



U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

JUL 28 2011

The Honorable Roy Cooper
Attorney General for the
State of North Carolina
Department of Justice
9001 Mail Service Center
Raleigh, NC 27699

Re: United States' Investigation of the North Carolina Mental Health System
Pursuant to the Americans with Disabilities Act

Dear Attorney General Cooper:

We write to report the findings of the Civil Rights Division's investigation of the State of North Carolina's (the "State") mental health system, which delivers services to persons with mental illness in adult care homes and other settings across the State. During our investigation, we assessed the State's compliance with Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132, as interpreted by *Olmstead v. L.C.*, 527 U.S. 581 (1999), requiring that individuals with disabilities receive services in the most integrated setting appropriate to their needs. The Department of Justice is authorized to seek a remedy for violations of Title II of the ADA. 42 U.S.C. § 12133.

Consistent with legal requirements set forth in the ADA and in Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d-1, we write to provide you notice of the State's failure to comply with the ADA and of the minimum steps North Carolina needs to take to meet its obligations under the law.

I. SUMMARY OF FINDINGS

We conclude that the State 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 serve individuals in adult care homes rather than in integrated settings. Adult care homes are institutional settings that segregate residents from the community and impede residents' interactions with people who do not have disabilities. Most people with mental illness receiving services in adult care homes could be served in more integrated settings, but are relegated

indefinitely and unnecessarily to adult care homes because of systemic State actions and policies, which include:

- The State's failure to develop a sufficient quantity of community-based alternatives for individuals with mental illness unnecessarily and indefinitely confined to adult care homes;
- The State's failure to redirect resources already available to expand community-based alternatives;
- The State's prioritization of investment in institutional settings at the expense of community-based settings; and
- The use of policies and practices that cause individuals with mental illness to enter adult care homes to obtain support services.

Our findings are consistent with the following conclusions made in several State-issued and State-funded reports:

- Adult care homes "are not optimal for community integration" and "[r]esidents of ACHs may be cut off from active participation in the local community . . .";¹
- Adult care homes are "highly likely to qualify as restricted settings";²
- There is an "institutional bias" in North Carolina: "People who enter an ACH or other type of facility can obtain certain financial assistance, services, and supports that are not equally available to people with similar levels of disability and financial need who choose to remain in their own homes";³
- "[M]any with mental illnesses continue to live in long term care settings because there are not yet more appropriate alternatives available to them in their communities";⁴

¹SHORT- AND LONG-TERM SOLUTIONS FOR CO-LOCATION IN ADULT AND FAMILY CARE HOMES: A REPORT OF THE NCIOM TASK FORCE ON THE CO-LOCATION OF DIFFERENT POPULATIONS IN ADULT CARE HOMES, North Carolina Institute of Medicine, at 34 (January 2011).

² STUDY OF ADULT CARE HOMES, FAMILY CARE HOMES, GROUP HOMES AND PERMANENT SUPPORTIVE HOUSING FOR PEOPLE WITH DISABILITIES IN NORTH CAROLINA, DRAFT 3, Technical Assistance Collaborative, at 51 (January 11, 2009).

³ SHORT- AND LONG-TERM SOLUTIONS FOR CO-LOCATION, at 32.

⁴ STUDY OF ISSUES RELATED TO PERSONS WITH MENTAL ILLNESS IN LONG-TERM CARE FACILITIES, Dep't of Health and Human Servs., at 4 (December 1, 2005).

- Adult care homes are not the most appropriate setting for people with mental illness because they are not designed to provide services to allow people with mental illness to achieve greater independence;⁵ and
- Supportive housing promotes community integration and achieves “positive impacts in terms of cost-effectiveness and improvement in quality of life, housing stability and health and behavioral outcomes for people with mental illnesses, developmental disabilities and substance abuse disorders.”⁶

We agree with these conclusions and observations. Reliance on unnecessary institutional settings violates the civil rights of people with disabilities. Community integration will permit the State to support people with disabilities in settings appropriate to their needs in a cost effective manner.

II. INVESTIGATION

On November 17, 2010, we notified the State that we were opening an investigation of North Carolina’s mental health system pursuant to Title II of the ADA. The State began producing requested documents and information in January 2011. We have reviewed the State’s documents and information, gathered additional evidence, and considered the informed opinions of individuals knowledgeable about the State’s mental health system. In March 2011, we toured numerous adult care homes in Durham, Wake Forest, Cary, Wilson, Fremont, Greensboro, and Rocky Mount. During our site visits, we and our expert interviewed residents about their personal experiences, and during several visits, we also spoke with adult care home staff. We also spoke with numerous community-service providers and stakeholders who were extremely knowledgeable about the State’s mental health system, as well as individuals with mental illness receiving services in their own apartments and members of psychosocial rehabilitation clubhouses and centers. In late April, we again visited numerous adult care homes, this time in Louisburg, Kannapolis, Morganton, Wilkesboro, Nebo, Conover, and other surrounding communities. We also met with members of the long-term care and adult care home industries.

Before proceeding to the detailed substance of the letter, we would first like to thank the State for the assistance and cooperation extended to us thus far, and to acknowledge the courtesy and professionalism of all of the State officials and counsel involved in this matter to date. We appreciate that the State provided us with helpful, responsive documents and information in response to our written requests. We hope that going forward there is a desire to work toward an amicable resolution to this matter.

⁵ Id.

⁶ SUPPORTIVE HOUSING AS AN ALTERNATIVE TO PSYCHIATRIC HOSPITALIZATION, Dep’t of Health and Human Servs., at 47 (March 15, 2011).

III. BACKGROUND

North Carolina has a mental health service system through which it delivers services to persons with mental illness. State law requires North Carolina “to provide mental health . . . services through a delivery system designed to meet the needs of clients in the least restrictive, therapeutically most appropriate setting available” and “to provide community-based services when such services are appropriate, unopposed by the affected individuals, and can be reasonably accommodated within available resources and taking into account the needs of other persons for mental health, developmental disabilities, and substance abuse services.”⁷

The North Carolina Department of Health & Human Services (DHHS) is responsible for developing and implementing the State plan for the delivery of mental health services. In doing so, among other activities, it sets strategic goals and determines how State, local, and federal resources will be deployed. The DHHS Secretary has overall responsibility for the administration of DHHS, including overseeing the development of the State plan for mental health services and ensuring coordination with the North Carolina Medicaid State Plan.

Among the Department’s programs and services are community support and residential care programs. The range of services existing in North Carolina’s mental health service system include Assertive Community Treatment (ACT) Teams, Community Support Teams, case management services, peer support services, supported employment, and a range of crisis services.

Several divisions within DHHS are also responsible for North Carolina’s mental health care delivery program and services. The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH) is responsible for managing the mental health service system, including promulgating and enforcing policies and regulations, allocating public funds, and managing the community mental health system. The Division of Medical Assistance (DMA) manages the State’s Medicaid program, which includes coverage of mental health, developmental disabilities, substance abuse, and other services to Medicaid-eligible individuals in adult care homes and other settings.

The Division of Health Service Regulation (DHSR) licenses, regulates, and supervises adult care homes. It is also responsible for implementing the State’s certificate of need law, which provides that “[n]o person shall offer or develop a new institutional health service without first obtaining a certificate of need[.]”⁸ In doing so, DHSR reviews and determines whether to approve or reject applications for certificates of need submitted by adult care homes. The Division of Aging and Adult Services (DAAS) is responsible for overseeing social services and certain benefits programs for persons with disabilities, including the State-County Special Assistance for Adults program, which provides a cash supplement to individuals with low incomes residing in adult care homes to pay for their care.

⁷ N.C. Gen. Stat. § 122C-2 (2010).

⁸ N.C. Gen. Stat. § 131E-178. See <http://www.ncdhhs.gov/dhsr/coneed/index.html> (last visited July 11, 2011).

Adult care homes are a type of assisted living residence licensed by DHHS to provide room and board, housekeeping, and personal care services for two or more unrelated adults. Thousands of people with mental illness are congregated in adult care homes across the State of North Carolina. Approximately 5,800 individuals with mental illness are congregated at 288 adult care homes with at least twenty beds and at least ten percent of the population comprised of individuals with mental illness. Roughly 4,800 of these individuals are congregated at 196 facilities with fifty or more licensed beds, and approximately 1,100 of these individuals are receiving services in one of 35 facilities with 100 or more licensed beds.

Even though adult care homes are not appropriate settings for persons with mental illness and State law prohibits the admission of persons to adult care homes for the treatment of mental illness, the facilities have become a major part of the State's mental health service system. Thousands of people with mental illness receive services in adult care homes—although they could be served in more integrated settings—because there are few community-based options available to them.

IV. FINDINGS

We conclude that the State fails to provide services to individuals with mental illness in the most integrated setting appropriate to their needs as required by the ADA. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d). The State plans, administers, and funds its mental health service system in a manner that unnecessarily segregates persons with mental illness in institutional adult care homes, rather than providing services to them in community-based settings. See 28 C.F.R. § 35.130(b) and (d). As a result, thousands of individuals with mental illness, who could be served in the community with the types of services and supports that exist in North Carolina's mental health service system, are needlessly institutionalized.

Congress enacted the ADA in 1990 “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” 42 U.S.C. § 12101(b)(1). Congress found that “historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” *Id.* § 12101(a)(2). For these reasons, Congress prohibited discrimination against individuals with disabilities by public entities:

[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.

Id. § 12132.⁹ “The ADA is intended to insure that qualified individuals receive services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides, and ignores them.” Helen L. v. DiDario, 46 F.3d 325, 335 (3d Cir. 1995).

One form of discrimination prohibited by Title II of the ADA is violation of the “integration mandate.” The integration mandate arises out of Congress’s explicit findings in the ADA, the Attorney General’s regulations implementing Title II,¹⁰ and the Supreme Court’s decision in Olmstead, 527 U.S. at 587. In Olmstead, the Supreme Court held that public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate, (b) the affected persons do not oppose community-based treatment, and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of other persons with disabilities. Id. at 607.

In so holding, the Court explained that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.” Id. at 600. It also recognized the harm caused by unnecessary institutionalization: “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” Id. at 601.¹¹

The State fails to provide services to individuals with mental illness in the most integrated setting appropriate to their needs, in violation of its obligations under the ADA and Olmstead. As a result of the way the State administers its mental health service system, individuals with mental illness are unnecessarily institutionalized in adult care homes throughout the State.

⁹ Section 504 of the Rehabilitation Act of 1973 similarly prohibits disability-based discrimination. 29 U.S.C. § 794(a). The ADA and Section 504 are generally construed to impose similar requirements. See Sanchez v. Johnson, 416 F.3d 1051, 1062 (9th Cir. 2005). This principle follows from the similar language employed in the two acts. It also derives from the Congressional directive that implementation and interpretation of the two acts “be coordinated to prevent imposition of inconsistent or conflicting standards for the same requirements under the two statutes.” Baird ex rel. Baird v. Rose, 192 F.3d 462, 468-69 (4th Cir. 1999) (citing 42 U.S.C. § 12117(b)) (alteration omitted).

¹⁰ The regulations provide that “a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). See also 28 C.F.R. § 41.51(d). The preamble discussion of the “integration regulation” explains that “the most integrated setting” is one that “enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible[.]” 28 C.F.R. § 35.130(d), App. A. at 572 (2010).

¹¹ Olmstead therefore makes clear that the aim of the integration mandate is to eliminate unnecessary institutionalization and enable individuals with disabilities to participate in all aspects of community life. Accord Press Release, The White House, “President Obama Commemorates Anniversary of Olmstead and Announces New Initiatives to Assist Americans with Disabilities” (June 22, 2009) (In announcing the Year of Community Living Initiative, President Obama affirmed “one of the most fundamental rights of Americans with disabilities: Having the choice to live independently.”).

A. Adult Care Homes Are Segregated, Institutional Settings

A public entity must “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). To determine whether a setting is the most integrated the appropriate inquiry is whether the setting “enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” Frederick L. v. Dep’t of Pub. Welfare, 364 F.3d 487, 491 (3d Cir. 2004) (citing 28 C.F.R. § 35.130(d) and 28 C.F.R. pt. 35 app. A); Disability Advocates, Inc. v. Paterson, 598 F. Supp. 2d 289, 321-22 (E.D.N.Y. 2009).

Adult care homes do not enable interactions with nondisabled persons to the fullest extent possible. To the contrary, they impede community integration and interactions with persons who do not have disabilities. Adult care homes appear and function as institutions, not homes where people without disabilities live. People with mental illness who reside in adult care homes live in close quarters primarily with other persons with disabilities, and most aspects of their daily lives are highly regimented and limited by rigid rules and practices. Cf. Disability Advocates, Inc. v. Paterson, 653 F. Supp. 2d 184, 224 (E.D.N.Y. 2009) (finding that “many people with mental illness living together in one setting with few or no nondisabled persons contributes to the segregation of [a]dult [h]ome residents from the community.”). See also Benjamin v. Dep’t of Pub. Welfare, 768 F. Supp. 2d 747, 750 (M.D. Pa. 2011) (noting that individuals in facilities were segregated where they lived in units ranging from 16 to 20 people, primarily received services on the grounds of the facilities and had limited opportunities to interact with non-disabled peers).

In appearance, adult care homes closely resemble institutional settings. Many facilities are structured in long corridors or wards, with some wards organized by type of disability and mental illness. Staff and administrators maintain areas, including office space and restrooms, that are separate from the areas of the facilities that are freely accessible to residents. The offices in some adult care homes display video screens on which the movements and activities of residents are monitored. Staff dispense medications by cart or residents are required to queue at a medication-station, and many residents see on-site doctors and psychiatrists. Paging systems interrupt individuals’ days on a regular basis at many facilities.

The rules and practices of adult care homes impose significant barriers to integration and interactions with nondisabled persons. Residents in many facilities are subject to curfews after which the facility doors are locked, as well as highly regimented meal and medication times. In many facilities, residents and visitors must sign in and sign out, and some facilities do not permit residents to leave the grounds unaccompanied, or otherwise restrict where residents may go. Some facilities have alarmed doors that alert any time a door is opened, while other facilities require staff to enter key codes for entry and exit, thereby stripping residents of their liberty to move about freely and with dignity.

Residents consistently described the regimentation and control exerted over them by facility staff and policies. Some residents reported that they can only leave the facility to attend

medical appointments and, as a result, their days are “depressing” and “boring.” One resident explained that the adult care home “controls when you get up, when you eat, and when you go to bed.” A resident of another facility described her life as “living on a closed ward” because she is locked in at all times and does not have the freedom to walk into town. Another resident secured a job outside the facility, but was let go within the first few days because he was unable to get there from the facility. Likewise, a resident explained that she misses the “freedom” of doing things with people in her community and that it is upsetting to her when staff talk to her “like [she] will be there until [she] die[s].”

To the extent activities exist, they are largely infantile and consist of activities such as bingo, arts and crafts, puzzles, movie-watching, and board games. Due to the lack of activities that are meaningful for adults and the restrictions on community access, many residents reported that they spend their days smoking and napping to pass the time. One resident stated that most of the residents of his adult care home spend their days “vegetating” and “smoking” because there is nothing else to do, while another resident stated that he “roams” the facility property to pass the time.

Some adult care homes take residents on organized trips to nearby shopping centers or stores, but these outings contribute little to community integration. Such outings are limited and rigidly scheduled. Residents travel together as a group, typically in the facility’s bus or van, and the number of individuals attending the outing is usually limited to the number of individuals who can fit in the vehicle. Some residents reported they are in need of clothing and other necessities but have no way of getting to the store.

The facilities provide virtually no privacy, and individuals are assigned to small, shared rooms with one to three other people. Typically, residents cannot lock their bedroom doors, and staff retain room keys of individuals who can. Regardless of whether a room is locked or a door is shut, staff in many facilities maintain the ability to enter at any given time. One resident stated, for example, that despite her attempts to keep her door closed, it is frequently left open by staff. Bathroom areas are congregate and often not lockable, with towels and other items often stored in separate areas not readily available to residents. Common areas tend to be very large, impersonal settings that afford little privacy.

Residents have very little choice or autonomy in their daily lives. Often, they are assigned roommates and have little or no choice in what they eat or with whom they sit for meals. In many facilities, residents do not manage their own funds, nor do these facilities present it as an option. Likewise, facilities typically control individuals’ medications and residents reported that staff have made errors in distributing medications. In many facilities, residents are not permitted to do their own laundry, and in most facilities, residents are not permitted to cook their own meals.

Given these and other characteristics, adult care homes are institutional, segregated settings that through their restrictive practices and control over individualization and independence limit a person’s ability to interact with other people who do not have disabilities.

Our findings are consistent with State-sponsored reports acknowledging that adult care homes are not the most integrated setting appropriate for individuals with mental illness. In a recent report regarding the co-location of different populations in adult care homes, a task force comprised of State officials and employees, as well as various stakeholders, recognized that adult care homes “are not optimal for community integration,” and that “[r]esidents of ACHs may be cut off from active participation in the local community because of the lack of transportation and the structured format (i.e., the schedule of meals and personal care) of many residential care homes.”¹²

A 2005 report issued by DHHS similarly acknowledged that “many with mental illnesses continue to live in long term care settings because there are not yet more appropriate alternatives available to them in their communities” and that adult care homes are not designed to allow persons with mental illnesses “to achieve a greater measure of independence.”¹³ Likewise, a 2009 draft report prepared by a State-contracted consultant concluded that “[a]dult [c]are [h]omes are, in fact, highly likely to qualify as restricted settings, and that there is a substantial basis for being concerned about ADA and Olmstead issues in North Carolina.”¹⁴

B. The Majority of Adult Care Home Residents with Mental Illness Could Be Served in More Integrated Settings

States have an obligation to provide services in community-based settings where such placement is appropriate for, and not opposed by, persons with disabilities. Olmstead, 527 U.S. at 607. Individuals with mental illness in adult care homes could be served in more integrated settings. The placement of persons with mental illness in adult care homes is not based on a determination that such placement is clinically necessary. Instead, people with mental illness tend to end up in adult care homes simply because there are no available residential services in the community. As the State has acknowledged, adult care homes are not the most appropriate settings for persons with mental illness, because, among other things, they are not designed to provide any recovery-oriented or rehabilitative services, or to afford people with mental illness opportunities for achieving greater independence and community integration.¹⁵

¹² SHORT- AND LONG-TERM SOLUTIONS FOR CO-LOCATION IN ADULT AND FAMILY CARE HOMES: A REPORT OF THE NCIOM TASK FORCE ON THE CO-LOCATION OF DIFFERENT POPULATIONS IN ADULT CARE HOMES, North Carolina Institute of Medicine, at 34 (January 2011).

¹³ STUDY OF ISSUES RELATED TO PERSONS WITH MENTAL ILLNESS IN LONG-TERM CARE FACILITIES, Dep’t of Health and Human Servs., at 4 (December 1, 2005).

¹⁴ STUDY OF ADULT CARE HOMES, FAMILY CARE HOMES, GROUP HOMES AND PERMANENT SUPPORTIVE HOUSING FOR PEOPLE WITH DISABILITIES IN NORTH CAROLINA, DRAFT 3, Technical Assistance Collaborative, at 51 (January 11, 2009).

¹⁵ See, e.g., STUDY OF ISSUES RELATED TO PERSONS WITH MENTAL ILLNESS IN LONG-TERM CARE FACILITIES, Dep’t of Health and Human Servs., at 4 (December 1, 2005).

In contrast, and as the State has also acknowledged, supportive housing—integrated, community-based housing that provides tenants with all the rights of tenancy and services and supports that meet their needs—is an appropriate and effective service setting for persons with serious mental illness.¹⁶ Supportive housing is a setting in which individuals live in their own home and receive services to support their success as tenants and their integration into the community. The State has recognized that supportive housing is both cost-effective and achieves positive outcomes in terms of housing and health stability and improvement in quality of life for persons with mental illness.¹⁷ Thus, supportive housing can meet the needs of adult care home residents with mental illness. Accord Disability Advocates, 653 F. Supp. 2d at 228 (finding that “supported housing provides individuals with mental illness with a permanent place to live coupled with flexible support services customized to each individual’s specific needs.”).

Moreover, there are people with the same diagnoses and symptoms as adult care home residents who live successfully in more independent settings, with the supports and services existing in the State’s community mental health system. See Disability Advocates, 653 F. Supp. 2d at 245 (evidence that adult home residents had same diagnoses as people with mental illness in supported housing supported finding that such residents were qualified to receive services in the community). During the course of our investigation, community service providers communicated their belief that most persons with mental illness in adult care homes could be served successfully in more independent settings. Cf. id. at 247 (evidence that community providers did not “view [a]dult [h]ome residents as having needs incompatible with supported housing” supported finding that people with mental illness in assisted living facilities could be served in more integrated setting).

After visiting many adult care homes, interviewing numerous adult care home residents with mental illness, speaking with community mental health service providers and consumers, and reviewing hundreds of resident records, our mental health expert similarly concluded that most adult care home residents with mental illness can be served successfully in supportive housing. He found that people with mental illness in adult care homes are not materially different than individuals with mental illness who currently thrive in community-based settings. He further concluded that the types of services and supports that exist in North Carolina’s community mental health service system are well able to meet the needs of people with mental illness confined to adult care homes.

In addition to being qualified for community-based service settings, people with mental illness in adult care homes would not be opposed to moving to integrated settings if they had a choice and a realistic opportunity to do so. Olmstead, 527 U.S. at 607. Throughout our investigation, residents emphatically expressed their desire to leave their adult care homes and become members of their communities once again. For example, one resident told us she very

¹⁶ See SUPPORTIVE HOUSING AS AN ALTERNATIVE TO PSYCHIATRIC HOSPITALIZATION, Dep’t of Health and Human Servs., at 1 (March 15, 2011).

¹⁷ See SUPPORTIVE HOUSING AS AN ALTERNATIVE TO PSYCHIATRIC HOSPITALIZATION, Dep’t of Health and Human Servs., at 1-2, 47 (March 15, 2011).

much wants to move out to her own place again because she “want[s] to live [her] life before [she] die[s],” and to “feel like [she has] a home again.” Another resident stated that she wants to move back into her own place because she “want[s] to be free.” The facility is always noisy; people are always telling her what to do all day; and there is nothing to do. Similarly, another resident reported that in the facility she is “just a number” and she would very much like to move out. Likewise, another resident explained that in the facility he “feel[s] cut out,” and he wants to “live [his] life and be part of society.” And another resident relayed that “[he] would do anything to get out; this is a prison.” These sentiments were echoed by numerous other residents we met during our visits.

C. North Carolina Administers Its Mental Health System in a Way that Segregates Individuals with Mental Illness in Institutional Settings

Under the ADA, public entities are required to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). A state is liable under the ADA where it administers its programs or services in a manner that unnecessarily segregates persons with disabilities in privately owned facilities. 28 C.F.R. § 35.130(b) (prohibiting public entities from using contractual or other arrangements, or utilizing criteria or methods of administration, that have the effect of subjecting qualified individuals with disabilities to discrimination). See also Disability Advocates, 598 F. Supp. 2d at 317 (“It is immaterial [for purposes of Title II liability] that DAI’s constituents are receiving mental health services in privately operated facilities.”); Rolland v. Celluci, 52 F. Supp. 2d 231, 237 (D. Mass. 1999) (holding that it is immaterial for purposes of Title II ADA claim that plaintiffs lived in private nursing facilities, rather than state-operated facilities).

Despite its acknowledgement that supportive housing is a good investment for North Carolina and a preferred placement for people with mental illness, the State relies on institutional adult care homes as settings in which to provide services to persons with mental illness. The State plans, oversees, funds, and regulates programs and services for individuals with mental illness in a manner that leaves thousands of individuals with mental illness isolated in large, segregated adult care homes. Due to the State’s policies and practices, adult care homes are the only service setting available to many individuals with mental illness, even though such facilities are not the most integrated setting appropriate.

The State has failed to develop a sufficient capacity of community-based mental health service settings. Although some supportive housing exists in North Carolina’s service system, the State has not developed it in sufficient capacity to meet the needs of unnecessarily institutionalized persons. As the State has acknowledged, individuals with mental illness end up in adult care homes because existing housing programs are woefully inadequate.¹⁸

¹⁸ SERVING PERSONS WITH DISABILITIES IN APPROPRIATE SETTINGS: THE NORTH CAROLINA PLAN, Dep’t of Health and Human Servs., at 32-33 (April 2003) (“Often people with severe and persistent mental illness end up in Adult Care Homes because there are no other appropriate residential services in the community The existing housing resources are woefully inadequate to address the housing needs of people with severe and persistent mental

Instead of allocating resources to community-based settings, the State has opted to fund a substantial portion of the cost of providing care in adult care homes. Through its State-County Special Assistance Program, North Carolina subsidizes the cost for individuals with disabilities to live in adult care homes. This state supplement—which provides support for nearly three-quarters of the residents in adult care homes and amounts to roughly \$550 per person per month for persons receiving Supplemental Security Income—makes up the difference between a person’s income and the total cost of residing in an adult care home (approximately \$1182 per person per month). Aside from limited circumstances, the State has not made this supplement available to persons with disabilities living in the community.

The State also operates its personal care service (“PCS”) program in a manner that perpetuates the institutional bias in its service system. North Carolina offers PCS as an optional Medicaid State Plan service, which provides assistance with certain activities of daily living to eligible Medicaid beneficiaries in their own homes, as well as to eligible Medicaid beneficiaries in adult care homes and certain other facilities. The State’s criteria for receipt of PCS by persons living in their own homes are more stringent than the criteria for persons living in adult care homes. As a result, it is more difficult to obtain PCS in a community-based setting than in an adult care home, and the ease of obtaining PCS in an adult care home further advances the institutional bias existing in the system.

Additionally, North Carolina has long used—and continues to use—adult care homes as places to discharge persons leaving its psychiatric hospitals. From 2001 to 2010, the State discharged from psychiatric hospitals to adult care homes and family care homes 7,595 individuals with mental illness.¹⁹ Many residents with whom we spoke reported that, upon discharge from a hospital, they were provided with no choice of service setting other than an adult care home or selection of adult care homes. Similarly, other residents reported that they were placed in an adult care home by their State Department of Social Services social worker, without any opportunity to choose an alternative setting.

The State also exerts direct control over the availability of adult care home beds through the certificate of need process. New adult care home beds cannot be developed without a certification from the State that a need for those beds exists. Thus, the State has authority to issue certifications based on availability of other programs in which mental health services are provided. It has used this authority to enable the development of adult care home beds to the detriment of community-based alternatives.

illness.”). See also DMH SCOPE OF WORK: TECHNICAL ASSISTANCE COLLABORATIVE, Div. of Mental Health, Developmental Disabilities and Substance Abuse Servs., Attachment B, at 1 (“Adults with mental illness, developmental disabilities or substance abuse need safe, affordable housing with appropriate service availability in order to live successfully in the community. The need for supported housing is especially critical for the 6,000+ adults with serious mental illness . . . who currently reside in adult care facilities in North Carolina.”).

¹⁹ ADULT CARE HOME REPORT: HOSPITAL DISCHARGES 2000-2010, DHHS Div. of State Operated Healthcare Facilities.

The State's failure to redirect resources and its failure to prioritize community-based settings over institutional care has confined thousands of people with mental illness unnecessarily and indefinitely in adult care homes and puts many others at risk of unnecessary institutionalization.

D. Individuals with Mental Illness Are At Risk of Unnecessary Institutionalization in Adult Care Homes

The ADA's integration mandate applies both to people who are currently institutionalized and to people who are at risk of unnecessary institutionalization. See Radaszewski v. Maram, 383 F.3d 599 (7th Cir. 2004) (ADA applied to individual at risk of entering nursing home); Fisher v. Okla. Health Care Auth., 335 F.3d 1175 (10th Cir. 2003) (same); Marlo M. v. Cansler, 679 F. Supp. 2d 635 (E.D.N.C. 2010); Pitts v. Greenstein, No. 10-635-JJB-SR, 2011 WL 1897552, *3 (M.D. La. May 18, 2011) ("A State's program violates the ADA's integration mandate if it creates the *risk* of segregation; neither present nor inevitable segregation is required.").

Because of the State's reliance on adult care homes and its failure to deploy resources to develop a sufficient capacity of community-based options, many people with mental illness in the community are at risk of entering an adult care home to obtain services. Additionally, because of the lack of community-based options, many people with mental illness discharged from psychiatric and other hospitals, as well as jails, will have no choice but to enter an adult care home to receive services in the State's mental health service system.

E. Serving People with Mental Illness in Integrated Settings Can Be Reasonably Accommodated

Providing services to adult care home residents with mental illness in community-based settings can be reasonably accommodated. The types of services needed to support people with mental illness in community-based settings already exist in North Carolina's community-based mental health service system. These services include ACT Teams, Community Support Teams, case management services, peer support services, supported employment services, and crisis services and are capable of supporting people with mental illness with varying needs in community-based settings. Additionally, the State could redirect the Special Assistance and Medicaid funds it already spends to support persons with mental illness in adult care homes to support them in community-based settings. The amount of money spent on Special Assistance is roughly equivalent to what it would cost to support a person in supported housing, and some of the Medicaid services provided to adult care home residents are the same services they would need in the community.

Given the array of mental health services in North Carolina and the existence of funds that could be redirected to community-based settings, providing services to people with mental illness in more integrated settings can be reasonably accommodated.

V. RECOMMENDED REMEDIAL MEASURES

To remedy the deficiencies discussed above and protect the civil rights of individuals with mental illness who receive services in adult care homes, the State should promptly implement the minimum remedial measures set forth below.

A. **Serving Individuals with Mental Illness in the Community**

The State must develop sufficient supported housing to enable those unnecessarily confined to adult care homes and those at risk of entry into adult care homes to receive services in the most integrated setting appropriate to their needs. Supported housing is permanent housing with tenancy rights and support services that enable individuals with mental illness to attain and maintain integrated, affordable housing. Support services offered to people in supported housing are flexible and available as needed, but are not mandated as a condition of tenancy.

The State should realign its funds away from institutional adult care homes to prioritize integrated, community settings. All new supported housing should be scattered site, with no more than 10% of a residential setting allocated to persons with disabilities.

The State must ensure that people with mental illness who move to supported housing are connected to the array and intensity of services and supports they need to successfully transition to and live in supported housing. These services, which already exist in North Carolina's mental health service system, include ACT Teams, Community Support Teams, case management services, peer support services, supported employment, and a range of crisis services. For each service recipient, an individual service plan should be developed and implemented by a case manager who is clinically responsible for ensuring that all components of the service plan and all needed services are provided in a coordinated manner.

The State should ensure that its quality management systems are sufficient to assure that all mental health services funded by the State are of good quality and are sufficient to help individuals achieve positive outcomes, including increased integration, independence, and self-determination in all life domains (e.g., community living, employment, education, recreation, healthcare, and relationships); stable community living; avoidance of harms; and decreased hospitalization and institutionalization.

B. **Discharge and Transition Planning**

The State must implement an effective plan to transition people with mental illness unnecessarily institutionalized in adult care homes to supported housing. Each person with mental illness in adult care homes should receive an independent, professionally appropriate, and person-centered assessment, by a transition team, of his or her preferences, strengths, and needs

in order to determine the community-based services necessary for him or her to live in supported housing.²⁰

All assessments should include an individualized analysis of the services and supports necessary to ensure successful transition to and residence in supported housing. Discharge assessments should be based on the principle that with sufficient supports and services, individuals with mental illness can live in an integrated community setting.

The State should ensure that community mental health service providers and peer specialists conduct frequent and effective in-reach to adult care home residents to build trust and actively support them in moving to more integrated settings, including supported housing. In-reach should include full explanations of the benefits of living in supported housing and about available community-based services.

No one who is qualified for supported housing should be placed in an adult care home, or other congregate setting, unless after being fully informed, he or she declines the opportunity to receive services in supported housing. The State should ensure that the steps taken to assure informed choice are documented. Individuals with mental illness who remain in an adult care home after the assessment process should be assessed regularly for transition to a more integrated setting, and more frequently upon request.

V. CONCLUSION

Please note that this findings letter is a public document. It will be posted on the Civil Rights Division's website. Although we will provide a copy of this letter to any individual or entity upon request, as a matter of courtesy, we will not post this letter on the Civil Rights Division's website until ten calendar days from the date of this letter.

We hope to continue working with the State in an amicable and cooperative fashion to resolve our outstanding concerns with respect to the State's failure to provide its services and programs in the most integrated setting appropriate.

We hope that you will give this letter careful consideration and that it will assist in facilitating a dialogue swiftly addressing the areas that require attention.

We are obligated to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, the Attorney General may initiate a lawsuit pursuant to the ADA once we have determined that we cannot secure compliance voluntarily, 42 U.S.C. § 2000d-1, to correct deficiencies of the kind identified in this letter. We would prefer, however,

²⁰ The DOJ's separate, on-going investigation of the State's psychiatric hospitals similarly determined that the hospitals failed to adequately assess hospital residents. This general failure included failing to assess residents' strengths and needs for discharge planning. Our psychiatric hospital investigation determined that the hospitals' discharge planning was virtually non-existent, and did not include any meaningful transition service planning, or coordination with community service provider entities.

to resolve this matter by working cooperatively with the State and are confident that we will be able to do so. The Department of Justice attorney assigned to this investigation will be contacting the State's attorneys to discuss this matter in further detail. If you have any questions regarding this letter, please call Allison Nichol, Chief of the Civil Rights Division's Disability Rights Section, at (202) 514-8301.

Sincerely,

A handwritten signature in black ink, appearing to read 'T. E. Perez', with a stylized flourish at the end.

Thomas E. Perez
Assistant Attorney General