Understanding the Challenges and Options of Transitioning People with Developmental Disabilities from Institutions to Community Living

Summary

The Supreme Court's decision in *<u>Olmstead v. L.C.</u>* left no question of the future of services for persons with developmental and other disabilities. Although deinstitutionalization has accompanied the national trend in favor of community living, several challenges exist that will impede the transition from a system based on institutions to one based on home and community care if left unaddressed.

A Tale of Two Systems

Introduction

In the state of Georgia, persons with developmental disabilities are served by two different systems. Many live in their own homes where they receive residential services that provide support as needed. Many others, however, are still served within institutions where they are grouped together and separated from the community because of their disability. The differences between the two systems are a matter of choice, inclusion, and integration.

The movement toward community living for all persons with developmental disabilities has been gradually gaining momentum. That community living is not only a fundamental part of being human, but is also a cost-effective way of providing long term care, is widely accepted as true. Additionally, in 1999 the Supreme Court ruled in *<u>Olmstead v. L.C.</u>* that unjustified isolation of individuals with disabilities is discriminatory, adding a legal basis for deinstitutionalization.

The *Olmstead* decision left no question of the future of services for persons with developmental and other disabilities. The present issue for the state of Georgia is how to go about completing the transition to a system of home and community based services. Georgia, like many other states, faces several major hurdles along the pathway to community living for all. This paper attempts to illuminate and discuss the challenges of deinstitutionalization and concludes by proposing solutions.

Background

Home and community based services are becoming the standard in care giving for persons with disabilities. Every year, the demand for home and community based services increases as the population grows, people live longer, and litigation continues to shape the system of service delivery to those with disabilities.[1]

Deinstitutionalization has accompanied this national trend in favor of community living. The height of institutionalization of persons with disabilities occurred in the 1960s and has been generally declining since. Since 1991, eight states and the District of Columbia have closed all of their institutions and most states have closed at least one state-operated institution.[2] However, this positive trend has slowed in recent years. The lowest rate of deinstitutionalization in the past 30 years occurred in the period of 2001 to 2003.[3]

In 1999, the Supreme Court issued a ruling that cleared up any remaining doubt about the importance of community living. The court ruled in *<u>Olmstead v. L.C.</u>* that the unjustified isolation of individuals with disabilities constitutes discrimination based on disability. The *Olmstead* decision established community living as a right, meaning that each state must make the option of living in the community available and feasible.

In Georgia, approximately 1,400 people with intellectual and developmental disabilities live in state-run institutions with more than 16 residents and 1,800 live in nursing facilities.[4] Georgia's Department of Community Health lists 144 children who are growing up in institutions across the state.[5] Additionally, Georgia ranks lowest in the nation in the number of persons with disabilities living in small community residential settings per 100,000 in the population.[6]

Although the national momentum favors community living, opposition to the transition of these individuals exists. Families of some institutionalized individuals are concerned about the adequacy of home care. Many employees of institutions are wary of the transition process and uncertain of the future of their jobs. Others recognize the magnitude of the responsibility that providers of community services will be required to bear and question the ability of providers to meet the needs of those requiring services. Finally, the financing of long term care remains institutionally biased. The following section examines each of these challenges.

Understanding the Challenges

Families

Georgia's system-wide change will be realized on an individual level. Person by person, moves will be made out of institutions and into communities. Behind each individual is a family that harbors concerns for their affected family member. Many times, the family made the decision to institutionalize their family member decades ago, when few or no viable alternatives were available. Families' lack of understanding and trust in the new system and guilt over the old system may cause the family to oppose their family member's transition from the institution into the community.

The family may feel like "the bad ones" for institutionalizing their family member in the past, causing them to react negatively to the change. In reaction to feelings of guilt, families may insist that institutionalization is the only possible living situation for their disabled family member.

The family may not believe that community placement is possible for their family member or they may not understand how residential services are structured. Families commonly voice concern over the safety of their family member, which they fear will be jeopardized in a community setting. Or, the family may be intimidated by the change itself and may feel overwhelmed with fears of the unknown future.

Workforce

The quality of care received by persons with disabilities is closely related to important aspects of job quality for the workers providing the care. The front-line workers who serve those with disabilities earn little pay and few benefits as a whole. These inadequacies result in high rates of job dissatisfaction, turnover and problems with recruitment, issues that directly affect deinstitutionalization. The quality of a person's direct support may have more impact on the individual's quality of life than any other factor, and the quality of direct support workers may be most affected by the wages and benefits of the job.[7]

Multiple factors affect the workforce issue. As health insurance costs rise, so does demand for workers within similar service industries in the private sector.[8] Because public dollars fund many of the direct support services for people with disabilities, providers are less and less able to compete for employees, especially considering the changing economic conditions. While other industries in the private sector have the flexibility to adjust wages to attract employees, providers of direct support services for persons with disabilities are paid by the state according to fixed reimbursement rates that may lag behind the current wage conditions in other sectors.

In particular, wages of those “in privately operated community-based long-term care programs are well below the wages” of similar occupations and state-operated direct support staff.[9] Often, direct support wages are near or below poverty levels. One study reports that 66% of respondents were not able to cover basic living expenses and 35% held another job.[10] According to a survey of state agencies and private residential provider associations, the average wages of workers employed by non-state residential service providers was 77.2% of those employed by states, although many states, including Georgia, manage some community services, as well as insitutions.[11]

Benefits are also less than adequate in the direct support profession. One in four direct care workers is without health insurance nationally, a number that is 50% higher than in the general population under age 65.[12] When employees are new or work part time, as many direct support workers do, obtaining employer-sponsored benefits is even more difficult.

In summary, despite the necessity of their work, direct support professionals are not considered or treated as professionals, often do not receive a high enough salary to support a family and receive fewer benefits than other professions. They are not compensated for advanced training in their field and they are not considered important to the management of service delivery to people with developmental disabilities.

As institutions close, former residents will need competent, well-trained direct support staff to serve them in the community. For Georgia, this means that the direct support profession must be an attractive option for those already in the field and for those employees of state-operated institutions who decide to transition into the community along with their former clients.

Providers

The third major set of players involved with deinstitutionalization are the service provider agencies. Providers are reimbursed by the state and pay their administrative costs and employees’ wages with these funds. Consequently, many of the workforce issues also negatively affect service providers, who are responsible for maintaining a workforce capable of meeting the needs of their consumers.

Turnover among private residential service provider agencies ranges from 50-75% per year, over twice the rate among state-operated services.[13] This inordinately high turnover rate channels resources toward constant recruitment and training and away from other necessary expenditures.

Would-be providers may be discouraged by the start-up costs necessary in the provider business. Provider agencies need vehicles, medical supplies, and other basic materials and these costs of capitalization can be prohibitive. Providers also need some form of cash flow to keep their business afloat while waiting for reimbursement for their services. The “lag time” between services rendered and payment may prevent potential providers from entering the field.

Some of the individuals who currently live in Georgia’s institutions will require complex sets of services that providers of residential services may not be prepared for. These services may include oxygen therapy, nutrition counseling, mobility therapy, and specialized dental care, among others. Such a wide range of needs calls for a wide range of providers within a geographic area. Especially in the rural areas of Georgia, this variety of services is difficult to find.

The consumers of residential services need both choice and quality of providers. Cultivating and supporting a thriving field of provider agencies will be a vital step in Georgia's transition process.

Finance

For some time, the difference in costs of serving individuals in institutions and serving them in the community has been known. Nationally, the average yearly cost of care for residents of state-operated institutions serving at least 16 people was $146,325 in 2004, as compared to the average cost of $21,021 that went to a person receiving supported living and personal assistance in the community.[14]

However, the financial arrangements that govern the payment of Medicaid services remain institutionally biased. Most residential services are funded by the Home and Community Based Services (HCBS) waiver to the state's Medicaid regulations. The waiver population, the number of people with developmental disabilities the state decides will receive residential services, is proposed by the state. In Georgia, the state then pays 40% of the costs directly out of its budget and the federal government matches this amount with the additional 60% of costs.

Payment for the institutional care of persons with developmental disabilities is structured similarly. Georgia reports the numbers of developmentally disabled persons living in institutions to the federal government, which assists the state by giving it 60% of the costs of caring for them. The cost of institutional care, on the other hand, does not have to be a line-item budget expense, as do home and community based services. Instead, the funding of institutional care can be spread out, a much more politically suitable financial arrangement.

These federal dollars are used to support Georgia's institutions, which house individuals with mental illnesses as well as those with developmental disabilities. When a developmentally disabled individual moves into the community, federal law allows them to take with them the dollars used to care for them in the institutions. The "money follows the person" through the transition. However, individuals who have been institutionalized for mental health reasons cannot bring funds with them when an institution closes.

The financial aspect of transitioning from institutional to residential care presents two challenges. First, for those individuals living in the community, Georgia must make an effort to find and pay the 40% of costs, whereas the state is not held accountable for its percentage of institutional costs. Additionally, once an institution closes, the mental health patients that relied on the federal dollars brought in by those with developmental disabilities must be wholly supported by the state.

The transition from institutional to home and community based care will not happen overnight. While the transition is ongoing, Georgia must finance both systems. This endeavor may be costly, but is a temporary part of the process. At present, Georgia is still channeling large amounts of money to institutions. Some of Georgia's citizens and lawmakers may view the cost of funding home and community based services as an extra burden on the state's budget, instead of viewing the expense from a long-term perspective.

Despite the cost-effectiveness of community care for individuals with developmental disabilities, the system of payment remains institutionally biased. This bias serves as a powerful disincentive to a successful transition.

Finding Solutions

Families

When River's Crossing closed in 1996, becoming Georgia's first permanent institutional closure, the families involved were surveyed throughout the process. Once the institution closed, 37 out of 39 residents moved into the community. Of the families of these individuals, over half felt only negative feelings prior to the closure, and just over a quarter had mixed feelings.[15] Many families experienced general feelings of anxiety, fear, and distress. Their main concerns were over the safety of the family member and the quality of his or her caregiver.

At the end of the transition process, the families were surveyed again. This time, over half of the families were "very satisfied" with their family member's life in the community and a quarter were "satisfied".[16] The turnaround observed in the families of River's Crossing shows that fear and concern is to be expected from families, but that families often recognize and appreciate the improvements in their family member once the move into the community is completed.

In order to overcome initial resistance to the transition, families need to be informed. One-on-one discussions meant to foster trust while providing information about the changes the system has undergone are necessary. Families need to know how the services will be structured, and may need constant reassurance. They may wish to participate in the process of transition, including the selection of a provider agency. In order to facilitate Georgia's transition, those involved with the transition will need to be prepared to discuss and be sensitive to the concerns of families.

Workforce

Many creative solutions have been devised to address workforce challenges to a completed transition. Individuals with developmental disabilities who rely on direct support workers can only benefit from improvements in the wages, health benefits, or other career enhancement opportunities of community direct support workers.

In response to the short supply of direct support professionals, the Governor's Council on Developmental Disabilities worked with several partners to foster the Workforce Development Project. The project featured a newly developed Certificate Program Curriculum, which was piloted at three of Georgia's technical schools in the fall of 2004. In order to develop the direct support workforce, experts designed two courses based on national standards to train direct support workers in core values and skills and to enable them to address the support issues and challenges of developmental disabilities.

The Governor's Council on Developmental Disabilities also funded the establishment of the Georgia Alliance for Direct Support Professionals, a professional membership organization, to facilitate the exchange of information and ideas and to encourage interactions among employees in the field of direct support to individuals with developmental disabilities. The Alliance was meant to enhance the work culture and professionalism of the field of direct support, and should play a role in the transition process.

Direct support workers need to be viewed as professionals whose input is valued. To do this, the Alliance should be invited to the table as a stakeholder to participate in planning and orchestrating the transition of people with developmental disabilities. The Alliance, as well as the Certificate Program Curriculum, needs to be expanded into communities experiencing transition so that direct support workers have access to training in preparation for the transition.

Another approach to strengthening the direct support profession has been taken by California, where self-employed home care workers were successful in getting their state to create county level "home care public authorities".[17] Although the primary purpose was to provide an employer of record for home care workers so that they could collectively bargain with the state for benefits and wage increases, the public authorities also facilitated a consumer-majority board to oversee its work, a registry to help consumers and workers find each other, and access to training for both parties, as well.[18] They also serve as purchasing agents that allow self-employed workers to be enrolled in a health insurance plan.[19] In addition, they advanced the consumer-directed model of service delivery and served as a vehicle for gaining access to federal and state technical assistance.

As home and community based services becomes the primary mode of service delivery for people with developmental disabilities, it is in Georgia's best interest for persons formerly employed by state-operated institutions to move into the community. In order for direct support work to be a viable option for former employees of the state, Georgia should consider temporarily subsidizing the salaries of state institutional employees who decide to move to private providers. During the first year of new employment, for example, former state employees could keep their former salary. Then, as the provider rate is increased and the direct support profession grows stronger, the subsidy would correspondingly decrease.

Perhaps the most direct way of eliminating the disparity in wages and benefits between direct service workers in the community and state direct service personnel is by law. In 2001, Maryland enacted a law that scheduled increases in the reimbursement rate to providers of community service and stipulated that the increases be used specifically to increase the compensation of the direct service employees.

Maryland's reimbursement rate will increase each year for five years until the wages and benefits of community workers reach those of state workers that perform comparable duties. To begin the process, Maryland commissioned a study to discover the existing disparity between private direct service workers and state direct service staff. They found that state staff were paid 55% more in wages and received 12.6% more in benefits.[20]

States have tackled the problem of inadequate insurance coverage for direct support workers in several ways. Some states have permitted direct support workers to be covered by a public employee insurance plan. Connecticut allows personal care assistants who belong to a professional association to buy health insurance through a municipal health insurance plan.[21] Maine is trying a different approach by offering subsidies for low-income workers who work at least 20 hours a week and are employed by a business with less than 50 employees to purchase employer-based private health insurance. Maine's new plan is funded in part by federal matching assistance.[22]

Washington is both allowing and helping direct support workers to enroll in a public insurance program by providing subsidies that make the state's Basic Health Plan accessible and affordable to uninsured low-income workers.[23] Because of the seriousness of the direct support workforce crisis and the crucial role that direct support workers play in the lives of the people they serve, Georgia will need to consider taking similar steps to improve the situation.

Providers

Many of the recommendations to strengthen the direct support workforce overlap with recommendations concerning the providers, because private providers employ most of the direct support workforce in Georgia. For example, lack of insurance is an issue that affects both workers and providers directly.

One way to address the challenge of providing insurance is by allowing a number of providers to form a limited liability corporation through which they could purchase insurance as a group. Purchasing insurance as a pool lowers the cost to each provider to an affordable level, thus hurdling a major barrier to insuring the workers in small provider agencies. The participating providers could use the corporation to purchase motor pool insurance, health insurance, and even goods and supplies.

There are numerous simple, straight-forward ways to go about promoting the work of providing community services. For example, Georgia could sponsor informational seminars held around the state on a rotating basis. These seminars could promote the work while focusing on issues of quality control.

Another simple solution is to develop the state's capacity to give technical assistance to providers that want to enter the field. Georgia can incentivize the work of providing services to counteract the intimidating and difficult environment faced by private providers in several ways. Many people become providers because they love the work. Potential providers may just need a little encouragement.

For example, Georgia could help providers establish a cash flow. One possibility is for the state to allocate new provider agencies several months of initial operating expenses to help them get on their feet.

Finance

Two pieces of recent federal legislation have attempted to eliminate the institutional bias in funding for services to persons with disabilities. The first is the Medicaid Community-Based Attendant Services and Supports Act, MiCASSA, which promotes disabled individuals' right to choose where their services will be provided and offers a variety of payment methods such as vouchers, direct cash payments, or by using a fiscal agent.[24]

The Money Follows the Person Demonstration would provide $1.8 billion over 5 years for states to provide 12 months of long term care services in a community setting to individuals who currently receive Medicaid services in a nursing home. For one year, the federal government pays the total costs of the community services.[25] Both of these bills will further the implementation of the *Olmstead* decision by giving persons with disabilities greater choice and independence and by supporting their integration into communities.

The challenge of maintaining both systems of service delivery during the transition process is probably the most difficult one facing Georgia. Federal initiatives such as MiCASSA and Money Follows the Person are important steps in the right direction but, ultimately, a deep commitment by the state is required to make community living a reality for all of Georgia's citizens with developmental and other disabilities. Financially supporting two systems is a temporary necessity. In order to fully transition, Georgia's leaders will need to invest in the system of home and community based services before closing the institutions, so that the infrastructure is there first.

Conclusion

The Governor's Council on Developmental Disabilities of Georgia recommends that the state actively engage the challenges of transitioning people from institutions into the community. In addition to the suggestions already put forward in this memorandum, the Council strongly recommends a comprehensive planning process that brings consumers and their families, direct support professionals, and provider agencies to the table as valued stakeholders.

The planning process should draw on the expertise of persons who have been a part of successful transition efforts in other states. At all stages of the planning process, person centered planning should be used as the framework for transitioning individuals. The permanency of homes in the community for developmentally disabled individuals should be a major focus of consideration.

To implement *Olmstead* and make the transition a reality, Georgia will need to commit to a multi-year process and multiple years of funding to rebalance support from institutional service delivery to home and community-based service delivery. Legislative support in each of the communities where transitions will take place is vital to the success of the transition process.

Notes

1. David Braddock and others, *The State of the States in Developmental Disabilities 2005* (Denver, CO: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, 2005), 2.

2. Ibid., 49.

3. Robert W. Prouty, Gary Smith and K. Charlie Lakin, eds., *Residential Services for Persons with Disabilities: Status and Trends Through 2003* (Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2004), 9-13.

4. Braddock, *The State of the States in Developmental Disabilities 2005*, 112.

5. *Children's Freedom Initiative: A Summit for Change*, Information handed out to attendees August 25, 2006.

6. Braddock, *The State of the States in Developmental Disabilities 2005*, 21.

7. Wisconsin Council on Developmental Disabilities, *Wage and Benefits for Wisconsin Direct Support Workers* (Madison, WI: WCDD, 2003), 1.

8. Braddock, *The State of the States in Developmental Disabilities 2005*, 24.

9. Ibid., 24.

10. Bonnie Shoultz and others, "Status of Institutional Closure Efforts," *Policy Research Brief* 16, no. 1. (2005): 4.

11. Barbara Polister, K. Charlie Lakin and Robert Prouty, "Wages of Direct Support Professionals Serving Persons with Intellectual and Developmental Disabilities: A Survey of State Agencies and Private Residential Provider Trade Associations," *Policy Research Brief* 14, no. 2 (2003): 3.

12. Shoultz, "Status of Institutional Closure Efforts," 4.

13. Polister, "Wages of Direct Support Professionals," 2.

14. Braddock, *The State of the States in Developmental Disabilities 2005*, 22.

15. Zolinda Stoneman and Beverly Al-Deen, *River's Crossing: Transition from Institution to the Community* (Athens, GA: University of Georgia, College of Family and Consumer Sciences, Institute on Human and Developmental Disabilities, 1999), 26.

16. Ibid., 28.

17. Janet Heinritz-Canterbury, *Collaborating to Improve In-Home Supportive Services: Stakeholder Perspectives on Implementing California's Public Authorities* (New York: Paraprofessional Healthcare Institute, 2002), 4.

18. Ibid., 4.

19. Debra Lipson and Carol Reagan, "Health Insurance Coverage for Direct Care Workers: Riding Out the Storm," *Better Jobs Better Care Issue Brief*, no. 3 (March 2004): 8.

20. "Direct Care Personnel: Maryland Wage Parity," http://www.ucp.org/ucp_generaldoc.cfm/1/8/10889/10889-10889/1862.

21. Lipson, "Health Insurance Coverage for Direct Care Workers," 8.

22. Ibid., 7.

23. Ibid., 8.

24. United Spinal Association, *Home and Community-Based Services vs. Institutionalism: Olmstead Implementation and Rebalancing Long-Term Services and Supports* (Jackson Heights, NY: United Spinal Association, 2004), 3.

25. Ibid., 4.

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