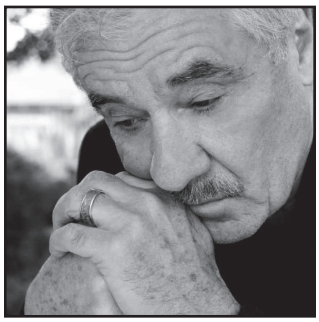
Understanding Co-Location

Chapter 2



North Carolina's adult and family care homes (ACH)[a] provide lodging and personal care services for more than 18,000 individuals with mental illness, intellectual and developmental disabilities, or Alzheimer disease/dementia.[b] In 2009, these individuals accounted for 64% of all residents in ACHs and more than 75% of residents aged 18 to 64 years.[1] Although ACHs are often thought of as providing care for the frail elderly, they have become a critical part of the mental health system by providing housing and personal care services to large numbers of individuals with disabilities, many of whom do not have other housing and support service options.

Deinstitutionalization and the Move to Community-Based Services and Supports

Before the 1970s, most individuals with mental illness, substance abuse problems, intellectual and developmental disabilities, or other disabilities (referred to collectively as individuals with disabilities in this report) received services in large residential institutional settings or lived with their families with very little support from the government. This began to change as advocates, families, and individuals with disabilities began to challenge the idea that people with disabilities could receive services only in large congregate settings. States began to move people out of large, state-run residential facilities and into more community-based settings. The federal government has supported this shift by providing funding options to support community-based care. In 1981, the federal government established home- and community-based services (HCBS) waivers, which augmented the services already covered by Medicaid.[c] These waivers gave states the option of offering more comprehensive home- and community-based services for individuals who would otherwise qualify for institutional services.[2] This shift was further supported by the case titled *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999).[d] The Supreme Court held in this case that states must offer community-based services for individuals with mental disabilities who might otherwise be institutionalized if their physician believes that community-based services are appropriate, the individuals do not object, and the services can be accommodated by the state. Although the ruling

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a For the purposes of this report, unless otherwise specified, the abbreviation ACH will be used to refer to both adult and family care homes.

b The state collects data on the number of residents in adult care homes with a primary diagnosis of mental illness, intellectual or developmental disability, or Alzheimer disease/dementia. The state does not collect data on the number of people in adult care homes with a substance use disorder. For the purposes of this report, people with disabilities refers to anyone with either a mental health, intellectual or other developmental disability, or substance use disorder.

c See chapter 3 for a more detailed discussion of HCBS.

d The Court found that under certain circumstances, the unjustified institutionalization of people with disabilities could constitute unlawful discrimination under the Americans with Disabilities Act (ADA). Specifically, the Supreme Court held that "under Title II of the ADA, States are required to provide community-based treatment of persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the treatment can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

does not explicitly address ACHs as an institutional setting, it emphasizes the belief that, in many cases, individuals with disabilities have the right to be treated in their home communities.

The Olmstead case spurred further mental health reforms in 2001 in North Carolina that called for closing many of the remaining centralized residential facilities. This move further increased the need for housing at the community level for individuals with disabilities. Caring for individuals in their home community in the least restrictive setting possible is the goal for most individuals aged 18 to 64 years who have disabilities. However, many individuals with disabilities do need some level of services and supports, and these supports are not always available to individuals living independently in their community. Because of a shortage of more appropriate community options for individuals with disabilities and the financial incentives embedded in the system, many individuals with disabilities move into ACHs to gain access to the needed services and supports[3] (see Chapter 3 for more details).

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Pathways into Adult and Family Care Homes

Residents come to live in ACHs in various ways: some move to ACHs directly from their own home or the home of a family member; others move into an ACH after spending time in a hospital, state psychiatric hospital, or community hospital psychiatric unit; a smaller number move into ACHs after spending time in prison or jail. Some residents decide which facility to move into on their own or with the help of family. In other cases, staff at the local department of social services (DSS), local management entity (LME), or hospital (if the individual is being discharged to an ACH directly from the hospital) help the individual or family find an appropriate placement.

The Role of Placement Workers

Although everyone involved in the placement process would prefer to find a placement for each individual that can meet all of his or her needs, in reality placement decisions for individuals with disabilities are often a compromise. Finding a bed in a long-term care facility for an individual with disabilities can be quite difficult, depending on their diagnosis, care needs, and history. In looking for a placement for someone with long-term care needs, screening and assessment can help determine the most appropriate care setting (see Chapter 4 for more details).

Ideally, everyone would have a choice about where to live and would be placed only in an appropriate care setting. However, in reality, the availability of beds, willingness of facilities to take an individual, and timing all play into the decision. Because of differences in the number, size, and types of long-term care facilities in each county and region, the availability of beds in different types of long-term care facilities varies greatly by county and region. No private

residential facility—whether it is a nursing facility, 122C group home,[e] or ACH—is required to admit any individual into their facility. Thus, the willingness of facilities to take an individual is particularly influential when dealing with residents with high needs. Often the process to place an individual in a nursing home or 122C takes longer than the process to place an individual in an ACH (largely because of differences in rules and regulations around screening and assessment). Timing can play a major role when determining placement for individuals who need an immediate placement or who are in a medical facility waiting to be discharged. In addition, hospital discharge planners and others assisting individuals with placement decisions may not know about other available housing options. For these reasons and others discussed throughout the report, the Task Force heard from placement workers and others involved in the placement process that some people with significant behavioral difficulties are placed in ACHs even when another type of facility or a community-based placement might better suit the individual's needs.

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The Role of the Adult or Family Care Home

ACHs vary in the ways that they decide to admit patients. Ideally, ACH staff would do a thorough screening before admission to determine the individual's medical condition, mental health, and cognitive and physical functional abilities, as well as any behavioral problems the individual may exhibit. On the basis of the findings of this screening, the ACH would determine whether they could care for the potential resident. Some ACHs currently attempt to gather such information, but it is not always easy for ACHs to obtain all this information before placement. As described more fully in Chapter 4, the screening tool that ACHs are required to use before admission does not capture all the relevant information. Furthermore, people who are helping others find a placement may not know this information or may not be forthcoming about prospective residents with acute behavioral problems. In addition, the financial reality of operating an ACH requires that a certain percentage of a facility's beds be occupied. In 2009, North Carolina's ACH administrators reported an occupancy rate of approximately 65%.[f,1] Thus, some facilities may decide to admit individuals whom they would not otherwise admit in order to maintain optimal occupancy.

e 122C group homes are "24-hour facilities which provide residential services to individuals in a home environment where the primary purpose of these services is the care, habilitation or rehabilitation of individuals who have a mental illness, a developmental disability or disabilities, or a substance abuse disorder and require supervision when in residence." Elliott M. Making the rules work for people: licensed supervised living for persons with mental illnesses, intellectual disabilities, and substance abuse. Presented to: North Carolina Institute of Medicine Task Force on the Co-Location of Different Populations in Adult Care Homes; March 3, 2010; Morrisville, NC.

f The 2009 Occupancy Rates for all HAL Facilities report from the North Carolina Department of Health and Human Services Office of the Controller found that adult care homes with 7 or more beds had an average occupancy rate of 79%.

The Population in Adult and Family Care Homes

North Carolina has more than 1,200 ACHs that can provide lodging and personal care services for up to 40,000 residents.[g] North Carolina's ACHs are assisted living facilities that are designed to "provide room, board, and care for more than two unrelated adults who, because of a temporary or chronic physical condition or mental disability, need a substitute home and the availability of 24-hour scheduled and unscheduled personal care services."[4] Personal care services that are provided include assistance with activities of daily living (e.g., dressing, bathing, toileting, eating, or moving from one place to another), help taking medications, or other health care-related needs. Adult care homes house seven or more residents, whereas family care homes provide a residential setting for two to six residents. It is important to note that ACHs are not a uniform group; the number of residents, mix of resident needs, ages, disabilities, location, and sources of financing vary tremendously across North Carolina.

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Unfortunately, although the state collects some information on the number of people in ACHs who have a primary diagnosis of mental illness, intellectual and developmental disabilities (IDD), or Alzheimer disease/dementia, it does not specifically collect information on the number of people who exhibit inappropriate verbal, sexual, or physical behaviors that pose a threat to themselves or others. Therefore, the size of the population that this Task Force was most interested in, those individuals with disabilities who exhibit behavior problems, could not be determined. Instead, the numbers below reflect the size of the population that is at risk for behavioral problems because of their diagnosis.[5-7]

Basic data on the population in ACHs is collected through the annual license renewal process. When facilities complete the paperwork to renew the license, they must provide information on the demographic characteristics of residents in their facility (including information about the number of residents who have mental illness, IDD, or Alzheimer disease/dementia). In August of 2009, ACH administrators reported that more than 26,000 residents were living in adult care homes in North Carolina, and approximately 2,500 were living in family care homes.[h,1] Most residents in both adult and family care homes are older adults (age 65 or older). Of the 26,000 residents living in adult care homes in 2010, most (62.4%) had a mental illness, IDD, or Alzheimer disease/dementia.[1] Similarly, 80.4% of the residents in family care homes had one of these conditions[1] (see Table 2.1). As a general rule, older residents were more likely to have Alzheimer disease, whereas younger residents were more likely to have a mental illness. The state does not collect information on the number of residents with a primary diagnosis of substance use disorder.

g North Carolina's 1,258 adult and family care homes have beds for 40,098 residents; however, facilities are not full all the time. In December 2009, ACHs reported that approximately 35% of bed spaces were empty. Adult Care Licensure Section, Division of Health Service Regulation, North Carolina Department of Health and Human Services. Diagnosis Data by Age Groups 2009, 2010 License Renewal Application.

h Data come from the License Renewal forms completed by ACH administrators and submitted to the North Carolina DHSR.

Table 2.1
Diverse Needs of Residents of Adult Care Homes and Family Care Homes (2010)

Characteristic	Adult Care Homes	Family Care Homes
Total residents	**26,040**	**2,535**
Total with mental illness, intellectual and developmental disability, or Alzheimer disease or dementia	16,272 (62.5%)	2,038 (80.4%)
Mental illness	6,435 (24.7%)	1,283 (50.6%)
Intellectual and other developmental disability	1,315 (5.0%)	444 (17.5%)
Alzheimer disease or dementia	8,522 (32.7%)	311 (12.3%)
Residents aged 18-64 years	**6,156 (23.6%)**	**1,490 (58.8%)**
Total with mental illness, intellectual and developmental disability, or Alzheimer disease or dementia	77.5%	85.1%
Mental illness	57.7%	62.9%
Intellectual and other developmental disability	13.5%	20.7%
Alzheimer disease or dementia	6.3%	1.5%
Residents aged ≥65 years	**19,884 (76.4%)**	**1,045 (41.2%)**
Total with mental illness, intellectual and developmental disability, or Alzheimer disease or dementia	57.8%	73.7%
Mental illness	14.5%	33.1%
Intellectual and other developmental disability	2.4%	12.9%
Alzheimer disease or dementia	40.9%	27.7%

Source: NCIOM analysis of Adult Care Licensure Section, Division of Health Service Regulation, North Carolina Department of Health and Human Services. Diagnosis Data by Age Groups 2009, 2010 License Renewal Application.

These data illustrate that although many people think that ACHs are primarily for the frail elderly, these homes provide care for a diverse population. Furthermore, many residents of ACHs have significant mental health, behavioral health, rehabilitative, or other needs in addition to their personal care needs.

Co-Location Can Be a Problem

The Task Force tried, unsuccessfully, to get more information about residents and their needs to capture the extent of the problem of co-location of people with behavioral problems with the frail elderly or other people with disabilities. Documenting problems due to co-location of different populations is difficult. There are a number of systems that gather information, such as local law enforcement, the Division of Health Service Regulation (DHSR), the Ombudsman program, and DSS, that collect information about problems in ACHs, including problems related to co-location. However, these data sources

are not linked and some, such as local law enforcement, cannot be aggregated in any way to show the prevalence of problems. Using a number of different data sources provides the best picture of the population in ACHs and the problems that arise from housing people with such diverse needs together.

One way to look at the types of problems that can occur is to review complaints against ACHs. Complaints, by residents, family members, guardians, or others, can be made to the complaint intake unit of a county DSS or the DHSR Complaint Intake Unit. This triggers an investigation by the county DSS. The county DSS may refer serious conditions that affect the quality of care or that place residents in danger to the Adult Care Licensure Section of the DHSR. Regional ombudsmen can assist residents with informal grievances mediation.[i,4]

The best solution to preventing the problems that can occur when these populations are co-located is to ensure that there are other viable options for individuals with disabilities in terms of their living arrangements and support services.

When serious complaints are referred to the Adult Care Licensure Section of the DHSR, a complaint investigation takes place. The DHSR penalty records show that 64 of the serious violations resulting in penalties from 2006 to 2010 were related to problems of co-location. In the majority of cases (44 [69%]), an individual with mental health problems was unsupervised. In 12 (19%) of the 64 cases, an individual with mental health problems physically or sexually assaulted another resident; in 13 (20%) of the 64 cases, an individual with mental health problems harmed themselves, or the lack of supervision resulted in conditions that could have resulted in serious harm to the individual or other residents.[j]

Regional long-term care ombudsmen, professionals who advocate for residents in long-term care facilities, often help resolve less serious complaints. As a first step in resolving the complaint, the regional ombudsmen visits the resident in the ACH and then works with the resident, other representatives of the resident, and the facility to resolve the complaint. Ombudsman complaint records are not aggregated and are not reported in detail; however, a 2005 analysis showed that from 2003 to 2004 "adult care residents younger than 60 who had documented mental health problems generated more than 380 instances of criminal activities and violent, threatening, or inappropriate sexual acts."[8]

Long- and Short-Term Solutions to Co-Location

In considering the issue of co-locating different populations in adult care homes, the Task Force discussed both long- and short-term solutions. The best solution to preventing the problems that can occur when these populations are co-located is to ensure that there are other viable options for individuals with disabilities in terms of their living arrangements and support services (see Chapter 3). The Task Force would like to see individuals with disabilities provided with a range of options for living independently in their community with care and support services aimed at recovery and self-sufficiency, but they

i In 2009, the 17 regional ombudsmen assisted in resolving 1,661 complaints.
j Ryan B. Chief, Adult Care Licensure Section, Division of Health Service Regulation. Written (email) communication April 20, 2010.

recognize that this will take time. In order to meet some of the more immediate needs of the residents and staff of ACHs, the Task Force considered ways to restructure the current screening, assessment, and care planning process as well to ensure that staff of ACHs receive training about the populations they serve and their behavioral health needs (see Chapters 4 and 5). Although the recommendations are discussed individually, it is important to consider them as a whole to understand the Task Force's vision. Each recommendation is an important piece in fixing the problem of co-location of different populations in ACHs. Taken as a whole, they represent a collection of recommendations that could improve residents' experiences in ACHs today and prevent the problems associated with co-location in the future.

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