Executive Summary

Although most people think of North Carolina's adult and family care homes (ACH) as residents for the frail elderly, more than 60% of residents have a mental illness, intellectual or developmental disabilities, or Alzheimer disease/dementia diagnosis.[1] The placement of individuals with mental illness, substance abuse problems, intellectual and developmental disabilities, and other disabilities[a] that may result in serious behavioral problems in ACHs can pose a threat to the health and safety of other residents, especially the frail elderly, other people with disabilities, and staff. Problems reported in North Carolina ACH over the past five years have included physical harm, sexual assault, and verbal and psychological abuse.[b,2]

More than 60% of residents of adult and family care homes have a mental illness, intellectual or developmental disabilities, or Alzheimer disease/dementia diagnosis.

Individuals with disabilities often require services and supports in their daily lives. Most 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 and the financial incentives embedded in the system, many individuals with disabilities move into ACHs to gain access to needed supports.[3] 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.[1] In doing so, ACH 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 adult and family care home 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 adult care homes. 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 developed nine recommendations including recommendations to improve and strengthen the current system as well as recommendations to increase housing and support options for people with disabilities so they can live more independently. Two recommendations were designated as priority recommendations.

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.

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

The problems of co-location could be prevented if individuals with disabilities 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 other individuals with disabilities who also have behavioral problems. Currently, many individuals with disabilities have few other viable options if they need housing and support services. To address this problem, the Task Force's recommendations had both long-term and short-term goals.

The placement of [individuals with disabilities] that may result in serious behavioral problems in ACHs can pose a threat to the health and safety of other residents, and staff.

Over the long term, the Task Force recommended expansion of housing and support services to enable people with disabilities to live more independently in their communities. However, developing appropriate housing assistance programs and expanding the array of community-based services and supports will take time. Thus, the Task Force also developed shorter-term recommendations to improve the ability of ACHs to handle the co-located populations. Although the recommendations are discussed individually, it is important to consider them as a whole to understand the Task Force's vision. 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 a plan that would 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 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 how modest investments and reallocations of existing funds could be used to achieve these goals.

Providing 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 community with care and support services aimed at recovery and self-sufficiency. North Carolina does not 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, as recommended by the U.S. Surgeon General and the U.S. Department of Health and Human Services.[4,5]

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 system, particularly community-based services and supports. However, such investments are critical to ensuring that individuals with disabilities have

a range of appropriate options for housing, supports, and services. Therefore, the Task Force recommends:

Recommendation 3.1: Pilot Program (PRIORITY RECOMMENDATION)

The North Carolina Department of Health and Human Services (DHHS) should develop a pilot program to evaluate the costs, quality, consumer satisfaction, and patient outcomes of a program that supports individuals who would otherwise be in an adult or family care home and who want to move into independent supported housing.

Recommendation 3.2: Increase Funding for Housing for Individuals with Disabilities

To help individuals with disabilities better afford housing, the North Carolina General Assembly should appropriate $10 million in additional recurring funding beginning in state fiscal year 2011 to the North Carolina Housing Finance Agency to increase funding to the North Carolina Housing Trust Fund. A significant portion of the funding should be targeted for housing for individuals with disabilities. The North Carolina Department of Health and Human Services should work with the Housing Finance Agency to explore options to create transitional housing for people who need short-term stabilization options to help them make a transition to more independent living in the community.

Recommendation 3.3: Create an Inventory of Community Housing Options for Individuals with Disabilities

Local management entities should develop a real-time inventory of community housing options including 122C therapeutic mental health, substance abuse and developmental disability group homes, adult and family care homes, supported living arrangements, and independent living options, and make this inventory available to families.

Improving the Current System

In addition to increasing options for individuals with disabilities, North Carolina must also work to ensure 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 few community alternatives available, individuals with disabilities will continue to enter ACHs.[1] The current ACH system does not have adequate screening, assessment, care planning procedures, and staff training requirements in place to ensure 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 do a disservice to both facilities and residents. Increasing the type and quality of information gathered would help prevent inappropriate placement, assure facilities were knowledgeable about the care needs of prospective residents and better prepared to provide necessary services to residents, and ensure that other appropriate agencies or organizations are included in the care planning process. All of these elements are critical to ensuring successful placements and the safety of residents and staff. To meet these goals, the Task Force recommends:

Recommendation 4.1: Requiring Standardized Preadmission Screening, Level of Services, and Assessment Instruments in Adult and Family Care Homes and 122C Facilities (PRIORITY RECOMMENDATION)

The North Carolina General Assembly should direct the Department of Health and Human Services to require adult care homes and family care homes, and 122C mental health, developmental disability, and substance abuse group homes to use standardized preadmission screenings, level of services determinations, assessments and care planning instruments.

Recommendation 4.3: Case-Mix Adjusted Payments

The North Carolina Department of Health and Human Services should use the information obtained from validated assessment instruments to develop case-mix adjusted payments for adult and family care homes, and 122C facilities.

In addition to system changes, improving the current system of care for individuals with disabilities in ACHs 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.[6] 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 within 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**:**

Recommendation 4.2: Local Management Entity Outreach and Education for Adult and Family Care Home Staff

The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services should require local management entities (LME) to hold an informational forum at least twice a year for staff of adult and family care homes (ACH) and geriatric adult specialty teams (GASTs). The LME forum should help ACH and GAST staff understand the LME's purpose and function, as well as the resources and services accessible through the LME, including crisis services.

Increasing Staff Training on How to Interact with Individuals with Disabilities

Due to their history and perception as providing care to the frail elderly, the training requirements for staff of ACH 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 Alzheimer disease/dementia diagnosis, there is a need to train staff to more effectively work with individuals with disabilities. While not all individuals with these diagnoses manifest inappropriate behavioral problems, many of them do exhibit aggressive or combative behaviors that pose a threat to the safety of other residents and staff.[4] 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 with individuals who manifest aggressive or combative behaviors. To improve the training of ACH staff, the Task Force recommends:

Recommendation 5.1: Use Geriatric/Adult Mental Health Specialty Teams to Provide Training in all ACHs

NCGA should enact legislation to require all adult and family care homes to receive geriatric/adult mental health specialty teams training at least three times per year. The training should be tailored to the needs of the specific ACH but should, at a minimum, cover person-centered thinking and de-escalation skills.

Recommendation 5.2: Require Adult and Family Care Home Staff to Be Trained and to Exhibit Competency in Person-Centered Thinking and Crisis Prevention

The North Carolina General Assembly should require all adult and family care home direct care workers, personal care aides, medication aides, and supervisors to be trained and to have passed the competency exam for state-approved crisis intervention 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:

Recommendation 5.3: Pilot New Behavioral Health Training and Competency Examination Requirements for New Direct Care Workers

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, should 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 and others with disabilities with individuals who have behavioral problems poses a threat to the safety of residents and staff of ACHs. Improving North Carolina's current ACH system and making changes to the overall mental health system so that individuals with disabilities have a range of options—from facility-based care for those who need it to living independently in their community with care and support services—are critical to improving the care and well-being of some of our most vulnerable citizens. The recommendations in this report provide a roadmap both to 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 improve the safety and well-being of residents and staff of ACHs as well as individuals with disabilities in North Carolina.

References

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