

Trapped in a Fractured System

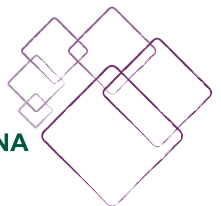
People with Mental Illness in Adult Care Homes

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DISABILITY RIGHTS
NORTH CAROLINA

Champions for Equality and Justice



North Carolina's Protection and Advocacy System

www.disabilityrightsn.org

An Overview

Although it has been twenty years since the Americans with Disabilities Act (ADA) was signed into law, people with disabilities are still fighting to enforce the ADA's community integration mandate as articulated in *Olmstead v. L.C.* more than ten years ago. Adults with mental illness should be able to live in the least restrictive setting of their choice with appropriate supports. Yet, thousands of adults with mental illness in North Carolina find themselves with nowhere to go. In North Carolina, many live in adult care homes — large institutional settings for elderly individuals and adults with disabilities who may require 24-hour supervision and assistance with personal care needs.

Over the past several months, Disability Rights NC has reviewed death and incident reports and, with the help of several UNC law students, visited fifteen adult care homes throughout North Carolina. What we found confirmed our suspicions in vibrant detail: adults in their twenties were living together with adults in their seventies; many facilities had 100% of residents with serious mental illness but offered no therapeutic or rehabilitative services; and many adult care home residents were subjected to stark institutional living environments. The adult care home industry has readily admitted for years that they take these individuals when no one else will. Many of the residents have been evicted from other residential settings, struggle with substance abuse, or have a dual developmental disability diagnosis. Others have lived in an adult care home setting for so long they can no longer think about living in their own home with proper community supports.

The State of North Carolina lacks a realistic plan that supports all adults with mental illness living in the community in a truly integrated setting. North Carolina's *Olmstead* Plan is less than two pages. By law, our state/county special assistance program for rental assistance can be used only for community living for up to 15% of all recipients. The remaining recipients reside in adult care homes.

This report describes the dangerous conditions that can result in these facilities when adults with severe and persistent mental illness are warehoused in such a way. Despite the conditions and incidents detailed in this report, all of these adult care homes remain open with a significant population of adults with mental illness. We asked the U.S. Department of Justice to investigate the situation in North Carolina and enforce the integration mandate of the ADA on behalf of North Carolinians with mental illness. Twenty years after the enactment of the ADA, it is past time for North Carolina to create a real strategy to achieve the community integration mandate of the ADA.

Trapped in a Fractured System: People with Mental Illness in Adult Care Homes

What Is an Adult Care Home and Why are People with Mental Illnesses There?

Adult Care Homes are licensed assisted living facilities that provide, at a minimum, one meal a day, housekeeping services, and personal care services to seven or more residents. Homes where care is provided for two to six unrelated residents are called **Family Care Homes**. State law forbids Adult Care Homes from admitting residents for the “treatment of mental illness.” N.C. Admin. Code 10A.13F .0701(b). According to information provided to an N.C. Institute of Medicine (IOM) Task Force in December 2009, North Carolina had 631 Family Care Homes with 3,533 beds and 627 Adult Care Homes with 36,564 beds.

A 2008 report by the Technical Assistance Collaborative, Inc. concluded that more than 5,000 adults with mental health disabilities were living in North Carolina’s Adult Care Homes. A 2010 report to the IOM revealed that 6,432 persons with mental illness reside in Adult Care Homes and Family Care Homes.

Despite the prominent role Adult Care Homes play in the North Carolina mental health system, Adult Care Homes are not regulated as mental health facilities. They are “assisted living residences” licensed by N.C. DHHS under rules adopted by the state medical care

commission. Staffing requirements and qualifications are not designed for care of residents with mental health needs. For example, during the first and second shifts, an Adult Care Home with 41 to 50 residents is legally required to have only three staff present (a 1:16.6 ratio). At night on third shift, only two staff need be present (1:25 ratio). N.C. Admin. Code 10A.13F .0603. In mental health group homes the population is limited to six residents, a ratio of 1:6. Additionally, staff at a mental health group home are supervised by a MH/DD/SAS qualified professional. N.C. Admin. Code 10A.27G .0104, .0204, .5603.

Permanent Supportive Housing is the Best Practice

Permanent supportive housing allows persons with disabilities access to decent, safe, and affordable housing that is integrated into the community. Individually tailored and flexible supportive services are provided in the community setting. Nationwide and in North Carolina, supported housing is considered the “best practice” for housing people with disabilities because it is successful, cost-effective and promotes integration, consumer choice and dignity.

North Carolina has provided some state funding to develop permanent supportive housing units in the state. These “Targeted Units” are designed to serve

people with disabilities (not limited to mental illness) who need assistance in obtaining housing and continued access to supportive services to be successful. Approximately 900 people with disabilities are currently living in Targeted Units. Tenants cannot directly apply for these Targeted Units but must be referred by an approved human services agency. Anecdotal evidence suggests that a narrow group of people with disabilities is accepted into this program. There are also federally funded Section 811 projects, which provide supported housing but in a segregated setting. The

number of supported housing units is far from adequately serving the population, and is particularly lacking for adults with severe and persistent mental illness who have aggressive behaviors or who may need more than a very minimal level of services in the community. Additionally, there is concern that erosion to services in the community could jeopardize these few placements.

Stable housing is a prerequisite for improved functioning for people with mental disabilities and a powerful motivator for people to seek and sustain treatment.

Useful Acronyms

N.C. DHHS: North Carolina Department of Health and Human Services

N.C. DHSR: North Carolina Division of Health Service Regulation

MH/DD/SAS: the Division of Mental Health/Developmental Disabilities/Substance Abuse Services, the division in the N.C. Department of Health and Human Services (DHHS) that provides oversight for the mental health, substance abuse, and developmental disability services statewide.

SA: Special Assistance, the common name for a state- and county-funded program that provides cash supplements to help low-income residents of Adult Care Homes pay for their care.

TAC: Technical Assistance Collaborative, Inc. is a national nonprofit organization that works to find and implement solutions to the housing and community support needs of vulnerable low-income people with significant and long-term disabilities. For more information, see www.tacinc.org.

Life in an Adult Care Home: Danger in Close Quarters

Case #1: Death of LM

Adult Care Home licensed to care for 80 residents located in the sandhills of North Carolina

During a routine check on December 27, 2008, staff found LM in his room, face down and unresponsive. His roommate, MG, was sitting on top of him and said that he was tired of being accused of stealing. Paramedics were called. LM was pronounced dead at the scene.

LM, a 69-year-old with a diagnosis of paranoid schizophrenia, had lived at the Adult Care Home for just over a year. According to the N.C. DHSR investigation complaint survey, LM was known to accuse other residents and staff of stealing his belongings. The facility manager described him as loud and sometimes confrontational. The local mental health team had provided training to facility staff in ways to redirect and de-escalate LM. Clearly, staff cannot be present at all times when the ratios are 16:1 or 25:1.

MG, 60, had lived at the facility since 2000. He was diagnosed with schizophrenia and dementia. Because of MG's quiet and non-confrontational demeanor, he was eventually paired with LM.

He was charged with second-degree murder and convicted in 2010 of voluntary manslaughter.

The N.C. DHSR investigation found that the facility failed to meet minimum staffing requirements, but also recognized that with minimal rate increases in the past five years, it was difficult to keep competent staff at the facility.

Case #2: Death of JL

Adult Care Home licensed to care for 65 residents located in the middle of the State

JL, 27, had diagnoses of schizoaffective disorder, bipolar disorder, intermittent explosive disorder and Asperger's disorder. On May 21, 2009, JL became agitated. He left the facility and was brought back by staff. JL and staff were on the facility's porch when DE, a 55-year-old resident diagnosed with schizophrenia, crossed the porch and started swinging his metal cane at JL. JL dodged some swings but was then hit several times in the head, shoulder, and arm. DE continued to hit JL with the cane until staff separated them. Later, staff offered JL a bag of ice when he complained of

head pain from an observable knot on the back of his head.

According to the report of death sent to N.C. DHR, JL continued to be “verbal and agitated after the attack.” A facility administrator petitioned a Magistrate for the involuntary commitment of JL. He was picked up by law enforcement and taken to a local hospital for evaluation for the commitment. During the evaluation, JL began vomiting. A test showed a large bleed in the right brain. He was airlifted to N.C. Baptist Hospital, where he died on May 25, 2009. The cause of death was blunt trauma to the head.

According to newspaper reports, facility management told the family and law enforcement that JL hurt his head as he was backing away from DE, stumbled on some bicycles, fell, and hit his head on the corner of an air conditioning unit and then on the cement porch. Surveillance footage of the attack, however, shows DE swinging at JL with his metal cane, missing, and then hitting JL in the side of the head with his cane in a baseball-type swing. In the video, the bicycles are still upright when JL falls.

Later the same day, DE was arrested for threatening an employee with his cane. He was subsequently charged with the second-degree murder of JL. In 2010 he was convicted of voluntary manslaughter and sentenced to 129–164 months in the N.C. Department of Correction.

A complaint investigation was conducted by Surry County Department of Social Services and N.C. DHR. The report concluded that all allegations were unsubstantiated.

Case #3: Death of RS

Adult Care Home licensed to care for 56 residents located in the foothills of North Carolina

RS lived in a facility that was newer but very hospital-like. The facility has its own bus that takes residents to and from activities in the community, although this service has been cut back recently. Residents have a choice between menu options at mealtimes. Yet staff appear generally apathetic to residents’ needs and there are coded locks on many of the doors.

RS, 70, was assaulted and killed on July 8, 2009, by 43-year-old DS, another resident. Staff heard a disturbance outside on the smoking patio. According to newspaper reports, DS repeatedly hit RS in the head with a stick. Facility staff observed part of the assault and saw blood splattered on the patio and on DS.

According to the N.C. DHR report, 29 of the 50 residents residing in the facility at the time had diagnoses that included mental illness. The Adult Care Home had received 29 police calls in the 18 months prior to RS’s death, including three assaults and

The N.C. DHR investigation found that the facility failed to meet minimum staffing requirements but recognized that the minimal rate increases in the past five years made it difficult for the facility to keep competent staff.

“Unjustified isolation . . . is properly regarded as discrimination based on disability.”

Olmstead, 527 U.S. 597



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four attempted suicides. According to the facility staff, outbursts, violence and threats of violence were not uncommon.

Disability Rights NC’s recent monitoring visit found several residents who wanted to live in the community and appeared capable of doing so.

Case #4: Death of WD

Adult Care Home licensed to care for 80 residents in western North Carolina

At the time of Disability Rights NC’s recent monitoring visit to this adult care home, the 80-bed facility was approximately 80% full and 100% of the residents had a mental illness. Resident age varied from late-20s to 70s. Residents waited in long lines for medication and food and had very little community interaction. Nearly every resident interviewed was unhappy living at the facility, lamenting their lack of freedom. They had cycled in and out of state psychiatric hospitals, jails and other facilities, finding themselves at this adult care home as a last resort.

The stay of two residents at this facility ended in great tragedy last fall. On October 26, 2009 resident KH, 43, killed WD, 67, by severely beating him. The incident resulted from a dispute over \$4.25. According to information gathered by Disability Rights NC, facility staff were in a nearby room when the beating occurred. KH is now in jail with a pending murder charge.

N.C. DHSR staff assisted the local department of social services in a complaint investigation against the adult care home, but there were no findings to substantiate a complaint.

Case #5

Adult Care Home licensed to care for 48 residents in central North Carolina

N.C. DHSR found in a 2008 survey that all 32 residents of this facility had a diagnosis that included mental illness. N.C. DHSR also found the facility failed to provide supervision to meet the needs of the residents, in some cases acutely exacerbating their mental illness. In some cases this led to injuries, either self-inflicted or inflicted by other residents. N.C. DHSR found that the facility failed to discharge three residents whose behaviors placed themselves or others at risk for serious physical harm and/or death.

Now, in the summer of 2010, this Adult Care Home no longer accepts young residents or individuals with a history of substance abuse or criminal behavior. Many residents have mobility issues.

Other than smoking and watching television, there are few social activities available for the residents. Transportation is available only for doctor visits. The facility remains surrounded by a barbed wire fence.

The major issues reported by the residents were idleness and isolation. The facility director reported that most residents are at the facility merely because of an inability to manage their medication intake properly. Many residents agreed that this is their sole barrier to living in the community.

Case #6

Adult Care Home licensed to care for 81 residents in southeastern North Carolina

A resident at this facility who was diagnosed with schizophrenia, paranoid type, intermittent disorientation and a history of wandering and verbal abuse died when he walked into the street and was hit by a vehicle. After his death, the physician employed by the facility stated that the facility was not appropriate for him due to his advanced mental diagnosis. N.C. DHSR learned during its investigation that the facility did not contact the physician until after the resident had returned from a hospitalization when, according to the doctor, he was then left to “manage his symptoms.” The facility’s protocol was to call the physician upon change in condition or behavior, but the physician stated he had not been called by the facility, even after the resident refused medication.

Another resident, who had a history of paranoid schizophrenia and a developmental disability, tied a scarf around her own neck and pulled, resulting in bruises on her neck. An ambulance was called and the physician was informed, but the resident refused to go to the hospital. The doctor ordered 15-minute checks and an increase in medication, but questioned whether the facility was an appropriate setting for the resident.

N.C. DHSR issued a Type A Violation based on the facility’s failure to “provide supervision of residents in accordance with each resident’s assessed needs, care plan and current symptoms.” 10A NCAC §13F.0901. The Directed Plan of Correction required the facility to assess new and current residents and implement interventions to address their needs.

Adult Care Homes Are Not the Most Integrated Setting

The Americans with Disabilities Act, Title II, requires a state to provide services to individuals with disabilities “in the most integrated setting appropriate to their needs.” 28 CFR §35.130(d); 28 CFR §41.45(d).

As the Supreme Court explained in *Olmstead v. L.M.*, “institutional placement of persons who can handle the benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life ...” *Olmstead* at 600. “[I]nstitutional confinement,” the Court wrote, “severely diminishes individuals’ everyday activities,” including family relations, social contact, work options, educational advancement and cultural enrichment.

The “most integrated setting” is “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” 28 CFR Pt. 35 App. A. 35.130, at 469. This is commonly known as the “integration mandate.”

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What It Means...

Type A violation: A violation of the regulations, standards and requirements governing Adult Care Homes that results in a death, serious physical harm or a substantial risk that either death or serious physical harm will occur. N.C. Gen. Stat.

§ 122C-24.1.

Directed Plan of Action: When a Type A violation is identified the regulator must immediately inform the administrator of the facility what must be done to correct the violation. Thus, the plan of correction is directed by the regulator.

Report of Death: North Carolina law requires facilities to report to N.C. DHSR when a resident's death results from violence, accident, suicide or homicide, and further requires N.C. DHSR to notify Disability Rights NC of the report of death.

Complaint Investigation: The N.C. DHSR Complaint Intake Unit receives complaints regarding the care and services provided to patients, residents and consumers by the health care facilities, agencies or homes they license. Each complaint is prioritized for investigation according to the seriousness of the situation. N.C. DHSR staff forward complaints about Adult Care Homes to the local Department of Social Services for investigation. On a case-by-case basis, staff from N.C. DHSR may also be involved in the complaint investigation regarding an Adult Care Home.

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Case #7

Adult Care Home licensed to care for 80 residents in southeastern North Carolina

A 2008 N.C. DHSR survey found a number of incidents involving four residents at the facility during a five-month period. These included sexual threats to aides, sexual assault of another resident, assaults and property damage.

In one instance, staff locked themselves in a medication room for their own safety. Confidential interviews conducted with residents revealed that two of them carried weapons as protection from a fellow resident.

Disability Rights NC's recent visit to this Adult Care Home found it at 75% capacity with nearly all residents with a mental illness. Residents ranged in age from late 20s to early 70s. The facility is said to have improved significantly under new leadership since the events of 2008. Although the facility feels more personalized and homey than many other Adult Care Homes, the residents still have limited interaction with the community, consisting only of facility visitors and medical appointments. Despite some planned daily activities, many residents were eager to live elsewhere and be active in the community. One resident, BJ, is a hoarder and has a diagnosis of Obsessive-Compulsive Disorder in addition to a minor physical disability. She lived independently until an eviction due to her hoarding left her with nowhere else to go. BJ could live successfully in the community with supportive services.

In Conclusion

The list of the dangerous consequences of inappropriate placements goes on and on. One 40-bed Adult Care Home in a large North Carolina city made 58 calls to 911 over an eight-month period — including 21 for disturbances, eight for fights or assaults and four involving alcohol or drugs. In one Family Care Home in the north-central part of the state, residents with diagnoses including schizophrenia, schizoaffective disorder, mental retardation and depression were left alone while staff ran errands and one resident assaulted and injured another while the staff was away. (This resulted in a Type A violation; one of the items in the Directed Plan of Correction was to utilize Mental Health to develop behavior plans for residents.)

It Doesn't Have to Be This Way: Achieving Community Integration

The UNC students and DRNC staff who visited the clubhouses throughout the state found a positive, contrasting point of view from the experiences witnessed at the adult care homes. A clubhouse is a non-residential, rehabilitative service that provides its members with social opportunities, meaningful work, and recreational activities during the day.

Clubhouse members live in community settings, ranging from mental health group homes to their own apartments. When they are at the clubhouse, members can choose to participate in activities like games, dances or visits to places in the community. They have access to computers, telephones, and assistance with employment readiness. One clubhouse had a GED program for its members. Members may also hold jobs at the clubhouse, like running the snack bar. Although this is not required, members often participate because they are given encouragement and the opportunity to learn new skills. Some members also have part-time employment in the community. Even for those individuals who live in group homes, clubhouses provide opportunities to positively integrate into the community at large.

For example, clubhouse member PD, diagnosed with schizophrenia, has previously lived in adult care homes, group homes, and hospitals. PD now lives in an apartment run by a clubhouse and says that he cannot imagine a return to life in an adult care home. The apartments are available for members who have become sufficiently independent, and are intended to improve members' autonomy and self-esteem. PD says that he is the happiest he has ever been since his first schizophrenic episode. According to PD, the activities offered at the house (such as gardening, cooking for other members, etc.) encouraged him to become productive and responsible, and have increased his feelings of self-worth.

MM is another example of a person with severe and persistent mental illness who has successfully achieved community living in an integrated setting. MM is a 60-year-old woman diagnosed with bipolar disorder. She has been hospitalized for her mental illness several times in the past. She now lives on her own in an apartment in the community. She gets assistance from an aide who takes her shopping and helps her clean her yard. Her church sends a bus to pick her up and take her to services on Sunday mornings. On days when she is not going to therapy, she comes to the local clubhouse. She says she has made friends there and is happy to help out and do some of the jobs offered to members such as working in the kitchen, helping out at the snack bar, and decorating the hallways.

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In a 2010 report, the Institute of Medicine revealed that 6,432 persons with mental illness live in Adult Care Homes and Family Care Homes in North Carolina.

Disability Rights North Carolina is a federally mandated protection and advocacy system with funding from the U.S. Department of Health and Human Services, the U.S. Department of Education, and the Social Security Administration. Disability Rights NC is a 501(c)(3) nonprofit organization.

Upon request, information is available in alternate formats.

What Happens Now That a US Department of Justice Complaint Has Been Filed?

On July 26, 2010, Disability Rights NC filed with the U.S. Department of Justice (DOJ) a complaint against the State of North Carolina on behalf of all persons with mental illness living in Adult Care Homes in North Carolina. A complaint filed with the DOJ is not the same as a legal action filed in a court of law.

The Disability Rights Section of the Civil Rights Division of the DOJ is responsible for enforcing the Americans with Disabilities Act. The Division investigates complaints and conducts compliance reviews. It may initiate litigation based on its investigation or may intervene in legal actions brought by private parties. There is no set timeline for a DOJ investigation.

Through its complaint, Disability Rights NC has asked DOJ to investigate its claim that people with mental illness in North Carolina are being placed improperly in Adult Care Homes in violation of the integration mandate of the Americans with Disabilities Act. DOJ will first determine if there is sufficient evidence for it to initiate an investigation. If DOJ conducts an independent investigation and finds merit to the claims made in the complaint, it can work with the State of North Carolina to effect policy changes to correct the civil rights violations or, if necessary, file legal action against the State of North Carolina.

Disability Rights NC is North Carolina's Protection and Advocacy (P&A) system, charged by federal law to protect people with disabilities from abuse and neglect. To assist with the fulfillment of this mandate, federal law grants all P&As "reasonable unaccompanied access" to facilities that serve individuals with mental illness. Federal regulations explicitly state that one of the purposes of P&A access authority is to "monitor compliance with respect to the rights and safety of residents." Disability Rights NC will continue to monitor Adult Care Homes and to advocate for clients who are inappropriately placed there without adequate services and care. We hope the DOJ will assist us with tackling this issue more broadly.

UNC Law Students Assist in Interviewing Adult Care Home Residents



Left to Right: Andrew Strickland (Disability Rights NC staff attorney) and University of North Carolina law students John Villalon, Virginia Niehaus, Devin Schoonmaker, Merab Faulkner, Jonathan Wells, Leann Gerlach, Ryan Ostrow and Peary Tarwasokono.

To augment its own P&A resources, Disability Rights NC enlisted the assistance of eight students from the University of North Carolina School of Law to conduct fieldwork at various Adult Care Homes in May 2010. Disability Rights NC identified 15 Adult Care Homes across North Carolina where many adults with mental illness were believed to be residing. The students were divided into teams of four; each team was accompanied and supervised by one or two Disability Rights NC staff members. Over the course of two weeks, the students and Disability Rights NC staff observed the conditions of each facility and spoke to the residents, administrators, and staff. Through this investigation, Disability Rights NC obtained a better understanding of the day-to-day experience of Adult Care Home residents and the common factors that necessitated their placement in an Adult Care Home. **The investigation revealed the large size and institutional quality of the Adult Care Homes visited, as well as a near total lack of community interaction for residents, most of whom desire to live more independently.**

“The ADA literally opened millions of doors for individuals with disabilities across this nation.”

Thomas E. Perez
Assistant U.S. Attorney General

Recommendations

Disability Rights NC calls on the State of North Carolina to:

- ◆ **Develop a meaningful, detailed Olmstead plan for true community integration of people with disabilities in North Carolina, with particular attention to adults with mental illness who are inappropriately placed and receiving no community mental health services.**
- ◆ **Continue development and investment in permanent supportive housing for adults with severe and persistent mental illness.**
- ◆ **Develop long term care services and supports in the community for adults with severe and persistent mental illness, including but not limited to the clubhouse model of day programming, personal care services and peer support.**
- ◆ **Remove the institutional bias in state/county special assistance funding to allow more individuals to live in a home setting.**
- ◆ **Ensure that recent changes to Medicaid funded personal care services do not further increase the number of individuals with mental illness inappropriately placed in Adult Care Homes.**
- ◆ **Develop a robust supported employment initiative for adults with mental illness.**

Disability Rights NC values the dignity of ALL people and their freedom to control their own lives. We work for justice upholding the fundamental rights of people with disabilities to live free from harm in the communities of their choice, with the opportunity to participate fully and equally in society.

We provide advocacy for all North Carolinians with disabilities. You could be eligible for our services if:

- ◆ You have a developmental or intellectual disability;
- ◆ You have a psychiatric or emotional disability;
- ◆ You are a patient in a state psychiatric hospital;
- ◆ You have a physical, learning, or sensory disability; or
- ◆ You have a traumatic brain injury.