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ABSTRACT

This newsletter theme issue focuses on the need to accelerate the closing of institutions for people with mental retardation. Articles are by both current and former residents of institutions and by professionals, and include: "The Realities of Institutions" (Tia Nelis); "I Cry Out So That I Won't Go Insane" (Mary F. Hayden); "Trends in Institution Closure" (K. Charlie Lakin and Robert Prouty); "Deinstitutionalization Litigation: Experiences and Outcomes" (Judith A. Gran); "Thoughts and Impressions on Institutional Closure" (Steve Taylor); "Inside and Out: Former Residents Reflect on Their Lives" (Russell Daniels and Mark Samis); "Operation Close the Doors: Working for Freedom" (Tia Nelis and Nancy Ward); "On the Outside Looking In" (Ruthie-Marie Beckwith); "There Is a Hell: One Parent's Story" (Kathy Hayduke); "Parental Attitudes toward Deinstitutionalization" (Lynda Anderson and Sheryl A. Larson); "Voluntary Closure: The Homeward Bound' Experience" (Donna Hoverman); "Community Medical Care: Barriers, Recommendations" (Mary F. Hayden and K. Charlie Lakin); "Closing Brandon Training School" (Bonnie Shoultz and Charles Moseley); "Developing Individualized Supports While Closing Institutions" (John O'Brien and Steve Taylor); "Building Community Capacity" (Michael W. Small and Susan Burke-Harrison); and "The Final Stages: Community Services for People Considered the Most Difficult To Serve" (Tom Fitzpatrick and K. Charlie Lakin). (DB)

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IMPACT

INSTITUTE ON
COMMUNITY INTEGRATION
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Feature Issue on Institution Closures **Volume 9 (1) Winter 1995/96**

The Realities of Institutions

by Tia Nelis

"Should we spend money on institutions or to support people in communities?" As a self-advocate, it bothers me that people are still arguing about this. I'm not quite sure what all the graphs and charts and numbers mean, or what the latest research says, or whose reports to believe. So, I judge by what I know. I listen to the people who live in the institutions.

Tia Nelis (right) and Nancy Ward, on behalf of Self Advocates Becoming Empowered, receive an award from the American Association on Mental Retardation recognizing the organization's accomplishments, including efforts to close institutions. See story on page 12.

■ Privacy? What Privacy?

How can you have much privacy when you live on a campus with 100 or more people, in a unit with 10-15 people, and share a bedroom with at least one or two roommates? Struggling college students may need to live under such conditions temporarily, but not a 32-year-old woman with a job. Institutions provide little privacy.

When I visit the institution the staff think I'm another "client", so I get to see the real story. I see shower rooms with the doors open and curtains pulled back. I see staff opening the doors to people's bedrooms without knocking and walking inside. I see people carrying all of their valuables with them – "hoarding behavior" I think it's called by professionals; the truth is that people are afraid their valuables will be stolen when they leave their rooms. No free access to phones. No privacy when caring for personal matters, sleeping, entertaining that special someone, or just plain wanting to be alone. Bedroom doors are never closed or locked; I have noticed locks on nurses' stations, staff lounges and bathrooms, often with a sign that says "staff only" or "knock first." Whose home is this anyway? Administrators and state officials have escorted me through people's homes and invited me into their bedrooms without people's knowledge. I think the picture is very clear: Institutional living allows people very little, if any, privacy.

Realities, continued on page 27

From the Editors

This issue of *IMPACT* is focused on a critically important step in the honoring of full citizenship of persons with developmental disabilities: the closing of institutions. We dedicate this issue to Roland Johnson, who passed away in August, 1994. Roland's personal experience of living in an institution propelled him to become a leader in the civil rights movement for persons with disabilities. His unwavering conviction that institutions must be closed and that people with disabilities need to live in the community continues to be a driving force behind the advocacy and self-advocacy efforts of many people who knew him.

Roland was one of the founding members of the organization, Self Advocates Becoming Empowered. Pat Gerke, an advisor for the organization, recalls that Roland, in personal conversations, would frequently ask the question, "What are YOU going to do about getting people out of institutions?" She believes that he knew in some way that he wouldn't be around to see many of the changes he had dreamed of, so he sought to challenge others to understand that people's lives are at stake. With the help of self-advocates who, carrying on in Roland's spirit, worked with us on this *IMPACT*, we present that same challenge to our readers.

CONTENTS

A publication of the Institute on Community Integration (UAP) and the Research and Training Center on Residential Services and Community Living, College of Education and Human Development, University of Minnesota. Dedicated to improving community services and social supports for persons with disabilities and their families.

I Cry Out So That I Won't Go Insane

by Mary F. Hayden

I personally find it maddening that people still believe that institutions are tolerable and that they may not be "that bad."

As I've shared with professional colleagues the fact that I'm writing this article addressing the issue of institutional closure, I've been bombarded with comments based upon two beliefs. First, many people believe that discussing the issue will be like beating a dead horse ("Everyone is in favor of closing institutions. You are singing to the choir", and "There is only a small number of people with mental retardation who live in institutions now. They are steadily leaving. Be patient."). The second belief that has been expressed is that institutions are not that bad ("Institutions are licensed, therefore, the care is at acceptable levels." "Institutions are not the horror chambers they were in the 1950s and '60s."). I personally find it maddening that people still believe that institutions are tolerable and that they may not be "that bad."

Closing institutions *is* still a profoundly important issue, particularly to the people still incarcerated in institutions and nursing homes. There has been a dramatic decrease in the number of people with mental retardation and other developmental disabilities (MR/DD) living in large, state-operated facilities, but tens of thousands of individuals remain behind. There are even larger numbers of people with MR/DD in large, privately-operated residential care facilities and nursing homes. As of June 30, 1994, there were 143,819 people with MR/DD in large institutions and nursing homes (Prouty & Lakin, 1995). Of this number, 65,735 lived in state-operated facilities, 41,887 lived in non-state operated institutions, and 36,197 lived in nursing homes.

When past and current average daily population rates are compared, the actual pace of deinstitutionalization is slow, particularly among private institutions. The total decrease in populations of state-operated institutions between 1980 and 1994 was an annual average of about 4,228 people (Prouty & Lakin, 1995). Between 1977 and 1994, the total number of residents in non-state operated institutions was reduced by an annual average of about 637 people. A national study estimated that the annual average number of residents in non-specialized nursing homes decreased by about 405 people per year between 1991 and 1994 (Prouty & Lakin, 1995). At these rates, it will take 16 years to move everyone out of state-operated institutions, nearly 66 years for those who live in non-state operated institutions, and 89.5 years for those in nursing homes.

These rates may be optimistic. In the face of feared budget cuts and pressures from vested interests, some states are resisting or slowing former commitments to closing institutions. For example, in New York former Governor Cuomo had planned that all state-operated institutions would close by year 2000. When Governor Pataki came into office, however, he placed a moratorium on further closures until an examination of the initial decision was conducted. In Illinois, the governor announced in 1995 that Kiley Developmental Center (KDC) would close within two years. KDC was selected because, compared to the other developmental centers, (1) the number of residents with placement goals in the next two years was the highest, (2) KDC ranked highest for the percentage of residents who received their day program off campus, (3) the percentage of individuals who were not capable of walking was the lowest, (4) the portion of the population requiring weekly or more physician/nurse services was the second lowest, and (5) the percentage of people who required intensive behavior management programming was the lowest (Handy, 1995). In addition, Illinois would save money by closing it and there were a sufficient number of area service providers to develop alternatives to meet families' choice of location. There was strong opposition, however, and the two-year plan was withdrawn and a five-year "transition" plan is being promoted.

For people who believe that institutions are not that bad, there is evidence that demonstrates that abuse and poor care continue. For example, the *New York Times* reported the following on March 13, 1995 regarding the Southbury Training School in Connecticut: "Justice Department investigators have described several dozen examples of abuse and neglect. On Jan. 31, 1993, one patient was found in bed with a broken coat hanger in his hand, bleeding from the nostrils, with blood covering the sheets and on the floor. Three days later, he was found with blood on his shirt and a broken hanger in his hand. A month later, he was found again in bed with hangers and a bloody face. The Justice Department observed that feeding practices posed 'immediate life-threatening problems' from choking, that psychotropic drugs were overused and that most residents were 'almost never engaged'" (Rabinovitz, 1995, p B6). Poor or inadequate medical care continues to be an issue for Southbury. The *New York Times* reported the following this past August: "... today an expert on the medical care of the retarded... testified that several Southbury residents had died because of inadequate treatment and that a review of 15 residents' records showed that serious medical problems went unattended ." (Rabinovitz, 1995, p A1).

Another example is the Arlington Development Center in Tennessee. In the *United States of America v. State of Tennessee* (1993), the judge stated: "Weighing all of the expert testimony in this case, including the testimony of individuals who were consultants or employees of Arlington Development Center, it is clear that the care actually provided to residents at Arlington Development Center falls below any minimum standard and well below the medical malpractice standard....But the Court should note specifically that in the medical care area and in the area of direct staff supervision of patients or residents, conditions at Arlington Development Center pose an immediate danger of irreparable harm, including an active risk of death to patients at Arlington Development Center. Medical care within the institution, particularly for patients with seizure disorders, is so deviant from any recognized principles of medical care that any patient suffering prolonged seizures or status epilepticus may be in immediate peril of his life" (p.25, 28).

More compelling than the findings in lawsuits, are the stories told by people who have lived in institutions, stories of abuse, confinement, neglect, lack of choices, lack of privacy, poor food, and overcrowding. Sadly, there is some evidence to suggest that abuse can be hidden in institutions.

> In the face of feared budget cuts and pressures from vested interests, some states are resisting or slowing former commitments to closing institutions.

For example, one individual who lived in a Maryland institution said, 'Sometimes it was good. Sometimes it wasn't. Like if the Health Department was there, then it was good, but when the Health Department wasn't there, they did their own thing." Another example of alleged efforts to conceal abuse is found in the court's ruling in *United States v. State of Tennessee* (1993): "Two highly sought after employees in psychology left Arlington Development Center when their efforts to compile and report to the administration a list of suspected physical and verbal abuse by direct care staff were detected....they found their jobs made impossible, understandably, because of the actions of the administrators intent on protect(ing) possible abusers as opposed to protecting and disciplining individuals for the offense...No investigation was conducted regarding the employees who were identified as possible abusers" (pp 30-31).

For many parents, closing institutions is very threatening. Consequently, many deny the abuse and lack of services in institutions and believe institutions are the only alternative for their children. To this end, many who are guardians believe that they can refuse to approve community placement or request that community placement goals can be removed from their children's habilitation plans. In reality, there has been legal precedence that persons under "legal disability" retain the rights of other citizens and that parents and guardians lack the power to waive the fundamental rights of their children and wards. Thus, a minor or ward has standing to sue to enjoin violations of his or her constitutional rights despite the parents' or guardians' consent to the practices or conditions being challenged (*Bonnie S. v. Altman*, 1988; *Childress v. Madison County*, 1989; *Kirk v. Thomas S. by Brooks*, 1986; *Milonas v. Williams*, 1983; *Thomas S. by Brooks v. Morrow*, 1986, as cited in *People First of Tennessee v. Arlington Developmental Center*, 1995). Consequently, the next era of lawsuits may result in people with disabilities not only suing the state, but also suing parents or parent organizations that attempt to stop people from leaving institutions.

The challenges and issues of closing institutions will not go away. Their closing will continue to be a complex and contentious process. Proponents of institutions will ignore the facts and discount the experiences and testimony of people who have lived in institutions. But, they must recognize that opposition from people with disabilities and their allies will never die. Opposition will continue for reasons shared in this closing vignette: "The Buddhist monk went to the town square every day to speak out for peace and justice. When his cries went on for years without halting his country's warmaking, his fellow monks said to him, 'Stop! You are having no effect. No one is paying attention to your pleas. Everyone in the nation has gone insane with the war. Why go on?' The monk answered, 'I cry out for peace so that I won't go insane.'" (Buddhist Peace Fellowship, 1995).

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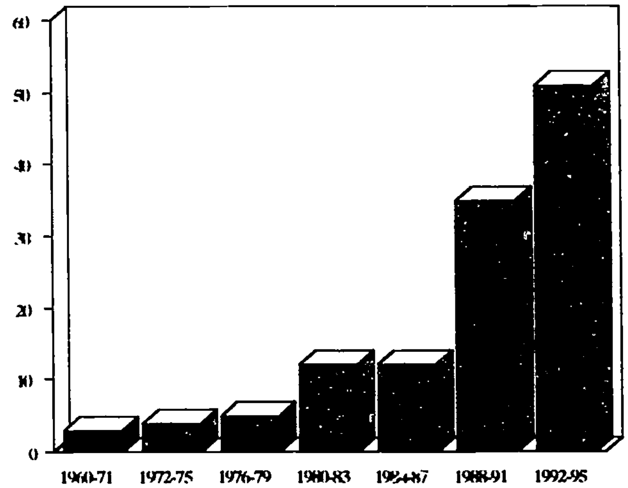
Trends in Institution Closure

by K. Charlie Lakin and Robert Prouty

In the past decade, there has been a remarkable increase in the number of closures of state mental retardation/developmental disabilities (MR/DD) institutions in the United States. Figure 1 shows the number of large state MR/DD facilities, and MR/DD units in large state facilities primarily serving other populations, that have closed since 1960. As shown, between 1960 and 1971 only three large state MR/DD facilities were closed, an average of .25 per year. Between 1972 and 1975 there were four closures, an average of one per year. In every subsequent four-year period, closures have occurred at an increasing rate. There were 5 closures between 1976 and 1979 (an average of 1.25 per year), 12 between 1980-1983 (an average of 3 per year), and 12 between 1984-1987 (an average of 3 per year). Between 1988 and 1991 closures increased rapidly to 35 (an average of 8.75 per year). In the Fiscal Years 1992-1995, there were 51 closures (an average of 12.75 per year).

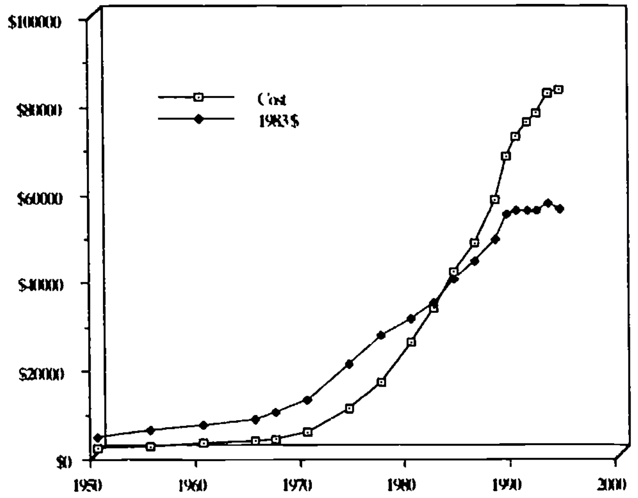
Today, four states (District of Columbia, New Hampshire, Rhode Island, and Vermont) no longer operate large state MR/DD institutions. A number of other states are currently developing plans for total or very significant reductions in the number of large state operated MR/DD residential facilities. For example, Michigan and Hawaii anticipate operating no state institutions by the end of the century.

Figure 1: Number of Large State MR/DD Institutions and Units Closed Between 1960-1995



A number of factors contribute to states' decisions to close institutions. One is simply that much less state institution capacity is needed or desired in most states. In June 1994, state institution populations were barely one-third of 1967 populations, decreasing from 194,650 to 65,735 over the period. A second factor in the recent spate of institution closures has been the rapidly increasing costs of state institutions care. As shown in Figure 2, average annual state institution costs in 1994 were about $82,300 per year.

Figure 2: Average Annual Per Resident Expenditures in State MR/DD Institutions, 1950-1994



In part, these costs are the result of decreasing occupancy of institutions with high fixed costs. In many cases, costs are high because of physical and program improvements resulting from federal and state court actions. Costs are high because of the high costs of complying with federal standards for participation in the Medicaid Intermediate Care Facility/Mental Retardation (ICF/MR) program. The ICF-MR program provides federal cost-sharing of from 50%-80% of the costs of care in ICFs-MR, which has provided huge subsidies for the rapidly increasing state institution costs since 95% of all state institution residents living in ICF/MR units. However, with impending Medicaid block grants, all state institution costs in effect become state expenditures, and it seems likely that in the face of general revenue restrictions and loss of direct federal subsidies, many states will reevaluate their ability to afford state institution care.

One of the major challenges facing states considering reduction in the number of the institutions they operate is the economic impact on and resistance from local communities and public employee unions. While some states like Rhode Island and New York have responded by developing community services operated by state employees, many states find the wage and benefits costs, union work rules, and the desire to clearly separate the state oversight and service purchasing

Table 1: Alternative Uses of 99 State Institutions Closed or Planned for Closure (1970-2000)

The closed state MR/DD institution became:

• Correctional Facility (includes Juvenile)	17
• Psychiatric Facility (includes MR/DD Units closed)	18
• College/Educational Programs (includes Job Corps)	6
• Rehabilitation/Medical/Skilled Nursing Facility	4
• Facility for Another State/Local Agency (administration or program)	19
• Facility for a Federal Agency (other than Justice)	1
• Unoccupied/Declared Unsafe/Demolished	12
• Use Still Undetermined/ For Sale/Presumed Useful	22

(Source: Braddock et al., 1995. *State of the States* (4th ed.). Washington, DC: American Association on Mental Retardation).

role from the service providing role, leads them to respond to community and union concerns by trying to develop alternative uses for the state institution sites. Table 1 uses information collected by Braddock and colleagues at the University of Illinois at Chicago to show alternative uses for 99 state institutions that have been closed or are projected to close between 1970 and 1999. As shown, a majority have become correctional facilities, exclusively dedicated psychiatric facilities, or have had the buildings taken over to house other public agencies. Twenty-two facilities were still in the process of exploring alternative uses, while 12 were judged as so outdated, asbestos contaminated or otherwise expensive to rehabilitate that they are considered unusable. Of all alternative uses, it seems at present the one of greatest favor is as correctional facilities. Corrections is a major growth industry in the United States, and offers substantial employment opportunities of similar pay and benefits to persons with backgrounds similar to the direct care staff of state institutions. In the growing number of conversions of state instiutions to federal and state prisons it is often hard to overlook the irony that places that will this year be argued to be wonderful homes for persons with developmental disabilities, next year will be argued to be wonderful places in which to incarcerate convicted felons. But so it goes.

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Leaving Institutions: Effects on Those Who Move

Within the past 25 years, many people with developmental disabilities have moved out of large institutions into smaller, community homes. Originally, people with mild or moderate mental retardation moved, while those with severe or profound mental retardation were thought to be better served in larger institutions. However, in recent years people of all ability levels have been shown to benefit from living in community settings. A review of 18 research studies following the movement of over 1,350 people – the majority having severe or profound disabilities – from large institutions to small community settings between 1976 and 1988 found the following:

- All of the studies measured adaptive skills and reported at least some improvement in either overall adaptive behavior or in self-care and domestic skills with movement to small homes.
- The eight studies that compared the adaptive behaviors of those who left the institution and those who stayed found significant improvements in overall adaptive ability on the part of movers, sometimes as soon as nine to twelve months after moving to smaller settings.
- Five of the ten studies that measured people's adaptive skills while living in the institution and after moving to the community found marked improvement in overall adaptive behavior or in basic self-help and domestic skills. The remaining studies found modest, but not statistically significant improvements in these areas.

In these studies, smaller residential settings had a positive impact on the ability of people with mental retardation, regardless of level of disability, to gain in the areas of self care and domestic skills. Living in smaller settings may be especially beneficial to people with severe and profound disabilities by promoting greater growth and independence in self-help and adaptive behavior skills. But, the benefits of community living go beyond improvement in ability, offering the opportunity to live in the same communities as the general population and to learn to function as a part of those communities.

Contributed by Lynda Anderson, Research Assistant, and Sheryl A. Larson, Research Fellow, with the Center on Residential Services and Community Living, University of Minnesota, Minneapolis. They may be reached at 612 / 624-6024.

Reference: The review of the 18 studies is found in Larson, S.A. & Lakin, K.C. (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. *Journal of the Association for Persons with Severe Handicaps, 14* (4), 324-332.

Deinstitutionalization Litigation: Experiences and Outcomes

by Judith A. Gran

Since the early 1970s, more than 45 lawsuits have been filed by persons with disabilities and their advocates against state institutions. These lawsuits have been enormously successful by any measure. In the great majority of cases, persons with disabilities have prevailed and received significant relief from ill treatment and other wrongs. By the end of the 1980s, court orders in 16 states and the District of Columbia had resulted in a significant expansion of community services in those states (e.g., Connecticut, Florida, Louisiana, Maine, Michigan, Minnesota, Nebraska, New Hampshire, New York, North Carolina, North Dakota, Oklahoma, Pennsylvania, Rhode Island, Vermont, and West Virginia).

In the 1990s, the number of states experiencing institutional litigation continued to grow, and court orders and decrees were entered in California, Illinois, New Mexico, Tennessee, Utah, and Wyoming. By the mid-1990s, three states – New Hampshire, Rhode Island, and Vermont – and the District of Columbia were institution-free, all as a result of litigation, and other states had expanded community services dramatically. For example, North Dakota reduced its institutional population by 80% during the first 10 years after the court's order in *Arc of North Dakota v. Olson* and increased community spending more than twenty-fold. Wyoming has achieved a comparable reduction in institutional population in the four years since the consent decree was entered in *Westin v. Wyoming State Training School*, along with the creation of a comprehensive array of services in the community.

The vast majority of these cases were brought as class-action lawsuits seeking to enforce institutional residents' constitutional and federal statutory rights. Some highly successful cases have been brought in state court under state law, and in a few cases advocates have won deinstitutionalization with the creative use of state commitment statutes. The plaintiffs have been individual institutional residents (including persons with developmental disabilities inappropriately confined in nursing facilities and state mental health facilities), state Arc affiliates, Protection and Advocacy systems, and parent groups. More recently, People First organizations have initiated lawsuits against institutions in Tennessee and Connecticut.

The successful litigation strategies of plaintiffs in institutional litigation include use of institutional residents' rights under the Due Process Clause of the Fourteenth Amendment. In *Youngberg v. Romeo*, the U.S. Supreme Court held that those rights include safety; freedom from harm; freedom from restraint; adequate food, shelter, and medical care; and habilitation in accordance with professional standards. Plaintiffs in institutional litigation have used the Romeo rights to secure community placement using two related strategies. First, they have shown that the congregate, artificial, and segregated nature of the institutional environment presents overwhelming obstacles to the delivery of appropriate services to persons with severe disabilities. The evidence in most institutional cases shows not only that residents are being harmed in a particular institution, but that institutions inherently deny to persons with significant disabilities exactly what they need the most – the opportunity to learn skills in the natural environments where those skills are practiced, the benefits of close, personal attention in a family-like environment; and the advantages of modeling peers without disabilities.

Second, plaintiffs have won community placement by showing that "habilitation in accordance with professional standards" means the opportunity to develop one's abilities (habilitation) in a normal community setting. To date, four of the twelve federal Courts of Appeal and a number of district courts have found that institutional residents whose interdisciplinary teams recommend community placement are entitled to services in the community, either as a remedy for violation of their right to adequate habilitation in the institution or to prevent violation of their right to adequate habilitation in the future. When plaintiffs prove that habilitation in a community setting is needed to comply with the law that institutionalized persons be given minimally adequate habilitation in accordance with professional standards, courts have ordered community placement.

In some cases, plaintiffs have won community services by using the integration requirement of Section 504 of the Rehabilitation Act of 1973 and, more recently, the analogous provision of the Americans with Disabilities Act. Both statutes prohibit segregated services unless segregation is necessary to provide services effectively. In *Jackson v. Fort Stanton Hospital and Training School*, the district court held that Section 504 required the provision of community services to institutional residents whose interdisciplinary teams had recommended community placement. In a recent decision, the Court of Appeals for the Third Circuit endorsed the same reasoning and held that Pennsylvania officials could not deny home and community basic personal assistance services to a nursing facility resident who could live outside the nursing facility if provided those services.

Institutional litigation has had a profound impact on the lives of persons with disabilities and on state developmental disabilities service systems. The outcomes of institutional litigation include:

- Significantly higher quality of life for former institutional residents, as measured by gains in adaptive behavior, reduced challenging behavior, increased number of service hours, increased family and consumer satisfaction, and expanded opportunities for community integration.
- Significant increases in public spending for persons with developmental disabilities.
- Dramatic expansion in community services and reduction of institutional populations.
- Demonstration that institutions are not needed to serve persons with significant disabilities.
- Remarkable changes in the configuration of community services in states that have experienced litigation.

Research shows a high correlation between institutional litigation, reduction of institutional populations, and increases in MR/DD spending in both the institution and the community (Braddock, et al., 1995). Each of the five states that ranked highest in reduction of institutional populations between 1988 and 1992 – the District of Columbia, New Hampshire, West Virginia, Michigan, and North Dakota – was the object of a court order or consent decree requiring expansion of community services in the 1980s. Of the 10 states ranked highest in 1992 in fiscal effort on community services, all but Iowa have experienced litigation.

Among the most striking outcomes of institutional litigation is its impact on the development of community service technology. Unlike traditional deinstitutionalization, which has often led to community placement of persons with relatively mild disabilities while persons with greater needs remain at the institution, court-ordered deinstitutionalization requiring community placement of all those who would benefit from community services has forced state and local authorities to develop community services for all institutional residents.

As a result, institutional litigation has dramatically changed the shape of community services systems. For example, the Pennhurst litigation in Pennsylvania resulted in the placement of virtually all residents of Pennhurst Center in the community. Before the court's orders in 1978, community living arrangements (CLAs) in the city of Philadelphia served only persons with mild disabilities and city officials sent nearly all Philadelphians with significant disabilities to institutions far from home. Ten years later, when Pennhurst closed, the number of persons living in CLAs in Philadelphia had doubled and the community service system had developed the capacity to serve persons with the most complex needs possible.

In Oklahoma, at the time that *Homeward Bound v. The Hissom Memorial Center* was filed in 1985, there were hardly any community services for persons with significant disabilities and indeed no real community service delivery system. A small number of service providers contracted directly with the state to serve persons with very mild disabilities in large group homes with minimal staffing at rates of less than $30 a day. Case management and family support services were almost nonexistent. As a result, many children were institutionalized at age six and remained there with no hope of discharge except to a nursing facility where persons with developmental disabilities were housed at bargain basement rates. Nine years later, as Hissom closed, the state had developed a system capable of supporting all persons with disabilities that was recognized throughout the nation as a model of quality individualized services.

Litigation has also stimulated the development of community services technology as the courts and the parties to consent decrees have crafted remedial orders to reflect best practices. In the late 1970s, the Pennhurst court ordered the defendants to develop new case management systems, with small caseloads, based in outside provider agencies. The Homeward Bound court ordered the state to develop community services including supported living, intensive family support, and supported employment.

During the 1990s, both in new deinstitutionalization lawsuits and older cases, plaintiffs have focused more attention than ever on the improvement of services and implementation of state-of-the-art practices in the community. For example, the consent decree in *Coffelt v. DDS* requires systemic reform of community service systems in northern California, including the provision of more individualized and person-centered service models and the development of quality assurance systems. Similarly, the consent decree in *Nelson v. Snider* in Pennsylvania requires person-centered planning, supported employment as the preferred daytime activity, consumer and family monitoring in the community, and the option to use consumer-driven financing for all members of the plaintiff class. The most recent orders in the 21-year-old Pennhurst litigation in Pennsylvania require the development of a comprehensive quality assurance system for class members in Philadelphia, and the parties have negotiated improvements in the court-ordered individual habilitation plan (IHP) process to make it more person-centered. As we move toward the close of this remarkable century of social and attitudinal change, litigation will continue to be a valuable tool in institutional depopulation and closure, and a powerful instrument for honoring and ensuring the full citizenship of persons with disabilities.

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Reference: Braddock, D., Hemp, R., Bachelder, L., & Fujiura, G. (1995). *The State of the States in Developmental Disabilities (4th edition)*. Washington, DC: American Association on Mental Retardation.

Thoughts and Impressions on Institutional Closure

by Steve Taylor

Having followed successful institutional closures from a distance, observed less successful efforts closer to home, and participated in numerous meetings on the planned closure of Syracuse Developmental Center, I have formed some thoughts and impressions on the closure process. Of course, no definitive conclusions about institutional closure can be reached yet. We need more examples of how to close institutions in all regions of the country and in states not noted for their forward-looking administration of developmental disability services before we write the step-by-step instructions, if ever we can. However, it is not too early to begin to draw some generalizations about institutional closure from experiences to date:

- **There are different ways to close an institution.** Institutions have been closed successfully in one of two major ways. The first is to announce the closure far in advance with broad political and public support. The second is to gradually and quietly depopulate an institution to the point at which the costs of continued operation are prohibitive and no responsible public official can justify the expense. Which strategy works best? The former seems to have worked in Vermont, while the latter seems to have been effective in New Hampshire. It is preferable to have political consensus in favor of closure and to close an institution through a planned, orderly, and public process. However, the political and economic climate will dictate the strategy that will work best in any particular state; in some states, circumstances may argue against a public announcement of closure far in advance. What is most important is not which strategy is used, but whether responsible officials do, in fact, have a strategy for closure.

The Community Imperative

A Refutation of All Arguments in Support of Institutionalizing Anybody Because of Mental Retardation

In the domain of Human Rights:
All people have fundamental
moral and constitutional rights.
These rights must not be abrogated
merely because a person has a
mental or physical disability.
Among these fundamental rights is the
right to community living.
In the domain of Educational Programming
and Human Service:
All people, as human beings, are
inherently valuable.
All people can grow and develop.
All people are entitled to conditions
which foster their development.
Such conditions are optimally provided in
community settings.
Therefore:
In fulfillment of fundamental human rights,
and
In securing optimum
developmental opportunities,
All people, regardless of the severity of their
disabilities, are entitled to community living.

The *Community Imperative*, was issued by the Center on Human Policy, Syracuse University, in 1979 in response to backlash against deinstitutionalization.

- **Where the people go is more important than whether an institution is closed.** Institutional closure is a worthy goal, but it is merely the means to the end -- community integration and inclusion. If an institution is closed through transfers to other public or private institutions, the creation of mini-institutions in the community, or the re-naming of units on institutional grounds, then little has been accomplished and, potentially, much harm has been done. Institutions must be closed in a manner that gives each person increased opportunities to participate in community life.

- **Compromises need to be made in the closure process.** No state has replaced an institution with a totally individualized system of community supports. The goals of institutional closure and the development of individualized services are inconsistent, and perhaps contradictory. This creates a difficult dilemma. Should people be forced to remain in institutions while states realign their policies and fiscal mechanisms and service providers develop the capacity to offer individualized services on a large scale? Or, should institutional closure proceed even though all people will not be able to be supported in individualized ways? Either path represents a compromise in values and desired outcomes. The only reasonable way to approach the dilemma is to ask which path will cause the least harm to the fewest people. From this vantage point, continued institutionalization cannot be justified. Even if ideal services cannot be developed, people should not be denied the opportunity to live a better life in the community. Institutional closure will require compromises. Compromises are most dangerous when they are not acknowledged as such.

- **People with the most significant needs should be moved into the community throughout the institutional closure process.** People with the most severe disabilities, including those with complex medical and behavioral needs, should have equal opportunity to live in the community. For this reason alone, they should be moved into the community during all stages of institutional closure. More than that, community providers need time to develop the capacity to support people with the most significant needs in the most responsive and individualized ways. When people with severe disabilities, as a group, are the last to leave an institution, it is likely that they will be placed in the most restrictive and least integrated settings, simply because planners and providers lack the skills and experience to support them in other ways.

- **Institutional closure should proceed with concrete benchmarks and tangible indicators of progress.** The more carefully planned an institutional closure, the greater the probability that an institution will be closed in timely fashion and replaced with responsive services in the community. At the minimum, administrators and planners should establish targets for census reduction and the development of residential, vocational, medical, and other community supports and services as well as vehicles to monitor progress toward meeting those targets. In instances in which closure has been initiated by bodies or officials other than administrators responsible for closing an institution, closure plans should address implementation steps, specific descriptions of the kinds of community services to be developed, and strategies for safeguarding quality.

- **When the goal of institutional closure is explicit, all relevant parties should be involved in the process and information should be readily available.** Institutional closure can be controversial, but this does not justify excluding relevant parties – advocates, parents, institutional staff, local elected representatives, community providers, and others – from planning or withholding information about the process. Once a policy of closure has been adopted, all interested persons should have the opportunity to participate in planning and to voice their concerns. Suspicion, distrust, low morale, and rumors serve no one's interests.

- **Institutional parents should not be treated as the enemy.** In some states, institutional parent groups have been vocal opponents of closure. Many parents placed their sons and daughters in institutions years ago on the advice of professionals when few, if any options were available. Now, some parents are fearful of losing the sense of security provided by the bricks and mortar of the institution. These parents are mistaken in believing that their sons and daughters belong in institutions and that security cannot be provided in the community. But they did not create the institutions and are deserving of sympathy and respect. Quality community services and the long-term commitment of community providers will eventually allay parental fears and concerns.

- **Advocates and administrators have complementary roles to play in institutional closure.** Advocates have served as important catalysts for change, including the closing of institutions, and have a critical role to play in monitoring the closure process and the quality of services in the community. Yet the success of closure efforts will depend upon competent and committed administrators. Advocates should not attempt to manage the closure process, but should direct their efforts to making sure that the right persons are in position to accomplish the goal. The most successful administrators know how to work with advocacy groups and are open to external scrutiny and review.

- **Closure should be accomplished in a manner that minimizes disruptions in people's lives.** Under the best of circumstances, moving from a highly regimented and controlled life in an institution to less restrictive settings in the community can be a disorienting experience. Repeated movement of people from one institutional unit to another prior to closure should be avoided at all costs.

- **Institutional closure should result in a decentralization of decision-making regarding services.** With the closure of public institutions, decision-making should shift from state capitals to local communities. People with developmental disabilities themselves and those who are close to them should have a major say over where and with whom they will live and how they will be supported. Decentralization of decision-making does not mean that appropriate governmental bodies should abandon their legitimate oversight role.

Despite progress, the fact that nearly 150,000 people with developmental disabilities remain in public and private institutions and nursing homes is a sobering reality. Regional and state variations in deinstitutionalization efforts are striking. We need to be reminded that not everyone agrees that all people with mental retardation belong among us and have fundamental human rights. Many of the same arguments made previously to oppose deinstitutionalization are used today to oppose school inclusion, non-aversive interventions, and other humanistic efforts. We must continue to speak out clearly and forcefully on the issue of institution versus community living so that all people, regardless of the severity of their disabilities, are afforded the opportunity to live in the community and experience the associated rights and responsibilities of citizenship.

Steve Taylor is Director of the Center on Human Policy, Syracuse University, Syracuse, New York. He may be reached at (315) 443-4484.

Inside and Out: Former Residents Reflect on Their Lives

Below are the stories of two individuals who were once residents of state institutions. Today, they live in their own homes and are actively working to improve the lives of all persons with disabilities through their involvement with Self Advocates Becoming Empowered, the national self-advocacy group.

■ Russ' Story

My name is Russell Daniels. I was 12 years old when I was sent to a state school. When I left there I was 28 years old. I'm 50 years old now. I went in April of '58. It was a rainy day. I went to the institution because I had problems with going to school and stuff like that. You know, when you don't like school that's what happens. And that's one reason why I had to go to the institution, because I was a problem child. Everybody, you know, sometimes gets in trouble and they don't like to go to school, and stuff like that.

I wasn't allowed to see my family the first day. They give you a week without seeing them. After awhile they start letting you have visitors. In those days they let you go out for the day but when you came back you would be searched. You couldn't have money, watches, rings, or anything. They'd take everything away because that was the rules and regulations.

I'm really proud to be out and I never want to go back to any institution at all. It was terrible. They treat you like dirt. You don't get treated like a human being. They treat you mean, like, you know, you do something, they slap you. "Do this, and do that. Sit down and don't say a word." So, when I got about 17, something like that, I took off. Packed up my lunch and took off and went into the woods and went on the highway and started walking. Then I got picked up by the police. So they brought me back and put me in seclusion. They put you in a room by yourself for awhile and let you stay there, and later on they let you out. Then you couldn't go anywhere for that amount of time.

I wanted to leave because I didn't like it after that first time. I didn't like it at all. I was scared, and didn't know anybody, and all that. But after awhile I got used to it. I got friendly with everybody. Yeah, it was all right then. Yet, I wasn't given any choices. I wasn't abused, but other people were. Other people got abused, got pushed around, banged around and stuff like that. I mean it was terrible, you know.

During the day they put you in a room with a bunch of other people and they'd stay there. After I got used to being there I went to school and I had a job. I used to help clean the place up and do dishes and set tables. They didn't pay you. That was a job, and that's what you had to do. For fun they would have movies and dances and stuff like that.

You'd have to get up at six in the morning, get dressed, make sure everybody else is up, make your bed, and then everybody went downstairs in the day hall. They are ready to go down for breakfast at seven o'clock. We all had to be in line. The second shift comes in, they go outdoors and play, you know, play baseball or something like that, lunchtime was about noon, and then they come in about five o'clock. Everybody comes in, washes their face and hands, line up and get a tray and get their food in line and sit down. At night they watched TV until nine, which was bedtime. Everything shut off, the lights off and that's it.

Now, I live like a king. I'm happy I do what I want, go where I want. I can come back when I want. Nobody tells me, "You can't go here, you can't go there." 'Cause that's annoying. I live by myself. I pay my own rent. I pay my bills. I work at the Senior Center. I have been working there for about three years. I'm a janitor. I clean up the place and lock up and help the elderly people out. You know, help them down stairs and stuff. I love it. And they all love me.

I am working on the Self Advocates Becoming Empowered subcommittee, Operation Close the Doors. We passed a petition around for people to sign to show their support. I brought that to some people and they said they wouldn't sign it because they didn't think it was a good idea all places should be closed. So I just looked at them and I said, "Why do you say that?" Because they're not getting the care, treatment like they used to get when they were in an institution. That's what they were saying. When they used to be there, they used to get a dentist, a doctor—everything right there on the campus. Today, doctors may refuse to take a patient with a disability. Like last time I went they took me, but there was another person that used to live in an institution, I know him well, they refused to take him. The next person came in. They took that person and had the other person wait. And I went up there and I said, "This person has been waiting for an hour. It's not right to take the next person when he just walked in the door and this other guy has been sitting there for an hour, and the other guy without a disability that came in, they took him right away. That really bugged me, so I got up there and I told the person. I said, "This is not right for you to do. Have this disability person wait that long and wait on the other person that didn't have a disability." You know, they said, "Well, you got a point there." So what they did, they listened to me and they took that person and had the other person sit down and wait. Because I got up there and I told them how I felt about it. I told them I used to live in institutions myself and I know how they are when they do something like that.

I have friends that I visit in the institution. They tell me they want to leave because they saw me leaving. They said, "Well, gee, how come this guy is leaving?" So I said, "All you have to do is be patient. You'll be next." There was one person that didn't want to leave the place because he was afraid to go out into the community because he didn't figure he would get the care. I said, "Don't worry about that. You will get the care like everybody else." So, they didn't think he would make it, but he did. He got out, and he made it. I saw him the day I left to come here. He said, "Well, wherever you go, you make sure that you bring up that I made it."

Russ Daniels is a board member of the self-advocacy organization Open Door Club and is active in Operation Close the Doors. He lives in Belchertown, Massachusetts, and may be reached at 413 / 323-6036.

■ Mark's Story

My name is Mark Samis. I was 15 when I went into the institution and I lived there for 12 years. When I entered the state hospital and school back then I was scared 'cause I thought I would never see my family, 'cause there were people up there whose family just put them up there and forgot about their love.

I had no rights. I could not speak up for my rights. If I did, the supervisor or attendants would work me over, flatten me out or things like that. I had no privacy. I could not go to a room to cool down when felt sad about something or didn't want to be bugged, things like that. And I could not sit outside and visit friends of mine who lived on other wards. I could not sit on the merry-go-round, swing set, what have you, to visit with my friends. I had no girlfriend up there. I couldn't talk to my male friends. If I did, an attendant would chase me back. Again, I couldn't say nothing or I'd get slapped up or what have you. A few times they would slap me up for not saying something. They'd use a stick. Like, I could not have friends, they were telling me.

There was this one substitute attendant who would not let me sit at a table, paint-by-numbers, play card games, things like that. He'd force me to watch TV when I didn't want to watch TV 'cause I'm not a soap opera fan. That's all they'd watch. So, if I'm working on this paint-by-numbers set, he would put his hand on it to smear it up and say, "Nice job." He didn't actually smear it up, though he would have felt like doing it. He just he kept getting on my nerves so I would say something. He was just waiting for me to say something, but I wouldn't play his game. So when he was on, I knew I would just go put away the paint-by-numbers as soon as he walked in the door, and go and watch TV. Sometimes when he was officially on duty he would come over and say, "You're lucky you made this decision. You're over here watching TV." Again, I wouldn't say nothing. He just couldn't get me to play his game, hoping I would say the wrong thing. Then in the evening during prime time when there is programs I wanted to watch, he would not let me watch them.

And they forced me to do things against my will. They intimidated me, put it that way. Now, I would say I was physically and mentally abused. Like speaking up for my rights, my God-given rights, they would slap me up and things like that. They called me every name underneath the sun you can think of. That's how I was mentally abused.

When January 8, 1974 came – the day I was to leave – I wanted to get away from that place. It was the worst experience I ever faced. I don't want nobody to go through that. I felt like I was in a warehouse or something.

Now, I travel telling my story to college students who are being teachers or working in special education and things like that. I just go around and give them a message: Treat people with disabilities as you want to be treated 'cause one day you students might become the parent of a child with disabilities and you would want that child to be treated as anybody else would be treated. I tell them, "Look at a person with disabilities as a person first, not their disabilities. You want respect, so do we people with disabilities want respect."

I also went back to the institution and told my story. The superintendent and I went riding around in these golf carts touring because I wanted to see that building I described where I had no rights. I explained to him what it was like, what this building was like. It's like when survivors of World War II go back to these death camps how they remember this was the gas chamber, this was the barracks and things like that, this is where we ate, things like that – I could remember that building just like it was still there.

Now, in the past few years my life has all turned around. Nothing but great things have happened to me since leaving the institution. Maybe it took awhile. Like they say, patience is always rewarded. So I'm very proud of what I do now. I'm hoping to see these institutions all over the United States close and I don't care what they do with them once they get them closed. As far as I'm concerned they can drop a bomb on them once they get the people out.

Mark Samis is Vice President of People First of South Dakota, Vice Chair of the South Dakota DD Planning Council, a board member of Self Advocates Becoming Empowered, and is active in Operation Close the Doors. He lives in Pierre, and may be reached at 605 / 224-6486.

Operation Close the Doors: Working for Freedom

by Tia Nelis and Nancy Ward

Self Advocates Becoming Empowered is a national grassroots organization of local self-advocacy groups in the United States. Our organization believes that people with disabilities should be treated as equals. That means people should be given decisions, choices, rights, responsibilities, chances to speak up to empower ourselves, and opportunities to make new friendships and renew old friendships just like everyone else. We should be able to learn from our mistakes like everyone else. Not all members of Self-Advocates Becoming Empowered lived in institutions. We all have friends who have lived in them. Other members still live in institutions. We all know the stories. We know that in some ways they are the stories of us all. That is why one of our major goals is to close institutions. That is why we believe that people should live in their own communities.

This past June, our Operation Close the Doors committee met in Chicago to develop a plan outlining strategies to close institutions and to open the way to community living. This plan was adopted at the national steering committee meeting in April. The plan outlines what local, state and national organizations can do to close institutions and how to place pressure on local and state service systems. The plan also describes how these organizations can support individuals who live in institutions and those who are moving into the community. Tools needed by local, state and national groups were also identified.

As part of this project, we are interviewing friends and others who have lived in institutions to tell their stories about what it was like to live in an institution and what it is like now to live in the community. Hearing these stories has strengthened our conviction that those of us who are on the outside cannot rest while others are still shut away and not treated as real citizens of our communities. The following are examples of some of the stories we've heard:

- One person from Pennsylvania said, "[The institution] I lived in was run like a prison. I felt I had no freedom. I only got to leave to visit my family four times a year. There was no variety of foods. I feel more like my own person living in the community. I like having choices. I have always wanted to live like everybody else. I feel that these institutions should be closed down. If I had [the] opportunity to change all that I would."
- An individual from Massachusetts wrote us a letter and said, "Many terrible things happened to me. I was yelled at by porters and nurses. One porter pushed me down the stairs. Another pushed glass into my eye. I needed surgery to have it removed. Another time my fingers were bent back as punishment. I now have friends in the community. I am able to go places. I think institutions are rotten, they are like jails. It's worse than a prison!!!"
- A person who had lived in a New Hampshire institution remembered, "I was abused terribly! The attendants hit and slapped people and myself. We didn't have the freedom to do things on our own. If you didn't do what they told you, you would be locked up in a room. They forced you to do things." He then said, "Now I live in my own apartment and I am happy.... I have a tutor and two jobs.... I enjoy meeting people and volunteering."
- In New Jersey, a woman told us her story. She said, "[My sister] told me I was going to learn something [in the institution]. I didn't learn anything good. I learned that staff say they don't believe in hitting, but they hit me. I don't know why. I always got beat up in the institution. My hair was pulled. I was punched in the mouth. My teeth bled. I had two operations. The first was a tracheotomy. A consumer in the institution forced a key down my throat. The second was a tubular ligation. I bled so much that they had to perform a hysterectomy. I wanted to have kids. I now have scars that remind me of those days." She then said, " I [now] live in a supervised apartment. I have more independence. I get to do things for myself. I like going places.... see trees blowing in the wind, people walking on the beach. It makes me very happy to see other people happy."

A self-advocate from Oklahoma sums up the reason why Self Advocates Becoming Empowered has undertaken Operation Close the Doors: "Everybody has rights, just because we are different or look different does not make us have to be in institutions. We are people just like you and anyone else, so start treating us like other people, and not animals." Some of us from Self Advocates Becoming Empowered were at the White House for the celebration of the Americans with Disabilities Act. The President told us, "We have made great strides as a nation in fulfilling America's promise of common sense justice. Still, much remains to be done." We know we must do something. The first step in "all that remains to be done" is to set our people free. End their exile. Join us and our allies in ending this long sad chapter in America's history.

Tia Nelis and Nancy Ward are Co-Chairs of Self Advocates Becoming Empowered. Tia is also Chair of Operation Close the Doors and Self-Advocacy Advisor with the Institute on Human Development, University of Illinois at Chicago. Tia may be reached at 312 / 413-1284; Nancy may be reached at 402 / 476-0002.

On the Outside Looking In

by Ruthie-Marie Beckwith

Whenever we first drive up to one of Tennessee's large state-run institutions, our first impression is that of a fortress, island or maze. There are green lawns, and lots of buildings with names like Canteen, General Maintenance and Operations, and Infirmary. At the entrance, I sit in my car and rapidly feel small and insignificant as we try to discern the route that will take us to the people we want to visit. I feel my resolve begin to waver as some of the people in the car begin to point the way because they are experts – they used to live there. They have agreed to come back to visit people and work to establish fragile relationships that are defined by bureaucracy and history, a history of people who live lives so invisible that people from the outside looking in cannot be totally sure of their existence.

They have agreed to come back to visit people...who live lives so invisible that people from the outside looking in cannot be totally sure of their existence.

Frances Hamblen, one of our state self-advocacy leaders, has said, "I care about getting the people out in public and letting them talk about what is going on. So, we go to talk to our members of People First of Nashville [who live in the institution], trying to get them to come to our meetings; to go and listen to them, try to find out what their needs are, and how they want to move out. If they need help, they can call us to do more visits."

Charles Hall, another Nashville People First member, is firmly committed to this work. He's the first to proclaim, "The people in the institutions need more freedom, like the freedom to do what's right for themselves and others. For example, I would like to invite a friend of mine over to my apartment for my birthday, but I don't know if the institution will let her or not. We hope we can get more people out. We want them to have more freedom. It means I'm talking to people about getting into People First and about the rights we have. If we are going to free our people someday, we need to do it right away – get them into group homes or apartments, whatever they want to do. I don't know if the Superintendent agrees with me or not."

The visits that Frances and Charles make are one of many ways that members of People First of Tennessee have been reaching out to people who live in Tennessee's developmental centers for the past 12 years. Other efforts include:

- Helping people in institutions to have their own self-advocacy chapter.
- Helping people in institutions who join a community self-advocacy group.
- Providing personal support and advocacy.
- Providing self-advocacy training to individuals on the inside.
- Testifying at hearings about closing institutions.
- Including people who live in institutions in all aspects of self-advocacy work.
- Filing litigation on behalf of members in institutions.

Members who have been involved in this work value it highly. "I got to know how one of our members feels about [the institution], reaching out to her and trying to help the ones that are still there. We went out to eat and helped her find somebody she can talk to", says Frances. Charles agrees. "It makes me feel good when I'm out there listening to people. It makes me sad when I have to leave. I like to talk to the people. The thing is, we don't have much transportation to get there as much as I would like to."

So, we find our way and park in front of the cottage where several People First members live. We have all signed the appropriate visitor forms and given the names of the people we want to see. We know we won't have much time to visit or much privacy. Sometimes we walk around outside and sometimes we leave the facility and go out to eat. Each time we visit is another opportunity to connect. Usually we are the only people who have visited some people in several years.

Each time we visit is another opportunity to connect. Usually we are the only people who have visited some people in several years.

Helping people become visible is hard work. Members who want to visit are dependent on other people's schedules and transportation. Calling and making arrangements can be complicated by the institution's bureaucracy. Sometimes we are met with outright resistance and refusals to honor our visitation requests. However, when schedules permit and there's gas in the tank, we go. People First of Tennessee members will keep going until everyone is free.

Ruthie-Marie Beckwith is Staff Advisor to People First of Tennessee, Nashville. She may be reached at 615 / 259-0490.

There is a Hell: One Parent's Story

by Kathy Hayduke

As a parent of an adult woman with mental retardation, I can say there is a hell. Mine is created out of the guilt of having put my daughter into it. The hell I speak of is called an institution. We put our children into institutions because we reach the end of our rope; we are in total despair. We feel grateful for a place where they have three meals a day and people who are willing to care for them.

Our daughter Stacey was 4 1/2 years old when we put her in an institution. She was a happy, cute, bright-eyed little girl. At this age her brother and sister were terrified of her. We were not welcome in any of our family's homes, or any of the neighbors'. We took her to the institution for the first time in November, and we came home completely exhausted. I said to my husband, "Do you hear it?" He said, "Hear what?" I said, "Yes, it's the silence. The children are not crying any more." We didn't know how to deal with her, so we put her away. No one offered us choices. No one said this is how you help her. We didn't want to abandon our daughter to hell. But we couldn't go on. Nothing else was offered. It was our only option.

On our first visit after three days, Stacey's shine and sparkle in her eyes was gone. Before her admission, they'd taken us on a tour where they said she'd be living. On our second visit, they said she'd been moved and put with the seven to ten year olds. They explained that it was because she didn't mean to hurt anyone, but she was hurting the little people. We said we understood because that's why we put her away. We thought no one else would take Stacey, that she would have no permanency in her life: what an obscene thought for a parent. Stacey has had to deal with the constant array of strange people taking care of her. She's had to deal with moving from ward to ward, institution to institution, institution to group home.

While Stacey was in the institution, we brought her home every weekend. It didn't take long for us to see the sores starting to appear on her hands. If you look at her hands today you can see the scars: the scars of someone who has nothing to do, the scars of someone who's hungry but it's not time to eat. She chewed on her hands until she made sores. Every weekend I'd bring her home and her rear-end would be broken into a rash. We asked why, and they said it was the diet; they said that they couldn't give her food that she wasn't allergic to because they were feeding the masses.

I never picked her up or dropped her off that I didn't cry my heart out. How can you love someone and do this to your own child? If she had been at home, with the help I needed to keep her, she would not have had to deal with these things. I remember picking her up one day. She was sitting in the chair by the door. I took her hand to help her out of the chair, and her legs collapsed beneath her. I thought, "My God, how much does one person have to suffer?" I asked the nurse what was wrong: she said arthritis. It was a lie. It wasn't until years later that I learned that she'd been a victim of physical abuse. You want to believe that these are nice people taking care of innocent children.

Stacey was nine when she was transferred to a smaller facility near our home. My first vision of her at this place was of her sitting on a chair being punished for flooding the bathroom. She spent a lot of time sitting on that chair.

She may be slow, but she is inquisitive. They weren't giving any toys to the children because they said that the kids used them as weapons against each other. She created her own toys by stealing peoples' shoelaces and soles of their shoes. One staff person said, "Stacey's such a delight. Always doing something. When she's bored, she and her friend look for something to play with. Sometimes it's a fly or a spider." They call that a type of play? She was desperate for stimulation. Maybe in a smaller setting, like a group home, she wouldn't have to play with flies. One time I went to pick her up, and the place was loaded with toys. Someone had delivered tons and tons of toys. When I brought her back that night there wasn't a toy in sight. They said that the kids started to use them as weapons, so they were put away.

Around the age of 13 the sexual abuse started. I think back, and all the time she was trying to tell me what was happening, but I couldn't read her signs. I would say to staff, "Why's she have all those black and blue marks?" And they would say that they didn't know, but that she just keeps hitting herself. It was her way of telling us what was going on. When Stacey moved into a group home she had to be treated for a venereal disease. I have my proof that she was abused at that institution. Two years ago a former foster grandparent came to our place of business. She was happy to hear that Stacey was not at the institution any more. She said to me, "Aren't you glad she'd not being sexually abused any more? We foster grandparents used to say how terrible it was."

Stacey still lives in a group home. Her life is much better now, but it's far from perfect. We'd like to see her have a home of her own, with the help she needs, and a real job in the community. However, with proposed federal and state budget cuts it looks like things may get worse, and it's very frightening. People may have to go back to institutions, and they won't be able to live in the community any more. I'm concerned that families aren't going to get the help they need to keep people out of institutions.

Kathy Hayduke is a founding member of Parents for Positive Futures and has been actively involved in numerous New York parent and advocacy groups.

Parental Attitudes Toward Deinstitutionalization

by Lynda Anderson and Sheryl A. Larson

With the growing number of state institution closures, many parents are concerned about finding and maintaining a safe, caring, respectful, and permanent home in the community for their sons and daughters who have mental retardation. The possibilities and uncertainty of the move away from institutions have stimulated parental responses ranging from ardent support for deinstitutionalization to adamant opposition. Many studies have examined parental attitudes and expectations related to deinstitutionalization. Twenty-one such studies reviewed by Larson and Lakin (1991) reported on observations by parents regarding the move from institutions to the community, and offered suggestions for families and individuals in making the transition. From these studies, the following conclusions emerged about parent attitudes toward their son's and daughter's lives in institutions and in the community:

- **The vast majority of parents were satisfied (secure, content, and comfortable) with their family member's public institution placement.** Eleven of the studies surveyed parents while their family members lived at the institution on their opinion about moving to a community setting. Ninety-one per cent of the parents were somewhat or very satisfied with the institution. Only 21% of the parents supported the idea of having their son or daughter move to a community setting.
- **The vast majority of parents changed their attitudes about community placement after their family member had moved to the community.** Four studies surveyed parents before and after their family member moved to a community setting from the institution. Only 15% of these parents had a positive reaction to their family member moving before the move occurred; after the move, 62% of the parents expressed a positive opinion about the move to the community. Before the move, 83% of the parents reported satisfaction with the institution; after the move 87% were satisfied with the community setting.
- **After experiencing community services, parents viewed the institution less positively than they did when their family member lived there.** Seven studies interviewed parents whose sons or daughters had moved from an institution to a community home about their satisfaction with the institution, the community setting, and their opinion of the move. Only 52% of these parents expressed satisfaction with the institution, and 56% of the parents reported they had a positive reaction about their family member moving to a community home before it happened. This compares with an 83% predischarge rate of satisfaction with the institution and a 15% rate of support for the move. The same parents reported an 88% rate of satisfaction with their children's community living experiences.
- **Parents observed improved quality of life and relationships for their family member after the move.** In five studies, more than 65% of the parents reported after the move that their family member was happier, that relationships between their son or daughter and other people improved, that needed services were available, and that staff members in the homes were competent. Fewer than 12% reported negative changes in these areas. The only area in which parents reported considerable uncertainty was the 31% who felt that community funding was less secure than institutional funding.

Those parents initially opposed to their child's move to the community offered a number of reasons for their attitude. In open-ended responses in 16 studies, parents said they were initially opposed to the move because they felt that the institutions were better than community homes at responding to the specific characteristics or needs of their children; available homes were inadequate in terms of safety, service quality or staffing; the process involved in the decision to move people was unfair, improper or disrespectful; or they felt movement to the community would increase the caregiving responsibilities of the family members. While most parents were ultimately satisfied with the community placement, many offered recommendations for lessening the fear about the move. They suggested those planning for people's moving must acknowledge as legitimate the fears and wishes of the family and respond to them as well as they can. They must include the person who is going to move and the family members in decisions related to the move. Visits should be arranged for family members to potential community sites, and parents who have been involved in previous moves should act as guides in these visits and/or be available in other ways to parents. Government agencies should assist in establishing communication between families and community providers. Finally, they emphasized the importance of public articulation of government commitments to funding and other policies to ensure the viability, continuity, and quality of community settings.

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Reference: Larson, S.A. & Lakin, K.C. (1991). Parents attitudes about residential placement before and after deinstitutionalization: A research synthesis. *Journal of the Association for Persons with Severe Handicaps, 16*(1), 25-38.

Voluntary Closure: The *Homeward Bound* Experience

by Donna Hoverman

There are 63 children and young adults whose "home" is Homeward Bound's main facility in New Hope, Minnesota. Thirteen of the individuals have lived there for nearly 20 years. A sixty-fourth "bed" is licensed for respite services and is typically used by a dozen children who live in family or foster homes. This facility was developed by families and in earlier years was the preferred alternative for many children who were living in hospitals, nursing homes or state institutions. It was, in many cases, the only alternative for children whose families were not able to access the appropriate resources to maintain their child in their own home because such services simply didn't exist.

Most of the people who receive services from Homeward Bound are considered medically fragile. Terms like *hypothermia, hyperthermia, traumatic brain injury, spastic quadriplegia, cancer diseases, cerebral palsy, Batten's Disease, San Filippo Syndrome (Type A), hydrocephalic, microcephalic*, and *seizure disorder* are familiar at Homeward Bound. Orthotics, prosthetics, sidelyers, prone standers, wedges, mats, wheelchairs, walkers, gastrostomy tubes, tracheostomy tubes, and medication carts define the environment. Some of the individuals require monitoring by nurses 24 hours a day; everyone receives it.

Learning takes place at Homeward Bound. Some people have learned to walk, others to move their wheelchairs independently. Several have learned to eat with less assistance from another person. All have learned to tolerate sharing their immediate living environment with 15 other people in one of four "households." All have learned to tolerate the potential for at least 21 different staff members to provide their personal care assistance in any given week. Many of the children have learned how to communicate their needs and preferences. Many of the staff have learned how to "read" the most subtle messages that are communicated to them: A smile or frown, a gaze or a blink, a slight turn of the head or shoulder, a cry, a scream, an arm being flung, a chin dropping down. And sometimes a very direct and clear communication of "I want... I need... I am..." There are many desires, many fears, many hopes , and many dreams at New Hope.

It is a commonly-held belief that people who have severe and complex disabilities need to receive services in a 64-person environment. In 1990, 12 of the children living at the New Hope facility moved to two six-person group homes. These homes are owned and managed by Homeward Bound. None of these children or their families would choose to move back to the New Hope facility. The group homes became models within the organization to demonstrate that medically fragile kids could live in homes that were more similar to those of the general population, homes with private spaces, homes that are designed for special needs and special equipment. Direct service staff were appropriately trained and supported to assure that each individual's health, developmental, and social needs are being met and their preferences nurtured and respected.

In 1991 and 1992, learning was taking place for the management and board of directors of Homeward Bound. They learned that it was becoming more difficult to recruit and maintain the excellent human resources who were able to provide the support required by Homeward Bound's population. Projections into the future suggested that this dilemma would only intensify as fewer people would be available in the workforce. The skill levels required to support individuals with complex disabilities in a respectful and continuously improving environment were also increasing. The management learned that there was not enough money through existing funding streams to adequately support existing services, much less make substantial improvements in meeting the expectations of more enlightened and communicative residents and families. They learned that the projections for the future of health care funding were, at best, dismal. Finally, they found through a series of interchanges with the persons being served, their families, and personal representatives, that everyone at the New Hope facility preferred smaller living environments. The building was designed for children; many were now young adults. All the living areas were crowded and becoming unsafe. The noise level was unacceptable and personal space was nonexistent.

As a result of this discovery process two major events occurred. *HBI 2000* was launched, and the board of directors made the decision to work toward the development of alternative living environments for everyone at the New Hope facility. HBI 2000 is a position and a vision. The position is that it is important to protect and preserve what had been learned about supporting people with severe and complex disabilities. In light of fewer human or financial resources, Homeward Bound had to create a way for services to continue to improve, while assuring each person's respect and dignity. The vision is that through the infusion of technology into every aspect of the service delivery system a higher quality of services could be offered at a lower cost. For instance, one appropriate lifting device and four beds that provide for repositioning in one home could replace the need for one additional staff person overnight. The savings in the staffing costs, with the cost of purchasing the equipment, and multiplied by 16 new environments results in a saving of $2.3 million over five years. Perhaps some of that staff time could be better used when people are awake and available. That's one example.

The other major event – the decision to develop alternative environments and close the facility – was a courageous one when considering the large balance on the mortgage and the start up costs associated with new environments. In 1994, the organization approached various foundations in the community for their support in accomplishing the vision of HBI 2000. This would begin via the closure of the New Hope facility, the transition into new environments, and the infusion of technology. The response from the private sector, as represented by these foundations, was very positive. Recommendations for further development activity included soliciting participation from the public sector. In 1995, legislation was introduced to specifically provide for the development of home and community based waivers for the persons residing at New Hope. Existing waiver allocation systems could not accommodate the higher than average costs that would be incurred. Ultimately this was granted as part of the waiver rate allocation restructuring legislation. This was tangible evidence of longstanding public sector support for the closure of facilities such as New Hope. At the time of this writing, negotiations between the county, state, and Homeward Bound are taking place to facilitate the closure and transition process. Homeward Bound is also working with foundations, corporations, and individuals in the community to secure the private sector support required to make HBI 2000 a reality.

We know it will be a struggle to make our dreams a reality, but we have no choice. We have made our commitment to people and we understand that the next step in that commitment is not negotiable. As an organization we cannot succeed until all current New Hope residents are successful and integrated citizens of their communities.

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Remembering with Dignity: Looking at the Past, Present, and Future

Honoring those who lived and died in Minnesota's state institutions by telling their stories and preserving our history. This is the mission of Remembering with Dignity, a collaboration of self-advocates, community activists, disability organizations, and others seeking to publicly recognize our forgotten citizens in state institutions. With the planned closing of Minnesota's regional treatment centers within this decade, the group believes that a respectful acknowledgment of those who lived and died within institutions will serve as a closing chapter to our history of institutionalizing persons with developmental disabilities, and as a poignant reminder of how easy it is to separate ourselves from those we see as different.

When we've closed the doors of institutions, and the cemeteries are abandoned, who will remember the people who lived there? We have books and even museums honoring the superintendents of these facilities, praising them for medical and educational progress. But what of the thousands who lived and died under the auspices of social welfare and medical progress? "Think of the horrible things that have been done in institutions," says Gloria Steinbring, a member of Remembering with Dignity. "People have been used as guinea pigs, as slave labor. Women were sterilized against their will. I know, because they did it to me. We need to remember what these institutions were about."

The project has three areas of focus: (1) placing headstones with names on the unmarked gravesites of former residents; (2) collecting oral histories of life in institutions from current and former residents and using those stories in a lasting public exhibit; and (3) using the media to increase public awareness of the historical role of institutions for people with disabilities through sharing the personal stories and project goals.

"We haven't taught others to respect those of us with disabilities," says Gloria. I have this recurring dream where a family member comes down to Minneapolis, hires a lawyer, and tries to place me in a state institution. They say that I'm no longer capable of living in the community. This really scares me, and I think, who can I call? I have friends in the community – my pastor, people I work with at Advocating Change Together, the many friends I've made over the years. The case goes to court. I don't have a lawyer, because I can't afford one. But my friends speak out. They tell the judge that I'm capable of living independently. The judge agrees. But I still remember that someone wants to lock me away just because of my disability."

Remembering with Dignity is working to restore the respect denied to many of Minnesota's citizens, and to ensure that when the doors of institutions finally close, they remain closed.

Contributed by Gloria Steinbring, Treasurer and a founding member of Advocating Change Together (ACT), a self-advocacy organization in St. Paul, Minnesota, and a member of Remembering with Dignity; and by Jerry Smith, Communications Director for ACT. They may be reached at 612/641-0297.

Community Medical Care: Barriers, Recommendations

by Mary F. Hayden and K. Charlie Lakin

In 1994, nearly 10,000 persons with developmental disabilities who required monthly or more frequent specialized medical care lived in small community residential settings. Thousands of additional individuals with similar needs are today living with their families. It is apparent that needed medical supports can be and are being provided to people with complex medical needs to enable them to live in the community. However, it is also true that some people living in the community have unmet medical needs, and the availability of and access to health services remains problematic for others. These contradictory findings indicate that it is possible to meet the medical needs of persons with developmental disabilities and significant health problems in the community, but health care access and delivery must be improved. Until improvements are made, lack of access to adequate health care will continue to be a cause for resistance to the movement of people from institutions.

Barriers to the provision of medical care and services must be acknowledged, and policies and strategies developed to assure that quality medical care is available. Current barriers include the following:

- **Disincentives and impediments to developing adequate community support** of people with mental retardation and significant medical needs. Primary disincentives include reimbursement rates for costs of services in community settings that are far below those of institutions, and the resulting shortage of foster and small group homes able to afford intensive support needs of some persons.
- **Problems related to the financing of specific medical services.** One problem includes the limited availability of funding for in-home medical and support services that may not be covered by private insurance companies or under the regular Medicaid program even though they are financed at even higher total costs in institutions. In addition, the Medicaid fee structures in many states are viewed as reducing the number of health providers available to provide health services.
- **Problems related to inadequate preparation of health service providers.** Specifically, some physicians lack formal training related to persons with developmental disabilities. Some medical service providers are hesitant to provide health care because of a lack of experience with persons with disabilities. Inadequate dissemination of information between developmental disabilities and health care professionals and between these professionals and direct care providers is also a problem.
- **Major problems in the availability and accessibility of medical care and services** as a result of geographical location or poor coordination of community heath care.

Recommendations to improve community medical care and services include the following:

- **Maximize resources** by developing transitional care homes, providing trained in-home service providers, increasing support services such as physical therapy, providing funding support to enable individuals with more complex medical needs to remain with their families or in their own homes, and providing sufficient respite care, medical care, and other medical support services to families, support providers, roommates, and others.
- **Provide a broader base of preservice and inservice training** and education for both medical personnel and direct care providers.
- **Improve interdisciplinary and interagency coordination** between professionals in the developmental disabilities and medical/health care fields.
- **Provide ongoing monitoring of health and development** by appropriate case managers, including the use of primary care physicians to supervise individual care, coordinate needed specialty care, and monitor care outcomes and the performance of health care and other professionals.

It is inevitable that the need for specialized medical and allied health profession services for community residents with developmental disabilities will grow. Meeting this need in a future of Medicaid caps, enrollment of all Medicaid recipients in managed care plans, and other changes will require considerable vigilance and advocacy. But ultimately there is no reason that protecting one's health should ever be accepted as a reason for denying one's citizenship in the community.

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Note: A more complete review of barriers and recommendations can be found in Hayden, M.F. and DePaepe, P.A. (1991). Medical conditions, level of care needs and health related outcomes of persons with mental retardation. *Journal of the Association for Persons with Severe Handicaps, 16* (4),188-206.

Closing Brandon Training School

by Bonnie Shoultz and Charles Moseley

Vermont's only public institution for people with mental retardation and developmental disabilities, Brandon Training School (BTS), closed in 1993. An official closing ceremony was held on the BTS campus on December 9. A huge tent was erected, and people came from all over the state to celebrate what BTS had been and how it had closed.

Many Vermonters worked for years to move people into the community and to achieve the conditions whereby the institution could be closed. Two events in the late 1970s laid the foundation for the eventual placement of all residents into the community. The first, the Brandon Judicial Review Law, established a legal process requiring the review of each resident's needs to determine if he or she could be served in a less restrictive community setting. The second event was the filing of a lawsuit on behalf of Robert Brace and five other residents who wanted to move into the community. The settlement in 1980 of this lawsuit, called the *Brace decree*, included a 10-year plan for developing community resources and moving most of the approximately 300 residents out of Brandon Training School. Although the settlement did not mention closure of Brandon, one of the lawyers commented, "We knew that if in fact they carried out the terms of the settlement...they were going to end up with three people in the place."

Nearly 250 people moved into the community in 1979 and the early 1980s, due in part to the state's successful application for and use of the Medicaid Home and Community Based Services (HCBS) waiver, which allowed the state to develop services in the community. Vermont was one of the first states to see the value of the HCBS waiver and to use it to move people out of the institution. Later, community placements dropped and admissions into BTS continued, as resources and political support for movement dwindled.

By 1988, the average daily census of residents in Brandon was nearly 200, not much lower than in 1982. The Division of Mental Retardation was at a crossroads, operating a costly two-track system supporting both institutional and community programs. Although local agencies had built the capacity to serve individuals with all levels of disability, and admissions to the Training School had been frozen, the need to support increasing institutional costs prevented the further development of the community based service delivery system. The Division wrote a "unification plan" that outlined the problems and a solution: unifying the system by closing Brandon and converting to a fully community based system.

The unification plan was an important part of the effort to persuade stakeholders such as the governor, the legislature, the parent organizations, the employee union, and others that closure was necessary and could be achieved. Unlike in New Hampshire, where closure of Laconia State School was not announced as a goal in advance, the Vermont Division of Mental Retardation decided to make its purposes public and to work to create conditions wherein each of the major stakeholders would cooperate to carry them out.

After the publication of the unification plan and some initial resistance, the Vermont provider group met to develop a plan of implementation. At the time, the community services were primarily provided through nine community mental health centers, each of which had a mental retardation program, and four free-standing agencies serving only people with mental retardation. The directors of these programs, along with a few other program directors with whom these programs contracted, played a major role in the closure of BTS. In concert with the state, they expanded the community system by developing individual placements and building an infrastructure that could serve all people including those with challenging needs. Most importantly, they collaborated with each other to ensure that everyone in BTS would be served in the community.

After the unification plan was accepted by the governor, the Division of Mental Retardation began monthly meetings with local agencies to plan for the move of BTS residents to the communities of their choice. Individuals were identified and procedures set up to ensure the involvement of the residents, their parents or guardians, local agencies and state staff in all decisions regarding placement and transition. The staff of BTS were also encouraged to be involved in the process. Together, the state and the mental retardation programs developed services and funding that were individualized. Some people moved in with existing families (often with former BTS employees with whom they already had a relationship). Others found homes with nondisabled roommates. Still others received support from neighbors, and a few people moved into group situations, but not many.

The closure process was very difficult for some persons, but was made easier by the Division's efforts to listen and provide for what people said they needed. The Brandon story is both unique to the state of Vermont and typical of institution closures that are well planned and carefully done. We would hope that all institution closures could achieve such positive results for most of the people involved and for the state and local agencies and officials who undertake the challenge.

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Developing Individualized Supports While Closing Institutions

by John O'Brien and Steve Taylor

Policymakers and administrators face a significant leadership challenge in developing, negotiating, and implementing strategies to effectively balance two important goals:

- To close institutions within reasonable periods of time by moving thousands of people from institutions into local services and, in many cases, expanding the system to provide services to people now living with their families.
- To create individualized community supports for as many people as possible by changing the pattern of service provision to encourage the development of services based on individual choice and needs, rather than placing people into programs designed to serve groups on the basis of common, professionally assessed characteristics.

Both of these goals are highly desirable. People now living in institutions deserve the chance to live outside the restrictions and stigma of institutional life, and all people with developmental disabilities benefit from supports developed to fit their individual capacities, interests, and needs. Achieving either goal is demanding. Implementing a substantial increase in local service capacity and moving a large number of people into new arrangements while honoring commitments to family members, local agencies, and state workers calls for effective administration. Learning to transform the ways in which people receive necessary support requires strong and skillful leadership. Pursuing both goals within a short span of time creates a powerful strategic problem: How can available human, organizational, and fiscal resources be aligned to both close institutions and create new forms of assistance? Engaging this problem thoughtfully and carefully could greatly expand the opportunities available to people with developmental disabilities.

■ Progress and Conflicts

It is important to recognize that progress toward closing institutions on a certain timeline could take precedence over developing the individualized supports that people deserve. There are at least four reasons why this could happen:

- On-time closure fits statewide priorities and plans, and is thus likely to have greater weight when the two objectives conflict.
- Developing more places in existing types of services calls for doing more of what providers and administrators already know how to do. Developing more individualized supports calls for learning new ways to design, fund, deliver, and manage services and assure quality.
- Many service systems lack the necessary capacity or flexibility in funding and regulation to allow the provision of individualized supports.
- The ability to provide individualized supports on a large scale takes years rather than months to develop. This is especially true when a strong group of service providing agencies must undergo significant change in order to provide individualized supports.

An important positive outcome of the work of closing institutions is that over time a slowly growing number of people benefit from individualized supports. This happens even though most people initially move into small congregate programs rather than from institutions directly into individualized supports. But once in the community, people are much more likely to move from existing, congregate programs into more individualized supports. So even though the process of closing institutions under relatively short timelines often inhibits realization of the ideal of individualized supports, it is important that it be viewed as a dream deferred, not lost.

■ Building Commitment to Change

Ultimately the opportunity for people to benefit from individualized supports as institutions are closed depends on how effectively public agencies, service providers, and local advocates can deal with four key issues:

- Building commitment to organizing responses to people around individualized supports.
- Redesigning systems and reorganizing patterns of service in ways that provide individualized supports.
- Systematically, and very substantially, decreasing the time elapsed between identifying the nature and organization of individually responsive services for a person and decisions about allocation of resources to provide those services.
- Managing the closure of institutions in a way that frees resources (including time) to focus on identifying and developing supports needed by each individual.

Many people are deeply concerned that the opportunity to provide individualized supports will be lost due to failure to build a clear understanding of what they are and how they are different from existing services. They point out that the path of least resistance lies in changing rhetoric, rather than patterns of service. Taking this path would contribute to cynicism as, for example, group living arrangements are relabeled "people's own homes." Avoiding cynicism means living publicly with a substantial gap between what opinion leaders espouse and service providers deliver to most people.

It has become increasingly common to identify individualized supports with service labels (such as "supported living" or "supported employment" or "family support") or with service principles (such as "separate housing and support" or "use non-licensed facilities"). These are helpful as far as they go. But a deeper understanding of individualized supports calls for continuing debate and discussion. It also and more fundamentally involves a different and more valued role for the service receiver. Even within this theme of closing institutions, it is clearly implied that what is happening is controlled by the service providers.

In providing truly individualized supports, the experience of successful service providers and service users suggests that a very different pattern of action is necessary. In the direct service, provider management, and system management roles, people accustomed to administering programs for groups of people must learn to listen better to people with developmental disabilities and their families and friends. They must be able to enlist active involvement from families, associations, organizations, and political decision-makers in helping get what they want. They must become more committed to and better able to identify and organize supports based on understanding of individual capacities, interests, and needs, and modify supports over time. The individual support pattern is cyclic: better individual support results in better understanding of individual capacities, interests, and needs, which restarts the cycle of learning.

In direct service roles, providing individualized supports means learning and commitment to do the following:

- Remain available to people as their interests and needs change.
- Continuously increase the effective control people have over the supports they receive and the choices they make.
- Revise and repair supports as people change and as better information becomes available.
- Actively negotiate for necessary changes in agency and system practice and policy.
- Help people make the best possible use of available system funds and of opportunities to meet needs and fulfill desires through no cost or low costs activities.

In agency management level, providing individualized supports means:

- Matching people with developmental disabilities with support people whom they want to have support them, and sustaining and contributing to the improved effectiveness of these relationships.
- Focusing on problem solving and actively searching for community opportunities that contribute to people's lives.
- Developing community opportunities in short supply, such as accessible housing and transportation, recreational options, and jobs.
- Making system and agency resources for people as flexible as possible to accommodate changing support needs, including actively negotiating for necessary changes in system policy and practice.

In system level roles (e.g., county, region, state), providing individualized support means:

- Negotiating common mission, strategies, and mutual accountability among the people and agencies that provide and govern services.
- Continuously increasing the flexibility and responsiveness of available public funds by creating new ways to insure accountability and to budget and disburse funds.
- Discovering and communicating what is possible for people with developmental disabilities
- Promoting learning from action by discovering and disseminating what works and what doesn't work in providing individualized supports.
- Systematically shifting the system's "center of gravity" from group service provision to individualized supports.
- Clarifying the differences between truly individualized supports and improved versions of traditional approaches.

Thoughtfully and carefully engaging the problem of developing individualized services while closing institutions can increase the opportunities available to people with developmental disabilities. Failure to acknowledge the complexities presented in simultaneously dealing with both organizational and individual needs is likely to create difficult problems for the future. But, however short of the individualized service ideal people may fall in closing an institution, the commitment to it can be maintained and eventually realized.

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Note: This article grew out of meetings with policymakers, providers, and advocates, sponsored by the Center on Human Policy, in cooperation with New York State's Office of Mental Retardation and Developmental Disabilities.

Building Community Capacity

by Michael W. Smull and Susan Burke-Harrison

In 1989, we were asked if we could assist a group of people to move from Maryland institutions to the community. All of the traditional efforts, including sending packets of information to potential providers and calling about existing vacancies, had not been productive. As a result, these people were described as "not ready for the community." The responsible state officials felt trapped as they had made all the usual efforts, while a lawsuit was threatened because the people in question did not meet the legal admission criteria for institutional placement (as determined in their "due process hearings"). As we got to know these individuals we discovered that most of them were people with histories of challenging behaviors. For many of these people, their histories had led to what we called "severe reputations." However, most of these behaviors simply reflected their non-verbal critiques of the circumstances under which they lived. The perception of "not ready for the community" had been created by not listening to how they wanted to live.

In our initial efforts we found several things to be true: (1) It was essential that potential providers learned who the person was before they read of the events that had created the reputation; (2) learning and describing what was important to the person was an effective way to assist providers in developing services that were responsive to how each person wanted to live; and (3) community service capacity needed to be assessed to see where current capacity could be simply expanded, current capacity could be extended with technical assistance, and new community capacity had to be developed. Over half of this group of people moved to community settings after good community agencies were introduced to the people rather than their reputations. Most of the remaining people were able to move when community service providers were offered technical assistance in developing and maintaining appropriate supports. The few people who remained had come to the institution through the criminal justice system and could only move as agencies willing and able to develop the needed capacity were slowly recruited and the missing supports were developed. Within three years all of the people had successfully moved to the community.

These successful efforts to help this group of people led to further requests for assistance and the development of a new person-centered planning process, *Essential Lifestyle Planning*. As important and useful as this planning format is, it is only part of a process. We have found that success in helping people move into lives that they really want requires that those responsible do the following:

- Start by deciding who will move and when they will move, rather than funding provider expansion and then asking them to find people who "fit".
- Learn what is important to each person in how they want to live (before where they will live is decided).
- Develop a plan that provides a prioritized description of what is important, how specific issues of health or safety must be addressed, and what needs to happen to support the person in their desired life.
- Ask those who are interested in supporting the people to submit a proposal that describes how they would implement the plan and how much it would cost.
- Assist the people with disabilities and/or those who know and care about them to select the proposal that demonstrates that those who wrote it know the person (and not just the plan) and best describes the supports that will insure that what is important to the person is present.
- Negotiate an acceptable cost to implement the plan.
- Require that the selected proposal include plans for transition, how the person is to spend their day, and a timetable for support development and transition.
- Monitor transition and implementation, not only to insure that the plan is being implemented, but to listen for how the plan must be changed as the person begins to adapt to their new life.

Our experience with this process indicates that it takes more time than traditional methods, but yields better results. The people who move and their families indicate greater satisfaction, while administrators have found that far fewer people are "returned" to the institution. The process is simple, but it requires that the people who carry it out acquire new skills and new ways of thinking. The greatest challenge is to start with *how* people want to live before focusing on *where* they will live. We continue to think that people with a particular set of disability characteristics "belong" in a particular type of setting. We move people to the setting that reflects current practice rather than what is important to the person. We confuse the services needed with the setting where they are typically provided. For years we have been saying that smaller is better and our experiences have tended to suggest that this is true. However, if I live with two other people and hate one of them, my life may be worse than it was in the institution. If I need quiet and live with someone who is noisy I will tell you with my behavior that I'm unhappy. If I must be supported by people that I trust but have no say in who supports me, I have not gotten the life I was promised. To support people in the lives that they want, we must [illegible] questions that tell us what should be present and what should be absent in the life of the person, including:

- What is important in relationships with others? What people should be present or absent? What material things are wanted? What are the activities that matter?
- How can specific issues of health or safety needs be addressed with the least compromise to how the person wants to live?
- How can the person get the life described at a cost that the system can afford?

Once the first two sets of questions are answered, the settings that will and will not work for the person become clear. The challenge is then to support the person in the lives that they want at a cost that the system can afford. The better the description of what is important to the person the more possibilities emerge for how they can be supported.

As supported living becomes more routinized, the goal that needs to be kept in mind is to help people get the lives that they want, not to have people blindly move to the latest way of providing support. Real supported living is not, for example, defined by home ownership or the number of people living together. Real supported living is present when people with disabilities have the lives that they want and can change their lives without having to change their address.

The final lesson that we have learned is to continue to listen to people. We have a system designed for people to move very infrequently: People are "placed" instead of helped to move. Once placed, they are expected to stay and it is administratively difficult to respond to requests for change. Requests for change are often viewed as grounds for behavior programs. Our experience is that it typically takes six months to a year to really get to know people and for them to learn what they want after they have left an institution. We must commit to continue to listen and to honor the reasonable requests that we hear.

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Challenging Behaviors and Community Living

A large proportion of individuals remaining in large, state-operated facilities are reported to engage in serious patterns of challenging behavior. While longitudinal studies of people moving from public institutions to community settings show that positive gains in basic skills of daily living are consistently associated with community placement, this same research indicates no predictable pattern of reduction or increase in behavior problems associated with the change. Providing community programs that can meet the behavioral challenges of persons yet to be discharged from institutional settings will require significant advances in access to and application of behavior management technology in community settings.

Because individuals with problematic behaviors present substantial challenges to service providers, a significant portion of training and technical assistance must focus on methods of assessing and implementing proactive instructional procedures that address problem behavior. Proactive instructional procedures are those that provide the individual with skills designed to replace or serve the same function as the challenging behavior. The essential assumptions of positive approaches include the following:

- Assessment and intervention must occur in a range of relevant, integrated settings.
- Assessment and intervention procedures must address the long-term maintenance of socially acceptable behaviors in integrated settings.
- Measures used to evaluate the effectiveness of interventions must address the range of functional skills developed to replace challenging behaviors, the generalizability of these new skills, and natural contingencies that will maintain these behaviors.
- Assessment and intervention procedures must promote and accommodate involvement of family and friends.
- Assessment, intervention, and training procedures must be community friendly. That is, they must minimize the need for people in the community to alter their behavior to accommodate the person with challenging behavior.
- Research and practice must avoid intervention strategies that isolate, stigmatize or cause physical discomfort.

In recent years, researchers, advocates, and people with developmental disabilities have begun to evaluate community and institutional services not solely on *where* the services are provided, but also on quality of life issues. To realize a valued life within the community for people with developmental disabilities requires better understanding of how to manage behavior within the less easily controlled contingencies of community environments.

Excerpted from Reichle, J. & Light, C. (1992). Positive approaches to managing challenging behavior among persons with developmental disabilities living in the community. *Policy Research Brief, 4*(1). Minneapolis: University of Minnesota, Institute on Community Integration.

The Final Stages: Community Services for People Considered the Most Difficult to Serve

by Tom Fitzpatrick and K. Charlie Lakin

Minnesota is in the final stages of public institution operation for persons with developmental disabilities. Between June 1990 and June 1995, Minnesota state institution populations were reduced by 63%, from 1,410 to 524 people. It is clear that those state institutions that have not already been closed or converted to other uses, or are in the process of conversion, soon will be. As this future is anticipated, the Residential Services Division of Minnesota's Department of Human Services has considered it important to examine the current uses of Minnesota's state institutions, both in terms of function (e.g., short term emergency placements) and clientele (e.g., persons with records of assaultive behavior), to identify alternative services that will be needed to fulfill functions currently fulfilled by the state institutions.

> In closing institutions, states often face ethical and fiscal questions in deciding how and where to serve individuals with developmental disabilities and behavioral concerns that impact on public safety.

One step in this process has been to interview officials and service providers in states that have undertaken similar examinations, especially with respect to services for persons whose behavior is particularly difficult to accommodate in community residential programs because it has been threatening to others, criminal in nature or viewed as potentially dangerous to others or self. Thirteen states were selected for extensive interviews on the basis of: 1) having closed all state operated institutions; 2) having developed plans to close all institutions and greatly reduced the number of persons living in state institutions; 3) being under court order to close a state institution without transferring people to other institutions; and 4) having developed programs of relevance for the populations noted above. The states were California, Connecticut, District of Columbia, Maine, Massachusetts, Michigan, Nevada, New Hampshire, New York, Oregon, Rhode Island, Utah, and Vermont.

Common Themes

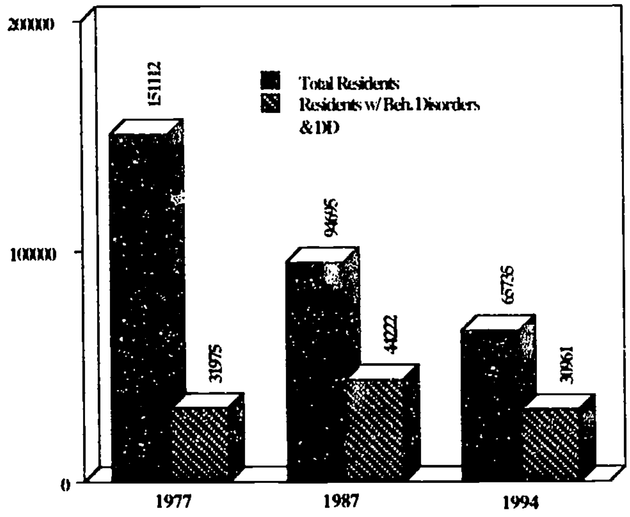
In reviewing the state interviews, there were a number of common themes that emerged:

- States that are successful in final stages of closing state institutions have developed ways to virtually eliminate admissions to those institutions. Such states admit individuals to state institutions only in extreme situations, if at all. They allocate resources and develop programs to respond to crisis events and to offer special support to particularly challenging people in community settings, replacing the role traditionally given to state institutions.
- Some successful states have decided to retain state-operated programs, but in community rather than institutional settings, and only for certain specific situations or groups of persons. In states in which provider communities have traditionally exercised relative freedom (or license) to reject difficult-to-serve people through demissions or non-acceptance, there appears to be a stronger tendency toward developing or expanding such state-operated services.
- A growing number of states have developed or are considering statewide crisis prevention and crisis intervention systems. Several states have developed programs that feature training, prevention and 24-hour response services. The emphasis of these programs is to provide necessary supports to allow individuals to remain in or return to current living situations, or to serve as a non-institutional transition to more suitable arrangements.
- Several states have improved access to more experienced, higher quality psychiatric services for persons with "dual diagnosis" (i.e., both intellectual and psychiatric disabilities). Some of these states have recruited highly regarded psychiatrists to provide consultation and individual treatment in efforts to improve services for such people.
- Sex offenders with developmental disabilities are commonly viewed as the most difficult population for state programs to serve. States feel particular pressure and obligation to address public safety concerns. A number of programs for sex offenders have been located in rural areas with special security and staffing considerations.
- A growing number of states have contracted for specialized programs to address unique needs of certain types of persons with assaultive or other dangerous behavior. These programs have high costs to operate because of the wages and benefit costs associated with attracting a highly trained and competent staff, people working under stressful conditions, and high staff-to-resident ratios. Special environmental features of these programs add costs, as well.
- Individual and environmental accommodations are increasingly used to enhance the effectiveness of programs.

Many states are emphasizing environmental accommodations in designing programs for individuals with histories of extremely challenging behavior, including space and privacy accommodations, such as single bedrooms with private bathrooms. Some programs are located in rural settings to allow participants more freedom of movement without jeopardizing public safety. Some programs feature extensive security features, such as inward curving unclimbable fences and personal duress alarm systems. The high cost of repeated failure to make programs work for groups of individuals has increased interest in personal futures and other desired lifestyle planning approaches.

- The commitment of the provider community and the ability of that community and the state to work together are viewed as essential to being able to serve all people in the community. The states that have closed state institutions acknowledge that it could not have been done without the commitment of the provider community. States note that until the private provider community no longer views state institution readmissions as the solution to their problems, it is extremely difficult to close the last resort "safety net" of the state institutions.

Proportion of Persons with Behavior Disorders and Developmental Disabilities in State Institutions Nationwide



Source: Prouty & Lakin (1995)

■ Recommendations

Four recommendations were drawn from the state interviewees about the lessons learned through experiences in providing community services to persons with developmental disabilities and difficult behavioral challenges:

- In closing state institutions, proceed as slowly as needed to move individuals into the community "one person at a time." Several states commented that they moved too many people too quickly. In retrospect, they felt that rapid deinstitutionalization overstressed the provider community, causing problems affecting the quality of care, and that some community placements were made without adequately considering the appropriateness. A corollary was that if people must be moved in groups initially, it is important to avoid situations that are difficult to change.
- Provide effective staff training and continuous staff development. States commented on the importance of training for program effectiveness and staff safety. States also spoke of the importance of supporting staff to maintain consistently good services and to reduce staff stress and burnout. One example was even cited of an inadequately trained staff member being beaten to death by an individual with developmental disabilities who was known to be dangerously assaultive.
- Encourage creativity and flexibility in developing programs to serve challenging individuals. Several states reported that they are "avoiding rules" whenever possible to work with provider agencies to creatively serve individuals with behavioral challenges. There is no one way; creativity and responsiveness to individuals are critical, but being overly naive can also be dangerous.
- Collaborate with the corrections and mental health systems. Many states feel that they have not had adequate working relationships with these systems. As institutions are closed, the states increasingly appreciate the need for such collaboration to properly address the unique needs and circumstances of the small proportion of persons with developmental disabilities who are sex offenders, dually diagnosed, and possess other histories of behavior of serious concern.

As public institutions are closed, states have been successful in serving persons with developmental disabilities and serious challenging behaviors in a variety of community programs. In doing so, they often face ethical and fiscal questions in deciding how and where to serve individuals with developmental disabilities and behavioral concerns that impact on public safety. But none of the states that have faced these challenges and made these commitments expresses any regrets that they are now operating the residential services systems without state institutions.

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Reference: R.W. Prouty & K.C. Lakin (Eds.) (1995). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1994.* Minneapolis: University of Minnesota, Center on Residential Services and Community Living.

Resources

The following publications provide a wide range of information about institution use and closures, and about life in institutions and in the community. Please contact the publishers of each for information about costs and ordering.

- **Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1995 (Report 48)** (1996). By R. Prouty, L. Anderson, K.C. Lakin, & B. Polister. This report summarizes the status of residential services in each of the states and the U.S. as of June 30, 1995. It provides breakdowns of public and private institution populations as well as the number of people living in community settings of different sizes and types. It also reports completed and projected institutional closures. Available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • 612 / 624-4512.

- **The State of the States in Developmental Disabilities** (4th Ed.), (1995). By D. Braddock, R. Hemp, L. Bachelder, & G. Fujiura. This volume reports statistics on public and private institution utilization and expenditures for each of the states and the U.S. In addition to detailed statistics for 1988-92, trends are provided on a number of important indicators of change beginning with 1977. Available from the American Association on Mental Retardation, 444 North Capitol St. NW, #846, Washington, DC 20001-1570 • 800 / 424-3688.

- **Guidebook on Consumer Controlled Housing** (1995). By T. Fields, K.C. Lakin, B. Seltzer, and R. Wobschall. This resource guide outlines options available to persons with developmental disabilities for creating consumer controlled housing arrangements. It describes major planning, housing, service, support, and funding considerations and contains worksheets and personal stories. Written for Minnesota, much of the material is applicable elsewhere. Available from Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • 612 / 624-4512.

- **Supporting People with Severe Reputations in the Community** (1992). By M. Smull and S. Harrison. Nearly 50% of the persons remaining in institutions are reported to have behavioral disorders. This handbook describes, through many practical examples, methods of planning community living with people who have histories of challenging those around them. Available from the National Association of State Directors of Developmental Disabilities Services, 113 Oronoco St., Alexandria, VA 22314 • 803 / 683-4202.

- **Out of Bedlam: The Truth About Deinstitutionalization** (1990). By A.B. Johnson. This book focuses on the deinstitutionalization of persons with psychiatric disabilities and a "great social experiment" that yielded much less than promised and which now seems out of control. The book contains many observations and lessons of relevance to final phases of moving people with developmental disabilities out of public institutions. Published by Basic Books, New York, New York.

- **The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis** (1985). By J. W. Conroy & V. J. Bradley. This report describes findings of the most comprehensive study of persons released from a large public institution in the U.S. It reports on a major court-ordered deinstitutionalization effort in Pennsylvania and highlights outcomes for people as well as issues related to financing post-institutional community life. Other studies of court-ordered deinstitutionalization are also available, focusing on New Hampshire, Connecticut, Louisiana, and California. Available from Conroy Outcome Analysts, 113 Sibley Ave., Ardmore, PA 19003 • 610 / 896-9134.

- **The Willowbrook Wars** (1984). By D. Rothman and S. Rothman. This study describes the implementation of the 1975 Willowbrook consent agreement on the closure of the Willowbrook Developmental Center in the state of New York. It describes the years of adversarial relationships and struggle between the state and plaintiffs in achieving the mutually agreed-upon goals of the consent decree. Published by Harper and Row, New York, NY.

- **The Origin and Nature of Our Institutional Models** (1975). By W. Wolfensberger. This concise but scholarly volume describes the evolution of institutional care in the U.S. from the high ideals and hopes of early "pioneers" to the current era. It chronicles this story through the words of the institution superintendents and pictures of the people who lived under their care. Available from the Center on Human Policy, Syracuse University, 805 S. Crouse Ave. Syracuse, NY 13244-2280 • 315 / 443-3851.

- **Christmas in Purgatory - A Photographic Essay on Mental Retardation** (1974). By B. Blatt and F. Kaplan. This book of photographs depicts the conditions of public institutions in the period just a few years after the deinstitutionalization was begun and major federal reforms were instituted. It is a powerful presentation of the legacy of institutional care. Available from the Center on Human Policy, Syracuse University, 805 S. Crouse Ave. Syracuse, NY 13244-2280 • 315 / 443-3851.

Realities, continued from page 1

Living "on the outside" as my friends who live in the institution call it, you decide how much privacy you want. If you like people around all the time, you may choose to live with five or six others. If you don't like noise, then you live with a quiet person. Your phone conversations are private because it's your phone. Your mail is private because you get it from your own mailbox. When people walk into your home, it's because you have invited them. It is your home and you make up the rules. It's called "choice."

■ Choice...Another Popular Word

People who live in institutions or other large facilities have fewer choices to make because many decisions are made for them, including simple decisions that are made for staff convenience or cost savings. Decisions so important and basic to most people that if we insisted on making these decisions for our friends or families people would think we were nuts. When you are "placed" (my friends and I like to say "incarcerated") many decisions are taken away, like where you will live and with whom, how you will spend your day, and when you want to eat, sleep, and work. Institutional advocates like to say we can't make choices, don't know how to make good decisions, and are not responsible, or that it is easier for us to have them make our choices.

Making choices about our lives gives all of us pride about who we are and what we have done with our lives. I was visiting an institution here in Illinois just last winter. The day staff came in from a shopping spree with new comforters for the 10 people who lived in this "cottage." One of the men who lived there said he wanted a pink bedroom and the staff laughed. I could hardly believe what I heard – they actually laughed and said pink is for girls. Well, I have a Mickey Mouse comforter and purple walls and I love it because it's mine. It says something about me. It may not be your choice. In fact, you may think that it was a bad choice, but it's not your decision to make. It's mine.

The bottom line about choices is that in the institution you get to make very few choices and the ones you do make are not the big ones. Living in the community you have opportunities to make choices about all parts of your life, from what comforter you may choose to where and with whom you will live. You even get to make bad choices and live with them. It sounds like making choices is a privilege, when it should be the rule.

■ Consumers...The New Buzz Word

I want to get a few things straight about this word "consumer" for all people who receive services. Consumer is a funny word to describe people who use some type of support services. When I first heard of people with disabilities called consumers, it was in a skit put on by professionals. They showed people with disabilities shopping at a store and choosing different foods depending on what they liked. "We (providers of service) should treat people with disabilities as consumers of our goods and services. Our goal should be to provide quality services that people make choices about." It sounds good, doesn't it? But what government agency or service provider is going to say, "If I don't meet the quality and demand of the services you want, then I will go out of business"? People with disabilities don't have control over the money nor do they have many choices about what service provider or type of service they receive. The consumer idea is a nice thought, but really just another name to set us apart as being different from the rest of the world.

■ A Few Things I Am Sure Of

From my experiences with institutions and with life "on the outside," there are some things that I know to be true:

- I've never met anyone who would choose to live in an institution once they have moved out.
- Putting people away because they have a disability is wrong, just like segregation is wrong. People should only be locked up if they are dangerous.
- Everyone should be allowed to make mistakes and learn from these mistakes. I'm not talking about putting people's lives in danger, but about mistakes like spending all your money so you can't buy snacks for a week.
- People with disabilities want to be friends and neighbors and coworkers with lots of different kinds of people, not just other people with disabilities.
- People who have lived in institutions all of their lives don't know how to make choices because they are not given the opportunity. We need to teach people how to make decisions and allow them to fail, too.
- Community living is not always easy, perfect or safe, but at least the people who live in the community are free.

Next time people start talking about closing institutions, make sure you're asking and listening to the right people – those who live there. They know the truth about these places.

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- Provision of Community Medical Care
- Developing Individualized Supports
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- The Final Stages
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