

North Carolina's Institutional Bias: Enforcing the ADA's Integration Mandate

Vicki Smith

Last year, the US Department of Justice determined that the state of North Carolina was violating the Americans with Disabilities Act by inappropriately institutionalizing people in adult care homes rather than providing them with housing and appropriate supports in the community. The state's long-standing institutional bias must now be corrected.

Decline in Mental Health Services for North Carolina Adults

In 2001, North Carolina undertook a massive effort to reform mental health care. Steps taken included the privatization of many mental health services and the creation of regional management entities which replaced local county mental health agencies. The result was North Carolina's State Plan 2001: A Blueprint for Change, which emphasized the need to provide meaningful integrated services in accessible community settings for adults with severe and persistent mental illness.

The promise of a robust system of community-based services for people with mental illness has gone unfulfilled. Many of the new Medicaid services that were developed and designed to help build infrastructure for individuals requiring services in the community have been eliminated or have been limited by redefinition. For example, the previous definition of personal care services (PCS) allowed reimbursement for an aide to run errands such as transporting an individual to a medical appointment. Errands are no longer a reimbursable activity. And the state has failed to devote significant resources to the development of a system in which integrated housing would be readily available for people with mental illness.

More than 20 years after the passage of the Americans with Disabilities Act of 2001 (ADA), and more than 10 years after the US Supreme Court's decision in *Olmstead v. L.C.* (which found that the unjustified institutionalization of people with mental illness or intellectual disabilities violates the Americans with Disabilities Act) [1], the state of North Carolina continues to rely on institutional placements for the long-term care of many adults with disabilities, including those with severe and persistent mental illness.

Institutions versus Community Settings

There are stark differences between living in an institu-

tion and living in a more integrated setting in the community. In an institution, schedules are determined by staffing needs. Institutional residents typically eat meals at the same time every day. They have limited choice. Their freedom of movement is restricted. Decisions are frequently made on their behalf—decisions about what they eat, how much food they are allotted, with whom they spend their time, what activities they engage in, and the like. Their roommates are assigned. Their personal relationships often are restricted or controlled. They have little privacy. Institutions establish rules to suit the majority and not the individual. Staff members make decisions based on what they believe is best for the majority of residents, given the resources available.

In more integrated settings, schedules are driven by the needs and preferences of the individual resident. Individuals develop independent living skills. They learn how to shop and cook and decide what, when, and where to eat. They set their own schedules. They can choose whom they live with and control their personal space. They have much more control over their own lives. An integrated setting does not separate people from community life but includes them in it.

The state of North Carolina classifies adult care homes (ACHs) and other large group homes as "community settings." In practice, however, these facilities are institutions with a high bed capacity whose residents lack individual autonomy and are isolated from the general community.

Three Aspects of North Carolina's Institutional Bias

Today, North Carolina faces three distinct challenges relating to how it provides services to citizens with mental illness. First, the state is in immediate jeopardy of losing Medicaid payments for ACHs that are deemed to be Institutions for Mental Disease (IMD). Second, the state's system for providing personal care services (PCS) and in-home support to eligible Medicaid recipients has not yet been approved by the federal Centers for Medicare and Medicaid Services (CMS). Finally, in response to a com-

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Address correspondence to Ms. Vicki Smith, Disability Rights North Carolina, 2626 Glenwood Ave, Ste 550, Raleigh NC 27608 (vicki.smith@disabilityrightsncc.org).

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plaint filed by Disability Rights North Carolina (the state's Protection and Advocacy system, established by federal law to protect people with disabilities from abuse and neglect) [2], the US Department of Justice (DOJ) has issued a Letter of Finding concluding that the state is violating the ADA by inappropriately housing people with mental illness in ACHs.

Institutions for Mental Disease

A simplified definition of an IMD is any facility with more than 16 beds, 50% or more of whose residents have been placed there because of their mental illness. Residents of IMDs are not eligible for Medicaid. ACHs are licensed assisted-living facilities that, at a minimum, provide one meal a day, housekeeping services, and personal services to at least 7 residents; many house a much larger number of residents. North Carolina state law forbids admitting residents to an ACH for the "treatment of mental illnesses."

The federal regulation prohibiting Medicaid funding for those living in IMDs has been part of the Medicaid system since 1978. North Carolina's use of large ACHs to house people with mental illness violates this regulation, and the CMS is unwilling to ignore this violation any longer. The state, at the direction of the CMS, has identified at least 25 ACHs as potential IMDs. If they are found to be IMDs, that would render all of their residents ineligible for Medicaid. These ACHs have been operating on Medicaid dollars for years; without Medicaid funding, they will be forced to close their doors, with little time for residents to find alternative living arrangements.

Personal Care Support Services

The CMS started asking questions about the handling of personal care support services in North Carolina almost 2 years ago, when the state asked permission to make it harder for individuals living in their own home to get Medicaid reimbursement for PCS. According to the North Carolina Medicaid State Plan, such services are intended to provide person-to-person hands-on assistance with the common activities of daily living (ADLs), such as eating, dressing, bathing, toileting, and mobility. Under the state's proposal, an individual living at home would receive Medicaid reimbursement for PCS only if they needed help with at least 2 ADLs. The state proposed this change as a way to save money and balance the state budget.

The eligibility criteria for receiving PCS in an ACH or other group home are far less stringent than the criteria for receiving them at home. This means that, on average, an individual in an ACH receives more of these services, at a higher cost to the state, than does an individual living in the community who has the same needs. An individual in an ACH can be authorized through a nonspecific assessment by an ACH employee to receive PCS using eligibility criteria as basic as a combination of needing assistance with medication administration and general ongoing supervision.

Although personal care services are not specifically services for individuals with mental illness, many such indi-

viduals need these services, because their mental illness affects their ability to independently conduct the activities of daily living. By reducing the availability of community PCS, the state is creating a bias in favor of ACH placement. The state's elimination of various community support services and its encouragement of the use of ACHs violate the important principles affirmed in the Olmstead decision. A person no longer considered eligible to receive PCS in the community could walk in the door of an ACH and qualify to be a resident and receive personal care services there. An individual could thus be forced into an institutional setting because of his or her personal care needs, even if he or she did not need the supervision and other restrictive aspects of an ACH. By severely limiting the availability of community PCS, the state is unnecessarily putting thousands of North Carolinians at risk of institutionalization at a huge cost to the state. Providing in-home PCS will keep these individuals in the community and will cost less than serving those individuals in ACHs [5].

After months of negotiation, the CMS gave approval for a short-term service called In-Home Care for Adults (IHCA) to be effective from June 1, 2011 to February 29, 2012. This service was offered while North Carolina developed a new application for Home- and Community-Based Services called the 1915(i) option for Medicaid [3]. The CMS has warned that the disparities in the service definitions for IHCA and ACH PCS leave the state vulnerable to the claim that it is violating the ADA. Nevertheless, the state has chosen to proceed with the IHCA definition, which is currently being challenged in federal court, as well as with its application for the 1915(i) option. In late April 2012, the state submitted its final version of the 1915(i) option to the CMS and is currently working with the CMS to finalize the option and plans for implementation.

DOJ Findings

In a complaint filed in 2010 with the DOJ, Disability Rights North Carolina asked the DOJ to investigate whether North Carolina's reliance on placement in institutions such as ACHs constitutes a violation of the ADA under the principles referred to as the Integration Mandate, articulated in the Olmstead decision. At the time the DOJ complaint was filed, a total of 26,040 North Carolina residents lived in ACHs, 24.7% of whom had a mental illness [4]. By early January 2011, the number of people living in ACHs had grown to more than 28,000 [5]. Some ACHs exclusively serve elderly adults, adults with mental illness, or adults with Alzheimer's disease or other memory disorders; other ACHs serve a combination of these populations.

In its July 28, 2011, Letter of Finding, the DOJ determined that North Carolina "fails to provide services to individuals with mental illness in the most integrated setting appropriate to their needs in violation of the ADA. The State plans, structures, and administers its mental health service system to deliver services to thousands of persons with mental illness in large, segregated adult care homes, and to allocate

funding to service individuals in adult care homes rather than in integrated settings"[6]. The state and the DOJ now are negotiating to develop a plan for addressing the needs of people with mental illness that complies with the ADA. In a similar case, the DOJ entered into a comprehensive settlement agreement in October 2010 to transform the state of Georgia's mental health and developmental disability system. Negotiations with the Commonwealth of Virginia on the same issue are ongoing.

Going Forward

As the state proceeds with addressing each piece of this conundrum, we must acknowledge that each of the 3 challenges is part of a larger evolution toward community-integrated services and housing for all people with disabilities. Although CMS regulations, US Supreme Court opinions, and legislative actions set the rules by which such integration will be accomplished, the driving force must be respect for the inherent dignity and value of the people involved. **NCMJ**

Vicki Smith executive director, Disability Rights North Carolina, Raleigh, North Carolina.

Acknowledgment

Potential conflicts of interest. V.S. has no relevant conflicts of interest.

References

1. Olmstead v. L.C., 527 US 581 (1999).
2. See the Protection and Advocacy for Individuals with Mental Illness Act, 42 USC §10801 et seq (1986); the Developmental Disabilities Assistance and Bill of Rights Act, 42 USC §15001 et seq (1975); and the Protection and Advocacy for Individual Rights Program, 29 USC §794e et seq (1992); and all of the accompanying regulations.
3. 42 USC §1396n (2010).
4. North Carolina Institute of Medicine (NCIOM). Interim Report to the North Carolina General Assembly: A Report of the Task Force on the Co-Location of Different Populations in Adult Care Homes. Morrisville, NC: NCIOM; 2010. http://www.ncmedicaljournal.com/wp-content/uploads/NCIOM/projects/adult_care/AC_InterimReport_Final.pdf. Accessed April 6, 2012.
5. North Carolina Institute of Medicine (NCIOM). Short- and Long-Term Solutions for Co-Location in Adult and Family Care Homes: A Report of the Task Force on the Co-Location of Different Populations in Adult Care Homes. Morrisville, NC: NCIOM; 2011. http://nciom.org/wp-content/uploads/2010/10/AdultCareHomes_wcover.pdf. Accessed April 6, 2012.
6. Letter to Roy Cooper, Attorney General, State of North Carolina, from Thomas Perez, Assistant US Attorney General, Civil Rights Division, p. 1 (July 28, 2011). Text available at http://www.ada.gov/olmstead/documents/nc_findings_letter.pdf.



It seems like it was yesterday when we learned to ride our bikes **together**, discovered that we both liked to dance and speak our language. It seems like we were **never apart** and everyone knew we were **best friends**. When we decided to go to school, we made sure we were going to be roommates. When you finally landed that first job after all your hard work, I was the first to say **"congratulations."** When you said you wanted to help the youth on the reservation, I said, **"Let's do it together."** Then came a time when you told me that you have a **mental health problem**, like **depression and anxiety**. Now I know that anyone can experience mental health problems, even **Native People**. We thought we knew everything, yet I really didn't **understand** what a **difference** my support can make in your recovery. Well, I am here for you. I **will** be here for you. And—as always—**we will recover together.**

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