

Meeting the Challenges of Community-Based Care

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North Carolina is responding to multiple and interrelated challenges associated with the housing and support services for individuals with mental health needs, particularly those currently living in Adult Care Homes. Addressing the concerns raised by federal agencies provides an opportunity to reshape community mental health services.

North Carolina is currently confronted with multiple challenges related to the provision of housing and support services for vulnerable individuals across the state especially in adult care homes (ACHs). These challenges have grown out of an array of policy and funding decisions made over the past 2 decades, as well as the lack of affordable housing for individuals with disabilities in North Carolina. Recently, the US Department of Justice's Civil Rights Division (USDOJ) and the Centers for Medicare and Medicaid Services (CMS), have raised issues regarding institutional bias and the ability of individuals with disabilities to receive equal housing supports in the community. The concerns expressed by the USDOJ and CMS have to do with a complex set of interrelated issues that affect ACHs and their residents. Addressing these issues will require a comprehensive effort over the next few years and will necessitate changes in policy, funding mechanisms, and philosophy.

On July 11, 2011, the USDOJ sent North Carolina Attorney General Roy Cooper a findings letter [1] outlining concerns about the state's compliance with the Title II of the Americans with Disabilities Act of 1990 (ADA) [2] as interpreted by the US Supreme Court's *Olmstead* decision [3]. The letter focuses on the needs of the large number of adults with mental illness who currently reside in ACHs. The USDOJ contends that large ACHs do not meet the ADA requirement that people receive community-based care in the least restrictive setting possible. In the findings letter, the USDOJ also alleges that North Carolina's State-County Special Assistance for Adults program creates a financial incentive for individuals to reside in ACHs rather than remaining in their own homes.

One of CMS's concerns is that some of the ACHs in North Carolina, based on their size and concentration of mentally ill residents, may well be classifiable under federal rules as institutions for mental disease (IMDs). CMS does not allow the use of Medicaid funding for individuals living in an IMD.

Another of CMS's concerns is that in North Carolina, eligibility requirements for personal care services (PCS) make it easier to qualify for such services if you live in an ACH than if you reside in your own home. In addition, CMS has issued new guidelines requiring that individuals receiving home and community-based services must live in residences having characteristics that reflect the home- and community-based living standards that HCBS funds were designed to support. Some ACHs in North Carolina today may have difficulty meeting these home and community-based living standards without making changes to their facilities and their operating models.

The Americans with Disabilities Act

The ADA prohibits public entities from discriminating against individuals with disabilities by excluding them from participation in, or denying them the benefits of, services. The federal government has issued regulations implementing the ADA that require public entities to administer services in the most integrated setting—that is, the setting in which individuals with disabilities interact with individuals without disabilities to the “fullest extent possible.”

In 1999, the US Supreme Court found in the *Olmstead* case that the state of Georgia had not allowed 2 women to move from an institution and live in the community even though medical professionals had determined that these women could live safely in the community. In deciding the case, the court held that under the ADA, public entities must provide community-based services to persons with disabilities when those services are appropriate, are unopposed by the person with a disability, and can be reasonably accommodated.

USDOJ Findings Letter

In its findings letter, the USDOJ alleges that ACH residents with mental illness could be served in more integrated settings in the community, and that state policies

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and actions have led to people with mental illness being “confined . . . indefinitely and unnecessarily in adult care homes” [1]. The USDOJ also alleges that the reliance on unnecessary institutional settings violates the civil rights of people with disabilities. North Carolina and the USDOJ are currently involved in a negotiation process that seeks to create a settlement agreement to address these issues. These discussions have been taking place since the fall of 2011 and have involved the North Carolina Attorney General’s Office and representatives from the North Carolina Department of Health and Human Services. It should be noted that over the past several years, the USDOJ has reached settlement agreements with a number of other states regarding similar ADA/Olmstead allegations. Those settlement agreements have focused on the development and implementation of effective measures to prevent inappropriate institutionalization and to provide adequate and appropriate public services and supports in the most clinically appropriate integrated setting to meet the needs of persons in a defined target population (eg, adults with mental illness currently residing in ACHs).

Based on previous USDOJ settlement agreements in other states, it is anticipated that a potential settlement will include the following measures: identifying a specific target population; implementing a process for screening entrants to large facilities and congregate living settings, and ensuring that those entrants have other smaller community options for residential placements; requiring a multiyear response and commitment for system change and additional state funding; expanding community services (including crisis services, supported employment, and community-based supported housing alternatives) to support individuals living in the community; providing extensive education, “in-reach,” and treatment planning to actively encourage long-time residents to move to smaller community living situations and out of larger congregate settings; implementing extensive quality management and monitoring programs; and federal oversight of the state’s compliance with the settlement agreement.

Regardless of whether a settlement is reached, North Carolina is taking steps to address potential concerns about ADA and Olmstead issues by working proactively on initiatives for all individuals living in institutions. Those steps include actively identifying existing resources—such as Medicaid, block grant, housing and Money Follows the Person funding—whose use could be expanded to support individuals with disabilities living in integrated community settings; updating the state’s Olmstead plan; committing savings achieved through the implementation of the 1915(b)/(c) Medicaid waiver to provide additional home- and community-based slots in the Community Alternatives Program waivers for individuals with intellectual or developmental disabilities; developing integrated settings (such as targeted and pre-financed housing units) for individuals with disabilities; and creating financial incentives under the 1915(b)/(c) waiver for local management entities to provide

services for individuals in community settings rather than in institutions.

Special Assistance. North Carolina spends \$144 million in State-County Special Assistance funding each year; \$118 million of this is for people living in ACHs, nearly \$16 million is for those living in a Special Care Unit within an ACH, and \$10 million supports the Special Assistance In-Home Program. Both the USDOJ (in its findings letter) and CMS have raised concerns that the State-County Special Assistance for Adults program (which provides cash supplements for low-income individuals living in ACHs) creates an incentive for individuals to reside in an ACH or other congregate setting rather than in their own home. Special assistance funding is mandatory for individuals in ACHs; however, the in-home program is optional, and 9 counties do not offer in-home assistance. The level of funding support for an individual in the in-home program is also lower than that for an individual residing in an ACH. Changes to address these disparities will require a statutory change by the North Carolina General Assembly.

Adult Care Homes as Institutions for Mental Disease

An institution for mental disease (IMD) can be defined as any facility with more than 16 beds, where at least 50% of residents have a mental illness, and where the facility has attributes that indicate it is a psychiatric facility. North Carolina has 436 ACHs that have more than 16 beds. Those homes have a total of more than 27,000 licensed beds, but fewer than 14,000 of those beds are occupied by residents who receive Medicaid. According to data from the NC Division of Medical Assistance (DMA), approximately 3,350 of those residents receiving Medicaid are individuals with mental illness diagnoses (DMA, unpublished data). This number does not include individuals with developmental disabilities. CMS believes that some ACHs may have so many residents with mental health diagnoses that their federal status should be changed to IMD. CMS generally does not pay for disabled adults living in IMDs, and those institutions that are determined to be an IMD lose federal funding for all residents in that facility. CMS is requiring North Carolina to conduct facility reviews and determine whether ACHs with more than 16 beds are IMDs. This IMD determination process requires the state to take into account the overall attributes of the facility itself as well as whether more than 50 percent of the residents have a mental disease other than dementia or Alzheimer’s.

Based on a North Carolina Department of Health and Human Services’ initial analysis of ACHs, 25 facilities and more than 700 residents are being assessed. The state has agreed to complete initial reviews no later than June 30, 2012. All ACHs will be reviewed for IMD status by September 1, 2012. Individuals in ACHs that are determined to be IMDs may be transitioned to alternative housing options if they choose to move to a non-IMD setting. The ACH also may make the necessary changes to no longer be identified as

Preparing to Come Home: Recommendations for Transition Planning from North Carolina's Money Follows the Person Demonstration Project

Trish Farnham

When Christina moved back home to live with her family after years of residing in an institution, her mother noted, "She's so much happier now." When Ronald transitioned back into his community after years in a state hospital, he soon became a regular at his local Starbucks. After Jabreel moved out of an institution and into an apartment with a support companion, his mother observed, "My son now has a warm, broad network of people in his life."

These life-changing experiences were facilitated by the state, regional and local partners of North Carolina's Money Follows the Person (MFP) Demonstration Project. The federal MFP program has since its inception in 2005 become an increasingly robust vehicle that North Carolina and other states have used to strengthen and expand their home- and community-based service structure. It is used to help Medicaid recipients transition from institutions back to the community. In North Carolina, MFP participants have priority access to certain community-based support services; currently, all of them qualify for one of the Community Alternatives Programs or the Program of All-Inclusive Care for the Elderly [1]. They also have access to additional resources, such as "start-up funds" and transition coordination services.

MFP assistance is available only to individuals who meet the project's federal criteria; to qualify, an individual must be Medicaid-eligible and have resided for at least 90 days in a skilled nursing facility, an intermediate care facility for individuals with intellectual or developmental disabilities, an acute care hospital, or a psychiatric facility (if they are under the age of 21 or over the age of 65) [2, 3]. However, the practices that have been developed and adopted by the project can be used in transition efforts of all kinds. Many of these practices are based on experience gained in earlier transition efforts (such as North Carolina's Nursing Home Transition Grant) and were recommended in reports from the North Carolina

Institute of Medicine [4], Mathematica Policy Research [5], and other organizations [6, 7]. These practices are grounded in basic, common-sense principles that serve as the foundation of every quality transition experience: person-centered transition planning, establishment of a clear locus of responsibility, continuity of care, and clear communication among transition team members.

Insights gained during the implementation of North Carolina's MFP Demonstration Project can help shape the state's transition practices as the state renews its commitment to provide community-based services to persons with disabilities (as required by the US Supreme Court's *Olmstead* decision [8]) and works to strengthen its home and community service options for individuals in adult care homes.

Recommendations Based on Lessons Learned From MFP

Learning from its own experience and the experience of other transition initiatives, the North Carolina MFP project has come up with 11 suggestions for those supporting individuals to transition from an institution to home- and community-based supports. (1) Keep the person who is transitioning at the center of the transition effort by supporting his or her active participation in the planning process and empowering him or her to assume responsibility for completing transition-related tasks whenever possible. (2) Have a clearly designated, well-trained transition coordinator who enjoys supporting people as they return to their communities and has a strong understanding of both the formal services and the informal resources available. (3) Have a clear, documented transition plan that addresses the person's community-based needs; it should not only plan for the "essentials" (housing, medical care, and attendant care) but also explore employment, transportation, and financial management options, consider the needs of family caregivers, and build a community net-

an IMD. Federal Medicaid funding for a facility will cease the day it is determined to be an IMD. A transition plan and process are in place to help individuals identify alternative living arrangements and to support their transition to a new setting.

Personal Care Services

CMS alleges that North Carolina's eligibility criteria and payment rates for Personal Care Services (PCS) are not "comparable" between ACH and in-home settings. A combined total of approximately 45,000 individuals receive such services at an annual cost to the state's

Medicaid Program of more than \$400 million (DMA, unpublished data). North Carolina has worked with CMS to develop a 1915(i) Medicaid state plan option that will address these comparability concerns and try to meet the demands for PCS across both settings while meeting state budget expectations. The state's agreement with CMS and its plan of correction allow the current PCS program to operate through the end of December 2012. Effective January 1, 2013, a new PCS program operating under the 1915(i) authority will be in place. This new PCS program will address the "comparability" issues by basing PCS eligibility on a set of target population criteria and by requiring

work. (4) Set up agreements and schedules that ensure ongoing conversation among transition team members and make it clear who is doing what. (5) Because strong collaboration between those providing medical and social supports is essential for individuals with complex support needs, make sure the person in transition is enrolled in Community Care of North Carolina (CCNC) and signed up for behavioral health services (if those are needed) before discharge. (6) Engage peer support wherever possible. Recently transitioned individuals say that access to peers—individuals who have also transitioned—is useful while they are adjusting to being back in a community setting. The peer support model has been demonstrated to be particularly effective with individuals experiencing severe and persistent mental illness [9]. (7) Finding affordable accessible housing is often the biggest barrier to transition. In addition to applying for subsidized housing, members of the team should explore other services and supports (such as shared living arrangements, adult foster care arrangements, and telesupport options if appropriate) that may help meet the transitioning person's housing needs. (8) Give people in the community who will be assisting the person after transition—attendant care staff, therapists, and other clinicians—an opportunity to get to know the individual before the transition happens. To better ensure continuity of care, staff training and consultation should take place before the transition occurs. (9) Procure start-up funding before the transition takes place. Start-up funds are often used to pay rent deposits or to meet other household needs, but consider using them to fund additional pre-transition training and consultation. (10) Have transition coordinators follow an individual's progress for several months after transition occurs. Individuals often experience unforeseen challenges immediately after the transition is made. (11) Do not rush. North Carolina's MFP program has made its biggest mistakes when it allowed the sense of urgency that is inevitable in any transition endeavor to eclipse the principles and practices outlined here.

Although each transition will have its unique elements and individual dynamic, these practices and principles form a strong, unifying foundation that ensures successful, effective transitions for people wishing to return to their homes and rejoin their communities. NCMJ

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ACHs to meet the standards for home- and community-based care. An independent assessment will be required to receive PCS under the 1915(i) state plan option.

Standards for Home- and Community-Based Services

CMS has issued a proposed rule requiring that individuals receiving funding for home and community-based services (HCBS) live in residences that have an environment that is not institutional in nature [4]. The proposed rule specifies that PCS funding can only be used in residential settings that reflect the requirements contained in HCBS. North

Carolina has worked with CMS to develop an understanding of HCBS that will meet the new requirements, which include the expectation that facilities be integrated into the community and the expectation that residents be allowed the same freedom to exercise personal choice that is typical of home settings. For instance, residents must be allowed to choose treatment providers, roommates, and room decorations, and to decide when and where to go on community outings, when to eat and sleep, and when to receive visitors and engage with others.

In order to continue to receive Medicaid funding, ACHs will need to attest that they meet HCBS characteristics by

June 30, 2012. The state will monitor ACH compliance with these CMS standards.

Conclusion

North Carolina is committed to supporting individuals with disabilities in the most integrated, community-based setting of the individual's choice. Transitioning our current system of housing and supports to meet that commitment and to satisfy the requirements of our federal partners is a complex and challenging process. Our success must be founded on partnership with providers, advocates, local community agencies, and the General Assembly. We are confronted with a complex and interrelated set of issues that must be understood and addressed. The task ahead is difficult and not without consequences. However, we have the rare opportunity to set in motion events that will reshape and revitalize our community mental health service system. NCMJ

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