DDS pays the state match for Medicaid-funded center-based services (Developmental Day Treatment Clinic Services, which include preschool, adult development, and sheltered workshops).
- DDS also funds some services for people not eligible for Medicaid services.

**Noteworthy:**

- Arkansas was part of a three-state demonstration in which Medicaid enrollees eligible for personal assistance services received a monthly allowance to purchase services, instead of obtaining them through a home care agency. Mathematica Policy Research, Inc., released an independent analysis of this program, called IndependentChoices, in 2003. The report concluded that the program considerably increased consumer satisfaction. Although only a portion of those served in this project are individuals with developmental disabilities, the state is planning to modify its waiver to develop an Independent Plus template specifically for those with developmental disabilities.

**Interviewee Reflections:**

- Planning for all of life's transitions should start at birth. There is a need to bring agencies together to work with the whole person, instead of fragmenting the individual to match the structure of the administrative organization.
- There should be more flexibility in providing services, because people change and their attitudes about what they want also change.
- There needs to be a true continuum of services. A person should not have to go into a large institution because of the lack of a physician or a school district's unwillingness to integrate a child into the classroom.
- There should be easy access to information about community resources so that individuals can make responsible decisions for themselves and their family members.

## CALIFORNIA

# State-Operated Institutions Remaining: 7

Approximate Census: 3,600

# State-Operated Institutions Closed: 5

Closed Since 1993: 2

### Service System:

- The Department of Developmental Services (DDS) is responsible for providing services to people with developmental disabilities under the Lanterman Act, which has been interpreted by the State Supreme Court in *Association for Retarded Citizens v. Dept. of Developmental Services* (1985) as an entitlement for services.
- DDS executes its responsibilities through two systems: One is through 21 community-based nonprofit organizations known as Regional Centers that contract with DDS to provide community services in specific geographic areas. DDS is responsible for ensuring the quality of services provided by the Regional Centers. The other system comprises five state-operated developmental centers and two smaller state-operated community facilities. The developmental centers combine medical care and habilitation and training services.

### Alternative Use(s) for Closed Institution(s):

Camarillo facility is now part of the state university system.

The Santa Clara campus of Agnews was closed and land was sold to Sun Microsystems, with money going into the general fund.

### Institutional Closure Information:

- In April 2002, the California Health and Human Services Agency Long Term Care Council (chaired by CHHSA Secretary and including directors of relevant state departments) directed its staff to prepare the development of an Olmstead Plan for California. After a series of local Olmstead Forums, a work group was organized composed of consumers and stakeholders to identify options and make recommendations. This culminated in a plan presented to the legislature in 2003.
- Litigation has played an important role in leading to institutional closure. *Coffelt v. DDS* (1990) determined that the state had failed to fulfill its mandatory statutory obligations under the Lanterman Act (1969) by restricting Regional Centers from implementing individual program plans (IPP) for those in the class, so that individuals were denied entitlement to appropriate, more independent, and more productive community living arrangements.
- The *Coffelt* case was not about closure of any specific developmental center, but it resulted in significant downsizing. During the settlement period, the number of individuals in state institutions decreased significantly. The result was the consolidation of two campuses and the closure of two others due to escalating costs.
- The 2003-04 Governor's Budget directs the Department to develop a plan to close Agnews Developmental Center in San Jose by July 2005. Welfare and Institutions Code Section 4474.1 provides direction on what must occur in the development of the plan, including a requirement that there be legislative approval before its

implementation. The plan will be developed with input from an Advisory Committee consisting of consumers currently and formerly living at Agnews, their families, employees, regional centers, advocates, and others. A website has been created to provide timely and accurate information on the Agnews Closure Plan.

### **Opposition:**

- Unions lobbied legislators and publicized only negative aspects of life in the community. AFSCME has been in opposition to the closing of Agnews, using the argument that there is a need to protect clients in institutions and that there is concern about transfer trauma.
- The Service Employees International Union (SEIU) has become more supportive of community integration efforts.
- There have been behind-the-scenes negotiations with unions brought about by the realities of the budget crisis. The idea has been to try to ensure that no one will become unemployed as a result of deinstitutionalization.
- In the late 1990s, Arc-California sent out a memo asking for a two-year moratorium on people leaving institutions. Four of the Arc chapters went to The Arc of the United States asking for an investigation of this pro-institution position. This led to a change in the organization's structure and led to the expulsion of several local chapters. In total, 15 chapters resigned and formed their own California Association for the Retarded.
- A group of parents making up the California Association of State Hospital Parent Councils for the Retarded (CASH-PCR) have aligned themselves with unions such as the California Association of Psychiatric Technicians, which has supplied staff support for their work in opposing institutional closure.
- There has been some concern expressed over the concentration of group homes in particular communities.
- There was also some opposition to closure of the Stockton facility by the local Chamber of Commerce. The state sought to overcome this opposition by providing those staff that had been transferred to Napa with transportation, in order that they could continue to live in Stockton and contribute to the local economy.

### **Transition and Community Living:**

- Half of those who left the institutions went to ICFs-MR and half went to group homes that are categorized into four levels, according to the degree of disability.
- Regional Centers are required to assess the needs of those in the institutions to determine what they will need in the community. As an example, in the San Francisco Bay Area, the Regional Center worked with the Housing Corporation to build two four-person facilities in a senior housing complex for people who use gurneys.
- Deinstitutionalization depends on the attitudes and competency of the individual professionals who are involved. In order for closure to succeed, the directors of the Regional Centers must be committed to the downsizing process for it to work

well. In the case of Agnews, much time has been spent trying to gain institutional commitment to deinstitutionalization.

- Services are monitored in the community by the Regional Center responsible for the area where the individual is living and by the P&A.
- Articles in the *San Francisco Chronicle* in 1997 took the lead from studies conducted by researchers at UC Riverside, which asserted that there is a higher death rate in the community than in institutions. A discussion of these studies and others that reached different conclusions can be found in *Mental Retardation*, v. 36, no. 5 (October 1998).
- A report submitted to the state by The Center for Outcome Analysis in 2002 concluded that people were better off in the community than in the Developmental Centers. It also revealed dramatic positive changes in parental attitudes toward community placement after their relatives began living in the community.

### **Economics:**

- There is concern that cuts in Medicaid might lead to many individuals' being forced to return to institutions.
- CMS, which has some reservations about the regional center system, has placed the state on probation due to the use of some federal funds to replace funds paid by state rather than to support appropriate programs.
- Because there is a statutory "entitlement" to services, one may appeal to receive services whether or not Medicaid funding is involved (the state is spending approximately \$1 billion on its own).

### **Noteworthy:**

- The Lanterman Act, which asserted an entitlement to services, has been a key factor in legal and policy strategies for developing and enhancing community services.
- California has community monitoring teams of volunteers supervised by local area boards to conduct Life Quality Assessments through observation and interviews. Volunteer monitoring has been viewed as useful for allowing people the opportunity to give feedback on their lives and on services being offered.
- A class-action lawsuit filed in 2002 by the California Protection & Advocacy, Inc., (*Capitol People First et al. v. California Department of Developmental Services et al.*) alleges that individuals are being segregated in large congregate public and private facilities and that the lack of appropriate community services places them at risk of institutionalization. The lawsuit asks the Court to require the state to offer a full range of Medicaid HCBS and to strengthen other features of community services.
- *Sanchez v. Grantland Johnson*, filed in the U.S. District Court for the Northern District of California, challenges the differential in wages and benefits provided by the state to staff in community programs versus those in institutions. It argues that the gap creates high community staff turnover and instability in the community, subjecting consumers to unnecessary institutionalization and

- segregation. The average salary noted for community-based workers is \$18,500 compared with from \$36,000 to \$52,000 for state institutional staff.
- In order to facilitate community living for those with behavioral disorders, DDS has focused on the development of significant programs for working with these individuals.
  - In 1997, the legislature passed a bill to start self-determination pilot projects at three of the 21 Regional Centers, making California the only state in which a self-determination effort was a part of legislation. Each center worked with 30 participants and families. A longitudinal study of these projects concluded that there were “rapid and significant benefits” to self-determination in shifting power from professionals to people and their relatives.
  - The Service Employees International Union (SEIU), in conjunction with Art Bolton (who as legislative staffer was responsible for writing the Lanterman Act) developed the Workforce Services Centers (WSC) legislative proposal, Assembly Bill (AB) 649. The proposal was presented as providing new opportunities to draw down additional federal funding and maximize efficiency in the system. If created, the WSC would have a registry from which consumers could choose services from provider agencies or directly from staff referred by the WSC. WSC functions would include serving as fiscal intermediaries, providing individuals with the right to hire, supervise, and terminate staff as they wish. The WSC model would establish a negotiated contract between the union and the WSC if the employees elect to be represented by a union. AB 649 met with opposition from several provider organizations, including the California Rehabilitation Association, representing 130 community-based, private nonprofit agencies and Arc-California. The bill was tabled for consideration in next year’s legislative session.
  - A recent study analyzes the challenges of reconciling diverse interests in the grassroots unionizing activities by SEIU of California’s homecare workers, suggesting that these activities will have an impact on social policy for the care of the elderly and those with disabilities. (*Labor Studies Journal*, Vol. 27, No. 1, pp. 1-23, Spring 2002)

### **Interviewee Reflections:**

- One should transition the most difficult cases out of institutions first, because once you know how to meet these needs, anyone can be moved into the community. If you do the opposite, at the end of the process, when you want to close an institution, the argument will be raised that one must keep institutions open to handle the difficult cases.
- The key to successful deinstitutionalization will be to prepare providers for meeting these individuals’ needs.
- One should take care not to transfer institutional models into the community. For example, group homes of six individuals represent a model for economic efficiency rather than one of self-determination. Why should one be required to live together with six other individuals with disabilities?
- A major problem with medical care is to get physicians to treat individuals with disabilities as patients like any other with medical problems rather than viewing

mental retardation as the key issue. Any movement toward “developmental medicine” may exacerbate this problem.

- State departments should continually focus on the development of community resources so that there will be no need for quick fixes once an institution closes.

## COLORADO

**# State-Operated Institutions Remaining: 2**

**Approximate Census: 70**

**# State-Operated Institutions Closed: 1**

**Closed Since 1993: 0**

### **Service System:**

Division for Developmental Disabilities (DDD) is the state office that provides for the direction, funding, and operation of services. DDD services are administered under the Office of Adult, Disability and Rehabilitation Services of the Department of Human Services. The state contracts with 20 private nonprofit Community Centered Boards (CCBs) to deliver community services.

### **Alternative Use(s) for Closed Institution(s):**

- Some buildings of the Pueblo Regional Center reverted to the State Mental Health Institute; others were torn down.
- The Colorado Land Board has sold some of the land at Wheat Ridge (although it's not completely closed), portions of which are being used as a community college and for private homes.

### **Institutional Closure Information:**

- All large private ICFs-MR have been closed in Colorado.
- In the early 1980s, Colorado began using state-operated community-integrated and dispersed group homes to facilitate downsizing the main campus of each center to move people into smaller community-based state-operated group homes. These homes are operated by the Regional Centers.
- From 1986 to 1992, the population of the three Regional Centers decreased by more than half.
- The closure process was facilitated by the support of governors from both parties and their department heads.
- The closure of the Pueblo Regional Center campus was complicated by the need to continuously reconfigure it during the downsizing process.
- During the last decade, the state has been aggressive in moving people from the large and expensive congregate-care facilities (more than 15 people) to Medicaid waiver-funded community-based comprehensive services (8 or fewer).
- Efforts are now underway to further downsize Grand Junction by moving people off the large campus.
- The state is looking at maintaining a campus setting for those with developmental disabilities who are danger to self or others (mainly sex offenders). There are six five-bed homes left at Wheat Ridge and about 40 individuals remaining at Grand Junction.

### **Opposition:**

- The role of the Regional Centers is still controversial. Some view these centers as safety nets for those who they feel cannot succeed in the community; others disagree and want to see them closed.

- Further closure has been stalled because Regional Center staff and parents, fearful of more state closures, have sought to mobilize opposition in legislature against funding further downsizing.
- With regard to downsizing and planned closure of Wheat Ridge, there were town meetings with parents testifying about the positive aspects of the institution. Discussion of issues pertaining to downsizing of institutions became confused with problems over implementation of community integration. Meetings with parents to overcome their opposition failed and were seen only to provide fodder for the media and an impetus for galvanizing opposition to closure.
- A working group was created by DDD in Wheat Ridge that included key people from the institution who were most sympathetic to closure. Advocacy groups, parent representatives, and union representatives met monthly. The focus at these meetings was on the operational aspect of aiding downsizing efforts.

### **Transition and Community Living:**

- Both the Regional Centers and the CCBs are involved in the process of integrating individuals into the community. Many of the group homes are being run by Regional Centers (although only 400 out of 12,000 people in the community are actually under the auspices of centers).
- If the community cannot meet the individual's needs or there is no appropriate vacancy, the Regional Center may need to waitlist the person until appropriate placement can be found.
- In 1996, the legislature called on DDS to prepare a plan for funding community services that would include fiscal and programmatic changes, anticipated efficiencies, a system for assurances and individual appeals, timelines for implementation, justification for configuration of a service delivery system, and avenues for stakeholder involvement in formulating a plan.
- The P&A's branch office in Grand Junction aided the transitioning process. If individuals said that they did not want to leave, then the staff would work only with those inclined to move.
- CCBs were the driving forces as to which community services were actually made available to individuals.
- Follow-up evaluations about the transition of family members who had been in Grand Junction revealed a high level of satisfaction about the planning process, actual move, current services, and overall condition of individuals in the community.

### **Economics:**

- In the mid-1990s, in order to develop a more efficient delivery system, a Systems Change Project was designed that sought to increase flexibility, efficiency, and choice within the system. CCBs negotiated payment rates with providers; "per person funding" was adopted to promote increased flexibility at the local level. The Human Services Research Institute (HSRI) published an evaluation of this system in 2002.

**Noteworthy:**

- There is a case, supported by the Arc of Colorado, pending against the state in the U.S. District Court for the District of Colorado (*Mandy R. et al. v. Owens et. al.*) for the failure to provide mandated ICF-MR services with reasonable promptness to eligible individuals with developmental disabilities.

**Interviewee Reflections:**

- In retrospect, it would have been helpful to do a better job at publicizing individual success stories in order to represent life in the community in a positive way. The media should have been educated to understand the benefits of community integration and shown that many parents, initially opposed to moves into the community, became quite satisfied once the transition had taken place.
- Don't try to deinstitutionalize by first moving individuals into larger group homes and then subsequently trying to move them into smaller settings. It has been difficult to get families to support moving individuals from larger group homes once they are settled there after leaving the institution.

## CONNECTICUT

**# State-Operated Institutions Remaining: 5**      **Approximate Census: 670**  
**# State-Operated Institutions Closed: 4**      **Closed Since 1993: 4**

### **Service System:**

The Department of Mental Retardation (DMR) is organized into three geographic regions (decreased from five in May 2003) and administered out of a Central Office located in Hartford. DMR provides case management, residential service, and supports to group homes, Regional Centers, and the Southbury Training School (STS).

### **Alternative Use(s) for Closed Institution(s):**

Uses include a corrections facility, a job corps facility, and administrative offices.

### **Institutional Closure Information:**

- There was a class action lawsuit relating to conditions at the Mansfield Training School that was settled in a consent decree (*CARC v. Thorne*, 1984). The consent decree reduced Mansfield Training School to about 100 individuals, and then the facility was ultimately closed by the DMR in 1993.
- *Messier et al. v. Southbury Training School et al.* is a federal case originally filed in 1994 by private attorneys on behalf of six STS clients seeking to close the institution. A decision in the case is pending.
- There is a mission statement from the DMR that every individual should be able to participate in town life.
- There is one large institution left and four Regional Centers. There is presently a policy that no one can be admitted to Southbury Training School.

### **Opposition:**

- The main stumbling block with the Mansfield union was the relocation of staff in jobs that would not require them to travel far from their homes. There were some agreements to place group homes in areas that would be convenient for the staff.
- In Mansfield, where guardians were not as prevalent as at Southbury, there was an intensive effort by the P&A and others to make families understand that closure was imminent.
- A residents' parents' organization, the Southbury Training School Foundation, established a corporate guardianship program for those who do not have a family member or others to assume the role of guardian. The program now serves several hundred people.
- Friends of Retarded Citizens of Connecticut (FORConn), an organization affiliated with Voice of the Retarded (VOR), is a group of parents that supports institutions as a choice offered to parents and guardians when individuals are unable to make decisions for themselves.
- There were reports in the *Hartford Courant* about untimely deaths in the community. A follow-up in-depth report by the Legislature's Program Review Committee disagreed with many of the article's findings. It determined that

appropriate systems were in place, although in some instances, they had not been followed appropriately.

### **Transition and Community Living:**

- *United States of America v. State of Connecticut* involved allegations of civil rights violations based on conditions at STS. The case was settled through a 1986 consent decree. Federal officials in 1994 concluded that residents were not being adequately cared for and recommended the appointment of a special master, who, after a series of appeals, was appointed in 1997. Part of the consent decree included a shutdown on intake at STS. The P&A took on the subsequent role of assuring that residents receive advocacy services as well as monitoring instances of client assault through the P&A's special Protective Services unit.
- There is an ongoing lawsuit, *Arc/Connecticut et al. v. Southbury Training School*, filed on behalf of nine named plaintiffs who have been waitlisted for HCBS Waivers and have asserted that the state has failed to furnish these services.
- The focus has been on Independent Support Agreements, started with the support of a Robert Wood Johnson grant in 1995-96. ISAs allow for money to be in the hands of families and consumers, who can develop their own services with a team (including family, friends, and neighbors) that assesses the individual's goals and the financial needs for providing services to meet these goals.
- DMR contracts with the private agencies that provide group homes. The new providers visit the training schools to find ways to ensure that services will be matched with the needs of the individual.
- Services are monitored through licensing and through contracting with case managers for those in private community living arrangements. A supervisory structure providing an "arch of oversight" has also been established.
- The Community Options Task Force, an advisory group established by the Long-Term Care Planning Committee and the Department of Social Services, and comprising adults with various disabilities, family members of persons with disabilities, and representatives from the elder community, worked for two years to develop a comprehensive plan for community integration by increasing community options to enable individuals to live in more integrated settings. Its report, "Choices are for Everyone," was released in 2002.

### **Economics:**

- In general, ISAs are less expensive than both institutions and group homes, although people with very significant needs may receive substantial funding in excess of \$100,000.
- Direct Medicaid funding mechanisms are not used for community or institutional services. All funding is from the state budget with Medicaid reimbursement then returned to the general fund.

### **Noteworthy:**

- There was a longitudinal study made to assess whether people who had been living in Mansfield were better off in the community. That study, conducted by what is now the Center for Outcome Analysis, was presented to the DMR in

January 1991. It included an individual assessment tool (the Connecticut Individual Evaluation Report), a site review package, and a family survey. Conclusions were that in almost every area, class members were much better off in their new community homes.

- There is a pending Medicaid lawsuit (*Arc/Connecticut e. al. v. O'Meara et al.*) expected to go to trial in June 2004. This lawsuit alleges that the state has not furnished adequate residential and day care services to HCBS Waiver participations, has not afforded them a realistic choice between waiver and institutional services, has not provided services in the most integrated settings, and has restricted the services that an individual can receive. The state rejects these allegations. The court granted class certification in January 2003, expanding the scope to all 1,700 individuals on the waiting list.
- DMR has developed a Five Year Plan (2002-2007), including a report of accomplishments from the previous five years. Those activities included implementing the HCBS Waiver for family supports, developing a new Quality Improvement and Review System, closing Seaside Center, preparing to open new respite centers to support families, and increasing the number of individualized budgets while continuing to put decision making and resources in the hands of people with mental retardation and their families.
- The state participates in the NASDDDS Core Indicators Project, which aims to support state authorities in developing and implementing performance/outcome indicators that will enable them to measure service delivery system performance.

## DELAWARE

**# State-Operated Institutions Remaining: 1      Approximate Census: 160**  
**# State-Operated Institutions Closed: 0**

### **Service System:**

The Division of Developmental Disabilities Services (DDDS), a division of the Delaware Health and Human Services (DHHS), contracts with local community provider organizations to provide residential, day program, and support services.

### **Institutional Closure Information:**

- The Stockley Center is the state's only public facility licensed as an ICF-MR. There are no plans to close Stockley; however, it is slowly downsizing, with approximately 24 residents moving to the community every year.
- Stockley does not admit new residents; however, it will remain open for people currently residing there who have medically complex issues, or for those individuals who require a highly structured setting. In May 2003, legislation (H.B. 174) was introduced in the Delaware General Assembly to repeal statutes authorizing involuntary commitment to Stockley. DHHS is authorized to maintain a voluntary admission system, but it is unused.

### **Opposition:**

- There is no organized opposition because there is no threat of Stockley closing; however, there are parents and employees who may oppose the closure.
- Employees did not participate in the committee that developed the downsizing plan.
- Stockley is located in a rural setting, and the institution is one of the largest employers in the area.

### **Transition and Community Living:**

- Treatment professionals identify which Stockley residents will move to the community. Residential alternatives include a neighborhood group home, consisting of four to five people, an apartment, or a foster care setting. A resident, however, may choose not to leave Stockley.
- Every residential DDDS client has an annually updated Essential Life Plan (ELP) developed that covers all areas of activities of daily living. Nonresidential DDDS clients may have a less comprehensive individual program plan. DDDS maintains a sophisticated, computerized client database that covers needs, services, and client profiles.
- For all qualified individuals, DDDS uses a service-planning model that is person-centered and emphasizes informed choice involvement of service recipients.
- A population that is most difficult to serve in the community is people with MR/DD who are medically complex and who need special resources and supports. Another group is persons with co-occurring mental illness or behavior disorders who are served by the DDDS Special Populations unit and specialized contract agencies.

- Therapy services and a medical community that is more conversant with the needs of persons with MR/DD were identified as the most difficult needs or services to fill in the community.
- DDDS Case Managers monitor the services in the community for quality of care.

**Economics:**

- Optimally, the resources for meeting all community placement needs, including urgent placements, come from a variety of sources, including general fund appropriations, reallocation of Stockley Center positions, internal budget realignments to maximize revenues, and natural attrition. (*Delaware Olmstead Plan, 2002*)
- Delaware has a number of Medicaid waivers. Medicaid matches the state 50/50. The DDDS HCBS Waiver pays for habilitation and vocational programs for persons in the DDDS community-based residences and foster homes. Individuals who live with their families are generally not eligible for the waiver but are often covered by the general Medicaid program.

**Noteworthy:**

- *The ARC of Delaware et al. v. Meconi* is a class action lawsuit against the state DDDS. It charges that Delaware has failed to meet the needs of eligible people who are waiting for Medicaid Waiver and/or community ICF/MR services. The plaintiffs include individuals who live with aging caregivers and Stockley residents who have been assessed as appropriate for community services.
- A legislative initiative (H.R. 90) established the Commission on Community-Based Alternatives for Persons with Disabilities. This group, consisting of various policymakers and advocacy organizations, issued a report to the Legislature in the spring of 2003 that addresses Olmstead-related issues and the support areas that need to be developed in the community to promote community inclusion.
- Delaware participates in the NASDDDS Core Indicators Project, which aims to support state authorities in developing and implementing performance/outcome indicators that will enable them to measure service delivery system performance.

**Interviewee Reflections:**

- It should be public policy that people who are eligible get services in a certain amount of time – and that everyone gets served in the community. There’s a high rate of institutionalization in Delaware for the size and population of the state.

## FLORIDA

**# State-Operated Institutions Remaining: 4**      **Approximate Census: 1,500**  
**# State-Operated Institutions Closed: 2**      **Closed Since 1993: 0**

### **Service System:**

The Developmental Disabilities Program (DDP) office, part of the Department of Children and Families (DCF) is in Tallahassee, with supports and services provided through 14 district offices throughout the state.

### **Alternative Use(s) for Closed Institution(s):**

Due to asbestos, the two that have already closed are not being used.

### **Institutional Closure Information:**

- The Orlando and Tallahassee centers, now closed, were TB hospitals before they were used as facilities for individuals with developmental disabilities. They had poor physical plants in deteriorating neighborhoods with insufficient staffs (resulting in a high percentage of tube feeding, among other problems).
- The Landmark Center in Miami is being phased down and is expected to close in June 2005. The anticipated closure has been encouraged by the Governor and DCF after legislative recommendation. There are efforts underway to get new providers ready for the closure. One of the alternatives being considered is to use Landmark as a community mall, with providers setting up services there for such supports as physical therapy, day programs, and charter schools.
- While there is no mandate to close the remaining institutions, there is a trend to build community services, reducing beds by attrition rather than confronting the ideology of institutions.
- In 1979, the Florida Association for Retarded Citizens, represented by the Southern Legal Counsel, brought a class action lawsuit challenging conditions at Sunland Training Center (Orlando), a state institution that served 520 people, primarily people who had severe medical needs. That lawsuit resulted in a 1982 order directing the closure of the Orlando center. A permanent injunction was entered on behalf of the class. The Sunland Training Center (Tallahassee) was also closed in part as a result of this litigation. In 2003, the parties agreed to consolidate the scope of ongoing decree requirements (adaptive equipment; medications; mealtime and positioning programs; gastrostomy review process; physical and nutritional management standards; provision of lists of class members by district, facility or home; provision of lists of class members intubated for feeding for longer than 30 days), and the case was administratively closed.
- In 1998, the Florida Advocacy Center (P&A) brought a class action lawsuit against conditions in the remaining four institutions, alleging Medicaid, Rehabilitations Act, and ADA violations. In an unpublished February 2000 decision, the Eleventh Circuit limited the class to individuals eligible for and receiving Medicaid who have “properly and formally” requested community placement and whose treating professionals have recommended community

placement. This case, *Brown v. Bush*, is presently set for mediation in 2003 and trial in 2004.

**Opposition:**

- Some families of people in Landmark have been opposed to closure. The result has been emphasis on choice, including remaining in an institution. There have been monthly meetings with the families, counseling them regarding choices available and introducing them to providers and community inclusion specialists.
- Efforts have been made to meet with unions in preparation for the Landmark closure, as well as to assist staff in getting jobs with private providers.

**Transition and Community Living:**

- The state has undertaken a major expansion of developmental services. Since 1998, funding for services has tripled and the number of persons participating in the HCBS Waiver program has doubled with use of the federal Independence Plus Initiative. As of mid-2003, over 25,000 people are enrolled in Florida's HCBS Waiver.
- In the winter of 2002, the Governor directed DDP to dramatically redesign the system and address problems with assessment, communications, rates, provider billing, and support coordination, and to design a new individual budgeting and flexible service system. The need to increase opportunities for people to work in integrated settings was also added to the scope of the redesign.
- The Advocacy Center [P&A] filed a complaint directly challenging the state's policies in operating its HCBS Waiver program. The complaint was amended to include the state's waitlisted individuals. The settlement agreement for this *Prado-Steinman* lawsuit provided that individuals waiting for services as of July 1, 1999, would receive services by 2001 and that the state would make substantial changes in the operation of its waiver program. The Governor's promise to eliminate the original waiting list by meeting the needs of more than 20,000 individuals appears to have been met. Nonetheless, there has been an emergence of a post-*Prado* waiting list estimated at well over 10,000 (because these individuals have sought services after 1999, they are not a part of the settlement). People seeking to leave publicly operated institutions are not given any priority unless they are leaving Landmark. In 2002, the P&A filed a Notice of Material Breach of the *Prado* settlement, contending that systemic problems have led to the failure to authorize sufficient services in the community. Mediation of those issues resulted in an agreed-upon continuation of federal jurisdiction until July 1, 2003.
- "Guidelines for Residential Transitions" are being developed under the auspices of the Center for Prevention and Early Intervention Policy at Florida State University and sponsored by the Florida Developmental Disabilities Council, Inc. These are being developed because in the past, far too many individuals moved from the large congregate facilities to new community homes without proper planning and cooperative relationships among those who were to help them.
- In September 2001, the Agency for Health Care Administration entered into a contract with the Delmarva Foundation for the implementation of a Statewide

Quality Assurance Program of all providers whose services are funded through the HCBS Waiver (report available online at [www.dfmc-florida.org](http://www.dfmc-florida.org)).

- DDP has developed an informal program, Citizens Helping to Assess, Maintain and Provide Supports (CHAMPS) as an informal part of the statewide monitoring system. CHAMPS, supported by a grant from the DD Council, is designed to be used by citizens at large to identify services and supports that are positively impacting a person's life, as well as reporting health, safety, or other concerns. While individuals have volunteered to be citizen monitors, there is no system in place for their utilization, and their role is neither supervised nor measured by DDP.
- The waiver was changed so that some individuals preparing to leave an institution can receive help from a support coordinator up to 90 days before the move although no payments are made to the independent support coordinators until such time as the move occurs.
- Most people moving from the institutions go into group homes of six beds and under, but some are transferred to other state-operated ICFs, large private ICFs, and/or nursing homes. Some staff in institutions on ICF payrolls have been allowed to work in the group homes.

#### **Economics:**

- In Miami, some staff quit when they discovered that closure was imminent. This has increased costs because of the need for more overtime. In phasing out an institution, additional funds are sometimes necessary to cover such costs as well as for those incurred making down payments on apartments and buying specialized equipment necessary for some individuals.
- Chief funding sources are Medicaid waivers, general revenue funds, vocational rehabilitation funds, and State Department of Education funds.
- During fiscal year 2002-2003, targets for adding new people to the HCBS Waiver were missed due to budget deficits and shortfalls. Only 30 new people per month, deemed in crisis, are being enrolled.

#### **Noteworthy:**

- In 2001, DDP entered a four-year contract with the Delmarva Foundation for the development of a statewide Quality Assurance program for consumers participating in the Medicaid HCBS Waiver. The first annual report, which reflected person-centered interviews and on-site provider performance reviews, presented recommendations for improving outcomes for people receiving community services through the waiver.
- Florida now has one of the few approved expanded programs for consumer-directed care. In this program, some consumers on the waiver direct their own Medicaid HCBS funds instead of an agency directing services for them. This program evolved from the state's participation as one of four states in the national Cash and Counseling Demonstration, which was funded by the Robert Wood Johnson Foundation.

## GEORGIA

**# State-Operated Institutions Remaining: 8**

**Approximate Census: 1,400**

**# State-Operated Institutions Closed: 3**

**Closed Since 1993: 3**

### **Service System:**

The Department of Human Resources (DHR), divided into seven regions, provides direct state-operated services and contracts out for services for those with developmental disabilities. The regions oversee implementation of statewide initiatives, monitor providers, and oversee consumer protection activities, working with other agencies and divisions as advocates for consumers.

### **Alternative Use for Closed Institutions:**

- Rivers' Crossing began as a UAP, so when it ceased to be an institution, it was returned to the University of Georgia, where it again houses a UAP, the Institute on Human Development and Disability.
- Brook Run sat on prime Atlanta real estate that was by sold by the state to the county for a relatively small sum. This was viewed as the only way to prevent the residents of the surrounding upscale community, who did not want commercial development in the area, from joining families of those in the institution to oppose closure.
- At Bainbridge, the Department of Corrections opened a low-security six-month treatment program for low-risk offenders with substance abuse.

### **Institutional Closure Information:**

- Institutional closures were driven both by the need to save money and by a policy to serve individuals in the community.
- The fact that the Governor stood fast in the face of heated opposition to the closure of the institutions was important for assuring DHR that its deinstitutionalization plans would be implemented.
- While the Legislature did not have to approve closure, it did have control over budget allotted for de-institutionalization. Some members of the Legislature played important behind-the-scenes roles in gaining support for closure.
- Because not all of the funds that were saved in closing the institutions were returned to the DD system, this may have made closure more palatable for some legislators who could use the funds for other projects.
- Some problems during the closure of Brook Run were due to the speed with which this took place. As the closure neared its completion, there were people in the institution who underwent multiple transitions before settling into their final placements, despite efforts to minimize this process.
- Because of the numbers of people being transitioned in a compressed time period, there was a special waiver for the Brook Run closure (approved by the federal government), which required providers to demonstrate solid financial underwriting. The result was that only five large providers met the financial qualifications, giving them greater leverage and control over the transition process. The financial requirement is no longer part of this waiver.

- A 2001 summary closure report on Bainbridge State Hospital (BSH), including recommendations for future closures, noted that it was selected for closure because the number of consumers at the facility was declining, the physical plant was many years old and in need of considerable renovation, and there was another state hospital only 50 miles away. A draft plan to close BSH was developed in 1999, prior to final approval of the closure. It was written in order to begin dialogue with officials, families, and employees. Employees participated in training by the Department of Labor and met with representatives from the Department of Corrections about available jobs.
- State-operated community homes are being utilized to retain trained employees, who are still state employees and continue to receive state benefits.
- There is little if any discussion about subsequent closures. Moreover, the state has decided to create DD units in regional hospitals, a process which may lead to some reinstitutionalization.
- Grants were received from the Robert Wood Johnson Foundation for what was hoped would be a concise plan for community inclusion. What resulted instead was what has been described as “a plan to plan.” Instead of adopting the recommendations, the previous Governor merely issued a general executive order with no budget for implementation.

### **Opposition:**

- The union made efforts to try to gain membership by arguing that this would help prevent closure.
- With the Brook Run closure, to overcome opposition of those parents of residents who felt that institutions were more stable than community placements, the DD Council brought in parents from Hissom (Oklahoma) to speak about their positive experience with community integration.
- There were legislators opposed, but the Governor had lined up House and Senate leadership to support closure of the institution in Atlanta.
- There was opposition in some communities to group homes, but DHR was determined not to back down and worked to find activities that would help build relationships with neighbors and aid individuals in becoming an integral part of their neighborhoods.

### **Transition and Community Living:**

- The summary report of the BSH closure noted that although families at Rivers’ Crossing, Brook Run, and BSH were given a choice in placement decisions for family members, this did not always result in the optimal placement of the consumer, based on treatment needs, and in some cases was even contrary to consumer wishes.
- Some of the institutional staff followed clients into the community, providing positive feedback to their colleagues about the success of transitioning. Moreover, DHR sought to send institutional staff and other state employees to conferences to expand their knowledge base and train them to consider various alternatives for living in different community settings.

- The state has sought to implement person-centered planning for every individual, including the people with disabilities themselves, in the planning discussions, often for the first time. In addition, this year, as part of the process, the state has begun to use the Health Risk Screening Tool (developed by Karen Green McGowan and used in a dozen states), which aids in anticipating risk factors pertaining to health and medical issues.
- There were provider fairs and study tours for clients and their families.
- Some of large providers, who are purchasing the smaller providers, have been found wanting in terms of services and performance, and it is often difficult to terminate these services. The fact that Medicaid allows providers the choice of whether to offer services to an individual has led to the creation of more state-operated homes, where a person cannot be denied services in the community.
- Three-fourths of individuals who left the institutions went to community-based private residences. Others went to state-operated homes and other state facilities. Georgia also has about 1,000 individuals with developmental disabilities living in nursing homes.
- There was an exposé in *The Atlanta Journal-Constitution* (December 2001) revealing some failure to protect those in community waiver homes. Articles revealed problems in carrying out the transition process and the need for a better infrastructure in the community, which is often difficult in rural parts of the state.
- Monitoring and Quality Assurance have been major issues for the state. Currently, a support coordinator must monitor a minimum of once a month in the client's home. The state contracts with independent organizations that provide these monitoring services, and these agencies then receive money directly from Medicaid.
- Plans are underway to do formal evaluations with all 65 individuals who are being transitioned during this year.

**Economics:**

- While it has been estimated that life in the community costs less than in an institution, the preferred argument for community integration is that the money is being put to better use because it is going directly to consumers.
- Waivers are a key, but they have reached a maximum level in terms of the availability of state matching funds.

**Noteworthy:**

- There is an “Unlock the Waiting Lists” campaign that is targeted by a coalition of disability and aging organizations to educate the public about community integration and to change public policy so that waiting lists will be reduced and eventually eliminated. This past advocacy cycle, the Unlock campaign included both those who need services to remain in the community and those in institutions who are appropriate for living in the community.

**Interviewee Reflections:**

- One must recognize that it took many families a long time to decide to place their family member in an institution. Now patience must be exhibited in educating them about the reasons for community inclusion.
- Time for transitioning should be neither too long nor too short. The recommended range for completion of the process is about 24-36 months.

## HAWAII

**# State-Operated Institutions Remaining: 0**

**# State-Operated Institutions Closed: 1**

**Closed Since 1993: 1**

### **Service System:**

The Developmental Disabilities Division (DDD) funds the system with each county (by island) organizing a staff under a District Health Officer for operational purposes. Programmatic issues remain under the DDD.

### **Alternative Use(s) for Closed Institution(s):**

The Public Safety Department (Training) and the Department of Land and Natural Resources took over many of the buildings at Waimano Training School and Hospital when it closed in 1999. Some private providers that had offered services such as day programs remained on the campus. A small, highly secure home for children with sexually-abusive tendencies toward their siblings was also located on the campus.

Initially, three domiciliary homes in the community (five individuals per residential home) and a crisis shelter on campus were opened and administered by former Waimano staff. However, all were closed within two years because advocates felt that the homes and crisis shelter were just a carryover from Waimano and not really community integration, and also that Act 189/95 required provision of case management services independent of the direct service provider. Currently, a Quality Assurance unit, a Neurotrauma unit, and a Foster Home/Domiciliary Home Licensing/Certification unit remain on the Waimano site.

### **Institutional Closure Information:**

- Recognizing the high cost of running institutions, there was strong support from the Legislature to ensure that Waimano would be closed and to plan for a smooth transition for residents into the community. Once educated about the issue, the Legislature and the Department of Health worked with the unions to implement the transition plan.
- The Department of Health, the State Council on DD, and others conducted outreach on the closure of Waimano.

### **Opposition:**

- Initially, some parents of residents were opposed to the closing of the institution, since many families had children who were placed in Waimano many years ago, and now these adult children were either returning home or being placed in the community. Meetings with parents were conducted to educate them about the benefits of community living. These meetings proved to be successful in that the parents did not try to block the closure of the institution through the Legislature.
- Many of the residents were also fearful of leaving the institution. However, many enjoyed their newfound independence once placed in the community.

- A large percentage of the state’s employees are in a union. Unions were involved early on in the closure process, since union members were being displaced from their jobs at Waimano. Despite some union opposition, Act 189/95 was passed in 1995 to close the institution.

**Transition and Community Living:**

- The Department of Health was required to convene a panel in 1995 to create a plan to provide services in the community and ensure a smooth transition into the community for former Waimano residents. By June 30, 1998, all programs and services, including those provided by Waimano, were to be provided in the community. Residential and other service providers needed to be expanded quickly in order to build enough capacity for the increased number of individuals now moving into the community.
- The last 40 or so individuals were harder to place because these individuals were the more difficult ones with behavioral or other problems that some providers could not handle.
- A major problem was finding accessible housing, especially for the individuals who wished to live with their friends or on their own.
- Most of the individuals leaving Waimano moved into adult foster homes (maximum of two individuals) or other community-based homes or private community ICFs-MR (maximum of five individuals).
- The Department of Health is still in the process of monitoring the *Makin vs. State of Hawaii* settlement decree, which stipulated that individuals with DD/MR living at home or in noninstitutional or homelike settings who are on a waitlist for HCBS and denied such services solely because of a lack of state funding for those services may be entitled to those benefits. The settlement required the state to provide needed services to at least 700 qualified individuals with DD/MR from the waitlist by June 30, 2003, and at a reasonable pace thereafter.
- A special April 2002 published report of the Hawaii Disability Rights Center (Hawaii P&A) expressed concern about the need for improving the infrastructure that delivers health services to those with developmental disabilities.

**Economics:**

- DDD was not successful in getting funds to follow the individual, so “savings” were returned to the state’s general fund.
- For the last few years, cuts in state funding have become a reality due to the poor economic conditions in Hawaii. Other sources such as grants may be needed to make up for cuts in funding.
- The Medicaid waiver has had a major impact on DDD. Over 90% of DDD’s total program funding is matched by Medicaid (58%). Efforts are underway to review existing waivers and to apply for other waivers to meet needs.

**Noteworthy:**

- Act 133/98 was the first law in the nation to statutorily delineate the means to ensure self-determination for those with developmental disabilities.
- The state participates in the NASDDDS Core Indicators Project, which aims to support state authorities in developing and implementing performance/outcome indicators that will enable them to measure service delivery system performance.

**Interviewee Reflections:**

- Infrastructure should be in place before transition to the community takes place.
- Hawaii still does not have enough service provider capacity. Too few choices are available for individuals with DD/MR and their families.

## IDAHO

# State-Operated Institutions Remaining: 1

Approximate Census: 105

# State-Operated Institutions Closed: 0

### Service System:

The state's Department of Health and Welfare (DHW) is organized into seven geographical regions. Each region serves several counties. Regional service centers, which provide the hub for service delivery in the counties they serve, are located in the larger communities of the state. Each regional office has field office local branches. Administrative oversight is conducted by the central office.

### Institutional Closure Information:

- There are four different populations in the institution: individuals who are severely and profoundly disabled, individuals with serious medical problems, children diagnosed with DD/MI, and court-committed sexual offenders who cannot be adjudicated due to competency issues.
- Although there is no explicit plan to close the institution, staff at Idaho State School and Hospital (ISSH) is committed to downsizing the institution by working with partners in the state and private sector to create community-based supports to promote deinstitutionalization and to prevent admission to more restrictive environments. The P&A is also working to get individuals out on a case-by-case basis.
- After a negative review of ISSH by the Bureau of Facility Standards Legislation, legislation was approved to renovate ISSH; this legislation was opposed by the P&A and some consumer groups. ISSH has subsequently passed review.

### Opposition:

- When any discussion arises about closing ISSH, the parents and relatives of individuals living there oppose it. About one-third of those at the institution have guardians determined to prevent their move into the community.
- Opposition to closure has come from some prosecutors, DHW, families of individuals living in institutions, and small-bed ICF/MR providers, who do not want to be responsible for integrating what they consider difficult cases into the community.
- A coalition, the Consortium of Idahoans for Individuals with Disabilities, has been created by organizations that seek to promote the significant downsizing of ISSH.

### Transition and Community Living:

- Among the ISSH activities to promote deinstitutionalization and transitioning to the community are these:
  - Contacting provider agencies to develop supportive living services for individuals in communities where these services had previously not existed. As a result, 62 consumers now live in their own homes rather than in facilities;

- Maintaining a list of vacancies in community-based programs and disseminating this information to case managers throughout the state, with the result that more individuals who were on the referral list for ISSH are being diverted to community placements;
- Providing start-up funds, including the first month's rent, cleaning deposit, groceries, etc., for individuals who are being discharged to their own homes or apartments; and
- Providing training, support, and crisis stabilization services to community providers to prevent the loss of community placements.
- There is a problem finding qualified providers. Future caregivers are encouraged to spend time with the individual so that they get to know the person, a process that they have found to decrease the likelihood of returning to the institution.
- The most difficult people are moved to supported living (two to three persons) because of support from the HCBS Waiver. ICF-MR group homes do not get rates that are high enough to take care of the most difficult cases, and they are concerned about receiving evaluations that indicate that they are not adequately caring for these individuals.
- There is some resentment against paying parents to be providers.
- Idaho is a rural state and the social aspect of community integration is limited because someone may be miles from city. Waivers allow for apartments with supervision, but apartments are more expensive so individuals are often placed in single homes, which can lead to a greater sense of isolation.
- Work is now being undertaken to improve the monitoring teams, which have been hampered due to budget cuts.

**Economics:**

- Recently, plans were nixed to implement previously announced plans to change eligibility requirements in DD Waivers. This would have affected 317 people, who would have lost home and community-based support.
- The main funding source is Medicaid (75 federal/25 state).
- Because of cost restraints, an individual is forced to live with at least one other person with disabilities in the community. This also can be a barrier to deinstitutionalizing those individuals who may not be able to live with another person in the community.

**Noteworthy:**

- The state is in the process of developing a crisis center home near the institution so that individuals having difficulty living in the community will not be forced to return to the institution.

**Interviewee Reflections:**

- The priority should be to focus on getting people out of the institution and on opposing any new building at the institution.
- If the professional staff at the institution recommends that a person can live in the community, the institution should have the duty to transition the person regardless of the position of the guardian.

## ILLINOIS

# State-Operated Institutions Remaining: 9      Approximate Census: 2,770  
# State-Operated Institutions Closed: 5      Closed Since 1993: 2

### Service System:

- The Illinois Department of Human Services (DHS) is organized into divisions, offices, and bureaus. The Division of Developmental Disabilities (DDD) provides services and supports for individuals with developmental disabilities (DD). DHS funds service providers for community-based residential and support services. Support services include assessment and case management, consumer and family supports and assistance, vocational programs, and respite care.
- The Illinois DD service system is divided into eight geographic areas, called *networks*. The network system provides a structure for communication, implementation, and coordination of DD programs. State staff are assigned to each network, and service providers are assigned networks, based on their geographic service area. Networks are divided into two groups that each cover four areas: The Chicago Metro Network and the Greater Illinois Network. Each has a head facilitator who reports to his or her respective area network coordinator.
- Individuals seeking services are directed to a preadmission screening at one of the 18 Independent Service Coordination (ISC) agencies that serve every county in Illinois. These agencies are the entry-points to the Illinois state-funded system. Service coordinators screen individuals to determine eligibility for services, and they assist each person in finding services in the least restrictive setting appropriate to his or her needs and preferences. ISC also assists the individual/family to develop a service plan and makes referrals to local service providers.
- Services are offered depending on the availability of funding and other criteria.

### Alternative Use(s) for Closed Institution(s):

Some of the uses include correctional facilities (at three sites), a Head Start program and numerous other educational and/or community programs, and some administrative offices.

### Institutional Closure Information:

- The most recent facility closure is the Lincoln Developmental Center in 2002.
  - Several incidents at Lincoln were documented over the period of a decade, in which staff failed to provide proper supervision to residents, placing them at risk for serious injury and even death. The Governor cited continued “health and safety issues” due to substandard staff performance, despite the fact that the facility’s staffing levels were among the highest ratios of any state-run facility in Illinois.
  - Lincoln was not able to come into compliance with federal standards under an agreement reached by DHS, the Department of Public Aid (DPA), and the Department of Public Health (DPH), which act as

regulators for the federal government. Lincoln ultimately lost its Medicaid funding, which represented one-half of Lincoln's \$35million budget.

- The Health Facilities Planning Board reviewed the application of DHS to close Lincoln and voted unanimously to issue the permit allowing the permanent closure.
- Lincoln began to downsize its population as legal and administrative battles ensued.
- Newspapers across the state played a role in the Lincoln closure by writing articles that gave voice to the different constituencies. The *Chicago Tribune*, however, wrote three strongly worded editorials on the facility, stating that Lincoln "illustrated perfectly how entrenched politics and job preservation too often nudge aside the health and safety of the state's most vulnerable individuals...The center's curious endurance also helps explain why Illinois lags so pathetically behind the rest of the country in the way it cares for mentally and developmentally disabled adults." (June 30, 2002)
- Admitting an individual to a state-operated facility is supposed to be a "last resort" option in Illinois. In 2002, despite the fact that 38 residents from Shapiro Developmental Center were placed in the community, the facility showed an increased census of eight people from the previous year. This increase, however, was due to 46 individuals moving to Shapiro from Lincoln.
- The most admission activity is seen in facilities located in southern Illinois. This is due, in part, to there being fewer service providers in that region and a lack of easy access to community-based mental health services to address behavioral issues.

### **Opposition:**

- The Lincoln closure was a contentious issue in the state. Members of the Lincoln Parent Association, the Voice of the Retarded, the AFSCME union, legislators from the Lincoln region, and the local chamber of commerce were the most vocal in their opposition to closure.
- There were a series of unsuccessful legal proceedings to prevent Lincoln from closing, spearheaded by AFSCME and parents of a Lincoln resident. However, this litigation temporarily prevented DHS from moving more residents out of Lincoln.
- One year after Lincoln's closure, local legislators continue to strongly lobby newly elected Governor Blagojevich for it to reopen. Both candidates who ran for Governor in the past election asserted that they would reopen this institution in some form if elected.

### **Transition and Community Living:**

- There was a census of approximately 370 when the circumstances that led to the Lincoln closure began. Out of this population, 287 moved to another state-operated facility and only 48 residents moved to community integrated living arrangements (CILAs). The remaining residents went to Intermediate Care Facilities for the Developmentally Disabled (ICFDDs) or skilled nursing homes, or moved home.

- A CILA is a combination of supports and services individually tailored to meet the needs of an adult with DD. The individual may live in his or her own home, in a family home, or in a community setting with no more than seven other adults.
- DHS licenses and provides Quality Assurance oversight to the community-based service provider agencies that provide CILA services. Services typically include in-home supports, day or employment-related services, community transportation, and limited health supports.
- There are 26 Community Living Facilities licensed by DPH that typically have 12 to 16 beds and are designed to serve higher functioning individuals who are almost ready for transition into the community, though, in reality, lower functioning individuals are also served in this type of setting. Other residential options in the community include Special Home Placements (specialized foster care) and Supported Living Arrangements that provide support for an individual to maximize his or her independent living skills.
- DHS administers state spending for ICFDDs. These are long-term care facilities that generally provide care to people with greater medical needs, and they range in size from 16 to 300 beds. ICFDDs may also serve four to sixteen individuals who have less complex medical needs but still require 24-hour care. Additionally, another model ICFDD that is licensed for 16 or fewer individuals may consist of three or four separate residences, not on the same property, developed so that people with more severe medical and/or behavioral problems could live in a home environment. In Illinois, there are 256 ICFDDs that have 16 or fewer beds and 21 ICFDDs that have 16 or more beds. ICFDDs are licensed, monitored, and reviewed for Medicaid certification by DPH, and DPA enrolls these facilities for Medicaid.

#### **Economics:**

- In 1983, Illinois began changing the funding sources of some community programs from 100% state general revenue funds to HCBS Waiver funds on a very gradual basis.
- Illinois increased its institutional spending during 1996-2000 for public and private institutional facilities for 16 or more people. The state ranked 47<sup>th</sup> in the percent (57%) of total MR/DD spending allocated for community services in FY 2000. (Braddock et al., 2002)
- In FY 2000 Illinois was ranked 48<sup>th</sup> in its per capita federal spending level and percent of waiver spending of the state's total spending. Twenty-four percent of state funds were potentially available to match additional federal Medicaid funding. (Braddock et al., 2002)
- Funding does not follow the individual from the institutional setting to the community. In the case of the Lincoln closure, any money saved was put into general state funds and was not used to expand the community service delivery system.

#### **Noteworthy:**

- "It is impossible to disentangle the evolution of residential services in Illinois from its political system." (Parish, 2002)

- Political patronage has influenced the development of residential services for people with developmental disabilities, as institutional employment has evolved into an integral part of state politics.
- In 1973, Governor Dan Walker issued an Executive Order that allowed state workers to seek union representation. AFSCME went on to win the fight (over the Illinois State Employee Association) to represent 12,000 institutional employees. Over time, AFSCME has developed into an entity with significant political clout in the state. It has contributed to the slow development of community-based residences by throwing its considerable support behind keeping institutions open.
- In 1995, the Department of Mental Health and Developmental Disabilities, now known as DHS, announced plans to close the Kiley Developmental Center. In response to the controversy and opposition created by the announcement, a modified plan was developed, describing a five-year transition. Nearly four years later, in 1999, newly elected Governor Ryan vowed to keep Kiley open, and it remains open today. The evaluation of the closure of the Kiley Center became a follow-up of people transferred in a modified downsizing. A report was published that summarizes what happened to a limited number of residents who transferred to other residential settings under the transition plan. It concluded that the dedication and professionalism of staff, rather than just community living versus institutional living, brought about the most positive results in terms of health, inclusion, behavior, satisfaction, and supports for people. The data supported the concept, however, that having a strong service delivery system in the community is essential because “living beyond the walls of the large congregate setting is not an outcome unto itself. It is merely the beginning of the process.” (*Kiley Center Evaluation, Final Report*, 2001)
- A lawsuit was filed in 2000 (formerly *Boudreau et al. v. Ryan et al.*, currently *Bruggeman et al. v. Blagojevich et al.*) on behalf of individuals with developmental disabilities who are eligible for Medicaid services and seeking, but not receiving, ICFDD placement or HCBS Waiver services. The plaintiffs reside with aging caregivers and need such services.
- Advocates United, an independent organization of people with disabilities, their families, advocates, and professionals, hosts a biennial election year legislative forum to which the candidates for Governor and for the State Senate and House are invited to speak and respond to questions regarding “the poor record of Illinois toward people with disabilities.” A special feature of Advocates United is that its membership includes families whose offspring reside in both community and institutional settings.
- Access Living, a nonresidential Center for Independent Living (CIL), established the Peer Counseling Program for Adults with Cognitive Disabilities in 1999, with support from a grant from the Joseph K. Kennedy, Jr. Foundation. It included four main components 1) peer support groups, 2) peer mentoring, 3) monthly seminars, and 4) networking and outreach. The project’s goal was to develop the participants’ self-esteem and to enhance their independent living and self-advocacy skills. The project coordinator, who had a cognitive disability, led support groups in places where participants resided and worked, such as

- community group homes and Howe Developmental Center, a state-operated institution. Overall, the project had a positive impact on the participants, who stated that the support group helped them to live on their own, solve problems on their own, take care of themselves, and learn how to get along better with other people. Two participants said the support group helped them to change their living situation, and they now live in smaller settings outside the institution.
- The Illinois Council on Developmental Disabilities funded a five-year grant called Illinois Life Span Project. It is a free information and referral service for people with developmental disabilities. Life Span has established a toll-free 24-hour hotline for consumers to call in about services and a website was developed ([www.illinoislifeproject.org](http://www.illinoislifeproject.org)) that lists all service providers in Illinois that accept Medicaid. The plans are to add to the website all physicians, by county, who accept Medicaid. Life Span staff are meeting with different advocacy groups to work toward solidifying services and to identify gaps that need to be filled in the advocacy and service delivery system.

### **Interviewee Reflections:**

- There's still some institutional-like thinking in the community. Staff are out with groups of people, but they still need training to do things differently.
- There is a considerable need for respite beds for people living in the community. Shapiro wanted to hold five or six beds for this purpose, but has not been able to.
- Unless you are a large agency, it is more difficult to provide services in Illinois. There is no capital for improvements in community residences and residential rates have not kept up with the change in costs. Four-person residences are a money-loser, and so six- to eight-bed residences have been developed because of financial pressures. The state saves money by having larger homes.
- There is a lack of attention being paid to provide community agencies with financial support. Many of these agencies are on the brink of disaster.
- Illinois is among the states having the lowest-paid direct care workers in the country. This is a huge barrier, and it leads to understaffing or undertrained staff. It has homogenized care by refusing to provide a rate that's tailored to meet the person's needs.
- Blanket low rates produce "one size fits all" programs, in which people least in need of services are favored for admission and retention, while people with greater needs are turned away as too expensive to serve. That is why admissions to state-operated facilities continue to be robust.
- Illinois is one of the few states in the country that refuse to maintain a waiting list and an effective plan to provide services to eligible people.

## INDIANA

**# State-Operated Institutions Remaining: 6**      **Approximate Census: 680**

**# State-Operated Institutions Closed: 5\***      **Closed Since 1993: 4**

\* including MR/DD units in state-operated psychiatric facilities

### **Service System:**

The Bureau of Developmental Disabilities Services (BDDS), a part of the Division of Disability, Aging and Rehabilitative Services, a division of Family and Social Services Administration (FSSA), administers services through eight District Offices in locations throughout Indiana. Requests for services, general intake, evaluation, and assessment to determine eligibility for services are conducted at the nearest District Office. A service coordinator assures that an individual's person-centered plan is developed and a person's needs are matched with available funding sources in the community.

### **Alternative Use(s) for Closed Institution(s):**

The original buildings of New Castle were razed and a prison was built.

### **Institutional Closure Information:**

- The most recent state developmental closure, New Castle in 1998, was prompted by a scandal involving abuse and neglect of residents. An abuse incident was captured on videotape and publicized by the media. The Governor ultimately ordered the institution closed.
- As a result of the publicized ill treatment, the Department of Justice became involved with New Castle and has expanded its presence to two other state developmental centers.
- It took approximately 18 months to move residents to the community after the decision was made to close.

### **Opposition:**

- There was a parent/guardian voice on both sides of the institutional closure issue, but a strong parent group was attached to the anti-closure side. The parents who were opposed lobbied legislators to slow down the process. The Arc of Indiana tried to reassure skeptical parents by showing them success stories in the community.
- Newspaper articles were mixed on the closure issue. Articles varied from improving institutions to consumer success stories in the community. Groups such as the Arc and the Indiana P&A emphasized to the public that, "It's about a person's right to live in the community."
- There was significant concern in the local community, New Castle, regarding the loss of jobs. The Chamber of Commerce inquired of the state what new jobs would replace the lost ones, thus the location of the prison on the property.
- Two employee unions were involved in closure discussions from the beginning, but "They were not sure what to do. . . . They became more involved with the prospects of closure of another institution, Muscatatuck State Developmental Center, in Butlerville, later on."

### **Transition and Community Living:**

- There was a change in leadership at New Castle due to the scandal. As a result, BDDS contracted with an agency from out of state to conduct the transition planning for the closure. This agency worked with the remaining staff and helped bring structure to the process. They were able to bring in new program directors, specialized therapists, QMRPs, and other professionals, who tried to get to know the residents so that effective individualized planning could take place.
- The Indiana Institute on Disability and Community also provided advice and training on how to best close New Castle.
- Service coordinators from the District Office were involved in the service planning for those individuals returning to their native counties. They brought information to the county providers to see what available services existed and which ones needed to be developed. Though many residents returned to their area of geographic tie, a resident's relationship with other residents was also taken into consideration in the development process.
- There was an emphasis on person-centered planning. The Indiana P&A staff attended planning meetings and tried to "assure" informed consent. Individual service plans were developed by guardians and institutional staff prior to leaving New Castle, but at times the plans were not developed enough and a person's needs may not have been adequately met. There were some mixed results as to the success of community placements, but most of those placed have continued to reside in the community.
- Individuals residing in the community who are deemed eligible for Medicaid receive case management services, funded through the HCBS Waiver program. For those individuals who are not eligible for Medicaid, their case manager services were supported by state funds.
- Most of the New Castle residents moved to homes for one to four other residents in a Community-Supported Living setting. Community providers either rented or bought homes or apartments through local realtors. Integrating residences throughout a community was the intended goal. Homes were adapted, modified, and made accessible to meet the needs of the individual.
- The state spent considerable funds to retrain institutional employees to work in community programs. Some employees became providers in the community, found employment with existing providers, or became employees at District offices.
- In 2000 (post-New Castle), Indiana developed a Bureau of Quality Improvement Services (BQIS). Incident reports are reviewed daily by four staff members, who alert the service coordinators in the District Offices when there are problems with particular providers. Additionally, the BQIS developed a pre- and post-transition checklist for people who move to another address. Service coordinators ensure that the "new" home is adequately equipped, that the neighborhood is safe, that a person's medical/psychiatric contacts are established, and that the needs identified in the Individual Service Plan are addressed. There is a seven-day and 30-day follow-up to check on the status of the individual. The results of these visits are communicated to the provider and, if needed, a Correction Plan with timelines is developed by the provider. In addition, these visits are entered into a database as a

- record of the individual's needs and to see trends of all providers who are planning the transition.
- *Outcomes of Community Placement at One Year for the People who Moved from New Castle and Northern Indiana State Developmental Centers*, a report by Conroy and Seiders, The Center for Outcome Analysis, published in 2000, asked a series of questions that quantified whether people are better off, worse off, or about the same, and in what ways, and how much. The result: "The overwhelming pattern of these quality of life outcomes is positive," indicates that, on the average, people are "better off" after one year of residing in homes in the community.
  - Individuals with a diagnosis of DD/MI are the most difficult group to serve in the community. A lack of purposeful vocational activities is the most challenging need to fill.

**Economics:**

- The state is making a clear case that institutions are not cost-effective and they are going to cost taxpayers millions of dollars just to maintain the buildings.
- BDDS is currently reviewing all people who live alone so that, if possible, living expenses and community supports/services may be shared. If people live with at least one other person, the state can then make services available to more people.
- All people who receive supported living services have an Individual Community Living Budget. This shows the state what the residential living expenses and the service costs are, if the individual is not receiving community- and home-based waiver services, and identifies the individual's contribution and the state's contribution. The individual is not responsible for sharing in the cost of the services, only in the residential living expenses.

**Noteworthy:**

- No one is admitted into a state hospital or state developmental center in Indiana except by Court Order.
- In 1999, the Governor created the Governor's Council on State-Operated Care Facilities with the goal of developing a long-range plan to ensure the provision of cost-efficient quality of care in the remaining state-operated facilities. A key recommendation was "the need to improve the linkages that exist between facilities and community resources." The Council recommended that the state regionalize its system of care for the distinct populations being served, by developing a wide range of services within each region and strengthening the community resources and community capacity. High-quality services could be provided in regional multiservice centers that once served as state-operated residential facilities.
- Muscatatuck State Developmental Center was scheduled to close in 2003, but families fought the closure with a lawsuit, and legislative action was taken to keep the facility open until 2005. However, the state legislature is trying to revise that section of the law that gives parents and guardians a say over where residents will be moved (even though the person-centered planning process and the guidelines for service coordinators, as placement authority, state no moves are approved

without the consent of the guardian). Language has now been inserted into the new budget bill that eliminates guardians' rights under state law to approve relocations of residents. Guardians have been granted a temporary court injunction that bars the state from transferring patients to group homes without the consent of families or guardians, and they are pursuing a permanent injunction. The effort to accelerate the closure of Muscatatuck is prompted by budgetary concerns. It costs \$850 a day for each of the 159 residents who reside at this facility. A legislator stated, "It's a very expensive proposition, particularly in light of the fact the general belief is folks are better off in smaller homes." (*Indianapolis Star*, May 1, 2003)

**Interviewee Reflections:**

- In the last three years Indiana has had three different people in the position of Secretary of the FSSA. The lack of continuity has made it difficult for the District Offices, as well as the consumers and families. Collectively, the FSSA has been involved in the transition of people from the large institutions. It has learned about community integration in recent years. There was some resistance; however, it has adopted the point of view that community integration is the right thing to do.
- It's very important to have enough time to do adequate planning well in advance of any closure. The amount of time taken to talk with families and employees regarding the benefits of community-based living and the availability of jobs, respectively, made an extremely positive difference when one of the private ICFs-MR closed during 2002.

## IOWA

**# State-Operated Institutions Remaining: 2**

**Approximate Census: 700**

**# State-Operated Institutions Closed: 0**

### **Service System:**

The Division of Mental Health and Developmental Disabilities (MH/DD) in the Department of Human Services is the agency designated as the state mental health authority by the Governor. It plans for state services for people with mental retardation and developmental disabilities, works with the counties in the development and implementation of their service plans, and provides consultation, technical assistance, and accreditation for providers of MH/DD services. The state has a county system in which counties are given free rein to provide services as long as they meet the state and federal regulatory requirements. Institutions are the responsibility of the counties, which pay 80% of a capped per diem for the cost of the residents (the remainder comes from the state).

### **Institutional Closure Information:**

- Downsizing at the two institutions of Woodward and Glenwood has reached a standstill.
- When the two state institutions were converted to ICFs-MR as part of the state's Medicaid program, there were no private ICFs. No effort was made to place restrictions on the development of private institutions, with the result that Iowa has the nation's highest per capita residing in ICFs-MR.
- In 1994, the court certified a consent decree, *Conner v. Branstad*. This decree grew out of a 1986 lawsuit, and among those items stipulated were referral of individuals residing in institutions to appropriate and available community programs, development of individual program plans, development of a training consortium for people supporting those with disabilities, and the development of a five-year plan to identify and provide for the development of appropriate community supports and services.

### **Opposition:**

- There has been opposition in communities to the closure of state institutions and ICFs-MR, because they are most often in rural areas and represent the communities' largest or second-largest employer.
- Legislators from localities where state institutions are located are strong supporters of the institutions.

### **Transition and Community Living:**

- Most who left the institutions did so in the late 1980s and early 1990s.
- The Division of MH/DD Real Choices Application (July 2001) identified as systemic weaknesses the "institutional" bias driven by funding sources rather than by individual needs and preferences, the lack of availability of comprehensive community-based supportive service options statewide, and a lack of a coordinated transition service to support individuals seeking to leave institutions.

- Many providers are reluctant to accept individuals with complicated medical issues.
- In the past seven years, the state has imposed uniform concrete criteria on the counties for providing services.
- Individuals are often in need of only limited support, but this is still necessary to prevent deterioration. The lack of service options has prevented many of these individuals from moving into the community.

**Economics:**

- The main funding source is Medicaid. The state utilizes six different waivers, but the budget crisis has made it difficult to develop more options within the Medicaid system.

**Noteworthy:**

- There is an investigative reporter at the *Des Moines Register*, who has written some effective articles (November 2002) drawing attention to the U.S. Department of Justice investigations of Iowa's two state-run institutions and criticizing their excessive use of physical and chemical restraints and absence of proper medical oversight. The DOJ investigation of the two facilities also criticized the failures to implement adequate steps to assess individuals, resulting in denial of opportunities to live in the most integrated setting appropriate to their needs.
- In January 2002, the central administration lost over half of the staff that worked with disabilities, due to budgetary considerations.
- The state participates in the NASDDDS Core Indicators Project, which aims to support state authorities in developing and implementing performance/outcome indicators that will enable them to measure service delivery system performance.

**Interviewee Reflections:**

- Both the Department of Human Services and those who brought the *Conner* lawsuit claim to have "won." Since nothing seems to have changed, this suggests that the state did win.
- Often the staff in group homes have set up individuals for failure, with the result that many are forced to return to an institutional setting. Low pay for community workers contributes to this problem.
- Iowa dug itself into a hole when it placed no restrictions on the development of ICFs-MRs or on their cost. The state is now faced with overcoming opposition from a very powerful lobby just to get "normal" guidelines.

## KANSAS

**# State-Operated Institutions Remaining: 2**

**Approximate Census: 380**

**# State-Operated Institutions Closed: 2**

**Closed Since 1993: 1**

### **Service System:**

There are 28 community developmental disability organizations, which are the single point of entry for receiving developmental disabilities services. Each county designates a Community Developmental Disability Organization that receives state and federal funding. CDDOs are responsible to determine the qualification for services, to aid clients in choosing among an array of service options, and to make referrals to other agencies if additional supports are needed.

### **Alternative Use(s) for Closed Institution(s):**

- The oldest facility was Winfield State Hospital, which had been downsizing over 30 years. Half of that facility had been turned into a Department of Corrections minimum-security facility. Once Winfield finally closed, the remainder became an assisted living facility licensed by the Kansas Department of Health and Environment and used as a home for elderly veterans.
- Norton is being used by the Department of Corrections.

### **Institutional Closure Information:**

- The Legislature authorized the Hospital Closure Commission to review the three state developmental disability institutions and the four state psychiatric institutions for closure recommendations. In terms of the DD institutions, the Commission's recommendation to close Winfield State Hospital was subsequently approved by the legislature. This effort to use the "military-base closure" approach sought to avoid partisan politics in the choice of which institution to close.
- The DD Council, P&A, and UAP formed a coalition to work for closure and to evaluate the closure process after Winfield was named as the institution that was going to be closed.
- Before closure, there were studies prepared for the Department of Social and Rehabilitation Services (SRS) to assess the economic impact of relocating individuals into the community.
- There is a voluntary closure policy for ICFs-MR in which SRS uses HCBS Waiver funding as carrots to encourage ICFs-MR to transform themselves into community providers.
- State law and implementing regulations (K.S.A. 39-1801 et seq. implemented with regulations, Articles 63 and 64, 1996) favor integration. The legislation was the culmination of several years of commitment by families, advocates, the Legislature, the Governor, and SRS to enhancing the system of services for people with disabilities.
- A study by The Center for Outcome Analysis found improved quality of life outcomes for those who had been transitioned to the community.

**Opposition:**

- The Winfield City Manager tried to prevent closure by comparing the loss of the hospital to closing Boeing in Wichita (which at the time employed over 20,000 out of a total population of 315,000).
- A majority of the active parents of residents opposed closure, fearing that family members would not get proper care in the community.
- The *Winfield Courier* was opposed to closure and published articles and editorials expressing this opposition at the time it was first proposed. Subsequent to closure, the newspaper published a series of articles that sought to detail in an objective fashion the history, process, and results of the Winfield closure.
- VOR is now trying to ensure that there are no further closures by arguing that Olmstead requires a “continuum of services” and that institutions are necessary to provide this continuum.

**Transition and Community Living:**

- There is a shift to a supportive lifestyle model, in which everyone can live in a home of his or her own choice (within means) and be productive in a job. The provider is a helper, advisor, and advocate for the person, who exercises informed choice.
- A guardian opinion survey is conducted annually by the Department of Social and Rehabilitation Services
- A majority of parents placed their family members in community programs in the Winfield area. Three new community-based programs serve 250 clients in the county. Some 120 of them are from the institution. Moreover, many staff from Winfield State Hospital went to work in these homes, carrying over an institutional atmosphere into the community.
- An Essential Lifestyle Plan was used to ensure a person-centered planning process. Attempts were made to match residents’ needs and desires with a particular program.
- There is difficulty in finding modern accessible housing in rural areas.
- There are regional quality enhancement coordinators who cover the state, going to providers to make sure that services exist at an acceptable level.

**Economics:**

- A problem was noted that Social and Rehabilitation Services (SRS) is a monolithic organization with responsibility for mental retardation, mental illness, developmental disabilities, and substance abuse. Often people with these disabilities must compete for limited funding from SRS.
- Most of funding comes from the HCBS MR/DD Waiver. In addition to state funds, there are also other waivers for children and youth and those with physical disabilities.

**Noteworthy:**

- In a legislative report, James Conroy of The Center for Outcome Analysis noted of Winfield, “In our years of studying institutional changes and

deinstitutionalization, this is the first time we have seen such a small town absorb so many people with developmental disabilities into its own housing market.”

- A problem has arisen in that now various organizations providing housing in Winfield are recruiting people to fill their beds. Providers are going out with stories to try to convince people not to move into smaller homes, and this is creating a form of mini-institutionalization.
- Litigation did not play a key role in closure.
- A Community Integration Project handbook was developed for use by all those staff working on moving people from institutions into communities.

**Interviewee Reflections:**

- One problem was that service providers controlled the agenda as to where people would be placed, because once it was decided to close, there was nothing much to do except accept what was available, since the state did not want large group homes.
- More time should have been taken to reassure parents. While there were provider fairs, these took place within only a couple of months of closure.

## KENTUCKY

**# State-Operated Institutions Remaining: 4**      **Approximate Census: 740**  
**# State-Operated Institutions Closed: 1**      **Closed Since 1993: 0**

### **Service System:**

The state Division of Mental Retardation contracts for services through 14 Regional Mental Health/Mental Retardation Boards and other qualified private providers. These include the following services: case management, residential, vocational, respite, crisis intervention, leisure/recreation, habilitative, and in-home support.

### **Alternative Use(s) for Closed Institution(s):**

There is a state office building on the Frankfort site.

### **Institutional Closure Information:**

- Frankfort closed in 1972. Another institution, Outwood, identified as “closed” in *Braddock et al.* (2002), continues to be owned by the state, but it is now run privately. For the purpose of this project, Outwood remains open and operational, similar to other state institutions.
- There are no plans to close any of the institutions; however, there is an effort to downsize them.
- There is a moratorium on building any new large institutions.
- In 1997, the Office of Public Advocacy (Kentucky P&A) successfully moved out all of the individuals with developmental disabilities from four public psychiatric facilities in the state – approximately 120 people. This took a couple of years to complete.

### **Opposition:**

- There are philosophical differences between members of Voice of the Retarded (VOR), other parent groups, and advocacy groups. In Kentucky, VOR has come a long way in supporting community as a *choice*. All the groups have compromised with *choice*, which is significant in the changes that have occurred in the state.
- Employees of state-operated facilities are not organized in unions. The wage scale for direct-care employees in the institution is equivalent to the wages of the workers providing the same service in the community.

### **Transition and Community Living:**

- The Kentucky P&A attended the Supports Planning meetings for the individuals with developmental disabilities who were living in state psychiatric hospitals, and they followed these individuals in the community for 60-90 days.
- The state has the highest utilization of people living in residential settings of 16 people or more.
- A majority of individuals who have been transitioned out of an institution in at least the last five years are living in community-supported living arrangements or group homes of three people or less. Some of these residences have 24-hour supervision.

- Compared with other states, Kentucky is unique, with over half of its citizens residing in rural settings. The distance between social agencies and people needing support has created logistical and economy of scale issues. (*Mercer Report*, 2001)

### **Economics:**

- Supports for Community Living (SCL) is an HCBS Waiver under the Kentucky Medicaid program and is developed for residents with developmental disabilities as an alternative to institutional care. SCL allows the resident to remain in or return to the community. More than 2,000 people are on the waiting list for waiver services.
- The Supported Living Grant, which comes from the state general funds that the Legislature sets aside, allows the individual to manage his or her own money. There are coordinators in each region who are supposed to assist people to apply for these grants.

### **Noteworthy:**

- Kentucky Governor Paul Patton recently signed legislation to create a model for self-determination that funds supports for people with developmental disabilities and mental retardation. The Webb and Brown Self-Determination Act, HB 501, is intended to increase the everyday decision-making power of individuals and their families around choosing services and providers, and to ensure multiple systems of accountability – guaranteeing both needed supports and the proper use of public dollars. (*NASDDDS Community Services Reporter*, May 2003)
- House Bill 144, signed by the Governor in 2000, was the result of the numerous efforts to bring positive changes to Kentucky’s system of services for individuals with developmental disabilities. HB 144 created a Commission to serve in an advisory capacity to advise the Governor and the General Assembly concerning the needs of this population. This Commission is responsible for:
  - 1) developing funding strategies to support community services to address the needs of the people with developmental disabilities on the waiting list for services;
  - 2) creating a 10-year plan for providing services to all individuals who could live in community settings – the legislature allocated 250 slots this year for individuals to leave the ICF-MR setting to a residential alternative in the community and for people on the waiting list for residential services – state dollars will be combined with federal Medicaid dollars; and
  - 3) implementing an awareness and education plan about services and supports for individuals with disabilities and their families.
- In 2002, the Kentucky Protection & Advocacy filed a lawsuit on behalf of four people with mental retardation and their caregivers against the state’s Cabinet for Health Services and the Departments for Medicaid Services and Mental Health and Mental Retardation (*Michelle P. et al. v. Morgan et al.*). The lawsuit charges that Kentucky has improperly waitlisted individuals for Medicaid services. The plaintiffs sought class action certification on behalf of other waitlisted persons. The District Court granted class certification. A trial is scheduled for 2004.

- Kentucky participates in the National CORE Indicators (NCI) study that assesses performance and outcome indicators for state developmental disability service systems.

**Interviewee Reflections:**

- The money needs to follow the person. More Medicaid funding is needed.
- With such a huge waitlist, only the emergencies are being addressed– some people are getting absolutely nothing.

## LOUISIANA

**# State-Operated Institutions Remaining: 9      Approximate Census: 1,690**

**# State-Operated Institutions Closed: 0**

### **Service System:**

The Office for Citizens with Developmental Disabilities (OCDD), a division of the Department of Health and Hospitals, administers the Louisiana MR/DD Services System. It provides oversight to the state-operated Developmental Centers, directly administers eight Regional Offices, and collaborates with the local entities, the Jefferson Parish Human Services Authority (JPHSA) and the Capitol Area Human Services District (CAHSD), for delivery of supports and services.

### **Institutional Closure Information:**

- The Department of Health and Hospitals has asked for the closure of four Developmental Centers, which would save an estimated \$66 million in the FY 2004 budget. The Governor, however, is publicly backing away from the plan.
- In FY 2002, only 65 individuals moved out of Louisiana's Developmental Centers while 76 individuals moved in.
- Grassroots advocacy groups are in favor of the closure of Developmental Centers, and other large congregate living settings, but they cannot support a closure plan that does not include quality planning.

### **Opposition:**

- There is a strong parent/guardian organization at every Developmental Center. This group feels threatened when there are any discussions regarding change in the Developmental Centers. This has not been a significant issue in Louisiana, however, as no state-operated institution has closed.
- When there have been battles in the legislature, both the unions and parents have weighed in by lobbying. The legislators respond to these groups because the institutions are located in rural areas.

### **Transition and Community Living:**

- An Individual Service Plan (ISP) is developed for every resident who leaves the Developmental Center.
- Social/recreational activities have been the most difficult service to fill in the community.
- Dual diagnosis DD/MI individuals are the most challenging to serve in a community group home environment.
- Quality assurance is a multifaceted system in Louisiana:
  - There is a toll-free telephone line on which complaints can be filed with the State Medicaid Waiver unit. Repeated complaints about the same provider trigger a quality monitoring review.
  - Each HCBS Waiver recipient has a case manager who is responsible for developing this or her plan of care and ensuring that the plan is fully

implemented by the agency and support staff. There must be quarterly face-to-face contacts with clients.

- The OCDD and Medicaid Unit staff have received training by The Council on Quality Leadership to state and regional staff, as well as case managers. The goal is to get quality reviews geared more toward outcomes of services.
- All providers of the HCBS Waiver program in the state are required to be licensed by the Division of Social Services.

**Economics:**

- Louisiana is authorized to provide four different HCBS Waiver programs. These programs are managed out of the Department of Health and Hospitals, Bureau of Health Services Financing.
- 9% of the people are served in state-operated developmental centers, but use 35.29% of the Medicaid funding.
- In FY 2002, over \$357 million was spent on 24-hour public and private ICFs-MR, though many of Louisiana's residents may not require 24-hour care.
- Louisiana ranks last nationwide for direct-support wages and benefits for workers in the developmental disabilities private provider sector. There is a considerable disparity in wages and benefits between private and public direct-support staff doing comparable work.

**Noteworthy:**

- 78.6% of all individuals in residential settings reside in ICFs-MR, compared with a national average of 29.4%. Louisiana ranks first in the nation in the number of residents in all ICF-MR settings per capita. Louisiana has 11 private large ICFs-MR and 435 designated group homes (small private ICFs-MR).
- The Louisiana Advocacy Center (P&A) has an Ombudsman Program in which staff members make routine visits to group homes. Visits do not, however, include supported living residences.
- There are 9,000-10,000 people on the waiting list for HCBS Waiver services.

## MAINE

**# State-Operated Institutions Remaining: 1**      **Approximate Census: 15**  
**# State-Operated Institutions Closed: 1**      **Closed Since 1993: 1**

### **Service System:**

The Maine Department of Behavioral and Developmental Services (BDS) oversees the public sector provision for mental retardation in the state. Operations are carried out through a Central Administrative Office along with three Regional Offices and satellite sites in 10 locations throughout Maine. Additionally, BDS provides services through three MR/DD residential facilities. The Regional Offices provide direct services, such as case management and crisis intervention.

### **Alternative Use(s) for Closed Institution(s):**

A nonprofit foundation bought the Pineland campus and is developing it for business and nonprofit entities.

### **Institutional Closure Information:**

- The bureau director of BDS decided to close Pineland and initiated the process. In 1978, the institution was downsized to half of what it had been, and in the 1990s 350 people were still residing there.
- Pineland finally closed in 1996, due to the class action lawsuit *Wouri et al. v. Zitnay*, which had been initiated in 1975. The original consent decree in that case was renegotiated in 1994 and is now known as the Community Consent Decree. It governs community services to former Pineland residents.
- The remaining state-operated institution, Aroostook Residential Center, has a very small census of less than 16 residents. This facility is slated to close in July 2004.

### **Opposition:**

- The unions were opposed to the closure but were not a significant issue. State administration, however, held community meetings with staff, and three years before Pineland closed, the union began working out “deals” with the state to move into community programs. Union employees allegedly leaked certain confidential information about residents to the press – as there was already a track record of people leaving Pineland. The media’s impact was not major, and articles and editorials were mostly in favor of closing Pineland. The union became resigned to the closure.
- The state set up a referral service to community providers, and they helped the union staff develop their own “waiver” homes, so that the worker could take home residents in a foster care setting. Real estate could be bought through the waiver. The worker did not necessarily own the home but could become the staff in the home that was operated by a community agency.
- The union waived seniority rules – rather, the priority became who was the best worker. These staff were assigned to be crisis workers, and they retained state employee status. The state tried to ensure that workers were not “dumped.”

- The Friends of Pineland parent group did not take a group position against closure, but many parents were nervous about the impending change. Some of the older parents were more actively opposed. An attempt was made to align with the union, and parents also met with and lobbied legislators. The state worked with the parents and guardians to ensure that they were satisfied with the planning process. The state was also able to blunt opposition by providing a “guarantee” about certain provisions in the community.

### **Transition and Community Living:**

- Since Pineland was designated as an ICF-MR, it was funded with federal dollars. Therefore, every resident qualified for the waiver and residences in the community were developed with waiver money. The funding followed the person into the community.
- The parents/guardians, the community agency, and the state advocates all had to agree with the person-centered plan. Depending on the individual, there could be multiple visits to a prospective placement.
- It took almost three years to move all the residents out of Pineland.
- There are smaller state-owned ICFs-MR operated by BDS, all of which are 20 beds or less. One of these centers, Aroostook Residential Center, is geared for individuals with significant behavioral issues, some of whom may have previously “failed” in the community.
- A majority of the Pineland residents moved to a “waiver” home – a rehabbed house in a rural area with two to three individuals. As described above, a former institutional employee(s) might have followed the resident to staff one of these homes. Some residents, however, went to nursing homes, ICFs-MR, or other community-supported living arrangements.
- Interviewees stated that the transition process from Pineland to the community was successful for most residents. It is felt that many of the former residents are generally making a real connection with the community and engaging in enjoyable activities, and that there are more opportunities available to them.
- All former Pineland residents have an annual Person-Centered Plan, a requirement of the Community Consent Decree, which addresses professional services and the range of activities of daily living.
- There was a Behavior Stabilization Unit (BSU) at Pineland. The structured setting it provided has not been replicated in the community, but there are crisis services and four two-bed state-run crisis homes that provide some of the services that the BSU did. It is felt, however, that there are not enough behavior therapists to address the need. The population most difficult to serve in the community is MI/DD.
- Dental and specialty services, such as OT and PT, for the MR/DD population were also identified as being in short supply.
- Individual support coordinators (ISCs) advocate for the individuals they support as well as for systemic issues.

**Economics:**

- Only 4% of all funding for mental retardation services is not matched by the federal Medicaid program. (BDS website, 2002 Report)

**Noteworthy:**

- A Consumer Advisory Board was mandated by the consent decree and was further defined in a statute by the Legislature in 1995. It carries out numerous responsibilities identified in the decree, including periodic meetings with BDS to discuss unmet needs and crisis services, and it reviews severely intrusive behavior plans and rights violations reports, provided by the Office of Advocacy.
- MaineCare provides health care coverage to people who meet the program's financial guidelines (income and asset). In order to obtain services from BDS, an individual must apply and enroll in MaineCare. BDS administers/manages specific MaineCare benefits for members with MR/DD or autism. In addition to the full benefits package, including physical exams, behavioral health services, inpatient and outpatient hospital services, specialized therapies, transportation, and prescriptions, BDS administers MaineCare for the following services: ICFs-MR, Day Habilitation Services, and Home and Community-Based Waiver Services.
- The state Office of Advocacy is responsible for ensuring that Pineland "class" members and other people with disabilities are getting what they should. This office investigates abuse and neglect issues.
- State case managers license community residences and are required to visit each residence twice annually. There is no comprehensive Quality Assurance plan.

**Interviewee Reflections:**

- The changes in Medicaid policy allowed for more creative solutions. This brought about a philosophical change that influenced the decision to close the institution.
- The community probably costs a little bit more. If any money was saved, the consent decree states that money is supposed to go to providing MR/DD services in the community and to implement provisions of the decree.
- There needs to be more ongoing quality assurance on placement – more involvement by case managers outside of state government. State guardians don't do a good enough job.
- Make sure there is a credible QA system in place, independent of the state, with a clear mission to build the trust of parents. There should be a coterie of people whose job it is to determine the quality of life by objective determinants. Build the trust of constituency groups.

## MARYLAND

**# State-Operated Institutions Remaining: 4**

**Approximate Census: 460**

**# State-Operated Institutions Closed: 4**

**Closed Since 1993: 1**

### **Service System:**

The Developmental Disabilities Administration (DDA) within the Department of Health and Mental Hygiene (DHMH) provides a coordinated service delivery system through a combination of four state Residential Centers and a wide array of community-based services delivered primarily through a network of nonprofit providers (about 120 statewide). Services are obtained by contacting one of the four Regional Offices of the DDA, which control funding and quality control. These Regional Offices receive plans for the person and work with providers on budgeting. The Statewide Office then issues final approval.

### **Alternative Use(s) for Closed Institution(s):**

Uses include a private juvenile facility and a private senior retirement community, as well as a purchase by Johns Hopkins University.

### **Institutional Closure Information:**

- Although there is no formal policy, state practice is toward downsizing. The focus is on those people who want to leave the institutions, with no effort to pressure those families who object.
- After Olmstead, a group was convened by the Governor's executive order to downsize institutions, including nursing homes, psychiatric hospitals, and other state residences. The idea was to downsize by 60 to 80 individuals each year. The group was chaired by the Secretary of the Department of Health and Mental Hygiene and the Director of the Governor's Office for People with Disabilities, and it included individuals with disabilities, parents, and representatives of the DDA, the Mental Health Administration, a psychiatrist, a representative of the Nursing Home Association, the Medicaid Administration, and the Department of Budget and Management.
- The Department of Justice and the P&A filed lawsuits pertaining to the Great Oaks Center (GOC), but these never went to court. The outgoing governor recommended its closure, and the incoming governor did not rescind this order.
- The DDA and its current director are very supportive of institutional closure with careful planning for transitioning individuals into the community.

### **Opposition:**

- A study was conducted of the residents at GOC, which found that fewer than 20% of families were involved with residents. These people did become active in trying to keep the institution open.
- Efforts were made to allay fears of parents and guardians at GOC (Great Oaks Parents Association) through such activities as regular "family to family" meetings. However, these were not successful in convincing parents to support closure.

- Attempts by parents to prevent closure by using a legislative budget process were defeated.
- People on the Go, a group supported by the Arc of Maryland, is composed of many individuals who themselves had left an institutional setting. This group came to GOC and let self-advocates speak about the advantages of community life.
- Unions did try to prevent closure. Efforts were made to help find other jobs in the DHMH. Some direct care staff went to work for nonprofits, and some nurses went to work in homes with medically fragile individuals. There was a wage enhancement bill that provided additional money to the DDA budget to partially offset loss of benefits by direct care workers.
- There was strong opposition to closure in those communities where institutions were major employers. Some neighbors were concerned about the prospect of transforming one institution into a juvenile facility. In addition, DHMH spent time talking with some homeowners who were worried about a decline in property values if group homes were established in their neighborhoods.

#### **Transition and Community Living:**

- Person-centered planning was utilized for people leaving GOC when it was closed in 1996. Before this, community service was provider-driven. At the outset, many people were aided with more supports than necessary to provide families with a comfort level in moving family members to the community. Even 24-hour supervision in the community was less expensive than institutional costs. After a while, it was recognized that many of the supports were not necessary, and so over a five-year period, these unnecessary supports were gradually eliminated.
- In preparation for the GOC closure, families visited a provider fair with 186 providers and about 300 visitors participating. Before the fair, the families were supplied with sample questions that could be asked. Parents were also told that they were not making irreversible decisions.
- Community placement was determined by using “Essential Life Style Planning” (developed by Michael Smull at the University of Maryland and Susan Harrison at the DDA), which is a person-centered planning technique that helps people with disabilities and the people who are most important to them (including institutional staff) identify the way that each person wants to live his or her life. Letters were subsequently sent to providers asking of their interest in meeting the individual.
- Money was allotted for a Parent Monitoring Group to visit homes during the first three years after closure. Parents in this group were trained about client rights and those factors to observe on the site visits.
- A community-based consortium of Emergency and Behavioral Support Services was designed to help those with behavioral disorders who receive DDA support. Another group of people that presented challenges for living in the community are those with medical complications. Karen Green McGowan’s “Functional Life Planning” and “head-to-toe” medical assessment tools were used to assist with the careful, in-depth person-centered planning before any of these individuals left GOC. The homes where these individuals live are staffed with RNs, LPNs, and

certified nursing assistants. This is expensive but provides a high level of services for those with medical complications living in the community.

**Economics:**

- There is portability with DDA funds for services so that a person can take his or her money and change service providers. Previously, people were free to change to another provider, but the funding stayed with the provider and created a “funded vacancy.”
- A Waiting List Equity Fund was created from the sale of Great Oaks. Distribution of the fund is prioritized on the basis of the age of the caregiver. In addition, the previous Governor, Parris Glendening, included \$115 million in the fund in his budget in FY 1999 that was approved by the Legislature. This is the last year of the five-year initiative.
- The average cost for an individual living in the community (full-service) is approximately half of what it was at GOC.
- Service providers are allowed to take any specially built equipment with them, so that an individual will not lose needed supports when moving into the community.

**Noteworthy:**

- The Arc of Maryland and People on the Go operated the Ask Me! monitoring project with funding from the DDA and the Maryland Developmental Disabilities Council. Interviewers work in pairs and provide information that can be used by service providers to evaluate their own services, by funders to evaluate the services of the different agencies they fund, and by consumers to differentiate between service options.
- An in-depth survey of nine states was conducted by DDA on deinstitutionalization and community integration. Focus of the surveys was on four central issues: families, employees and unions, quality assurance in the community, and alternative uses of buildings once an institution has closed.

**Interviewee Reflections:**

- When you try to advocate for support of community services, use a key sound bite, “fairness.” Ask whether it is fair to spend \$195,000 to support someone in an institution or use those funds to support several in the community and reduce the waiting list.
- In planning for deinstitutionalization, try initially to move a mixture of different individuals with different needs, so that people in varied circumstances can see the positive aspects of living in the community.
- Make sure that you have enough time to have conversations with families to calm their fears and satisfy their personal concerns about transitioning into the community.

## MASSACHUSETTS

**# State-Operated Institutions Remaining: 6**      **Approximate Census: 1,200**  
**# State-Operated Institutions Closed: 3**      **Closed Since 1993: 2**

### **Service System:**

The Department of Mental Retardation (DMR) provides statewide funding from a Central Office to five Regional Offices. There are several Area Offices within each region.

### **Alternative Use(s) for Closed Institution(s):**

Undetermined

### **Institutional Closure Information:**

- Three institutions and one campus of a fourth institution are now closed. They were located in areas across the state.
- In the 1970s, the parents of residents of state-operated institutions and the Arc Massachusetts sued the Commonwealth of Massachusetts to draw attention to the lack of services and poor living conditions in those facilities (*Ricci v. Greenblatt* and *MARC v. Dukakis*). A Consent Decree from these successful class action lawsuits ordered improved conditions and regular individualized programming in the institutions under the watch of a Court Monitor. This Consent Decree included a “Community Plan” that signaled the beginning of a community-based service delivery system, as residents from all the institutions were being identified to live in a less restrictive environment.

### **Opposition:**

- There was significant parent and union opposition to the most recent closure, the Paul Dever State School, which finally closed in 2001 – eight years after the closure was announced. A vocal coalition of parent groups joined forces with the AFSCME union. Together they lobbied legislators and were able to influence State Senator Pacheco, whose constituency resided in the Dever geographic area, to write the Pacheco Bill in 1993.
- The Pacheco Bill is the most restrictive state anti-privatization legislation in the nation. It mandates that in order to contract out any service currently delivered by state employees, a state agency must compare the cost of using a private vendor not to actual current costs but to the cost if employees were to work “in the most cost-efficient manner.” (Pioneer Institute, Agenda for Leadership, 2002). This bill impacted the closure timelines for Dever.
- The DMR developed the idea of building “social units” as part of a resident’s transition plan to the community. It was asserted that “this is about consumers, parents and guardians making decisions – let the consumers choose the staff they want as part of their transition plan.” This proposal went against the traditional notion of staff seniority and “bumping rights” for job retention. One safeguard in place was that staff had to be past the six-month probationary employment period in order to participate, if chosen by a consumer, family, etc. The “super” seniority group identified by consumers could either stay at Dever or move to the

community – they were exempt from being “bumped.” The DMR agreed that 60% of the union employees leaving Dever would move into state-operated community residences and 40% into provider services.

### **Transition and Community Living:**

- An Individual Transition Plan was developed for every Dever resident.
- As noted above, the consumer and family/guardian had the opportunity to identify staff who would remain with the client through the transition process and into the community.
- Part of the union negotiation was that several hundred staff would follow consumers to work in state-operated residences, approximately half of the residences in the community.
- Most of the residences were four-person homes.
- Supported employment opportunities have been difficult to provide due to the need for more individualized staffing, and thus higher funding rates, for people who require more than intermittent support during the day.

### **Economics:**

- It is conjecture whether Massachusetts saved money when it closed the doors at Dever, due to the costly union agreement. Although Massachusetts was able to reallocate funding during the Dever closure for individuals who needed emergency services and developed a medical safeguarding system program in the Southeast Region, the initiatives were limited, due to the costly union agreement.
- In 2000, the Commonwealth announced a five-year plan to eliminate the waiting list for services throughout the state. (Waiting List lawsuit: *Boulet v. Cellucci*) Under this \$114 million plan, of which \$85 million is new funding, the state pledged to create approximately 400 residential placements per year over five years. This plan also guarantees additional support services, such as respite, transportation services, and recreational activities to be available to assist these individuals while they wait for residential placement.
- As a result of the provisions of the settlement regarding *Rolland v. Cellucci*, a comprehensive plan was developed to provide community-based care to hundreds of individuals currently residing in nursing facilities. Additionally, more than a 1,000 nursing home residents are getting new supports and specialized services that had not been available prior to the legal settlement.

### **Noteworthy:**

- Governor Romney’s FY 2004 budget shows a \$5 million cut in funding for state-operated facilities for people with developmental disabilities. It is anticipated that Fernald State School will close in 2004. (*Community Services Reporter*, April 2003)
- Human Services Research Institute and the Boston University School of Social Work conducted an external evaluation of the experiences of adults 18 years or older and their families who are receiving services from the DMR. The objective of this evaluation was to provide information to the DMR about the performance and quality of their services, along with recommendations to increase consumer

satisfaction. Several recommendations were outlined based on the findings. These include 1) creating an accessible, responsive service and support system; 2) ensuring basic service coordination and health care for all consumers; 3) addressing perceived and apparent inequities in the service system, forging stronger links with underserved groups with links to the DMR, such as nursing home residents; 4) ensuring that all consumers have opportunities to make important life decisions; and 5) developing strategies to reduce staff turnover and improve quality of direct-care staff. (*Evaluation of Services and Supports to People with Mental Retardation and Their Families in Massachusetts, Executive Summary*, 2001)

- Massachusetts is one of 17 states participating in the Core Indicators Project that was launched by the National Association of State Directors of Developmental Disabilities Services (NASDDDS). This enables agencies to track system performance and outcomes on an annual basis.
- The New England Index, maintained by the Shriver Center in Boston, and the Federation for Children with Special Needs both maintain a database of physicians and other health care professionals who provide care for DMR consumers. Additionally, the Arc Massachusetts is in the process of launching TheArcLink.org for Massachusetts, which will allow individuals and families to search for providers interactively on the web.

#### **Interviewee Reflections:**

- It's vital to involve the families and individuals with disabilities from day one during transitions so that they can be active participants in choosing or developing their services. This may include the need for visiting several options in the community.
- The press plays a role in educating the public during the period of State School closures, but it is made up of many individuals and groups. The time required to adequately work with the press is often not available to advocacy groups, such as the Arc, Protection and Advocacy groups, or the state entities involved in systems change.
- Promote consumers' having a voice – to what extent can you advance the mutuality of interest between that of the union and of the consumer?

## MICHIGAN

**# State-Operated Institutions Remaining: 1**

**Approximate Census: 150**

**# State-Operated Institutions Closed: 12**

**Closed Since 1993: 2**

### **Service System:**

The state has a county system in which there are 55 Mental Health Boards in 80 counties. These boards contract with private providers (Community Mental Health Service Programs) for services.

### **Alternative Uses for Closed Institutions:**

They have been used for county/state offices, corrections, the Department of Defense, and community development or have reverted to state use.

### **Institutional Closure Information:**

- The state has gone from 13 institutions in 1972 with about 14,000 residents to one with less than 150 residents. The process of closure involved dramatization of conditions in the institutions by the media (in February 1978 in the *Detroit Free Press*) and a lawsuit focusing on the state's Plymouth Center, *Michigan ARC v. Smith* (1979). The subsequent consent decree led to the closure of Plymouth Center in 1984 and the acceleration of the development of community services, which in turn led to the closure of other institutions throughout the state.
- Community advocates were organized and cohesive and able to point to the issue both as one concerning human rights and one involving economic savings during a period when the state had one of the worst economies in the country.
- There is no strong advocacy for closure of the remaining institution, since the focus is on the need to address the problems of the waiting list and the quality of services.
- Several state legislators became advocates for community residences, and this facilitated early legislation in the 1970s and 1980s.
- The Macomb-Oakland Regional Center (MORC) concentrated first on preventing new admissions to any institution by finding a place in the community for anyone who needed help. This involved about 35 people a year. The center also sought to get 100 out each year, mainly into six-bed group homes.

### **Opposition:**

- Unions fought to keep institutions open, but when it became too expensive to keep institutions because of downsizing, the state ignored the unions and began closing the institutions.
- SEIU is now looking into the possibility of unionizing community-based program staff.
- State legislators in communities where institutions were major employers fought to keep them open.
- The community placement program was developed with strong support by Governor Milliken. Many municipalities filed challenges to the state's zoning laws to prevent development of community-based residential services, but the

courts ruled against localities. Despite rulings, there was continued opposition to development of community group homes, with firebombing incidents in 1982.

- The Plymouth Parent group joined The Arc Michigan in filing the Plymouth lawsuit in order to improve conditions at Plymouth. When closure was being considered, the parents opposed (there was a split among parents). Now many of the parents have become advocates for group homes in the community.

### **Transition and Community Living:**

- There was dedicated leadership at centers such as MORC, which, rather than merely exist as freestanding institutions, developed group homes in the community as part of the Department of Community Health. This early work helped establish norms for community services.
- Efforts are made to use “person-centered planning,” with its emphasis on the person’s desires or needs, rather than the regulatory standards that previously drove the planning process through requirements regarding which assessments must be completed and which professionals must be engaged.
- At the outset, choices were limited, as there were basically two residential models, six-bed group homes and foster homes. (It should be noted that the number six was arrived at because six individuals and two staff members could fit in a van.) In beginning the process of community integration, families were trained and paid to have people live with them in foster homes.
- It was found that the key in placing people together was friendships and compatibility of interests rather than intellectual level because, often, the more capable individual tries to help care for the others who share his or her interest.
- Two lawsuits have been filed pertaining to state support for individuals desiring to live in the community. In September 1999, the Michigan P&A filed a lawsuit, *Olesky et al. v. Haveman et al.*, on behalf of six individuals with developmental disabilities and/or mental illness who resided in nursing homes but wanted services in the community instead. Settlement was reached as the state agreed to assure appropriate and timely community placement of individuals not requiring nursing care. In March 2002, a case was filed in the U.S. District Court for the Western District of Michigan seeking to overturn the state’s freeze on enrollments to a Medicaid HCBS Waiver program, MIChoice Program.
- Developmental Disability Institute at Wayne State University has conducted evaluations and outcome studies, with focus on improving the effectiveness of special education so that the future clientele of adults can become more independent.
- There have been recent articles in the press about poor conditions in the community and a lack of community services.

### **Economics:**

- There was no initial savings because there was a need to fund both the institutional and the community service system. As institutional population dropped, the per capita costs for institutions skyrocketed.
- A demonstration project, Self-determination Initiative (funded by the Robert Wood Johnson Foundation), allowed people with developmental disabilities,

- together with their guardians, to design agreements with community mental health agencies, in which they have access to an individual budget to purchase some, all, or none of the services that they had previously received. In addition to giving consumers choice and control, the average community cost of those in the project was \$17,000, compared with \$45,000 for those in group homes, suggesting that when people are allowed to choose the services they want, they often spend less than when services are chosen and directed by staff on the basis of assessments.
- Funds played a role in determining the type of living arrangement, since group homes were less expensive than two individuals living in an apartment, and transporting six individuals in a van was less expensive than using other passenger vehicles. The same was true for employment, where creating a 125-person workshop was less expensive than having job coaches for different jobs.
  - Reliance on Medicaid dollars has become even greater today with budget cuts.

**Noteworthy:**

- Despite Michigan's success with closing its institutions, there is some movement towards reinstitutionalization, as some providers are planning on opening 20+-person homes. This is due both to insufficient staff in the community and convenience for the provider.
- Michigan's experience with deinstitutionalization has been highlighted in a comparative study published in 2002 that contrasts its experiences in successfully closing institutions with those of Illinois. (Susan Parish, "Forces Shaping Developmental Disabilities Services in the States: A Comparative Study," in David Braddock, ed., *Disability at the Dawn of the 21<sup>st</sup> Century and the State of the States.*) The study concluded that "the most important factor that influenced the transformation of the state's residential service system was the convergence of leadership among the ARC, a number of legislators, and the DMH," (p. 402) whose leaders came from MORC beginning in the 1970s. From that period, MORC provided visionary leadership and innovative programs, quickly developing community residences and serving people with severe impairments. Other contributions noted were the following:

- The DD Council's funding of pilot projects and providing technical assistance to legislators;
- The P&A's providing lawyers for Plymouth lawsuit, providing monitoring functions, and advocating for systems change;
- The Governor's philosophical and financial support and leadership in pushing for community integration;
- The engagement of a few legislators in supporting efforts necessary to provide a foundation for community integration;
- The recession's providing some justification for cutting institutional jobs and developing less expensive community homes.

**Interviewee Reflections:**

- There is a need for a public information campaign about what deinstitutionalization means, particularly with the building of larger group homes.
- There is a need to recruit families to talk about successes in the community.

- The movement of an individual into the community is an ongoing process, as needs and desires may change. The service coordinator is a key to responding to individuals' changing needs.
- The difference between community and institution is like night and day. The self-stimulation prominent in institutions doesn't take place in the community because people have other things to occupy them, even if it is merely talking to the mailman, watching children play outside, planting flowers in the yard, or planning meals.
- Once you begin with an open school system that integrates children with disabilities, parents will never allow their children to be placed in an institution.
- The prior more centralized state system was better than the present decentralized county system because now we have a system with people getting different levels of services depending on the county in which they reside. There is a fragmentation of responsibility in a county-based system.
- The key to success was that the Department of Community Health had a strong dedicated group of individuals determined to close institutions. Illinois, Alabama, and New Jersey—to name a few—haven't succeeded because groups like VOR are more adamant than the deinstitutionalization side.

## MINNESOTA

# State-Operated Institutions Remaining: 0

# State-Operated Institutions Closed: 8

Closed Since 1993: 6

### Service System:

A state-supervised (Department of Human Services [DHS], Disability Services Division) county administrative system determines eligibility and then contracts with private providers for services. Counties provide case management, with a few also providing direct services, such as training and habilitation.

### Alternative Use(s) for Closed Institution(s):

- Faribault is now used as a prison.
- Brainerd is a neurobehavioral hospital for brain injury.
- Moose Lake is a corrections facility for sex offenders.
- Cambridge has limited use by Human Services.

### Institutional Closure Information:

- Minnesota has closed all its Regional Treatment Centers (RTCs) for individuals with developmental disabilities with the exception of a fourplex of town homes for a maximum of 36 people, organized together to provide a “safety-net program” for those with developmental disabilities who are public safety threats. This program, called Minnesota Extended Treatment Options (METO), serves 36 people at any one time and seeks to develop models of services and work as an alternative to jail.
- In September of 1980, a consent decree was signed in the *Welsch* class action lawsuit, which sought to require the state to develop proper treatment procedures and less restrictive, community-based alternatives for individuals with mental retardation and became a major stimulus for beginning the downsizing process. This consent decree required reduction in the institutional population and improvements in the delivery of services to people with mental retardation both in state institutions and in the community. It was followed by a negotiated settlement in 1987 that sought to avoid protracted litigation over compliance with the earlier consent decree.
- The DD Council, which is outside of DHS, supported studies in 1984 that provided a basis to support decisions for downsizing and community integration. The studies included a discussion of the age and maintenance of institutions; a comparison of the energy consumption of each building; a comparison of the cost of the community versus the institution; and an economic impact analysis, which showed that economic impact is more a function of employee zip codes than where the institution is located. The latter revealed that as most people did not live in the communities where the institutions were located, wages were not, for the most part, being spent there. The conclusion was that the direct impact from closure would therefore be less damaging to those communities than anticipated.
- The Legislature created a Board of State Agency Commissioners, composed of people from each affected state agency/department. Board members went on tours to other states (Rhode Island and Michigan) to view what occurred when those states deinstitutionalized.

- People First advocates were helpful in encouraging community integration and self-determination by providing firsthand information to legislators.
- In 1989, legislation was passed that came out of a Committee on Human Services composed of key stakeholders (unions, advocates, parents, legislators, governmental officials) that set the stage for eventual closure of institutions. One important result was that the Legislature established state-operated community services, thus satisfying union demands and overcoming the major obstacle to deinstitutionalization.
- To ensure efficiency and prevent any administrative competitive power game in preparation for closure, an interagency team was established, headed by an individual who reported directly to the Governor's chief of staff. The team met weekly to plan for closure and transitioning of people into the community.
- On June 30, 2000, Governor Ventura announced that a man who had spent 29 of his 52 years in a state treatment center had moved into a group home as the last person to be institutionalized by the state. This accomplishment was due both to the impact of the waiver that encouraged community integration and to continued support over the years by governors and legislators committed to promoting community inclusion and self-sufficiency.

### **Opposition:**

- Opposition came from parents of residents. Money was set aside to provide for counseling for parents and to show previous successes in movement to the community. DHS decided not to force people to move out but rather to focus first on those who wanted to leave the institution. Once these people moved out and others saw their success, they became less fearful.
- State-operated group homes in the community were developed to help neutralize initial union opposition to downsizing and closure. Currently there are about 1,400 state employees in the community in residential, day, and vocational rehabilitation services. Estimates are that about half of the employees went to private providers and half to state-ops. State employees also went to crisis centers whose goal was to try to retain people in the community.
- The state-operated homes served the most difficult individuals (only about 2.5% of the population), which the private providers did not want to serve.
- The Service Employees International Union (SEIU) is considered sympathetic to community inclusion.

### **Transition and Community Living**

- A longitudinal study by the University of Minnesota submitted to the Minnesota Legislature was conducted to evaluate results of living in various community settings. Among the key findings in the study published in 1996 were these: settings with four or fewer individuals are most cost-effective, former RTC residents who moved to the community showed substantially better outcomes at greatly lower cost than did their peers who remained in the RTC, and person-centered approaches to service planning can assist people in achieving lifestyles that are more satisfying and have better outcomes.

- Transitioning is administered by county agencies. The state and counties hosted a series of informational meetings for family members. The Arc set up person-to-person assistance, working with family members who already had people in the community. The goal was to make people clear about their options. Counties also worked with the P&A to get consumer information out to people. They also worked to put together videos, which people could view away from the influences of county and state officials.
- County officials assess an individual's abilities and then meet with family and friends to present various options. Screening is mandated to evaluate what services are needed and where the individual would like to live. No provider is allowed in these meetings because of the desire not to have providers shopping for clients. If it has been determined to use the HCBS Waiver, a decision is made as to what services are necessary. The county then conducts a competitive RFP process, noting the types of services needed and the cost parameters. After hearing from providers, the case management team informs the family so that they may begin visiting providers and making final choices.
- State-operated community providers received start-up funds of up to \$30,000 per home for furnishing homes. The staff that moved from institutions to the community found that they had different responsibilities, as it was necessary for them to cook, clean, and do some maintenance, jobs handled by different staff in the institutions.
- Moving to the community has been considered positive for most residents. After the closure of Faribault, there were follow-up interviews that found that individuals exhibited greater independence and positive behavioral changes in general. Improvements were noted among those with the most challenging behavior, because services had been tailored to meet their particular needs.
- Paper reviews are conducted by the state. The counties do the licensing surveys. When bad residences have been found, they have been closed. The state works with the union to address the problems.
- The counties investigate abuse and neglect allegations, but the state will also investigate very serious matters, particularly if it is felt that the county investigation is insufficient.
- The Consumer Directed Community Supports program, allowing individuals to have some control over how money will be spent, has been well-received by those participating in it, as revealed in a survey produced and published by the Minnesota Governor's Council on Developmental Disabilities (May 2002).
- Articles in the *Star Tribune* in 2001 revealed problems of abuse and neglect that pointed to a need for improving the monitoring system in the community.
- Problems exist in providing sufficient psychiatric and dental care.

#### **Economics:**

- HCBS Waivers have been a key funding source for moving people out of institutions, allowing the flexibility in funding to support those with the most complex needs. Since its introduction in 1984, the HCBS program has helped decrease the state institution population by 2,400.
- Approximately 15,000 people are enrolled in waivers (of these about 26% are children).

- Community services have provided new revenue to localities.

### **Noteworthy:**

- One key to success was preventing children from being placed in institutions. Working to get already-institutionalized children integrated into schools, even while they were in Regional Centers, and helping adults find jobs in the community served to prepare people for the idea that community inclusion is both practical and preferred.
- Consumer-directed support programs provide consumers with control over funds, with the concomitant shift in power in a marketplace environment.
- The Association of Residential Resources of Minnesota (ARRM) is suing the Department of Human Services over the recalculation of the waiver (*Association for Residential Resources in Minnesota et al. v. Goodno et al.*), arguing that the effect of this “rebasings” will be to adversely affect funds available for individuals. A temporary restraining order halting rebasing has been issued pending the court’s decision on a motion for a preliminary injunction.
- In a similar lawsuit filed by the Minnesota Disability Law Center (the state’s P&A), four individuals and Arc Minnesota are also suing over rebasing (*Masterman et al. v. Goodno*), contending that rebasing will adversely affect the choice between HCBS Waiver and institutional services.

### **Interviewee Reflections:**

- In Minnesota there is consistent agreement around the vision for community inclusion even though there may be differences regarding how this is to be implemented. If we had to go through the process again, we would avoid the ICF model entirely. We would also use fewer nurses because they tend to utilize a medical model. Nonetheless, the nurses did make parents feel more at ease with the transitioning process.
- One must work to separate property/housing from services so an individual can change providers without fear of losing residence.
- In working with the unions, it was necessary to gain their trust. Nothing should be hidden from them, as it is necessary to have a long-term partnership with the unions if the community system is to work.
- Research is incontrovertible that even mini-institutions (group homes) are better than mega-institutions; the challenge is how to create the motivation for the need to make people an active part of the community rather than just living in the community.
- In making the shift from institutions to the community, one should conduct a study to refinance the system.
- In working to close institutions, the focus should be primarily on developing a strategy to prevent any new admissions.
- Why has Minnesota been one of the most successful states? Every governor has contributed to make things better, starting from the 1950s, when the first Arc National Conference was held in Minnesota and Governor Luther Youngdahl worked toward the goal of community integration.

## MISSISSIPPI

**# State-Operated Institutions Remaining: 5**

**Approximate Census: 1,360**

**# State-Operated Institutions Closed: 0**

### **Service System:**

The Bureau of Mental Retardation (BMR) is one of the three bureaus of the Department of Mental Health (DMH). The service delivery system comprises five state-operated comprehensive Regional Centers, a state-operated facility for youth who require specialized treatment, 15 regional community Mental Health/Mental Retardation Centers, and other nonprofit community agencies/organizations that provide community services.

### **Institutional Closure Information:**

- There is no focus on the closure of institutions; rather, the goal is to prevent inappropriate placement in institutions by conducting effective assessments of individuals and seeking to enhance community service programs. There are some situations in which communities originally welcomed group homes and then opposed them once they found out that individuals with profound disabilities would be living in these homes. There are now 147 MR/DD locations throughout the state.

### **Transition and Community Living:**

- There is an effort to ensure that all legislators have some services and programs in their districts.
- BMR asks communities to provide property at no cost for building community residential programs. Communities understand that if they refuse, then there will be another locality willing to offer property, so Chambers of Commerce are often allies with BMR in convincing local governments to cooperate.
- Services are provided mainly by the state through its Regional Centers. In addition there are 15 Mental Health Centers, which also have sections for individuals with developmental disabilities.
- There has been some discussion about transferring funds from public institutions to community services.
- BMR has no direct responsibility for private ICFs-MR, but when the latter discharge individuals (often due to inability to provide necessary services for them), the responsibility falls back on BMR.
- Because the community and institutions operate within the same regional system, staff often move back and forth.
- Experts for services have been difficult to find in some rural counties.
- In May 2002, the Coalition for Citizens with Disabilities filed a class action complaint alleging that state policies result in unnecessary segregation of individuals with disabilities in nursing homes by not making home and community services available to them. The lawsuit is scheduled for trial in November 2003.

**Economics:**

- Medicaid, state general fund appropriations, and a small amount from grants, in addition to clients' social security and earned income, provide funding.
- This was one of the last states to get the HCBS Waiver, which has now increased enormously and is only limited by the amount of matching funds made available. Medicaid has provided BMR with means to redirect people away from institutions to less restrictive settings, often encouraging them to stay home and arrange for various therapies in the community.
- BMR is currently authorized to serve 2450 people in the HCBS Waiver program, but at present there are funds for only 1,755. It is seeking to find \$1 million from other sources to care for the others.

**Noteworthy:**

- The state Arc is involved in a three- to five-year self-determination project funded by the Developmental Disability Council to train people for living in the community.
- The University of Southern Mississippi is sponsoring a program, Home of Your Own, to encourage individuals to live independently. The program serves about 50 individuals, including some with mental illness.

**Interviewee Reflections:**

- There should be some coordination with or control over private ICFs-MR, because if they go out of business, their clients become the state's responsibility. There has yet to be any movement in this direction.
- Given sufficient financial aid and personnel resources, everyone could be served in the community.
- Services are provided by DMH and some small private programs. More competition would breed a better level of service.
- There seems to be little capacity to serve people in the community at this time. Efforts were made to go around the state to talk about self-determination and living in the community. But with a waiting list of from 600 to 1,000, the result of this activity has been to create false hopes among many parents.

## MISSOURI

# State-Operated Institutions Remaining: 6      Approximate Census: 1,170

# State-Operated Institutions Closed: 0

### Service System:

- The Division of Mental Retardation and Developmental Disabilities (DMRDD) provides supports and services to eligible people who have developmental disabilities and to their families.
- The primary points of entry for services are through 11 Regional Centers. Each Regional Center, supported by affiliated satellite locations, receives an annual appropriation of resources that can be spent throughout a 12-month period of time.
- Regional Centers formerly had residential facilities where assessments or evaluations for individuals with developmental disabilities were done. The length of stay was from 14 to 60 days. This practice has been discontinued.
- Eligibility assessments by service coordinators are completed at the Regional Centers. The Centers purchase other services from contract agencies. Many of the services will vary by geographic location and contract providers, though generally these include access to early intervention, vocational services, residential services, specialized therapies, in-home supports, respite care, and crisis intervention.

### Institutional Closure Information:

- None of the state-operated institutions, known as Habilitation Centers, have closed. The DMRDD operates Habilitation Centers that primarily serve individuals who are severely disabled, behaviorally disordered, court-committed, or medically fragile. The primary mission of these centers is to provide residential support and treatment services to people referred by the Regional Centers.
- Some people are admitted to a Habilitation Center by court order if required for forensic purposes, such as a sexual offender. The Regional Center is the primary contact for eligibility determination and for referral to a Habilitation Center.
- There are no set quotas for moving people out of the institutions.
- One of the Habilitation Centers, the St. Louis Developmental Disabilities Treatment Center, has four campuses throughout St. Louis. Half of the residents from one of the sites serving people with extreme physical disabilities moved into the community in 2002, and the campus is expected to close in 1½ years.

### Opposition:

- There is no concerted effort to close the remaining institutions.
- In each Habilitation Center there is a small parent/guardian group. Its members are generally very political, and they want the centers to remain open. Most of the residents have a guardian.

### Transition and Community Living:

- After the landmark Supreme Court Olmstead decision (*L.C. v. Olmstead*, 1999), case managers from the Regional Centers conducted proactive outreach to

parents/guardians of institutional residents to help interpret the legal decision and what it means for their son or daughter. They were told that the DMRDD would support them in their choice for community living.

- Each resident of a Habilitation Center has an Annual Plan. Missouri has initiated a Transition Team pilot project in St. Louis, in which case managers from the Regional Center maintain an office at the institution and attend each resident's Annual Plan meeting. The case manager becomes familiar with the resident and can inform the guardian about appropriate options that exist in the community. The regional staff members receive training on how to effectively work with families. The model will be initiated statewide within the year.
- Approximately 10 to 15 years ago, the state set up several four- to five-person group homes in response to a parents'/guardians' stance that they would only agree to have their son or daughter placed in the community if there was state oversight. The direct care staff in these settings are state employees, and the Regional Centers provide the case management. The state leases the residences.
- There are a wide variety of large and small residential options for congregate living in Missouri. These include residential care facilities, licensed by the Division of Health and Senior Services; group homes; apartments for semi-independent living; Individualized Supported Living for one to three people; and Family Living Arrangements.
- The biggest "boom" is with Individualized Supported Living, where the rates are individualized and tailored to meet the support needs of the person. In group homes, there is an identical daily fixed rate for each resident, independent of their needs.
- Each person who resides in the community has an Annual Plan that identifies a range of needs and activities particular to that person.
- Medical/dental and behavioral mental health services are the most difficult services to fill in the community. Individuals who are medically fragile or have complex behavioral issues are hard populations to serve in the community setting.

### **Economics:**

- The salary of the direct care employee in the Habilitation Center is similar to the direct care staff working in a community residence, but the employee benefits may be very different. In FY 2001, there was new money appropriated by the legislature to increase staff salaries of direct care staff working in all settings.
- There are a variety of funding sources to provide services to people with developmental disabilities. These include State of Missouri tax revenue, federal funding for specific programs, or a combination of state and federal funds. In some cases, there may also be cooperative funding with other state agencies. Some county boards also have funding from county tax levies and some spend dollars on community services.
- The HCBS Waiver is used as the primary source of funding for people with developmental disabilities living in the community.
  - The DMRDD uses general revenue funds to match federal Medicaid dollars to pay for services. Medicaid funding in Missouri consists of matching 40 percent state tax dollars to 60 percent federal dollars.

- Services in the community available through the HCBS Waiver include residential habilitation, Individualized Supported Living, employment programs, transportation, crisis intervention, community specialists, counseling, environmental accessibility adaptations, personal assistants, and specialized therapies.
- The number of people who can be served under the waiver is limited by the availability of state funds. The Regional Center will add names to a waiting list for those individuals who are determined eligible for the waiver but denied participation because the maximum number of people are being served by available resources.

**Noteworthy:**

- Certification and Quality Enhancement for community programs is a twofold process in Missouri. In 1993, the Missouri Legislature passed a rule that called for a certification process to address the quality of life for consumers supported by the DMRDD under the Medicaid waiver program. The rule established criteria for two separate review teams.
  - In the first stage, providers that receive funding from the HCBS Waiver are evaluated by the agency and the Regional Center, and an enhancement plan is developed to ensure desired outcomes are met and to develop community linkages for its consumers.
  - In the second phase, the Missouri Alliance for Individuals with Developmental Disabilities (MOAIDD), a statewide volunteer organization consisting of individuals with developmental disabilities and family members of this group, monitors and makes recommendations to improve the quality of life of consumers with developmental disabilities. MOAIDD functions as an advocate for the individual, ensures that the individual and/or family make choices regarding his or her life, and monitors the degree of power and choice that the individual has in making decisions about daily life. A goal of MOAIDD is to promote an atmosphere of cooperation between consumers and/or families, providers, the DMRDD, and MOAIDD.

**Interviewee Reflections:**

- The challenge is getting more people into the waiver program. We gave back slots because Missouri couldn't match the funds. The money should follow the person.

## MONTANA

**# State-Operated Institutions Remaining: 2      Approximate Census: 120**  
**# State-Operated Institutions Closed: 0**

### **Service System:**

The Disability Services Division (DSD) of the Department of Public Health and Human Services (DPHHS) is a funding and administrative agency that contracts with private nonprofit corporations to provide services to individuals with developmental disabilities through five Regional Offices. These service programs are located throughout communities in Montana.

### **Transition/Community Living:**

- In 1995, there was a proposal to close Eastmont Human Services Center, but the Legislature halted this plan. Many of these residents are nonverbal, have medical needs, and require intensive physical therapy. However, the 2003 Legislature approved closure of Eastmont for financial reasons. The plan is to move about 10 or 12 residents to community services and the remaining 18 or 20 residents to the other institution, Montana Developmental Center (MDC).
- A joint meeting with the institutional staff, community service staff, parent/guardian, and resident is held to discuss and develop community alternatives and transition plans, once an individual has been accepted into a particular community services opening.
- Residential options include: 1) Adult Community Homes, which serve three to eight adults in each residence and provide assistance with activities of daily living; 2) Intensive Community Homes, which generally serve six adults who have few self-help skills and/or have challenging behaviors; 3) Senior Community Homes, which serve seven to eight elderly people who require assistance in maintaining self-help skills; and 4) Supported Living services, which are individually tailored arrangements of resources and supports that allow individuals to live in the most integrated way. Currently more individuals receive Supported Living services than other residential options.
- Once individuals are placed in the community, there is a 30-day plan in which a range of activities and needs are identified.
- Providing social/recreational activities and obtaining transportation services are identified as difficult community services to fill.

### **Opposition:**

- Despite the opposition of some parents of residents, union members, and legislators, the Montana Legislature decided during 2003 to close Eastmont by the end of 2003. The legislature did so to consolidate costs at one institution. The majority of the money saved from the closure was directed to the state general fund and not re-invested in community services for people with developmental disabilities.

**Noteworthy:**

- The class action litigation filed in 1996, *Travis D. v. Eastmont*, seeks community-based developmental disabilities services for people who are currently residing in state-run facilities and who have resided in such facilities at any time since August 23, 1996. The court narrowed the class to exclude individuals in the community who are at risk of institutionalization, i.e. the “waiting list” group. The Montana Advocacy Program (P&A) is now proceeding toward trial. There is a preliminary injunction hearing scheduled in July 2003 to address health and safety issues at MDC.
- The DSD office fields complaints, and the Adult Protective Services investigates abuse and neglect. There is no clear-cut monitoring process for quality of care, programming, and consumer safety.

**Economics:**

- The state general fund and the Medicaid waiver are the funding sources for financing community services in Montana.
- There are two ways to leave the institutional setting: 1) By special legislative initiative to move out a number of people. In this case, a Request for Proposal goes out to community providers, and the provider determines how many people can be served. In this option, funding for services are portable; or 2) An opening in an existing slot. For this option, services is *not* portable, and there is competition for available slots from individuals on the waiting list for services, although beginning July 1, 2003, the funds supporting the services will be portable. The only services that will not be portable are institutional services.

## NEBRASKA

# State-Operated Institutions Remaining: 1

Approximate Census: 370

# State-Operated Institutions Closed: 0

### Service System:

The key components of the Health and Human Services System (HHS) are service coordination, contracting for community-based services, certification of community-based providers, technical assistance and support offered to providers, and the Beatrice State Developmental Center (BSDC), providing 24-hour residential, habilitative, and medical services in an institutional setting. The HHS system consists of three geographic areas, Western and Central, which are mainly rural, and Eastern, which includes the two most highly populated cities of Lincoln and Omaha.

### Institutional Closure Information:

- The Preamble to the DD Service Act Article 12 states the goal to increase independence and productivity in the community. The state practice is to give choice to individuals, whether for the institution or the community.
- There was one closure during the 1980s of an ICF-MR, the Omaha Developmental Center, with about 100 people. Some moved to the community, others to BSDC, and some to private ICFs-MR. There are no plans to close BSDC.
- In the last decade, approximately 50 people at BSDC who have requested placement in the community have received services in communities throughout the state.
- In 1969, the Nebraska Legislature had created a statewide system of community-based services for individuals with mental retardation. The resulting disparity in the conditions and services between community-based services and institution-based services led to a lawsuit being filed in U.S. District Court in September 1972 (*Horacek v. Exon*), which alleged rights violations in the Beatrice State Home. The settlement decree entered in 1975 required that individuals with mental retardation receive adequate care in the least restrictive setting and set the goal for reducing the population of the Beatrice State Home by 250 people within three years.
- The Planning Council on Developmental Disabilities was very involved in the *Horacek* case, funding a panel that determined which services were to be developed as a result of the consent decree. The Center for Excellence (formerly University Affiliated Program) was also involved, as its head was the chair of the *Horacek* panel.

### Opposition:

- Those parents who opted out of 1975 *Horacek* consent decree to have children placed in community have been prepared to fight any effort to close BSDC.
- AFSCME was concerned about the lower pay scale in the community. Some indication of the union position can be found in AFSCME's opposition to closing institutions for those with mental illness.

### **Transition and Community Living:**

- BSDC works in partnership with families and community teams to assess individuals to tailor a plan that will maximize success in the community. Annual reports are published with data on the center's Outreach and Intensive Treatment Services programs.
- The director of Behavioral Health Service is responsible for both the institution and the community. Either the interdisciplinary team or guardian of those people residing at BSDC may decide on the need to explore community-based services, working together with the service coordination unit in the area of the state where the person desires to live.
- In 1993, a program was formalized for BSDC to provide intensive behavioral support for those living in the community. This program offers inpatient and outpatient services to those with dual diagnoses or several behavioral concerns. The program was developed so that inappropriate psychiatric hospital admissions could be avoided for such individuals when the concerns are the result of the person's developmental disabilities, rather than mental illness.

### **Economics:**

- In 1990, the Medicaid waiver was approved to offer home and community-based services to people in their family homes, further expanding their choices of where to live. Waivers have been key to enabling more people to be served by the system.

### **Noteworthy:**

- In 2002, the American Association on Mental Retardation published an in-depth study of the development of Nebraska's service system, *Out of Darkness and Into the Light* (Robert L. Schalock). This book suggests some reasons why efforts toward full inclusion of individuals with developmental disabilities have stalled, one of which is that the vision that was so clear in Nebraska during the 1960s and 1970s has faded and has not been reenergized by new visionaries, organizers, and implementers, as was the case during that pioneer period.
- Concern was noted in the above volume about the potential conflict of interest in having social service workers, who should be professional advocates for their clients, employed by the state's service-providing agency.
- One model program is the Outreach and Intensive Services program, which is designed both to prevent unnecessary reinstitutionalization in the BSDC and to address aggressive and injurious behavior appropriately (rather than in inappropriate settings such as jails or psychiatric hospitals).
- The state participates in the NASDDDS Core Indicators Project, which aims to support state authorities in developing and implementing performance/outcome indicators that will enable them to measure service delivery system performance.

### **Interviewee Reflections:**

- Animus still remains among parent groups, providers, and advocacy organizations as a result of the *Horacek* lawsuit. This raises the question of whether or not litigation is the way to go.

- Part of the problem with implementation of the *Horacek* decree has been that there were political party changes for three successive key governors. This lack of consistency led to a weaker plan than anticipated.
- There should be greater funding to support programs for working with family members and others to allay their fears about what awaits them in the community.
- One should be careful that downsizing does not lead to loss of expertise that exists in the institution.

## NEVADA

# State-Operated Institutions Remaining: 2

Approximate Census: 110

# State-Operated Institutions Closed: 0

### Service System:

There is a regionwide system with the Division of Mental Health and Developmental Services of the Department of Human Resources (DHR) responsible for planning, administration, policy setting, monitoring, and budget development of all state-funded mental health and developmental services programs. Three Regional Centers provide services for people with developmental disabilities, two of which have large residential programs and all three of which offer community-based services.

### Institutional Closure Information:

- While there is a relatively low number of institutional beds in the state, a 2002 strategic plan of the DHR criticized some failures in the community service system that have led to many individuals not being served in the most integrated settings.
- Since 1990, there has been a plan to increase the percentage of those being served in the community. Discussion has focused on redirecting funding to developing community residential and other program resources.
- One means for reducing the waiting list has been to assert that particular services can only be provided in the institution, which has resulted in the failure to transition some individuals to the community.

### Opposition:

- There has been some opposition from guardians and parents of residents, although it has not been well organized.
- Employees have sought to avoid complete closure by supporting the gradual transitioning of individuals. This gradual approach helped avoid political battles. Staff was told that even if beds were eliminated, there would be no loss of jobs. However, for those being hired now, they are being told that it probably won't be long-term.

### Transition and Community Living:

- The Sparks School District lobbied to build more beds in institutions in order to ease the stress on parents of some particularly difficult students with disabilities. Instead, the DHR worked to improve community resources by creating pilot family support and respite programs to help alleviate pressure on families.
- Since institutions also offer services in the communities where people live, connections are maintained between client and staff.
- There is an individualized process to identify a person's requirements for living in the community and then offering a choice of providers who can meet these needs.
- It is often difficult to get sufficient funding to frame an appropriate treatment plan or to ensure an adequate supply of providers with appropriately trained and supported personnel. To improve the quality of providers, the state is now

- working on a Quality Assurance program and has even suggested a 15% pay increase for those in the community to alleviate the high staff turnover.
- There is a quarterly schedule with service coordinators who meet with clients on the waiver to see how they are managing. There is a requirement for a 90-day program review for all others, the intensity of which varies (e.g. it may consist merely of a telephone conversation with the family).

**Economics:**

- Funding comes from Medicaid waivers, the General Fund (room and board), Title XX, and TANF (for children).

**Noteworthy:**

- There was a New Opportunities Workgroup Plan used to downsize 12 beds in the Sierra Regional Center in 2002. The Workgroup was formed to guide the process as part of the quality improvement plan. In 2003, the center downsized another 12 beds, improving on what they had learned the previous year. The key to success was including representative stakeholders in the decision-making and planning process.
- The Nevada University Center for Excellence in Developmental Disabilities has regularly conducted personal outcome and satisfaction evaluations of developmental services, indicating which services have improved and which have declined. The latest report issued in June 2002 recommended improvement in the areas of increased individual participation in planning and in the periodic training of staff and families about the implications of personal outcomes and supports. The report suggested that the decline in satisfaction can be attributed in part to the economy's downturn having caused a reduction in services.
- A study by the Nevada University Affiliated Program in Developmental Disabilities, University in Washoe County has been developed for special education students between the ages of 18 and 22 to provide work and social experiences to the special education students in an age-appropriate inclusive setting. This is a joint project of the University and Community College System of Nevada, the Washoe County School District, and the Nevada University Center for Excellence in Disabilities.

**Interviewee Reflections:**

- The longer the planning process for individuals' transition into the community the better it will be for these individuals. More attention should be given to develop supports and mechanisms to live independently.
- Although there is a separation between the campus residential program and the community service program, the service coordinators who "know" the clients well often have "institutional attitudes" that can hamper integration efforts.
- Try not to take legislators on tours of institutions because "if it's a building, it's a program." Rather show them what is going on in the community.
- The reality is that people in the community are not the same population as those in institutions, and once some leave, they will cost more than what they cost in the

institution. We need to change expectations about the fact that everyone will cost less in the community. We should focus instead on the rights' issue.

- Once you have a core group of people committed to community integration, the process will move forward toward that goal.

## NEW HAMPSHIRE

# State-Operated Institutions Remaining: 0

# State-Operated Institutions Closed: 1

Closed Since 1993: 0

### Service System:

The Division of Developmental Services (DDS), part of the New Hampshire Department of Health and Human Services, is composed of a central office and 12 designated non-profit and specialized service agencies, referred to as Area Agencies, which represent specific geographic regions of New Hampshire. All direct services and supports to consumers with developmental disabilities or acquired brain disorders and their families are provided in accordance with contractual agreements between DDS and the Area Agencies.

### Alternative Use(s) for Closed Institution(s):

A corrections facility is now operating on the institutional grounds of the former Laconia State School, as well as Area Agency offices, and a small DD offender unit. Additionally, a state park was created.

### Institutional Closure Information:

Events that contributed to the downsizing and eventual closing of Laconia State School:

- RSA 171-A, a progressive statute, was enacted by the New Hampshire Legislature in 1975, entitled “Services for the Developmentally Impaired,” the purpose of which was to establish, maintain, implement, and coordinate a comprehensive service delivery system for individuals with developmental disabilities. The Association for Retarded Citizens was instrumental in gaining its passage.
- *Garrity v. Gallen*, a class action lawsuit initiated by parents of residents in Laconia State School in 1978, required both a plan of corrections for the facility itself and the creation of the community-based service system. While the court order did not specifically require the closure of the institution, the quality of the community services that were developed pursuant to the order resulted in the eventual closure of Laconia in 1991.
- *Action for Independence* was drafted to carry out the mandates of RSA 171-A and in response to the lawsuit. Ordered by the Governor, this was a policy master plan to develop community services and to deinstitutionalize Laconia residents within specified time frames. These time frames were periodically amended due to lack of sufficient funding.
- The state Legislature gave the authority to transfer institutional funds to the community. The money followed the resident. This occurred on a month-by-month basis for a 10-year period and under the specific oversight of a Legislative committee. The Legislature also gave the authority to transfer staff to privately owned residences.

### **Opposition:**

- Some parents of residents were against the lawsuit but never intervened. Six parents who opposed the lawsuit were deposed in court (*Garrity v. Gallen*). Five of the six parents said that they would be satisfied with very good community services for their son or daughter. Parent leaders were able to expose the conditions of Laconia to the media, which heightened people's awareness about problems at the institution and helped to change public attitude.
- The union/state employees association did not become amicus to the litigation. Extensive efforts to accommodate the staff were made, including job protection through transfer to other state agencies and facilities and to community-based services. Additionally, administrative capacity of the state agency was expanded through institutional staff transfers. A major emphasis on high-quality training at the institution resulted in a very skilled workforce that also moved into leadership roles in the private not-for-profit agencies. The last six years before Laconia closed, staff followed residents to the community. The association, however, was not at the discussion table. The superintendent of Laconia made the decision and came to an agreement with association leadership.
- There was community opposition to closing Laconia, primarily at a neighborhood level as new services were created. The Governor wanted to be receptive to the community. He made the decision not to mention "closure," but rather downsizing the institution.

### **Transition and Community Living:**

- The Area Agencies helped to identify or start a private nonprofit agency in the community. Case managers had the power to move people. A value-based system was developed.
- Approximately 60 Laconia residents moved into the community each year. It took one year to move out the remaining 40 residents once the decision to close was made.
- Most of the residents are living in less than three-person community living arrangements or another community support living arrangement. A high percentage (60%) of people are living in adult foster care.
- Laconia parents/guardians were involved in the decision-making process. Under New Hampshire law, if the state institution believes that a person is not able to make a decision, the resident must be appointed a guardian. An Office of Public Guardian was set up around the same time as the court order. It became guardians to many, if not most, of the residents. That office was progressive-thinking, another factor which facilitated the communitization effort.
- There were not many residential choices when Laconia was downsizing. Generally, family geographic considerations and a concern about finding a good match between the individual and provider were most important.
- Consumers who are medically fragile or have difficult-to-manage behaviors are living in an enhanced family care setting, e.g. adult foster care and staffed group homes with no more than four beds.
- There was no formal tool to determine the best community placement, but person-centered planning was utilized. An Individual Service Plan (ISP) was developed

for each resident at Laconia (as a result of the lawsuit), which included the transition period.

- At present, behavioral mental health and vocational activities are identified as being the hardest services to fill in the community. The most difficult population to serve is people with a dual diagnosis MI/DD and those individuals who are sexually dangerous.
- The Department of Public Health conducts licensing and a periodic review of life safety issues in community facilities where services are delivered. Case managers from the Area Agencies review ISPs. The Area Agency also provides Quality Assurance to the community providers.

### **Economics:**

- The funding source for financing the community service system is almost all from the Medicaid waiver. Some individuals live semi-independently. Funding for supports and services is provided through two primary mechanisms: the Medicaid Home and Community-Based Care Waiver and funds commonly referred to as “state flexible funding.”
- DDS operates two Medicaid home and community-based waivers. One waiver is for individuals with developmental disabilities (HCBC-DD), which serves approximately 2,700 people; the other waiver is geared for individuals with acquired brain disorders (HCBC-ABD), serving approximately 100 people. The state flexible funds provide services and supports to about 4,500 consumers and families to foster family stability and to prevent the need for more costly and intensive supports.
- The community system is less expensive than supporting an individual at Laconia on a per-person basis. The resident cost at Laconia was getting high as a result of improvements mandated by the consent decree. In addition, as the population declined, the institution became exorbitant to maintain. Financially, the state needed to look at alternative uses, e.g. corrections.
- It costs approximately \$42,000 to fund an adult in the community, which is less than half of what it cost to support an individual at Laconia in the late 1980s.

### **Noteworthy:**

See Institutional Closure Information.

- New Hampshire became the first state in the nation to close its institution.

### **Interviewee Reflections:**

- The state funding mechanism needs to be improved. There are hardly any independent state dollars and services are underfunded. The Medicaid waiver can't underwrite the whole system.
- Because of virtually flat funding over the past 10 years, the capacity of the system to serve more needy folks is reaching crisis proportions. The waitlist for services is also growing. Admissions of DD folks to the state mental health facility increased by 450% between 1998 and 2002. This may be attributed to the gross underfunding of the community system over the past 10 years.

## NEW JERSEY

# State-Operated Institutions Remaining: 7      Approximate Census: 3,300  
# State-Operated Institutions Closed: 3      Closed Since 1993: 1

### Service System:

- The state Division of Developmental Disability (DDD) funds services through four Regional Offices. Most services are provided through state contracts with private organizations or individuals. The availability of services depends on current resources, and types of services may vary in each county.
- DDD service provision includes case management, residential services, day programs, family support services, supported employment, personal and medical care, training, therapy, and supervision to those individuals residing in one of the seven Developmental Centers.

### Alternative Use(s) for Closed Institution(s):

There is a correctional facility on the grounds of one institution, and the other two locations are being used for commercial/recreational uses.

### Institutional Closure Information:

- The North Princeton Developmental Center closed in 1998 – three years after the closure was announced. This closure was part of a Master Plan developed by the Department of Human Services (DHS) to close one DD center and one MI hospital as an attempt to reduce the reliance on institutions. The DDD played a key role in the closure effort.
- The Governor was a strong executive who took the political heat by traveling throughout the state to announce the closure. She provided the financial wherewithal for closure and transition needs.
- The state Legislature needed to appropriate funds to make the closure possible, though their initial response was to oppose closure. The Legislature, however, permitted the funding for North Princeton to close and provided the oversight to appropriations. Once the legislation was passed, DHS was required to hold public hearings. Legislators also requested that the DHS Commissioner meet with constituents.
- Full-page newspaper ads were bought by *supporters* of the closing.

### Opposition:

- Many parents/guardians with family members in Developmental Centers were very vocal against closure. They became active when the state announced the plan, and they let their views be known at public hearings. Billboards were put up around Trenton in order to have the most impact on the Governor and legislators.
- The union was an active opponent and forged an alliance with parent groups in lobbying legislators. Their involvement escalated rapidly after the closure announcement. DHS could not promise that all staff would remain employed by the state, but there was a strong effort to hold every state opening and to request assistance from community providers for jobs. The state offered retraining and

outplacement services. There was some “bumping” and layoffs. The union, which was allowed to participate in the deliberations, wanted state-operated group homes. In the end, not many institutional employees followed residents into the community.

- The state made a commitment to hire an independent research group to evaluate how individuals were faring in the community.
- There were some aggressive reporters. The DHS Commissioner appeared on radio shows to respond to questions. DHS and/or DDD staff, along with advocates, met with the editorial boards of every major newspaper in New Jersey to dispel the notion that the closure was about saving money. Individual newspapers took their own point of view.

### **Transition and Community Living:**

- An Individual Habilitation Plan was developed for each resident by the family, the community provider, the institutional staff, and the consumer, as part of the planning process.
- Families and providers took an active role. There were events where contractors and providers could meet with families. The provider had to show how the needs of the family member were going to be met. This took considerable planning for the provider. However, in most cases, it was the provider who had the final choice of residents. In some cases, DDD required a provider to take one or two residents it did not want as part of a package.
- Self-advocates assisted North Princeton residents in making community choices for those who did not have a guardian.
- Most individuals moved to group homes that housed no more than six people and to other community-supported living arrangements.
- There are longitudinal studies of people who moved out of North Princeton and Johnstone Training and Research Center. These studies evaluated the closure of the two centers and the changes experienced by consumers, relying on objective assessments drawn from reports of staff/caregivers, family members/guardians, consumers themselves, and observational ratings by trained interviewers. All of the studies conclude that in terms of quality of life, people live better lives in the community due, in large part, to their increased contact with people in the community and their ability to make more choices for themselves. (Conroy and Seiders, of The Center for Outcome Analysis, 1994; Apgar, Lerman, and Jordan, of the Developmental Disabilities Planning Institute, 1998, 1999, 2000, 2001)
- A four-part special report was published in *The Star Ledger* in November 2002. The reporters reviewed seven years of incident report data from the state, which summarized specific allegations at Developmental Centers, including abuse and neglect, deaths, medical mistakes, inappropriate sexual contact, and supervision issues. The conclusion was that incidents of injury, assault, and abuse that resulted in serious injury have increased in the DD centers since 1997, and significant problems remain in these centers.
- *The Star Ledger* reporters also reviewed incident reports from 870 community group homes in the state that showed that there are real problems in the community as well regarding abuse and neglect. New Jersey and the federal

government are moving to increase their oversight of residential facilities with the state DDD initiating annual inspections and surprise visits.

- Behavioral and mental health services are identified as being the most difficult services to fill in the community. Consumers with a dual diagnosis of DD/MI and individuals with traumatic brain injury are the most difficult populations to serve.

#### **Economics:**

- Regarding the North Princeton closure, more federal dollars were drawn, but more state money was spent – “We spent out the money better.”
- Both institutional and community budgets have been increased; however, an interviewee noted that regarding the increase to the community, “We started pretty far behind, and it still does not approach the real need.”
- The Master Plan took into account many factors, e.g. the number of individuals with DD in the state and geographic considerations. The Master Plan was not economically driven.
- New Jersey uses federal and state funding sources for financing the community service system. There was a state bond issue. A \$160 million one-time amount was set aside for capital purchase requirements. General revenue funds were also utilized. Medicaid funds and the HCBS Waiver were critical.
- Houses were purchased with a “reversionary” deed – if the program is not successful, the deed goes back to the state.

#### **Noteworthy:**

- During the past two years, the federal Centers for Medicare and Medicaid Services (CMS) conducted inspections of New Jersey’s Developmental Centers. At that time, two of the centers were decertified by CMS. Currently, all New Jersey facilities are CMS certified. The Governor’s FY 2003 budget provided \$27 million in new funding to address quality-of-care issues in all of the developmental facilities. This funding will be provided for new direct care and professional staff, training, and new equipment. (*DHS Publication, 2002*)
- No money is included in the FY 2004 budget to move additional residents out of Developmental Centers. To date, less than half of the residents projected to move out of the centers through funding initiatives in 2000 and 2001 have actually moved out.
- DDD case management monitors community programs, though case managers do not play a clear Quality Assurance role. In many cases, case managers are not able to act as independent agents of quality, as they may be too integrated into the agencies that they oversee. (*Home and Community-Based Services for Persons with Developmental Disabilities in New Jersey, Charlie Lakin, University of Minnesota, 2000*)

#### **Interviewee Reflections:**

- Programs need to be more highly individualized, and there should be a better process for choosing providers – they don’t want to serve people with difficult behaviors. In New Jersey you get nothing or everything. Because the providers

pick the residents, a significant issue is that a resident with any kind of problematic behavior does not get picked.

- There is no ordered waiting list, so some of the residents who can live in the community with appropriate supports may never get the opportunity.
- More work need to be done for the empowerment of consumers – give them more choices and use the marketplace more with vouchers, cash payments, etc., as well as provide solid consumer education.
- A better partnership with the union and the parents would have made a big difference with North Princeton.
- The community residences shouldn't be congregated in one area. The self-advocates didn't want any restrictions – they didn't want the government to have the power to decide where people lived. The state used geo-mapping with providers to promote the fullest integration.

## NEW MEXICO

**# State-Operated Institutions Remaining: 0**

**# State-Operated Institutions Closed: 2**

**Closed Since 1993: 2**

### **Service System:**

There are five regions in the state, each with a designated number of counties. Funds are available based upon legislative appropriation, and the state contracts directly with approximately 240 service providers throughout the state, who may opt to serve one or more counties. The Department of Health's Long Term Services Division serves all geographic areas, with the majority of its staff distributed in five regional offices outside the central Santa Fe base. The Division also operates the Los Lunas Community Program, which serves as a "safety net" of crisis intervention services and a direct service provider in two regions.

### **Alternative Use(s) for Closed Institution(s):**

- One is a drug and alcohol treatment center.
- The other houses offices for providers for individuals who have been transitioned into the community, with other space rented out to other agencies.

### **Institutional Closure Information:**

- Los Lunas closed in 1997, indirectly as a result of the *Jackson v. Fort Stanton* class action lawsuit, when, as a result of downsizing, it was no longer fiscally feasible to keep it open.
- One of problems with closure was lack of services. Service providers came in from out of state because there was no infrastructure to handle movement into the community. The length of time necessary to close an institution depended on the types of individuals involved and whether or not a provider was available to provide services to those individuals in the community.

### **Opposition:**

- There was significant opposition to the closure of the institution by parents or residents, unions, and the community where the institution was located.
- Parents used a University of California, Riverside, study (Strauss) that suggested that community living was more dangerous than institutions.
- The P&A sat on transition planning teams and sought to speak and encourage parents about transfer to community living. Arc also tried to work with parents to decrease opposition.
- Unions opposed closure. In some cases there were three generations of families who had been working at Los Lunas. To overcome employee opposition, some assurances were given and other state jobs opened up because of the need to implement and monitor deinstitutionalization.
- Many former state hospital employees were employed by community providers.

**Transition and Community Living:**

- In order to alleviate the problem of an insufficient number of providers, providers were encouraged to move in from out of state. Many of the mistakes that were made were due to attempts to move people quickly into the community with new and unproven providers.
- Efforts were made to give families at least two choices of providers, but there were often problems in the rural areas, where fewer providers were available.
- At present there is a waiting list for services (approximately 2,600). Decreasing the length of the waiting list is a major priority of the Department of Health.
- An individual seeking services first fills out an eligibility application at the Income Support Division office in the county where he or she desires to reside. If the person is deemed eligible after a subsequent interview, then he or she is placed on a central registry or a waiting list.
- Individuals are placed primarily in supported living environments (four or fewer individuals with up to 24-hour service) or in supervised living environments (individualized settings, which may vary from one to three people). In addition, there is home-based service for individuals who wish to be in a more family-like situation (which varies from one to three individuals in a private home and does not operate on a shift staff basis). The home-based service pays a companion, including family members, approximately \$2,100/month to care for the individual.

**Economics:**

- Most of the funding is provided by waivers (25/75 match).
- State General Funds are also utilized for other services to individuals not receiving waiver funding.

**Noteworthy:**

- The Department of Health has committed itself to creating a new self-directed DD waiver and is about to begin the design phase using money from the DD Planning Council.
- The Community Membership Program under Adult Services seeks to develop ties in the community and workplace skills so that individuals can be truly integrated. Community Membership is a first step toward the Supported Employment Services Option, in which the state subsidizes (for a limited period) the salary of individuals who are working either in individual supported employment (one-to-one ratio for coach/client), a group supported environment (more than one client per coach), or an intensive supported environment (for those with greater needs).

**Interviewee Reflections:**

- There needs to be more training of professional case managers and others involved in long-term care system.
- There were problems in determining what providers could actually accomplish. There should be more work done to ensure the quality of service providers.

## NEW YORK

**# State-Operated Institutions Remaining: 8**      **Approximate Census: 1,500**  
**# State-Operated Institutions Closed: 16**      **Closed Since 1993: 5**

### Service System:

- The Office of Mental Retardation and Developmental Disabilities (OMRDD) operates a central administrative office located in the state capital. The agency is responsible for planning services in cooperation with local governments and agencies, funding services, regulating services delivered by both state and private agencies, and being a direct provider of services.
- The OMRDD operates 13 regional Developmental Disabilities Services Offices (DDSOs). Each DDSO serves a geographic region of the state made up of one or more counties.
- In addition to providing direct services, the DDSOs also gives support and technical assistance to an extensive network of voluntary not-for-profit agencies that also provide services and supports to individuals with developmental disabilities. These voluntary agencies are authorized and certified by the state. (OMRDD: *Health Care Financing Administration Report*, NYS website)

### Alternative Use(s) for Closed Institution(s):

Some of the former state institutions are now being used in the following ways: corrections, state mental health and mental retardation offices, community college, ICFs-MR, private industry, and leased sites.

### Institutional Closure Information:

- In 1972, parents of people living at Willowbrook State School filed suit in federal court over the inhumane living conditions at the facility (*New York State Association for Retarded Children et al. and Parisi et al. v. Rockefeller*). The Willowbrook Consent Decree, signed in 1975, began the process of downsizing the school and developing the community services system for the “Willowbrook class” members. For the next eight years, Governor Carey extended similar benefits to all people living in institutions.
- Almost immediately after Willowbrook, funds were appropriated by the State Legislature for community development.
- The most recent closure is Letchworth Village Developmental Center, located within the region of the Hudson Valley DDSO. This closure was representative of New York administrative policy, which is to *downsize* the state institutions, until the closure becomes logical, and to develop community alternatives.
- The remaining state-operated facilities are serving special populations, e.g. individuals with significant behavioral issues, sex offenders, and/or those involved in the criminal justice system. These regional behavioral units are an important resource to the community, as they provide behavioral consultation to individuals in the community on a short-term basis.
- It takes approximately 18 to 24 months from announcing the closure to completion.

### **Opposition:**

- The unions have been opposed to downsizing and closures of institutions, and they have funded campaigns against deinstitutionalization. There is a commitment by the state to work with the unions. Task forces were formed involving all the stakeholders, so all parties felt committed to the same goal. As facilities were downsized, all union staff were guaranteed jobs. They were given choices, and it was done by employee seniority. Collective bargaining has helped to shape New York policy. The union “issue” was thwarted, as staff were placed in state-operated community residences.
- In the New York City region, 25% of the community residences are state-operated; 60% are state-operated in upstate New York.
- Historically, parents weren’t advocating for closure, but rather for downsizing the facilities and increasing alternatives in the community. Due to the quality of the current community system, there are few problems expressed by parents as a group. OMRDD has forged an active alliance with parents and consumers.

### **Transition and Community Living:**

- New York has a strong community-based system. Individuals who still reside in an institution generally fall into two categories: a small, growing population caught in the criminal justice system and individuals with significant behavioral problems. There is also a small group with serious health issues.
- Governor Pataki budgeted for 300 individuals to move from institutions to the community in 2003.
- The majority of homes are 8 to 12 beds (58%-60%), but no newly developed programs are this large. This size is declining in favor of one- to four-person residences.
- All ICFs-MR are not-for-profit and are regulated by the federal Medicaid program. In New York, an ICF-MR has, on average, a 10-bed capacity, but may have as many as 30 beds. Some ICFs-MR are being converted to waiver programs, which will allow the program to offer more choices and flexibility.
- Community Residences are single-family homes with up to 14 individuals and receive 24-hour supervision from staff. This option is less restrictive than the ICF-MR, and residents participate more in daily activities in the community.
- Supervised Apartments can accommodate up to four people. They are geared to individuals who are more independent. Supervision is provided on a 24-hour basis.
- Supportive Apartments are for individuals who require minimal staff assistance. Each apartment may accommodate one to four people. There is no overnight supervision, and staff support varies depending on an individual’s need.
- An Individualized Residential Alternative (IRA) is a home for 1 to 14 people that provides room, board, and individualized protective oversight.
- In Family Care, or Foster Care, providers who are homeowners receive a monthly stipend to provide services within their family home environment. District Offices administer and provide a technical assistance role to Family Care providers.
- Self-determination is playing a larger role in how placement is determined. The OMRDD sponsored a retreat with members of the NYS Self-Advocacy

Association to discuss how the two entities can work productively together. This self-advocacy association receives state funds and AmeriCorps grant funds. It provides support to 40-50 AmeriCorps self-advocates.

### **Economics:**

- The OMRDD is a computer-based, sophisticated system. Every person who registers in the state who needs services can be identified.
- Federal Medicaid dollars are maximized. The state gets \$3,000/day from Medicaid – \$750 comes from the state. Any additional funds are put into the MR/DD system. New York State currently operates the largest Home and Community-Based Services (HCBS) Federal Medicaid Waiver in the country. It runs eight separate HCBS Waiver programs.
- In 1998, Governor Pataki announced a comprehensive five-year plan to help eliminate the waiting list for residential services for people with developmental disabilities. This is called NYS CARES: Creating Alternatives in Residential Environments & Services and is primarily funded by the HCBS Waiver. The plan is slated to add nearly 4,900 new community-based beds and approximately 1,000 new day service opportunities. Annually, more than 1,600 individuals are to be offered an out-of-home placement in each of the five years.
- In August 2002, the state received federal approval for an amendment to its HCBS Waiver. The action authorizes \$135 million over the next three years to support the NYS CARES program and other initiatives.
- Governor Pataki has committed funding for a new 10-year residential program, called NYS CARES II, in the 2003-2004 budget. This is projected to provide 1,900 residential and 370 day service opportunities over the next decade. CARES II is addressing the needs of the 6,000 people on the waiting list for services.

### **Noteworthy:**

- The Division of Quality Assurance of the OMRDD is an independent division responsible for the survey and certification of community programs. There are 160 surveyors who make unannounced program/agency visits. They look at multiple issues, including consumer choice, abuse, inclusion, and programming. Each community program is visited at least once annually, but the number of visits will vary considerably if known problems exist. A standardized protocol is used to ensure compliance.
  - An “early alert” system warns every department in the OMRDD when an agency/program is experiencing a problem in a particular area. A weekly hot sheet is produced that lists the agencies, providers, or perhaps one program within an agency that is demonstrating difficulty in providing quality services. This sheet, shared with the P&A and the specific community agencies, facilitates communication and offers the ability to address problems from many different levels. An action plan is developed to help resolve the issue(s). If the agency cannot meet the established standards, OMRDD may take over the management and put out an RFP for another agency to operate the program effectively.

- There is a history of strong legislative support for the DD community system. In September 2002, the Most Integrated Setting Bill (S.7342) was signed into law by Governor Pataki. This bill establishes a council to develop a comprehensive statewide plan for providing supports and services in the most integrated setting to people with disabilities of all ages.
- The Parent to Parent of NYS program, funded by the OMRDD, puts parents in contact on a one-to-one basis with a trained supportive parent whose child has a similar or related disability.
- A Direct Care Worker Incentive Program, a “Master Worker” Demonstration Project, was submitted to the OMRDD by the NYS Association of Community and Residential Agencies (NYSACRA) and the John F. Kennedy, Jr. Institute for Worker Education at CUNY. Its objective is to link employee tenure, higher education, and competency requirements to a financial incentive for exemplary staff employed by participating OMRDD-funded nonprofit agencies.
- NYSACRA presented a study, *Serving Persons with Mental Retardation and Developmental Disabilities: The Impact of Residential and Community Facilities on the Local Economy* (1998) that emphasized local expenditures in several categories to show the positive impact community residences have on the local economy. Specifically, the study proved that the local economy was impacted by their providing jobs throughout municipalities and counties, and stimulating local commerce with a large infusion of state and federal dollars.

#### **Interviewee Reflections:**

- While the Willowbrook lawsuit played a major role in our current service delivery system, it was the separate OMRDD that truly has made the difference in New York. This state office is 100% involved with MR/DD issues 100% of the time. The creation of OMRDD has given New York State a leading role in services for people with MR/DD.
- Life for the individual with developmental disabilities is better today than in the '70s, but there are still challenges. Receiving adequate medical care is a concern, as group home staff doesn't always recognize the signs and symptoms of illness, and the community agency may not have a policy for dealing with illness. Many physicians are not trained for treating very impaired people.
- Direct care staff salaries are a big issue. There was a 10% increase last year and 9% this year. There is still a high turnover problem, but not as high this year because of the economy. State employees working in state-operated residences are still making 1½ to 2 times more than staff employed by a not-for-profit private vendor.

## NORTH CAROLINA

**# State-Operated Institutions Remaining: 5**      **Approximate Census: 1,900**

**# State-Operated Institutions Closed: 0**

### **Service System:**

- The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMH/DD/SAS), part of the North Carolina Department of Health and Human Services, is responsible for oversight of North Carolina's public service system provided through state facilities, 38 area programs, and a large number of contracted service providers.
- The 38 area programs are at the center of community-based delivery of services and supports. Services are provided directly, or the area program contracts to provide services. Area programs have specified geographical catchment areas that cover the state's 100 counties.
- Except for two counties, an Area Authority (generally a local political subdivision of the state) currently governs each area program. County commissioners appoint each Area Authorities' board members.

### **Institutional Closure Information:**

- There is no official closure plan for the five Mental Retardation Centers. They are certified as ICFs-MR level of care and primarily serve adults with severe and profound mental retardation, many of whom have significant physical disabilities and/or medical fragility. The MR Centers are reported to have greater expertise in supporting individuals with severe problems. The centers are the only places in the system that receive funding to provide intense supports or supervision.

### **Opposition:**

There is no organized effort to close any state-operated Mental Retardation Center. Generally, the parents/guardians of residents have been very opposed to closure discussion and are considered a "powerful" group.

### **Transition and Community Living:**

- It is more common for individuals with developmental disabilities in North Carolina to be residing in relatively large living arrangements than in other states. A higher proportion of people were served in large state-run facilities and ICF-MR group homes than in other states and a significantly lower proportion resided in residences of one to three people.
- There are 336 private ICFs-MR, of which 92% are six-bed homes.
- In 2000, the use of ICF-MR services was one-third higher than the national level.
- Dental services are difficult to obtain in the community. Some individuals with developmental disabilities return to the state-operated institution for this service.
- Individuals with severe and profound mental retardation are the most challenging populations to serve in the community.
- Individuals are unable to move about throughout the community due to the serious lack of transportation for work and recreational services.

- The Division of Facilities Services (DFS) has primary responsibility for overseeing DD facilities and agencies. In addition to initial licensure, the DFS conducts regular inspections of these facilities. It monitors for safety and is also supposed to monitor quality of care.

### **Economics:**

- Despite the reduction in the census at Mental Retardation Centers during the 1990s, the spending to support the centers (adjusted for inflation) was higher in 2000 than in 1990. Also, between 1990 and 2000, the center per-resident costs grew by almost 50% (after taking inflation into account).
- The Medicaid HCBS Waiver (CAP MR-DD) offers a broad array of services, including Adult Day Health programs, offering supports to seniors and those with medical needs who otherwise might not receive appropriate services through the traditional DD system.

### **Noteworthy:**

- In 1982, the *Thomas S.* class action lawsuit was filed against the state. The plaintiffs were individuals with mental retardation who, the Federal Court determined, were inappropriately placed in state-operated psychiatric hospitals. The Court ordered the state to develop “best practice” services and supports in the community. The Court dissolved the injunction in 1998; however, the state had served 1,166 individuals at an average cost in 1997-1998 of \$94,000 per person. Services and supports for the class members improved significantly, but this group was less than 1% of the individuals served by the system. (HSRI, 2001)
- In 2000, more North Carolinians with developmental disabilities were served in large state-run facilities than the nationwide norm. Relative to population, about 43% more individuals were served in the Mental Retardation Centers than in comparable centers nationwide. Additionally, the pace at which the state has been reducing the numbers of people served at its centers has been significantly slower than the rate of institutional census reduction nationwide. (HSRI, 2001)
- The “State Plan 2001: Blueprint for Change,” a legislative initiative, was developed to address the shortfalls of the current system in adequately addressing the needs of individuals with developmental disabilities and other disabilities. An overview:
  - This plan is being phased in over a five-year period and ensures ongoing consumer and family involvement and oversight.
  - Providing services to targeted populations with the most severe disabilities is the primary focus of the new system.
  - The plan calls for the use of a statewide system contractor to provide referral, crisis hotline services, and utilization management. It requires that a full array of services be available to people in all target populations, including housing options and employment opportunities.
  - Local business plans will be developed for each community and approved by county commissioners. They will be administered on the local level by local management entities (LMEs). The LME will develop, implement, oversee, monitor, and evaluate services in a specific region.

- North Carolina participates in the NASDDDS Core Indicators Project, the objective of which is to develop strategies for measuring service delivery system performance.

**Interviewee Reflections:**

- Waivers need to have more impact on community services. The waiver is “frozen,” and the state won’t put more funds into it. It is difficult to place people in the community without waivers.
- There’s no money – we need to put more pressure on policy makers, and we need to re-focus on getting people out of institutions.

## NORTH DAKOTA

**# State-Operated Institutions Remaining: 1**      **Approximate Census: 150**  
**# State-Operated Institutions Closed: 1**      **Closed Since 1993: 0**

### **Service System:**

North Dakota is a state-operated system. The Department of Human Services, Division of Developmental Disabilities, funds eight Regional Offices according to the number of consumers with developmental disabilities that reside in each region. Regional Offices contract with individual service providers to provide habilitation and vocational services.

### **Alternative Use(s) for Closed Institution(s):**

San Haven was located in an isolated geographic area of the state, on the grounds of a Native American Reservation. As soon as it became clear that the institution was closing, citizens formed a committee to find an alternative use for the facility. A textile company utilized the space after a building was renovated, but it has subsequently moved out.

### **Institutional Closure Information:**

- San Haven was closed in 1987 as a result of a class action lawsuit filed by the Arc of North Dakota in 1980, *Association for Retarded Citizens of North Dakota et al. v. State of North Dakota*. The court ruling in 1982 resulted in substantial court-ordered changes to the state's service system for people with developmental disabilities. The court order, implemented in 1984 with the assistance of a court monitor, issued monthly reports from the state. A partnership grew between the court monitor, the state, the Arc, and community service providers. The Arc was actively involved in insuring compliance with the order.
- The media followed the lawsuit. In fact, the lawsuit was the top news story for the state for two to three years. The news articles were never framed in terms of closure of all institutions. Rather, the press discussion was focused on improving services provided in the least restrictive appropriate environment and establishing a community service delivery system that would accommodate the people living at the institution who had been recommended for community placement.
- All the San Haven residents originally came from the Grafton State School (now called the Developmental Center at Grafton). Grafton still operates, with approximately 150 residents.

### **Opposition:**

- There was no organized resistance to closure.
- Parents and guardians of residents expressed mixed feelings regarding institutional closure, but strong vocal opposition was limited. Parents presented testimony in court and talked to the press.
- At the time, employees were not unionized, but there was a state employees association that was very concerned about the loss of their jobs. The employees generally understood, however, that their jobs were not more important than the rights of the people they served. Though there was never any formal agreement with employees, some staff moved from San Haven to Grafton State School to work or

followed the residents into the community (though most residents moved far from the isolated San Haven locale).

- The institution was the only major employer in San Haven, so the closure affected many citizens.

### **Transition and Community Living:**

- There was a lot of time spent on planning, e.g. on the needs of the individual residents, on geographic considerations. Individuals, their family members, and the institutional team jointly decided what community supports and services would be needed.
- The state approached local communities and issued a Request for Proposal if a community vendor needed to be recruited from a particular area. The community would establish the provider, as the community was invested in its success.
- All resident transition and placement plans encouraged multiple visits to the prospective community residence in an effort to address any objections and to ensure that the person's needs would be met.
- The vast majority of San Haven residents left the institution over a five-year period, 1982-1987.
- Group homes were newly constructed. Most of the residents moved to a group home setting for eight people. There were a significant number of high-functioning individuals at San Haven who moved to more independent Community-Supported Living Arrangements, where the supervision required was minimal. There were also Individual Supported Living Arrangements (ISLAs), which were staffed apartments with people who required more staff intervention. This is typically an individual living alone, but with 12- to 24-hour supervision.
- A service plan for each person was developed after he or she was placed in the community and was updated after placement. There was a bias against institutional assessments, and some providers took time to re-evaluate their residents.
- Social/recreational activities had been identified as a difficult service to fill in the community. Most of the San Haven residents had never been exposed to any recreation. Obtaining dental services remains difficult, as does securing behavioral intervention, especially in rural areas.
- People with maladaptive behaviors, e.g. sexual deviation, have been hard to serve in the community. People with such behaviors have been sent back to Grafton.
- There is a multilayered approach to monitoring services for quality of care. All programs are accredited and licensed (ICF-MR regulations); the Department of Health does an annual Title 19 survey; and the Accreditation Council does an accreditation for one to three years, depending on a percent of standards that are met. The state employs case managers who are required to meet with each consumer in his or her residence every 90 days to perform a Quality Assurance review. The Protection and Advocacy Project (P&A) also does periodic, random checks. The Arc completes consumer reviews and informs the P&A of the results.

### **Economics:**

- San Haven closed because of a court order – it would not have closed without a lawsuit. Economics may have been considered informally, but on paper it wasn't

playing a role. The cost per person comparison in North Dakota between institutional and community care was litigated. The state said that a comparison cannot be made and contended that the cost of care was equal. However, a typical ISLA contract was compared with the same services in the institution and was shown to be less costly. The court simply ruled that community care should not be more expensive than institutional care.

**Noteworthy:**

- The Arc of North Dakota contracted with David Braddock, executive director of the University of Colorado's Coleman Institute for Cognitive Disabilities, to conduct a statewide comprehensive update of the state's residential and community services. The most recent analysis reviews the structure, financing, and quality assurance of the state's DD services through fiscal year 2002. There were a number of negative findings in this report, including an indication that there has been an increase in institutional placements since 1995 and a slowed growth rate in the state's use of matching federal funds. (*Developmental Disabilities in North Dakota: The Year 2002 Report*)

**Interviewee Reflections:**

- Community integration should be planned for the future, more than for the present. We originally planned for group homes, but we would now like more ISLAs. It's hard to get them now because of budget constraints. Additional ISLA placements would assist in being more fully integrated. We invested too much in brick and mortar (a big mistake!). Invest more in services!
- The transitioning planning process went very well, given the complexity of moving so many people in a certain time frame.
- Resistance to integration is truly an educational issue. The more information there was, the less resistance we experienced.

## OHIO

**# State-Operated Institutions Remaining: 12**      **Approximate Census: 1,860**  
**# State-Operated Institutions Closed: 3**      **Closed Since 1993: 0**

### **Service System:**

- The Ohio Department of Mental Retardation and Developmental Disabilities (ODMR/DD) provides administrative oversight to county boards across the state that provide supports and services to individuals with disabilities living in the community.
- County boards of MR/DD are an integral part of the community service system. These boards are mandated by the legislation to plan for local services and to monitor the quality of those services, and they are funded, in large part, by local tax levies.
- Private organizations enter into contracts with county boards to provide residential services and supported living; however, both are regulated by ODMR/DD.

### **Alternative Use(s) for Closed Institution(s):**

Orient Developmental Center became a correctional facility; Cleveland Developmental Center was sold to the city of Cleveland, who transferred it to the Broadway Area Housing Coalition to be utilized for a housing complex; Broadview Developmental Center became administrative offices and a recreational center for the city of Broadview Heights.

### **Institutional Closure Information:**

- Three institutions have closed in Ohio. Orient Developmental Center closed in 1984. The state was under court order to eliminate overcrowding in prisons and wanted to use Orient for a correctional facility. Cleveland Developmental Center closed due to labor issues, certification problems, and a Department of Justice inquiry. Broadview Developmental Center, the most recent closure, could not maintain ICF/MR certification. Legislation was introduced to keep the center open for four years to obtain Medicaid certification.
- There were significant problems in the community when Orient Developmental Center closed – the closure happened quickly, with minimal planning and with little involvement at the local county level. Health and safety issues among some providers led to the director's resignation. A legislative oversight committee was formed as a result of some negative outcomes in the community.
- In the Broadview closure, the local County Board of MR/DD, Cuyahoga County, developed the community alternatives, and community outcomes were improved.

### **Opposition:**

- Some parents of individuals who live/lived in state-operated facilities are against state-operated facility closure. One group, the Ohio League, has been vocal and organized in its opposition.

- Employees of state-operated institutions are organized in unions, and they, too, have been vocal in their opposition to any closure.
- In the Broadview closure, parents were active stakeholders in a state-sponsored Oversight Committee, and they helped to establish the criteria for what was needed to support their son or daughter in the community.

### **Transition and Community Living:**

- The transition plans for residents of Broadview were highly individualized. The resident and his or her family/guardian were involved in the service plan development. The Cuyahoga County Board worked in conjunction with the staff at the institution. A resident or family member/guardian could refuse a prospective placement and request another one or have the option of transferring to another institution.
- After establishing the criteria for what was required to meet client needs, Broadview asked for a Request for Proposals from the community to develop services to meet specific needs.
- It took almost two years to move all residents to the community.
- A majority of the residents went to new eight-bed Intermediate Care Facilities that were created at that time. Another large number of residents went to congregate living dwellings, operated by community vendors, with six or fewer beds.
- Four areas identified as being the hardest services or needs to fill in the community are: 1) transportation – in addition, the providers complain that they don't receive adequate reimbursement for this service; 2) dental; 3) maintaining quality direct support staff; and 4) insufficient quantity of some specialty support staff, such as physical and occupational therapists.

### **Economics:**

- The state provides a subsidy to county boards that is based on the number of people enrolled in certain programs, such as adult habilitation, family support, and case management.
- Supported Living is funded by county dollars. Medicaid (mostly waivers) is federal and county or state match, depending on the circumstances

### **Noteworthy:**

- In 2001, the Ohio Office of Budget and Management submitted a report to Governor Taft, entitled *Ohio Access for People with Disabilities*. This report is an ambitious blueprint, that is, a plan to plan, for Ohio's future in addressing community-based supports for people with disabilities.
- In January 2003, Governor Taft proposed to gradually move people with mental retardation and developmental disabilities from institutions to community-based settings as one way to reduce the state's health care spending. In response to this proposal, the ODMR/DD states it has targeted two additional developmental centers (Springview and Apple Creek) for closure over the next two years (*Community Services Reporter*, Feb. 2003). The state legislature is considering, in three different bills, a requirement that closure decisions be recommended by a committee that would be established once the governor recommended closing

- state institutions. A bill containing this language has passed the Ohio Senate and is on the fast track in the Ohio House.
- Supported Living funding has been a major catalyst in changing the face of service delivery for individuals with disabilities in Ohio. Supported Living philosophy is to assist individuals with disabilities to live as independently as possible in their own communities with the supports that they choose. Since 1990, all state funding goes to the HCBS Waiver and Supported Living residences (no more than four people living together).
  - Ohio is among the states with the highest number of private ICFs-MR in the country (463), serving about 7,900 people.

**Interviewee Reflections:**

- Try to design a process that closely adheres to self-determination, i.e. driven by the individual and the people closest to him or her. Consistently and equitably establish the amount of money designated for each person.
- It's important to have the commitment and concept in place and then to figure out how to fund it. There is a need to maximize the federal dollars. Currently, the system is patchwork. Medicaid is redesigning the residential system.

## OKLAHOMA

**# State-Operated Institutions Remaining: 3\***      **Approximate Census: 400**

**# State-Operated Institutions Closed: 1**      **Closed Since 1993: 1**

\*One facility (Greer Center) continues to operate on the campus of another institution (Northern Oklahoma Resource Center), but services are out-sourced to a private provider.

### **Service System:**

The Developmental Disabilities Services Division (DDSD) provides direction, support, and funding to three area offices. The area office provides case management, service coordination, monitoring, service provider recruitment, and resource development.

### **Alternative Use(s) for Closed Institution(s):**

Corrections and educational services are utilizing the former Hissom Center.

### **Institutional Closure Information:**

- Hissom Memorial Center closed in 1994. Six parents of residents sued the institution in the *Homeward Bound v. Hissom Memorial Center* class action lawsuit in 1985, which compelled the state to create community-based alternatives to Hissom. The federal court order in 1988 required the institution to close. A court monitor was originally appointed, but was replaced by a three-person review panel in 1990, the same year as the consent decree. Only one member is currently serving on the panel.
- No additional public facilities may close without legislative approval.

### **Opposition:**

- There were a larger number of parents/guardians of residents against the closure of Hissom than those who had filed the lawsuit; however, this group was not organized enough to present a strong opposition.
- A State Employees Association tried to obtain assistance from the Legislature, but the association does not have the strength of unions that exist in some other states. They were opposed, but not strongly organized. Hissom was located near Tulsa, so employment was not the issue it may have been if it was located in a rural area. The Department of Human Services provided training and priority re-hiring. Very few employees transferred to other institutions or to community-based programs.
- Initially, the Tulsa media was very negative about the closure, but over time they changed their views. DDSD worked collaboratively with the Tulsa Community Services Council to educate the community and to break down barriers.

### **Transition and Community Living:**

- Every resident was assigned a case manager, who began the process of developing a plan that identified the resident's needs in the community and a community provider.
- Staff tried to return residents to their home communities.
- A primary physician and hospital also had to be identified prior to leaving the institution.

- A transition packet was then sent to the review panel, who insured that safeguards were in place.
- The review panel made recommendations and forwarded them to the judge.
- Currently, the area manager has to sign off on the Transition Plan, using these same criteria.
- Every Hissom resident moved to the community, either to a group home with six people, one's own home/apartment with staff, or a home with two to three people and staff.
- Initially DDSR rented apartments and paid the provider rate to staff. This eventually changed to a room-and-board supplement. Delays in the approval process complicated the acquisition and training of staff, and frequently slowed down the transition process.
- It was forbidden to move a Hissom resident to another state-operated facility.
- Parents and guardians were able to interview providers. Depending on where a resident wanted to live, there was a broad choice of providers available.
- Individuals with challenging behaviors have been the most difficult to serve in the community. For this reason, DDSR has contracted with a private provider for 24-hour behavioral support.

#### **Economics:**

- DDSR services are funded through Medicaid HCBS Waivers and through state funds.
- It was a requirement of the consent decree that services in the community must not exceed the aggregate cost of the institution.
- Generally, the state is saving money by serving individuals in the community. Out of 3,000 people placed in the community, only 700 service plans cost more than institutional living. The high cost of these plans is driven by staffing needs.

#### **Noteworthy:**

- There is an extensive Quality Assurance program in Oklahoma.
- The consent decree included a provision to create an outcome-oriented monitoring system. James Conroy, Ph.D., of the Center for Outcome Analysis, has provided reports over a 10-year period to evaluate whether peoples' lives improved living in the community. The reports focus on one question: "Are the people who once lived at Hissom Memorial Center (and other institutions) better off now than they would have been had they remained at Hissom?" The database, composed of objective, reliable measures of several factors related to quality of life, looks for changes in adaptive behaviors. Overall, results indicate "strong positive" quality changes in most Life Areas and show that the great majority of Class Members are better off living in the community. "Nearly all of the Class Members are living in regular homes, in regular neighborhoods, with 24-hour support, with no more than two roommates....They now have a chance to live with a level of quality that was hardly imagined when the lawsuit began." Every Class Member and service system is visited every year. (*A Decade of Change: The Oklahoma Quality Tracking Project, 1990-2000*, Conroy & Fullerton, 2002)

- The Oklahoma Department of Human Services contracted with the Tulsa ARC to establish and operate a monitoring program, called Oklahoma Advocates Involved with Monitoring (OK AIM). This group includes people with disabilities and their family members. They visit 1500 to 1700 people annually and randomly do a person-centered evaluation. These advocates meet with state officials on a quarterly basis.
- The Oklahoma Developmental Disabilities Council funded a project that elicited personal stories of 22 individuals with developmental disabilities who once lived in state-operated institutions and now reside in the community. They were asked questions related to five areas of their lives: home, employment, relationships, community, and dignity and attitudes. Through these life stories, the reader “can see the realities of life in institutions and the necessity – as well as the feasibility – of moving people from such segregated settings into the freedom of community life.” (Hayden, 1997) *Living in the Freedom World: Personal Stories of Living in the Community by People Who Once Lived in Oklahoma’s Institutions* is available in booklet form and in video.
- Oklahoma participates in the National CORE Indicators (NCI) study that assesses performance and outcome indicators for state developmental disability service systems.

**Interviewee Reflections:**

- Lawsuits can increase the complexity of doing things – it can’t help but become adversarial.
- Don’t get in a residential service system that’s difficult to maintain. Make it a reasonable system for everybody.
- Invest in behavioral support!

## OREGON

**# State-Operated Institutions Remaining: 1**      **Approximate Census: 45**  
**# State-Operated Institutions Closed: 2**      **Closed Since 1993: 1**

### **Service System:**

The Department of Human Services, Office of Developmental Disability Services (ODDS), funds services through the Oregon county system. The county contracts with local service providers, and the state also contracts directly for some services.

### **Alternative Use(s) for Closed Institution(s):**

Investors have bought the land that will most likely be developed for mixed use, including light industry, housing, and education. Legislation was developed that requires any profits made from the sale of the Fairview property go back into the developmental disabilities system.

### **Institutional Closure Information:**

- Beginning in the early 1980s, there was a combination of state policy and outside forces that ultimately contributed to the closure of the Fairview Training Center. First, in 1981, legislation was passed that enabled ODDS to plan and facilitate community services, and it obligated the state to move people out of institutions during every budget cycle, which is two years. Second, the Centers for Medicaid and Medicare Services (CMS) decertified Fairview in 1985 and 1987, citing poor living conditions. Lastly, the U.S. Department of Justice sued the State of Oregon (1985-1993), from which a consent decree was entered.
- During this period, there were no children admitted to Fairview, and residents with the *most* challenging behaviors were moved to the community.
- In 1995, there was a supplement added to the consent decree that required a plan for closure, and in 1997, the Legislature approved this plan. The Legislature approved the necessary additional appropriations for closure in 1999.
- Another factor that had a significant impact on community inclusion for people with developmental disabilities at this same time period was the settlement agreement from the lawsuit *Staley v. Kitzhaber*, filed against the State of Oregon in 2000.
- This lawsuit was intended to eliminate or greatly reduce the number of people waiting for services by increasing the availability of comprehensive services in the community. In summary, it alleged that the state had failed to provide services in the most integrated setting for adults who were eligible for placement in an ICF-MR under the state Medicaid plan.
- The settlement agreement implements Oregon's Universal Access Plan, which aims to ensure that all individuals who need publicly funded services will receive at least a basic level of supports. To implement this plan under the settlement, the state expanded the waiver to unserved individuals – albeit a different service model using brokered services with a capped rate.
- The decision to close Fairview was also, in part, a financial issue – the cost of keeping Fairview operational was very expensive.

- A Quality Assurance Task Force, convened by the Oregon Council on Developmental Disabilities, met monthly from 1995 to 2000 to address the Fairview downsizing/closure and issues pertaining to the community service delivery system. This group consisted of representatives from ODDS, the Arc, the Oregon Advocacy Center, community service providers, self-advocates, labor, and the parent organization. During these meetings, the ODDS methodically reviewed every issue. This was documented by ODDS so that it could demonstrate that it was responding to issues that had been publicly identified. Consensus, however, was still not reached.

### **Opposition:**

- There was significant organized opposition to closure by the Fairview Parent Association, Voice of the Retarded, and the state employee unions.
- Resistance from the parents/guardians came largely out of fear of the unknown, i.e. community living for their son/daughter.
- The parent groups aligned with the union and went to the legislators and to the press.
- The parents were invited to the planning and negotiation table at all times.
- One strategy utilized to overcome parent group opposition was to develop success stories from parents who accepted placement first. However, certain parents stood firm in their opposition, and their son or daughter was placed in the final closure phase.
- The unions were not eager to give up excellent salaries, benefits, and retirement plans. They were engaged in discussions about closure before there was a decision to close the institution.
- A Labor Sub-Group was formed that addressed what the institution would do to help employees find jobs elsewhere. This assistance included the Department of Labor setting up an employment office at Fairview; the Governor directing other state agencies to prioritize employees for other state positions, especially in corrections; and retraining for other state positions.
- The unions never agreed to the closure but stated that if closure was inevitable, then certain conditions should be put in place.
- In the end, the state cut a deal for 500 state employees to work in state-operated community residences, carrying their state employee contract out of the institution into the community. Less than 100 staff were laid off.

### **Transition and Community Living:**

- It took four years to move residents out of Fairview after the decision was made to close the facility. However, closure occurred ahead of schedule by six months.
- All planning was based on individual “person-centered plans.” The family/guardian of the individual was recognized as a key decision maker in the transition planning process and was supposed to be involved in the plan at all stages of development.
- Each resident had an Individual Transition Plan that addressed a wide range of factors. ODDS developed a Transition Manual that outlines critical elements and provides an example of transition plans for two very different individuals.

- Fairview created Development Teams who had small caseloads and whose job it was to develop the transition plan and follow the residents into the community.
- The state hired individuals from the People First organization (which originated in Oregon) to set up an office at Fairview. They counseled residents who were in transition from Fairview to the community. This was a Peer Mentoring project administered by The Council on Developmental Disabilities.
- Three months prior to discharge, every person leaving Fairview was assigned a case manager from the County Developmental Disability Program. The case manager followed the individual for one to two years, visiting on a monthly basis in the home and at the employment site.
- Sixty of the 300 residents from Fairview originally went into state-operated community residences, with three to five residents in each home. There were two types of homes: those for medically fragile individuals and those for people with significant behavior issues. Presently 145 people are served in state-operated homes, out of 4,500 served in the system.
- Most of the other residents moved to some community-supported living arrangement or group home in which five or fewer people resided. Additionally, a number of Fairview residents moved to foster care settings where a former Fairview state employee was the primary care-giver. No residents moved to a nursing home or a private ICF-MR.
- At the neighborhood level there was resistance to Fairview residents moving there, especially sex offenders. A great deal of work was done with neighborhood associations to address issues of safety, staffing, etc. At the same time, the Attorney General was concerned and cautious about discrimination and the Fair Housing Act.

#### **Economics:**

- Fairview became the most expensive institution in the nation to operate because of the conditions set forth in the consent decree.
- Savings from the closure were re-invested in the community service system, including the waitlist. A Fairview Dividend contributed to a brokerage system with a capped benefit package and to raises given to direct care workers.
- It was not argued that the community is cheaper and that there would be a great deal of extra money, but rather that more people could be served if Fairview closed.

#### **Noteworthy:**

- In 1989, ODDS set up a network of community crisis homes. The state was divided into six regions, with 15 to 20 beds in each region. The crisis bed environments are similar to specialized foster homes. Crisis Team staff also support local providers to help a resident remain in his or her home. The three staff per region include one medical specialist and one behavioral specialist.
- Oregon has an improved data system that shows state resident profiles. These profiles can be compared with those of individuals who have never been institutionalized. Overall, the data documents that the institutional resident is not more disabled than the noninstitutionalized individual.

- There is a designated Quality Assurance presence in every county. QA staff lead the SERT Team (Serious Events Review Team), which documents data about abuse and deaths.

**Interviewee Reflections:**

- Don't freeze out any players.
- If you want to be successful, you can't force things to happen faster than they can – you're dealing with real people's lives, histories, interest groups, and economic groups. I would maintain an ideological goal with practicality.
- The level of diplomacy and sensitivity to the various groups was very high. Most importantly, all throughout the process we talked about quality – that we're going to pay attention to the community.
- Addressing community capacity and overcoming neighborhood resistance was a challenging part of the process.

## PENNSYLVANIA

**# State-Operated Institutions Remaining: 6**      **Approximate Census: 1,590**

**# State-Operated Institutions Closed: 17\***      **Closed Since 1993: 6**

\* including MR/DD units in state-operated psychiatric facilities

### **Service System:**

The Office of Mental Retardation (OMR) supports a comprehensive array of residential and day support services and supports in the community for people with disabilities, which are either administered by or, in a few cases, operated by county MH/MR programs; contracted private residential intermediate care facilities for people with mental retardation (ICFs-MR) services, or services in state centers. The mental retardation system is funded through federal, state and county funds.

### **Alternative Use(s) for Closed Institution(s):**

Uses include a corrections facility; a veterans' medical center; a private institution; private industry, and a mental health facility. Some institutional land/buildings remain vacant or it is undetermined how the land is being used.

### **Institutional Closure Information:**

- Mayview, an MR/DD unit in a psychiatric facility, was closed in 2001. An announcement about the closure was made one week in advance. It closed due to fiscal considerations and, in part, to OMR's philosophy of moving away from large, congregate settings.
- The second most recent closure in the state was the Western Center, a state-operated facility for persons with DD/MR, in 2000. Western Center closed due to the Settlement Agreement in 1992 related to the class action lawsuit, *Richard C. v. Houstoun*.
- A 1998 law requires that a public hearing be held when a state institution for MR/DD people loses 20% of its population.

### **Opposition:**

- The Western Center's Parents Group voiced very strong opposition to the Western Center closure.
- Informing the media and lobbying legislators were used to counteract closure. In addition, the parent group requested that the Auditor General perform an audit of the costs related to institution versus community services.
- In 1998, a few family members who had long opposed the settlement agreement and the closure sought to intervene by asserting the Olmstead decision in their own lawsuit. However, the family members' motion to intervene was denied.
- There was still considerable parent opposition in the final days of the Western Center closure. State police assisted in moving residents out.

- There were no formal agreements with employees at the Western Center. People “bumped” other state employees who had less seniority, and for the most part, were able to transfer to other state jobs.

### **Transition and Community Living:**

- Each person residing in a state Developmental Center has an individual planning team that includes the person, family, and state and county mental retardation professionals. The team shares the responsibility for evaluating information, determining the person’s needs, and making decisions. The county MH/MR program is responsible for taking the lead in developing the Individualized Support Plan, which highlights the services that the county will arrange for and supervise when the individual moves to the community. Once the community service provider is selected, the provider agency participates on the transition team under the direction of the county case manager. The individual is able to make trial visits to the community residence prior to discharge, and the individual and family have regular contact with the county case manager.
- The state used person-centered planning, and residents had a choice of community providers. There is a Medicaid beneficiary choice process – the individual must choose between the community and ICF-MR services.
- It took approximately 18 months for residents to move out of Western Center after the decision was made to close it.
- The vast majority of the Western Center residents have moved to community-supported living arrangements, with varying staffing levels, and to staffed group homes with three beds or less. Some moved to private ICFs-MR or to other state-operated facilities.
- Pennsylvania has over 100 private ICFs-MR. Most of these residences are 16 beds or fewer, several are more than 60 beds, one is more than 125 beds, and one is more than 300. The residents of the private ICFs-MR are 40% children. There are no children living in public state-operated institutions.
- Individuals with a dual diagnosis of MH/DD, complex medical needs, and intense behavioral needs are the most difficult to service in the community, and dental services and psychiatric services were identified as the most difficult services to fill.

### **Economics:**

- State funds and Medicaid waivers are the funding sources for financing the community service system.
- Waivers are the primary funding source for mental retardation supports and services. Pennsylvania generally has a 50/50 split of federal and state funds.

### **Noteworthy:**

- In 1997, a *Multi-Year Plan for Pennsylvania’s Mental Retardation Service System* was developed by a Planning Advisory Committee consisting of representatives from numerous constituencies, from people with disabilities to state policy makers and legislative staff. This plan was finalized with recommendations for system reform after it was discussed at public forums throughout the state and

verbal and written comments were incorporated into the final document. One of the recommendations requires the state to place a specific number of people into the community per year from a state-operated facility. Though there has been ongoing downsizing of state facilities, the goals set for community placement were not met due to the lack of community capacity. The goals set forth in this plan will be met in seven years from the onset, rather than in five years as originally planned.

- The Office of Mental Retardation's philosophy is documented in *Everyday Lives: Making it Happen* (2001) and provides the conceptual framework for the Multi-Year Plan. This booklet highlights the concept of self-determination and people having a life that is typical of the general population. It focuses on all areas of daily living in the community that normally impact a person's life and the status of these services for people with disabilities in Pennsylvania.
- Every county (46) has an Independent Monitoring Program that participates in the state's Independent Monitoring for Quality (IM4Q) program, part of an emerging quality management framework within the mental retardation system. The IM4Q instrument was developed from a recommendation in the Multi-Year Plan. Teams use IM4Q to interview individuals receiving services and their families about the quality of services in the context of their daily lives. Independent monitoring teams consist of people with disabilities, their family members, and other concerned citizens who are independent of the services they are reviewing. The teams are trained and supported from funding available under contract with the County Mental Health and Mental Retardation Programs. (*Report of Independent Monitoring for Quality in the PA MR System, 2002*)
- OMR contracts with the Pennsylvania P&A to provide direct advocacy in the state-operated Developmental Centers. The P&A also monitors residents after they are discharged from the institution.
- The Home and Community Services Information Systems (HCSIS) has been developed for OMR, to support the changes in business activities that are performed by counties and the reporting requirements needed by the state. It is expected that the HCSIS system will enable OMR to improve an array of activities related broadly to Quality Management, Consumers, and Finances by automating the collection and storage of information.

#### **Interviewee Reflections:**

- It's essential to build coalitions with all involved stakeholders. Hundreds of people now have better lives in the community because of litigation, though it did have the effect of polarizing stakeholders. The litigation caused heartache and sorrow for the Western Center families – but the conditions there were deplorable.
- If you don't have the same people in the DD state agency in place, it's difficult to make progress. Constancy enables you to forge relationships...turnover can be very disruptive.
- Medicaid is good, but it comes with strings attached. There are clear Medicaid requirements, and you need to have an infrastructure that includes quality and monitoring functions. If the waiver match is not 85%, there's work to be done [this is in reference to an estimate of how much of a state's program can be

funded through Medicaid, maximizing federal earnings]. Some people do not require services every month, and for those whose needs are minimal, enrollment in the waiver program can bring more administrative activity than the amount of service the person might get.

- Questions that should be considered: What does the state's program look like? How is it structured to proactively deal with problems? How much is it connected to outcomes? If you structure without heart and momentum, it's useless.

## RHODE ISLAND

**# State-Operated Institutions Remaining: 0**

**# State-Operated Institutions Closed: 1**

**Closed Since 1993: 1**

### **Service System:**

The Division of Developmental Disabilities (DDD), within the Department of Mental Health, Retardation and Hospitals (DMHRH), is responsible for planning, providing, and administering supports for adults with developmental disabilities in Rhode Island.

### **Alternative Use(s) for Closed Institution(s):**

Some of the buildings of the former institution are occupied by a group home and a residential substance abuse/detoxification center, including a small transitional program for women with substance abuse issues.

### **Institutional Closure Information:**

Ladd Center closed in 1994. The downsizing and eventual closing of this state facility occurred in increments. The consent decree and order (1982), from the class action litigation *Iasimone et al. v. Garrahy et al.*, spelled out the details of this process and stimulated institutional reform and community development. It took 12 years to finally close. There were four court monitors appointed to oversee the transition and placement of Ladd class members.

### **Opposition:**

- The AFSCME union was very opposed to the closure, as they didn't want to lose jobs. The union assessed the situation and worked out a deal politically on the inside. A no-layoff contract was signed in the early 1980s. In the end, the union was not a major issue in the closure discussion – they received a generous contract early in the process. State employees followed residents into the community in the state-operated group homes.
- There was no formal parent/guardian organization, though there were a few strong voices in opposition to the closure. The Arc worked to convince parents that closure was important.
- The media played a critical role in the Ladd closure by doing an investigative story in 1977 that lasted six months. This story, along with editorials, highlighted the poor living conditions at Ladd, and the public was outraged by these press reports.

### **Transition and Community Living:**

- A set of group homes was built for most of the 290 residents left at Ladd when the closure was announced in 1986. In the late 1980s and early 1990s the state erected 35 six-person group homes. This expanded to supervised apartment settings. Many of the homes were built in isolated areas, and placement had little to do with the needs of the individual.
- There were three 15-bed special care facilities for people who were medically fragile.

- The last 100 people to leave Ladd had different levels of abilities. There were some instances of inappropriate matches of people in a community residence and untrained staff that had previously worked at Ladd. The transition was not ideal, but for the most part, people moved with residents and staff they knew.
- Residents were not offered choices in community services and supports.
- A court monitor has to approve every plan that involves a class member moving to another residence.
- The consent decree states that class members must have annual assessments by way of an Individualized Service Plan.
- The state office of Quality Assurance investigates abuse and neglect, and licenses community residences. Concerned that there is a lack of quality oversight, the Rhode Island Disability Law Center (Rhode Island P&A) would like to impact the way the services in the community are monitored.

#### **Economics:**

- The state had to improve conditions at Ladd as the institution began to downsize, before closure could occur.
- There was not a lot of money saved when Ladd closed, due to the expensive union contracts that were created.
- The Medicaid waiver has had a very significant impact in closing Ladd and increasing community services.

#### **Noteworthy:**

- The one state-operated institution for people with developmental disabilities was closed in 1994; however, there are individuals with developmental disabilities residing in other institutional facilities, such as state psychiatric and long-term facilities. The Rhode Island Disability Law Center filed a class action lawsuit, *T.L. et al. v. R.I. Dept. of MHRH et al.*, (pending) against DMHRH and DDD about eligibility for DD services and alleges a lack of procedural due process and discrimination against individuals with mental illness. The lawsuit claims that individuals whose primary diagnosis is mental illness and/or whose mental illness is their developmental disability are being denied eligibility for services with DDD.
- The Rhode Island CHOICES program (Citizenship, Health, Opportunities, Interdependence, Choices, Environments, Supports) uses an integrated health/medical (acute care) and community supports (long-term care) approach to providing home and community-based services. CHOICES uses principles of managed care to give adults with developmental disabilities a greater role in designing and purchasing health and community support services.
- Rhode Island participates in the NASDDDS-sponsored National Core Indicators (NCI) study that assesses performance and outcome indicators for state developmental disabilities service systems.

#### **Interviewee Reflections:**

- Medicaid waivers have had a big impact on community services, but it could be bigger. The DDD doesn't do as well with waivers as the mental health side.

- “Group home” doesn’t mean that people are integrated into the community.
- People need something meaningful to do – knowing staff and peers is not enough.
- All the stakeholders need to talk early in the process. You may need to give the union a piece of the action.
- Institutions are OK as long as they’re in the process of closing.

## SOUTH CAROLINA

**# State-Operated Institutions Remaining: 5**

**Approximate Census: 1,100**

**# State-Operated Institutions Closed: 0**

### **Service System:**

- The Department of Disabilities and Special Needs (DDSN) is the state agency that plans, develops, coordinates, and funds services for those with mental disabilities.
- A seven-member commission appointed by the Governor and representing each of the state's six Congressional districts and one at-large member governs DDSN. The State Director (appointed by the Commission) has jurisdiction over the central administrative office, five regional centers, and all services provided through contracts with local agencies.
- Most of these local agencies are called Disabilities and Special Needs (DSN) Boards, and they serve every county. Through a contract with DDSN, each board operates a service coordination program employing service coordinators who conduct an evaluation and planning process to determine if a person is eligible for services, and, if so, who works with the person and/or the family and others to select a plan facilitator, if desired, to identify needs, and to develop, implement, and monitor a plan of services. DDSN is responsible for promoting and coordinating other state agency efforts, and local DSN Boards are responsible for developing and coordinating services and funds from local agencies and governments. Most local DSN Boards deliver services directly, but some arrange for a specific service to be delivered by other community organizations.
- The community system is county-based. There are 46 counties with 39 county boards that serve as financial agents and provide services.

### **Institutional Closure Information:**

- The senior management of DDSN is committed to providing parents and consumers with options, including Regional Centers and the community. Regional Centers will continue to exist as long as parents and consumers choose that option. There is a continuum of residential options with enabling legislation that focuses on community integration.
- During the past five years, there has been a 50% reduction in the institutional population.
- Occasionally, a building on the grounds of a Regional Center is closed.
- The one large ICF-MR run by the private nonprofit Babcock Center was closed and those individuals placed in two- to three-bed homes. Babcock still provides residential services to a large number of clients.
- The P&A aims to advocate for consumers' choice of residence and services, to improve conditions in both institutions and the community, and to decrease the number of those living in institutions.

### **Opposition:**

- Each of the Regional Centers has an active group of parents who work closely with the local legislative delegation. Parents do honor peers who seek to have

children leave institutions, something that more parents are considering as the community system continues to grow.

- Parents who are willing to take their children out of institutions are assured that their children will have a bed reserved for them in the institution for at least 90 days after leaving. From one perspective, this calms the parents' fears that their child might not be able to live in the community. From another, it increases the risk that the child will be reinstitutionalized.
- There is also opposition from some staff at the DDSN centers and the DSN Boards, who are less supportive of community living options and often steer clients into institutional settings.

### **Transition and Community Living:**

- In 2001, the State's Home and Community Based Services Task Force submitted to the Governor its status report with recommendations on Olmstead compliance.
- There is a video being made about choices in the community for consumers and parents.
- Parents and consumers in the institutions are regularly asked to consider going into the community. Once the choice is made to leave an institution, a person-centered approach (adopted by the DDSN and DSN in 1998) is used to develop a transition plan to identify needs, preferences, interests, and goals, as well as the services and resources necessary for their realization. Overnight visits into the community are encouraged to assess various community agencies that can serve the individual.
- Funds follow individuals into the community so that parents have opportunities to develop community options.
- Directed by a state law, the DSN Boards' contracts with private agencies specify that direct care professionals in the community must receive the same salaries and most of the same benefits as state employees.
- There is a need for improvement in the crisis intervention program.
- Dually diagnosed individuals have been the most difficult to serve.
- There is a problem of isolation, particularly in rural areas, where sometimes insufficient or unmotivated staff does not provide clients with more integrated activities in the community.
- The goal is for community placement to be determined by the individual, together with his or her circle of support. A facilitator, who may be either a private professional or an employee of the local DSN Board, guides this process. In the latter case, one problem identified was the service coordinators' control in directing the family to a relatively narrow list of choices that correspond to the services offered by the DSN Board, often the exclusive provider of services in the county.
- There is a system of monitoring and assessment conducted by the DDSN's Division on Quality Assurance and Improvement. Last year, consumer satisfaction surveys were conducted by the HSRI. In addition, the Council on Quality and Leadership has been administering monthly personal outcome measures and interviews with consumers.

**Economics:**

- Medicaid waivers helped to drive community-based programs. Although there is a desire to expand Medicaid and provide greater flexibility, limits on state funding, combined with political pressure from groups such as the nursing home lobby, restrict expansion of the Medicaid program.

**Noteworthy:**

- Quality Assurance efforts present a model program for improving assessment and monitoring techniques for those living in the community.
- Problems at Babcock Center related to Medicaid fraud and allegations of abuse and neglect have been reported in state newspapers. In March 2003, an incident now under investigation was also reported in which a resident of a Babcock facility suffered second- and third-degree burns on his head, face, and body.

**Interviewee Reflections:**

- Regional and local autonomy, while efficient, can sometimes lead to a lack of statewide consistency, as some localities may refuse to provide recommended services.
- Money is not the only barrier to building a community-based program. Many things could be accomplished in a budget-neutral fashion if the state had the will to do so. Allowing institutional money to follow individuals into the community costs nothing and would help many people live on their own.

## SOUTH DAKOTA

**# State-Operated Institutions Remaining: 1**      **Approximate Census: 190**  
**# State-Operated Institutions Closed: 1**      **Closed Since 1993: 1**

### **Service System:**

The Division of Developmental Disabilities (DDD) funds 17 nonprofit community agencies, known as Adjustment Training Centers, to provide a variety of services to over 2,000 individuals.

### **Alternative Use(s) for Closed Institution(s):**

Juvenile corrections boot camp

### **Institutional Closure Information:**

- Custer closed in 1996 due to fiscal issues. It serviced individuals who had the most severe disabilities and required total care.
- The Governor had to take a role in the closure. He participated in a town meeting with the residents of the local community. The closure became very political between the two major parties but had little to do with closing Custer.
- Prior to leaving Custer, physically challenged residents worked toward gaining mobility. Residents moved into the community or to another state-operated facility.
- The remaining institution, Redfield, continues to serve residents with significant behavior problems.

### **Opposition:**

- There was no organized opposition to the Custer closure.
- Some local area residents were concerned about continued employment. There is a State Employees Association, but it is not unionized. There were no overt agreements made with employees, though they were given priority for state jobs at other public facilities. Some employees followed residents out to community-based programs (community and state wages are similar) and others were laid off.
- Opposition by parents/guardians of residents was individual and sporadic. Five or six parents were vocal with their concerns and asked why the closure couldn't happen by attrition. They lobbied legislators, who held several evening meetings with them. Within the first few months after community placement, however, parents who opposed the community placement saw that family members were receiving quality services.

### **Transition/Community Living:**

- In preparation for the closure, the state DDD met with community programs across the state to ask their interest in serving Custer residents. The facility director at Custer also helped to locate community-based placements. Some "deals" were made with providers.
- Many of the Custer residents had severe cognitive disabilities. South Dakota is a large rural state, so there was not a plethora of choices in community services and supports.
- Parents visited prospective community programs; residents had pre-placement visits.

- Most of the Custer residents moved to group homes with a maximum of eight residents. Others moved to an ICF-MR (now decertified and closed), supervised apartment settings, foster care, or home with parents.
- An Individual Service Plan that covered a range of activities in the community was developed for every resident.
- Behavioral issues and the needs of individuals with a dual diagnosis of MI/DD and those with traumatic brain injury are the most difficult to address in the community.

#### **Economics:**

- The argument for closing Custer was that care would be provided for less money in the community but would also meet the person's needs. Custer was a large institution with very old buildings, so the inability to adequately maintain them was part of the economic discussion.
- The funding sources for financing the community service system are primarily Title XIX/Medicaid and the state dollars for the federal match and for services that don't qualify for Medicaid. The Medicaid HCBS Waiver program, available since 1981 in South Dakota, provides funding for case management, training and rehabilitation services, prevocational training, and supported employment.
- Community Training Services (CTS) is the only funding source available for services that is strictly from state general funds. It is a flexible funding program that is typically utilized for individuals who need less intensive services or who do not meet the financial eligibility for HCBS-funded services.

#### **Noteworthy:**

- The DDD is responsible for providing Quality Assurance to the 17 Adjustment Training Centers. These agencies remain certified by undergoing review activities conducted by the DDD, including Life Quality Reviews and Administrative Rules of South Dakota Reviews.
  - The Life Quality Certification Review tool has 25 outcomes grouped according to six categories that are measured on an individual basis for each consumer determined through a random pick. The categories include Choice (daily routines); Relationships (friendships and community experiences); Lifestyle (independence and productivity); Health and Well-Being (obtaining health care and personal safety); Rights (exercising rights and responsibilities, having an advocate, being treated with dignity); and Satisfaction (overall happiness with services and supports).

#### **Interviewee Reflections:**

- There clearly need to be more economic incentives for agencies to be more involved in community integration (not a carrot-and-stick approach). There is not true integration. The agencies really need to think about individuality and integration issues so that people have a meaningful chance to interact with other people in the community, rather than just with staff. Today, parents who use the Adjustment Training Centers want their son or daughter living in the community.

- Try to avoid politicizing institutional closure. Spend enough time working with local legislators to avoid problems. Work closer with the Governor. Closure shouldn't have been tied to creating a correctional facility, as it confused issues.
- We have no unhappy parents out there today.

## TENNESSEE

**# State-Operated Institutions Remaining: 3**      **Approximate Census: 770**  
**# State-Operated Institutions Closed: 1**      **Closed Since 1993: 1**

### **Service System:**

The Tennessee Division of Mental Retardation Services (DMRS) allocates money to three Regional Offices. The Regional Offices and DMRS Central Office oversee the delivery of home and community-based services.

### **Alternative Use(s) for Closed Institution(s):**

Unknown

### **Institutional Closure Information:**

- The most recent closure is Nat T. Winston Developmental Center in 1998. Winston, a relatively small unit in a rural area, served individuals who had a dual diagnosis of mental illness and developmental disability. The Governor was ordered to close Winston by the court.
- Arlington Developmental Center was scheduled to close in 2003-04, but the judge rejected a Tennessee state plan, citing that the closure plan was not “adequate and reasonable” and that Arlington should remain open “in sufficient form for the medically and behaviorally fragile.”

### **Opposition:**

- The Winston parent group was relatively small but fought the closure. There is a Parent/Guardian Association in each facility. In general, the Parent/Guardian Associations have been very vocal and active in their opposition to closure.
- Institutional employees are part of a state employees association. This association is not unionized. There was no organized movement against the closure. Most of the Winston employees were offered jobs at different state facilities.

### **Transition and Community Living:**

- *Let's Get Moving* is a substantial operational guide that was developed by the state in the late 1990s to be used for individuals moving from any of the three Developmental Centers into the community. The objective is to have a transition/moving-out process that is orderly and understood by all the participants, especially the individual and the parents/guardians. Reasonable accommodations are made for parents/guardians in all aspects of the transition process. In addition, adequate time should be provided for the individual and parents/guardians to make informed decisions. A detailed plan with a specific time frame is to be written by all the involved parties, generally with a 90-day transition period.
- A private, nonprofit Independent Support Coordination (ISC) System is in place that helps people living at the Developmental Centers and their parents look at the available choices in the community. ICS services are paid for with HCBS Waiver and state funds once a person moves into a community home.

- The Winston closure was done under court pressure. It was expressed that the state DMRS and Winston administration could have done a better job with developing the necessary behavioral and psychiatric supports in the community, as there is a gap in the system. Communication from Winston to the community providers was considered “very bumpy.” There was a general lack of community capacity to serve the individuals with a dual diagnosis.
- It took approximately two years to move residents from Winston to the community.
- At the time of the closure of Winston, state law still allowed up to eight people to reside in a group home. However, most of the ex-Winston residents moved to one-, two-, and three-person homes due to the state’s emphasis on supported living becoming the residential option of choice. With later revisions to Title 33, the Tennessee code that regulates services in the areas of mental health and developmental disabilities, it became law that there cannot be more than four people living in a community residence.
- An Individualized Service Plan (ISP) is developed in the institution for each resident, then a 90-day Transition Plan is made, and finally a new ISP is developed after the individual is in the community. The community ISP is updated yearly.

#### **Economics:**

- The Arlington lawsuit (*People First of Tennessee v. Arlington*) that the state was fighting was very costly, and it impacted the amount of money saved by the closure of Winston. Money was re-allocated with the resident moving to the community. There are also significant legal requirements of the Arlington court order and the Clover Bottom and Green Valley settlement Agreement that require the state to improve services and quality of life in all of the Developmental Centers.

#### **Noteworthy:**

- In 1995-1996, People First, a self-advocacy group, and the U.S. Department of Justice sued the State of Tennessee (*People First and the U.S. Department of Justice v. Clover Bottom et al.*) for violating the civil rights of institutionalized people. This lawsuit pertains to Clover Bottom, which includes the Harold Jordon Center, and to Green Valley Developmental Center. Arlington Developmental Center operates under a remedial order from a previous lawsuit (see above). The settlement agreement, conditionally approved in 1997, calls for the state to provide community services, among other things, for all institutional residents whose interdisciplinary teams recommend them for community placement. The settlement agreement never calls for closing the state’s Developmental Centers. It does, however, state “all citizens must be provided services in the least separate, most integrated setting appropriate to meet is or her individual needs.”
- There is a state Quality Assurance survey/licensure of each agency completed on an annual basis. “Class” members are monitored by a court monitor and a quality review panel. Regional monitors, state employees at the Regional Offices, monitor “class” members for quality-of-life issues.

**Interviewee Reflections:**

- States should systematically plan for deinstitutionalization and building community capacity. Why can't we plan creative waivers? Other states, like New Hampshire, never mentioned the word "closure." I don't think we should argue "closure."
- There should be more emphasis on communication with families – they have to be part of the entire process. It's important to have all the ancillary supports in place and have communication upfront with the providers. Most private professionals are not equipped to deal with the complexities. We need to bridge the gap between the state and the community, and help the community build capacity.

## TEXAS

# State-Operated Institutions Remaining: 13

Approximate Census: 5,000

# State-Operated Institutions Closed: 2

Closed Since 1993: 2

### Service System:

- Services are provided by three distinct groups:
  - There are 42 local Mental Retardation Authorities (MRAs--governmental entities), each of which is responsible for services within a specified local service area that may be one county or several. They provide a range of services, including eligibility determination, service coordination, training services, support services, specialized therapies, Medicaid waiver services, and ICF/MR programs, as well as referrals to other providers, as appropriate.
  - A network of private providers, located throughout the state but owned and operated by private corporations, individuals, or not-for-profit organizations, provide Medicaid waiver services, ICF/MR programs, or other provider services.
  - The 13 State Mental Retardation Facilities (SMRFs) are available for statewide access but operate in geographic regions for which they have traditionally provided residential long-term care.
- A major operation change in the past 20 years has been the conversion of state-operated community mental retardation services in some parts of the state from state-operated community centers administered by the state facilities to centers that are now operated by local community authority boards. As of September 2000, all community-based services have converted to local control.

### Alternative Use(s) for Closed Institution(s):

At one site, the buildings were designated for use by local community social services and programs. Open areas of one facility were leased for cattle grazing. Community-represented workgroups determined the choice of alternative uses.

### Institutional Closure Information:

- The Legislature has statutory authority to determine closure of SMRFs. There is no specific policy to close SMRFs. The Department of Mental Health and Mental Retardation ((MHMR) recognizes a continuum of services. Recent legislation included both consumer choice/preferences and authorization for expanded community-based waiver services.
- Closure resulted from a lawsuit, *Lelsz v. Kavanaugh*, that was dismissed when the Legislature agreed to close two SMRFs and move residents who had been recommended for community placements. The legislation passed, and it required the Governor to appoint a Facility Review Task Force to study each facility and make recommendations regarding disposition.
- An individualized approach to community placements and transfers resulted in implementation of the closure plan over a four-year period.

- Texas has more children in institutions than in any other state (approximately 1,200 under the age of 22 in SMRFs, ICFs-MR, and three- to four-bed waiver homes defined in legislation as institutions). State policy supports the concept of children living either at home or in a family-based alternative. One organization, Every Child, Inc., is operating a pilot in one part of the state to develop alternative family settings by recruiting and training interested families.
- A May 2003 column written by the State Controller in the *Austin American-Statesman* noted that a recent report from MHMR noted an overall 17.2 % vacancy rate in SMRFs, with predictions for additional declines. The state controller recommended closure of one or two of the facilities. Final legislation did not include closure of any SMRFs; however, a rider was passed that required the Health and Human Services Commission to study closure or consolidation of a SMRF and present recommendations to the next session in 2005.

### **Opposition:**

- A parent group, PART (Parents Association for the Retarded of Texas), was an intervenor in the *Lelsz* lawsuit and opposed closure.
- The state attempted to overcome opposition of parents with frequent parent meetings at each of the 15 facilities. People were transferred to other state facilities of the person's, legally authorized representative's, or family's choice, if they were not recommended for community placement. Transportation and support services were provided to residents and families to visit the state facilities prior to making their decisions.
- When the Mexia State School was recommended for closure, many of those opposed came to Austin to make their voices heard. The result was that the Governor did not accept the recommendation to close the Mexia facility but did accept an alternative recommendation to close the Ft. Worth and Travis State Schools.
- The Texas Employees Union opposed closure, but the leader of ADAPT had developed close connections with the unions and has been working to encourage them to deliver a different message than mere opposition to closure when testifying before the Legislature.
- Opposition has come from some state senators and representatives with a SMRF in their districts.

### **Transition and Community Living:**

- Most of the residents from the two closed facilities were not recommended for community placements and went to other state-operated facilities. Those residents recommended for community placement were moved to small group homes with six or fewer residents. The result was that approximately 624 were moved to other state-operated facilities, and 272 moved to group homes with six or fewer residents.
- Formal evaluations were conducted of employees and parents/families of individuals through the Southwest Institute for Developmental Disabilities at Abilene State School. The study cited a high satisfaction rate for individuals and their families after closure of the two state schools.

- For those individuals receiving services through waiver and general revenue programs, services in the community are monitored by local MRA staff, who conduct face-to-face interviews with a random sample of consumers and families every six months. Interview results are compiled, analyzed, and written up into Quality Improvement Plans. Results are tracked over time and reviewed by the Central Office QA Staff. Central Office staff visit the local MRAs every one to three years. Consumers receiving ICF/MR services have quality of care monitored by the Department of Human Service–Long Term Care.
- The service delivery system has experienced a high turnover rate of direct care employees in recent years.

#### **Economics:**

- Savings from the closure of the two facilities were either reallocated to the remaining SMRFs or to the community programs that accepted the referrals from the two facilities that closed.
- Primary funding sources for the state-operated and community residential services system comes from Medicaid. Medicaid waivers have provided more opportunity for people desiring to move to the community from state facilities.
- The waiver programs allow the state to exceed the individual cost caps through a utilization review process. This process is crucial to ensure that those with greater needs may be supported with appropriate services in the community, while keeping costs under control.

#### **Noteworthy:**

- Rider 37 of the General Appropriations Act of the 77<sup>th</sup> Legislature requires the Texas Department of Human Services to allow the money to follow the consumer from the nursing facility and to purchase community care. Money is prohibited from following a client from community care services to an institution. Representative comments about Rider 37 by advocates supporting institutions, advocates supporting community services, and providers can be found at [www.hhsc.state.tx.us/pubs/102502\\_HB966\\_InstCareStudy.pdf](http://www.hhsc.state.tx.us/pubs/102502_HB966_InstCareStudy.pdf) in a publication submitted by the Health and Human Services Commission (HHSC) (House Bill 966 Report, October 25, 2002, pp. 25-29).
- A Community Integration Project is being conducted in Austin, San Antonio, and Richmond (Houston area) by the P&A, DD Council, and Center for Excellence.
- In response to *Olmstead*, HHSC embarked on a Promoting Independence Initiative in January 2000 to review the existing service system in order to remove barriers that impede opportunity for community placement of individuals with developmental disabilities.
- The 78<sup>th</sup> Legislature has passed a bill to reorganize 13 Health and Human Service agencies into four, while maintaining a Health and Human Services Commission. Each agency under the commission, and the HHSC itself, will no longer have a board but will have advisory policy councils. Mental retardation services will be combined with other long-term supports and services under a new Department of Aging and Disability Services.

- The 78<sup>th</sup> Legislature also passed a bill calling for the privatization of one state school, if a private provider can maintain the same level of quality, maintain ICF-MR status, and maintain the school for 25% less than the state does.

**Interviewee Reflections:**

- When three ICFs-MR closed either because of poor quality of service or going out of business, there was a lack of good individualized plans, which meant that many people went to nursing homes or other large facilities, despite the fact that almost three-fourths of them said that they wanted to move into the community.
- There is a need to educate families and staff about what community-based services are available so that they make the right choices for individuals who want to move into the community.

## UTAH

**# State-Operated Institutions Remaining: 1      Approximate Census: 230**

**# State-Operated Institutions Closed: 0**

### **Service System:**

The Division of Services for People with Disabilities (DSPD) Regional Offices are the “service delivery arm” of the Department of Human Services. Most services for people with disabilities are coordinated and delivered through four Regional Offices located throughout Utah.

### **Institutional Closure Information:**

- There have been no institutional closures in Utah.
- In 1988 there was a legislative mandate for a “least restrictive environment” provision within fiscal appropriations for services provided by DSPD. This statutory provision was a response to an effort to reduce the number of individuals in the Utah State Developmental Center, which was being threatened to be de-certified by Medicaid.
- A Settlement Agreement in 1993 came from the class action lawsuit, *Parrant et al. v. Stewart et al.*, initiated in 1989. In essence, this agreement asserted that persons with disabilities “be afforded services and supports in the least restrictive and most enabling environment which meets the individual’s needs and promotes the independence and productivity of the individual.” It also asserted that no person who can be served in a community-based program will be admitted to the institution, except in accordance with certain statutory provisions. Additionally, it stated that appropriateness of community placement for residents of the institution must be reviewed annually.
- The population has remained static in both the one state-operated institution and the private ICFs-MR.

### **Opposition:**

The parent group at the Utah State Developmental Center is vocal against institutional closure. This group has lobbied legislators, creating a political environment that prevents closure discussion. There are no employee unions in Utah.

### **Transition and Community Living:**

- Adults with developmental disabilities who reside in the community setting live in a variety of residences, including single-family group homes in which up to eight people may reside, though a majority are six or fewer people, and DSPD advocates for three or fewer; Supported Living services for individuals living in their own home/apartment alone or with roommates, who do not require 24-hour supervision, but training and support depending on the needs of the individual; Supervised Apartments, generally located in apartment complexes, in which up to three individuals reside, with the amount of supervision/support commensurate with the needs of the residents; and Host Homes, a foster care setting with supportive services.

- ICFs-MR are administered through the Department of Health, Division of Health Care Financing, and are operated by private for-profit or nonprofit providers. There are 13 private ICFs-MR in Utah, seven of which have more than 35 beds. This type of residence is geared for individuals who need a continuous program of active, intensive treatment. Programs are developed through an Individual Habilitation Plan.
- The resident's treatment team and parent/guardian develop the transition plan; the parent/guardian is making most of the choices.
- An Individual Service Plan is developed after the individual has moved to the community.
- The barriers for people who require specialized services are the lack of neurological, psychiatric, and physical therapy services.
- People who are medically fragile or have a dual diagnosis of MI/DD are the most difficult to serve in the community.

**Economics:**

- The per diem cost of institutional care is higher, on average, than providing services and supports to individuals residing in the community.
- There are significant overhead expenses (600 employees) at Utah State Developmental Center and no economy of scale.
- The HCBS Waiver, first used in Utah in 1986, funds all the residents who leave the institution.

**Noteworthy:**

- Utah instituted a "portability" policy that relates to funding for people who reside in private ICFs-MR and individuals who receive the Medicaid HCBS Waiver. It allows an individual living in a private ICF-MR to transfer to an HCBS Waiver residential program (or vice versa), after he or she has been in the ICF-MR for one year. In this way, people can bypass the waiting list for community services. Portability was discontinued in 2002.
- Case management is provided to eligible individuals from a DSPD Regional Office. Support coordinators work with individuals and their families to develop service and support plans that are necessary, based on the individual's needs and wishes.
- The state monitors services in the community for quality of care and programming with a Quality Enhancement Review. The purpose of this annual review is to promote quality of life as defined by the person receiving supports and services and to define and promote quality improvement efforts by provider agencies.

## VERMONT

**# State-Operated Institutions Remaining: 0**

**# State-Operated Institutions Closed: 1**

**Closed Since 1993: 1**

### **Service System:**

- The Division of Developmental Services (DDS), the programmatic division of the Vermont Department of Developmental and Mental Health Services, plans, coordinates, administers, monitors, evaluates, and funds services for people with developmental disabilities in Vermont. Services are provided through 10 Designated Agencies, four Specialized Service Agencies, and two Certified Providers.
- All providers are private, nonprofit developmental service agencies.
- Following the closure of the Brandon Training School in 1993, all services to people with developmental disabilities are provided in local communities throughout the state, where support coordination, home supports, work supports, crisis services, and family support are provided.

### **Alternative Use(s) for Closed Institution(s):**

Brandon's campus is being partially used by a variety of organizations, including a school, a child care center, and private industry.

### **Institutional Closure Information:**

- A lawsuit on behalf of Brandon residents who wanted to move out of the institution established a 10-year plan for developing resources around the state. This became known as the "Brace Decree" settlement.
- In FY 1992 and 1993, the legislature approved bridge funding to support new community services until savings could be transferred from the institution. There were fiscal concerns about the amount of money required for community services, but the DDS administration was able to appease the legislature by stating that it was a one-time cost.
- Approximately \$406,000 was appropriated each year to set up community placements for residents leaving Brandon.
- Vermont's objective was to convert the system of services to individuals with disabilities from a two-tiered system that supported both the institution and the community, to a unified community-based system.
- The former Department of Mental Retardation (DMR) continually revised its institutional downsizing plan to reflect the changing conditions. There was an effort to coordinate staff reductions and building closures with the rate of community placement. (*Closing the Doors of the Institution*, 1993)

### **Opposition:**

- Parents of residents formed a parent association that represented a small, but strong opposition group. Most parents ranged from "dubious to resistant" regarding community placement. Their primary concern was that there would be a guarantee of as good as or better service than what was received at Brandon.

- Parents hired a lawyer as a reaction to parts of the consent decree. DMR staff met the parent association and put out materials about protections that would be in the community.
- In response to these generalized anxieties, the DMR identified Brandon staff that the families trusted as communicators to assist during the transition period.
- Some parents insisted on a “conditional” discharge from the institution, which meant that the state still had legal responsibility for providing oversight and monitoring the well-being of their child.
- In the end there were no appeals to placement.
- The direct care staff was part of the union that represents state employees, called the Vermont State Employees Association. They were concerned about living conditions for residents at Brandon, and they were also active in protecting workers’ rights as closure became a reality.
- State government granted special priority for continued state employment to staff who worked at the institution. In addition, the Department of Employment and Training opened an office on campus with computer banks of jobs and held job fairs.
- Some staff became public guardians and/or foster parents for former residents whom they knew.

#### **Transition and Community Living:**

- The DMR relied on institutional staff assessment of residents to determine safety and support needs.
- There is a designated provider agency in each county. The provider was told how many individuals needed to be placed in its geographic area within a certain time frame.
- There was a commitment to place residents near their family; however, the counties close to Brandon had the most placements.
- Agencies had to build their capacity and expertise in order to serve new clients with challenging needs.
- Funding was provided to meet any critical infrastructure requirements that an agency identified, e.g. a part-time nurse, an additional supervisor.
- Each resident had an individualized budget that was tailored to meet his or her needs approved at the state level. There was no budgeting by categories or level of care.
- A majority of residents went to live in a family-style “Developmental Home,” usually one individual per home, where there was a single adult, or a couple, responsible for their care. This was thought to be an ideal way to transition into a community where a person’s social network was limited.
- Nine new homes in residential neighborhoods were built or renovated to house small groups of two to six former residents. In addition to new construction being a more costly alternative, most of the delays in the community placement process were due to new home construction or acquisition.
- It took approximately 2½ years to move out residents to the community after the decision was made to close Brandon.

**Economics:**

- The average per-person cost of supports in the most intensive community service category (e.g. 12 people with intensive medical needs residing in an ICF-MR) is \$133,056 per year, which is approximately 66% less than what the estimated per-person cost would have been at the Brandon Training School in FY 2002 (\$200,836 per year).
- In Vermont, on average, individualized supports cost less than group settings. (*Annual Report 2002, Division of Developmental Services*)
- Medicaid is 94.5% of DDS funding.

**Noteworthy:**

- The Vermont Crisis Intervention Network (VCIN) was developed as a three-level program to serve individuals in crisis and individuals who present severe behavioral challenges in individualized community settings: 1) Monthly meetings are held where members of agencies consult and problem solve. A state administrator attends these meetings, and decisions can be made about increased staff; 2) one or two people from VCIN can visit the individual and his or her family, and the agency providing services and a plan for change can be developed; and 3) if the individual is at risk, the Network provides emergency placement.
- VCIN played a critical role in preventing any new institutional admissions during the phase-down period. This Network also gave stakeholders a greater sense of security.

**Interviewee Reflections:**

- The whole system is pretty good. However, more training for people who are home providers on how to manage difficult behaviors, more time for the transition to the community, and some way for advocacy on the individual level to occur were mentioned as concerns. Access to people who live in a rural community can sometimes be more difficult. Generally, though, individuals have contact with many more people outside the service system than they had when they lived at Brandon.
- “Closing institutions is easy – the challenge is to keep community residences from becoming mini-institutions.”

## VIRGINIA

# State-Operated Institutions Remaining: 5

Approximate Census: 1,590

# State-Operated Institutions Closed: 0

### Service System:

- Community mental retardation services are provided by 40 community service boards (CSBs), behavioral health authorities, or local government departments with policy-advisory CSBs. These services include case management, day support, residential, and early intervention services. CSBs also assess individuals for admission to state mental retardation training centers and conduct predischarge planning for training center residents who have chosen community placements. CSBs also provide community mental health, substance abuse, and prevention programming.
- There are three types of CSBs: operating, administrative policy, and policy-advisory CSBs. CSBs are either agents or part of local governments. They are not part of the Department of Mental Health, Mental Retardation and Substance Abuse Services, which funds, monitors, licenses, regulates, and provides consultation.
- CSBs have boards of directors consisting of 6 to 18 members, appointed by city councils, and boards of supervisors that established CSB.
- The Department operates five mental retardation training centers, which provide residential care and training in areas such as language, self-care, independent living, socialization, academic skills, and motor development.

### Institutional Closure Information:

- The Department has never attempted to close a mental retardation training center. Since FY 1997, the number of training center beds has been reduced by 400 beds. The Medicaid waiver was instrumental in funding the continuation of treatment, training and supports for those residents who, with their legally authorized representatives or family members, chose to consider a community provider.
- With the support of the Governor, an Olmstead Task Force was created by the General Assembly in 2002, chaired by the Health and Human Resources Secretary and coordinated by the Department. Referred to as “One Virginia... *One Community*,” the goal is to make the state Olmstead plan accountable for years to come. The task force has been given responsibility to gather data on populations and services and to examine the needs of individuals with disabilities with regard to housing, employment, transition, services, qualified providers, and waivers.

### Opposition:

- There are no plans to close any institution. The issue is choice.
- Parents and Advocates for Institutionalized Retarded (PAIR), a group composed primarily of parents and family members of state mental retardation training center residents, is not opposed to individuals living in the community if they are able to do so, but it also supports institutions as an important part of the continuum of care.

**Transition and Community Living:**

- Most people are going to smaller group homes of four to six individuals. Very few people return to institutions.
- Individualized service plans for an array of services for those who choose community placement are formulated by the CSB in collaboration with the individual, his or her legally authorized representative, or family member.
- Prior to discharge from a state training center, the CSB ensures that the individual has received information about and has visited the sites of community providers that are available, consistent with consumer choice.
- In some regions, the facility and CSB staff maintain a close interaction with relation to consumers who have been placed and their progress. There is on-site observation with general and comprehensive assessment taking place to ensure that the community residence is appropriate.
- In some rural regions of the state, it is difficult to find providers for many of the needed services because they simply do not exist (e.g. psychiatry).

**Economics:**

- In 2001, Virginia requested HCBS Waiver service for 5,536 recipients.
- Waiver services available to eligible persons with mental retardation include residential support services, day support, supported employment, personal assistance, habilitation services, respite care, nursing services, crisis stabilization, crisis supervision, environmental modifications and assistive technology, and therapeutic consultation.

**Noteworthy:**

- A lawsuit, *Quibuyen v. Allen and Smith*, was filed in December 2000 alleging that the state impermissibly waitlisted people already enrolled in the waiver program rather than providing them with additional services that they had been assessed as requiring. In September 2001, the state agreed to change its policy so that waiver participants would receive all the services required, and the lawsuit was dismissed.

**Interviewee Reflections:**

- With prospects for closure small, the question becomes not whether institutions should exist, but rather what size they should be.
- There was an individual who had spent 30 years in an institution. Despite the fact that he was difficult to place in the community, he was placed in a group home for a trial period and was extremely happy in his new environment.
- When the P&A is involved, transitioning moves more quickly, but this is no way to run a system, for many people do not turn to the P&A for assistance. The goal should be to create a more streamlined system in which plans can be implemented in a reasonable time, but this requires sufficient funding.
- There is a broad coalition now to try to make current waivers work better. One thing that should be done is to have money follow the individual into the community.

## WASHINGTON

**# State-Operated Institutions Remaining: 5**      **Approximate Census: 1,100**

**# State-Operated Institutions Closed: 1**

### **Service System:**

Washington has a bifurcated system with a unique mixture of state- and county-funded services. The state contracts with, and funds, residential and family support programs, while the 39 counties manage day and employment programs. The counties and state subcontract with providers in the community. The state administers a case management system.

### **Alternative Use(s) for Closed Institution(s):**

It had been used as a private nursing facility, but it is currently vacant.

### **Institutional Closure Information:**

- Washington's state-operated institutions are called Residential Habilitation Centers (RHCs).
- Interlake, closed in 1994, was an old facility that needed repairs. The decision to close the facility was driven by economics, as it was deemed too expensive to repair.
- There is a current bill in the legislature to close Fircrest School over the next three years. The proceeds for the sale would be put into a trust fund for community placements of the former residents of Fircrest. Any additional funds would be used to provide services to the "unserved." This bill has not yet passed.

### **Opposition:**

- There was opposition raised by both families of residents and unions against the Interlake closure.
- Washington law states that work cannot be contracted out that is generally performed by state employees. Therefore, if the state changes working conditions, it has to negotiate with the state workers. Thus, the union participated in labor management meetings, once the closure plans were announced.
- Very few state employees were laid off. A majority of the employees moved to a nearby facility. Some went to other positions in state government and "bumped" staff through seniority. Others followed residents into the community to State-Operated Living Alternatives (SOLAs) - supported living residences in which three to four people live with support staff.
- The parents, active in the Friends of Institutions, were very opposed to the closure, and they formed an alliance with the union.
- Parent groups have successfully prevented the closure of one other institution.
- The parents' campaign consisted of going to the press, talking to legislators, writing and calling the Governor, and utilizing a lobbyist.
- Division of Developmental Disabilities (DDD) staff met with parents/guardians and solicited their input for planning.

### **Transition and Community Living:**

- Most of the residents at Interlake were nonverbal and did not personally participate in the planning process.
- A team of people convened to discuss placement, including institutional staff that knew the resident well, case managers from the community, and the parents/guardian. The team or parents/guardian chose the provider and visited different alternatives, including institutional.
- A majority of Interlake residents moved to Lakeland Village, located near Interlake, a state facility where there was capacity. Others chose to live in community alternatives staffed by private or state employees.
- Providers developed homes to accommodate wheelchairs.
- It took approximately 12-18 months to move residents out after the decision was made to close Interlake.
- In addition to RHCs and supported-living alternatives, Washington supports facility-based long-term care services. These include Community ICFs-MR (8); Group Homes that are licensed as boarding homes with 24-hour supervision (60 with 20 adults per home); Adult Family Homes with 24-hour supervision (438, each with 2-6 unrelated adults); and Adult Residential Care, licensed boarding homes with 24-hour supervision and a large congregate care setting (36 facilities, mixed DD and non-DD population).

### **Economics:**

- Interlake had to close because the cost of repairing the building structure was too expensive.
- Washington DDD spends an estimated \$300-\$400 per person per day for individuals who require intensive staffing and programming services. An example is a person living in a two- to three-bed home with full-time staff and requiring two-person transfers.

### **Noteworthy:**

- A Robert Wood Johnson project, *Composing a Life*, is a joint state/regional/county undertaking. It focuses on a very mixed housing neighborhood in the city of Spokane, where approximately 150 individuals with developmental disabilities reside. Living arrangements include children living with their families, adult family homes, foster homes, group homes, individuals living in their own homes with supports (from a few hours per day to 24-hour staffing), and people with disabilities who are living independently. The purpose of the project is to work with people in this neighborhood to bring more self-determination to them and their families and more control over resources so that they have choices about every nuance within the support delivery system. Another goal is to build capacity in the community and to connect people with disabilities to existing supports.
- In adopting the state's 2001-2003 capital budget, the Washington Legislature commissioned the Joint Legislative Audit and Review Committee (JLARC) to examine the capital assets of the five remaining RHCs to determine if there are possible alternative uses of the land and facilities. The report recommended that

the Washington Legislature authorize the sale of excess land on the grounds of these centers and “weigh the future need for these facilities in light of the steady decline in the resident population over the past three decades.” (*Community Services Reporter*, February 2003; a copy of JLARC’s full report can be found online at <http://jlarc.leg.wa.gov>)

- Washington’s DDD participates in the National Core Indicators (NCI) study that assesses performance and outcome indicators for state developmental disabilities service systems. This study is sponsored and conducted by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI). This is a major component of DDD’s Quality Assurance Plan.
- Community providers go through a certification process every two years with the state Quality Assurance program. Quality Assurance is now centralized – at one time it was located in each of the six regions of the state.
- DDD case managers often have a 200-300 person caseload. Requests for services exceed the resources available to clients (*DDD Final Report, Executive Summary, Sterling Assoc.*, May 2002). This ratio may be the highest in the country.
- A general lack of medical professionals in the community who are able to address the needs of persons with disabilities was identified as one of the hardest services to fill in the community. In addition, there is a general lack of services to individuals with developmental disabilities who have mental health needs. Many of these individuals continue to cycle through the state psychiatric facilities. The Washington P&A has filed and settled two class action lawsuits regarding this issue (*Allen v. Western State Hospital* and *Marr v. Eastern State Hospital*). There is now a work plan (State Strategic Plan 2004-2009, DDD/MHD Workplan) to address some of the issues raised in these cases. Another lawsuit, *Smith v. Western State Hospital*, was recently filed by the P&A on behalf of a group of individuals with developmental disabilities who are not being discharged from the state psychiatric facility in a timely manner, in violation of federal law.

#### **Interviewee Reflections:**

- Once given the green light by the legislature, DDD has been successful in moving hundreds of people out of nursing homes and other institutions. You need a Quality Assurance team who is dedicated to the job of transition planning and who meets regularly with case managers. You also need to have providers willing and ready with appropriate services.
- This state used the HCBS Waiver program as a funding source rather than as a program. It takes a substantial commitment from a large number of individuals, over a period of time, to create a system that actually meets the needs of these individuals.

## WEST VIRGINIA

# State-Operated Institutions Remaining: 0

# State-Operated Institutions Closed: 4

Closed Since 1993: 1

### Service System:

The Division of Developmental Disabilities (DDD) is within the Bureau for Behavioral Health, which is within the Department of Health and Human Resources (DHHR). DDD oversees a statewide system with 55 counties divided into 14 regions of from two to seven counties each. DDD contracts for services with private providers in these regions.

### Alternative Use(s) for Closed Institution(s):

Of the four centers closed, one became a community college; another, a medium security correctional facility; one was demolished; and another is vacant.

### Institutional Closure Information:

- There were two consent decrees that were key to the process of closure:
  - *Medley v. Ginsberg* (1981): A court order stated that Colin Anderson Behavioral Health Center be closed by July 1996 and that DHHR coordinate a process in order to assure that the institutionalization of disabled youth does not recur.
  - *Hartley v. Matin* (1983): This case concerned mental health hospitals and DD facilities, finding that many of these were uninhabitable. The result of the *Hartley* consent decree was that there was a mass exodus from many hospitals and facilities, with many people ending up in six- to eight- bed ICFs/MR. Advocates are now trying to get these mini-institutions closed. The Greenbrier Center, which closed in 1993, was an ICF-MR campus facility that housed 55 people. Most of those individuals had co-occurring psychiatric disorders. That closure occurred, in part, from an order in the *Hartley* case.
- The DD Council and West Virginia Advocates, Inc. (P&A), were instrumental in fueling discussion and keeping pressure on key stakeholders regarding closure. Governor Caperton put forward a bill for closure. That closure bill (SB22) was passed by the Legislature in February 1995.
- The Colin Anderson Center (CAC) closed over a long period of time (more than 15 years). The process involved refusal to place either children or adults in the institutions. The decreasing numbers of people at the facility eventually caused it to be uneconomical to keep it open. In moving people out of CAC, DHHR moved children and the most vulnerable population first. The result was that by the time the closure occurred, most individuals with high medical support needs had left and no one was forced to lose services upon leaving the institution.
- A Colin Anderson Center Guidebook (1995) was developed by DHHR and the court to assist CAC residents, families, and planning teams in the move from CAC to communities throughout the state.

**Opposition:**

- There was opposition from union employees of CAC, some parents of residents, city and county officials, and local state legislators where the institution was located.
- Union employees were not incorporated into discussions about closure before the decision to close was made, and nothing was “put on the table” that made closure acceptable to the union.
- The union developed a media campaign to fight for keeping the facility open.
- Families organized a support group that was very active in fighting the closure of the facilities. About 60% of families resisted the closure attempt. DHHR met regularly with the families and residents to listen to their concerns. The P&A and DD Council sought to educate families regarding community integration.
- Efforts were made to overcome parents’ opposition by getting parents who had success with the transition process to talk with others.
- Employees were offered career counseling, tax incentives, early retirement, preferential status for other state jobs, and alternative offers to work in prisons. Management staff, as employees of private nonprofit companies, were offered other employment options through the private corporation.

**Transition and Community Living:**

- As openings were available in state ICF-MR group homes (six- to eight-bed homes), agencies proposed placements to interdisciplinary teams in areas where people were to reside. Individuals, teams, and families visited and reviewed placements.
- People who resided in the facility had the option of waiver vs. ICF/MR.
- The first person was discharged from the facilities within a month of the Governor’s signing the bill into law.
- Some employees went to work for community agencies despite the loss of some benefits.
- The state provided funding for existing community agencies to develop new homes or day services and/or to renovate existing services.
- Video cameras for virtual tours of community living sites were used when individuals could not visit the sites with their families.
- There is anecdotal evidence that the need for medication went down dramatically when individuals were moved into the community. One problem noted, however, was that some individuals lost social contacts when they were placed in smaller settings.
- Some individuals moved home with staff.
- There were monthly evaluations completed by community advocates and case managers to assess the transition process. The state now participates in the NASDDDS Core Indicators Project (CIP), which seeks to develop and implement performance/outcome indicators and related data collection strategies that will enable a state to measure its service delivery system performance.

**Economics:**

- The state saved approximately \$1 million to \$1.2 million annually as a result of the closure of CAC. The savings was used for the development of community crisis respite services, for those items not covered by Medicaid, and also to match the waiver.
- The DHHR had to report monthly (during closure and for three years post-closure) to the State Legislature on the progress of the closure, status of individuals, and costs.
- In response to *Benjamin H. v. Ohl* (1999), a class action complaint alleging failure to provide long-term services with reasonable promptness to those eligible, the DHHR agreed to add at least 875 individuals to the waiver program, in addition to the 2,800 people across the state now being served.

**Noteworthy:**

- Closure was monitored by several entities: the State, WVDD Council, the P&A, the Court, and the Legislature. There was a grant from the DD Council to have a full-time employee to monitor all closure activities. This person monitored the Compliance Clock, the tool used to monitor services for individuals once they were discharged from CAC. An interdisciplinary team composed of the individual, family, facility staff, community staff, and advocates listed the required/desired services and frequency of those services. If a placement was not successful, modifications were sought once the problem was identified. Only after 18 months of success with the Compliance Clock would the transition be considered complete.
- The Family Support Program provides assistance in locating resources in the community to meet individual needs. There is a state program director overseeing the project, and each of 14 regions has a family support coordinator who is employed by the region's Behavioral Health Center. This coordinator works with the Regional Family Support Council, which is composed of parents, caregivers, and people with disabilities.

**Interviewee Reflections:**

- It is important to get the Legislature to understand the high cost of keeping institutions open. Although community services will eventually be less expensive, it is better to go into the process by stating that the move to the community is cost neutral.
- Many times there is misunderstanding about what life is like in the institution. The tricky part is presenting the negative of life in the institution without trashing the staff.
- The problem with institutional staff moving home with clients is that "you can take staff out of an institution, but it is difficult to take the institution out of staff."
- Try to avoid ICFs-MR completely, since people are not going to "graduate" from ICFs to smaller settings. The ICFs and other congregate settings fail to prepare people for greater self-determination.

## WISCONSIN

**# State-Operated Institutions Remaining: 3**

**Approximate Census: 800**

**# State-Operated Institutions Closed: 0**

### **Service System:**

The state Department of Health and Family Services' (DHFS) Bureau of Developmental Disabilities Services (BDDS), located in the Division of Disability and Elder Services (DDES), is the primary agency responsible for the development and implementation of statewide policy, services, and supports for people with developmental disabilities. The DDES Administrator's Office is responsible for oversight of the three State Centers for the Developmentally Disabled (ICFs-MR). The state has a county-based system.

### **Institutional Closure Information:**

- There have been closures of nursing homes, mostly due to financial issues but also due to a "rightsizing" policy, in which those who were placed there because of no community living situation are now being moved, usually to community settings.
- ICFs-MR are also being closed. In the process of being closed is Hearthside, which has approximately 180 residents in the Milwaukee area. Hearthside had been placed under receivership by the state as a result of the loss of federal certification. The state spent a considerable sum in renovating the facility to bring it up to acceptable standards for the transition and now has a contract with a consulting firm that is directing final closure and transitioning residents into the community. Another ICF, the Jackson Center, was also closed during the past year under a similar circumstance of state receivership, with most of the 100 individuals going to community settings.
- DHFS has had an internal policy that the state would be committed to community integration and has sought to avoid institutionalizing people since the early 1990s. The state and counties have been moving individuals from state centers and ICFs-MR since the early 1980s.
- There was an attempt to close Southern Wisconsin Center (SWC) in Union Grove in 1996. This plan was abandoned after meeting significant union, family, and legislative opposition. Disability advocates were also not strongly supportive of this attempted closing, in part because the plan included transferring the majority of residents to the other two state centers.
- In 2003, DHFS made the final decision to significantly downsize the Northern Wisconsin Center (NWC) in Chippewa Falls. Downsizing has been taking place there since the 1970s and began in full force in 1983 with the home and community-based waiver (CIP). NWC has been chosen to be phased out because it has the smallest population, the highest daily rate for Medicaid reimbursement, and no competing initiatives in the area, such as the closure of Jackson Center, Hearthside, and Marian Franciscan in the Milwaukee area that limited the availability of community providers and staff time when SWC attempted to close. (SWC serves a large number of Milwaukee County individuals and NWC does not).
- Plans for downsizing NWC through eliminating long-term care services were initially made using a state statute (Chapter 50) that allows a nursing home or ICF-MR to significantly downsize through administrative relocation. There is also a provision in

the CIP waiver statute that allows for an enhanced rate for the counties for community placement if there is an approved Chapter 50 Relocation plan. These plans were announced as part of the Governor's State of the State address. DHFS informed NWC staff and guardians of the forthcoming announcement earlier that same day.

- Another difference between the potential success of downsizing NWC and the lack of success at SWC has been the willingness of the present Governor and DHFS Secretary to remain committed to community placements. They have met with parents and staff at NWC and have taken much criticism for their decision to downsize the center. In addition, having learned from the 1996 SWC experience, those favoring closure (P&A, People First, Arc, DHFS, and Wisconsin County Human Services Association) are mobilized to counterbalance opposition to downsizing.
- The DHFS Secretary originally noted that 150 long-term beds at NWC would be eliminated by June 2004, as well as 300 positions required to support those beds. Twenty short-term intensive treatment beds would remain, preserving about 75 staff positions. This has recently been modified in an attempt to reach an agreement with the Legislature in the budget writing process, which, if approved, will preserve additional services at NWC and more jobs, and avoid having to transfer any NWC residents to the Central Wisconsin Center (CWC) in Madison.
- To facilitate downsizing, the first meeting of the NWC's Chapter 50 Relocation Team, composed of community integration specialists and representatives from the State Central and Regional Offices, NWC, the Wisconsin Coalition for Advocacy (P&A), and the county, was held in April 2003, and the team is scheduled to meet every two weeks throughout the downsizing process. While Wisconsin has a complex system of state and county responsibilities, the state (with the DHFS secretary actively involved) is supervising and overseeing the downsizing process as specified in Chapter 50. It has been helpful that there has not been a great amount of turnover in the DDES Division in the last decade and that the new secretary is returning to the Department where she had once worked.
- The NWC property is considered to be quite valuable. The recent legislative budget proposal calls for turning a former NWC building into an Alcohol and Other Drug Abuse (AODA) treatment center for the Department of Corrections (creating 150 new jobs) and the sale of 220 acres of property. It is unclear what the funds from the land sale will go toward at this time, except that the Legislature has earmarked them to help offset costs of retaining some services at NWC.

### **Opposition:**

- Unions, particularly AFSCME, have in the past opposed closing institutions. Even when there was a suggestion for a task force with representation from all constituencies, AFSCME succeeded in getting it vetoed by the former Governor. SEIU did support creation of the task force, and there is some hope for collaboration with this union. With regard to planned downsizing of NWC, plans are underway to give staff funds for moving if they want to relocate to work in other facilities. Job fairs and resume writing seminars will also be conducted.

- Legislators, the union, and other interested parties suggest that the state consider expanding other programs (brain injury, respite, autistic treatment) with the hope that the staff could be placed in other jobs, perhaps at the center itself. Advocates expressed opposition to this proposal of developing programs on center campuses that could be and are already being provided in the community (They do support the temporary housing of short-term, crisis, and specialty services at the centers that are necessary to keep people living in the community out of institutions). The state considered these proposals and concluded it was not feasible to consider them for NWC.
- The majority of parents and guardians of those remaining in institutions have opposed closure. This is often related to their satisfaction with the quality and scope of services at the center and their concerns that this won't be available in the community. The concerns of guardians have been mostly because of a lack of information and knowledge about what can be provided in a community setting. Five guardians of NWC residents have filed a lawsuit against the state, seeking an injunction to stop the downsizing, as well as class certification status.
- There is local resistance to closing NWC because the center has been providing employment for many generations of families in the area since 1887 and because of the economic impact the loss of state business will have on the area.

#### **Transition and Community Living:**

- There is some variation among counties regarding the aggressiveness of moving individuals from the state centers. The amount of additional local funding available to fund community programs can be limited because of existing mandates for counties to provide specified services whether or not they are able to do so, and whether or not state and federal funding keep pace with the needs.
- A guardian mentoring program, supported with CMS-funded System Change Grant funds, part of the CMS New Freedom Initiative, is being instituted, in which guardians with community experience will be paid to work part-time and serve as resources for other guardians preparing to transition their family members to the community. People First has been talking with parents to encourage them about the positive factors of living in the community and collecting relocation success stories that involve former state center residents and staff.
- A hotline for NWC guardians was created to field calls that range from expressing anger at the downsizing to questions about what should be done to facilitate the transition process. The hotline was used by approximately 25% of the NWC guardians within the first three weeks of its existence. Few calls have taken place since the inception of other local and regional meetings, which guardians were invited to attend.
- The process for transitioning individuals begins with the county doing a preliminary assessment of the needs of the individuals, identifying potential providers, and determining a preliminary estimate of costs, based on an individual's needs. The county then coordinates with the guardian to identify providers and services. Some counties request an Essential Lifestyle Plan (developed by Michael Smull and Susan Burke Harrison). Guardians are involved throughout the entire process and have a

choice of providers. Most counties have a provider network, and many counties are coordinating their efforts to expand the provider network.

- The identified provider will come to visit the person and work with staff to learn how to best support the individual. Once the provider has information, it is the typical practice to have the person go on at least one preplacement visit. Provider staff are encouraged to come to the center, and the center staff offer assistance in the community. In certain cases, videos of an individual may be used to give a sense of particular behaviors that must be considered in the community. The goal is to have community providers learn as much about the person as possible.
- After the person moves, it is CIP waiver policy that state community integration staff, in conjunction with the guardian, county staff, and NWC staff, will provide a 30-day follow-up visit at the person's home. The amount of follow-up after that visit is determined by the needs of the person and can be continued, particularly in situations in which providers encounter difficulties in serving the individual.
- There is an annual Guardian Satisfaction survey sent to all guardians of waiver participants. There is a 70% return rate on the almost 10,000 surveys sent each year with a consistent 96% to 98% overall satisfaction with services. All guardians receive a letter with the name and phone number of the community integration specialist assigned to the county where the person lives, and it encourages guardians to call if they have any concerns. There is also a waiver requirement that the county case manager must have monthly contact with each participant.
- The state is looking closely at the issue of transfer trauma. Two universities are conducting studies, and there is consideration for doing a study as NWC completes its process of downsizing.
- There are cooperative ventures among counties, which seek to share resources, such as having providers accept individuals from neighboring counties whenever possible.
- The state is now piloting a long-term care reform initiative called Family Care in nine counties. Authorized by the Governor and Legislature in 1998, the program was created to give people better choices of where they live and what kinds of services and supports they receive to meet their needs, to improve access to services, and to create a cost-effective system for the future. The two organizational components are, first, aging and disability resource centers where individuals and their families can get information and advice about a wide range of resources available to them in their local communities; second, care management organizations (CMO) for managing and delivering the new Family Care benefit, which combines funding and services from a variety of existing programs into one flexible long-term care benefit tailored to each individual's needs. CMOs now offer Family Care benefit packages in five of the counties.

#### **Economics:**

- When an individual is moved into the community, the county receives money from the state. The amount of money the county receives, which is deducted from the budget of the institution the next time it is reviewed by the Legislature, is determined by the Legislature, based on the request from DHFS during each biennial budget process. The current CIP 1A rate is \$225/day, while the current cost of State Centers

averages \$477/day. The Governor's proposal to increase the rate to \$325/day has thus far received the endorsement of the Legislature's Joint Finance Committee.

- The Medicaid HCBS program, which provides long-term care to people in their own homes or other non-institutional settings, has limited funding and is not an entitlement. This is one reason that the state decided to develop its Family Care program.

#### **Noteworthy:**

- DHFS has contracted with the Innovative Resource Group to conduct an independent assessment of the Family Care program during the first two years of its Family Care waiver, working in collaboration with MetaStar, the external quality review organization for Family Care.
- The Wisconsin Supreme Court's decision in *Dunn v. Judy K.* (2002 WI 87), litigated by the Wisconsin P&A, required the county to find placement funding for the plaintiff, noting that Wis. State § 55.06 (9)(a) (199-2000) required the county to show that it had made a good faith, reasonable effort to find and fund an appropriate placement.
- People First Wisconsin has been actively engaged in conducting studies of other states with regard to deinstitutionalization and community integration. In addition, People First members who have previously been at centers have been engaged in spreading the word to legislators to encourage downsizing and community integration.
- In addition to litigation, the P&A has been a key player in virtually all phases of the transition to the community. It has been on the relocation team at various downsized facilities, including Hearthiside and the NWC; monitored quality care in both institutional and community settings, and played a role in the public policy issues in the area with both the Legislature and the DHFS.

#### **Interviewee Reflections:**

- There are concerns that staff disapproval and frustration about closing a facility can be conveyed to clients, creating a self-fulfilling transfer trauma. This makes it all the more important to work to ensure a buy-in by everyone involved in the transitioning process.
- Some former NWC institutional staff have said that although they are being paid less in the community, they are managing fine and find work in the community to be far less stressful than in the institution. This suggests that perhaps money is not the only factor under consideration when trying to convince state workers to move to the community.
- Because it takes time to change a system, one should get started early in preparing future plans despite the fact that money may be scarce. Then, when the funds become available, plans for deinstitutionalization and community integration can be efficiently implemented.
- Since any future proposal to close SWC will face even stronger opposition, creating a task force of all constituencies may provide a way to ensure that the move to downsize or close SWC can also be successful.

## WYOMING

**# State-Operated Institutions Remaining: 1**      **Approximate Census: 90**  
**# State-Operated Institutions Closed: 0**      **Closed Since 1993: 0**

### **Service System:**

The Department of Health, Developmental Disabilities Division (DDD) has six service clusters: the state institution in Lander, adult services, preschool and infant services, the children's waiver, the child state respite program, and Targeted Case Management. It provides funding for services to individuals with developmental disabilities from its central office in Cheyenne to the nine-member Regional Service Providers of Wyoming, who are all CARF certified and are given a certain number of waiver slots. There are also smaller programs/providers that have been developed.

### **Alternative Use(s) for Closed Institution(s):**

Though the Wyoming State Training School (WSTS) has not closed, the census has diminished. The role of the Training School is changing. Some of the buildings on campus are being used to house other programs, including an alternative high school, a brain injury program, a program for individuals with emotional and drug problems, a special education program, and a farm school for young men.

### **Institutional Closure Information:**

- Though WSTS remains open, there is a continuous, ongoing effort to move people to the community. The residents who still live there have either chosen to remain living there or the parent/guardian made this choice.
- There are still infrequent admittances to WSTS.
- This institution is part of the spectrum of services for the state.
- Services increased in the institution, as well as the community, as a result of the lawsuit and consent decree described below, *Weston et al. v. Wyoming State Training School*.

### **Opposition:**

- Parents/guardians have spoken out against closure; however, there has been no formal effort to close the WSTS.
- There are no employee unions.

### **Transition and Community Living:**

- Prior to moving to the community, there are several meetings that occur between a resident, parent/guardian, interdisciplinary institutional staff, and the community vendor staff. Transition to community living is a lengthy process.
- Under the terms of the consent decree, services and supports are tailored to meet the needs of each resident. An Individual Program Plan (IPP) is developed that includes a time frame for transitioning to the least restrictive setting and day

- programming for the individual. Class members are discharged only when appropriate community alternatives are developed and in place.
- The case manager from the community, in conjunction with the area resource specialist (ARS), identifies appropriate community service providers. The role of the ARS was created as a requirement of the *Weston* civil suit. The ARS and Central Office staff members provide DDD's oversight throughout the state in the administration of the Medicaid HCBS Waivers and other statutory requirements of DDD.
  - WSTS class members are discharged to community settings such as independent living, parental/guardian homes, adult companion homes, shared living arrangements, specialized home care, or supported living arrangements.
  - Each class member is placed in a location as close as possible, or practical, to the geographic area in which parents/guardians reside.
  - The Wyoming Protection & Advocacy (P&A) organization visits each program in the community. Visits are generally unannounced, and random files are reviewed to determine if the program is doing what it stated. The director of the Department of Health writes a letter to programs that states that the P&A has open access. DDD has a contract with the P&A to financially support its independent monitoring and assessment.
  - DDD has developed a database that serves both as a record of clients served and as an outcome and performance system that can be used in a continuous quality improvement process. This system includes the Inventory of Client and Agency Planning (ICAP) data set. The ICAP is a standardized instrument that assesses adaptive and maladaptive functioning. The ICAP form includes demographic data, services received or needed, present placement, and the placement recommended for two years in the future. It also records recreational and social activities in which the person participated in the 30 days before the completion of the form. Specific factors that may limit those activities are noted. Part of this process is extensive use of client satisfaction surveys.
  - Dental services are identified as being a hard service to fill in the community: "There's no money to pay for dental services in the state" except for children's dental needs and tooth extraction for adults.

### **Economics:**

- The annual cost to provide services to an individual at WSTS is \$147,000. The *average* annual cost to provide services in the community is \$61,000 per person.
- Wyoming changed its method for determining home and community-based services cost limits for people with developmental disabilities in 1998 to make funding levels more sensitive to individual needs and to reduce the appeals of local service planning decisions.
- Wyoming established individual budgets for its HCBS Waivers for people with DD to improve equity among waiver participants and to allow more gradual variation in participants' cost limits.
- To calculate the individual budgets, Wyoming uses a reimbursement model called DOORS. The state identifies factors that influence the level of support a person needs and are consistent with the state's policy that individual service costs

- should be independent of provider choice. Factors include living arrangement, work setting, the type of services received in the past, and functional and medical information from the assessment. State data on these factors are included in a statistical analysis to calculate the participants' individual budgets. (*Promising Practices in Home and Community-Based Services*, prepared for Centers for Medicare & Medicaid Services (CMS), 2001)
- Wyoming tests everyone for eligibility who applies for services, and adds the name to the waiting list, if eligible. By July 2003, the waiting list for services will be 80 adults and 10 children.
  - The Individual Budgeted Amount (IBA) model is perceived as fair and equitable because of the detailed information required of each eligible person. This drives the money – the more need established, the more money given to meet the need. This procedure adds funds to some plans and takes money away from others, based on characteristics and needs of the people served, considering the whole group. These data help to give legislators information on how to serve people with disabilities in the state.
  - Direct care staff wages in the community used to be one of the lowest in the country. In an effort to address the problem of attracting quality individuals to and retaining them in direct care positions, the Wyoming State Legislature directed the Department of Health to study wages and salaries of nonprofessional direct care workers in developmental disabilities programs and state institutions, among others. The study recommended an increase in wages to an average of \$10.23 per hour in order to recruit and retain nonprofessional direct care staff in the future. The funds required to implement the study recommendations were approved by the legislature and implemented by DDD in 2002, resulting in an \$8.00 minimum entry wage. As a result of the increased wage, there has been a 50% reduction in employee turnover.
  - Wyoming was one of the last states to join the HCBS Waiver program. In response to the *Weston* agreement, Wyoming officials began to obtain ICF-MR certification and federal matching funds. Between FY 1990 and 1999 federal contributions to the state's service system for ICF-MR (at WSTS) and HCBS went from \$0 to a combined total of nearly \$35,000,000.

**Noteworthy:**

- After conducting a review of the Wyoming system for services to people with developmental disabilities in 1989, Wyoming Protection and Advocacy, Inc., filed legal action against the State of Wyoming. It had concluded that the entire service system, including WSTS, was inadequate to meet the basic needs of people with MR/DD.
- Legal action was filed in 1990, *Weston et al. v. Wyoming State Training School*, and in 1991, that class action was settled. The settlement agreement in 1995 established specific census ceilings, sharply reducing the population. The *Weston* consent decree also specified that people with a broad array of disabilities have the opportunities to live in community settings. The lawsuit was successfully dismissed in 1996. It is the only deinstitutionalization lawsuit in which a state was not found in contempt.

- The state won the national Ben Censoni Public Service Award in 1999 for the rapid improvements in the statewide DD service system in the 1990's.

**Interviewee Reflections:**

- Institution is not a dirty word in Wyoming. It's part of the continuum of services.

## SECTION II: SITE VISITS

### MINNESOTA

On May 12-13, 2003, we met separately with Bruce Johnson, who was the “de-institutionalization Czar” at the time of planning for closure, and with Dr. Colleen Wieck, Executive Director of the Governor’s Council on Developmental Disabilities. Mr. Johnson spoke about the process of engaging representatives from relevant state departments in the process to ensure commitment to closure as well as successful implementation.

The meeting with Dr. Wieck took place at the site of the Association of Residential Resources of Minnesota’s provider convention. Conducting the interview at this site allowed us to review materials from various providers and ask questions of provider staff.

In response to our inquiry related to the basis underlying the push to close institutions in Minnesota, Dr. Wieck indicated that the state has been undertaking efforts to close institutions since the 1980s. However, she indicated that to be successful, all involved parties had to reach compromises.

According to Wieck, starting in 1981, a push for closure of institutions commenced as a budget savings in the Governor’s home district in Rochester. In 1983, a waiver program was developed to secure reimbursement from the federal government. In 1984, in an effort to prevent the use of the waiver program to assist in the closure of institutions, six bills were introduced by AFSCME to eliminate the waiver program. At that time AFSCME believed that the waiver program was a threat to the institutions, and they wanted a plan for the future.

In 1984, the DD Council, which is outside of Minnesota’s Department of Human Services, was directed to conduct a study regarding the impact of closure. The DD Council conducted eight discrete studies between May 1984 and January 1985 to address the impact of closing the institutions, among which were the following:

1. A study of the age and maintenance of each institution and possible alternative uses for the buildings for such things as state or federal prisons. Many groups claimed that the buildings were on the historic register and therefore could not be changed. In fact, none of the institutions was identified on any historic register.
2. A study comparing the energy consumption of each institutional building that identified which campus was the most inefficient.
3. A study that analyzed the cost of serving the individuals in the community vs. the cost of continuing to serve the individuals in the institution.

4. An economic impact study that utilized Zip Codes to identify where staff lived and then analyzed buying patterns to see if wages were generally spent in the community where staff lived rather than in the community where the institution was located. Most staff did not reside in the community where the institution was located, and the study documented that money from wages was being spent in the community where staff lived and not in the community where the institution was located.
5. An employee survey as to what the employee would do if the institution closed. Survey results showed that employees preferred continued public employment.

As the studies were being conducted, the state held meetings with the unions, parents, and business community groups that opposed closure of the institutions. The state also created a board made up of people from each affected state agency/department. Board members went on tours to Rhode Island and Michigan to see what had happened when those states deinstitutionalized.

The DD Council Board passed the matter to the Legislature without recommending closure of any institution. The Governor, however, wanted a plan for deinstitutionalization because he had a nephew with significant disabilities and was a strong proponent of the rights of individuals with disabilities.

A “negotiated investment strategy” was then developed as a means to bring all the stakeholders into the room to develop a plan to close all DD units in institutions by the year 2000, with half of the individuals going into public sector programs and the other half into the private sector.

Dr. Wieck indicated several significant cases helped bring the issue to the forefront. In 1980, the *Welsch* consent decree was signed, which was a major stimulus for beginning the downsizing process, requiring reduction in the institutional population and improvements in the delivery of services both to those in the community and in state institutions.

Wieck indicated that the timing of the settlement was good in terms of the work of the investment strategy group. Pressure from the Attorney General, the Governor, the Department of Human Services, and the P&A to do something led to recommending that all individuals be removed from the institutions by 2000.

Dr. Wieck related that it was critical to devise an effective closure process to be utilized with the first institutional closing in order to have an effective process for the remaining closures that would follow.

During Governor Ventura’s administration, state services included a few ICFs with a four-person waiver program. For economic reasons, the state is considering raising that

to a five-person ICF. Day programs and crisis services are also provided through state services.

Dr. Wieck indicated that there remains a pay differential between state community employees and the private provider employees. This differential results from the closure plan, which included a memorandum of understanding (MOU) and a bargaining agreement with the union. Part of the MOU included a provision that state system employees receive lifetime perpetual employment. Many have suggested that such a solution creates problems and that it would be better to have a phase-out of state employees with retirements.

Dr. Wieck made the following recommendations with respect to any effort to close institutions in Illinois:

- Shift to the Medicaid Forecast model to remove the state funding review from the legislators.
- Conduct a study to refinance the system. Two experts in looking at better uses of Medicaid waiver programs are Gary Smith and Robin Cooper. Michigan also has a large waiver program, and their financing system might be of interest.
- The waiver for individuals with the most severe disabilities should be enhanced and a waiver-screening tool used to identify the level of funding that should be used. Additionally, ensure that waiver moves with the individual.

She recommended the following role for the Illinois Council on Developmental Disabilities:

- Fund a Medicaid maximization study. Bill Copeland is an expert in Title 19 and 20 funding. Another expert is retired University of Chicago Professor William Pollak, whose specialty is long-term care financing.
- Fund a study to determine methods of implementing the CIPP recommendations. Robert Gettings may be an expert in this area.
- Fund Equip for Equality's Training Institute to serve as co-trainers with people with disabilities who could lead workshops for the residents in institutions interested in transitioning to the community.

Dr. Wieck also indicated that the *Sanchez* lawsuit in California, which utilized the ADA in a parity/bias argument related to funding issues, might provide useful guidance. She also stressed that the process should include education of parents and parent mentoring when individuals are ready to leave the institutions.

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On May 14, 2003, we met with Mike Tessneer, CEO of the State Operated Services, Mike Maus, Director of Minnesota Extended Treatment Options Program, and Roger Deneen, Director of Minnesota State Operated Community Services Program (collectively referred to as the interviewees). The meeting was held at the state offices of

the Department of Aging and lasted for approximately two hours. Mr. Tessneer was unable to stay for the entire meeting due to the ongoing legislative session.

In response to questions regarding the basis underlying the switch from institutional services to a community-based service delivery system, the interviewees indicated that the switch had the support of a Democratic governor and legislature. When the switch was made to a community-based service delivery model for individuals with developmental disabilities, the private providers opposed the government's coming in as a provider. However, the state began to serve the most difficult individuals, which amounted to only about 2.5% of the population. These were the individuals whom the private providers did not want to serve.

One of the compromises reached in the process was an agreement between the state and AFSCME, which included not only an early retirement and buy-out program, but also significant protection for union jobs through access to new positions in the community and within other departments of the state.

The state also believed that for the switch to a community-based service delivery model to be successful, the state would have to educate guardians and bring in private providers to work with the state to set up state-operated community programs. Furthermore, the state recognized that it would have to "deinstitutionalize" the state employees and address the risks in the community that did not exist in the institutions.

A very important aspect of the closure of the institutions was the development of community support services. The state developed a statewide program of experts and highly trained technicians who will come into a community provider to assist with an "out-of-control" resident. This team will assess the support system around the resident and determine what needs to be provided to allow the individual to remain in his or her home. Recommendations are then made to the provider. Only if the team is unable to help reduce the difficulty the resident is experiencing will the resident be moved to a different setting for more intensive assessments. The removal is of short duration, with the goal to return the resident quickly to the community. Using this system prevents transfers of residents into mental health facilities or into the criminal justice system.

Since the mid-1980s, approximately 2,000 people have moved back to the community. Ultimately the unions became supportive of the switch because they saw that the state-operated institutions were not the way of the future. The state has spent a lot of time working and developing relationships with the unions. During the last four closures, the union was very supportive and even testified in favor of the closures. The interviewees believe that union support resulted from the agreement to protect union jobs. Currently there are 1,400 state employees in the community in residential, day, and vocational rehabilitation services.

The interviewees believed that it was critical for the state to gain the trust of the union. The union is provided with information from the Department of Human Services, including budget information, and nothing is hidden. It is imperative to develop a long-

term partnership with the union if the community system is to work. It is also imperative for there to be buy-in from all the stakeholders, each of whom must be flexible and willing to compromise to reach the end goal.

The interviewees indicated that the partnership with the union and the community providers was the most important. While they did not see the governor's office as a critical player in the process, that office must also be supportive for the switch to a community-based service delivery model to be successful.

As the state was moving residents, it found that moving whole units at the same time was more successful. Otherwise, the residents who were moved early in the process had many choices as to other placements, but by the end of the process, the choices were much more limited. The interviewees believe that the guardians and the counties made most of the placement decisions rather than the individuals.

As state-operated community providers were established, they received \$30,000 per home from the state as start-up money to purchase furnishings, decorations, etc. State employees had to undertake different responsibilities in the community, such as cooking, cleaning, maintenance, and shopping, which were jobs that other staff handled in the institutions. Approximately one-half of the state-operated homes in the community are leased by the state. The state does not want the state-operated community system to expand; rather it is the state's intention for the private sector to eventually take over the entire system.

In response to questions regarding the utilization of campuses following the closure of institutions, the interviewees indicated that the state has worked with local communities to turn over control of the land to the community. However, the state remains responsible for tearing down the old institutions and removing the debris. The local communities have leased some space back to the state.

The state has found that while local communities support the idea of taking the land back, some legislators are not as supportive of the proposition. The prison system has found some of the buildings problematic because that system was forced to bring the buildings up to code before utilizing the facilities for prisoners.

Since the mid-1990s, one campus has been used to house a small population of individuals with mild mental retardation who are also violent and dangerous. This population has been growing in Minnesota since the mid-1990s. When this trend was identified, the state began to discuss ways to serve this population and developed a program on the campus of a closed institution in 12 six-bed homes.

In response to questions regarding the current oversight system, the interviewees indicated that the state conducts "paper reviews." As Minnesota has a county-based service system, the counties do the licensing surveys. The counties have closed homes when serious problems have been identified. There can be multiple agencies investigating the same incident. If the state believes that the county has not done a good

job of investigating, they may investigate as well. Serious injuries and deaths are reported to the State Ombudsman. The interviewees describe the reporting system as very good under the Vulnerable Adults Act.

In response to questions regarding the role of the DD Council, the interviewees found the studies done by the council to be critical, as the studies provided the basis upon which to support the decision for the switch to a community-based service delivery system. Some of the data developed during the studies drove decision-making. The analysis done by Dr. Wieck was described as so thorough that it provided the basis for some of the decisions. In addition, the policy papers, pictures, and real-life stories about the community were helpful.

In retrospect, the interviewees indicated that if they had to go through the process again, they would avoid the intermediate care facility model entirely. Also they would utilize fewer nurses because nurses operate using a medical model. On the other hand, having more nurses made the parents feel more at ease over the switch to a community-based service delivery model.

Additionally, the interviewees indicated that the service delivery system must be structured in such a way to keep people moving out into more and more independent settings, which are not dependent on how many “slots” are available. They also suggested that there need to be various models available and that whatever reasonable suggestions the stakeholders have should be tried. They believe that Medicaid waiver programs offer good flexibility.

## NEW YORK

### Site Visit 1:

During our visit to Albany, New York, we had the opportunity to visit two residential and several day program sites that are operated by Liberty, the Montgomery County Chapter of the New York State ARC (NYSARC). We met with Frank Capone, Executive Director, who provided the tours.

In visiting the day program sites, it was apparent that they have very suitable staffing patterns in all areas of the day program. Individuals that were medically fragile were in an environment that was rich in appropriate stimulation. The physical environment was tastefully decorated with warm, indirect lighting, and they had enough staff to ensure that everyone was engaged in activities and that their physical needs were being met. The correct positioning of individuals was taken very seriously by staff. The program had many positioning devices, such as tumble-forms (positioning blocks made out of foam rubber). Hospital-type beds, molded wheelchairs, and recliners were also available. A full-time physical therapist trains staff in individual positioning needs and regularly checks to ensure that they appropriately utilize the equipment. There were many switch devices that enabled participants to independently listen to music, play games, turn lights on and off, etc. In addition to the physical therapist, they had a full-time occupational therapist and speech and language therapist. For individuals who were unable to take feedings orally, the speech therapist assisted them with pleasure feedings. This enabled individuals with swallowing difficulties to enjoy the flavor of various foods and feel they were part of the community at meal times.

We also visited the vocational workshop that is operated by Liberty. There are numerous types of work that are available to consumers. New York has a set-aside law that has provided many opportunities for contractual work for NYSARC chapters. There are over 300 people in supportive employment. Supportive employment is the first option explored for individuals, as the organization believes that every person should work in the community as independently as possible. Liberty runs a workshop with jobs ranging from cooking eggs for the prisons to packaging cleaning supplies. Quality control is completed as it is in any regular manufacturing job. The expectation is that the consumers are capable of performing the assigned job duties. Liberty staff does not “create work” for individuals that will require it to be redone by staff.

We visited two different residential sites, both operated by Liberty. The first setting was a four-person Individual Residential Alternative (IRA). This was a single-family dwelling in a rural neighborhood setting. The home was accessible, with common living areas, such as living room, dining room, and kitchen. Two individuals shared a room and the other two residents had their own rooms. They had a dog, and the care of the dog was shared by two of the individuals living in the home. Cooking duties were shared, with each individual taking responsibility for an evening meal. They had several evenings planned for outings to local restaurants or for ordering takeout. One of the residents stated that cooking was helping him with his reading, as he had to read the cookbook to fix dinner.

The house was tastefully decorated, and the bedrooms were very individualized by the residents. They had their own phone lines, and two of the individuals had their own computers.

Liberty does not use standardized behavior intervention plans. The residential director told us that if someone is having difficulties with “behavior,” they tend to put the person on one-to-one staffing and encourage the individual to take part in activities that engage them in positive interactions. The staff meet with the resident to figure out the cause of the behavior and how to effectively address it.

We also visited a 12-bed ICF-MR. This home was a single-story ranch-type house in a rural setting. There were neighboring houses about a half block away from each other. This house was wheelchair accessible, with wide doorways and hallways. The bathrooms had lifts that were attached to the ceiling that enabled staff to move nonambulatory residents from their wheelchair to the toilet or to the bathtub.

### **Site Visit 2:**

We met with Gary Lind, Director of Policy, Planning and Individualized Initiatives and Jan Abelseth, Deputy Commissioner for Quality Assurance of the state Office of Mental Retardation and Developmental Disabilities (OMRDD). We discussed how New York State has been able to successfully downsize and eventually close many of its institutions for people with developmental disabilities.

OMRDD ensures that all stakeholders are at the discussion/negotiation table and that their input is used to develop a plan specific to the developmental center. In the past, union employees were guaranteed jobs that included a choice in location and job role. Mr. Lind and Ms. Abelseth stressed the importance of “buy-in” by all stakeholders and that everyone must feel that his or her concerns are heard.

The state OMRDD has invested in oversight and has a program survey and certification program that oversees 600 programs in the state. They have 160 employees working in the field conducting unannounced visits and using a standardized protocol to ensure compliance. New York has developed an “early alert” system. This is a very organized system in which all departments involved in oversight meet on a monthly basis to discuss the salient issues related to the agencies that are experiencing problems, and a plan of action is formulated.

New York has strong support from the Legislature, parent groups, the union, and local communities for moving people with developmental disabilities into community settings. There are several types of established programs to help meet the needs of a wide range of individuals who are in need of residential services. Self-determination is starting to play a larger role in how residential placement is determined.

New York has approximately 6,000 people on a waiting list for residential services. The New York Cares I and II Projects were established by Governor Pataki to address, in large part, the waiting list for residential services.

The following recommendations were suggested by OMRDD staff for the benefit of the Illinois Council on Developmental Disabilities (ICDD):

- To fund self-determination grants
- To form a joint committee of representatives of the ICDD, the state Quality Assurance, the Protection & Advocacy organization, and People First to determine what projects to pursue
- To organize a retreat with all stakeholders to start planning for the downsizing of Illinois' state-operated institutions.

**Site Visit 3:**

We met with Steve Holmes, the Executive Director of The Self-Advocacy Association of New York State, and with Chester Finn, who is an active member of this organization and who works as a Consumer Advocate for OMRDD in the state office. The organization's voice is heard in the planning of services and in areas of facility closure and community development. They receive funding from the state, as well as from private sources. Mr. Holmes and Mr. Finn strongly encouraged Illinois to plan a retreat for all stakeholders so that planning can be initiated. This group is currently going into facilities and asking residents if they want to move to smaller settings. If the answer is yes, they are using the Olmstead ruling to help people move to smaller, less restrictive environments.

**Site Visit 4:**

The New York State ARC (NYSARC) is a \$1 billion nonprofit corporation. Two-thirds of the state Board of Directors is composed of family members of individuals with developmental disabilities. We met with Marc Brandt, the Executive Director.

Mr. Brandt stated that community services in New York are state of the art, and some of the reasons include the following: New York maximizes the federal money that is available, the service delivery system is user-friendly, and there is strong legislative support for a community-based system. He asserted that the parent groups are strong advocates for community settings and that self-advocacy has played a significant role as well. Mr. Brandt also stated that having a competent administration to oversee the Federal Waiver Program has been very instrumental in ensuring that the money is utilized in the best way possible. He recommended that ICDD develop some pilot programs to bring all stakeholders together and start working on joint projects that will help organize parents and self-advocates.

**Site Visit 5:**

We met with several staff of the New York State Commission on Quality of Care (CQC), the designated New York Protection and Advocacy organization. They also commented on the importance of OMRDD oversight. CQC staff stated that the weekly "hot sheet" produced by OMRDD, part of the early warning system mentioned previously, helps all agencies/programs improve services and address problems from many different levels. CQC staff stated that for downsizing and closure to succeed, the following must be in place:

- Executive commitment

- Parent/family advocacy
- Consumer self-advocacy
- Maximized federal dollars
- A strong state Quality Assurance model

**Site Visit 6:**

We met with Ann Hardiman, Executive Director of the New York State Association of Community and Residential Agencies (NYSACRA) and two staff who work in community programs. They recommended that ICDD contribute to funding self-advocacy and parent/family advocacy. They stated that these two groups had very large roles in planning and moving forward the downsizing and closure of state-operated facilities in New York. They also recommended that we read the Values-Based Training material that is published by the Keystone Institute.

## WISCONSIN

Three separate site visits were made to Wisconsin to learn about its current experience with downsizing and closing one private and one state-operated facility.

### **Site Visit 1: Milwaukee**

The first visit was to Milwaukee to meet with team members responsible for closing and providing transition services for residents of the Hearthside Center, a private ICF-MR with a census of 183. The closure was announced in May 2002 and Hearthside will be closed by December 2003. We met with Janet Eakins, the Chief of the Provider Regulation and Quality Improvement Section of the Wisconsin Bureau of Quality Assurance; Steve Biondi, the Vice President of Pathway Health Services, the consulting agency hired by the state to close Hearthside and provide transition services; and April Olsen, the Pathway social worker.

Hearthside had been placed under state's receivership as a result of the termination of federal programs for two years. During that time, the conditions at the facility did not substantially improve, and, lacking the necessary funds to keep the facility open, Hearthside was taken over by the state. Pathway Health Services was then hired to close the facility, and \$300,000 in state funds was used to make needed renovations and increase staffing levels in the meantime. To prevent loss of staff during transition, each staff person was given a retention bonus if he/she agreed to continue working until the facility closed.

Many parents/guardians were initially angry when the closure announcement was made and were most concerned about where residents would be placed. There was a natural tendency to look at another private ICF-MR or a nursing home for placement. The team sought to educate the parents/guardians about the residential options available in the community. Parents/guardians felt they were getting a mixed message about closure because the building was being upgraded and brought up to standards, residents were getting more active treatment, and other positive changes were occurring during the transition period. One of the modifications that Pathway made was grouping residents according to functional ability, which improved adaptive behavior and increased social interaction.

An interagency meeting convenes every other week to discuss transitioning of individuals from Hearthside. This group includes representatives from the state, county, and advocacy groups. The residents are discussed individually to determine the most appropriate, least restrictive placement. Each resident had been met with to disclose the change and to discuss residential options. All residents have been offered choices in the community and have the opportunity to visit prospective programs, including an overnight visit. The community agencies that provide residential services to Hearthside residents will receive an enhanced waiver rate.

We toured the renovated Hearthside, where it was noted that the facility had new overhead lighting throughout the resident areas; newly-painted hallways and resident

rooms; centralized, open nursing stations; and new floors. Staff were welcoming and were actively engaged with residents.

### **Site Visit 2: Madison**

We traveled to Madison to meet with Michael Linak, the Assistant Bureau Director, Bureau of Developmental Disabilities, of the Department of Health and Family Services, to discuss Wisconsin's first state-operated institutional downsizing effort, the Northern Wisconsin Center (NWC). Northern is the smallest institution, with a census of approximately 175. It is expected that about 20 residents will remain there in a short-term intensive behavioral care unit. Downsizing at NWC has been ongoing since 1996, when a new administrator was in place who was committed to moving people into the community. NWC has an established track record of successfully placing residents in community alternatives. The final downsizing is now scheduled for between July and December 2004. (For a full account of the issues related to NWC, read the Wisconsin State Profile).

After the meeting with Mr. Linak, we toured a vocational and residential site with Marge Steingraber, a Community Integration Specialist with the Bureau of Developmental Disabilities, Division of Supportive Living. We visited numerous work stations in state government offices to meet and observe individuals with a range of developmental disabilities do a variety of tasks, from shredding documents, to picking up recycling materials from offices, to fixing boxes for election judges for an upcoming election. Some of the individuals had been working at this site for as long as 20 years. They are generally paid about \$4 to \$5 an hour. The unions have been supportive of these job placements, as the work being done is not taking jobs away from someone else. One problem that was identified is that the rate of pay is "frozen" at the rate that the person received when he or she moved out of the institution. A private contractor with Dane County places and provides job coaching.

We also visited a single family home in the community where four women lived. Unfortunately, all of the residents were still at their day programs, but we did have the opportunity to tour the house with two staff. The house had been modified and adapted to meet the needs of the residents who had physical disabilities.

### **Site Visit 3: Northern Wisconsin Center, Chippewa Falls**

On May 13, 2003, we had the opportunity to visit the NWC for the Developmentally Disabled in Chippewa Falls, Wisconsin. We first met with Dawn Koepen, Volunteer Coordinator, who was able to provide us with a historical overview of the center and a tour of the facility. A book has been written about NWC, *Island of Refuge*, which traces the 100 years of history surrounding the center.

We toured the workshops that included the Northern Industries workshop, Leinenkugel workshop, Wal-Mart workshop, and a craft workshop. Individuals spend half a day working in the workshop and then go back to their living units for lunch. Work that was available included assembling hardware kits for truck hitches, relabeling Wal-Mart boxes, stuffing the Sunday advertisements into the Sunday paper, and making necklaces

and bracelets for sale. Although the individuals were obtaining vocational experience through subcontract work provided by the Leinenkugel Brewery at the facility, it has been suggested that the facility consider working on the assembly of the master carton boxes at the company in order to more fully integrate the individuals into the community and assist the individual in transitioning from the institution to community employment.

In each of the work areas, the staff-to-client ratio appeared to be 1:8 and per staff report appeared to be manageable. The program participants appeared to like the work they were completing and seemed focused on the task. It appeared that staff had to spend a lot of time on quality control, and only a few individuals were working at a time so that staff could closely supervise the work activity. Staffing levels are low due to the downsizing and staff leaving for other employment.

We walked through the campus and saw the outside of the various buildings. Staff indicated that person-centered programming occurs at NWC and that procedures are in place to minimize the use of mechanical restraints. Attempts are made to have the individuals involved in the community as much as possible, and a Human Rights Committee oversees the development of behavior plans.

In the afternoon, we met with Mary Green, Developmental Disabilities Program Manager of the Department of Health and Family Services (DHFS). She explained how NWC was chosen for the significant downsizing, and the challenges of accomplishing this. There was a discussion with a representative from DHFS, who indicated that the state is in the early stages of significantly reducing the client enrollment at NWC. Although there are budget problems in Wisconsin, the state has been interested in downsizing its state-operated facilities and had attempted to do so previously. Past and present efforts to close state-operated institutions have been met with resistance from the union, parents, and legislators, and have often received negative coverage from the media. Staff had contacted other states for technical assistance in meeting this opposition, only to discover that these states had also experienced similar patterns of resistance. Some of the challenges during the initial downsizing stages have been maintaining enough staff, communicating with families and guardians, and assisting the community providers in developing services.

It was also noted that it had been helpful to have People First become more politically involved in the process, as well as to have the Wisconsin Protection and Advocacy System “at the table” from the beginning. Initiating the formation of a parents group has also helped. Conversely, not having all stakeholders (guardians, staff, residents, community) involved in the process from the beginning was viewed, in hindsight, by the state as a step that would need to change for any future endeavors.

Some approaches utilized by the state to improve the downsizing process include a toll-free hotline operated by DHFS staff to respond to concerns and questions, and a guardian mentoring network that authored a “most commonly asked questions and answers” pamphlet and created links between those parents and guardians with community experience and those whose family members were soon to be transitioned to the

community. Finally, Wisconsin has offered an enhanced rate to providers for serving individuals from NWC. Staff from the institution are now applying to become providers, and seemingly this would benefit the individuals in the transition to the community.

## SECTION III: LEGAL CASE STUDIES

### INTRODUCTION

Using a variety of sources – the docket of the National Association of Protection and Advocacy Systems;<sup>7</sup> published summaries of community integration litigation;<sup>8</sup> legal research tools; anecdotal information from lawyers in other states; and information from the interviews conducted by the CIPP Project’s primary investigators– we compiled a list of all known community integration litigation in the country. We included cases brought on behalf of people with mental illness and physical disabilities in this list, as the legal theories used in such cases are generally applicable to cases for people with developmental disabilities. We identified 44 states in which some type of community integration case has been brought.

We then gathered relevant documents from the identified litigation, including complaints, memoranda, and court decisions. We now have a document file for every state in which a community integration case has been filed. After reviewing these materials, we selected three states to look at more intensively – Pennsylvania, Tennessee, and New Mexico. The three states were chosen using a variety of factors, with no single factor being dispositive: high volume of litigation, particularly effective litigation, use of a broad range of legal theories, and representation of a broad range of plaintiffs. We carefully analyzed all of the pleadings and decisions in each state’s community integration cases, and also conducted interviews of some of the key players in the litigation. The cases analyzed in the three state studies are set forth in chronological order, to allow the reader to see the historical evolution of community integration litigation in each state.<sup>9</sup>

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<sup>7</sup> [www.napas.org](http://www.napas.org)

<sup>8</sup> Gary Smith, April 28, 2003, Status Report: Litigation Concerning Home and Community Services for People with Disabilities, *Human Services Research Institute*, Tualatin, Oregon, [www.hsri.org](http://www.hsri.org); Mary Hayden, 1997, Class Action, Civil Rights Litigation for Institutionalized Persons with Mental Retardation and Other Developmental Disabilities: A Review, *21 Mental & Physical Disability L. Rep.* 41.

<sup>9</sup> The Supreme Court’s decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), has and will continue to play an important role in community integration cases relying on the Americans with Disabilities Act (ADA), so will be briefly summarized here. In that case, two women with developmental disabilities and mental illness living in a state-operated facility sued under the ADA because they were not permitted to move into the community, despite the fact that state treatment professionals deemed them appropriate for community-based placements. The Court held that unwarranted institutionalization of people with disabilities is a form of discrimination that is actionable under Title II of the ADA. The Court thus ruled that the ADA requires states to serve people with disabilities in community settings, rather than in segregated institutions, when three factors are present: treatment professionals determine community placement is appropriate; the person does not oppose community placement; and the placement can be reasonably accommodated taking into account the resources available to the state and the needs of others who are receiving state-supported services.

The Court also held, however, that a state’s responsibility for community placement “is not boundless.” 527 U.S. at 603. States are not required to make modifications that will entail a fundamental alteration of the state’s services and programs: “Sensibly construed, the fundamental alteration component of the reasonable modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has

The goal behind all of these efforts is a simple one: to learn from the litigation experiences in other states about the efficacy of particular litigation strategies and how those strategies may be utilized to address community integration issues in Illinois.<sup>10</sup>

## **CASE STUDIES**<sup>11</sup>

### **PENNSYLVANIA**

Pennsylvania residents with disabilities, aided by a dedicated group of disability rights lawyers, have made extensive use of the federal court system to vindicate their right to live in the community. Plaintiffs in these cases represent a significant cross-section of the disability community, including adults, children, people with mental illness, people with developmental disabilities, people living at home, and people living in institutions. Plaintiffs have relied on a number of different legal theories, including ones based on the U.S. Constitution, the Medicaid laws, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act. Pennsylvania's volume of cases, combined with the variety of plaintiffs and legal theories involved in the cases, makes it an obvious state to look at when evaluating litigation as a tool to achieve community integration for people with disabilities. In addition, there are many similarities between Pennsylvania and Illinois. Both are northern industrial states that also have large rural populations. The rural population of each state is generally more politically conservative than the urban population. Each has a strong union movement.

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undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.” 527 U.S. at 604. Thus, a state could meet its obligations under the ADA if it had a “comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated.” 527 U.S. at 606.

<sup>10</sup> In Bruggeman v. Blagojevich, 2003 WL 1793049 (7<sup>th</sup> Cir.), plaintiffs, who resided at home with their parents, sought ICF/DD services. The State had offered the plaintiffs placement only at ICF/DDs located at a considerable distance from their home, which plaintiffs argued violated several provisions of the Medicaid Act, as well as Section 504 of the Rehabilitation Act and Title II of the ADA. The Court of Appeals upheld the district court’s dismissal of the Medicaid claims, finding that none of the provisions relied on by the plaintiffs required the State to offer ICF/DDs closer to their family homes. The Court of Appeals reversed the district court’s dismissal on Eleventh Amendment grounds of the ADA claims, overruling its previous decision in Walker v. Snyder and holding that plaintiffs could sue state officials under the ADA. The Court remanded the case to the district court to consider plaintiffs’ claims under the ADA and the Rehabilitation Act, directing the district court to consider whether Illinois has a plan to end segregation and isolation for developmentally disabled adults. The case is still pending in the district court. The Court of Appeals’ holding that plaintiffs may sue state officials under Title II of the ADA is a positive development in the law for any future community integration litigation.

<sup>11</sup> Parentheticals next to the titles of the cases are used to provide a “thumbnail sketch” of each case. The first indicator states whether the plaintiffs have DD, MI, physical disabilities, or consist of a mixture of plaintiffs – for example, some with MI and some with DD. The second indicator states whether the plaintiffs live in the community, an institution, or consist of a mixture of plaintiffs – some who live in the community and some who live in institutions. The third indicator states the legal theories of the case – Medicaid Act, the ADA, the Constitution, etc. The final indicator states whether the case was an action on behalf of individuals, an organization, the federal government, or a class.

The lawyers of the Disability Law Project and the Public Interest Law Center of Philadelphia deserve enormous praise for their relentless efforts to obtain community services for Pennsylvanians with disabilities. Indeed, their productivity has been so high that not all of their community integration cases are described below.

**Halderman v. Pennhurst State School and Hospital** (DD/institution/Constitution, Section 504, state and federal DD statutes/class)

In one of his final published decisions in Pennhurst, Judge Broderick, who presided over the case for its entire 25 years, summarized the tremendous importance of the case:

The *Pennhurst* case has brought numerous benefits to the plaintiffs in this class action as well as to other persons with mental retardation throughout Pennsylvania and the country. The *Pennhurst* litigation is widely credited with creating a general awareness that persons with mental retardation do have rights: the right to be free from abuse and mistreatment, the right not to be warehoused in institutions, and the right to receive habilitation and training. In short, the *Pennhurst* case stands for the principle that persons with mental retardation have the right to minimally adequate habilitation in the least restrictive environment.

*Pennhurst* has served as a model for deinstitutionalization litigation across the country.

995 F. Supp. 534, 542 (E.D. Pa. 1998)

A detailed account of the Pennhurst case is beyond the scope of this report. However, a basic understanding of the case is necessary because of its tremendous importance to the community integration movement. Much of the information which follows comes from the court's 1998 decision, cited above, and from the original decision after trial, 446 F. Supp. 1295 (E.D. Pa. 1977).

In 1974, a class action was filed on behalf of the more than 1200 residents of Pennhurst State School and Hospital. Pennhurst was founded in 1908 and dedicated by the Pennsylvania Legislature to the "segregation ... of epileptic, idiotic, imbecile, or feeble-minded persons." The plaintiffs alleged numerous constitutional and statutory violations.

After a 32 day trial, the court issued findings of fact, conclusions of law, and a corresponding order. 446 F. Supp. 1295 (E.D. Pa. 1977). In essence, the court found a deplorable institution. Specific problems included overcrowding, understaffing, no contact with the outside community, grossly unsanitary conditions, no privacy for residents, overuse of restraint and seclusion, no meaningful habilitation for most of the

residents, no plans for return to the community for most of the residents, inadequate medical care, rampant abuse (both resident-on-resident and staff-on-resident), and misuse of psychotropic medications. The court then issued five holdings.

First, the court held that, when a state involuntarily commits a person with mental retardation, it must provide them with habilitation to acquire and maintain life skills. The court found that the residents of Pennhurst had not received this minimally adequate habilitation and, furthermore, that such habilitation could not be provided at Pennhurst, because its segregated, institutional atmosphere was not “conducive to normalization which is so vital to the retarded if they are to be given the opportunity to acquire, maintain, and improve their life skills.” 446 F. Supp. at 1318. Due process, the court held, “demands that if a state undertakes the habilitation of a retarded person, it must do so in the least restrictive setting consistent with that individual’s needs.” 446 F. Supp at 1319. Thus the court defined the State’s obligation to Pennhurst residents as habilitation in the least restrictive setting.

Second, the court found that the residents had an Eight and Fourteenth Amendment right to be free from physical abuse, which had been violated by the excessive abuse at Pennhurst. Third, the court found that “the confinement and isolation in the institution called Pennhurst is segregation in a facility that is clearly separate and not equal,” in violation of the residents’ rights under the Equal Protection Clause of the United States Constitution. 446 F. Supp. at 1322. Fourth, the court found that the defendants violated their state statutory obligation to provide habilitation to Pennhurst residents. 446 F. Supp. at 1322. Finally, the court found that the residents’ rights under the Rehabilitation Act were violated, as Section 504 “prohibits the segregation of the retarded in an isolated institution such as Pennhurst where the habilitation provided the retarded does not meet minimally adequate standards.” 446 F. Supp. at 1324.

The court did not find any basis for awarding damages, as the court found that the defendants met their burden to show good faith immunity. The court did, however, order extensive injunctive relief. The court enjoined the defendants to provide suitable community living arrangements for all Pennhurst residents, and all people on the waiting list to enter Pennhurst. The court further ordered the development of individual plans for each member of the class and mechanisms to monitor class members in the community. The court prohibited the county defendants from seeking to admit anyone into Pennhurst. Finally, the court made several orders regarding conditions at Pennhurst, including restricting the use of restraint, seclusion, and psychotropic medications. The court appointed a special master to monitor the settlement.

A six year appeal process followed. The defendants appealed the court’s decision to the Third Circuit, which affirmed the decision on the basis of the Developmentally Disabled Assistance and Bill of Rights Act (“DD Act”), which the trial court had not considered. Defendants appealed to the Supreme Court, which found that the DD Act did not create any substantive rights for individuals with mental retardation, but was only a grant of federal money. The Supreme Court remanded the case back to the Third Circuit to consider the legal bases that the trial court had relied on in its ruling. The Third Circuit

again affirmed the trial court's decision, this time on the basis of Pennsylvania's statute, which the trial court had relied on as a basis for liability. The defendants again appealed to the Supreme Court, which held that the Eleventh Amendment bars a federal court from ordering prospective injunctive relief against state officials on the basis of a state law. The Supreme Court remanded to the Third Circuit to consider the remaining constitutional and statutory issues.

In 1984, while the case was pending in the Third Circuit (for the third time) the parties reached a settlement, which was entered by the court as a consent decree and which is described at 610 F. Supp. 1221 (E.D. Pa. 1985). Pennsylvania agreed to close Pennhurst by 1986 and, together with the county defendants, to provide community living arrangements and habilitation to the class members.

Pennhurst was finally closed in 1987. However, there were contempt findings against the defendants in 1989 and in 1994, based on the defendants' complete failure to provide former Pennhurst residents the community services to which they were entitled under the settlement. During this time, the defendants attempted many legal maneuvers to avoid their obligations under the consent decree. Between 1994 and 1998, under the guidance of a new special master, the defendants achieved substantial compliance with the consent decree. On July 21, 1998, Judge Broderick purged the findings of contempt against the defendants and closed the Office of the Special Master, though the court did retain jurisdiction of the case. Judge Broderick, who made an enormous contribution to the lives of people with mental retardation, died of cancer in August of 2000.

### **Youngberg v. Romeo** (DD/institution/Constitution/individual)

Although not a community integration case, this United States Supreme Court decision, 457 U.S. 307 (1982), has provided the legal foundation for many subsequent cases throughout the United States alleging unconstitutional conditions in state institutions and the right to receive habilitation in the community. Indeed, this case has been quoted in more than 2000 subsequent decisions. Nicholas Romeo, the plaintiff/respondent in the case, had profound mental retardation. He did not speak and lacked basic self-care skills. At the request of his mother, who was unable to care for him after his father died, he was involuntarily committed at the Pennhurst State School. There, he sustained many physical injuries, was frequently restrained, and was not provided with treatment or programs for his mental retardation.

The State conceded a duty to provide adequate food, shelter, clothing and medical care. The question before the Supreme Court was whether the State owed more than this – whether Romeo had a constitutional right, under the liberty clause of the Fourteenth Amendment, to safety, freedom from restraint, and training. The Court concluded that Romeo did indeed have a right to safety and freedom from restraint. With respect to training, the Court concluded that, at minimum, Romeo had a right to training related to his other liberty interests – safety and freedom from restraint. In other words, Romeo was constitutionally entitled to training that would help him remain safe and be free from restraints.

In terms of the standard to be applied to determine whether these liberty interests were violated in Romeo's case, the Court concluded that decisions, if made by professionals are presumptively valid. If, however, the decision was a substantial departure from accepted professional judgment, practice or standards, then liability could be imposed. The case was remanded for proceedings consistent with the Supreme Court's decision.

**Clark v. Cohen, et al.** (DD/institution/Constitution, Rehabilitation Act/individual)

The plaintiff in this case was a middle-aged woman who had spent her whole adult life at Laurelton Center, a state institution for people with mental retardation. She was initially committed there by a court when she was 15 years old. Throughout her commitment at Laurelton, she wanted to leave and repeatedly asked for a hearing. No hearing was ever provided, despite the fact that plaintiff's treatment team consistently expressed to the administration that she was too high-functioning for the institution and should be moved to the community. Plaintiff brought suit in federal court under Section 504 of the Rehabilitation Act and under the due process clause of the United States Constitution.

With respect to Section 504, plaintiff argued that "because other similarly situated people are provided services in more integrated settings such as CLAs, her retention at Laurelton constitutes unnecessarily separate or different treatment which the regulations declare discriminatory." 613 F. Supp. 684, 692 (E.D. Pa. 1985). Defendants argued that the Rehabilitation Act does not reach discrimination among groups of disabled people. The court rejected this notion (as Olmstead did with respect to the ADA many years later), but the court rejected her Rehabilitation Act claim nonetheless, finding that plaintiff was not detained at Laurelton "solely because of her handicap as required by the Act." 613 F. Supp. at 693. Instead, the court seemed to believe that the plaintiff was confined more because of bureaucratic ineptitude than any reason relating to her particular disability. 613 F. Supp. at 693. The judge contrasted this to a situation where a plaintiff could point to a disability-related reason that he was confined, such as that the level of his disability caused the state to exclude him from less restrictive options. 613 F. Supp. at 694.

With respect to her constitutional claims, the court found that the defendants had indeed violated her right to procedural due process. The court found that there had been several events in plaintiff's 29 year commitment that should have triggered a review of her commitment – her reaching the age of majority, the repeal of the commitment statute under which she was committed, and the repeal of the subsequent commitment statute. 613 F. Supp. at 699-701. The court also found that her substantive due process rights were violated. Citing the case of Goldy v. Beal, 429 F. Supp. 640 (M.D. Pa. 1976), the case which invalidated Pennsylvania's then commitment standard, the court found that individuals should not be placed in an institution unless a community placement cannot be developed. 613 F. Supp. at 702. The court also found that the defendants had violated plaintiff's substantive due process rights as defined in Youngberg. 613 F. Supp. at 703-04.

The court ordered a permanent injunction to remedy the violations it found. The defendants argued that they lacked the funds to implement the injunctive relief. In marked contrast to recent decisions, the court was utterly unpersuaded by the defendant's arguments. The court noted that defendants had discretionary funds that they could spend on plaintiff and that they had not requested from the legislature any funds for non-Pennhurst individuals waiting for community placement. Finally, the court noted that plaintiff's community placement would cost the State very little for the first two years, and that, after that, the defendants would realize a cost-savings. After years of living in an institution, the plaintiff was finally released into the community.

The defendants appealed the trial court decision. Though they did not argue for plaintiff's return to an institution, they argued that they should not be forced to fund her community placement. The Third Circuit affirmed the trial court decision. 794 F.2d 79 (3rd Cir. 1986). The court found that the relief ordered did not violate the Eleventh Amendment, as a federal court "may order state officials to fund from the state treasury remedial measures found necessary to undo the harmful affects of past constitutional violations." 794 F.2d at 84. The court then affirmed the trial court's determination that the plaintiff's substantive and procedural rights were violated. The Supreme Court declined to review the case. Cohen v. Clark, 479 U.S. 962 (1986)

**Richard C. v. Snider** (DD/institution/Constitution, Medicaid, Section 504/class)

This action was brought on behalf of residents of the Western Center, an institution for people with developmental disabilities. The complaint alleged violations of the Medicaid Act, the U.S. Constitution, and the Rehabilitation Act. The plaintiffs sought an order directing defendants to operate the Western Center in conformity with Title XIX ICF/MR regulations; to provide adequate treatment, care and protection from harm; to cease using excessive restraint; and to provide community services to appropriate class members.

The court certified a class and, subsequent to the court issuing that order, the parties reached a settlement. At the fairness hearing, parent group intervenors contended that the court should decertify the class and deny approval to the settlement agreement. The intervenors argued that class counsel could not properly represent both the class and the organizational plaintiffs (the ARC and Pennsylvania Protection and Advocacy); because both groups were philosophically opposed to institutions, their interests were contrary to the interests of some of the class members. The court disagreed, finding the goal of the organizational plaintiffs -- "the placement of appropriate Western Center residents in community facilities with adequate support programs" -- to be "consistent with the interests of the entire class." 1993 WL 757634 \*5 (W.D. Pa.) The court therefore declined to decertify the class. The court then approved the settlement agreement, finding there was not "any relief initially sought by the plaintiffs that has not been obtained through the provisions of the settlement agreement." 757634 at \*9.

In 1999, several class members and their guardians sought to intervene in the case. 196 F.R.D. 288 (W.D. Pa. 1999). They sought to stay the placement of Western Center residents into community-based programs based on the Supreme Court's decision in

Olmstead. In Olmstead, the Court concluded that states are required to provide community services when three criteria are met: the state's treatment professionals determine the placement is appropriate, the individual with the disability does not oppose the community placement, and the placement can be reasonably achieved, given the resources of the state. The proposed intervenors interpreted Olmstead as *precluding* the placement of an institutionalized person in a community-based treatment program unless the three criteria set forth by the Olmstead court are met.

The court rejected this interpretation. It held that, in setting forth the situations in which a state must provide community services, the Supreme Court was not saying that a state could not choose to deinstitutionalize even absent all three criteria being met: "Contrary to the assertion of the family applicants, it does not logically follow that institutionalization is required if any one of the three Olmstead criteria is not met." 196 F.R.D. at 292.

The court also concluded that the application to intervene was not timely. The proposed intervenors provided no explanation for their 5-year delay. Moreover, the closure of the Western Center was impending. Allowing intervention would result in class members remaining in an institution that was already partially closed and was operating with reduced staff.

**Nelson v. Snider** (DD/institution/Constitution/government, organization, class)

In 1993, the United States brought an action under the Civil Rights of Institutionalized Persons Act ("CRIPA") against Pennsylvania for its operation of Embreeville Center, an institution for people with mental retardation. The United States alleged that the State had, among other things, failed to protect residents from abuse and neglect, failed to provide adequate training and behavioral programs, and failed to provide adequate medical care. United States v. Pennsylvania, 832 F. Supp. 122 (E.D. Pa. 1993). This case was then consolidated with a class action brought by residents of Embreeville, Pennsylvania Protection and Advocacy, and the ARC of Pennsylvania.

In 1994, the court, over the objection of defendants, entered certain factual findings that had been made by Judge Broderick in the Pennhurst case. This order did not, however, resolve all of the disputed facts, nor did it resolve issues of law. 1994 WL 502352 (E.D. Pa.)

Later that year, the court approved a settlement that had been reached by the parties. The settlement provided for placement of Embreeville residents into the community; improved conditions at Embreeville while the facility remained open; protection of the rights of residents after they moved into the community; and a court monitor. 160 F.R.D. 46 (E.D. Pa. 1994) The prompt resolution of this case stands in rather dramatic contrast to the course of the Pennhurst litigation.

**Helen L. et al. v. Didario et al.** (physical disability/institution/ADA/individual)

This case was originally filed on behalf of Helen L., a woman who had sustained a traumatic brain injury as a child and who had been confined in a state psychiatric facility for most of her life. At the time she brought the lawsuit, she was still at Norristown State Hospital. She brought the case under the ADA, seeking release from the hospital, and under the U.S. Constitution, seeking damages for her unlawful confinement. In November of 1992, two additional plaintiffs joined the suit, asserting ADA claims -- Beverly D. and Ilene F. Both women had developed physical disabilities as adults, Beverly from a fire and Ilene from a stroke. Both women needed some assistance with daily living tasks, but neither needed nursing care. Both women were forced to live in a nursing home in order to receive this assistance, as both had been denied community attendant services. The defendants conceded that the women were appropriate for such services, but said that there was no money in the attendant service program to serve them. The defendants also conceded that it would cost the State less money to serve them in the community, even though the attendant service program, unlike the nursing home, was not receiving any federal reimbursement (which was available to the State, but for which the State had not applied).

Subsequent to Beverly D. and Ilene F. joining the lawsuit, Helen L. was released from the hospital, mooting her ADA claim for release, but leaving her constitutional claim. Beverly and Ilene continued to pursue the ADA claim. In January of 1994, the district court granted the defendants' motion for summary judgment on the ADA claims, but denied the motion for summary judgment on the constitutional claims, allowing them to go forward to trial. 1994 WL 22714 (E.D. Pa.)

In dismissing the ADA claims, the court concluded that the ADA's integration mandate, contained in 28 CFR Sec. 35.130 ("public entity shall administer services, programs, and activities in the most integrated setting appropriate to the need of qualified individuals with disabilities") cannot be invoked "unless there is first a finding of discrimination." 22714 at \*5 The court defined discrimination in relation to nondisabled persons. Citing a Massachusetts Supreme Court case, the court stated that the "focus of Federal disability discrimination statutes is to address discrimination in relation to nondisabled persons, rather than to eliminate all differences in ... services provided to individuals with differing types of disabilities." 22714 at \*4. Since plaintiffs were excluded from the program for funding reasons, not on the basis of their disability, the court concluded that there was no violation of the ADA. 22714 at \*4. Subsequent to this decision, Beverly D. and Ilene F. voluntarily dismissed their claims because they were discharged from the nursing home into the community. A new plaintiff, Idell S., was added; she, too, acquired physical disabilities as an adult and was confined to a nursing home to receive help with daily living tasks. Based on stipulations from the parties, the court entered summary judgment for the defendants on her claim as well. Idell S. then appealed.

The Court of Appeals had a very different view of the ADA's integration mandate, reversing summary judgment for the defendants and remanding the case to the district

court for entry of summary judgment for the plaintiff. The court rejected the district court's notion that discrimination must entail unequal treatment vis-a-vis nondisabled people. Instead, the court found that unnecessary segregation is "a form of discrimination against the disabled" and that the district court thus erred in holding that the integration mandate of the ADA "may not be invoked unless there is first a finding of discrimination." 46 F. 3d at 333.

The court then rejected the defendants' argument that providing services to Idell S. would cause a "fundamental alteration" of defendants' attendant care program. The court noted that the ADA requires no more than what Pennsylvania's state law on attendant care in the community requires. The court also rejected the argument that, because the nursing home program is on a different budget "line" than the attendant care program, the Secretary of Public Welfare cannot under the state constitution move the money from one program to another. The court simply said that the entire Commonwealth is bound by the ADA and will have to figure out a way to deliver services to Idell S. consistent with the ADA. The defendants appealed to the U.S. Supreme Court, which declined to review the case. 516 U.S. 813 (1995). Though the Supreme Court decision in Olmstead recognized many of the same rights of people with disabilities as the Third Circuit did in this case, the Olmstead case provided the states with more defenses.

**Charles Q. et al. v. Houstoun, et al.** (MI/institution/ADA, Constitution/individual)

The five plaintiffs in this case were residents in Harrisburg State Psychiatric Hospital who sought to be served in the community. The case was brought under the ADA and the United States Constitution (substantive due process). It was not brought as a class action. Two of the plaintiffs, Lisa E. and Daniel S., moved for summary judgment; defendants cross-moved for summary judgment. While the court granted the defendants' summary judgment motion on the constitutional claims, the court granted summary judgment to plaintiffs on their ADA claims. 1996 WL 447549 (M.D. Penn.) The court, noting that the treating professionals had recommended community placement for both Lisa and Daniel, concluded that the decision in Helen L. was controlling. The court rejected the defendants' rather desperate attempts to distinguish Helen L. 447549 \*4 -\*5. The court also rejected the defendants' fundamental alteration defense, using quite strong language:

[Defendants] contend that the appropriations for this fiscal year for mental health services have already been made, and that funds cannot be shifted either from those allocated to state mental hospitals or from those allocated to community based programs to provide services to plaintiffs. ... This argument has been foreclosed by Helen L. ... [which] stated that a fundamental alteration in a program must change its requirements or its substance. [citation] An agency's claim that it lacks funding to serve a disabled person is not sufficient.

After a hearing, the court also found for Charles Q. on his ADA claim, but not for Joseph K. See 1997 WL 827546.

**Kathleen S. et al. v. Department of Public Welfare, et al.** (MI/institution/ADA/class)

The plaintiffs in this case were five individuals with mental illness who were residents of Haverford State Hospital. The court certified a class consisting of all persons institutionalized at Haverford as of August 26, 1997. 1998 WL 83973 (E.D. Pa.). The complaint alleged that defendants had violated the ADA's integration mandate by failing to provide community services to those Haverford residents who could be effectively served in the community. The complaint also alleged that defendants had violated the ADA by using discriminatory methods of administration – failing to appropriately plan for community services so that people with mental illness who were institutionalized could be discharged to the community within a reasonable time from their being declared ready for community placement.

The case arose against an interesting backdrop. On August 16, 1997, the Commonwealth announced that it would close Haverford on June 30, 1998. In announcing the decision, the Secretary of Public Welfare cited the trend towards community placement for people with mental illness, and made much of the wisdom of this trend, in terms of cost-effectiveness and effective treatment.

During the trial, held in May of 1998, shortly before the facility was scheduled to close, the Commonwealth sang a quite different tune. 10 F. Supp. 2d 460 (E.D. Pa. 1998). Of the 251 class members, the Department of Public Welfare (“DPW”) had plans to move only 88 into the community. DPW identified an additional 95 class members who could live in the community, but, citing lack of resources, planned to move them to Norristown Hospital, an equally restrictive environment. Finally, DPW identified 68 members who it maintained would be impossible to serve in the community. DPW argued that placing any additional class members in the community would require a “fundamental alteration” of the mental health system. It also argued that plaintiffs were not really claiming that they had been discriminated against under the ADA, but instead were seeking “deinstitutionalization.”

The court decided in favor of the plaintiff class, holding that the defendants had violated the ADA's integration mandate and had used discriminatory methods of administration. In essence, the court found that DPW was discriminating against the 88 class members it was planning to move by not moving them earlier; was discriminating against the 95 class members who it was planning to transfer to Norristown by not making plans to move these residents into the community; and was discriminating against at least some of the 68 members who it claimed could not be served in the community by failing to accurately evaluate these residents for their potential to live in the community.

The court found that complying with the ADA's integration mandate would not require a “fundamental alteration” of DPW's program. The court noted that state law also had a “least restrictive mandate,” so that an order to follow the ADA's integration mandate

would not impose an obligation that was fundamentally different than what state law already required DPW to do. 10 F. Supp. 2d at 471. The court also found that plaintiffs were not, as defendants alleged, seeking “deinstitutionalization,” but rather were, as they claimed, seeking to be free of discrimination based on their disability. 10 F. Supp. 2d at 470. The court also rejected the defendants’ claim that that the provision of community based services would result in additional, unreasonable expenditures. Considering the cost savings from removing people from the institutions and the county and federal contributions available, the court found that the cost of serving the plaintiffs in the community would probably be less than the cost of serving them in Norristown. The court faulted DPW for not previously transferring funds from institutions to community programs. The court entered a quite specific order regarding the pace at which plaintiffs should be moved into the community. 10 F. Supp. 2d at 471-74.

The defendants appealed the court’s decision to the Third Circuit Court of Appeals. The parties settled the case before the Court of Appeals issued a decision, rendering the appeal moot. By the time of the settlement, many of the plaintiffs had already been placed in the community. The settlement essentially mirrored the district court’s decision, but provided a little additional time for defendants to achieve the community placements for the remaining plaintiffs.

**Delong v. Houston** (DD/Community/Medicaid/class)

This case was brought in August 2000 by three individuals with developmental disabilities, on their own behalf and on behalf of a class of similarly-situated people. Plaintiffs, who lived in their family homes, alleged that they had not been provided with community-based support services through the Medicaid Home and Community Based Services Waiver Program (called the Person/Family Directed Support Waiver or P/FDS in Pennsylvania). Available services included: day programming, prevocational service, supported employment services, homemaker services, respite care, accessibility adaptations, adaptive equipment, personal support services, therapy, and transportation services. Plaintiffs’ caregivers were unable to provide them with these services, due to their advanced age, disability, or need to work full-time. As a result of defendant’s failure to provide plaintiffs with needed services, plaintiffs risked regression and eventual institutionalization.

Plaintiffs alleged that Pennsylvania had failed to serve the number of people – 3,382 in the first year and 3,448 in the second year -- that it had committed to serve in its waiver application to the federal government. Despite a list of thousands of people waiting for services, DPW was only serving 2600 individuals under the waiver. Plaintiffs alleged that this failure to fully implement the waiver violated the Medicaid Act’s statewidedness provision. Plaintiffs also alleged violations of the Act’s requirements that (i) all individuals wishing to apply for services be allowed to do so, (ii) services be furnished to eligible individuals with reasonable promptness, and (iii) individuals be evaluated to determine their need for services and, if found to need an intermediate care facility, be given the choice between institutional care and waiver services.

Plaintiffs had to fight several procedural battles. On October 25, 2000, plaintiffs were denied class status. On October 26, 2000, plaintiffs survived defendant's motion to dismiss. 2000 WL 1689077 (E.D.Pa.). Subsequently, all the plaintiffs were provided with community services. Pennsylvania Protection and Advocacy then sought to carry on the action as an organizational plaintiff. In March of 2001, the court found that Pennsylvania Protection and Advocacy had standing to sue on its own behalf, but not on behalf of others, i.e. not as an associational plaintiff.

In April of 2002, the parties settled. Defendant agreed to request funding from the legislature to meet the needs of all 3,382 persons required to be served under the waiver.

**Frederick L., et al v. Department of Public Welfare, et al.** (MI/institution/ADA, Section 504/class)

This case was brought by four adults who were institutionalized at Norristown State Hospital, on behalf of themselves and a class of similarly situated people. Plaintiffs, who were people with mental illness, brought suit under the ADA and Section 504 to challenge defendants' failure to provide them services in the community. The facts and the legal theories of this case resemble the facts and legal theories of Olmstead.

The decision on defendants' motion to dismiss, published at 157 F. Supp. 2d 509 (E.D. Pa. 2001), was in most respects a victory for plaintiffs. The court found that (i) the Eleventh Amendment was not a bar to plaintiffs' Section 504 claims, since Pennsylvania had waived immunity by accepting federal monies and was or should have been aware of the integration mandate of Section 504; (ii) while Congress did not have authority to abrogate immunity in Title II of the ADA, plaintiffs could proceed for injunctive relief against State officials under Ex Parte Young; (iii) Section 1983 of the Civil Rights Act can be used in conjunction with the ADA and Section 504; (iv) Alexander v. Sandoval, 531 U.S. 1049 (2001) posed no bar to plaintiffs, since the regulations on which they were relying did not expand the scope of Section 504 and the ADA; and (v) plaintiffs had adequately pled their readiness for community placement to fall under the protection of Olmstead. Each of these holdings was supported by detailed legal analysis.

Subsequent to this decision, the court certified the case as a class action, defining the class as all residents of Norristown except for those confined to forensic units or otherwise subject to the jurisdiction of the criminal courts and those who were involuntarily committed pursuant to court order.

These early victories turned out not to be prescient of the district court's ultimate decision in the case. The trial lasted three days. In a decision published at 217 F. Supp. 2d 581 (E.D. Penn. 2002), the court found entirely on behalf of the defendants, denying plaintiffs the relief which they had requested: developing community placements for 60 additional Norristown residents per year. Relying on Olmstead, the court held that defendants "have made the necessary showing that the requested modification would cause a fundamental alteration of the Commonwealth's services and programs." 217 F. Supp. at 594. In support of this holding, the court found that: "Even if cost savings may

eventually be achieved through deinstitutionalization, *the immediate extra cost, and the concomitant lack of immediate aggregate cost saving*, is sufficient to establish that a ‘fundamental alteration’ would be required if the relief sought by plaintiffs –accelerated community placements—were granted in this case.” 217 F. Supp. at 593 (emphasis added). In essence, the court held that any plan that is not immediately budget neutral (or cost saving) is not required by the ADA or Section 504 because it constitutes a “fundamental alteration.” The decision seems in marked contrast to the Third Circuit decisions in Clark v. Cohen and Helen L., discussed above, and represents a very narrow interpretation of Olmstead, essentially obliterating Olmstead’s rights-creating language through an over-emphasis on the finances of the State.

Plaintiffs have appealed this case to the Third Circuit. Plaintiffs stated the issues for appeal as follows:

1. Did the district court erroneously interpret established law when it:
  - a. held that any relief not resulting in “immediate aggregate cost saving” constitutes a fundamental alteration;
  - b. held that Defendants’ decisions regarding the use of its resources are “beyond judicial scrutiny”; and
  - c. held that the cost of the requested relief must be measured only against the mental health budget of the Department of Public Welfare rather than its entire budget?
2. Did the district court err in holding that the requested relief would result in a fundamental alteration of Defendants’ programs?

See Brief for Appellants at 10.

Briefing on the appeal is complete, but oral argument has not been set. This is an important case to watch, since, while it purports to rely on Olmstead, it seems to offer states a financial defense that is so easy to make so as to essentially eviscerate Olmstead.

**Pennsylvania Protection and Advocacy, Inc. v. Department of Public Welfare, et al.**  
(“South Mountain”) (MI/institution/ADA, Section 504/organization)

This case was brought by Pennsylvania Protection and Advocacy, as plaintiff, on behalf of the residents of South Mountain Restoration Center, a state-run nursing facility that serves elderly people who have severe mental illness. The complaint alleged that many South Mountain residents could be served in the community if appropriate services were made available to them. It further alleged that the defendants’ failure to provide these services – and the resulting continued institutionalization of South Mountain residents – violated Section 504 of the Rehabilitation Act and the ADA. Plaintiff invoked the Medicaid Act to challenge various conditions in the nursing home, focusing primarily on the lack of programming. Plaintiff sought the appointment of an independent expert to identify South Mountain residents who could live in the community and an order directing the defendants to develop a plan for moving identified residents out of South Mountain with community services in place.

As in Frederick L., the court's ruling on the defendants' motion to dismiss was almost entirely in favor of the plaintiff. The court ruled that: (i) Pennsylvania Protection and Advocacy has standing to bring the claims both on its own behalf and on behalf of the residents; (ii) the Section 504 claim is not barred by the Eleventh Amendment because Pennsylvania has waived its immunity by accepting federal funds; (iii) plaintiff can sue State officials for prospective injunctive relief under Title II of the ADA and Section 504 under Ex Parte Young; (iv) Section 504's integration mandate regulation does not exceed the scope of the statute itself and thus can be a basis for plaintiff's claims; and (v) the Medicaid claims are enforceable through Section 1983 of the Civil Rights Act.

Unfortunately, also as in Frederick L., the early victory did not foretell the outcome of the case. On January 15, 2003, the court granted the state's motion for summary judgment and dismissed the lawsuit. 243 F. Supp. 184 (M.D. Pa. 2003). The court did not deny that many South Mountain residents could be served in the community. The court found, however, that the average costs of community placement would exceed average costs at South Mountain and, further, that costs of community placement would not, at least in the short run, be completely offset by reduced expenditures at South Mountain. The court held that the net increase in expenditures necessary to pay for community placements and to operate South Mountain for individuals who would not be placed in the community would cause a "fundamental alteration" to the state's program. The court rejected plaintiff's argument that the fundamental alteration question should be considered in a larger budgetary context, finding that the only relevant question was the effect on the dollars allocated for services for persons with mental disabilities.

The plaintiff has appealed this case. Because of the similarities to Frederick L., the parties have agreed to hold off on briefing until Frederick L. is decided by the appellate court.

**Sabree et al. v Houston (now Richman) et al.** (DD/community/Medicaid/class)

The named plaintiffs in this case are four individuals with developmental disabilities who live at home with their families and receive virtually no services from the Pennsylvania Department of Public Welfare (DPW). Due to the age and, in some instances, infirmity of their caretakers, the plaintiffs seek placement in small Intermediate Care Facilities for the Mentally Retarded (ICF-MR). Instead of providing such placement, DPW put the plaintiffs on a lengthy waiting list, violating plaintiffs' right under the Medicaid laws to receive ICF-MR services, and to receive such services with reasonable promptness. The plaintiffs relied solely on the Medicaid Act, §§1396a(a)(10)(A) and (a)(8), and Section 1983 of the Civil Rights Act: there are no allegations under the ADA or Section 504. The plaintiffs sought to certify a class "of all Pennsylvanians with mental retardation living in the community who are entitled to, in need of, but not receiving appropriate community residential and habilitative programs under the Medical Assistance Program." Complaint at Section IV.

On January 17, 2003, in an oddly reasoned decision, the district court granted the defendants' motion to dismiss and dismissed the entire complaint. 245 F. Supp. 2d 653.

The court stated the question before it as follows: “Did Congress, in enacting the Medicaid Act, unambiguously confer upon the mentally handicapped beneficiaries of the Act, a right to enforce the requirement that the State make available small, community based ICF/MR service and that such services be provided with reasonable promptness?” 245 F. Supp. 2d at 658.

The court concluded that section 1396 of the Medicaid Act “does not have rights-creating language integral to a showing of Congressional intent to confer rights” and thus cannot form the basis of a lawsuit under Section 1983 of the Civil Rights Act. 245 F. Supp. 2d at 659. The court determined that the statute simply defines what actions states must take to obtain funding from the federal government and does not define individual rights. Thus the plaintiffs have no right to bring an action for placement in ICF-MRs or to receive services with reasonable promptness, since neither of these are individual rights. 245 F. Supp. 2d at 660, 661.

Strangely, the court points to §1396a(a)(3) -- which allows for an individual to get a hearing before the state agency if his claim for medical assistance is denied or not acted on with reasonable promptness -- as evidence that the statute creates only aggregate, not individual, rights. 245 F. Supp. 2d at 660. The right to an individual hearing would seem to *support* the fact that the Medicaid Act creates individual rights. The court, however, concluded the opposite. The court seemed to confuse the right to an individual hearing with the elaborate procedure under the Family Educational Rights and Privacy Act (FERPA), discussed in Gonzaga University v. Doe, 536 U.S. 273, 122 S. Ct. 2268 (2002), for withholding federal funds from schools which violate FERPA. In Gonzaga, the Supreme Court concluded that this elaborate mechanism suggested that the statute was focused solely on federal funding for states, and thus found no individual rights enforceable under Section 1983. In contrast, the Medicaid Act creates a hearing mechanism for *individuals*, which would seem to indicate that Congress did create individual rights enforceable under Section 1983.

The plaintiffs have appealed the case to the Third Circuit Court of Appeals.

### ***Comments on Pennsylvania:***

The legal strategy used to achieve community integration in Pennsylvania has been to bring many, narrowly focused cases, rather than bringing just a few global cases, as has been done in many other states. All of the Pennsylvania cases have been brought on behalf of a single disability group – MI or DD - rather than combining types of plaintiffs. Most of the cases have relied on a single or a few legal theories, rather than including multiple theories. Many of the cases were brought on behalf of individual plaintiffs, rather than a class. Even the class actions tend to be on behalf of narrowly defined classes.

Community integration litigation in Pennsylvania has, in many respects, been quite successful. Pennhurst is closed. Clark was released from an institution into the community. Western Center is closed. Embreeville is closed. Idele S. received services

in the community. Plaintiffs in Charles Q. were released and served in the community. Haverford was closed and many of its former residents moved into the community. More people have been served under the waiver programs because of DeLong. Yet the post-Olmstead cases (with the exception of DeLong) have, ironically, not fared nearly so well. The district courts have viewed Olmstead not as a case that clarified the rights of people with disabilities under the ADA, but more as a case that established defenses for states under the ADA. By accepting Pennsylvania's fundamental alteration defenses, which are based on a very minor financial impact on state finances, these courts have missed the essence of Olmstead.

One message from these cases is that lawyers must carefully research issues relating to the state structure and financing for delivering services to people with disabilities. The legal team was able to make a strong showing in Frederick L. and in South Mountain that deinstitutionalization would not have massive financial or organizational implications. Unfortunately, the trial court judges applied such stringent financial standards that they found against the plaintiffs notwithstanding this evidence. But plaintiffs are certainly in a stronger position for the appeals than they would have been without this compelling evidence.

Another message is that lawyers should not reject all of the pre-Olmstead theories. Some of the early cases that relied on Constitutional theories may provide people with disabilities with still-viable causes of action to achieve community integration.

## TENNESSEE

Like Pennsylvania, Tennessee has had a significant amount of litigation directed at increasing community living opportunities for people with disabilities. In contrast to Pennsylvania's large number of cases, Tennessee has had two major initiatives – one on behalf of people residing in large, state-operated institutions and one on behalf of people residing in the community without adequate services. The first initiative covered several large institutions and invoked many different legal theories, thus differing from the cases brought in Pennsylvania. The strategies that have been employed in Tennessee are thus different than those that have been employed in Pennsylvania, thereby adding to our understanding of options for community integration litigation.

**People First of Tennessee, et al. v. Arlington Developmental Center, et al.**

(DD/institution/Constitution, ADA, 504, Medicaid/organization, class)

**United States v. Tennessee**(DD/institution/CRIPA/government)

**People First of Tennessee, et al. v. Clover Bottom, Greene Valley, and Nat T. Winston Developmental Centers, et al.** (DD/institution/Constitution, ADA, Section 504, Medicaid/organization, class)

These three related cases have brought about significant changes in Tennessee's delivery of services to people with mental retardation. As a result of the litigation, many people have been moved from Tennessee's developmental centers into community placements. Indeed, one developmental center was closed because all of its residents had been moved to the community. All residents remaining in the other three centers have been recommended for community placement. While the community settings to which former institution residents have been discharged have not been problem-free, they have offered many more opportunities for a full life than did the developmental centers.

This long and complex journey toward community placement began twelve years ago. On December 12, 1991, five residents of Arlington Developmental Center (Arlington) and People First of Tennessee brought an action against Arlington and the State of Tennessee, alleging that they were being denied the right to receive services in the community, and also that defendants had failed to meet their obligations properly to monitor and care for residents in the institution (hereafter referred to as the "People First case"). Plaintiffs brought claims under the Medicaid laws, Section 504 of the Rehabilitation Act, the Due Process and Equal Protection Clauses of the U.S. Constitution, the First Amendment to the Constitution, and the ADA. The plaintiffs sought injunctive and declaratory relief.

In December of the following year, the court ruled on defendants' motion to dismiss all of plaintiffs' claims, 878 F. Supp. 97. In response to defendants' Eleventh Amendment arguments, the court dismissed the state agencies as defendants on the constitutional and Medicaid claims. However the court did not dismiss on immunity grounds these same claims against state officials, noting that the Eleventh Amendment does not protect state officials in cases seeking prospective injunctive relief.

The court then dismissed plaintiffs' Medicaid claims on the grounds that there was "no private cause of action for enforcement of the standards of care which a facility must meet in order to retain federal funding." 878 F. Supp. at 100. The court's language is similar to that of many recent cases dismissing Medicaid claims on the ground that they cannot be enforced under Section 1983.

The court then dismissed plaintiffs' Section 504 and ADA claims, in which plaintiffs argued that Arlington residents were being denied community services, while other people with disabilities were receiving such services. The court concluded (contrary to what the Supreme Court eventually decided in Olmstead) that "an action asserting that certain plaintiffs have been the victim of discrimination vis-a-vis other handicapped people must fail because sec. 504 does not cover discrimination among similarly handicapped persons." 878 F. Supp. at 101. The court similarly dismissed the plaintiffs' Equal Protection claims. 878 F. Supp. at 102.

The court allowed plaintiffs' substantive and procedural due process claims to stand, as well as their First Amendment claims. Plaintiffs' substantive due process claims included the right to be placed in a setting that was consistent with professional judgment – in essence, a right to be placed in the community if recommended by professionals. By separate order, the court granted the motion of the Parent Guardian Association (PGA) to intervene.

During this same time period, the United States Department of Justice (DOJ) sued the State of Tennessee for violations of the Civil Rights of Institutionalized Persons Act (CRIPA) based on the conditions at Arlington (hereafter referred to as the "United States case"). The defendants made a motion to dismiss or, in the alternative, for summary judgment. The defendants' primary argument was that most residents at Arlington had been placed there by their parents or guardians. Since the State did not use its governmental power to force the residents into Arlington or to keep them there, there can be no allegations that the State was abusing its power in any way. Defendants also argued that, since the residents were placed at Arlington by their parents or guardians, they have no constitutional rights to any standard of care, but merely rights under state tort law.

The court rejected defendants' arguments, holding that, even though most residents were placed at Arlington by their parents or guardians, as opposed to by court order, there was still sufficient state action in the admission process to trigger substantive due process rights. United States v. Tennessee, 798 F. Supp. 483, 487 (W.D. Tenn. 1992). The court also noted that, once an individual is confined to Arlington, regardless of how he initially arrived, the person is, by state law, under the exclusive care and custody of the superintendent of the institution.

In 1993, there was a two month trial in the United States case. The court found that the State's treatment of Arlington residents violated the U.S. Constitution. In 1994, the parties submitted and the court entered an extensive Remedial Order, which mandated many improvements at Arlington. The Remedial Order addressed such issues as abuse,

staffing levels, habilitation, use of restraints, use of drugs, and medical care. Importantly, it also mandated a reduction in the size of Arlington by transferring almost half of the residents to the community with services designed to meet their needs. The Order also prevented new admissions to Arlington, except in very limited situations.

In September of 1995, the court in the People First case certified a plaintiff class consisting of: “all persons who on or after December 12, 1989, have resided, or are residing at the Arlington Developmental Center; all persons who have been transferred from Arlington Developmental Center to other settings such as intermediate care facilities or skilled nursing facilities but remain defendants’ responsibility; and all persons at risk of being placed at Arlington Developmental Center.” The court then held that the relief granted in the United States case resolved the People First case’s due process claims (though not the First Amendment claims).<sup>12</sup> The court entered the Remedial Order from the United States case as the final order in the People First case regarding the due process claims.<sup>13</sup> The court gave intervenor status in the United States case to the People First class.

It was during this same period of time that the United States released its findings regarding the state’s three other developmental centers, Clover Bottom, Green Valley and Nat T. Wilson.<sup>14</sup> In December of 1995, People First filed suit against Clover Bottom. People First subsequently added Greene Valley and Nat T. Winston as defendants and also added named plaintiffs who resided at those institutions. After lengthy settlement discussions, a settlement was reached. DOJ then filed a CRIPA case against the institutions. All of these cases were consolidated. The settlement, which was approved after a fairness hearing over the objection of PGA, provided for, among other things, placement consistent with professional judgment. In the event that the State’s treatment team did not recommend community placement for a resident, an independent treatment team would evaluate the resident. The agreement also required improvements in the conditions of the centers. Though the agreement did not explicitly require closure, Nat T. Winston was closed in 1998 due to the fact that all of its residents had been moved into the community.

Meanwhile, during 1995 and 1996, several contempt motions were filed against the State for failing to comply with the Remedial Order that had been entered in both the United States case and the People First case. *See, e.g.*, 925 F. Supp. 1292 (W.D. Tenn. 1995). The State was in contempt of its obligation to improve Arlington, as well as its obligations with respect to community placement. As a way of resolving these contempt

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<sup>12</sup> In 1997, People First and the State settled the First Amendment issues. PGA objected to the settlement. PGA appealed in the People First case from the class certification order, the order approving the First Amendment settlement, the entering of the findings of the United States case, and several other issues. The Sixth Circuit affirmed all of the challenged trial court orders. 145 F.2d 1332 (6<sup>th</sup> Cir. 1998).

<sup>13</sup> In May of 1999, in an appeal by the State, the Sixth Circuit Court of Appeals upheld the application of the Remedial Order to the People First class. 181 F. 3d 105 (6th Cir. 1999)

<sup>14</sup> <http://www.comptroller.state.tn.us/orea/reports/mentrettd.pdf> (last visited June 12, 2003)

motions, the parties entered into a Stipulation of Settlement in 1996. As part of the Stipulation, the State agreed to place everyone at Arlington into the community if the State's team recommended community placement. In the event that community placement was not recommended, an independent team of experts would evaluate the person. The State also agreed, as part of the Stipulation, to develop a quite detailed plan for the creation of community services and for how it would successfully move people into the community. This entire plan became an order of the court in 1997.

In 1998, People First filed a contempt motion against the State regarding its failure to comply with the 1997 plan regarding community services. An Agreed Order was entered in 1999 to resolve this contempt motion. The Agreed Order established workgroups to facilitate implementation of the community plan. The court also issued an order regarding the definition of the People First class. On January 11, 2000, the court suspended activity of the workgroups for six months, apparently wishing to focus the parties on problems with the delivery of health care to class members in the community. On August 23, 2000, the court temporarily extended the suspension of the workgroups,

The orders clarifying the definition of the class and suspending the workgroups were appealed to the Sixth Circuit. The parties chose, however, to mediate the appeals. The parties reached a Mediation Settlement Agreement ("MSA") on December 10, 2001 that contained a provision to shut down Arlington. The parties and the State then requested that the MSA be entered by the court.

A decision was recently issued at 2003 WL 720099 (W.D. Tenn), denying approval of the MSA. The court relied on the fears expressed by parents and guardians that closure of Arlington would put medically fragile residents in jeopardy of injury or death. The court cited Olmstead as support for the idea that "...community placement of the developmentally disabled is not always feasible or wise!" 720099 at \*14. The court reasoned that states need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities and that institutions can play a role in this.

The DOJ has asked for the court to reconsider its decision. However, the decision has little practical impact on the case, since the previous orders (Remedial Order, Stipulation of Settlement, and Agreed Order) all remain in effect.

**Brown v. Tennessee Department of Finance, et al.** (DD/community/ Medicaid, ADA/organization, class)

**People First of Tennessee, et al., v. Neal et al.** (DD/community/Medicaid, ADA, Section 504, Constitution/organization, class)

These two pending class action lawsuits allege that Tennessee has violated federal law in its provision of Medicaid ICF/MR and waiver services. The two actions have very similar goals and, in May of 2002, were consolidated by the court for pre-trial and discovery purposes. Settlement efforts, which involve the plaintiffs and lawyers from both cases, are currently active.

The Brown case was brought in 2000 by six individuals, on their own behalf and on behalf of a similarly situated class. Tennessee Protection and Advocacy is an organizational plaintiff. The individual plaintiffs live with their parents, without even minimally adequate services. The complaint alleges that, due to capacity constraints in the ICF/MR system (all 668 beds were full at the time of filing and, by state law, no new ones could be created) and due to the limited number of waiver spots applied for by Tennessee, many people are being denied services. The complaint further alleges that defendants limit access to these programs by denying eligible individuals information about the pre-admission screening process and the right to appeal a denial of services. The complaint also alleges a failure of defendants to implement uniform application processes and a failure to accurately track the number of people waiting for services.

The complaint alleges that defendants' conduct violates their duty to provide services in adequate amount, duration and scope (42 U.S.C. §1396a(a)(10)); violates their duty to give individuals a choice between ICF/MR and waiver services (42 U.S.C. §1396(n)(c)(2)); violates their duty to provide plaintiffs with an opportunity to apply for services (42 U.S.C. §1396a(a)(8)); violates their duty to serve plaintiffs with reasonable promptness (42 U.S.C. §1396a(a)(8)); and violates the due process requirements of Medicaid law and of the United States Constitution. The complaint was later amended to include an ADA claim.

The People First v. Neal case was filed in 2001 by four individual plaintiffs, on behalf of themselves and others similarly situated, and on behalf of People First as an organizational plaintiff. Like Brown, the case seeks to enforce plaintiffs' right to receive ICF/MR or waiver services. The class definition is broader than in Brown, however, including people who had not officially applied for services, as well as children. There are several more defendants than in Brown. The complaint also has a strong focus on receiving services in the most integrated setting.

The complaint alleges that ICF/MR slots are capped at 668; that, in any event, ICF/MRs are unnecessarily segregated; and that waiver slots are only being given to people in dire emergency. As a result, people often wait years for services. Defendants limit demand for services by not informing eligible individuals of their rights to pre-admission screening and to appeal a service denial.

The specific claims are that defendants have failed to provide service with reasonable promptness, in violation of 42 U.S.C. §1396a(a)(8); have failed to provide services in the most integrated setting, in violation of Section 504 and the ADA; have failed to provide plaintiffs services that are no less in amount, duration, and scope than provided to other Medicaid recipients, in violation of 42 U.S.C. §1396a(a)(10); have failed to advise applicants of their right to apply for ICF/MR and waiver services, in violation of 42 U.S.C. §1396a(a)(8); have discriminated against some people with disabilities by not permitting them to obtain services for which they are eligible, in violation of Section 504 and the ADA; have failed to give plaintiffs a notice of denial and an opportunity to

appeal, in violation of the due process clause; and have failed to provide plaintiffs with freedom to choose the services they want, in violation of §1396n(c)(2).

***Comments on Tennessee:***

Tennessee has made great progress in reducing the population of its state-operated developmental centers. One was closed because all of its residents were moved to community placements. All residents in the remaining three institutions have been recommended for community placement, which will eventually lead to the emptying of all of Tennessee's developmental centers. Both private litigation and litigation brought by the Department of Justice have played a key role in this evolution. The ADA did not play a significant role in the litigation, but, instead, Constitutional theories based on conditions and services were the prevailing arguments. Note that, as was also true in many Pennsylvania cases, plaintiffs did not explicitly ask for closure of any institutions, but instead emphasized the need for residents to be individually evaluated for their ability to live in the community.

Community services in Tennessee remain inadequate in amount and quality for all people with developmental disabilities, but particularly for people who have never resided in a state-operated developmental center and thus are not members of the classes in those cases. Hopefully, the current settlement negotiations in the Brown and People First v. Neal cases will lead to an improvement in community services.

## NEW MEXICO

New Mexico was chosen for more intense scrutiny because it no longer has any large institutions for people with developmental disabilities. Like both Pennsylvania and Tennessee, litigation has played a major role in reaching this point. Like Tennessee, there have been two major initiatives—one for people confined to institutions and one for people living in the community without adequate services.

**Jackson v. Fort Stanton Hospital and Training School, 757 F. Supp. 1243 (D.C. N.M. 1990), 964 F.2d 980 (10th Cir. 1992)** (DD/institution/Section 504, Constitution, class, organization)

***Background:*** The plaintiffs filed this civil rights action challenging the institutionalization of developmentally disabled residents in two institutions, Fort Stanton Hospital and Training School (FSH & TS) and Los Lunas Hospital and Training School (LLH & TS) in New Mexico. These were state operated institutions and received federal funds under Title XIX of the Social Security Act. LLH & TS was established in 1925. As of the time of the lawsuit, it served 345 residents, ninety-three percent (93%) of whom were either severely or profoundly retarded. FSH & TS began serving people with mental retardation in 1966. Sixty-six percent (66%) of its 149 residents were severely or profoundly retarded and the remaining thirty-four percent (34%) were moderately or mildly retarded.

From 1984 to 1988, the rate of institutionalization in New Mexico fell within the national norm. However, during this same period, the number of persons with developmental disabilities residing in state operated institutions in New Mexico increased slightly, while the national average decreased by 16.6%. As of the time of the lawsuit, New Mexico lacked adequate community services to accommodate people with developmental disabilities. At the same time, existing community service providers tended to serve those persons with the least challenging needs based on the “implicit[] understanding that the state-operated institutions serve as a reserve.” 757 F. Supp. at 1295. For these reasons, institutional professionals declined to recommend residents of institutions for community placement. Even where a state court ordered a less restrictive placement for a resident, the resident usually remained in the institution due to lack of appropriate community services. The state had thus failed to make appropriate alternatives to institutionalization available.

Throughout the 1980s, several attempts at deinstitutionalization were made in New Mexico, to no avail. In 1983, the New Mexico Health and Environmental Department tried to transfer institutional residents to community based programs. However, in 1984, the New Mexico legislature effectively reversed this effort. In 1984, the Health and Environment Department created a task force to examine FSH & TS. The task force came to the conclusion that most residents of the institution would benefit from a more integrated, community-based setting, but the task force recommendations were never implemented. Similarly, in 1986, the governor of New Mexico appointed a DD Planning Council which studied the residential service needs in the State for people with DD and

recommended that the FSH & TS program be phased out and that the residential population in LLH & TS be reduced. Again, these recommendations were never implemented.

On October 27, 1989, the Department of Justice sued the State of New Mexico and the LLH & TS under CRIPA. On February 2, 1990, the parties developed a Settlement Agreement which required LLH & TS to make substantial changes in the following areas: training, use of restraints, medical care, staffing, use of psychotropic medications, and record keeping. The agreement focused on conditions, not on discharging residents to the community. As of the time of trial, LLH & TS was working to meet the terms of the settlement agreement and by the December 31, 1990 deadline. The court in *Jackson v. Fort Stanton* noted that the DOJ lawsuit had resulted in substantial improvements which the court considered in making its final determination.

***Procedural History:*** On July 8, 1987 twenty-one individual developmentally disabled citizens of New Mexico commenced a lawsuit on behalf of themselves and those similarly situated and on behalf of the Supporters of Developmentally Disabled New Mexicans, Inc. Plaintiffs sought to redress deficiencies within the institutions and to challenge “the validity of institutional life itself.” 757 F. Supp. at 1250. On October 16, 1989, the trial commenced.

The court created two distinct subclasses. The first subclass was certified on May 23, 1989 and sought expansion of community service programs for people with developmental disabilities and the transfer of residents to a community setting. Thirteen of the named plaintiffs were deemed class representatives for this subclass. Eleven of the thirteen named plaintiffs were profoundly or severely retarded and the other two were moderately retarded. These plaintiffs also had an array of other physical and mental disabilities. Intervenor included parents and guardians of residents and represent the second subclass. The district court granted leave to intervene on June 27, 1988 and the intervenors filed their Complaint in Intervention on July 6, 1988. Intervenor opposed plaintiffs’ efforts to have residents transferred into community settings, but supported their efforts to bring institutions into compliance with constitutional and statutory mandates.

***Legal Claims:*** The plaintiffs alleged violations of their rights under the United States Constitution (the First, Fourth, Ninth and Fourteenth Amendments) and several federal statutes, including the Rehabilitation Act of 1973, the Education of the Handicapped Act, and the Social Security Act. They moved for leave to amend their complaint in order to allege claims arising under the ADA, but the court denied their motion because the ADA, due to its effective dates, imposed no present enforceable duties on the defendants.

***Relief Sought:*** The plaintiffs sought declaratory and injunctive relief, including an increase in availability of community service programs for people with developmental disabilities and the transfer of residents of New Mexico institutions to community. The intervenors opposed the first subclass’s efforts to have residents transferred into community settings, rather they sought only to bring institutions into compliance with constitutional and statutory mandates.

***Holdings:*** The district court held that the defendants violated § 504 of the Rehabilitation Act by failing to make reasonable accommodations in order to place severely disabled residents who qualified for community integration into community programs. Additionally, the district court held that defendants violated the residents' substantive due process rights by failing to maintain constitutional conditions at the institutions, failing to implement recommendations for community placement, and by allowing the level of community resources to affect decisions as to whether or not to recommend residents for community service programs.

**Rehabilitation Act:** The court held that, as a recipient of federal funds, New Mexico violated the Rehabilitation Act because its community service system discriminated against persons with severe disabilities. The court found that the "severity of plaintiffs' handicaps is itself a handicap which, under §504, cannot be the sole reason for denying plaintiffs access to community programs." 757 F. Supp. at 1299. Community programs were not making reasonable accommodations for severely mentally and physically disabled persons. While the court recognized that in some cases an institution might be the least restrictive alternative appropriate for a person with severe mental or physical disabilities, it noted that in many cases, residents were not being recommended for community placement, "not because their individual needs require institutionalization or because community placement is inappropriate, but rather because community programs are not available in New Mexico for persons who have challenging behavior physical handicaps or special medical needs." 757 F. Supp. at 1298.

The court relied on the standard set out in Alexander v. Choate, 469 U.S. 287, 300, (1985) that, while a service provider "need not be required to make 'fundamental' or 'substantial' modifications to accommodate the handicapped, it may be required to make 'reasonable' ones." 757 F. Supp. at 1298. The court concluded that, in this case, the failure to ensure that existing community programs were available to people with severe disabilities was "unreasonable and discriminatory." 757 F. Supp. at 1299. The court held that defendants should require community programs that receive federal funds to make such reasonable improvements so as to accommodate those severely disabled individuals from LLH & TS and FSH & TS who could realize the benefits of a community setting. The court also held that when severely handicapped residents are "excluded from qualitatively different facilities" than their less disabled peers and where defendants can make reasonable accommodations to provide severely handicapped residents with similar facilities, the failure to do so is a form of segregation in violation of § 504 of the Rehabilitation Act. 757 F. Supp. at 1299

**Social Security Act:** Title XIX of the Social Security Act requires substantial compliance with the eight general 'conditions of participation' rather than the numerous standards included in the state's implementing regulations. The court held that mere violations of standards without any violation of overall conditions, is insufficient to warrant a private cause of action as long as the safety or health of clients is not in jeopardy. While LLH & TS and FSH & TS were not in compliance with two conditions of participation, both institutions underwent substantial changes as a result of the lawsuit and corrected these deficiencies. Furthermore, the health and safety of the residents was never in jeopardy.

Accordingly, the court held that the plaintiffs do not have a private cause of action under these provisions of the Social Security Act.

Education of the Handicapped Act (now called the Individuals with Disabilities Education Act): In order to sue under the Education of the Handicapped Act, all plaintiffs of a class must have exhausted all administrative remedies in order to bring a claim, unless pursuit of such remedies would be “futile or inadequate.” 757 F. Supp. at 1303. In this case, only two plaintiffs of the class had exhausted their administrative remedies and the court held that the exercise of such administrative options would not be futile. Nevertheless, the court held that defendants should be called upon to explain their efforts to ensure an “appropriate education” for residents of LLH & TS who were recipients of educational services within the institution. 757 F. Supp. at 1287.

Substantive Due Process under the United States Constitution: The court found substantive due process violations based on the following constitutional deficiencies:

- Poor maintenance of medical records;
- Failure to provide reasonable conditions of safety, which led to instances of physical and sexual abuses and repeated physical injury due to accidents;
- Use of physical restraints due to insufficient staffing;
- Failure to provide residents with minimally acceptable individual program plans;
- Failure to implement individual program plans;
- Lack of professionally acceptable training programs;
- Inadequate behavior management programming for the treatment of maladaptive behaviors;
- Failure to implement the recommendations of qualified professionals that residents be transferred to community-based programs;
- Improper consideration of availability of community resources in determining whether residents should be recommended for community programs.

The court also held that, while New Mexico had failed to abide by its own legislated goals under the Developmental Disabilities Community Services Act, this did not mean that there had been a constitutional violation. The court held that “the value of community placement does not necessarily translate into a legal entitlement.” 757 F. Supp. at 1313. For this reason, defendants are not required to provide community residential settings for all residents of LLH & TS and FSH & TS, rather the professionals must make a determination on a case-by-case basis.

The court went on to hold, however, that the defendants’ failure to implement their own recommendations for community placement violated substantive due process. The court also held that institutional professionals violated due process in taking into account community resources in order to make a determination on whether community placement was appropriate for particular residents. The court explained that, “the residents are entitled to treatment recommended by qualified professionals whose judgment is unsullied by consideration of the fact that the state does not provide funding for appropriate service in community settings.” 757 F. Supp. at 1312.

Procedural Due Process: While plaintiffs alleged that their state law substantive right to prompt treatment and habilitation services had been violated, the court held that because of the Eleventh Amendment, it could not order New Mexico or its officials to conform to substantive state law. (citing Pennhurst State School & Hosp. v. Halderman, 465 U.S. 89 (1984)). 757 F. Supp. at 1312

Equal Protection Clause: Plaintiffs alleged that New Mexico lacks a legitimate governmental purpose for segregating people with developmental disabilities from other groups. However, the court found convincing testimony from professionals, including some of the plaintiffs' experts, that some individuals would receive better care in an institutional setting. Therefore, the court rejected this argument.

***Relief Ordered***: The court ordered the parties to formulate a plan to correct deficiencies within LLH & TS and FSH & TS. The court enumerated eighteen areas of deficiency that the plan should address, including the development of appropriate and individualized programming, maintenance of medical records, systematic collection of data, increased staff supervision, improved training, and prevention of abuse, neglect and injury. In addressing these deficient areas, the court required that the plan include a written institutional policy, an identified point person, a description of strategies to be adopted in order to achieve specific goals, a timetable and means to ensure continued compliance with standards. The court ordered that the parties submit the plan by April 1, 1991 and that they correct all deficiencies by September 10, 1991.

The Court also ordered that defendants prepare a written plan for the transfer of residents who had been recommended for placement in a community setting but were still residing in an institutional setting. The defendants were to provide copies of this plan to the plaintiffs by March, 1991. With regard to residents who were not recommended for community integration for the sole reason of unavailability of community resources, the court ordered that defendants convene professional team meetings in order to reconsider their placement without taking community resources into account. The court enjoined the teams from taking availability or lack of availability of community services into account in their determination of the appropriateness of community placements.

***Appeal***: The intervenors appealed the district court's decision to the Tenth Circuit Court of Appeals on two grounds. First, they asserted that the district court erred in holding that the Rehabilitation Act and the due process clause required defendants to transfer residents who had been recommended for community placement. Second, they argued the district court erred in holding that consideration of the unavailability of community services in determining resident's placement in the community violated the due process clause.

With regard to the first issue on appeal, the Court of Appeals held that the issue of transferring residents to community settings was nonappealable because the terms of the settlement plan had not yet been implemented. The Court of Appeals explained that the court's discretion is "best exercised by allowing the district court to further 'resolve[] the remedial issues consistent with' the statutory and constitutional violations it has

identified at the two institutions.” 964 F. 2d 980, 990. As to the second issue, the Court of Appeals articulated the standard from Youngberg v. Romeo, 457 U.S. 307 (1982), that courts only have to determine that treatment teams exercise professional judgment in making a determination of whether or not community placement is appropriate. The court explained that “community placement is only one of various possible ways in which the state may comply with its constitution” and went on to hold that “the mere fact that the IDTs [professional teams] consider the availability or unavailability of community services when they make care and training recommendations does not, alone support a conclusion that the IDTs – and thus the state – fail to exercise reasonable judgment with respect to other alternatives by which the state may satisfactorily meet its constitutional obligations.” 964 F. 2d at 992. Accordingly, the Court of Appeals reversed and remanded the district court decision and held that consideration of resource availability does not violate the due process clause.

***Subsequent events:*** The parties, with the help of a court-appointed mediator, developed plans to address the violations identified by the court. One plan was developed for LLH & TS and another for FSH & TS. Both plans required improved conditions at the institutions and improved procedures for moving appropriate residents into the community. Neither plan explicitly called for closure.

The parties then agreed on a joint monitoring process, to monitor compliance with the plans. During the monitoring process, severe abuse (staff on resident) was discovered at FSH & TS. It was also discovered that the director had covered up much of the abuse. This led the State to close the facility. Similarly, monitoring revealed a large number of serious problems at LLH & TS, again leading the State to close the facility. Both facilities were closed by 1997. In 1997, the parties entered into a joint stipulation regarding the delivery of community services.

Former residents are now almost all in waiver programs, residing in very small community-based placements. Most of the placements have only three or four residents. The case remains open due to some remaining issues with implementation of the joint stipulation, including the provision of supported employment and day habilitation programs.

**Lewis et al. v. New Mexico Department of Health et al.** (DD, physically disabled/community, institution/ADA, Medicaid, Constitution/individual, organization)

This lawsuit was filed in January of 1999 by ten individual plaintiffs and by New Mexico Protection and Advocacy (“P & A”) as an organizational plaintiff. The case involves two New Mexico Medicaid waiver programs – the Developmental Disabilities Home and Community-Based Services Waiver (“DD Waiver”) and the Disabled and Elderly Home and Community-Based Services Waiver (“D&E Waiver”). The complaint alleged that waiver services, like other Medicaid services, must be provided with reasonable promptness. Plaintiffs claimed that defendants’ failure to provide such services with reasonable promptness violated the Medicaid Act, 42 U.S.C. §1396a(a)(8), as well as the Fifth and Fourteenth Amendments to the United States Constitution. Plaintiffs also alleged that the defendants’ failure to provide plaintiffs with waiver services resulted in

their living in unnecessarily segregated settings, in violation of the ADA. Four of the named plaintiffs were eligible for the DD Waiver but, because they had not received waiver services, were living in ICF/MRs. Two other plaintiffs were eligible for the DD waiver but were living with their parents without adequate services. Two plaintiffs were eligible for the D&E Waiver, but were likely to end up in nursing homes because they had not received waiver services.

In April of 2000, the court ruled on the State's motions to dismiss, which had been filed in June of 1999. 94 F. Supp. 2d 1217 (D.N.M. 2000). The court first examined various immunity arguments made by the defendants. After a detailed analysis, the court determined that plaintiffs could sue the state agency defendants under the ADA because Congress had properly abrogated immunity and thus the state agencies were not protected by Eleventh Amendment immunity. 94 F. Supp. 2d at 1229. Using an analysis that has subsequently been rejected in most circuits, the court then dismissed ADA claims against individual defendants, finding that Title II of the ADA allows suits only against "entities." 94 F. Supp. at 1230. The court did find, however, that plaintiffs' other (non-ADA) claims against individuals could be brought under Section 1983 of the Civil Rights Act.

The court then considered defendants' argument that plaintiffs had failed to state a claim. Defendants argued that, under existing laws, plaintiffs were not entitled to any relief, regardless of what facts they would later prove at trial. Specifically, defendants argued that, since states are not required to provide waiver services, the "reasonable promptness" provision of the Medicaid Act does not apply to waiver services. Defendants also pointed to the fact that, since there is a limit on the number of persons who can receive waiver services, there can be no right to waiver services. 94 F. Supp. at 1233. Plaintiffs responded that, once a state decides to offer waiver services, the state must comply with the "reasonable promptness" provision. The plaintiffs further argued that their right to receive waiver services with reasonable promptness is an enforceable right. 94 F. Supp. at 1233.

The court concluded that the "reasonable promptness" provision does indeed apply to waiver services and that it is judicially enforceable. 94 F. Supp. at 1234-35. The court rejected the defendants' argument that there is a fixed number of waiver slots and thus, by definition, waiver slots cannot be provided to all applicants with reasonable promptness. The court noted that nothing prevents states from applying for enough waiver slots to enable it to serve all applicants with reasonable promptness. The court also found that the "reasonable promptness" provision is not too vague to be enforceable.

The court allowed plaintiffs' procedural due process claims to stand. The court found that waiver applicants have a constitutionally protected interest in the benefits for which they have applied and thus are protected under the Constitution from arbitrary state action in the processing of those applications. 94 F. Supp. at 1237.

The defendants also moved to dismiss plaintiffs' ADA claims for failure to state a claim, arguing that the ADA only protects people with disabilities from discrimination vis-a-vis non-disabled people. The court rejected this argument, citing Olmstead, which had recently been decided. 94 F. Supp. at 1238. The court also rejected as premature defendants' argument that the integration mandate would impermissibly require the expenditure of state funds. 94 F. Supp. at 1239. Finally, the court found that the plaintiffs' allegations against the governor were sufficiently detailed to support the claim against him and thus did not dismiss him from the lawsuit.

The state appealed the trial court's decision<sup>15</sup> to the Tenth U.S. Circuit Court of Appeals. The trial court stayed the case pending the outcome of the appeal. The Court of Appeals did not issue its decision until August 2001, over a year after the district court's decision. The Court of Appeals affirmed the trial court's rulings on immunity. 261 F. 3d 970 (10th Cir. 2001). Specifically, the court found that, under Ex Parte Young, the plaintiffs could sue state officials for violation of the Medicaid Act and the Constitution because their claims were not frivolous and they were seeking prospective injunctive relief, rather than retroactive monetary relief. 261 F. 3d at 976-77. The court did not consider the trial court's rulings on defendants' motion to dismiss for failure to state a claim, declining to exercise its discretion to do so.

In July of 2002, the plaintiffs made a motion for summary judgment. Plaintiffs began by stating that the "case presents a simple, straight forward question of law: Are the Defendants required to provide Medicaid waiver services to all eligible individuals with reasonable promptness? The law is clear and unequivocal: the defendants are so required." Memorandum at 1. Plaintiffs argued that "waivers, though optional, are still subject to the requirements of federal law ... and included in the State Plan." Memorandum at 9.

Plaintiffs pointed to the fact that, in order to meet the reasonable promptness requirement, New Mexico may "request an increase in the number of persons who can be served under the waiver." Memorandum at 9. In any event, New Mexico was not currently even using all of its approved slots – 900 DD slots were unused and 450 D& E slots were unused. Memorandum at 9. As a result of defendants' actions, there were about 2600 people waiting for DD waiver services and about 2500 waiting for D&E waiver services. Memorandum at 10. Many people were on the waiting list for years. Memorandum at 4. The defendants were predicting an average waiting period of 60 months for the Fiscal Years of 2002 and 2003. Memorandum at 4. The plaintiffs also criticized the defendants' fiction that people on the waiting list were not actually applicants, but merely "registrants." Plaintiffs argued that, whatever one calls the people on the waiting list, they are entitled to receive services with reasonable promptness. Memorandum at 13-14.

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<sup>15</sup> Following the court's decision, the plaintiffs voluntarily dismissed all their ADA claims for strategic reasons, leaving only their claims under §1983 for violations of the Medicaid Act and the Constitution

In October 2002, the court issued a pretrial order. Contested issues of law include:

- whether Medicaid's reasonable promptness requirement applies to waiver programs and how reasonable promptness is defined;
- whether the Eleventh Amendment requires dismissal of the action (notwithstanding the Court of Appeals decision that it does not);
- whether the doctrine of legislative immunity bars claims against the governor;
- whether plaintiffs lack standing;
- whether plaintiffs' failure to plead and prove class allegations precludes them from seeking class-like relief; and,
- whether the requested relief would violate the constitutional doctrine of separation of powers.

In November 2002, the court issued rulings on several outstanding motions. It denied defendants' motion to dismiss the New Mexico P&A as plaintiff based on lack of standing, finding that the P&A could bring action under the doctrine of associational standing to benefit its constituents, even though it was not a traditional membership organization. The court, however, dismissed the claims of the remaining individual plaintiffs on the case, finding that, because they had received waiver services, their claims were moot. In dismissing these claims, the court rejected the argument that there was a reasonable expectation that these plaintiffs may lose their waiver services and thus be in the position of reapplying for them. The court also granted plaintiffs leave to file a Second Amended Complaint, containing a claim under Section 504 of the Rehabilitation Act.

To date, the court has still not ruled on plaintiffs' motion to dismiss, which was filed a year ago.

### *Comments on New Mexico:*

Despite its poverty, New Mexico has made great progress toward community integration for its residents with developmental disabilities. Both if its developmental centers are closed. All of the former residents of the developmental centers live in small community placements. As in Pennsylvania and Tennessee, litigation has played a key role in reaching these goals. The ADA did not play a role in the Jackson v. Fort Stanton case; the court relied on Section 504 and the United States Constitution.

Community services in New Mexico remain inadequate for people who are not members of the Jackson v. Fort Stanton class. The Lewis litigation is seeking community placement for these individuals. If the court in Lewis decides that waiver services are subject to the reasonable promptness standard, this would be an important development in community integration law.

## SECTION IV: FINDINGS

There has been a strong and consistent national movement toward institutional downsizing, closing institutions, and increasing community integration. Most often, 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 renegeing on the state's responsibilities to people with disabilities and their fundamental 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 the Community Integration Policy 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:

- **Litigation** has been utilized as a catalyst for moving states toward downsizing and eventually closing state-operated institutions and shifting monetary resources to developing community-based services.
- **Leadership** by the governor, the director of the state division of developmental disabilities, and/or state legislators has been instrumental in promoting change in the way services are delivered to people with developmental disabilities.

- States have been successful in securing some “**buy-in**” of key stakeholders, such as union members, advocacy groups, parents/guardians of institutional residents, legislators, and local politicians.
- **Home and Community-Based Services (HCBS) waiver programs** afford states the ability to develop a community-based service delivery system.
- Well-developed **Quality Assurance** monitoring programs are necessary to ensure that the community is consistently providing for the safety of individuals and that quality, individualized services and supports are delivered.

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, in conjunction with support from advocacy groups and state officials, 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 and raised public consciousness 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, once their children have been moved, a large percentage of parents initially opposed to closure are themselves satisfied with community living and believe 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. Budgetary limitations have, in some cases, 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.

## SECTION V: 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 downsizing state-operated facilities and steadily 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 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>16</sup> Thus, bringing about community integration in Illinois requires the state's political leaders, the 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>17</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.

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<sup>16</sup> Parish, Susan L. "Forces Shaping Developmental Disabilities Services in the States: A Comparative Study," in David Braddock, *supra* note 2, at 353.

<sup>17</sup> 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.

- Seek significant expansion of Medicaid funding for home and community-based services by following the recommendations made in the Gettings report (see footnote 7). Require the Departments of Public Aid, Public Health, and Human Services to each submit an annual report of their progress in significantly expanding federal Medicaid funding for in-home and community-based services and enhancement of their systems of oversight including in the areas of abuse and neglect and programming.

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 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, with recommendations

for reform to 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 into 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.

**Glossary of  
General Abbreviations and Acronyms for the  
Community Integration Policy Project**

(Abbreviations and acronyms specific to individual states  
appear in the State Profiles following the full titles.)

ADAPT - American Disabled for Attendant Programs Today

AFSCME - American Federation of State, County, and Municipal Employees

ARC/Arc - Association for Retarded Citizens

CARF - Commission on Accreditation of Rehabilitation Facilities

CIL - Center for Independent Living

CILA - Community Integrated Living Arrangements

CIP - Core Indicators Project

CIPP - Community Integration Policy Project

CMS - Centers for Medicare and Medicaid Services

DD - Developmental Disabilities

DMH - Department of Mental Health

FAS/FAE - fetal alcohol syndrome/ fetal alcohol effect

HCBS Waiver - Home and Community-Based Services Waiver (Medicaid)

HSRI - Human Services Research Institute

ICF-DD - Intermediate Care Facility – Developmental Disability

ICF-MR - Intermediate Care Facility-Mental Retardation

ISP - Individual Service Plan

MH - mental health

MI - mental illness

MR - mental retardation

NASDDDS - National Association of State Directors of Developmental Disabilities Services

NCI - National CORE Indicators

P&A - Protection and Advocacy (Agency)

PDD - pervasive developmental delay

QMRP - Qualified Mental Retardation Professional

RFP - request for proposal

RTC - Regional Treatment Center

TBI - traumatic brain injury

SEIU - Service Employees International Union

UAP - university affiliated program (now Center for Excellence)

VOR - Voice of the Retarded

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