

Complaint by Disability Rights NC to the United States Department of Justice on behalf of Individuals with Mental Illness living in Adult Care Homes in North Carolina

Disability Rights 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.¹ 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.² The PAIMI Act 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."³ P&As have included compliance with integration mandates as an important part of protecting the rights of residents, especially those capable of living more independently in true community settings with appropriate services. Disability Rights NC believes that thousands of adults with serious mental illnesses in North Carolina are inappropriately being warehoused in Adult Care Homes where they receive no mental health treatment and are frequently subject to unhealthy and dangerous conditions.

Twenty years after the passage of the Americans with Disabilities Act (ADA) and over ten years after the U.S. Supreme Court's decision in *Olmstead v. L.C.*,⁴ the state of North Carolina continues to rely on institutional placements for the long-term care of many adults with severe and persistent mental illness. While the State classifies these homes as "community settings," in practice Adult Care Homes are truly institutions, with a high bed capacity, a lack of individual autonomy, and isolation from the general community. In filing this complaint, Disability Rights NC respectfully requests the assistance of the U.S. Department of Justice in evaluating and investigating the appropriateness of placement of adults with mental illness in Adult Care Homes, and whether these placements constitute a violation of the ADA under the principles articulated in *Olmstead*.

Adult Care Homes in North Carolina

North Carolina General Statutes define Adult Care Homes as "assisted living residence[s] in which the housing management provides 24-hour scheduled and unscheduled personal care services to two or more residents."⁵ Adult Care Homes are explicitly forbidden from admitting residents for the "treatment of mental illness, or alcohol or drug abuse."⁶ Adult Care Homes are not expected to provide, and are not licensed for, the on-site treatment of any mental or medical condition.

Adult Care Homes are only licensed with personal care services (PCS) in mind because to be eligible for an Adult Care Home, the individual must require personal care services.⁷ According to the North Carolina State Medicaid Plan, personal care services are "intended to provide person-to-person hands on assistance...with common activities of daily living (ADLs) that [include] eating, dressing, bathing,

¹ See Protection and Advocacy for Individuals with Mental Illness Act ("PAIMI Act"), 42 U.S.C. § 10801 *et seq.*; Developmental Disabilities Assistance Bill of Rights Act ("DD Act"), 42 U.S.C. § 15001, *et seq.*; and Protection and Advocacy of Individual Rights Program ("PAIR"), 29 U.S.C. § 794e, *et seq.*; and all of the accompanying regulations.

² See 42 C.F.R. § 51.42(c) ("PAIMI Act regulations").

³ *Id.*

⁴ 527 U.S. 581 (1999).

⁵ N.C. GEN. STAT. § 131D-2.1(3) (2010). "Adult care homes" that serve two to six unrelated residents are separately regulated as "family care homes" and are not the subject of this Complaint. *Id.*

⁶ 10A N.C. ADMIN. CODE § 13F.0701(b) (2010).

⁷ N.C. GEN. STAT. § 131D-2.1(3).

toileting, and mobility.”⁸ The personal care services provided in Adult Care Homes are generally intended for “[a]ny adult...who, because of a temporary or chronic physical condition or mental disability, needs a substitute home....”⁹

The eligibility criteria for individuals to receive PCS in Adult Care Homes are far less stringent than those for in-home PCS.¹⁰ This means that, on average, an individual in an Adult Care Home receives more personal care services at a higher cost to the State than an individual living in the community with the same needs.¹¹ An individual in an Adult Care Home can be authorized through a non-specific assessment by an Adult Care Home employee to receive PCS if he requires supervision in one out of seven recognized ADLs: bathing, dressing, personal hygiene, ambulation or locomotion, transferring, toileting, and eating.¹² On the other hand, an individual living in the community only qualifies for community PCS if he is assessed by an independent assessment agency through a formalized process and found to require supervision in three out of five recognized ADLs: bathing, dressing, toileting, mobility and eating.¹³ The eligibility determination for community PCS no longer considers mental capacity as a factor. The only consideration given to mental capacity is that it may be used to determine whether supplemental hours are needed if a person already establishes eligibility for the service. Individuals with mental illness in the community may have previously qualified for PCS due to the effect the mental illness had on their ability to complete an ADL. Such an individual would no longer qualify for services because the mental capacity is currently not considered for eligibility purposes.¹⁴ Residents of Adult Care Homes can also qualify for Enhanced PCS and, unlike in community PCS, there is no explicit cap on the amount of services they can receive.¹⁵ Another significant difference is that as opposed to community PCS, no independent assessor reviews the individual.¹⁶

Someone with greater need in the community may go without PCS while someone with less need in an Adult Care Home is able to receive PCS in addition to services provided by state Special Assistance Adult Care Home funds. These funds are State money that is used to supplement an individual’s income to allow them to afford to stay in an Adult Care Home.¹⁷ Typically, it costs three times as much to support an individual in an Adult Care Home than it does to support him in his own home, and on average,

⁸ See N.C. Div. Med. Assistance, Clinical Coverage Policy 3C § 1.1 (revised Apr. 16, 2010).

⁹ 10A N.C. ADMIN. CODE § 13F.0701(a) (2010).

¹⁰ *Id.*

¹¹ *Id.*

¹² 10A N.C. ADMIN. CODE § 13F.0801 (2010).

¹³ 2010 N.C. Sess. Laws 31 § 10.68A(a) [hereinafter 2010 Budget Bill].

¹⁴ See *infra* p. 7 and note 52.

¹⁵ *Id.*

¹⁶ 10A N.C. ADMIN. CODE § 13F.0801. See also N.C. Div. Health & Human Services, Adult Care Home Case Management Services Manual, <http://info.dhhs.state.nc.us/olm/manuals/doa/achcm/man/index.htm>.

¹⁷ The maximum of \$1,228 is based on the maximum Adult Care Home rate of \$1,182 plus a personal needs allowance of \$46 per month. The State rarely pays the full 1,228 in Special Assistance funds because the person’s net countable monthly income is subtracted from the 1,228. To be eligible for Special Assistance, a person must be eligible for Medicaid and in NC the standard for adult Medicaid eligibility is tied directly to eligibility for SSI, therefore the standard rate of SSI is subtracted from the \$1,228 in every case, more if the person receives SSDI or other income. N.C. Div. Aging & Adult Services, *Special Assistance Adult Care Home Program: Help for North Carolinians who need care in an Adult Care Home* (Oct. 2009), available at <http://www.dhhs.state.nc.us/aging/adultsvcs/specialassistance.pdf>.

residents in Adult Care Homes receive more hours of PCS per person per month than the maximum hours a person with community-based PCS can receive in his or her home.¹⁸

A total of 627 Adult Care Homes operate in North Carolina, with a total number of residents of 24,040.¹⁹ Some Adult Care Homes exclusively serve elderly adults, adults with mental illness, or adults with Alzheimer’s Disease or other memory disorders; other Adult Care Homes serve a combination of these populations. In 2002, adults with mental illness occupied 4,495 Adult Care Home beds; today, some 6,435 adults with mental illness reside in Adult Care Homes—approximately 24.7 percent of all Adult Care Home residents.²⁰ Despite the growing population of individuals with mental illness in Adult Care Homes, the minimal staffing requirements of these facilities, as set out in state regulations, are not well suited to or designed for adequate care of residents with mental health needs.²¹ Adult Care Homes have very high resident to staff ratios, which contributes to common problems such as resident-on-resident violence, low-levels of supervision, and a lack of healthy staff-resident interaction. For example, up to 50 residents are supervised and served during the day by as few as three staff members, mostly aides. This high day ratio of approximately 16 residents to every one staff member worsens at night when only two direct care staff must be present in a facility with 50 residents (25:1 ratio).²² By comparison, the population of mental health group homes is limited to six residents per staff person (6:1 ratio). Unlike staff at an Adult Care Home, staff at a mental health group home must be supervised by a qualified mental health professional.²³

A 2008 study commissioned by the North Carolina General Assembly magnified Disability Rights NC’s concern about Adult Care Homes and the lack of true, integrated community placements for adults with mental illness in Adult Care Homes. A draft copy of this study, authored by the Technical Assistance Collaborative Inc. (TAC), is attached to this Complaint.²⁴ The TAC Report analyzed the current housing situation of individuals with mental illness as well as services and supports necessary to ensure successful community living. Ultimately, the TAC Report concluded that many Adult Care Home “placements are inconsistent with *Olmstead* and other disability rights laws for those people whom,

¹⁸ For every individual living in an ACH, the State pays \$1,182 per month in Special Assistance funds. For every individual living in an ACH that qualifies for PCS—nearly 100% of residents in ACH qualify for PCS—DMA pays an additional \$16.62 per resident per day for PCS in the adult care homes with thirty or fewer residents and \$18.21 per resident per day for PCS in the adult care homes with thirty-one or more residents. This rate is based on an average of 1.1 hours per day, regardless of whether or not the resident actually requires 1.1 hours per day. See N.C. Div. Med. Assistance, *Adult Care Home Daily Reimbursement Rates* (2010), available at http://www.dhhs.state.nc.us/dma/fee/ach_pcs_rates.pdf.

¹⁹ N.C. Institute of Medicine, *Interim Report to the General Assembly 23*, 71 (Mar. 2010).

²⁰ *Id.*

²¹ The precise staffing requirements slightly vary by the population of the Adult Care Home. See 10A N.C. ADMIN. CODE § 13F.060 (2010).

²² *Id.* Each Adult Care Home with 41 to 50 residents must provide at least 20 hours of direct care staffing, an aide-supervisor and an Administrator who is “on call” during both first and second shift. This would usually mean that three aides would be required, but the regulation allows the aide-supervisor to conduct four hours of aide duty. This means that two aides plus the aide supervisor can provide the direct care for up to 50 residents. To further decrease the number of on-site staff, the Administrator can be away from the facility if he or she is on-call and the administrator-in-charge on duty may simultaneously be the personal care aide supervisor if that person meets the administrator qualifications. 10A N.C. ADMIN. CODE § 13F.0602 (2010).

²³ See 10A N.C. ADMIN. CODE § 27G.0104, .0204, .5603.

²⁴ Founded in 1992, Technical Assistance Collaborative, Inc. is a non-profit organization that offers interdisciplinary teams of national experts to identify and offer solutions in areas of health, housing and social services. For more information about TAC, see their website at <http://www.tacinc.org>.

with the support of their treatment professional[s], desire to live in more integrated places.”²⁵ The General Assembly never publicly released this report.

Disability Rights NC Involvement

Disability Rights NC also received several reports of resident deaths occurring at Adult Care Homes, four of which occurred over a ten-month period. Each of these four deaths was caused by resident-on-resident violence, and each resident involved was an individual with a mental illness. A description of each incident is also attached to this complaint as part of a Disability Rights NC Internal Memorandum on the dangerous conditions found in Adult Care Homes.

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 we believed many adults with mental illness were 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 ACH residents, administrators, and staff. Through this investigation, Disability Rights NC obtained a better understanding of the day-to-day experience of ACH residents and the common factors that necessitated their placement in an ACH. 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. A description of each site visit made by a student-Disability Rights NC staff team to an Adult Care Home is attached to this complaint.

Decline in Mental Health Services for North Carolina Adults

In order to put the Adult Care Home issue in context, the following is a brief summary of important developments in the mental health delivery system in North Carolina over the last decade—the same decade during which other states were implementing *Olmstead* plans to increase community placements. In 2001, North Carolina undertook a massive effort to reform mental health care, including the privatization of many mental health services and the creation of regional management entities that replaced local county mental health agencies. North Carolina’s *State Plan 2001: A Blueprint for Change*, emphasized the need to provide meaningful integrated services in accessible community settings for adults with severe and persistent mental illness.²⁶

The creation and maintenance of a robust system of community-based services has proven to be problematic. New Medicaid services were developed and designed to help build infrastructure for individuals requiring services in the community, but most of these services have either been redefined to be extremely limited or completely eliminated.²⁷ A compounding problem has been that throughout the last decade, the State has undertaken very little, if any, serious effort to provide for an integrated housing option for people with mental illness. *State Plan 2001* recognized that individuals who had serious mental illnesses would be unable to “live successfully in the community without services,

²⁵ Technical Assistance Collaborative, Inc., *Draft Study of Adult Care Homes, Family Care Homes, Group Homes, and Permanent Supportive Housing for People with Disabilities in North Carolina* 7 (Oct. 1, 2008).

²⁶ N.C. Dep’t. Health & Human Services, *State Plan 2001: A Blueprint for Change* 2, 3 (Nov. 30, 2001).

²⁷ N.C. Dep’t. Health & Human Services, *MH/DD/SA Service Definitions* 12-16, 35-37 (Jan 1, 2003) [hereinafter *MH/DD/SA Service Definitions 2003*].

support, and guidance.”²⁸ Notwithstanding its recognition of the need, the State has made little progress in creating viable services and placements in the community.

Community Support:

Since 2001, several of the services developed during mental health reform have been eliminated, significantly reduced, or remain inaccessible to many North Carolina residents. The results have been devastating. In 2008, of North Carolina’s 100 counties, 25 counties had no practicing psychologists. An additional 15 counties had only one practicing psychologist.²⁹ Owing to the scarcity of qualified professional services, more individuals were forced to utilize Community Support services, a high-cost service option.³⁰ At that time, Community Support had been re-crafted as an “enhanced benefit” service, meaning that its definition encompassed an array of services intended to meet the needs of people with high support needs. Some of the higher level interventions included in this service included case management and first responder crisis services, as well as preventive, developmental and therapeutic services. Services such as “skill building” and “relational skills development” were also included as part of the Community Support service, but these components could be performed by staff with minimal education and training.³¹ Regardless of the staff requirements or type of service being performed under the Community Support service, the unit cost charged to Medicaid remained the same.³² Responding to perceived abuse of the Community Support service, the North Carolina General Assembly completely eliminated Community Support services in 2009.³³ This elimination left many individuals with no services at all; a problem that continues to resonate in the community and remains a significant factor in escalating admissions at North Carolina’s state psychiatric hospitals, emergency rooms, and jails.³⁴ Eventually, the situation developed into a crisis and a modified version of Community Support was reinstated. But the reinstated and limited program remains woefully inadequate to meet need: in its modified form, the maximum number of service hours allotted to any individual dropped from eight hours per day to eight hours *per week*.³⁵ Without such community-based supports, individuals with mental illness were increasingly moved or discharged to non-home settings such as Adult Care Homes.

Case Management:

An important piece of successful community living for adults with mental illness is the role case management plays in ensuring an appropriate complement of services that was individually crafted to

²⁸ *State Plan 2001: A Blueprint for Change*, *supra* note 26, at 16.

²⁹ ALISON GRAY, REFORMING MENTAL HEALTH REFORM, THE HISTORY OF MENTAL HEALTH REFORM IN NORTH CAROLINA 67 (2009).

³⁰ Although funding for mental health services more than doubled from 2001 to 2008, to more than \$1.5 billion, 90 percent of the new community spending was for community support, and “only 4.9 percent was spent on the seven services more likely to reduce the need for hospitalization. The number of private for-profit companies providing community support totals 784, but 98 percent of the work force used by these private companies are high school graduates who were paid \$61/hour to take patients to such activities as swimming, to the mall, to a movie, or to eat — activities with little therapeutic value.” *Id.* at 69.

³¹ N.C. Dep’t. Health & Human Services, *N.C. Medicaid Special Bulletin 1, 2* (Sept. 2005).

³² N.C. Div. Med. Assistance, *Fee Schedules*, available at <http://www.dhhs.state.nc.us/dma/fee>.

³³ Gary D. Robertson, *NC Budget-Writers Interested in Eliminating Support Services for Mental Health Patients*, ASSOCIATED PRESS, May 29, 2009, available at <http://www.sfoxaminer.com/economy/ap/46457967.html>.

³⁴ Michael Biesecker, *How Can N.C. Fix a Broken Mental Health System?*, NEWS & OBSERVER, Mar. 2, 2008, available at <http://www.newsobserver.com/2008/03/02/78807/how-can-nc-fix-a-broken-mental.html#storylink=misearch>.

³⁵ *Id.*; see also, N.C. Dep’t. Health & Human Services, *MH/DD/SA Service Definitions* 41 (Jun. 30, 2010), available at <http://www.dhhs.state.nc.us/mhddsas/stateplanimplementation/DMHDDSA%20Service%20Definitions%20Manua%20-%20Revisions%2015%20January%20.pdf>.

meet each recipient's needs. The Medicaid Case Management services developed through mental health reform were designed to link and integrate, "the educational, vocational, residential, mental health treatment, financial, social and other non-treatment needs" of individuals receiving services.³⁶ As the designated advocate and coordinator of client services, Case Managers' duties included tailoring service arrays to the needs of their clients.³⁷ Currently, North Carolina provides Targeted Case Management to individuals who receive MR/DD services.³⁸ To the detriment of community integration efforts, the N.C. General Assembly directed DHHS to eliminate Case Management as a service in 2009 as a stand-alone service to adults who receive mental health services.³⁹ Some of Case Management's functions have been absorbed into the new Community Support Team service,⁴⁰ but where Community Support Team services are inappropriate or unavailable, Case Management services do not exist.⁴¹

Access to Care:

In 2003, just two years following the initiation of mental health care reform, "a number of North Carolina communities were already 'seeing increasing numbers of psychiatrists refusing to see Medicaid patients due to low reimbursement levels.'"⁴² As area programs began the process of divestment and privatization efforts commenced, "staff flight created gaps in a public system" and resulted in an extreme workforce shortage as well as the loss of the knowledge that accompanies an experienced staff.⁴³ Diminished community services fueled increased hospitalizations, where once again, inadequate staffing created dangerous living environments for patients.⁴⁴ Discharge from a State psychiatric hospital, especially into a community placement became increasingly risky due to the lack of meaningful and appropriate community-based services and supports for those who have severe and persistent mental illness. An advocacy group, NC Policy Watch, reports that nearly 1,200 people who were discharged from psychiatric hospitals ended up in homeless shelters in 2007.⁴⁵

³⁶ *MH/DD/SA Service Definitions 2003*, *supra* note 27, at 12.

³⁷ *Id.*

³⁸ N.C. Dep't. Health & Human Services, *North Carolina Special Medicaid Bulletin VI: Targeted Case Management for Mentally Retarded/Developmentally Delayed (MR/DD) Individuals* (Oct. 25, 2005).

³⁹ 2009 N.C. Sess. L. 451, § 10.68(A)(a)(2)(a); *see also* N.C. Dep't. Health & Human Services, *MH/DD/SA Service Definitions ii* (Jun. 30, 2010) [hereinafter *MH/DD/SA Service Definitions 2010*].

⁴⁰ Community Support Team (CST) services consist of enhanced, intensive community-based mental health and substance abuse services and supports for individuals who have complex and extensive clinical treatment needs, in which discrete therapeutic interventions may be delivered by a team member. There are very strict eligibility criteria for these services, including deficits in at least two of the following areas of functioning: emotional, social, safety, housing, medical and health, educational, vocational, and legal, and failures in a less intensive residential settings. N.C. Div. Med. Assistance, *Clinical Coverage Policy 8A* (revised July 1, 2010). However, CST may not be available in many geographic areas.

⁴¹ *MH/DD/SA Service Definitions 2010*, *supra* note 39, at 82.

⁴² GRAY, *supra* note 29, at 68.

⁴³ *Id.*

⁴⁴ In 2008, *The News and Observer* reported that at least 82 out of 537 patients in North Carolina's mental institutions had died "in ways that raise questions, including homicides and suicides." Michael Biesecker & Brooke Cain, *Patients Die from Poor Care: Families Don't Hear Full Story*, NEWS & OBSERVER, Mar. 2, 2008, available at http://www.micahealbiesecker.com/Michael_Biesecker/Stories_files/Patients%20die%20from.html. On her 19th admission to state-run Cherry Hospital in Goldsboro, NC, Janella Williams died after being placed in restraints, heavily medicated, and left alone for several hours. *Id.*

⁴⁵ Chris Fitzsimon, *Mental Health Reform 2.0*, N.C. POL'Y WATCH (Jun. 9, 2008), <http://www.ncpolicywatch.com/cms/2008/06/09/mental-health-reform-20/>.

Evidence-based Practices:

State Plan 2001 envisions that North Carolina's mental health services would be "appropriate to the needs of the people with disabilities . . . and must meet standards derived from evidence-based practices and/or nationally recognized models."⁴⁶ In 2004, Dr. Beth Melcher, Project Director of North Carolina's Science to Service Project, delivered to MH/DD/SA a report entitled, "*Bridging Science to Service: A Plan to Implement Evidence-Based Practices for Adults with Mental Illness in North Carolina's Public Mental Health System.*"⁴⁷ The report defined a "comprehensive strategic plan for North Carolina to successfully implement evidence-based practices statewide"⁴⁸ and has "been recognized by some national experts as one of the best and most thoughtful plans in the country."⁴⁹ Despite the accolades and the mental health reform legislation calling for the use of evidence-based and 'best practice' treatment paradigms, their implementation has been limited,⁵⁰ largely because, "[a]rea programs [have been] left to 'read the literature' and make their best decision for a new treatment paradigm."⁵¹ This 'best decision' approach has created a fragmented and failing mental health system rather than the widely praised program that was originally planned and has subsequently let numerous NC citizens with mental illness fall through the cracks and into congregate, non-integrated settings.

One of the few evidence-based practices that has been in place since the beginning of reform is the Assertive Community Treatment Team (ACTT).⁵² ACTT provides a targeted intensive service array to "wrap services" around adults with serious mental illness, in order that they may live in the community rather than in an institution.⁵³ However, due to the rigor of its clinical and staffing requirements, it is rarely available in rural areas.⁵⁴ ACTT is one of many services that are not available to rural residents—a problem the State attributes to insufficient staffing, insufficient training, a high staff turnover rate, and individuals being referred to services that are locally available rather than the services that they need.⁵⁵

Recent Cuts Increasing the Institutional Bias toward ACHs versus Community Placements

The General Assembly's 2010 Budget Bill instructed the Department to replace Medicaid funded community PCS with two new services: In-Home Care for Children (IHCC) and In-Home Care for Adults (IHCA).⁵⁶ The In-Home Care services perform the same function as PCS, but the eligibility criteria for IHC

⁴⁶ *State Plan 2001: A Blueprint for Change*, *supra* note 26, at 23.

⁴⁷ Letter from Beth Melcher to Michael Mosley, Director, Department MH/DD/SAS 1 (Aug. 2, 2004), *available at* http://www.governorsinstitute.org/index.php?option=com_docman&task=doc_view&gid=24 (last viewed July 20, 2010)). This report was the culmination of work by North Carolina's Science to Service Consortium, which had received grants from the National Institute of Mental Health (NIMH) and the Substance Abuse Mental Health Services Administration (SAMHSA) to fund this project.

⁴⁸ *Id.*

⁴⁹ *Id.*

⁵⁰ See *State Plan 2001: A Blueprint for Change*, *supra* note 26, at 11; GRAY, *supra* note 29, at 69.

⁵¹ GRAY, *supra* note 29, at 69, quoting Carol Duncan Clayton, *Terms of Engagement: Implementing a Change Process at the Local Level*, N.C. MED. J., Sept./Oct. 2003, at 222.

⁵² *MH/DD/SA Service Definitions 2003*, *supra* note 27, at i.

⁵³ *Id.* at 4-7.

⁵⁴ Letter from North Carolina ACT Coalition to ACT Service Definition Workgroup (Aug. 28, 2009) (search "North Carolina ACT Coalition, ACT Service Definition Workgroup") (last viewed Jul. 22, 2010).

⁵⁵ N.C. Dep't. Health & Human Services, *State Strategic Plan 2007-2010 13* (Jul. 1, 2007), <http://www.dhhs.state.nc.us/MHDDSAS/announce/commbulletins/commbulletin074/strategicplan07-10finalweb-06-29-07.pdf> (last viewed Jul. 22, 2010)

⁵⁶ 2010 Budget Bill, *supra* note 13, at 75.

are much stricter.⁵⁷ It is estimated that more than one-half of the 37,000 current PCS recipients will not meet the eligibility criteria for IHCA and will subsequently lose the services that allow them to live in their own homes.⁵⁸ Earlier policy changes also altered the eligibility requirements to only authorize community PCS when a person required hands-on assistance in performing an ADL. Mental capacity was no longer considered to be a factor in eligibility, but instead could only be taken into consideration after a person was found to be eligible for community PCS, and only then to allow a small increase in the total number of hours.⁵⁹ While community PCS were drastically cut and access to the service restricted, PCS for Adult Care Home residents remained intact, essentially unaffected by budget cuts.⁶⁰ As a result of this drastic cut in community-based services, thousands of individuals who have been living successfully in the community will be at risk of institutionalization in violation of *Olmstead* as they will be forced into Adult Care Homes, Assisted Living Facilities, and other non-community settings in order to obtain needed Personal Care Services.⁶¹

Although it is not specifically a service for individuals with mental illness, many individuals with mental illness must rely on PCS for assistance—as they previously did with Community Support services—because their mental illness affects their ability to independently conduct activities of daily living. By reducing the availability of community PCS, the State is creating a bias in favor of Adult Care Homes placements.⁶² The State’s elimination of various community support services and its encouragement of the use of Adult Care Homes violate the important principles contained in *Olmstead*. With the reduced availability of community PCS, a person who would not be considered eligible for that community-based service could walk in the door of an Adult Care Home and qualify to be a resident and receive Adult Care Home PCS. This individual would be forced to accept an institutional setting because of personal care needs, although he does not need the supervision or other restrictive aspects of an Adult Care Home. By severely limiting community PCS, the State is unnecessarily putting thousands of North Carolinians at risk of institutionalization at a huge cost to the State. Providing community PCS will keep these individuals in the community and cost less than serving those individuals in Adult Care Homes.

Over the last decade, adults with mental illness in North Carolina have faced a deteriorating mental health delivery system and declining access to services because of the continual revision and elimination of services, inaccessibility of providers, and austere state budgets that disproportionately burden the state’s most vulnerable populations. Rather than providing adequate and comparable services for adults with severe and persistent mental illness, North Carolina has chosen to warehouse these individuals in Adult Care Homes, facilities that are explicitly prohibited, under state licensing requirements, from treating mental illness. This problem has reached a critical stage, resulting in

⁵⁷ *Id.*

⁵⁸ General Assembly Conference Report, *Roadmap to Restructuring Medicaid In-Home Personal Care Services* (June 2010).

⁵⁹ Clinical Coverage Policy 3C, *supra* note 8. Compare to previous policy which allowed cognitive impairment to be considered when calculating and thus assessing an individual on their ability to complete an ADL. N.C. Div. Med. Assistance, Clinical Coverage Policy 3C (Aug. 1, 2007).

⁶⁰ See 2010 Budget Bill, *supra* note 13.

⁶¹ See *Olmstead*, 527 U.S. at 581.

⁶² For example, a person living in the community needing help bathing may not qualify for in-home PCS, but the moment they walk into an ACH, the state will have to provide up to \$1,228 per month in Special Assistance. See *supra* note 17 (regarding special assistance). In addition to the \$1,228 received by the Adult Care Home from income/Special Assistance, the Adult Care Home also receives \$16.62 per day in an ACH with fewer than thirty-one residents or \$18.21 per day for an ACH with thirty-one or more residents, regardless of the individual’s actual need for 1.1 hours per day. *Id.*

frequent incidents of violence and multiple deaths. The most recent changes to Medicaid services available for this population only exacerbate the problem by creating an institutional bias away from community placements and toward Adult Care Homes. We urge the U.S. Department of Justice to thoroughly investigate this matter and enforce the Americans with Disabilities Act's prohibition on this insidious, discriminatory practice.

Adult Care Home Facility Summaries

Introduction

In order to investigate the condition of Adult Care Homes in North Carolina, Disability Rights NC partnered with the University of North Carolina School of Law to organize a pro bono project sending eight students across the state to monitor and survey fifteen Adult Care Homes. The project occurred over a two week period (May 17 – May 28, 2010), during which students and Disability Rights NC staff observed the condition of each facility and interviewed Adult Care Home residents, staff and administrators. Disability Rights NC chose five of the fifteen Adult Care Homes because of recent resident-on-resident deaths. The remaining ten facilities were chosen because Disability Rights NC believed these facilities had a large population of residents with mental illness. The investigation revealed the large size and institutional quality of the Adult Care Homes visited, as well as a dearth of community interaction for residents. Some facilities were not at full-capacity due to staffing shortages, sections of the facility being under construction, or the facility limiting its admissions only to residents without histories of substance abuse or violent tendencies. The majority of facilities visited were located in small, rural towns. In many cases, the lack of public transportation or other nearby activities contributed to the facilities' geographic and psychosocial isolation. A summary of the project findings follows.

1. Britthaven of Kannapolis

- Britthaven, located in Kannapolis, NC, is an Adult Care Home licensed for 106 residents. On the day of the student visit, it had approximately 83 residents, 90 percent of whom, or approximately 75 residents, had a mental illness. Resident ages varied widely from late twenties to late seventies.
- While at the facility, we noted overmedicated residents, long hallways, bad lighting, crowded rooms (three residents per room), offensive odors, reports of violent altercations among the residents, minimal and dilapidated furniture and a lack of anything to make it feel like home.
- Residents' community interactions were limited to the occasional group outing to the Dollar General discount store and to walking to a nearby gas station for soda, candy and cigarettes. The primary activities of the residents were watching television, pacing up and down the hallways, sleeping, and smoking.

Facility

Kannapolis is a rural suburb of Charlotte with a population of approximately 37,000. The facility was not easily identifiable from the road because it did not have a sign of any sort. Immediately upon entering Britthaven, the students noticed a strong, offensive odor that permeated throughout the facility. The students also smelled smoke in some of the rooms but did not observe anyone smoking inside. There were also flies throughout the facility, landing on patients during student interviews. Many residents complained about how loud it was at the facility. Others complained of a lack of privacy. The air conditioning made the facility extremely cold and several residents

complained that staff ignored requests to remedy the problem. Residents lying in bed had multiple blankets piled up on top of them. Many rooms lacked accessible bathrooms and there were complaints that the bathtubs were too small for bathing even though many residents find taking a shower very difficult.

Staff

The Britthaven staff appeared wary of the students' presence and made it quite clear upon their arrival that they were not welcome there, despite having scheduled the visit in advance. Several residents reported that they were not supposed to be talking to the students or that they were scared to talk to them. Students observed that staff members seemed generally inattentive and uncaring. Residents also complained that staff members are verbally abusive and unkind. One resident reported that she sometimes waits almost an hour to have her diaper changed after asking for assistance. Another resident had not been given feminine products and was consequently bleeding on her clothes and linens. Another resident reported that staff members yelled at her if she was unable to fall asleep when she was supposed to or if she had an accident in her bed.

Residents

Nearly every resident interviewed expressed unhappiness with life at Britthaven. A large number of residents displayed symptoms of overmedication including tardive dyskinesia, dilated pupils, tremors, anxiety, restlessness and confusion. There were complaints of a mean, disrespectful staff, substance abuse occurring in the facility and the presence of street drugs such as crack and alcohol as well as abuse of prescription medications. Many complained that they had no money to buy anything. Several residents said they were not diagnosed with a mental illness before they moved to Britthaven but as a result of their stay, they had developed anxiety and were now receiving medication for it. Many reported violent incidents between residents which seem to have unnerved many.

When students arrived, the facility cook was performing karaoke and one resident said this happened once a month. Residents did not appear engaged in the karaoke performance, and there were no signs of other organized activities during the visit. The residents' primary activities observed by the students were watching television, pacing up and down the hallways and lying in bed and smoking. Nearly every mobile resident spends a large portion of their day outside smoking. Residents are told when to go to bed at night, when to get up in the morning, when to shower and when to eat. Most residents seemed unhappy with this regimented schedule. At least one resident said he had previously been receiving therapy and no longer received it, despite his belief that he did need it. One resident complained that Britthaven gets a new psychiatrist every year and he does not feel like his medications, diagnoses, and treatments are the same from year to year. None of the residents reported receiving active treatment for their mental illness.

There are residents currently living at Britthaven that have successfully lived in the community in the past, express an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

2. Canterbury Hills

- Canterbury Hills, located in Candler, NC, is an Adult Care Home licensed for 99 residents. On the day of the student visit, it had approximately 94 residents, all of whom had mental illness. Resident ages varied widely from late twenties to late seventies.
- A guard shack at the entrance, residents waiting in long lines for medication and food, the constant shouting by staff and residents, overmedicated residents, and the “longest hallway in Western NC” made the facility feel like an institution.
- Residents’ community interaction was severely limited. The facility is isolated from the nearest town. Mountain Transportation, the local paratransit service, refuses to pick up or drop off Canterbury Hills residents and the facility only provides transportation for medical appointments. There have been objections voiced by neighbors of the facility because residents of the facility have caused trouble by stealing from nearby homes.

Facility

Candler is a small, rural unincorporated community near Asheville in Buncombe County. No residents are admitted who are not receiving SSI or other disability payments. On the day of the visit, there were 15 people on the waiting list for admission to the facility. The number of available beds had been reduced because the facility had turned off two bathtubs. The facility had an overall institutional feel. A guard shack greets every visitor entering and leaving Canterbury Hills. Most residents lived in rooms along a very long, shabby, and old institutional-style hallway. The operating manager, in fact, referred to the hallway as the “longest in Western NC,” which made it feel very much like a hospital. Residents lined up all day long in the hallway in order to receive medications and meals, as well as to purchase cigarettes, candy bars, and soft drinks from the “Country Store” at one end of the long hallway. Aside from the long lines, the facility had a chaotic atmosphere. There was a lot of noise in the facility, with residents constantly shouting, bartering, or running and walking up and down the hall. At different places in the facility, students noticed the smell of vomit and urine. There was no air conditioning and there were large, loud fans in the hallway in an attempt to increase ventilation.

Staff

One resident accused a staff member of stealing his medications and selling them. The staff member was not disciplined even after the accusations were substantiated. Staff shortages were a major problem. The facility had difficulty taking residents to their doctors’ appointments because there were not enough staff members to accompany residents to their appointments. The local paratransit service, Mountain Transportation refused to transport residents of the facility, so transportation was a chronic problem for residents trying to get out into the community. Although there were a few residential homes within walking distance of the facility, any true community interaction required transportation.

Residents

There were few activities available for patients’ recreation and rehabilitation. Students observed karaoke during their visit, but did not observe any other activities. Some residents reported living in fear of other violent residents. Theft among residents was also a problem. Residents complained about an underground bartering system at Canterbury Hills through which drugs,

cigarettes and other luxury items were traded. There were problems with drugs coming in from outside the facility, and abuse of prescribed medication became so frequent that a pill-crush policy was implemented for all crushable medications. A large number of residents displayed symptoms of overmedication including tardive dyskinesia, dilated pupils, tremors, anxiety, restlessness and confusion.

A number of the residents appear capable of living in a less restrictive/more integrated setting. One resident, G, reported that he had been in and out of hospitals for his mental health diagnosis (schizophrenia) at least 40 times. Prior to living at Canterbury Hills, G was living independently in his own home until it burned down. After losing his home, he spent a year in a state psychiatric hospital and was discharged to Canterbury Hills, where he has remained for two years. Another resident, R, had been given extensive responsibilities within the facility and acted as his own guardian. R and his girlfriend, Q, also a resident, expressed a desire to leave the facility and go to college. R and Q, who appeared to be in their late thirties, both have schizophrenia.

D, a resident in his late twenties, had already obtained a two-year degree and was interested in furthering his education. Another resident, P, reported that she felt that she did not belong at Canterbury Hills and had tried in vain to find a more independent living arrangement. P stated that she has been told she cannot participate in group outings because she “has too much sense.” It seems that P would be a good candidate for independent living.

There are residents currently living at Canterbury Hills that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

3. Cedarbrook

- Cedarbrook, located in Nebo, NC, is an Adult Care Home licensed for 80 residents. On the day of the student visit, it had approximately 67 residents, all of whom had mental illness. Resident ages varied widely from late twenties to late seventies.
- With residents queuing in long lines for medication and food, bad lighting, shabby interior, the long, hospital-like hallway, and residents constantly pacing up and down the hallway, the facility felt like an institution, not a home.
- Residents’ community interaction was severely limited. The facility is very isolated and there is little to no opportunity for residents to leave Cedarbrook. Their only interaction with non-disabled individuals was with the facility staff and on-site Community Support Team.

Facility

Nebo is a small, rural unincorporated community in McDowell County in the North Carolina mountains with a population of approximately 3,700. The facility was not easily identifiable from the road because it did not have a sign of any sort. Some parts of the facility, the smoking porch in particular, looked new, but most of the facility was quite dilapidated. There was no air conditioning, which makes the facility very uncomfortable during the summer. Most residents

lived along a long hallway, similar to the one seen at Canterbury Hills. The long, shabby hallway created an institutional feel. The facility does offer therapy and substance abuse counseling on-site. There is a garden, a snack bar, a pool table, and a racing video game for residents' use. However, most residents were smoking and walking up and down the hallway during the student visit. Only residents with individual Community Support Team members were allowed to go on facility outings. The residents must stand in line to receive medications and meals. There was a long line for food and medication observed throughout the student visit.

Staff

Students observed twelve to fourteen staff and Community Support Team members at the facility. There were more staff members present at Cedarbrook than at other facilities, and the staff seemed to care more about the residents than at other facilities. Residents were often accompanied by staff members, although the staff members did little to engage residents. Residents and staff members alike spent most of their time walking up and down the hallway or smoking.

Residents

Nearly every resident at Cedarbrook was unhappy with their life at the facility. Every resident had a diagnosis of mental illness and many were at the facility because of a court order. There was a general atmosphere of chaos, instability, and fear. Most residents had cycled in and out of state hospitals, jails, and other facilities, finding themselves at Cedarbrook as a last resort. One resident, N, had been expelled from another facility for smuggling liquor into the facility. B, a resident with bipolar disorder, had been expelled from his previous facility after he stabbed another resident with a box cutter. There were many incidents of violence and fighting among residents reported by the residents interviewed. One resident, W, had thrown another resident out of a window. W said that he had not been punished, because "nobody liked" the victim of his attack. W acknowledged that he had a mental illness diagnosis but did not want to discuss the diagnosis with students.

Residents complained about the lack of freedom and about not being given the opportunity to interact with anyone in the community. During the student visit, residents were primarily observed smoking, pacing up and down the hallway, standing in line, or lying in bed. A large number of residents displayed symptoms of overmedication including tardive dyskinesia, dilated pupils, tremors, anxiety, restlessness, and confusion. Only the few residents receiving Community Support Team services were allowed to leave the facility and go on outings.

Residents with a history of substance abuse expressed fear of relapse if they returned to the community. Other residents were unsure of their ability to manage their medications. These hesitations were usually based on the belief that they would have no community supports if they left the facility. Once told that they could receive supportive services in the community, some residents expressed a desire for a community placement. Some residents had held jobs in the community previously, and appeared to be able to function in a more integrated community placement with supportive services. Residents expressing some preference for Cedarbrook did so only because they found it preferable to jail.

There are residents currently living at Cedarbrook that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

4. Crescent Green

- Crescent Green, located in Carrboro, NC, is an Adult Care Home licensed for 120 residents. On the day of the student visit, it had approximately 72 residents, the majority of whom were elderly. Resident ages varied widely from forty-two to 100.
- Having a garden, chickens and a newer facility made Crescent Green appear less institutional than many Adult Care Homes visited by the students. However, the cinderblock walls, institutional-style furnishings, the general resident monotony, lack of vigor, and physical austerity were reminiscent of an institution.
- Residents living at Crescent Green had more opportunity for community interaction than most Adult Care Home residents due to the availability of public transportation.

Facility

Carrboro is a small town near Chapel Hill in Orange County with a population of approximately 18,000. Crescent Green was a newer facility and had an atmosphere more like a nursing home, but retained some qualities of an institution with its institutional-style furniture and cinderblock walls. The doors of the unisex bathroom off the central hallway had been removed, permitting residents no privacy. There was a large garden, which residents could tend, and several chickens fenced in near the garden. The facility provided a phone room that residents could use at any time. There were accessibility problems in the facility: residents in wheelchairs had difficulty navigating many of the doorways. The area near the smoking patio was muddy and as a result, residents and staff often tracked dirt inside. There was only one poster informing residents of their rights, and it was located at the far end of one hallway. Residents complained about the quality of the food at the facility and said that the staff would not accommodate the needs of those with dietary restrictions. Residents also complained that they were not receiving their full amount of SSI payments. Some said they received no money at all after the facility took their share of the SSI money.

Staff

As with most Adult Care Homes, the staff were generally apathetic. One staff member had been accused of stealing money from the residents. One resident, L, also accused the staff of opening or withholding her mail.

Residents

Residents at Crescent Green were a mixture of elderly adults and younger individuals (those under 50) with mental illness. The age disparity was more noticeable at Crescent Green than at other facilities. Younger individuals complained about feeling alone and isolated in the facility because they could find no companionship there. Younger individuals seemed generally less satisfied with the facility than the elderly residents. Elderly residents appeared to be the majority and they were more likely to report that they were happy living at Crescent Green. During the

student visit, residents were primarily observed smoking, pacing up and down the hallway, standing in line, or lying in bed.

One resident, L, had lived at Crescent Green since she had fallen a year and a half ago. She did not want to discuss her mental illness diagnosis but did mention her psychiatrist during the conversation. She expressed a strong desire to return to apartment living in Carrboro and appeared capable of taking care of herself. Residents F and B had previously received physical therapy, but told students they were no longer able to afford it because of Medicaid cuts. F and B wanted to continue physical therapy because they noticed that their physical condition was deteriorating. F was also suffering from depression. A few residents had an active interest in performing music and poetry. One resident, E, had previously held a job as a courier for UNC and had lived in his own apartment. He became very agitated when asked about his mental illness diagnosis, but did tell students that he had been in Butner (possibly referencing the state psychiatric facility, Central Regional Hospital, located in that town) before moving to Crescent Green. Because of E's young age and previous success in the community, E could likely be better served in an integrated community placement. Another resident, C, had been diagnosed with schizophrenia while she was attending Eastern Carolina University and had since cycled in and out of state psychiatric hospitals, homeless shelters, and other facilities. It appears that C, a previously successful college student, would be a good candidate for placement in the community.

Another resident, S, was clearly overmedicated to the point that her speech was affected. S was clearly intelligent and stated that she did not like living there. S disagreed with the doctor prescribing her medication. She was barely able to speak, drooled, and could not keep her mouth closed. Her eyes were bulging and she was wearing a housecoat when interviewed in a common area. Staff members walking by warned the interviewer to be careful because S was violent.

There are residents currently living at Crescent Green that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

5. GlenCare of Mount Olive

- GlenCare, located in Mount Olive, NC, is an Adult Care Home licensed for 121 residents. On the day of the student visit, it had approximately 50 residents, 50% of whom had mental illness. Resident ages varied widely from early thirties to late nineties.
- The lack of air conditioning, gaping holes where window units had been removed, dim lighting, sparse furnishings, and the residents' fear of the staff and administrator gave GlenCare a very institutional and frightening feel.
- Residents' interaction with the community was limited to facility visitors, medical appointments, and walking to a nearby convenience store. Although the facility had a van, residents reported it often needed repairs and had broken down in the past, making outings few and far between.

Facility:

Mount Olive is a small, rural town in eastern North Carolina with a population of approximately 5,000. The facility did not have air conditioning and was very hot and muggy. The administrator blamed the temperature on residents, claiming they turned on the heat. One wing of the facility was empty and the window-mounted air conditioners that had been in the wing had been removed, leaving gaping holes open to the outdoors. Residents complained that bugs and animals entered through the holes. The hallways were dimly lit and the common areas were cramped and cluttered. The game room had broken wood with nails in it on the floor. The common areas were sparsely furnished, and the only furniture present was old and uncomfortable. The bedrooms were fairly large, and residents were able to decorate their rooms as they please. The halls and bathrooms looked and smelled dirty, and a number of bathrooms were out of order or locked and unavailable for use. Some individual rooms had private bathrooms. Others had only toilets and mirrors. The dining area was reminiscent of a cafeteria because the residents lined up and staff placed food on plastic dishes.

Staff:

Residents accused staff members of abuse and neglect. Neither the staff nor the administrator were observed interacting with the residents. The residents seemed intimidated by the staff. The administrator followed the visiting students around, restricting private interaction with the residents.

Residents:

Residents at GlenCare are between the ages of thirty-three and ninety-nine. One-half of the residents have a diagnosis of mental illness and the remainder have a primary diagnosis of Alzheimer's Disease. Many of the residents had difficulty with mobility, and of these many were left lying in bed, undressed or with open gowns. Residents were free to come and go at any hour as long as they signed in and out. The unlocked doors allowed residents to spend time in the front and back yards. Many of the activities were religious or physical. Many residents had limited mobility, making it difficult for these residents to participate in the few physical activities provided by the facility. During the student visit, residents were primarily observed smoking, pacing up and down the hallway, standing in line, or lying in bed.

Most residents feared the administrator and staff, refusing to talk to students when either was present. When students were able to speak to residents in private, most expressed fear of the administrator and staff. C, the President of the Resident Council, told students that most residents would not participate in the council for fear of retaliation from the administrator and staff. One student was speaking with B, and when the administrator arrived, she quickly disengaged from the conversation, wanting to move on so she was not seen speaking with him.

R, a resident in her 70's, said that staff-turnover, neglect, and general living conditions were the main problems at the facility. R told students she had been retaliated against after she had complained about GlenCare. The administrator had threatened to evict her, had gone through her things, and ordered her to get rid of some of her personal belongings. R was forced to share a room with a roommate, even though her roommate's boyfriend often stayed in their room, making her very uncomfortable. R told students that another resident had become ill, wandering the halls for weeks, screaming and crying for her mother, before staff took her to a doctor. She

was diagnosed with a severe Urinary Tract Infection, an uncomfortable and painful condition that could have easily been treated with antibiotics and alleviated her discomfort much earlier. R said that staff were unhappy to work there, work multiple jobs, and often do not stick around for long. She said staff have thrown medicine bottles at residents when they are upset and threatened to evict residents in retaliation for reporting abuse. R's bed dry-rotted and fell apart beneath her, leaving her mattress lying on the floor. R is unhappy with her life in the Adult Care Home and said she would prefer placement in the community.

B, a 30-year-old GlenCare resident, said that she used to be employed as a registered nurse. B has a driver's license, can cook and clean, expressed a desire to live independently, and appeared capable of doing so. She had been in two bad car accidents and uses a wheelchair as a result. Those interviewing B believed that she may have a mental illness or a traumatic brain injury. However, B could likely be served in a community placement.

There are residents currently living at GlenCare that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

6. Greystone Manor

- Greystone Manor, located in Red Springs, NC, is an Adult Care Home licensed for 81 residents. On the day of the student visit, it had approximately 70 residents, nearly all of whom had mental illness. The administrator told students that most residents were between forty and fifty years old.
- Clean hallways and rooms, a well-furnished dining room, more personalized and less institution-like rooms, and a mini-library made this facility feel less like an institution than most facilities visited. However, coded and locked doors, constant announcements over the loudspeakers, and a lack of organized activities reminded students and residents of the facility's institutional feel.
- Residents' interactions with the nearby community were limited to facility visitors and medical appointments. Residents reported that there had been an outing to a bowling alley in the past and a trip to Wal-mart, but during these outings, residents only interacted with members of their group.

Facility:

Red Springs is a small town in Robeson and Hoke counties in eastern NC with a population of approximately 4,000. The town of Red Springs is approximately three square miles. The facility was well-maintained and clean overall. Some hallways had a slight odor and felt warm and humid. Individual rooms were spacious and had their own air conditioning units. The atmosphere was less institutional than other facilities. Some furnishings were uncomfortable. Handrails along the hallways helped residents navigate the halls. During the student visit, many announcements were made over the facility's loudspeaker system. Most residents were free to sign themselves out, but doors were coded and locked and some residents were not given the

code. In the past, some residents had gotten stuck in between the coded double doors. A review of the regulatory records for Greystone Manor showed that facility had been cited a number of times since 2006, including failing to provide supervision to a unsafe smoker; failing to provide supervision or initiating discharge of a resident with history of aggression who subsequently sexually assaulted another resident; failing to initiate CPR on a resident found unresponsive; failing to thicken liquids as ordered for two residents; and failing to correctly apply restraints to a resident.

Staff:

The staff was observed to have little interaction with the residents. Many staff appeared idle even though students noticed a number of residents clearly needing assistance getting around or help with daily tasks such as changing their linens. Several residents complained about poor treatment by staff.

Residents:

Although Greystone Manor had less of an institutional feel in some ways than other facilities, residents were still generally unhappy with life at the facility. Residents primarily complained about boredom and the lack of activities or community involvement. During the student visit, residents were primarily observed smoking, pacing up and down the hallway, standing in line, or lying in bed. Several residents were “parked” in wheelchairs in the lobby and remained there throughout the visit. The students did not observe any posted activities and the activity room was locked and not staffed. Some residents complained of violence and theft among residents. One resident, D, told students that two residents had committed suicide by walking in front of oncoming traffic on a nearby highway, although this claim was impossible to verify.

D had previously lived in two other Adult Care Homes and had been living in his own apartment until a bicycle accident two years ago. After the accident, D had been placed in Greystone Manor. D did not know what medications he took and told students he did not know the name of his “psychiatric illness,” although he seemed to think he had one. D expressed a desire to live in his own apartment again. Another resident, J, had been hospitalized after a suicide attempt and was later discharged to Greystone Manor. J stated that she can cook and do laundry and believes she can live more independently with some community support.

There are residents currently living at Greystone Manor that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

7. Lake Pointe

- Lake Pointe, located in Lake Waccamaw, NC, is an Adult Care Home licensed for 80 residents. On the day of the student visit, it had approximately 60 residents, nearly all of whom had mental illness. Residents varied in age from late twenties to early seventies.

- Clean hallways and rooms, a well-furnished dining room, more personalized and less institution-like rooms, and tasteful decorations made this facility feel less like an institution than most facilities visited.
- Residents' interaction with non-disabled individuals or the community was limited to facility visitors and medical appointments. Residents reported that there were occasional trips to Wal-mart and Dollar General, but during these times residents only interacted with members of their own group.

Facility:

Lake Waccamaw is a small, rural town in Columbus County in eastern NC with a population of approximately 1,500. The town of Lake Waccamaw is approximately three and a half square miles. The building and grounds are clean, well-maintained, and clearly designed for the comfort and accessibility of residents. Highlights include small tables in the dining area that create a less institution-like atmosphere, a wall-mounted hand railing throughout the hallways, and tasteful decoration throughout. The atmosphere is generally warm and welcoming. Announcements for meals and activities tended to disrupt the overall tranquility of the facility.

Staff:

The Lake Pointe staff members were friendly, easily identifiable, and knew all the residents by name. They brought medication to members on a cart, rather than making the residents line up for medication. The facility has apparently improved significantly under new leadership.

Residents:

The facility schedules daily activities, but residents were not engaged in any activities during the student visit. Scheduled activities included church and prayer services, separate women's and men's events, outings to stores, and outings to lakes and parks. Several residents said they really enjoyed the outings, but others said they did not think there was enough to do. Some activities were available at all times, such as a crafts room. However, the crafts room seemed to be poorly supplied and under-utilized.

Many residents felt out of place at the facility, stating that they could not find people with whom they could relate. They were eager to be active in the community and live elsewhere. Many residents expressed a desire to live more independently. One resident, B, appeared very capable of living on her own and expressed a strong desire to do so. B is a hoarder and has a diagnosis of Obsessive-Compulsive Disorder in addition to a minor physical disability. Prior to coming to Lake Pointe she lived independently and still has independent-living skills, as well as a car and driver's license. She was forced to come to Lake Pointe because her home was declared unsanitary by Social Services due to her hoarding. B could live successfully in the community with supportive services.

There are residents currently living at Lake Pointe that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

8. Pinebrook Residential Center

- Pinebrook Residential Center, located in Yadkinville, NC, is an Adult Care Home licensed for 112 residents. On the day of the student visit, it had approximately 89 residents, all of whom had a mental illness. Residents varied in age from late twenties to early seventies.
- Run-down, dirty buildings, sparsely furnished rooms, offensive odors, bad lighting, flies, and crowded rooms made this facility extremely institutional.
- Residents' community interactions were very limited. Residents are able to walk to the Dollar General and to a nearby convenience store, but have no meaningful interaction with non-disabled individuals.

Facility:

Yadkinville is a small, rural town in Yadkin County in western NC with a population of approximately 2,818. Yadkinville is the county seat and largest city in Yadkin County. The Facility consists of two unattached buildings, one of which is male-only housing and the other is co-ed. The buildings were run-down, dirty, and had very poor lighting. Furnishings were sparse and dilapidated. The hallways smelled like urine and the outside area had an even stronger offensive odor. Even though the facility was not operating at capacity, there were as many as three residents in a single room. Several rooms were "under construction." The rooms in use were sparsely furnished, containing only a bed and dresser. Despite "bug zappers" throughout the facility, the students noticed a number of flies. These qualities along with the poor condition of the common rooms, contributed to an overall institutional feel.

Staff:

There were more staff members at Pinebrook than at many facilities and they were also more engaged with residents than those at other facilities. There were some complaints that staff members were idle and lazy, but the students did not observe that firsthand during their limited visit.

Residents:

The residents have a fairly regimented daily schedule that includes set meal times and lining up three times each day for medication. Most residents seem satisfied with the staff members and food, although some complained of excessive rules. Many of the residents had been at Pinebrook for many years, some for over a decade. Several residents had been homeless before coming to Pinebrook. Residents can choose to participate in several different activities including a work program and math classes. At least one major activity is scheduled each day. The work program consists of household chores such as sweeping and mopping, and residents who participate receive credit for the snack shop. Organized community outings such as bowling are also scheduled from time to time. Karaoke was the activity for the day the students visited. Residents can also choose to walk to local stores on their own (a convenience store and a discount store are both within walking distance). Starting in July 2010, the facility plans to provide substantive therapy, including Peer Support, substance abuse counseling, and group/individual therapy. The provider for these services is partially owned by the owner of the facility.

There are residents currently living at Pinebrook that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

9. Pinewood Manor

- Pinewood Manor, located in Ahoskie, NC, is an Adult Care Home licensed for 121 residents. On the day of the student visit, it had approximately 60 residents, 90% whom had a mental illness. Residents varied in age from late thirties to early sixties.
- Comfortable furnishings, cleanliness, the presence of an aviary and garden, and a variety of daily activities made this facility feel less institutional compared to other facilities visited.
- Residents were much more involved in the community than residents at most Adult Care Homes. By allowing residents to spend time at Rachel's House in Windsor, a psychosocial rehabilitation day treatment program, and taking residents on frequent community outings, residents seemed generally happier than those interviewed at other facilities.

Facility:

Ahoskie is a small, rural town in Hertford County in eastern NC with a population of approximately 4,500. The facility is divided into three wings: two open-door wings for men and women primarily diagnosed with schizophrenia, and one locked "special care" unit for individuals with Alzheimer's Disease or dementia. The men's and women's wings were generally comfortable in temperature, furnishings, and cleanliness. In comparison, the dining room was cafeteria-like and had uncomfortable furniture. The furniture in other areas was more comfortable. The open-door wings were generally clean and did not smell bad. Residents had been allowed to creatively paint some of the walls and there were resident-created decorations throughout the open-door wings. The "special care" unit was not nearly as nice as the open-door wings. It had an offensive odor and was unbearably hot. Most of the residents were lying in bed with their doors open. There were bug zappers throughout the facility and flies were everywhere. There were telephones available for residents, but no private telephone area in the special care unit.

Staff:

The staff and administrator were friendly, eager to help, and easy to talk to. They interacted with residents and knew the residents by name. Staff members knew the residents' stories as well as personal preferences about activities, food, etc. Some staff members work exclusively in one wing while others move around.

Residents:

Residents at Pinewood appeared largely satisfied with their living situation. Many cleaned their own rooms and bathrooms and did their own laundry. Activities were posted on a calendar and included bingo, card games, arts and crafts, movies and popcorn, pool, shopping, a therapy dog, croquet, and birthday parties. Permanent fixtures like an aquarium and aviary bring nature indoors, and the facility planned to get a dog or cat for therapeutic purposes. Residents could come and go as they pleased and many took part in community activities such as the Rachel

House where they are able to spend three to four hours per day and remain involved in the community. Staff members take residents shopping, to walking trails, and other outings. A spiritual leader comes weekly to play music, pray, and sing with residents. Residents can also help with gardening around the facility. Residents in the special care unit have a much more limited activity calendar and much less access to activity rooms and outings.

Residents at Pinewood were much happier than those at most facilities. Having daily activities and being allowed to interact with non-disabled community members gave them a sense of purpose and enriched their lives. Even with the activities and amenities at Pinewood, several residents, such as M and C, still desired a more independent living arrangement. M has schizoaffective disorder and C has either a mental illness or a traumatic brain injury. These residents were not unhappy at Pinewood and appreciated the facility, but still wished to live on their own.

There are residents currently living at Pinewood that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

10. Reynolds House

- Reynolds House, located in Winston-Salem, NC, is an Adult Care Home licensed for 112 residents. On the day of the student visit, it had approximately 67 residents, 90% whom had a mental illness. Residents varied in age from late thirties to early seventies.
- Overmedicated residents, loud door buzzers, offensive odors, poor lighting, flies, peeling paint, institutional-style furniture, and a general atmosphere of malaise made this facility extremely unwelcoming and institutional.
- Residents living at Reynolds House have little to no interaction with non-disabled individuals outside of the facility. While many residents are able to check themselves in and out freely, their community interactions are meaningless with no one to facilitate the interaction.

Facility:

Winston-Salem is a medium-sized city located in Forsythe County, approximately twenty miles west of Greensboro, with a population of approximately 197,000. The building and property were in generally poor condition. The doors were equipped with loud, obnoxious buzzers. The hallways were also very loud and difficult to navigate due to poor lighting, very slick floors, and repairmen doing various projects. Residents complained about termites and a roof that leaked. Frequent and unnecessary announcements over loudspeakers contributed to the noise levels throughout the large facility. The furnishings were sparse, old and dilapidated, and there was peeling paint on the walls. The downstairs hallway had flies everywhere. The upstairs area had a very strong and offensive odor. One upstairs shower was shared by 15 residents. Rooms had institutional-style furnishings and hard, uncomfortable mattresses. A courtyard was barren and covered in cigarette butts and ashes. The general feel of the building was very institutional.

Staff:

Staff members were helpful, but tended to follow the students around, making private conversations with residents difficult. Staff members seemed nervous about the students' response to the condition of the facility. While students were present, the staff was attentive to sanitation concerns such as spills, but did not interact with residents very much. Several residents said that the staff did a good job.

Residents:

Reynolds House currently only admits residents over forty years old. However many younger residents admitted before this policy was adopted still reside there. Approximately forty percent of the residents act as their own guardian. These individuals could come and go by checking themselves out of the facility with two week's notice. Many residents were unhappy with their lives at Reynolds House, complaining about bad food, rundown facilities, and drug and alcohol abuse in the facility. Several residents also complained about not having enough money and some were seen panhandling near the facility.

Most of the residents were not engaged in any activity during the visit, although the loudspeaker did announce that popcorn, drinks, and bingo would be provided. During the student visit, residents were primarily observed smoking, pacing up and down the hallways, standing in line, or lying in bed. A large number of residents displayed symptoms of overmedication including tardive dyskinesia, dilated pupils, tremors, anxiety, restlessness, and confusion. Several residents complained of being bored, feeling overly restricted in their activity, or feeling fearful of other residents. One resident said he was beaten up by another resident. Students observed residents fighting upon their arrival at Reynolds House. One resident said that people in the facility live a "gang lifestyle."

S, a resident with bipolar disorder and depression, expressed a strong desire to leave Reynolds House. She has been threatened by other residents and fears for her safety. S would like to live independently, and stated that she can do her own chores and take care of herself. S stated that she has been so desperate to get away from Reynolds House that she voluntarily checked herself into a psychiatric hospital. S would like to go community college and get an education so that she can support herself. Another resident, N, also felt capable of returning to work and independent living. She has schizophrenia and had lived at Reynolds House for two years. She communicated clearly, dressed herself, and did her own shopping. N said she previously worked as a janitor and said she missed having a job. She has a guardian as well as friends and other contacts she has maintained in the community.

There are residents currently living at Reynolds House that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

11. Rosewood Assisted Living

- Rosewood Assisted Living, located in Gastonia, NC, is an Adult Care Home licensed for 48 residents. On the day of the student visit, it had approximately 19 residents, 17 of whom had a mental illness. Residents varied in age from early forties to early seventies.
- Isolation from the community, the barbed wire fence, and the dilapidated facilities made Rosewood very institutional.
- Residents living at Rosewood have little to no interaction with non-disabled individuals outside of the facility. Transportation from the facility is limited to medical appointments. Residents have little community involvement.

Facility

Gastonia is a rural suburb of Charlotte with a population of approximately 70,000. Although Rosewood is located close to the city center, it is surrounded by a barbed wire fence and is set back from the road by a long driveway. It was very intimidating from the outside and looked more like a prison than a home for individuals with mental illness. The building itself is old and in need of repair, but it did appear clean and well-kept. There were no offensive odors and residents generally seemed well cared for. Residents with mobility problems had difficulty accessing the smoking patio because the door to the patio was difficult to open. The facility is operating below capacity, partly because it no longer accepts young residents. Although the facility did have a residents' rights poster, there was no number posted for residents to call in case of a complaint or rights violation. North Carolina regulators have cited Rosewood often since 2008, finding at least five violations with substantial fines.

Staff

The staff members were kind and demonstrated genuine concern for the residents. Residents did not complain about the staff.

Residents

Because Rosewood had experienced problems with violent residents in the past, the facility limits the types of residents that it admits. No current residents had a history of substance abuse or criminal behavior. Residents at Rosewood were generally satisfied with their living arrangements and many did not express a desire to live independently. The facility director noted that most residents were at the facility because of an inability to manage their medications. She believed that many could live on their own if they had assistance with their medication. Other than smoking and watching television, there did not appear to be many activities available for residents. The facility director said that some activities, like bingo, took place regularly. Several residents did say that transportation into town and activities had been recently cut. Previously the center had provided buses to take residents into the community for activities, but currently the facility only provided transportation for medical appointments.

One resident, G, was involved in local church group, which would come pick her up and take her to church once a week. One student spoke at length to a member of G's church who was visiting G during the student visit. The church member stated that G could live alone as long as she received daily assistance with medications. G already received a great deal of support from her church. G only leaves the facility when someone from her church picks her up for church

services. Residents echoed the facility director's opinion that their major barrier to living alone would be medication management. With help taking medications, some of the residents felt that they would be able to live on their own.

12. Shadybrook

- Shadybrook, located in Black Mountain, NC, is an Adult Care Home licensed for 49 residents. On the day of the student visit, it had approximately 22 residents, all of whom had mental illness. Residents varied in age from early forties to early seventies.
- The smaller size, caring staff, and residential setting made Shadybrook appear less like an institution than most Adult Care Homes.
- Residents living at Shadybrook had more opportunity for community interaction than most Adult Care Home residents due to the availability of public transportation.

Facility

Black Mountain is small, rural town near Asheville in Buncombe County with a population of approximately 7,500. Shadybrook is a small, sparsely populated facility, located in the middle of a residential community. Public transportation is accessible from the facility which gives residents more freedom than most Adult Care Home residents. The small size of the facility allowed it to blend in with the residential neighborhood surrounding it, and rocking chairs out front gave the facility a welcoming feeling. However, students noticed black mold at the front entrance of the facility and were told the entrance floods every time it rains. The facility was well-worn but otherwise appeared clean. Shadybrook has been cited for three violations since 2008 for failing to provide prescribed antibiotics to a resident with respiratory congestion; failing to monitor a resident's blood sugar levels or provide the ordered amount of insulin; and failing to ensure that residents did not smoke in their rooms, which led to a fire in the room of a resident who was using oxygen and smoking.

Staff

Staff members appeared to be very active in the residents' lives. In the past, they said they had used their own money to pay for a resident's activities if the resident could not afford to pay. The administrator was particularly involved with the residents and had a good rapport with them. Although the facility currently has a good administrator and staff, the facility has had trouble with both in the past. The previous administrator had stolen residents' income rather than pay for residents' medical bills or the facility's bills and as a result, the facility was struggling to survive. The new administrator fired most of the staff members under the previous administrator because they either refused to take or failed a drug test.

Residents

Residents generally preferred Shadybrook to other Adult Care Homes in which they had lived. One resident, L, said that many residents had chosen to return to Shadybrook after being in other facilities. L complained that he had not been given the hearing aids he needed. L said that even though Shadybrook was nice, he felt disrespected and marginalized by the mental health system in North Carolina.

Another resident, S, appeared younger than the other residents and expressed a desire to live independently. S had taken the initiative to contact the housing authority, and was told he could not live independently because he needed help managing his medication. S did not discuss his mental illness diagnosis. S's needs could likely be served in the community if provided with appropriate support.

One resident had difficulty forming words and communicating verbally. He became frustrated when a student could not understand him and pulled out several internet printouts that explained his condition -- aphasia resulting from a stroke. Apart from his communication disability, the resident appeared able to care for himself.

There are residents currently living at Shadybrook that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

13. The Arc Community

- The Arc Community, located in Jacksonville, NC, is an Adult Care Home licensed for 32 residents. On the day of the student visit, it was at full capacity. All of the residents had a primary diagnosis of Alzheimer's Disease or dementia and a secondary diagnosis of mental illness. There is currently a waiting list for placement at The Arc Community. Most residents were in their seventies, although there were a few residents in their forties and fifties.
- The smaller size, devoted staff and warm atmosphere made The Arc Community appear less institutional than most Adult Care Homes.
- Despite being dually diagnosed with Alzheimer's or dementia and mental illness, residents at the Arc Community had more opportunity for community interaction than residents with less debilitating diagnoses at most Adult Care Homes. Residents often enjoyed a nearby park, went shopping, and often had visitors from the community.

Facility:

Jacksonville is a rural town in eastern NC approximately an hour north of Wilmington. It has a large military presence and a population of approximately 81,000. The building was pleasant, well-maintained, and very clean. There were no bad smells, but the air freshener/cleaner scent was quite strong in areas. The outdoor patio area was nicely furnished and well-maintained as a very nice space for residents. Residents' rooms were spacious and kept at a very comfortable temperature. Staff members would play the piano located in the main living area for the residents' enjoyment. The facility doors were coded and locked and an alarm sounds if anyone attempts to open the doors without the code. The door to the patio area remained open, but a tall fence surrounds the outdoor area to keep residents from wandering off.

Staff:

The staff members had a very positive, warm relationship with the residents. Most knew all residents by name and seemed well-attuned to their individual needs. Students observed staff

members hugging residents and generally treating them with love and respect. On all community outings the facility maintains a 1 to 3 staff to resident ratio.

Residents:

The majority of residents at The Arc Community appeared happy and seemed to enjoy interaction with each other and the staff. Many residents congregated in the common areas, rather than isolating themselves as was common in other facilities. An activities board detailed the months' activities including, daily inspirational, sing-a-long, exercise, bingo, trivia, wine and cheese, card games, resident pick, etc. Classic movies played on nice television sets in several lounge areas. The residents were very involved with the "staff and resident led" activities and snacks. The facility is located across the street from a public park and staff members often take residents to the park for a walk or a cookout. Staff members also take residents shopping and to medical appointments. Residents receive many visits from members of the local community. Rather than having residents line up for medication, staff members deliver their medication. Because of the special characteristics of the residents at The Arc Community, it is not likely that any of the residents are candidates for independent living. The Arc Community appeared to be a facility that was less like an institution with residents treated respectfully and kept engaged in life by a dedicated staff.

14. Walden House

- Walden House, located in Hickory, NC, is an Adult Care Home licensed for 56 residents. On the day of the student visit, it had approximately 45 residents, approximately one-half of whom had a mental illness. Resident ages varied widely from forties to late seventies.
- Although a newer facility, Walden's architecture and coded and locked doors created an institutional feel.
- Residents living at Walden House had limited interaction with non-disabled individuals in the community. Shopping trips to Wal-Mart and occasional bowling excursions did not produce meaningful community interaction.

Facility

Hickory is located in Catawba County in western NC with a population of approximately 50,000. The building appeared fairly new and was reminiscent of a hospital. The facility interior was pleasant and clean. Facility doors were locked and coded, but many residents knew the door codes and were able to move in and out freely. Posters about residents' rights were prominently posted throughout the facility. Residents had few complaints about the condition of the facility. Walden House had been cited with one violation since 2007 for failing to supervise two residents who were confused and disoriented who left the building and crossed a nearby highway.

Staff

The staff members at Walden seemed generally apathetic. Staff members ignored a woman beating on the pantry door, even though she was extremely loud. One resident, B, told students that staff hours had been cut because the facility was below capacity which also limited the number of activities and outings available to residents. B also complained that the facility

psychiatrist was in such high demand when he came to the facility that she was not able to see him when she needed to.

Residents

The facility appeared to offer a lot of activities, such as games, daily devotions, and shopping trips to Wal-Mart. Residents earn “points” by doing chores and then use those points to bid on items like soda or candy. Residents seemed to enjoy these “auctions.” The facility has its own bus that takes residents to and from activities in the community, although residents complained that transportation had been cut recently because the facility was not at full capacity. At mealtimes, residents can choose between menu options. The residents’ main complaint was that the facility no longer allowed pets. Residents expressed the desire for “pet days” during which therapeutic animals could visit them.

B, a resident suffering with depression, also expressed a desire to live on her own, telling a student she could live in a more independent setting with some community supports. B had been told by staff at Walden House that she would lose her Medicaid if she attempted to leave the facility. Another resident, M, told students she was able to drive and enjoyed playing the piano. She has spent time at Broughton Hospital and Banner Elk Hospital as a result of bipolar disorder. M’s needs could very likely be met in a more integrated community setting.

One young resident, T, had previously lived in a supported-housing style arrangement, and wished to return to a placement of that kind. T told students that he had a mental illness but did not want to discuss his diagnosis. Another resident, S, expressed a desire to live more independently and appeared highly functional. He told students he had previously lived in apartments and could do his own laundry and take care of himself if he had some community support. He mainly received assistance with medication management for bipolar disorder, a need that can be served in a community placement.

There are residents currently living at Walden House that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

15. Windsor House

- Windsor House, located in Windsor, NC, is an Adult Care Home licensed for 60 residents. On the day of the student visit, it had approximately 35 residents, the majority of whom have a primary diagnosis of Alzheimer’s or dementia. Residents were mainly over seventy.
- The newer facility, smaller size, attentive staff, and friendly atmosphere made Windsor House appear less institutional than most Adult Care Homes.
- Community interaction for residents living at Windsor House was limited to outings and visits with family and friends.

Facility:

Windsor is a small, rural town in Bertie County in eastern NC with a population of approximately 2,300. The town of Windsor is approximately two and a half square miles. The building is new and generally clean and comfortable inside. Classical music played over the sound system and decorations, including candles in the hallways, made it feel less like an institution. Hallways were quiet and there was a generally restful feeling throughout the facility. The facility doors were locked and coded. The building appeared well-maintained, although the landscaping was somewhat overgrown.

Staff:

The Windsor House staff members were open and helpful during the tour. They answered questions and led students around, but also allowed the students and residents to speak in private. The activities director knew every resident by name, where they were from, and their story. Staff members were dispensing medicine in residents' rooms rather than making them line up. The residents spoke highly of the staff.

Residents:

Every resident at Windsor had a diagnosis of Alzheimer's, dementia, or acquired brain injury (e.g., a stroke), and the majority were elderly. Many of the residents were non-verbal or unresponsive to students. Several residents were parked in wheelchairs in the hallway and appeared unable to move on their own. Residents had little community involvement. They were only able to leave the facility when family and friends visit. Activities for each day were posted and included visiting musicians, sing-along and karaoke, arts and crafts rooms, dolls and cribs, hair salon, and television. There were rocking chairs in a garden area outside that served as a popular area for mobile residents to smoke.

One resident, L, was an obvious misfit in Windsor House. L is in his late sixties and has been living at Windsor House for a year after moving there for treatment of his depression. L reported that he felt much better now that his medication had been adjusted. L feels unhappy and out of place at Windsor because other residents cannot communicate at his level due to their dementia. He wants very badly to live in the community and seems physically capable of doing so. He does his own dressing, grooming, and chores every day and believes he could also cook for himself. Before the visiting student left, L asked them to please help him because he feels like he is in jail.

There are residents currently living at Windsor House that have previously lived in the community with success. Many residents expressed an interest in returning to a community placement, and could be successfully served in an integrated and inclusive community setting.

Conclusion

The investigation Disability Rights NC conducted at fifteen large Adult Care Homes during two-weeks from May 17 to May 28, 2010, revealed a distressing picture of the fractured system of care through which adults with mental illness are falling. The interviews and on-site visits confirmed our fears that the State is warehousing scores of individuals with mental illness in unsuitable and dangerous institution-like facilities, where they lack appropriate care and treatment. Located in remote settings with inadequate staffing, few activities or diversions, and no opportunities for community integration, these institutions are wholly inadequate and illegal. If the principles embodied in the Americans with Disabilities Act and articulated in *Olmstead* are to have any meaning for the unfortunate individuals forced to live in these facilities, the State of North Carolina must make a concerted effort to create more humane options for the residential care of those with mental illness.



Memorandum

To: Disability Rights NC Team Leaders
From: Abuse Neglect/investigations Team
Date: July 22, 2010
Re: Dangerous Conditions in North Carolina's Adult Care Homes

SUMMARY OF FINDINGS

Between October 2008 and July 2009, four residents of North Carolina's Adult Care Homes died as a result of resident-on-resident assaults. Disability Rights North Carolina has learned that all of the residents involved had mental health diagnoses. Disability Rights North Carolina considers all of the people involved in these tragic assaults to be victims of North Carolina's failed policy decision to rely on Adult Care Homes¹ for the primary form of publicly-funded housing for people with mental health disabilities.

An account of each death is included in this memo. All the residents lived in large Adult Care Homes licensed to care for between 56 and 80 people. In each case, one of the residents involved—sometimes the victim and sometimes the aggressor—had a history of exhibiting difficult behaviors. In at least three cases, the Plan of Care and/or FL-2 noted behaviors such as “can be physically abusive and injurious to self and others,” “physical abuse, disruptive behavior and history of being injurious to others,” and “loud and sometimes confrontational.” Community mental health services were involved in three of the situations.

Disability Rights North Carolina also reviewed NC Department of Health Service Regulation (NC DHSR)² surveys at Adult Care Homes with dangerous situations that resulted, in serious violence and injuries. This memo provides the accounts of seven surveys from 2008 forward. In several cases the number of people with mental illness living in the congregate setting was startling: 29

¹ Adult Care Homes are licensed “assisted living facilities” that provide, at a minimum, one meal a day and housekeeping services and provide personal care services to two or more residents. Homes where care is provided to two to six unrelated residents are called Family Care Homes. According to information provided to the NC Institute of Medicine Task Force on co-locations of Different Populations in Adult Care Homes, as of December, 2009, North Carolina had 631 Family Care Homes with 3,533 beds, and 627 Adult Care Homes with 36,564 beds. See Interim Report to the N.C. General Assembly, March 2010, page 69.

² NC DHSR is a division of the NC Division of Health and Human Services that oversees medical, mental health and group homes.

July 29, 2010

out of 50 residents at one facility, and all 32 residents of another. Disability Rights NC found that hospital commitments play a role in both admission and discharge of residents from Adult Care Homes. Adult Care Homes are frequently a repeated hospital discharge destination and are sometimes inappropriate to the needs of the residents. The Adult Care Homes use the involuntary commitment process to remove or discharge a person with mental disabilities, continuing this dangerous cycle.

North Carolinians with mental health disabilities in need of housing do not live in Adult Care Homes because it is considered “best practice.” It is not. Nor did our State make an affirmative policy decision to use our public funds to support large congregate living settings for people with mental health disabilities. It did not. This situation exists because the State failed to have a plan to care for and treat the large number of people de-institutionalized pursuant to the 1999 U.S. Supreme Court ruling in *Olmstead v. L.C.*,³ and has allowed the Adult Care Homes to “fill the gap.” Historically, Adult Care Homes cared exclusively for the elderly in North Carolina. After *Olmstead*, they began accepting people who were being discharged from psychiatric facilities.

The Adult Care Home crisis continues today because the State has failed to adequately address both the need for treatment leading to recovery and the need for safe permanent housing in the community for people with disabilities. The failure of the current system of housing-support for people with mental health disabilities is well documented and has been acknowledged in official state reports for years. The North Carolina General Assembly ordered studies of the problem in 2004 and again in 2007. Many other studies and reports have been commissioned and produced. Currently, a third study ordered by the Legislature is ongoing at the North Carolina Institute of Medicine. So far the reports to the North Carolina Legislature have included band-aid type suggestions such as better screening of residents and better staff training—solutions which will not be sufficient to result in a safe and healthy future for citizens with mental health disabilities in North Carolina, nor achieve the state’s obligation under the Americans with Disabilities Act (ADA) to treat people in the most integrated setting appropriate to their needs.

The four resident-on-resident deaths described in this memo demonstrate it is critical that the state adopt a new approach to housing for people with mental health disabilities. In each of the cases investigated by Disability Rights North Carolina, the “band-aid solutions” identified in the reports to the Legislature (resident screening and staff training) would not have prevented the deadly assaults. In these cases, the problems were known by the facility before the assaults, the resident’s behaviors were identified and North Carolina’s mental health system was altered. The recommendations made to the Legislature fail to confront the root of the crisis: the large scale, publicly-supported transfer of people from hospitals to Adult Care Homes instead of to the community with services and supports.

³ 527 U.S. 581 (1999).

July 29, 2010

North Carolina is at a crossroads in terms of the appropriate use of public funds to support the housing needs of people with disabilities. Four people died while North Carolina spent time and resources on studies with recommendations, many of which have not been implemented. It is time to provide people with the best chance of recovery and a decent quality of life. North Carolina can largely achieve this goal without new expenditures by redirecting state and county money from Adult Care Homes to housing in the community with supports and services. Disability Rights North Carolina urges North Carolina to stop endangering our citizens by maintaining the status quo, and to start moving people with disabilities out of Adult Care Homes and into housing with greater community integration and better opportunity for recovery.

In addition to the deaths, Disability Rights North Carolina found other dangerous conditions and incidents at Adult Care Homes. These problems, including resident-on-resident assaults that resulted in non-life threatening injuries, raise substantial concern regarding the safety of residents in Adult Care Home settings.

I. Dangerous Conditions in North Carolina's Adult Care Homes.

In 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C.* that it is illegal for states to segregate individuals with disabilities in institutions in order to receive long-term services. At that time there were few places in North Carolina for low-income people with psychiatric disabilities to live. Using public funds to pay for part or all of the cost of a bed, Adult Care Homes, which historically cared for the elderly, became an alternative to homelessness for thousands of North Carolinians discharged from our hospitals and institutions. This movement of people with mental health disabilities from state institutions into private Adult Care Homes was **not** the product of careful planning. The 2005 *Study of Issues Related to Persons with Mental Illness in Long-Term Care Facilities, General Assembly of NC Session 2004 House Bill 1414 section 10.2(a) and (b)* ("2005 Report") well describes what happened:

"When the locus of care for persons with mental illness first shifted from the large state hospitals to the community decades ago, there were few residential options available to persons with mental illness, and many adult care homes stepped forward to fill that gap, providing shelter for those who had none..."

North Carolina's current mental health reform effort is designed to improve the state's capacity to meet the needs of persons with mental illness according to evidence based practices, but many with mental illness continue to live in long term care settings because there are not yet more appropriate alternatives available to them in their communities..."

*[L]ong term care facilities have been an unavoidable choice for many individuals with mental illness, **despite the fact that these facilities are not designed to provide psychiatric***

treatment or the rehabilitative services to allow persons with mental illnesses, particularly younger adults, to achieve a greater measure of independence.”

(2005 Report, page 4, emphasis added.)

Today, North Carolina Adult Care Homes continue to be the major component of the residential placement array for citizens with mental health disabilities. In 2004, five years after the U.S. Supreme Court decided *Olmstead*, North Carolina Department of Health and Human Services (NC DHHS) found that more than 40 percent of the Adult Care Home population carried an active diagnosis of mental illness.⁴ A yet to be released *Study of North Carolina’s Adult Care Homes, Family Care Homes, Group Homes and Permanent Supportive Housing for People with Disabilities in North Carolina* ordered by NC DHHS and prepared by Technical Assistance Collaborative, Incorporated (TAC) concluded in 2008 that more than 5,000 adults with mental health disabilities were living in North Carolina’s Adult Care Homes. Data reported in the March 1, 2008, “*Study of Rules and Regulations Regarding Housing Individuals with Mental Illness in the Same Facility Vicinity as Individuals without Mental Illness*” General Assembly of NC Session 2007, Session Law 2007-156, Senate Bill 164 (“2008 Report”) revealed 6,234 individuals with a primary diagnosis of mental illness resided in Adult Care Homes, including Family Care Homes, and 2010 data presented to the NC Institute of Medicine Task Force revealed 6,432 persons with mental illness were residents of North Carolina Adult and Family Care Homes.

Thousands Live in Dangerous Conditions

Despite the important 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 NC DHHS under rules adopted by the State Medical Care Commission. Staffing requirements and qualifications are not designed for the care of residents with mental health needs. For example, during first and second shifts an Adult Care Home with 41 to 50 residents is only required to have three staff present at the Home (1:16.6 ratio). At night only two staff need be present (1:25 ratio). 10A N.C.A.C. 13F.0604, Personal Care and Other Staffing. By contrast, mental health group homes are limited to a total of six residents, a ratio of 1:6. Additionally, staff at a mental health group home are supervised by a Mental Health/Developmental Disability/Substance Abuse Services qualified professional. 10A N.C.A.C. 27G.0104, .0204, .5603.

For some time there have been serious concerns raised about residents with mental illness who reside in Adult Care Homes. State policy makers have repeatedly been informed of the inadequacy of North Carolina’s response to the *Olmstead* mandate and to the de-institution of

⁴ “*Adult Care Home Mental Health Needs Assessment Report of Findings*,” *First Health*, July 15, 2004, referenced in “*Final Report and Recommendations of the Study of Issues Related to Persons with Mental Illness in Long Term Facilities*,” December 1, 2005, page 3.

North Carolinians with mental health disabilities. Consider the statements in the following study reports commissioned by our Legislature in 2004 (“2005 Report”) and again in 2007 (“2008 Report”):

Findings from the 2005 Report

- *“The issue of serving the mental health needs of long term care residents is not new and pre-dates the current re-design of the publicly funded MH/DD/SAS system. **In fact, state agencies and long-term health care providers have been engaged in a discussion of how best to provide this care for a decade or more.** [Page 3, emphasis added.]*
- *“While many persons with a diagnosis of mental illness reside in long term care settings without difficulties, others, because of the nature of their illness, inadequate treatment, or lack of expertise among facility staff, can exhibit behaviors that can impact other residents and/or pose a potential safety risk to staff and residents. [Page 5.]*
- *“...[I]ndustry representatives report that these facilities are increasingly struggling with safety issues related to a growing number of residents with challenging behaviors that have an impact on the safety of residents in the facilities. [Page 5.]*
- *“In adult care homes some older adult residents . . .cite concerns about the safety and the vulnerability of other older adults due to reports of behavior problems such as verbal/physical/sexual abuse by some younger residents. [Page 6.]”*

Findings from the 2008 Report

- *“Over the past several years, [NC DHHS] has worked to improve the care to individuals who have mental illness and are residing in adult care homes, while acknowledging that other housing and treatment options need to be available to serve this population.” [Page 2.]*
- *“The Department recognizes that there are serious concerns about residents with mental illness who are currently in assisted living facilities and who exhibit behaviors related to their illness.” [Page 19.]*
- *“The Division of MH/DD/SAS continues to explore the types of housing and residential services that can appropriately meet the varied needs of adults with mental illness [that] are not currently being met in long term care settings in North Carolina.” [Page 19.]*

Disability Rights North Carolina’s report of four resident-on-resident deaths over a ten-month period (October 2008 through July 2009) illustrates that North Carolina can no longer wait to

launch a new direction for housing people with disabilities. The eight people involved in these assaults are all victims of North Carolina's decisions, time and again, to provide only band-aid solutions for this dangerous situation.

The 2005 Report contained five recommendations including: implement a screening system prior to admission; implement an automated assessment and care planning system; and conduct a study to inform the development of a residential continuum designed to meet the needs of persons with mental illness. Only the recommendation for a study of housing needs materialized, and NC DHHS contracted with Technical Assistance Collaborative, Inc. (TAC) to provide recommendations and a plan for implementation of changes to North Carolina's residential service array. For reasons unknown to Disability Rights North Carolina, TAC's Draft 3 Report, dated January 11, 2009, has not been released by NC DHHS.⁵

The 2008 Report to the Legislature again recommended a screening and assessment system as well as staff training. The focus of the 2010 NC Institute of Medicine Task Force includes: how to appropriately identify/screen people for behavioral health disorders; and training of adult care home staff.⁶ For Disability Rights North Carolina, one more recommendation for a screening tool or for more staff training is not an adequate response to the situation. Rather than applying another band-aid, North Carolina must immediately adopt a new approach to disability housing policy.

Implementing Best Practices for Recovery

An equally important reason for a new approach is the dignity and recovery needs of people with disabilities. It is well-acknowledged by state officials that the current housing of people with mental health disabilities in Adult Care Homes is not best practice and is not aimed toward recovery for the persons with mental health disabilities. Again, consider the statements of North Carolina state agencies:

- *"Adequate and appropriate living arrangements have always been part of successful clinical treatment, habilitation and rehabilitation plans for persons with disabilities."*⁷
- *"...[M]any with mental illness continue to live in long term care settings because there are not yet more appropriate alternatives available to them in their communities."*⁸

⁵ DRNC learned of the TAC report and requested and obtained a copy through N.C.'s Public Records Law. In April 2010, a DHHS official confirmed the TAC report has not been "finalized or released."

⁶ See IOM Task Force "Interim Report to the North Carolina General Assembly, March 2010."

⁷ *Welcome Home! A Report on Housing North Carolinians with Disabilities, Task force on Housing, NC Commission for MH/DD/SAS. Presented August 2004.*

- “Permanent supportive housing is the recognized best practice in meeting the housing needs of the majority of persons with disabilities.”⁹

Nationwide, “permanent supportive housing” is recognized as the best-practice housing policy for people with disabilities. Permanent supportive housing allows persons with disabilities to live in safe and affordable community housing that is linked to individualized supports and services. While the type and intensity of services will differ according to the needs of the individual, the need for decent affordable housing units in the community is common across all disability populations.¹⁰ Moreover, the Americans with Disabilities Act and the *Olmstead* decision require that services and supports be provided in the most integrated, appropriate community setting. Supportive housing in the community is essential to improving personal outcomes, improving the quality of life for people with disabilities in North Carolina, and meeting the state’s legal responsibility under the ADA to treat people in the most integrated setting appropriate to their needs.

The Role of the “State/County Special Assistance for Adults” Fund

In North Carolina the large scale placement of low income people with mental health disabilities in Adult Care Homes is facilitated by a state and county funding program commonly called “Special Assistance.” Special Assistance provides a cash supplement that enables low-income individuals to reside in Adult Care Homes. The program was established 60 years ago as the “State Boarding Home Fund for the Aged and Infirm.” *Preface, Special Assistance for Adults, NC DHHS Manual*. The fund, now named “State/County Special Assistance for Adults,” **supplements** the resources the resident has; this is often the federal Supplemental Security Income (SSI) benefit received by people with disabilities and the elderly. Thus it is State and County funds through Supplemental Assistance that actually pay for housing of many people in Adult Care Homes, including people with mental health disabilities.

The Special Assistance payment is funded by 50 percent county dollars and 50 percent state dollars. Effective October 1, 2009, the basic rate the North Carolina General Assembly set for residents to pay the facility each month is \$1,182. The amount contributed to the Adult Care Home by Special Assistance is the difference between the resident’s monthly income and \$1,182, plus \$46.00 for the resident as personal allowance for clothes, co-pay requirements, and other incidental expenses. The standard federal SSI payment in 2010 is \$674.00 a month.

⁸ 2005 Report, page 4.

⁹ *Final Plan for Efficient and Effective use of State Resources in the Financing and Development of Independent and Supportive-living Apartments for Persons with Disabilities, prepared by NC DHHS and The North Carolina Housing Finance Agency, March 1, 2009, page 3.*

¹⁰ See “Interim Plan for Efficient and Effective use of State Resources in the Financing and Development of Independent and Supportive-living Apartments for Person with Disabilities,” for endorsement of this model as best practice for North Carolina, submitted to the Joint Legislative oversight Committee on MH/DD/SAS, March 1, 2008.

If the resident had no other income, the Adult Care Home would be paid \$674.00 by the resident and \$554.00 (\$508.00 toward the basic rate and \$46.00 for personal allowance for the resident) by the State/County Special Assistance funds. The Special Assistance budget for 2007-2008 exceeded \$148 million for more than 30,000 recipients.

The Technical Assistance Collaborative (TAC) Study

The 2005 Report to the North Carolina General Assembly recommended a study be funded to inform the development of a residential continuum designed to meet the needs of person with mental illness, and the 2008 Report confirmed that NC DHHS contracted with TAC to conduct the study and offer recommendations. Founded in 1992, TAC is a non-profit organization that offers interdisciplinary teams of national experts to identify and offer solutions in areas of health, housing and social services. From 2006 to 2009, TAC worked with NC DMH/DD/SAS to conduct a wide range of consulting and technical assistance services for the Division and its stakeholders, including the study of housing needs of people with disabilities.

In response to the 2005 Study recommendation, TAC was tasked to study the number of people needing service and treatment now residing in Adult Care Homes, and identify housing and service models that are evidence-based to help address the needs in North Carolina. TAC performed that study and delivered a draft "*Study of Adult Care Homes, Family Care Homes, Group Homes and Permanent Supportive Housing for People with Disabilities in North Carolina*" in January, 2009. TAC focused on individuals with disabilities who need a place to live and need services and supports to make community living successful. These individuals frequently end up receiving Special Assistance to reside in Adult Care Homes because there are no other options available.

TAC found that "North Carolina *already* spends substantial public resources for the current set of facility based housing services, and that *opportunities exist to redirect a portion of those resources into best practice models of housing and services without the necessity of new appropriations.*" (TAC Draft Report at p. 5 (emphasis added)). TAC concluded that the amount of funds North Carolina spends per person for facility-based care would be sufficient in many cases to cover the housing subsidy and housing-related service costs for individuals to live in permanent supported housing in the community. In fact, because the State does not spend sufficient funds on housing subsidies and housing-related service costs, TAC determined that the State's policies were in violation of *Olmstead*. TAC acknowledged that there are coordination, statutory and budgetary hurdles to be overcome in North Carolina, but concluded "it is not necessarily a lack of overall financial resources that prevents people with disabilities from having the option of living in integrated community settings." (TAC Draft Report, p. 36.)

Conclusion

Housing of people with mental health disabilities in Adult Care Homes not only creates dangers for all the residents, it also denies people the best chance for recovery and for a decent quality of life. The official studies and reports cited by Disability Rights North Carolina demonstrate that North Carolina understands it is funding dangerous and clinically unsupportable congregate housing for people with disabilities. Every report since 2004 has acknowledged the mis-placement of large numbers of people with mental health disabilities in Adult Care Homes—a situation that violates the integration mandates of the Americans with Disabilities Act and the U.S. Supreme Court’s *Olmstead* decision. NC DHHS recognizes that for many the best practice outcomes will flow from independent housing opportunities with full community integration. A new housing policy will both promote recovery and bring North Carolina in compliance with its obligation to provide services “in the most integrated setting appropriate for the needs of the individual.”¹¹

Adult Care Homes are neither designed nor equipped to meet the service needs of people with mental illness. Moreover, the State’s resources should follow and support the best recovery and integration practices available, rather than support dangerous congregate living settings in Adult Care Homes. North Carolina is at a crossroads in terms of the treatment and care of people with disabilities who are dependent on public sector support for their basic housing and service needs. It is time that North Carolina embrace the ruling in *Olmstead* that integration is fundamental to the purposes of the ADA. It is time for North Carolina to provide community-based services rather than institutional placements for individuals with disabilities. North Carolina must reshape the housing possibilities for people with disabilities now and commence to move people with mental illness out of Adult Care Homes and into greater community integration and recovery.

The state’s failure in this regard has resulted in preventable deaths and injuries to citizens in these homes. While official state reports since 2004 have called for developing a full continuum of housing for people with disabilities in the community, thousands of people with mental health disabilities remain in Adult Care Homes and remain without a community alternative available. Band-aid efforts such as resident screening and staff training are not a solution. Disability Rights North Carolina urges North Carolina policymakers, including the ongoing NC Institute of Medicine Task Force, to embrace new concepts for housing people with disabilities rather than focus on improved screening and more staff training.

¹¹ *Olmstead*, 527 U.S. at 592 (1999).

RECOMMENDATIONS

Supported Permanent Housing

Supported permanent housing is the best practice for meeting the housing and recovery needs of persons with mental health disabilities.

Permanent supportive housing allows persons with disabilities access to decent, safe, and affordable housing that is integrated into the community. Such housing also provides individually tailored and flexible supportive services in the community setting. Nationwide and in North Carolina¹² supported housing is considered the “best practice” for housing people with disabilities because it is successful, cost-effective¹³ and promotes integration, consumer choice and dignity. Since 2002, NC DHHS has partnered with the NC Housing Finance Agency to develop integrated permanent supporting housing across North Carolina. Their collaboration has produced approximately 250 integrated supported housing units each year since 2002, and is considered a model for supported housing development that is now being replicated in other states.

Many official reports commissioned by the State have recommended adoption of supported permanent housing. The 2004 Report *Welcome Home!* recommended using the North Carolina Special Assistance program for individuals with disabilities to reside in the community rather than licensed residential settings. In 2009, TAC made a similar recommendation to use funds to support individuals in supported housing in the community. In their 2009 *Final Plan For Efficient and Effective Use of State Resources In the Financing and Development of Independent and Supportive-living Apartments for Persons with Disabilities*, NC DHHS and the NC Housing Finance Agency urged the creation of supported housing through a tenant-based rental assistance program (TBRA). In 2009, NC DHHS recommended the Legislature continue to fund the expansion of supported housing units, in part by authorizing a Tenant-Based Rental Assistance Program (TBRA). TBRA would operate similar to the Special Assistance fund, currently used primarily to place

¹² Final Plan for Efficient and Effective Use of State Resources In the Financing and Development of Independent and Supportive-living Apartments for persons with Disabilities, NC DHHS and the North Carolina Housing Finance Agency, submitted to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance Abuse Services March 1, 2009, page 3 (After surveying practices nationwide and conducting additional research NC DHHS concluded in this Report that permanent supportive housing is the best practice in meeting the housing and recovery needs of people with mental health disabilities.).

¹³ The Cost-Effectiveness of Supportive Housing: A Service Cost Analysis of Lennox Chase Residents. UNC-CH School of Social Work, Jordan Institute for Families, 12/2007.
<http://www.ncdhhs.gov/homeless/pdfs/lennoxchase.pdf>

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people in Adult Care Homes. Unfortunately, the TBRA program was not implemented by the legislature in the 2009-10 legislative session.¹⁴

Disability Rights North Carolina recommends that North Carolina adopt these time-tested recommendations and establish concrete targets and timetables for moving a set number of Adult Care Home residents into more integrated settings with services and supports. It is now 11 years since the *Olmstead* decision, yet people with disabilities are still segregated in large facilities. North Carolina must initiate a new approach to the deinstitutionalization of people with mental health disabilities. It is time, before there are more deaths, to move people with disabilities out of Adult Care Homes and into safe community housing.

¹⁴ Supportive housing was further hampered in 2010 because 187 planned units of supported housing had not yet been completed. The budget for subsidized units was accordingly reduced by \$561,000.

FOUR DEATHS IN TEN MONTHS

Death of LM, CASE #1.

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

On December 27, 2008, during the start of second shift checks, LM was found in his room face down and unresponsive. His roommate, MG, was naked and in a sitting position on top of LM. MG said he was tired of being accused of stealing. Paramedics were called. LM was pronounced dead at the scene. MG was charged with second degree murder. In 2010 he was convicted of voluntary manslaughter. He received a suspended sentence and was placed on 60 months of supervised probation.

LM, 69-years-old, had been a resident of the 80 bed Adult Care Home for just over a year at the time of his death. LM had a diagnosis of paranoid schizophrenia. According to the NC DHSR investigation complaint survey, LM was known to accuse other residents and staff of stealing his belongings, and was described by the facility manager as loud and sometimes confrontational. The local mental health team was involved in LM's care and had provided training to facility staff in ways to redirect and de-escalate LM. Records show that LM was receiving his medication as prescribed.

MG, 60-years-old at the time, had lived at the facility since 2000. He was diagnosed with schizophrenia and dementia. Records show he received his medication as prescribed. MG was described by the facility manager as quiet and non-confrontational. Because of MG's calm demeanor he was eventually paired as LM's roommate. One resident stated that he saw MG walk away from LM when LM began to argue.

The NC DHSR investigation found that the facility failed to meet minimum staffing requirements. The facility scheduled three direct care staff for 1st and 2nd shift for the more than 60 residents when the Rule required a minimum of four direct care staff per shift for that size population. According to the complaint investigation report, "it could not determine that residents failed to receive adequate staff supervision."

Death of JL, CASE #2.

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

JL was 27-years-old and 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 sometime before 1:00 pm. JL and staff were on the porch of the facility when another resident, DE, who was 55-years-old and diagnosed with schizophrenia, came across the porch and started swinging his metal cane at JL. DE was angry because someone told him that JL had

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cursed and kicked his dog. JL dodged some swings but was then hit several times in the head, shoulder, and arm by the cane. DE continued to hit JL with the cane until staff separated the residents. Later, staff offered JL a bag of ice when he complained of head pain and staff observed a knot on the back of his head.

According to the facility report of death sent to NC DHSR, after the attack JL continued to be “verbal and agitated.” A facility administrator traveled to the Magistrate’s office and petitioned for the involuntary commitment of JL. He was picked up by law enforcement and transported to a local hospital for evaluation for the commitment. During his evaluation for involuntary commitment, JL began vomiting. A test showed a large hematoma in the right brain. JL was airlifted to NC 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 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. The bicycles are seen still upright when JL fell.

DE has a criminal history for assaults and was arrested later the same day as the attack on JL for threatening to hit an employee with his cane. Later DE was additionally charged with the second degree murder of JL. In 2010 he was convicted of voluntary manslaughter and sentenced to 129 – 164 months in the NC Department of Correction.

A complaint investigation survey was conducted by Surry County Department of Social Services and NC DHSR. No violation of rules was substantiated.

Death of RS, CASE #3.

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

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

RS was reported to be a quiet person and was receiving treatment for several heart-related illnesses. DS was diagnosed with paranoid schizophrenia with chronic alcohol and cannabis abuse in remission. In July 2009, DS was receiving mental health services and medication for his mental illness. DS’s care plan revealed his behaviors included a history of physical abuse, disruptive behavior and a history of being injurious to others.

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According to NC DHSR records, DS had a history of violent outbursts and fellow residents at the facility were afraid of him. It is reported that DS was verbally abusive towards the facility staff, using offensive slang and cursing. DS is charged with second degree murder and has been jailed since the attack. Charges remain pending.

According to the NC DHSR report, 29 of the 50 residents residing in the facility had diagnoses which included mental illness. The Adult Care Home had received 29 police calls from January 2008 to July 8, 2009. According to the reports, these calls included three assaults and four attempted suicides. According to the facility staff, outbursts, violence and threats of violence were not uncommon at the facility.

NC DHSR found seven deficiencies as a result of the investigation and issued Type A Violations with a Directed Plan of Correction, including: identify all residents who have behavioral symptoms that require supervision and develop individual care plans to assure the supervision is provided; provide supervision of residents in accordance with residents' assessed needs and current symptoms; develop and implement procedures to ensure accurate assessment of new and current residents specific to identification of at-risk behaviors; and provide training to staff by a mental health specialist.

The Death of WD, Case #4.

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

On October 26, 2009, WD, a 67-year-old resident, was killed by another resident of the facility who severely beat him with his hands and feet. The other resident was KH, who is 43-years-old. It is reported that the fight was over \$4.25. Both residents are reported to have mental health disabilities. WD received multiple injuries and was taken by EMS to a hospital where he died three days later on Oct. 29, 2009. The final autopsy diagnosis notes multiple blunt injuries of the face, head and neck, described in a newspaper report as a "cranial bleed." According to information gathered by Disability Rights North Carolina, facility staff were in a nearby room when the beating occurred.

KH was arrested on October 29, 2009 and charged with the murder of WD. As of the date of this report KH was still in the jail and the murder charge was still pending.

The facility filed a "Report of Death to DHHS" listing the cause of death as "unknown." On the death reporting form, the facility described the events surrounding the death including that WD "was involved in a[n] altercation with another male resident;" that WD received "multiple injuries requiring immediate medical attention;" and that he was "transported to a hospital by EMS." According to staff at the NC DHSR, because the facility wrote that the cause of death was "unknown" in the box on the form titled

“Cause of death,” NC DHSR did not forward the report to Disability Rights North Carolina as required by law.¹⁵ Disability Rights North Carolina did not learn of WD’s death until April 2010.

According to the November 2, 2009 complaint investigation report: “NC DHSR staff assisted the local department of social services with their complaint investigation¹⁶ related to a resident death. Based on the record review, staff, resident and resident family interviews there were no findings to substantiate the complaint.”

II. Accounts of Non-Lethal Assault and Fear in North Carolina Adult Care Homes

Disability Rights North Carolina also found incidents of resident-on-resident assaults that did not result in death but raise substantial concern regarding the safety of residents in Adult Care Home placements. The circumstances in the seven Adult Care Homes described below are documented in state investigations obtained by Disability Rights North Carolina. Disability Rights North Carolina’s goal is not to single out particular homes or operators, but rather to demonstrate the depth of the problems created by housing many people with mental illness in Adult Care Homes. Therefore we have only generally identified the location and size of each facility.

In a 40-bed Adult Care Home in a large North Carolina city, a NC DHSR 2008 survey found three (3) residents who repeatedly physically assaulted other residents and staff. There had been 58 calls to 911 from the facility over an eight-month period: 21 for disturbances, eight for fights or assaults and four were alcohol or drug related.

Resident #2¹⁷ was diagnosed with schizophrenia-paranoid type and was receiving ongoing mental health services. In five months, Resident #2:

- physically assaulted another resident who required emergency room treatment (4/17/08);
- physically assaulted another resident who “tried to stab him” (4/18/08);

¹⁵ N.C.G.S. 131D-34.1 requires facilities to report to NC DHSR when a resident’s death results from violence, accident, suicide or homicide, and further requires NC DHSR to notify the state Protection and Advocacy system, Disability Rights North Carolina, of the report of death.

¹⁶ The NC DHSR Complaint Intake Unit receives complaints regarding the care and services provided to patients/residents/consumers by the health care facilities/agencies/homes they license. Each complaint is prioritized for investigation according to the seriousness of the situation. Complaints about Adult Care Homes are forwarded to the local Department of Social Services for investigation. On a case-by-case basis staff from NC DHSR may also be involved in the complaint investigation regarding an Adult Care Home.

¹⁷ The residents are referred to in this report in the same way NC DHSR referred to them in its surveys.

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- was arrested, charged with assault on a handicapped person and readmitted to the facility the next day (5/6/08 and 5/7/08);
- assaulted a resident (6/29/08);
- was involved in a loud argument with another resident (9/4/08); and
- attempted to injure another resident (9/11/08).

Other residents reported they were afraid of Resident #2. The administrator reported the resident's behavior in the resident's records, thus making his transfer more difficult because few facilities would be willing to admit a resident with known violent propensities which made alternative placement difficult.

Resident #5, diagnosed with schizophrenia and mild retardation, shouted obscenities, threw a binder, and pushed a door into a staff member.

Resident #10 was diagnosed with paranoid schizophrenia and borderline intellectual functioning. He was referred to mental health for verbal abuse, hollering, yelling, screaming and angry outbursts. The resident physically fought with his roommate over a cigar and burned the facility walls in an attempt to "get rid of Jesus who is a faggot." Later he fought with two residents. Resident #10's Community Support case manager revealed she saw him weekly, that he periodically had delusions about religious figures, and will find a lighter and try to burn the walls, getting "Jesus out." She stated she felt the lax supervision at the Adult Care Home was not in the resident's best interest. The case manager was working on alternative placement but was having little success.

NC DHSR issued a Type A violation¹⁸ and ordered, in a Directed Plan of Correction,¹⁹ that the facility immediately review the FL-2s of all residents and evaluate their service and care needs to determine if each resident's behavior can be addressed with the level of supervision in the facility.

In a 48-bed Adult Care Home in central North Carolina NC DHSR found in a 2008 survey that *all 32 residents of the facility had a diagnosis that included mental illness*. NC DHSR found the

¹⁸ A Type A violation means a violation of the regulations, standards and requirements governing Adult Care Homes that results in a death or serious physical harm or results in a substantial risk that death or serious physical harm will occur. N.C.G.S. 122C-24.1.

¹⁹ 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.

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facility failed to discharge three residents whose behaviors placed themselves and/or others at risk for serious physical harm and/or death.

Resident #9 told staff she was seeing things, she was talking to herself and slapping at staff and residents. The resident was not added to a list of “aggressive” residents who should be checked every 15 minutes until days later—only after she cut another resident on the arm. Later, Resident #9 further decompensated (“very paranoid, trying to harm others, thinks people after her”). The resident was sent to the local hospital for evaluation for involuntary commitment. She was not committed and was returned to the facility.

Resident #2 was documented to have aggressive behaviors, elopements and psychotic breaks. Resident #2 tried to hit staff with a stick and said he wanted to kill himself. The resident was taken to the hospital for evaluation for involuntary commitment and returned the same evening. The next day Resident #2 was throwing books into the hallway. He took his roommate’s clothes and shoes out of the closet and threw them on the floor. Then the resident began throwing chairs. Resident #2’s physician was not notified *until one month later* when a change in medication orders was made. Over the course of two months Resident #2 was involuntarily committed twice and returned to the facility. Resident #2’s guardian planned to pursue alternative placement.

Resident #8 had a history of chronic paranoid schizophrenia. On June 17, 2008, he was admitted to the hospital for stabilization after acute exacerbation of his paranoid schizophrenia, including self injury. Resident #8 was discharged back to the facility seven days later. At the facility he refused some medication and eloped, returning seven days later. At that time, Resident #8 kicked and beat on the door asking for money. The facility called Crisis Services, which told the facility to call the police. Resident #8 then eloped and, upon return the next day, exhibited inappropriate sexual behavior toward another resident. The next day Resident #8 was involuntarily committed. The local Mental Health Agency filed for guardianship as the family had not responded to paperwork sent earlier. The case manager was to seek an alternative placement.

NC DHSR found the facility failed to provide supervision to meet the needs of the residents, in some cases exacerbating their mental illness leading to injury to self and threatened injury to others. A Type A Violation was issued with a Directed Plan of Correction to immediately review the FL-2s of residents and evaluate their service; care and supervision needs; and to provide services if the facility could meet the residents’ needs. If the facility cannot meet the needs of the resident, NC DHSR directed the facility to provide required discharge notification and establish a Quality Assurance System to assure compliance with the Plan of Correction.

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NC DHSR surveyed a Family Care Home (six beds or fewer) in a large North Carolina city in 2008 and issued a Type A penalty for violation of the Personal Care and Supervision rule. This family care home is no longer in operation under the 2008 name.

Based on review of records and local law enforcement reports, NC DHSR concluded that five out of six client records surveyed demonstrated a need for increased supervision. During a ten month period in 2008, police were called to this small facility 59 times. The nature of the 59 calls to law enforcement included assault (resident attacked staff, sitting on her chest and punching and hitting her in the face and chest, “going after her like some kind of animal”), disturbance, larceny, drugs, disturbance with weapon, threats (one resident would hit another and demand money and cigarettes) and involuntary commitment.

Resident #1’s diagnoses include bipolar disorder and substance abuse. Resident #2 was diagnosed with schizoaffective disorder and mild mental retardation. At the time of the survey, Resident #3, diagnosed with schizoaffective disorder and substance abuse/dependence, was recently hospitalized due to altered mental status from ingesting Zyprexa (antipsychotic) tablets. During the survey Resident #3 refused to eat the soup for lunch fearing the soup had “orange cyanide” in it. Resident #4 was diagnosed with paranoid schizophrenia and health problems. A care plan described Resident #4 as “verbally abusive, physically abusive, resists care, and injurious to self and property.” Resident #6 was diagnosed with schizoaffective disorder, substance abuse and borderline personality disorder.

NC DHSR issued a Directed Plan of Correction requiring the facility to: assess all current residents; develop a plan of care for supervision of any resident whose diagnoses and current symptoms place the resident at risk for aggression; have a plan in place to provide additional supervision to an aggressive/threatening resident to protect others from harm; provide training to the staff on care of persons with mental illness or dementia; and to assure adequate staffing to meet the residents’ needs.

In an 81-bed Adult Care Home in southeastern North Carolina NC DHSR found the following conditions during a 2010 survey:

Resident #1 was diagnosed with schizophrenia, paranoid type, intermittently disoriented, history as a wanderer and verbally abusive. On Dec. 18, 2009, Resident #1 died when he walked into the street and was run over. Resident #1 recently spent four months in a psychiatric hospital, returning to the facility 16 days before his death. At the hospital, Resident #1 received a diagnosis of schizoaffective disorder, lack of support and chronic severe psychiatric illness. The facility did not request or receive the discharge summary. The facility

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only had an FL-2 and a medication administration record. No one from the facility interviewed Resident #1 or reviewed his treatment at the hospital before accepting him back. According to NC DHSR interviews with facility staff, Resident #1 returned to the facility unchanged. Before hospitalization, Resident #1 eloped when angry, hit other residents and staff, and had a history of refusing medication.

After Resident #1 died, the physician employed by the facility stated Resident #1 was not appropriate for the facility due to his severe mental diagnosis. NC DHSR learned during the investigation that the facility did not contact the physician until after Resident #1 returned from his 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 was not called by the facility even after Resident #1 refused medication.

Resident #2, admitted December 2, 2009, had a history of paranoid schizophrenia and developmental disability, and was confused at times requiring re-orientation. Resident #2 was receiving medication for mental illness/behaviors but was not receiving mental health or developmental disability services. Resident #2 did not have a crisis plan. On December 21, 2009, a physician progress note reported Resident #2 was “severely mentally unstable.” Two days later Resident #2 tied a scarf around her neck and pulled twice 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 was unsure the facility was an appropriate setting for the resident.

NC 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.” The Directed Plan of Correction required the facility to assess new and current residents and implement interventions to address their needs.

A 2008 NC DHSR survey of a Family Care Home (six beds or fewer) in north-central part North Carolina found three residents with the following mental health diagnoses: schizophrenia; schizoaffective disorder/bipolar type; mental retardation, depression, schizoaffective disorder and altered mental status. On August 6, 2008, staff left the residents of this family care home alone to run errands. When staff left the facility, Resident #2 accused Resident #1 of taking his money. Resident #1 denied he took Resident #2’s money. Resident #2 became agitated and made threatening comments. Then Resident #2 assaulted Resident #1 outside on the sidewalk and driveway. Resident #1 suffered a black and purple eye and scratches on his face. Due to his report of pain, Resident #1’s jaw was x-rayed. The administrator was aware of Resident #2’s

behavior problem and of an earlier assault conviction but had no plan in place to address his behavior.

NC DHSR issued a Type A Violation for failing to supervise the residents in accordance with their needs, care plan and current symptoms. A Directed Plan of Correction instructed the facility to not leave residents unattended or unsupervised; to utilize Mental Health to develop plans for residents with behavior problems; and to discharge residents that have behaviors that cannot be addressed with the level of supervision in the facility.

A 2008 NC DHSR survey of a 60-bed Adult Care Home in the foothills of North Carolina found Resident #1 was diagnosed with alcohol-induced persisting dementia with functional limitations including “injurious to others.” Resident #1’s Assessment and Care Plan revealed she was verbally abusive, physically abusive, resists care, has disruptive behavior, is intrusive and is injurious to others. Resident #1’s plan did not include anything to address these behaviors.

On August 24, 2008, Resident #1 pushed down Resident #9 who sustained a hip fracture; hit Resident #9 causing black eyes on two separate occasions; and hit three other residents, each more than once.

The County Adult Care Specialist issued a Type A Violation finding the facility failed to provide adequate supervision of a resident who displayed behaviors placing themselves and/or others at risk for serious physical harm and/or death. The directed Plan of Correction required the facility to immediately provide supervision of residents to ensure the health, safety and welfare of all residents are not endangered; to assess residents to identify at-risk behaviors; to develop interventions (care plans) for residents at-risk; and to ensure all staff are aware of the individualized care plans.

A 2008 NC DHSR survey of an 80-bed Adult Care Home in southeastern North Carolina found the following situations at the facility during a five month period:

- Failure to notify doctors of changes in patient behavior
- Residents cycling in and out of psychiatric hospitals
- Residents physically and sexually attacking other residents
- Aides locking themselves in the medication room in order to protect themselves from residents
- Residents carrying weapons to protect themselves from other residents; and
- Deaths

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Resident #71, admitted to the facility in March 2008, was described on the FL-2 as constantly disoriented and “injurious to others.” Resident #71 began making sexual comments to two aides. The behavior caused the aides to lock themselves in the medication room. Resident #71 then redirected the sexual comments to two other aides who were unable to redirect him and also locked themselves in the medication room and called 911. Four of the direct care staff required by the Rules to be present to supervise residents were hiding in the medical room for their own safety. When law enforcement arrived, Resident #71 failed to comply with the police officer’s orders that he return to his room, and instead reached out at the police officer, who then tased Resident #71. Additional officers took Resident #71 to the local emergency room. He was discharged back to the facility the next day. No changes were made to Resident #71’s plan of care. Seven days later Resident #71 began making sexual comments to staff again. PRN medications were administered. Nine days later Resident #71 attacked a female resident at the picnic tables outside the facility. He pushed her to the ground, pinning her hands above her head and began feeling her genitals. A janitor ran out of the facility and found resident #71 getting off the female resident. She reported she had been attacked. Police arrived and arrested resident #71 for second degree sex offense.

In February, 2008, behavioral changes were noted in Resident #39. He hit two residents and fought another resident in self defense. His community mental health worker was contacted and she spoke with him. He later hit another resident causing the resident to bleed from the mouth. Four days later he hit another resident. Survey staff conducted confidential interviews with residents which revealed two of them carried weapons as protection from Resident #39.

Resident #38 exhibited the following behaviors in a two-month period: February 23, 2008 – wandered into town; March 13, 2008 - found sitting outside naked, became aggressive toward staff; March 18, 2008 - walked around naked half the night and flooded the men’s bathroom; March 25, 2008 - attempted to destroy mini blinds in the common room; March 26, 2008 - naked in the men’s dayroom; March 27, 2008 - walking through the facility with no pants on; March 28, 2008 - found unresponsive, transported to hospital and returned same morning; March 29, 2008 - put powders all over himself and his room; March 31, 2008 - stopped up the sink in the front lobby and flooded the floor and also had no pants on; April 2, 2008 - hit in the face by Resident #39 resulting in black eye and bloody swollen lip; April 4, 2008 – wandered; April 5, 2008 - broke out lights with a pool stick; April 5, 2008 - hit in the mouth by Resident #39; April 6, 2008 - wandered, found injured by another resident; April 8, 2008 - flooded the big bathroom; April 9, 2008 - flooded the men’s hall bathroom; and April 22, 2008 - observed wandering.

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Resident #40 was admitted to the facility September 28, 2007. Diagnoses on the FL-2 included altered mental status secondary to heavy sedation. Resident #40's record revealed: September 29, 2007 - involved in a fight with another resident while they were both trying to get out the facility's back door; October 20, 2007 - became agitated in the dining room and threw his plate on the floor and cursing; November 16, 2007 - threatened another resident; November 25, 2007 - tried to reach between a med tech's legs; December 30, 2007 - slapped another resident; January 30, 2008 - eloped; February 27, 2008 - made a female resident feel uncomfortable with offensive moves; March 12, 2008 - tossed Kool-Aid on another resident and grabbed, choked and punched a resident in the back.

Resident #37 was diagnosed with schizoaffective disorder - depressed. On January 28, 2008, he complained of being depressed and having "dead thoughts;" on January 30, 2008, he complained of suicidal thought; on March 19, 2008, he was depressed and wanted to get himself committed. He threatened to harm himself and was taken to the hospital and returned with orders to follow up with a psychiatrist and continue home medications. On March 25, 2008, another mental health referral was made. He refused medication 20 times between April 1, 2008, and April 21, 2008. On April 21, 2008, he told staff he was depressed and a mental health referral was made. On April 22, 2008, he told staff he was extremely depressed and was considering harming himself. He turned over razors to staff. On April 22, 2008, he was taken to hospital emergency department at request of the NC DHSR surveyor and kept there.

NC DHSR issued a Type A Violation concluding the facility failed to assure supervision was provided in accordance with assessments, care plans, and current symptoms for four residents who were documented to be physically and/or verbally aggressive and failed to assure referral and follow up for psychiatric medication refusals. A Directed Plan of Correction required the facility to assess all residents; develop plans of care for supervision; provide staff training on care for person with mental illness or dementia; and assure adequate staffing pattern to meet residents' needs.