



**DISABILITY  
LAW  
CENTER**  
Utah's Protection and Advocacy Agency

## **A DLC Policy Brief**

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## **Why the Disability Law Center is calling for the closure of the Utah State Developmental Center**

### **Background**

As a civil rights organization charged with strengthening the laws that protect the rights of people with disabilities in Utah, the DLC is opposed to placing individuals in segregated institutional settings.

We believe that people with disabilities are full and equal citizens under the law. They are entitled to equal access to the same opportunities afforded all members of society. People with disabilities are entitled to be free from abuse, neglect, exploitation, discrimination, and isolation, and to be treated with respect and dignity.

We believe, and data from around the nation confirms, that similar levels of service to that provided at the Utah State Developmental Center (USDC) can be provided in the community and that people with disabilities and their families are better off on a variety of dimensions when we stop segregation.

In fact, the Center for Outcome Analysis reported to the Delaware Division of Developmental Disabilities Services in June, 2003 that:

*In the case of people with developmental disabilities, moving from large institutions to small community homes has been extremely successful. From the large body of research evidence now available, we are able to make this statement: Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost-effective social experiments in the past two decades.*<sup>1</sup>

This study, which looks at the lives of thousands of people with developmental disabilities over 25 years, scientifically demonstrates that when people are integrated into the community, they are significantly healthier, happier, more independent, more active, have more friends, achieve more personal goals and experience fewer challenging behaviors.

### **Why are institutions harmful to people with disabilities?**

We believe that separating people from their communities, families and natural supports is wrong. We know, and research demonstrates, that when people move from institutional living to community-based services they thrive across a variety of spectrums. We have seen people with significant disabilities become contributing members of their communities when given appropriate support in integrated settings.

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<sup>1</sup> "Initial Outcomes of Community Placement For the People Who Moved From Stockley Center" Conroy, James W., Ph.D., Garrow, James, Fullerton, Amanda MS, Brown, Marguerite MS, Vasile, Francesca, Center for Outcome Analysis, report to the Division of Developmental Disabilities Services, State of Delaware, June 2003.

Oral Historian Chris Frazier put it best in her editorial to the *Salt Lake Tribune* on June 10, 2006:

*I don't care how attractively you wrap the institutional package because by its very nature an institution does not contribute to the well-being of an individual. In fact, I'd argue that institutions are actually contrary to development. A place that isolates people due to characteristics judged outside the norm suggests that society doesn't really want them around. Secondly, cutting off people from society precludes their inclusion. The doors are shut and no one from the outside is learning more about living next door to the person behind those closed doors.*

In addition, a recent study by the American Association on Mental Retardation underscores the medical and psychosocial reasons institutions are harmful.<sup>2</sup> The study compared the lives of individuals with developmental disabilities who stayed in institutions to those who moved into the community. The study concluded that "movers" made significant gains while "stayers" incurred losses in social skills and cognitive competencies.<sup>3</sup>

- The two important descriptive findings in the present study, namely, the loss of multicognitive competencies by institutional 'stayers' over a 6-7-year period and the significant gains in self-care competencies by community 'movers', have important implications for public policy as well as deinstitutionalization research.
- Remaining institutionalized from 1994-2001 had negative consequences.
- Remaining in institutions for 6 to 7 years by persons who were similar to community movers appears to be quite costly in human terms.

### **What about the families of people in the USDC?**

Families are justifiably concerned about discussions regarding closure of the USDC. It is imperative that those concerns be acknowledged and addressed. Residents of the USDC, should they move into the community, will need a range of intensive services, some of which may not currently exist in the community. The concerns of community providers also need to be recognized and addressed. Chief among these, is time to identify and develop the services needed and help residents of the USDC to develop greater independent living skills. As well, we must ensure a rate of pay sufficient to attract, retain and support an adequate number of qualified direct-care staff. These changes are possible and the experiences of many states show that the end outcome is good for families and their loved ones.

For example, in March of 2006, the Wisconsin Department of Health and Family Services Division of Disability and Elder Services conducted a survey of guardians of persons relocated from one of Wisconsin's large state institutions, the Northern Wisconsin Center (NWC).<sup>4</sup> As in other institutional closings, families were very concerned about the future. But the survey found that the individuals moved into the community generally feel safe in their new settings and experience increased opportunities for social interaction and participation in the community. Most guardians also indicated that their ward's social, emotional, physical and mental health needs are adequately met in their new setting. Finally most guardians also believe that their wards' overall happiness/satisfaction with their new living arrangement is either better or the same as it was while at NWC.

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<sup>2</sup> "Longitudinal Changes in Adaptive Behavior of Movers and Stayers;" Lerman, P., Apgar, D., Jordan, T. *Mental Retardation Journal*, American Association on Mental Retardation. February 2005

<sup>3</sup> The study compared adaptive behaviors of individuals who lived in the North Princeton Developmental Center. The study assessed 150 movers and 150 stayers and looked at longitudinal changes. Movers and stayers were matched according to age, gender, cognition, social-emotional functioning, self-care, mobility, and challenging behaviors.

<sup>4</sup> "A Survey of Guardians of Persons Relocated from Northern Wisconsin Center (NWC)" report to the Wisconsin Department of Health and Family Services (DHFS), Division of Disability and Elder Services (DDES) APS Healthcare, Inc., March 27, 2006

## What the DLC is asking

We believe that the Utah State Legislature has a responsibility to plan for and use its resources to the greatest benefit of all individuals with disabilities.

We are asking the Legislature to request a full and accurate accounting of all of the costs associated with providing services to the 230 residents of the USDC, the additional costs associated with the maintenance of this large campus and the value of the property itself. Having a complete picture will allow the citizenry to engage in an honest, fact-based and respectful debate about the future of this institution and will allow lawmakers to make sound public policy regarding services for people with disabilities.

We wish to stress that **we are not requesting an immediate closure of the institution.** We are calling on the state to recognize and plan for the inevitable closure of the institution as it is now configured. Similar institutions around the nation are closing rapidly. Studies show a significant benefit to individuals and families when people leave institutions. Federal policy now favors community services and the Deficit Reduction Act is providing resources to assist states in making this policy transition. And, we believe living in the community is, at its core, a basic civil right.

We are therefore calling on the Governor, the Division of Human Services and the Legislature to work with families, advocates and service providers to be proactive in designing and investing in community services and, most importantly, in helping the individuals currently residing in the institution and their families plan for a smooth transition to community-based services.

## Why is the DLC asking for this now?

### 1. Federal policy related to institutional services is changing

A basic rule of all Utah Medicaid services is that no requested service will be approved if there is a less costly, equally effective alternative service available. Many Utahns on Medicaid are denied a service recommended by their physician because of this rule. However, this fundamental rule has never been applied to the USDC. The USDC is far more expensive than other equally effective alternative services. Everyone who lives there can receive similar services in a more cost effective, community-based setting.

Institutional services are no longer the preferred model for services and supports funded by the federal government through Medicaid. In Utah, as in other states, institutional care has long been a last option for families who can no longer wait for community-based services or for individuals for whom insufficient levels of service currently exist in the community. In fact, there are approximately 1,700 individuals and families in Utah who have chosen to wait for community-based services rather than make use of the institutional services to which they are entitled.

The DLC is not alone in preferring community-based services over institutional care. When announcing his New Freedom Initiative, President Bush said *"This Administration will work to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life"*.

In addition, the Supreme Court decided in *Olmstead v. L.C.*, that the ADA requires the placement of persons with disabilities in community-integrated settings whenever possible. The Court concluded that "unjustified isolation," e.g., institutionalization when a doctor deems community treatment equally beneficial, "is properly regarded as discrimination based on disability." The Court also stated that individuals should not remain in an institution solely to keep the institution open.

Finally, the Deficit Reduction Act (DRA) includes provisions to assist states in the transition from institutional to community services. For example, in the "Money Follows the Person" provision of the DRA, the historic presumption that favored institutional services has been replaced in favor of

community-based supports and services. The Centers for Medicare and Medicaid Services are encouraging states to take advantage of this provision of the DRA to facilitate the transition of individuals with disabilities from institutions into the community.

## 2. The legislature is looking for cost containment and accountability in Medicaid services

The Legislature is charged with using tax dollars wisely and ensuring that their actions reflect what Utahns want and need from their government. Ideally, it develops sound public policy which enables the State to help as many people as possible with the resources available.

Approximately 230 individuals with developmental disabilities receive services at the USDC (representing 6% of people in services) while nearly 4,000 receive services in the community. However, nearly 25% of the Division of Services for People with Disabilities budget is dedicated to the USDC.<sup>5</sup> The exact costs associated with the institution are unclear. While the Division of Services for People with Disabilities (DSPD) budget lists the costs associated with the USDC at \$37.6 million dollars, this figure does not incorporate other ongoing and one time costs that Medicaid does not cover, such as landscaping, new construction and maintenance. We believe that the costs associated with the USDC are likely to be significantly higher than the budget presented to the Legislature annually.

According to a July 2006 study by the Research and Training Center on Community Living – Institute on Community Integration/UCEDD, *“In practically all prior studies, including more than 200 independent assessment of Medicaid Waivers, community costs have been found to be lower than public institutional costs, even for the same or comparable people.”*<sup>6</sup>

The USDC cannot reasonably be considered fiscally efficient. While the institution once housed in excess of 1,000 people, it now houses about 230, and it takes approximately 900 employees to support the facility. The cost containment question is: Is it the place or the people that cost so much?

States large and small have closed their large state-run institutions, and have demonstrated significant cost-savings in the process. In fact, the last large out-migration of individuals from the USDC into the community demonstrated that their service costs were often reduced. However, Utah has made no effort to quantify the cost of providing community-based services to those individuals living in the USDC now. The Legislature has not been given much, if any, information on potential cost-savings associated with community-based services. We are calling on the Legislature to request hard numbers about the relative cost of providing services **not based on location, but rather, individual need**. This is the only way sound policy decisions can be made.

The USDC is situated on a large and valuable piece of property which could be transformed into a valuable source of funding to better meet the needs of those individuals currently receiving institutionally-based services as well as those waiting for services. The property could be sold with revenues placed in the existing trust to fund smaller community-based residential services and provide support to the more than 1,700 people on the DSPD Waiting List.<sup>7</sup> It is crucial, however, that we be vigilant in insisting that these funds go to serve people with disabilities, and that the state continue its commitment to services once the fund is established. In California, the Court has ruled that such proceeds must go to provide community-based services.<sup>8</sup>

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<sup>5</sup> The 2007 fiscal year budget for the Utah Division of Services for People with Disabilities indicates that the USDC will receive \$37.6 million for services, or about \$400 per day per person, while the 3,835 people with developmental disabilities living within the community will share \$112.8 million, or about \$75 per person per day. There is no direct comparison between these populations by service need available; however, since the USDC is a set cost and community services are more individually designed.

<sup>6</sup> “Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2005.” Research and Training Center on Community Living – Institute on Community Integration/UCEDD. University of Minnesota. July 2006.

<sup>7</sup> U.C.A. § 63A-5-220, “Creation of Trust Fund for Persons with Disabilities.”

<sup>8</sup> California Code § 14672.9, “Lease of property within the grounds of Agnews State Hospital.”

### 3. People don't want institutional services

The USDC is an important part of Utah's rich history of service to our most vulnerable citizens. However, times have changed. Institutional care is no longer needed or preferred by the vast majority of people with disabilities and their families. Right now nearly 2,000 individuals and families are waiting for community-based care rather than institutional services. In Utah and across the nation, most people with disabilities receive care in the community and most people receiving services today do so without ever experiencing a day of institutionalization.

During the last three decades, the U.S. has made remarkable progress toward reducing the number of persons with intellectual and related developmental disabilities (MR/DD) residing in public institutions.

- Since the late 1960s the number of persons with MR/DD residing in both state MR/DD and psychiatric institutions has decreased by 78% – right now only 50,000 people live in institutions, down from a high of a quarter of a million in the 1960s.
- Only 56% of all state institutions operating in or established after 1960 remain in operation.
- Ten states have effectively closed all state MR/DD institutions.

Why are so many institutions closing? States have found community-based services to be more cost effective and beneficial. But the single most important factor is that today people simply do not want to live in institutions. A study by the University of New Hampshire states:

*Indeed, it is statistically demonstrable that the primary factor in the massive depopulation of state institutions has not been the number of people discharged from state institutions, but has been the reduction in the number of people who entered state institutions. Between 1970 and 1998, annual admissions to state MR/DD institutions decreased 84%.<sup>9</sup>*

#### What can you do?

1. Call your legislators and let them know what you think about the issue.
2. Write a letter to the editor.
3. Check the DLC website updates and alerts as the legislative session approaches!
4. Support this work with a donation to the DLC and become a partner in this important effort. You can help transform our community into a place where people of all abilities can live with purpose and dignity.

#### Summary

The USDC is an emotionally charged issue and one policy makers have avoided discussing for years. The DLC is in no way passing judgment on the families of those who have chosen to place their children at USDC. We believe that all individuals with disabilities in Utah should receive the services and supports they need. We also believe that the fundamental civil rights of individuals with disabilities, sound information, recognition of state needs and fiscal constraints and the change in federal direction should guide public policy in this matter.

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<sup>9</sup> Prouty, R., Lakin, K.C. (Eds.) Residential services for persons with developmental disabilities: Status and trends through 1999. Minneapolis: University of Minnesota, Research and Training Center on Community Living/Institute on Community Integration. 2000.