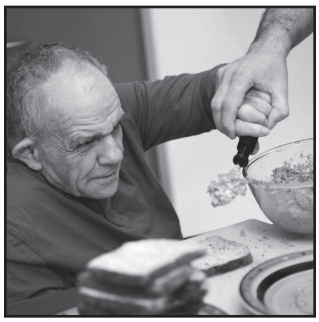
Increasing Options for Individuals with Disabilities

Chapter 3



In looking at the issue of co-location in adult and family care homes (ACH), the Task Force found that large numbers of individuals with disabilities are being served in ACHs even though best practices research indicates that these individuals may be better served in different settings.[1,2] This led to a major focus on ways to increase the options for individuals with disabilities. By increasing options for these individuals, over time, fewer would be placed in ACHs, thus reducing the problems associated with co-location of individuals with disabilities, who may have behavior problems, and the frail elderly.

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The long-term goal for individuals with disabilities, particularly those aged 18 to 64 years, should be recovery-oriented and habilitative care and supports so that individuals with disabilities can live and work in community settings of their choice.[1,2] A wider array of housing options and community-based services and supports is necessary to achieve this vision in North Carolina. To live successfully in communities of choice, individuals with disabilities often need clinical and personal care support services as well an array of appropriate housing and housing assistance options. Those with intense needs may need around-the-clock support or specialized medical/therapeutic services, whereas others may need services to assist in the development of skills of daily living.[1] This need for additional supports and services often limits an individual's choice of places to live. In North Carolina's current system, certain services and supports are not available in the community or are limited in their availability. Other types of services and supports are not financially viable options for individuals who wish to live on their own or with family members. North Carolina needs to develop more housing and community-based services options, so that individuals with disabilities have real choices in terms of where and with whom they live and the types of services and supports they choose to access. Increased availability of these appropriate options for individuals with disabilities could substantially alleviate the issue of co-location with the frail elderly. As stated earlier in the report, individuals with disabilities often end up, sometimes inappropriately, in ACHs because there is no place else for them to go.

A wider array of housing options and community-based services and supports is necessary.

In a January 14, 2000, letter to US governors, US Department of Health and Human Services Secretary Donna Shalala stated, "We can agree that no American should have to live in a nursing home or state institution if that individual can live in a community with the right mix of affordable supports."[3] Ten years later, 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 that promotes their maximum independence. As outlined by the Surgeon General, a comprehensive, effective service system includes "integrated community-based services, continuity of providers and treatments, family support services (including psychoeducation), and culturally sensitive services. Effective service delivery for individuals with the most severe conditions also requires supported housing and supported

employment."[2,4] The Task Force believes that this must be the long-term vision of North Carolina's service system for all individuals with disabilities.

North Carolina's Institutional Bias

Although individuals with disabilities in theory have the option to live independently, funding for supports and services is more easily obtained by individuals living in facilities because many funding streams, services, and supports are bundled to the place the individual lives. Most people with disabilities are living on Supplemental Security Income (SSI); in 2010, SSI benefits were $674 per month or $8,088 per year.[5] SSI does not provide enough monthly income for individuals in most communities to purchase non-subsidized housing or support services. People who enter an ACH or other type of facility can obtain certain financial assistance, services, and supports that are not equally available to people with similar levels of disability and financial need who choose to remain in their own homes.

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Cost Comparison of State-County Special Assistance for Recipients in ACHs and in Their Own Homes

Individuals can receive assistance in paying for an ACH if their income is below 145% of the federal poverty guidelines, or $1,228 per month.[8] Older individuals and individuals with disabilities who live in or are entering an ACH and who meet the age/disabilities standards as well as the income standard receive an income supplement called State-County Special Assistance (SA). SA is used to pay for room and board. Individuals receiving SA are automatically eligible for Medicaid, which is used to cover health care costs and the cost of personal care services.[a,6] The maximum SA payment for an individual with no other income would be $1,182 per month; however, most individuals have other sources of income to help pay for the care in the ACH.[7] SA is calculated by taking the maximum value and subtracting net monthly income (e.g., SSI and veteran's benefits).[8] The average value of SA for individuals in ACHs is $435 per month, or $5,220 per year.[7] This money is used by the individual to pay for their room and board at an ACH. The average Medicaid payment for personal care services per recipient in an ACH or supervised living facility in 2006, the last year for which comparable data are available, was $6,667 per year.[9] Thus, on average, ACH residents receive $11,890 per year in funding for housing and services (including personal care, health care, food, medication administration, activities, transportation services, and housekeeping and laundry services).

In contrast, people living at home in the community can qualify only for the SA-IHP and for Medicaid with incomes up to $903 per month ($325 per month less than the income qualifications for assistance in paying for an ACH).[8,10] In addition, they are not entitled to the full SA payment level. The maximum in-home SA payment is $887 per month, or 75% of what they would receive if living in an adult care home; like SA, the SA-IHP monthly amount is calculated

a Many of the people living in ACHs automatically qualify for Medicaid because they are receiving SSI payments. However, some of the people living in ACHs have slightly higher incomes and would not qualify for Medicaid were it not for the receipt of SA benefits.

by subtracting the individual's own income from the maximum amount.[11] The average value of SA in-home is $359 per month, or $4,308 per year in 2010. The average Medicaid payment for personal care services per SA in-home recipient was $6,979 per year.[9] Thus, on average, SA in-home recipients receive $11,290 per year ($600 less than SA recipients in ACHs) in funding for housing and personal care services.

Directly comparing the average SA and Medicaid payments of SA recipients in ACHs and SA in-home recipients does not include all costs for SA recipients. In 2007, the North Carolina Division of Aging and Adult Services (DAAS) completed a comparison of the costs for SA recipients in ACHs (SA ACH) and SA in-home recipients (SA-IHP) recipients, looking at all federal, state, and county costs for providing care for SA recipients.[b] DAAS found that when including federal, state, and county costs, SA ACH recipients cost 38.5% more per month, on average, than do SA-IHP recipients. Over the course of a year, SA ACH recipients cost $30,768 and SA-IHP recipients cost $22,224, on average. SA-IHP recipients cost, on average, $8,544 less per year. The majority of the savings are in federal funds ($4,572); however, the state saves $1,944 and the county $2,028 on average per year for SA-IHP recipients versus SA ACH recipients.[9]

Federal, state, and county governments could save money by providing services and supports to individuals in their homes versus in an ACH.

The difference in program rules between SA and Medicaid for those who live in ACHs and those who choose to remain at home or in their communities creates an "institutional bias"—providing greater financial coverage and health benefits for those who move into an ACH. Unbundling services and supports from the place an individual lives could go a long way toward helping individuals with disabilities afford to live in the community of their choosing. Additionally, the DAAS analysis shows that federal, state, and county governments could save money by providing services and supports to individuals in their homes versus in an ACH.

The Move toward Supported Housing

Over the past 50 years of deinstitutionalization, our knowledge of the types of housing and supports needed to help people with disabilities live independently has evolved. Initially, people who left larger state psychiatric hospitals and/or developmental centers might be placed in larger Intermediate Care Facilities for the Mentally Retarded (ICF-MRs) (with 16 or more beds) or in larger 122C group homes for people with mental illness, developmental disabilities, or substance abuse. Today, most people who are living in a 122C facility are in smaller group homes that house 6 or fewer individuals.[12] Some people with disabilities may be disqualified from living in certain group homes, if these homes were built with federal Housing and Urban Development (HUD) funds; some HUD programs explicitly preclude participants with prior criminal

b The cost to serve a typical SA in-home recipient included Medicaid, SA, Food Stamps, Home and Community Care Block Grant, and Social Services Block Grant funds. The cost to serve a typical SA ACH recipient included Medicaid and SA.

convictions, depending on the amount of time elapsed and the severity of the crime. Also, restrictions may also be placed on those actively using substances.[c] Thus, because of the limited housing options, many people with disabilities live in ACHs even though these residences do not meet all their needs. Although these types of living arrangements do help people who might otherwise be institutionalized live closer to their home communities, these residences are not optimal for community integration. Residents of ACHs may be cut off from active participation in the local community because of the lack of transportation and the structured format (i.e., the schedule of meals and personal care) of many residential care homes.[2,4]

Over the past decade, the concept of supported housing has emerged as the best practice model, individuals choose where they live, have tenancy rights, and have access to flexible support services to enable people to live independently, in housing that is safe, accessible, and affordable.

Over the past decade, the concept of supported housing has emerged as the best practice model for providing supports and services to individuals with disabilities. In this model, individuals choose where they live, have tenancy rights, and have access to flexible support services to enable people to live independently, in housing that is safe, accessible, and affordable.[1,13] There are two prerequisites for the success of this model. First, a person must have access to affordable housing. Most people with disabilities, many of whom currently reside in ACHs, are living on SSI. Because of this limited income, it is almost impossible for most people with disabilities who currently reside in ACHs to find affordable nonsubsidized housing. Second, the person must have access to services and supports to help him or her to live independently. By definition, people living in ACHs need assistance with activities of daily living (e.g., bathing, eating, ambulation, dressing, and/or toileting), and many need medication management or help with instrumental activities of daily living (e.g., light housework, preparing meals, using the telephone, shopping for groceries, and money management).[14] ACHs currently provide personal assistance and help with medication management. Thus, in addition to housing, many people with disabilities who are living in ACHs will need services and supports to help them live more independently. Support services need to be individualized, flexible, and responsive to an individual's changing needs. In this model, individuals are not "placed" in a residential facility but are able to choose where they want to live and to receive support services.[1]

Making Funding for Housing More Flexible

As discussed, most individuals with disabilities cannot afford independent housing without some sort of housing subsidy. In 91 counties in North Carolina, individuals who need an ACH level of care or who are in an ACH but would like to return home may be eligible for the SA-IHP.[d] This funding can be used to help pay for expenses such as rent, food, and clothing.[15] However, SA-IHP is not as readily available to individuals as SA ACH. As previously discussed, it is more difficult for individuals to qualify for SA-IHP (due to stricter income eligibility rules). In addition, North Carolina has limited the number of SA slots used to

c 24 CFR §982.533. Denial of admission and termination of assistance for criminals and alcohol abusers.
d Counties can choose whether to offer residents the SA-IHP program, and nine North Carolina counties have opted not to offer SA-IHP to residents.

provide SA-IHP to 15% of the total number of slots for SA.[e,16] Although this limit has not caused major problems in most communities to date, the artificial limit on the number of SA-IHP slots would prevent a large-scale effort to support people with disabilities in more independent community placements.

SA is an important funding tool for making housing more affordable for individuals with disabilities. Currently, North Carolina's SA programs are biased toward those individuals in or entering ACHs. Eliminating this bias would widen the range of affordable housing options for individuals with disabilities.

Increasing Housing Options

As noted earlier, access to services in the community and to funding to pay for housing will only work if there are affordable housing options for individuals with disabilities in the community. Affordable housing is defined by HUD as housing that costs no more than 30% of the household's income. This amounts to $202 per month for a single individual with disabilities who is living solely off SSI benefits.[5,17] To afford the average rent for a modest 1-bedroom apartment in North Carolina ($627 per month) under HUD's affordable housing definition, an individual must have an income of $2,090 per month, which amounts to $1,416 more than an individual with disability's SSI benefit.[18] This is why it is crucial that North Carolina increase the flexibility of the current SA-IHP, as discussed above. Although there are some affordable housing options in some North Carolina communities, if housing subsidies, such as the SA-IHP, were available to large numbers of individuals with disabilities, their needs could not be met by the current housing stock.

There is a need for more affordable housing options for individuals with disabilities in the community.

One opportunity for expanding affordable housing options is through the Housing Trust Fund, begun in 1987 by the North Carolina General Assembly. Since its creation, the General Assembly has appropriated up to $19 million in annual, generally non-recurring, funds to the North Carolina Housing Finance Agency for the Housing Trust Fund. The Fund helps to leverage private development funds in order to lower the costs of building single homes, multi-unit buildings, and apartment complexes so that housing becomes more affordable to populations who need it.[19] Low-income families, seniors, individuals with disabilities, as well as homeless individuals and victims of domestic violence might all benefit from such affordable housing. The Housing Trust Fund has the opportunity to have a significant impact on access to housing in North Carolina, because it is not subject to the same rent restrictions as federally funded projects through HUD, as previously described. Despite its potential benefit, however, funding constraints have limited the impact of the Housing Trust Fund. The North Carolina General Assembly should expand the volume of recurring funds appropriated to the Housing Trust Fund. One option for expansion would be to capture the interest from housing security deposits and to dedicate the funds to the Housing Trust Fund.

e Session Law 2007-323.

In addition to augmenting the funding to increase housing options for individuals with disabilities, North Carolina needs to better understand the demand for housing alternatives to ACHs. As discussed, the Task Force faced difficulties gathering information about the size of the population and the needs of individuals with disabilities in ACHs; future planning efforts would benefit from information on how many individuals in ACHs are interested in returning to the community. Currently, individuals in nursing homes are asked questions about their interest in returning to the community, whether they have a discharge plan in place, and whether they would like to talk to someone about returning to the community. North Carolina should include similar questions for individuals living in ACHs as part of the planned automated data collection system for ACHs (discussed more in Chapter 4).

Another way to increase housing options for individuals who may be able to live successfully in their home community with appropriate housing, supports, and services is for ACHs to branch out into providing other forms of housing and support. There are a number of models that support people to live more independently in the community, such as, but not limited to, multi-unit supported housing, shared housing, recovery-based scattered housing, and transitional housing.[2,20] With appropriate support and technical assistance, some ACHs may be interested in transitioning to some of these newer evidence-based models of housing for individuals with disabilities.

Increasing Community-Based Supports

One approach to increasing the supply of affordable community-based supports is to expand the availability of Medicaid home and community-based services (HCBS). Historically, the federal Medicaid law allowed states to provide additional HCBS to people who would otherwise need an institutional level of support (i.e., nursing facility, intermediate care facilities for people with developmental disabilities, and/or long-term hospitalization). For example, North Carolina operates a 1915(c) HCBS waiver that provides services and supports to people with intellectual and other developmental disabilities who would otherwise be eligible for ICF-MR placement (called the Community Alternatives Placement program for people with mental retardation/developmental disabilities or CAP/MR-DD). Some of the CAP/MR-DD-covered services include service coordination, case management, in-home supports, vocational services, day habilitation services, and respite care.[21] Unlike the situation for the regular Medicaid program—which is an entitlement to everyone who meets the states' eligibility rules—states have been allowed to limit the number of people it would serve under a HCBS waiver. It is also important to note that while HCBS funds can be used to pay for attendant services and supports, and other services needed to help a person live independently, the funds cannot be used to pay for housing.[22]

North Carolina 1915(i) State Plan Amendment

More recent changes in the federal waiver rules, along with changes under the federal Patient Protection and Affordable Care Act (PPACA), give states additional options to expand HCBS to additional people under the 1915(i) option. Before 2005, HCBS services could be provided under 1915(c) Medicaid waiver only to individuals meeting institutional level of care criteria (i.e., hospital care, nursing facility, or intermediate care facilities for people with developmental disabilities). Under the 1915(i) option, enacted as part of the 2005 Deficit Reduction Act, states can develop eligibility criteria that are less stringent than institutional level of care.[7] This opens the door for providing HCBS to a much wider range of individuals, including those with disabilities living at home or in an ACH. Under the 1915(i) option, states can cover HCBS such as case management, home health aides, personal care services, respite care, adult day health services, and other type of services and supports. States can also expand the income eligibility limit for people to qualify for HCBS.[f,7]

Under the 1915(i) option, enacted as part of the 2005 Deficit Reduction Act, states can develop eligibility criteria that are less stringent than institutional level of care. This opens the door for providing HCBS to a much wider range of individuals, including those with disabilities living at home or in an ACH.

The PPACA expanded the availability and funding for the 1915(i) program in order to provide an incentive to states to increase the amount of Medicaid long-term care funding spent on HCBS rather than on institutional care. North Carolina could qualify for a 2-percentage-point increase in the federal match for HCBS by expanding the 1915(i) program. As part of the PPACA, states can expand the types of people it serves and the types of HCBS offered.[g] However, if the state chooses this option, it is no longer allowed to limit the number of people served. Anyone who qualifies on the basis of the state's standard of need (i.e., income limits, resource limits, and functional limitations) would be eligible for the state-specified HCBS.[7] These services—including personal care services and supports—could help someone live more independently in the community.

Increasing Options for Individuals with Disabilities

The Task Force believes that in order to ameliorate the problem of co-location of individuals with disabilities with the frail elderly, options for individuals to remain in or return to their homes should be increased. The Task Force has developed short- and long-term recommendations for ways to increase options for individuals with disabilities. In the short-term, the Task Force recommends a pilot program to test ways of increasing supports and services for individuals with disabilities so that they have more independent living options. The Task Force also recommends that the state begin to work with ACHs that are interested in converting to other models of services and supports to assist individuals in living more independently.

f Under Section 10202 of the Patient Protection and Affordable Care Act, states can expand coverage for HCBS for people with incomes from 150% of the federal poverty guidelines (FPG) up to 300% of the SSI limits, or approximately 220% of the FPG. In contrast, the current NC income eligibility limit to qualify for SA is approximately 135% of the federal poverty guidelines. Thus, anyone who currently is receiving SA would be income-eligible for HCBS through a 1915(i) HCBS waiver.

g North Carolina has submitted a 1915(i) state plan amendment targeted to individuals in adult care homes. This waiver was submitted to address concerns raised by the Centers for Medicaid and Medicare Services (CMS) about the provision of different levels of personal care services in adult care homes versus in-home personal care services. More information about the state plan amendment is included in Chapter 4.

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 back into independent supported housing. As part of this, DHHS should:

a) **Submit a Medicaid 1915(i) state plan amendment or 1915(c) HCBS waiver to support individuals living in adult or family care homes (ACH) for 90 or more days who would like to move back to more independent living arrangements. The 1915(i) state plan amendment should be modeled after the state's Money Follows the Person[h] initiative for people in nursing facilities. The Medicaid 1915(i) state plan amendment should provide home and community-based services, including, but not limited to, personal care services, adult day care, and case management, and should pay for reasonable one-time transitional costs, including but not limited to security deposits, first month rent, or home modification.**

b) **DHHS should develop a process to evaluate people living in ACHs to determine whether people can appropriately live independently in the community with services and supports, and should provide counseling and transition services to appropriate individuals who want to move to more independent living arrangements.**

c) **The pilot program should initially be limited to 1,000 individuals who want to, and can appropriately, move to more independent living arrangements with services and supports. Individuals who move out of an ACH should continue to receive the same level of State-County Special Assistance (SA) payment in the community as they were receiving in the ACH. These SA in-home payments should be exempt from the SA in-home limits established as part of Session Law 2007-323.**

d) **DHHS should conduct an evaluation to examine costs, quality, individual satisfaction, and patient outcomes of this demonstration in supporting people with disabilities and the frail elderly who would otherwise need ACH level of care to live more independently in the community. The results of the evaluation should be shared with the appropriate legislative committees that address the needs of older adults and of people with mental illness, intellectual and developmental disabilities, and addiction disorders no later than fall 2013**

h Money Follows the Person is a nursing facility transition program that identifies consumers in institutions who wish to transition to the community and allows Medicaid funds budgeted for institutional services to be spent on home and community services when individuals move to the community. Centers for Medicare & Medicaid Services. *Real Choice Systems Change Grant Program: Money Follows the Person Initiatives.* US Department of Health and Human Services; 2006.

and annually thereafter. If the program is found to be successful, the North Carolina General Assembly should implement the program statewide both for individuals who are residing in ACHs and for those who have not yet entered an ACH but who meet the level of need criteria.

e) The North Carolina General Assembly should appropriate $100,000 non-recurring funds in state fiscal years 2012-2014 to the North Carolina Department of Health and Human Services to provide technical assistance to help interested ACHs create financially viable models that support people to live more independently in the community, such as, but not limited to, multi-unit supported housing, recovery-based scattered housing, transitional housing, and adult day care. DHHS should strive to work with rural, urban, large, and small ACH facilities.

f) DHHS should continue its work to remove statutory and regulatory barriers to independent living options for people with disabilities who receive services in the community.

The Task Force also recommends increasing funding for the NC Housing Trust fund to support the development of housing for individuals with disabilities. These funds should be allocated in the short term, because developing new or even modifying current housing stock is a long-term project that must start as soon as possible to ensure that needs can be met in the long run. Therefore the Task Force recommends:

Recommendation 3.2: Increase Funding for Housing for Individuals with Disabilities

a) 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.

b) DHHS 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.

Housing Inventory

In addition to a need for increased housing options for individuals with disabilities, there is a need for an inventory of all community housing options,

including 122C therapeutic mental health homes, substance abuse and developmental disability group homes, adult and family care homes, supported living arrangements, and independent living options. Such an inventory is important for planning purposes as the state works to increase independent living options for individuals with disabilities. Additionally, such an inventory should be available to placement workers and individuals with disabilities and their families so that they are fully informed about the housing options in their community. Some local management entities (LMEs) do an inventory as part of the community assessment they are required to do every three years, but this information is not always available to consumers and not all LMEs do this. (See Chapter 4 for more information on LMEs.) Therefore, the Task Force recommends:

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

As part of the local management entity's (LME) performance contract with the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS), DMHDDSAS should require LMEs, working with DMHDDSAS, the Division of Health Services Regulation, and the North Carolina Department of Health and Human Services housing specialists, to develop a real-time inventory of community housing options, including 122C therapeutic mental health homes, 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. The lists should be collected and aggregated at the state level and should be made available both online and in person through the LMEs.

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