Issue Brief

Short- and Long-Term Solutions for Co-Location in Adult and Family Care Homes

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Co-Location Is the Reality in North Carolina's Adult and Family Care Homes

Although most people think of North Carolina's adult and family care homes (ACH) as residences for the frail elderly, more than 60% of residents have a mental illness, intellectual or developmental disabilities, or an Alzheimer disease/dementia diagnosis. The placement of individuals with mental illnesses, substance abuse problems, intellectual and developmental disabilities, and other disabilities[a] that may result in serious behavioral problems can pose a threat to the health and safety of other residents, as well as to the staff of ACHs. Problems reported in North Carolina ACHs over the past five years have included physical harm, sexual assault, and verbal and psychological abuse.[b,1]

Individuals with disabilities often require services and supports in their daily lives. Many individuals with disabilities live on very limited incomes and need assistance with daily activities. Due to a shortage of more appropriate community options for individuals with disabilities, as well as the financial incentives embedded in the system, many individuals with disabilities move into ACHs to gain access to needed supports.[2] Today ACHs serve more than 18,000 individuals with disabilities by providing a place to live, assistance with activities of daily living (i.e. dressing, cooking, eating), and medication management. In doing so, ACHs have become a critical part of North Carolina's mental health, developmental disability and substance abuse system. Without substantial increases in community alternatives for individuals with disabilities, this population will continue to constitute a large portion of the ACH population.

To address these issues, the North Carolina General Assembly asked the North Carolina Institute of Medicine to convene a task force to study the co-location of the frail elderly with individuals with disabilities who may have behavioral problems in ACHs. The Task Force on the Co-Location of Different Populations in Adult Care Homes was chaired by Maria Spaulding, Deputy Secretary for Long-Term Care and Family Services, North Carolina Department of Health and Human Services; Representative Jean Farmer-Butterfield, North Carolina General Assembly; and Senator John Snow, North Carolina General Assembly. There were 41 additional Task Force and Steering Committee members. The Task Force was supported by funding from the North Carolina Department of Health and Human Services Division of Mental Health, Developmental Disabilities, and Substance Abuse Services through the North Carolina Substance Abuse Prevention and Treatment Block Grant from the Substance Abuse & Mental Health Services Administration. The Task Force developed nine recommendations, including recommendations for improving and strengthening the current system, as well as recommendations for expanding affordable housing options and increasing options for how and where people with disabilities can access services and supports. Two recommendations were designated as priority recommendations.

Improving the Current System While Maintaining a Long-Term Vision of Prevention

The problems of co-location could be minimized if individuals with behavioral problems and the frail elderly were not housed together in ACHs. While ACHs may be suitable residences for the frail elderly, they may be insufficient to meet the needs of individuals with disabilities who also have behavioral problems. Unfortunately, individuals with disabilities often have few other viable options if they need housing and support services.

a. Individuals with mental illness, substance abuse problems, intellectual and developmental disabilities, and other disabilities are referred to collectively as individuals with disabilities throughout this report.
b. Ryan B. Chief, Adult Care Licensure Section, Division of Health Service Regulation, North Carolina Department of Health and Human Services. Written (email) communication. April 20,2010.

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Developing appropriate housing assistance programs and community-based services and supports is a challenge that will take time. Therefore, the Task Force's recommendations had two goals: both to improve the ability of ACHs to handle the co-located populations in the short-term and, in the long-term, to provide more viable options for people with disabilities whose needs are not met by ACHs to live in their home communities, thus preventing co-location from occurring. Although the recommendations are discussed individually, to understand the Task Force's vision, it is important to consider them as a whole. While each recommendation is an important piece to fixing the problem of co-location of different populations in ACHs, taken as a whole they represent meaningful changes that could improve residents' experiences in ACHs today and prevent the problems associated with co-location in the future. Additionally, given the challenges facing North Carolina's mental health system and the state budget, the Task Force recognized that changes requiring major new investments are not likely in the immediate future. Therefore, the Task Force focused not only on what needs to be done, but also on how modest investments and reallocations of existing funds could be used to achieve these goals.

Providing More Choices

Ideally the Task Force would like to see individuals with disabilities, particularly those ages 18-64, provided with a range of options for living independently in their communities with care and support services aimed at recovery and self-sufficiency.[3] Unfortunately, North Carolina does not currently have the right mix of affordable supports in place to ensure that individuals with disabilities have the opportunity to live in housing that is integrated into the community and promotes their maximum independence.

Making funding for housing more flexible, developing more subsidized housing for individuals with disabilities, and greatly increasing community-based services and supports are all critical to ensuring that individuals with disabilities have choices about where they live and the kinds of services and supports they receive. Developing such options on the scale needed to meet the need will take considerable time and sustained investment in the mental health, developmental disabilities and substance abuse system, particularly community-based services and supports. As a first step in this process, the *Task Force recommends North Carolina develop and test a pilot project to evaluate the costs, quality, consumer satisfaction, and patient outcomes of a program that supports individuals who would otherwise be in an ACH who want to move back into independent supported housing in the community.* To ensure individuals with disabilities have access to affordable housing options in the future, the *Task Force recommends the North Carolina General Assembly increase funds allocated to the North Carolina Housing Trust Fund for housing for individuals with disabilities and the North Carolina Department of Health and Human Services work with the North Carolina Housing Finance Agency to explore transitional housing options.* To meet both short- and long-term goals, the *Task Force recommends the development of an inventory of community housing options for individuals with disabilities that is easily accessed by individuals, families, and others involved in helping individuals with disabilities explore their options.*

Improving the Current System

In addition to increasing options for individuals with disabilities, North Carolina must also work to ensure that ACHs are better prepared to meet the needs of individuals with disabilities who currently reside in ACHs. With more than 18,000 individuals with disabilities currently living in ACHs and with few community alternatives available, individuals with disabilities will continue to enter ACHs.[4] The current ACH system does not have adequate screening, assessment, care planning procedures, and staff training requirements in place to ensure that ACHs can meet the needs of those entering their facilities. To better serve individuals with disabilities as well as ensure the safety of staff and other residents, North Carolina needs to update the rules and regulations governing ACHs.

Thorough screening, assessment, and care planning tools are critical to ensuring that individuals can be appropriately cared for in any type of assisted living arrangement. The lack of information on the screening, assessment, and care planning tools currently used in North Carolina's ACHs does a disservice to both facilities and residents. Increasing the type and quality of information gathered would help prevent inappropriate placement, assure that facilities are knowledgeable about the care needs of prospective residents and better prepared to provide necessary care to residents, and ensure that other appropriate agencies or organizations are included in the care planning process. All of this is critical to ensuring successful placements and the safety of residents and staff. Therefore the *Task Force recommends the North Carolina Department of Health and Human Services require standardized and validated preadmission screenings,*

level of services determinations, assessments and care planning instruments, with automated data collection, that include more information on the mental and behavioral health of residents. Furthermore, the *Task Force recommends that the North Carolina Department of Health and Human Services use the data gathered through the new automated system to develop case-mix adjusted payments for ACHs and 122C facilities* to ensure that payments to facilities accurately reflect the needs of residents.

In addition to system changes, improving the current system of care in ACHs for individuals with disabilities will require better coordination between the ACHs that house and care for individuals with disabilities and local management entities (LMEs), the local agencies charged with managing, coordinating, and facilitating the provision of mental health, developmental disabilities, and substance abuse services for residents in their area.[5] The current lack of understanding between ACHs and LMEs often prevents them from working together. Strengthening the partnership between ACHs and LMEs would create a more seamless system for those in ACHs to receive necessary assessment and care coordination, by taking advantage of the existing expertise of the LMEs. To help improve the relationship between ACHs and LMEs, the *Task Force recommends the Division of Mental Health, Developmental Disabilities and Substance Abuse Services require LMEs to hold an informational forum at least twice a year and that the Division of Health Service Regulation encourage ACH staff to attend.*

Increasing Staff Training on How to Interact With Individuals with Disabilities

Due to the history of ACHs and the perception that they provide care to the frail elderly, the training requirements for staff of ACHs include little, if any, training on working with individuals with disabilities. As the majority of residents in ACHs have a mental health, intellectual or developmental disorder, or an Alzheimer disease/dementia diagnosis, there is a need for specific training on working with individuals with disabilities. While not all individuals with these diagnoses manifest behavioral problems, many of them do exhibit aggressive or combative behaviors that pose a threat to the safety of other residents and staff.[3] Such behavioral problems can often be safely managed by well-trained staff. Unfortunately, workers in ACHs are not required to receive specific training in managing individuals with behavioral problems, such as de-escalation skills during a crisis. This lack of formal training for staff contributes to the safety risks associated with co-locating older individuals with personal care needs alongside individuals who manifest aggressive or combative behaviors.

To improve the training of ACH staff, the *Task Force recommends the North Carolina General Assembly require all ACHs to receive geriatric/adult mental health specialty team training at least three times per year.* Furthermore, the *Task Force recommends the North Carolina General Assembly require all ACH direct care workers, personal care aides, medication aides, and supervisors to be trained and to have passed the competency exam for the prevention module of state-approved crisis intervention training, such as North Carolina Interventions Prevention training, by June 2013.*

In September 2010, North Carolina was awarded a three year federal Personal and Home Care Aide State Training Program (PHCAST) grant to develop, pilot test, implement, and evaluate the impact of a comprehensive training and competency program for direct care workers. As part of this work, the *Task Force recommends the North Carolina Division of Health Service Regulation, in conjunction with the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services and the Division of Medical Assistance, develop a standardized curriculum and competency test for new direct care workers as part of the federal Personal and Home Care Aide State Training Program grant.*

The current practice of co-locating the frail elderly with large numbers of individuals with disabilities, who may have behavioral problems, poses a threat to the safety of residents and staff of ACHs. North Carolina can address this problem by making appropriate changes to the current ACHs and the mental health, developmental disabilities, and substance abuse system so that individuals with disabilities have a range of options—from facility-based care, for those who want to live with other individuals in congregate living arrangements, to independent living arrangements in the community with care and support services. These changes are critical to improve the care and well-being of some of our most vulnerable citizens and the workers who provide services and supports to them. The recommendations in this report provide a roadmap to both addressing the challenges associated with co-location in ACHs and to increasing the options available to individuals with disabilities, which would reduce co-location in ACHs in the long-run. Implementing these recommendations would considerably improve the safety and well-being of residents and staff of ACHs, as well as individuals with disabilities, in North Carolina.

References

1 Goldsmith T. 'Reform' puts mentally ill in homes for frail elderly. *The News and Observer*. January 7, 2007:1A-12A.

2 North Carolina Study Commission on Aging. *Study of Issues Related to Persons with Mental Illness in Long-Term Care Facilities*. Raleigh, NC: North Carolina Department of Health and Human Services; 2005.

3 Substance Abuse and Mental Health Services Administration. Mental health: a report of the Surgeon General. Rockville, MD: US Public Health Service; 1999. http://www.surgeongeneral.gov/library/mentalhealth/home.html. Accessed September 22, 2010.

4 Adult Care Licensure Section, Division of Health Service Regulation. Diagnosis data by age groups 2009. 2010 License Renewal Application. North Carolina Department of Health and Human Services.

5 Division of Mental Health, Developmental Disabilities and Substance Abuse Services. LMEs by county. North Carolina Department of Health and Human Services. http://www.ncdhhs.gov/mhddsaslmedirectory.htm. Accessed December 14, 2010.

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A copy of the full report, including the complete recommendations, is available on the North Carolina Institute of Medicine website, http://www.nciom.org.

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