

Policy Research Brief

RESEARCH AND
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Status of Institutional Closure Efforts in 2005

This Policy Research Brief examines and summarizes the research and policy issues that state policymakers may face as they consider whether to increase, reduce, or close institutions in their own states. The review was written by Bonnie Shoultz, Pam Walker, and Steve Taylor of the Center on Human Policy at Syracuse University, Syracuse, New York and Sheryl A. Larson of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. Dr. Shoultz may be reached at (315) 443-4323 or bshoultz@syr.edu. Dr. Walker may be reached at (315) 443-4290 or pmwalker@syr.edu. Dr. Taylor may be reached at (315) 443-4484 or staylo01@syr.edu. Dr. Larson may be reached at 612/624-6024 or larso072@umn.edu.

■ Introduction

Advocates, self-advocates, parents and professionals have increasingly become concerned about threats to the remarkable progress made towards the inclusion of people with intellectual and/or developmental disabilities (ID/DD) in the fabric and mainstream of community life in America. In some places in the United States there are those who want to maintain and even expand the role of institutions, thus denying their residents (and all those at risk of being placed in institutions) freedom, opportunity, and other benefits of community life. This *Policy Research Brief* examines and summarizes the research and policy issues that state policymakers may face as they consider whether to increase, reduce, or close institutions in their own states.

■ Trends in Deinstitutionalization and Institution Closure

National Trends

Deinstitutionalization and institution closure have been critical policy directions in the past few decades that have had a significant impact on the lives of people with ID/DD. Since the mid-1970s, there has been a national trend toward deinstitutionalization and institution closure. The population of people with intellectual disabilities living in public institutions peaked at 194,650 in 1967; by 2004, this number had declined to 41,653 (Prouty, Smith, & Lakin, 2005). The number of individuals in private facilities for 16 or more people and the number of people with ID/DD living in nursing facilities has also been declining. In 1990, 44,903 people with ID/DD lived in nursing homes, and 32,926 lived in large private ICF/MRs (intermediate care facilities for persons with mental retardation). By 2002, these numbers had declined to 30,308 and 24,708 respectively (Rizzolo, Hemp, Braddock, & Pomeranz-Essley, 2004).

The trend in deinstitutionalization has been accompanied by a trend toward institution closure. Eight state institutions specifically for persons with ID/DD closed between 1960 and 1976, and 174 state institutions or special units of 16 or more persons with these disabilities closed between 1960 and 2004 (Prouty, Smith, & Lakin, 2005).

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UCEDD), College of Education and Human Development, University of Minnesota.



State Trends

Between 1977 and 1996, all states reduced the number of people living in public institutions. Then between 1996 and 2000, all states except Missouri and North Dakota reduced their public institutional populations (Braddock, 2002). However, there is wide variation between states with respect to trends in deinstitutionalization. The states with the greatest percentage reduction (40-86%) in public institution populations between 1996 and 2000 were Kansas, Maine, Minnesota, New York, Oregon, and Tennessee (Braddock, 2002). During the same time period, 15 other states reduced their institutional populations by less than 15%. These states are Arkansas, Delaware, Florida, Illinois, Iowa, Kentucky, Mississippi, Missouri, Nebraska, Nevada, North Carolina, North Dakota, Ohio, Texas, and Washington (Braddock, 2002).

In 1991, New Hampshire closed the Laconia State School and became the first state to close all of its public institutions. Since that time, the District of Columbia, Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia have also closed all of their public institutions (Prouty, Smith, & Lakin, 2004; Lakin, 2005). Thirty-eight states, including the District of Columbia, have closed at least one institution (Lakin, 2005).

In contrast, 13 states have not closed any public institutions. These states are Arkansas, Delaware, Idaho, Iowa, Louisiana, Mississippi, Nebraska, Nevada, North Carolina, Utah, Virginia, Wisconsin (however, Wisconsin is now very close to doing so), and Wyoming (Braddock, 2002; Hemp, 2005). States which continue to support an “extensive network of public institutions” are Arkansas, Louisiana, Mississippi, North Carolina, and Virginia (Braddock, 2002).

Current Issues

Two key factors have contributed to the policy shift away from institutions. First, there has been an expanding philosophical shift away from institutions and in support of community living. Second, the high costs of institutional care have made it more difficult for states to support institutional services (Lakin & Prouty, 1995/96). Within this overall trend are some caveats, however:

- Recently, there has been a slowing of the trend toward deinstitutionalization nationally. From 2001-2003, there was the smallest rate of reduction in institutional size in 30 years. “Without new priorities, incentives, and/or expectations, the increasing concentration of state institution residents in those states with the lowest rates of deinstitutionalization will continue to impede access to the ‘community-based alternatives’ to which President Bush in the New Freedom Initiative declared the United States to be committed” (Lakin, Prouty, Polister, & Coucouvanis, 2004, p. 243).

- One of the major challenges to continued deinstitutionalization and institution closure is development of the capacity to support individuals with high support needs in the community (Taylor, 1995/96).
- Another major challenge involves the economic impact on and resistance from local communities and public employee unions (Lakin & Prouty, 1995/96).

In the face of challenges to deinstitutionalization and institution closure, this *Policy Research Brief* reviews strategies being used by states, not only as they move to close institutions, but as they concomitantly make efforts to support increased consumer direction and support their workforce, all in the face of potential federal cuts in Medicaid, housing assistance, and other areas.

■ How Can All People Be Supported in the Community?

One common argument for keeping institutions open is that there are some people who cannot be supported in the community. Typically, these include people who have behavioral support needs, significant and complex medical needs and psychiatric disabilities, and people who have grown old in the institution. However, many states have successfully closed some or all of their institutions, replacing them with other successful strategies for supporting people with significant needs in the community. Based on data from the National Health Interview Survey on Disability and the Residential Information Systems Project, an estimated 92% of all Americans with ID/DD live with family members, spouses or alone, and 6% live in community-supported living arrangements, while only 1% live in large institutions and only 1% live in nursing homes (Larson, Doljanac, & Lakin, in press). In the states that have closed their state institutions, all such persons live in other settings. Clearly, many people with extensive support needs, similar to or more intensive than the needs of those now living in institutions, are living in the community today. Many of these people have never lived in an institution. Many others have moved from institutions into the community.

People with Challenging Behavior and/or Psychiatric Disabilities

While it is common to assert that institutions must be preserved for people who have challenging behavior and/or psychiatric disabilities, there are models of success in serving such individuals in the community. Between 1980 and 1999, all but 2 of 33 studies of people who have moved from institutions found improvements (or no significant change) in adaptive and challenging behavior after they move into the community (Kim, Larson, & Lakin, 2001).

Both of the studies showing an increase in challenging behavior were conducted in the 1980s, and in one of them, although challenging behavior increased in the community, it increased more among those remaining in the institution. A recent AAMR (American Association on Mental Retardation) monograph described programs in Vermont, Minnesota, California, Massachusetts, Iowa and Colorado that provide specialized behavioral support and crisis prevention/response for community-dwelling persons with disabilities (Hanson, Wiesler, & Lakin, 2002). That monograph also contained several chapters describing strategies that can be used at the state, provider, and individual levels to successfully support people with challenging behavior. Many states have shifted from group settings to individualized, person-centered support services, thus reducing the provocations that may trigger difficult behavior. The states that have closed their public institutions for people with ID/DD have also learned how to support people with psychiatric disabilities (so-called “dually diagnosed” individuals) in the community (Smull, 2001).

People with Significant and Complex Medical Needs

People who have medical conditions requiring sophisticated medical expertise and technology are living in the community in most states. For every person with such needs in institutions, others with the same or more complex needs live in the community (e.g., Hewitt, Larson, & Lakin, 2000). Their medical services are provided by community doctors, nurses, personal care assistants, provider agency staff persons, and trained family members. At times, specialized medical services must be created or packaged in order to meet needs. This often requires collaboration across health care and disability service systems (Gaylord, Abery, Cady, Simunds, & Palsbo, 2005). In a review of health utilization studies, people with significant and complex medical needs are a small percentage of people with ID/DD, and the data about their health outcomes is very limited (Hayden, Kim, & DePaepe, 2005). Some data show that most people’s health improves with a move to the community, and other data show that health outcomes for people with the most severe disabilities are slightly worse (Hayden, Kim, & DePaepe, 2005). However, where careful planning and implementation are done, those with complex medical conditions are living successfully in community settings. As a field, we know how to support people with complex medical needs in the community, and to do so in a manner that maintains their health and happiness (Gardner, 2003).

Despite our knowledge about supporting people with complex health needs, access to health care is a continuing concern, especially for individuals living on their own or with family members (Larson, Anderson, & Doljanac, in press). However, people with ID/DD living in small supported living arrangements (including many who formerly lived in large institutions) are significantly more

likely to have access to preventative care than those living with family members, foster families or on their own (e.g., Hewitt, Larson, & Lakin, 2000). This suggests that the bigger problem in access to health care is for people with significant or complex needs living in family or foster homes or on their own, rather than for people who have yet to move from institutions to community settings. Continued efforts to increase access to community-based health care will benefit all individuals with ID/DD, especially those who have never been institutionalized.

People Who Have Grown Old in the Institution

While the proportion of institution residents who are 63 years and older has increased from 3.7% to 9.8% between 1977 and 2004, the actual number of such residents has decreased from 5,591 to 4,082 (Lakin, Prouty, Coucouvanis, & Byun, 2005). Increasing numbers of older adults with ID/DD are living in various community settings. Many older adults who lived for years in institutions have moved into the community to live fulfilling, activity-filled lives (Felt & Walker, 1988; Traustadottir, 1991). As the then-90-year-old Gunnar Dybwad said, “A good old age is a universal aspiration...at its core is respect for the aging person’s human rights, dignity, choices and desire for a decent quality of life. Older people with developmental disabilities require – and deserve – no less.” (Dybwad, 1999, p. xv)

However, some older adults who have lived for many years in institutions indicate that their preference is to remain in the institution. This preference is often based on lack of experience with other alternatives and fear of something new and different. Individuals may also be reluctant to part with close friends and staff in the institution. Thus, it is particularly important that such individuals have the opportunity to have community experiences that assist them in learning about life in the community and various support options. When long-time institution residents relocate to community settings they also need opportunities for continued contact with friends made in the institution, as well as chances to make new connections within the community. Family members of older adults who have lived in the institution for many years are often fearful of community placement for their family member. Studies of deinstitutionalization show that parent and family attitudes about deinstitutionalization are often initially negative, but once a person has moved, those opinions shift in favor of the community setting (Larson & Lakin, 1991). It is essential that families be given information about the successful transition of those who are older into the community.

■ What are Economic Ramifications of Closure?

Costs/economic issues have been considered a significant factor in arguments for and against deinstitutionalization and institution closure. However, the issues related to maintaining institutions, as opposed to deinstitutionalization or closure, paired with development of quality community services, are complex and are highly interrelated with numerous other state policy decisions. Much depends on decisions made at the state level about issues such as infrastructure, community capacity-building, wages of community workers, and the like. For instance, the costs of running dual systems of services (institutional and community-based) take resources away from community services. Also, it is crucial that costs be viewed in the aggregate – that is, for a large group of people instead of on an individual basis. Making decisions about whether or not someone should live in the community based on the cost of serving that person is like saying that he or she may not be worth the expense. When costs are aggregated, the average per-person cost is the standard. Expenses will be higher for some individuals than others.

When comparing costs, it is difficult, if not impossible, to draw exact comparisons between institutional and community services (Walsh & Kastner, 2003). Some research does point to a generally lower cost for community services, as well as a higher quality of life (Stancliffe & Lakin, 2005). For example, in 2002, the average annual expenditure for ICF/MR residents was \$85,746 as compared to \$37,816 for each Home and Community Based Services (HCBS) recipient (Prouty, Smith, & Lakin, 2003). More recently, Stancliffe, Lakin, Shea, Prouty, and Coucouvanis (2005) found that costs are consistently 5% to 27% higher in institutions for comparable intensities of service. However, although most U.S. studies have showed that the community is less expensive, these may not have controlled for certain factors that influence cost (e.g, staff wages and benefits are significantly higher in U.S. state-operated institutions than in small community settings [Polister, Lakin, & Prouty, 2002]).

As states increasingly utilize individual budgets, there is need for study about comparative costs and outcomes (Moseley, Gettings, & Cooper, 2003; Moseley, Lakin, & Hewitt, 2004). To date, research comparing traditional services (institution or community-based) with individualized budgeting is inadequate to draw any cost conclusions. However, research comparing community ICF/MRs and HCBS-funded residences has found better outcomes in terms of self-determination, integration, quality of life, challenging behavior, and adaptive behavior in HCBS settings (Stancliffe, Abery, & Smith, 2000; Stancliffe, Hayden, Larson, & Lakin, 2002). Ultimately, a commitment

to a quality community life for all requires a commitment to providing the supports that individuals need, even when they are expensive, as well as to investing in a quality workforce. Experience has shown that states that are committed to the value of community life can find ways of making this a reality rather than just a vision.

■ How Can States Address Workforce Issues and Deinstitutionalization?

Research has indicated that the ability to find, train, and keep direct support staff is one of the biggest barriers to continued deinstitutionalization and the ability to sustain current community supports (Seidman, 2002; Hewitt & Lakin, 2001; Hewitt, Larson, & Lakin, 2000; Lakin & Hewitt, 2002; Test, Flowers, Hewitt, & Solow, 2003). For states, continued maintenance and development of a community service system, particularly one that offers quality community supports, will be reliant on dealing with issues of recruitment, retention, and training of direct support workers (Feldbaum, in press; Hewitt & Lakin, 2001, Larson & Hewitt, 2005). A key component of this is wages and benefits for community support staff. In most states, the wages of community support staff are consistently low, and institutional staff members have had significantly better wages and benefits (Seidman, 2002; Polister, Lakin, & Prouty, 2002). In one study, “The majority of them [direct support professionals] reported that their pay falls below or does not meet their basic living expenses (66%), and 35% had another job at which they worked an average of 23 hours per week” (Test et al., 2003, p. 281). In addition, there has traditionally been a lack of benefits for community support staff. “One in every four direct care workers lacks health insurance coverage, a rate that is 50 percent higher than those in the general population under age 65” (Lipson & Regan, 2004, p. 1). Some states are making efforts to remedy these situations, with initiatives for wage parity and to increase wages and benefits (Braddock, 2002; Feldbaum, in press; Larson & Hewitt, 2005). An important part of this is the continued expansion of consumer-directed support options. This is the option that offers the greatest flexibility in who is recruited and how much these individuals are paid (Hewitt & Lakin, 2001). States that have institutions that have not yet been downsized or closed can improve workforce outcomes by ensuring that, as they downsize or close, they provide wages and benefits comparable to those offered to institution staff for the direct support professionals who support people with ID/DD as they move to community living arrangements.

■ How Can States Maximize Individual Supports While Closing Institutions?

In past years, states closed institutions by creating group settings in the community. Today, there is much more interest in developing individualized supports into which people can move; the group home/community residence is increasingly viewed as an undesired, unnecessary type of residential setting as compared to homes designed and developed for individuals.

There are many issues and challenges in developing individualized supports while closing institutions (O'Brien, 1995). These include:

- Building a common understanding of what we mean by “individualized.”
- Placing effort on directing increasing proportions of resources into consumer-controlled, individualized supports.
- Placing effort on ensuring that the settings into which people move, if they aren't truly individualized, can be dismantled easily; that is, avoiding purpose-built facilities and agency-owned buildings.

States that have much to do to deinstitutionalize their citizens with ID/DD should incorporate strategies to address these issues and concerns into their plans.

■ Conclusion

States have found ways to close more than 174 institutions or institutional units since 1960. Several states operate entirely without state-operated institutions for persons with ID/DD. Clearly, cost, service quality, and lack of available successful community alternatives are not the reasons these institutions remain open. Instead, institutions for persons with ID/DD remain open because some states lack the political will to close or downsize them. Most states provide community supports to most or all of their citizens with ID/DD. Most states have made policy decisions that acknowledge the substantially better quality of life and quality of care in community settings, and which support the right articulated in the New Freedom Initiative for individuals to be free of unnecessarily restrictive living arrangements. The hope is that the others will soon provide similar opportunities to their citizens with disabilities.

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■ For Further Information

comparisons of community and institutional residential settings: Historical review of selected research. *Mental Retardation*, 41(2), 103-122.

The following resource may be of additional interest to readers:

“Community for All” Tool Kit: Resources to Support Closing Institutions [Ver. 1.1]. (2004, August). Produced by the American Association of Mental Retardation, The Arc of the United States, National Association of Councils on Developmental Disabilities, Center on Human Policy, The Council on Quality and Leadership, Research and Training Center on Community Living, and TASH. This document describes resources for supporting community living. It provides the philosophy, policy and research rationale that supports community supports and services for all people with disabilities, in the context of their families, their communities and their country. For more information, visit <http://thechp.syr.edu/toolkit/> or contact the Center on Human Policy, Syracuse University, Syracuse, New York, at (315) 443-3851.

For other resources on institution closure, please visit the “Closing Institutions” Department of the Systems Change Shop on the Quality Mall Web site at <http://qualitymall.org>.

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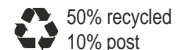
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