Community Living:

Transitioning People with Intellectual and Developmental Disabilities Out of Adult Care Homes

Special Report

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DISABILITY RIGHTS
NORTH CAROLINA
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Executive Summary

In September 2013, Disability Rights NC began a three-year project to examine the prevalence and circumstances of people with intellectual and developmental disabilities (I/DD) who were institutionalized in Adult Care Homes[1] (ACHs).

Funded by a grant from the NC Council on Developmental Disabilities (NCCDD), Disability Rights NC was charged with identifying how people with I/DD came to live in ACHs. The project was to identify barriers to transitioning from ACHs to homes in community settings, make recommendations for changes necessary to prevent people with I/DD from being placed in ACHs, and facilitate their transition to homes in the community. In addition, NCCDD asked Disability Rights NC to create a blueprint for transitioning others with I/DD from ACHs to homes of their own.

During the three-year project, Disability Rights NC staff identified 27 people with I/DD who were living in ACHs but wanted to live in the community. Staff helped 15 of those individuals transition to community settings.

At the beginning of the project staff identified that ACHs self-reported to the NC Department of Health and Human Services that 1,812 people with I/DD were living in those facilities, and hypothesized that number was not a comprehensive count. After three years, the exact number of people with I/DD is still unknown because of minimal screening requirements. The 2016 licensure renewal data indicates that 1,299 individuals living in ACHs are known to have an I/DD. Individuals entering an ACH are not specifically screened for an intellectual or developmental disability. All of the people with I/DD contacted as a part of this project were either not known to the I/DD service system or were not currently receiving I/DD services prior to staff involvement and, therefore, providers may not have included them in the count reported to the State.

A second hypothesis at the start of this project was "individuals with I/DD in adult care homes are segregated from the community and unable to live fully integrated lives because their isolation prevents them from accessing activities that contribute to quality of life such as education and/or employment opportunities; participating in volunteer work, recreational activities or worship services of their choice; and maintaining relationships with individuals outside the adult care home." This hypothesis was found to be true. ACHs are institutions for purposes of *Olmstead* compliance and Medicaid law as held by a federal

[1] Adult Care Homes were originally established as "rest homes" or "domiciliary care homes" to provide care for people who were aging and could no longer live independently. According to 2016 licensure information, 27,164 people live in 582 licensed ACHs in North Carolina. These facilities range in size from 7 beds to 180 beds. In a 2013 decision, the U.S. Court of Appeals for the Fourth Circuit upheld a lower court's ruling that ACHs are institutions. *Pashby v. Delia*, 709 F.3d 307 (4th Cir. 2013). This is important because in the 1999 landmark case of *Olmstead v. L.C.*, the U.S. Supreme Court held that people with disabilities are entitled to receive services in the most integrated setting appropriate to their needs, making institutional settings inappropriate for the vast majority of people with disabilities. While project participants were all between the ages of 18 and 51, the *Olmstead* decision applies to people of all ages.

Facilities that are licensed as ACHs vary widely. Some facilities choose to serve only older adults while others admit younger individuals who have mental health or I/DD diagnoses. Some facilities serve only those people who have private resources to pay while others serve individuals who have only disability benefits and Medicaid. For the purposes of this project, Disability Rights NC staff focused on individuals whose housing and services are provided with public dollars. Regardless of the population served, all ACHs must meet minimum standards overseen by the N.C. Department of Health and Human Services (DHHS). The rules governing ACHs do not require staff to have adequate training or expertise in serving individuals with I/DD or other specific disabilities.

appellate court in the *Pashby* case, and many are geographically isolated from community centers with little access to public transportation. There is little opportunity or support for residents to engage in community life.

A third hypothesis was "the guardians of some individuals with I/DD living in adult care homes do not want them to move to community settings. Available community services either do not exist or are not sufficient to enable some individuals to live successfully in the community." During the three years of this project, Disability Rights NC staff found many examples of a system struggling to address the particular needs of individuals with I/DD. Each individual identified as part of this grant presented different challenges due to the unique nature of their personal circumstances. However, there were common themes: lack of funding for individuals not on the Innovations Waiver; limited training for providers and guardians; the lack of case management; an insufficient array of services and providers of services; and an over-reliance on professional guardians.

This report uses the stories of some of the people found living in ACHs to illustrate the causes for placements in ACHs and the barriers to transitioning people with I/DD to community settings. Overall, people with I/DD who participated in this project presented complex pictures of troubled histories and family dynamics that included poverty, substance use, physical and mental health issues, as well as abuse and/or neglect. The more complex the history and diagnoses, the more likely it was that an ACH placement occurred at a particularly young age.

The reasons an individual with I/DD was placed in an ACH were very often the same reasons it was difficult for that person to leave — in effect, they had no options other than institutional settings. The recommendations address the many actions necessary to create a blueprint and identify strategies to assist people with I/DD to live with dignity in the community of their choice.

Note: As North Carolina's protection and advocacy agency (P&A), Disability Rights NC staff members regularly visit ACHs and other facilities across the state to monitor conditions and advocate for the rights of people with disabilities. The agency's unique authority to access facilities serving people with disabilities made it possible for the agency's staff to identify and meet with people with I/DD living in ACHs. But the agency has other obligations pursuant to its federal funding requirements to advocate for the rights of people with disabilities in North Carolina. As such, it is important to note that this project and the resulting report are not intended to be a neutral, academic assessment of the state's current system of supports for people with disabilities but, instead, is explicitly part of the agency's work to make it possible for more people with disabilities to live integrated in their communities.

As a part of this project, some ACH residents with I/DD were determined to be living in unsafe conditions that did not meet legal requirements, all of which Disability Rights NC staff reported to the proper authorities. The goal of this project was to transition people with I/DD out of ACHs and in so doing, develop an understanding of how people with I/DD come to live in ACHs along with a blueprint to guide efforts to assist individuals with I/DD to move from ACHs to integrated settings in the future.

Project Methodology

During this project, Disability Rights NC staff visited 25 ACHs across the state, talked with numerous ACH residents, and identified 27 residents with I/DD who appeared to meet the criteria for eligibility in the project. Participants identified for this project were geographically diverse and came from all four of the proposed consolidated MCO catchment areas. While these participants are relatively few in number, their challenges reflect the way in which our system operates for ACH residents with I/DD across the state. Each expressed great interest in participating. All potential participants communicated frustration and sadness when asked about their living situations and all expressed a desire to leave the facility.

When a person with I/DD living in an ACH was identified who fit the project criteria, Disability Rights NC staff contacted the guardian, if applicable, to obtain permission for the ACH resident to participate in the project. Next, they contacted the MCO to determine whether the individual was receiving or had received I/DD services or any services at all from the MCO. Then, they reviewed the individual's records to confirm eligibility for the project and to understand the individual's history and placement needs. A significant barrier during this stage was the lack of current or historical information about the consumers in their case files. In most of the files Disability Rights NC staff reviewed, important documents were missing; in nearly every case the case file had never been created, was out of date, or was incomplete. One consequence of the multiple reorganizations of North Carolina's MH/DD/SA service system over the last 15 years is that many records have been partially or completely lost. While self-reports were the best source of information available, for participants with brain injuries or other disabilities that affect memory, it was impossible to obtain complete social or medical history. Some individuals had received services at some time in the past, however none were receiving I/DD specific services or mental health services that addressed needs related to their developmental disability. Disability Rights NC staff sought new, comprehensive evaluations for each of the 18 people who became clients.

Fourteen of the 27 identified potential clients had guardians, and two Department of Social Services (DSS) guardians did not allow their wards to participate. One family member guardian signed initial papers for her brother to participate, but she became so overwhelmed with the paperwork, the important decisions to be made, and challenges in her own life that she chose to discontinue his inclusion in this project.

Fifteen of the 18 clients have already transitioned to the community, with another expected to begin transition imminently. Two other clients, who had particularly complex needs, were unable to transition during the project and have no plans to transition at this time.

Joshua - A New Start*

When Disability Rights NC staff met Joshua, he had lived in an ACH for 34 years. He was placed there when he was 17 years old after discharge from a state psychiatric hospital. Joshua has family members who are involved in his life, but he does not have a legal guardian. His family was his only contact with people outside the ACH during his 34-year stay. At some point after Joshua was admitted, the ACH became a locked special care unit for people with Alzheimer's and dementia. There was no recent evaluation in Joshua's record but, every year, a doctor signed the required form stating Joshua was appropriately placed in this locked setting. He was labeled as a "wanderer" even though he and his family said he had never wandered from the facility and had none of the characteristics associated with Alzheimer's or dementia.

Disability Rights NC staff immediately suspected that Joshua might have an I/DD and contacted the MCO to request an evaluation. The MCO had no record of Joshua's existence. The MCO did not have a provider who could complete an assessment in a timely manner, delaying confirmation of Joshua's eligibility for services. After months of working with Joshua and his family, project staff identified a residential provider who agreed to admit him without MCO funding. The provider scheduled a comprehensive psychological evaluation. Joshua was determined to have an IQ of 55 and is considered to have a moderate intellectual disability. The residential provider and family worked with the MCO to get Joshua on the Registry of Unmet Needs. The waiting list at this MCO is projected to be many years, so Joshua will likely continue to wait for those MCO services for a very long time.

After getting settled in his new group home, Joshua enrolled in classes at a local community college. He enjoys his classes and excitedly tells everyone that he is "in college." He also participates in a day program. If staff had not found Joshua, it is likely he would have continued to live at this locked facility for individuals with Alzheimer's and dementia for the rest of his life, never having the opportunity to live a full life as an included member of his community.

Jimmy - Finally Home

Jimmy is a 40 year old man with I/DD and a Traumatic Brain Injury. He had been living in an ACH for about 10 years when project staff met him. He wanted to live somewhere quieter and smaller. With assistance, Jimmy moved to a three-person group home with beautiful views of the mountains. After he moved into his new home, Jimmy pronounced, "I want to live here a long, long time." He now has the opportunity to engage in community activities like grocery shopping. "I haven't been to the grocery store in more than 10 years."

** The names of all people with I/DD who participated in this project have been changed in this report to protect their identities. Disability Rights NC received written authorization to use all photos included in this report.*

Institutional Bias in Medicaid

Historically, throughout the United States, Medicaid spending has been concentrated on care provided in institutional settings. Indeed, while many types of institutional care are mandatory services that each state must provide in order to draw down federal dollars for Medicaid, most home and community-based supports (HCBS) are optional services that states can choose to cover, or not, in their Medicaid programs. And while mandatory services have to be available to all eligible Medicaid enrollees in a state's program, using waivers and other optional services can be offered to a limited number of enrollees in a state. For a general discussion of institutional bias and Medicaid's long term services and supports, see the Kaiser Family Foundation's 2015 report *Medicaid and Long Term Services and Supports: A Primer*.

In 1999, the U.S. Supreme Court clarified in its *Olmstead v. L.C.* decision that unjustified institutionalization is discrimination. States began, in earnest, to work to rebalance their spending toward HCBS. In North Carolina, HCBS are available to people with I/DD through the Innovations Waiver and to a lesser degree outside of Medicaid through state-funded services. States' efforts to increase availability of HCBS and reduce reliance on institutions is discussed at length in the Kaiser Family Foundation 2014 report *Olmstead's Role in Community Integration for People with Disabilities Under Medicaid: 15 Years After the Supreme Court's Olmstead Decision*.

This historic funding imbalance, not yet fully resolved, is a major source of pressure toward institutional settings for North Carolinians with I/DD. The State uses a combination of Medicaid and state funding to

Medicaid's Institutional Bias

One of the policy decisions NC leaders have made is to choose to use Medicaid dollars to support care in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID), which is a type of facility available only for individuals in need of, and receiving, active treatment (AT) services. AT refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. AT does not include services to maintain generally independent clients who are able to function with little supervision and who do not require a continuous program of habilitation services.

The 1915(c) waivers or Home & Community – Based Waivers are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS Waiver program to individuals who quality for ICF/ID level of care. Programs can provide a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.

States may not limit access to ICF/ID placement, or have a waiting lists, as they may for other optional services including HCBS waivers such as Innovations. When states, such as North Carolina, underfund their HCBS waivers, it reinforces an institutional bias.

provide I/DD services. How North Carolina allocates those dollars is driven by its public policy. There are three major funding policies that contribute to the institutional bias experienced by North Carolinians with I/DD: Medicaid eligibility; Special Assistance; and Medicaid Waiver design and funding.

Medicaid Eligibility

In North Carolina, Medicaid provides health care coverage to nearly 2 million people. Many low-income people with disabilities or other specific conditions qualify for Medicaid. As a joint federal and state public health insurance program, Medicaid includes matching funds from the federal government (at an approximate ratio of 2 to 1) and mandates that states cover certain services, such as hospital and preventative care. That means that for every dollar the state spends on Medicaid eligible services, the federal government pays two dollars.

Medicaid mandates specific services that must be available to anyone who meets eligibility requirements. Mandated residential services include Skilled Nursing Facilities (SNF) which cover all medically necessary services for beneficiaries. However, a state may choose whether or not to provide optional services, such as Personal Care Services and Home and Community-Based waiver programs (including Innovations and CAP/ Disabled Adults), which enable individuals with disabilities or families living below the poverty line to live and receive services in their own communities and avoid costly institutionalization.

Although some requirements for the Medicaid program are set by the federal government, states have flexibility in administering the program. North Carolina determines eligibility criteria for Medicaid coverage.

Special Assistance

None of the people who were a part of this project had any funding other than their Social Security benefit, Special Assistance, and Medicaid. State law permits ACHs to receive $1,182 a month for room and board, which are often provided by a resident's Social Security benefits and supplemented by state and county Special Assistance funds, administered through the local DSS office. In total, this amounts to $1,248. From that, the resident receives $66 each month for personal allowance, which is used to pay for pharmacy bills as well as personal items such as toiletries or cigarettes. The result is that residents will have great difficulty in saving money or accumulating the necessary assets to plan to move out of the ACH.

Were they ever to accumulate the necessary assets to leave the ACH, an additional funding scheme stands in their way. Specifically, the state, so far, has chosen to cap at 15% the number of SA slots allocated to people living in their own homes (Special Assistance – In Home slots, or SA-IH), although the Secretary of Health and Human Services and the General Assembly have the authority to increase that amount. As a result, a number of counties reportedly have waiting lists for SA-IH slots, even though the statewide 15% cap has not been met. This indicates a need to reallocate existing slots or create additional slots.

Moreover, the State spends approximately $140 million annually on the Special Assistance program, with only about 10% going to people living in their own homes. In early 2016, the NC General Assembly appropriated additional Special Assistance funds to facilities to further support the cost of housing people in ACHs without an increase for people living in their own homes. This limits the opportunities for people with ID/DD to have access to an array of choices in housing and services outside of ACHs.

Together, and individually, these funding policies create a clear institutional bias that keeps people with I/DD from transitioning into private homes.

Medicaid Waiver Design and Funding

The North Carolina Innovations Waiver provides home and community-based (HCBS) Medicaid services and supports for individuals with I/DD who are eligible for ICF/ID level of care and are at risk of institutional placement in an ICF/ID. The goal is to provide an array of community-based services and supports to promote choice, control, and community integration as an alternative to institutionalization in an ICF/ID. Currently, there is a waiting list for individuals to get on the Innovations waiver. Beyond that, there are inconsistent levels of available community supports for individuals with I/DD in North Carolina, which often results in an ACH becoming the primary option in an otherwise limited service array. Unlike funding for placement in an ICF/ID institution, there is no entitlement to services with the Innovations Waiver.

The state has chosen to cap the total number of "slots" on the Innovations Waiver at 12,000, which has been at capacity for years. Accordingly, whenever an individual is found to be eligible for the Waiver, he or she will likely be on a waiting list for the waiver, called the "Registry of Unmet Needs," for years. There are a small number of emergency slots available but not enough to meet all new emergencies. Collectively, the waiting list for the Innovations Waiver is made up of approximately 11,000 people across the state who are unable to access needed services through the waiver.

Currently, each LME/MCO keeps its own waiting list, and Disability Rights NC staff believe the lists are incomplete. Notably, none of the individuals identified through this grant were on a waiting list for the Innovations Waiver. When Disability Rights NC staff first met them, 16 of the 18 clients in this project were not known to their MCO as having an I/DD. The other two had received I/DD services in the past, but were not currently receiving I/DD services. This suggests that the number of people with unmet needs in this state far exceeds 11,000, although it is difficult to predict exactly how many of the residents of ACHs with I/DD, or others, would be eligible for Innovations Waiver services but are currently unknown to their MCO.

When Disability Rights NC first met them, 16 of the 18 clients in this project were not known by their MCO as having an I/DD.

When Innovations Waiver or other appropriate services are not available, ACH placements are likely, resulting in further institutional bias.

The Long-Term Cost of the Innovations Waiting List

When people with I/DD are placed on the Innovations waiting list for an identified need, that means that need goes unmet, and so it continues to grow. As the need grows, the cost for addressing it will grow as well. The need may grow to an extent that more intensive institutional placement is sought, such as an ICF/ID or a Skilled Nursing Facility, which is the most expensive and restrictive option. By increasing funding for less expensive services in the community, the state can avoid costlier services and individuals with I/DD can be served in less restrictive settings. Relatedly, if a person without I/DD can receive necessary supports to live in the community, but a person with I/DD is forced to enter an institution to receive services, that raises concerns about possible violations of the ADA.

CAP/DA Waiver

CAP/DA (Disabled Adult) is another Medicaid Home and Community Based Services (HCBS) waiver that can be used for adults with disabilities, including people with I/DD. Eligibility for this waiver requires that recipients meet Skilled Nursing Facility Level of Care, are 18 years or older, live in a private residence and are at risk of institutionalization, or live in a Nursing Facility and want to return to a private residence. There is a waitlist for this program that varies depending on where you live in the state. In 2013, it was reported that there were more than 8,000 residents on the waitlist for CAP/DA.[2] Staff at Disability Rights NC have seen it take up to two years from application for a person with I/DD to receive a slot for this program.

One individual who participated in the project moved from an ACH to a Skilled Nursing Facility after his medical needs went untreated and he needed a higher level of care. After 90 days at the nursing facility, he became eligible for CAP/DA through the Money Follows the Person (MFP) program. This program allows an individual to be prioritized to the top of the existing waitlist if they have been in a Nursing Facility for 90 days or more and want to transition back to the community. Like the client with whom Disability Rights NC worked, lack of appropriate medical care in an ACH can lead to the need for a skilled nursing level of care for other individuals with I/DD, which also can make them eligible for CAP/DA through the MFP program.

[2] https://www2.ncdhhs.gov/dma/cap/CAPDA_Slot_Utilization_Waitlist_Mgmt.pdf

The Realities of Living in an Adult Care Home for People with I/DD

Admission Process

Failure to Screen for I/DD during Admission to an ACH

There are two statewide admission forms for ACHs, called the FL-2 and the Pre-Admission Screening and Resident Review (PASRR). These address current diagnoses, medications, and personal care needs such as bathing, toileting and eating. The PASRR also offers an opportunity to report both mental health and I/DD diagnoses. North Carolina does not require screening for I/DD for individuals seeking admission to an ACH. The inclusion of the PASRR in the admission process is an effort to implement the requirements of a 2012 settlement between the State and the U.S. Department of Justice regarding institutionalization of people with serious mental illness (see "DOJ Settlement" on page 9). According to senior staff at the NC Department of Health and Human Services, although the mental health information in the PASRR is used to establish eligibility for mental health services and supports, the I/DD information captured on the PASRR is not systematically recorded and used to identify needs. It is not clear what changes in data systems or elsewhere would have to be made to allow the I/DD data captured on the PASRR or another screening tool to be useful. When a hospital discharge or other urgent need to arrange for housing arises, a facility that does not have a lengthy admission process can appear to be the only choice. This means people with I/DD admitted to ACHs may not be known to the ACH staff as someone with I/DD; and even if they are, there are no services specifically for people with I/DD in ACHs. Even if known to the ACH staff, the ACH staff are not required to have any specialized training in working with people with I/DD. In contrast to the low information process that precedes ACH admission, residential service providers who serve people with I/DD have more selective admission processes that often include a thorough assessment of the needs of the individual.

Information about Services in ACHs

Among the people who transitioned out of ACHs in this project, most had a guardian or family member who consented to the ACH placement without a clear understanding of what services and supports would be available in the facility and/or a belief that ACHs were the only option available. Several guardians shared that they were told by doctors and social workers that the ACH placement was the only option for the person with I/DD because community placement was not possible or advisable for an individual with complex diagnoses. And because HCBS waiver services are not available to people living in an institutional setting, the Innovations waiver and the supports it offers are off limits to ACH residents.

For example, guardians often relied on professionals (including social workers, medical professionals, and other providers) to make appropriate referrals when their ward was in need of a transition from one placement to another. However, the lack of LME/MCO authorized funding for appropriate community services and supports (through state funded services, the Innovations Waiver, or Medicaid B3 services) limited community based alternatives and made placement in an ACH the default. One misunderstanding commonly cited by guardians was the belief that people with I/DD need 24/7 supervision and that such a high level of supervision would be available in an ACH. However, the resident to staff ratios at ACHs generally do not allow for close supervision of residents. For example, an ACH with 91 to 100 beds is required to have the full time equivalent of 5 aides during the first and second shift (a 20 to 1 resident to staff ratio), plus a supervisor for each shift. During the third shift, the staffing requirement drops to 3-4 aides with a supervisor on site.

Multiple guardians involved in this project believed ACHs were treatment facilities and did not understand the difference between ACHs, nursing homes, group homes, and family care homes. This was true for both family member guardians and professional guardians. There are inadequate requirements for ACHs to be trained to address the behavioral needs common to many people with I/DD.

DOJ Settlement

In July 2012 the State of North Carolina agreed to an eight-year plan to develop community-integrated housing and services for 3,000 individuals with mental illness living in ACHs. The plan was the State's attempt to address a July 28, 2011 Letter of Findings issued by the US Department of Justice (USDOJ) which found North Carolina in violation of the ADA. That letter was issued in response to a complaint filed on July 26, 2010 by Disability Rights NC alleging North Carolina's practice of warehousing people with mental illness in ACHs violated the ADA's integration mandate.

In the plan, North Carolina agreed to expand community-based services and supportive housing for people with mental illness over the next eight years. The state also agreed to establish a pre-admission screening process to prevent people with mental illness from unnecessarily entering institutional settings – specifically ACHs. In addition, the state agreed to create a person-centered institutional discharge planning process to help people move smoothly to community-based settings.

Find more information about the eight-year plan and the State's progress on Disability Rights NC's website -- www.disabilityrightsnc.org/ncs-transition-community-living-initiative.

There is a need for people with I/DD, guardians, and family members to have an understanding of the services and supports available in various placements so that they can make an informed decision about housing and services.

Responsibility of LME/MCOs Related to Discharge Planning for People with I/DD

In North Carolina, the Division of Medical Assistance (DMA) and Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMH) contract with LME/MCOs to administer Medicaid and state-funded behavioral health services.

North Carolina law requires that LME/MCOs coordinate care and provide a successful transition for consumers being discharged from state facilities or other inpatient settings into **ongoing treatment in the community**. N.C. Gen. Stat. § 122C-115.4(5). The LME/MCO is required to ensure that care "is coordinated, received when needed, *likely to produce good outcomes*, and is neither too little nor too much service to achieve the desired results." *Id*. (emphasis added). Care coordination from the LME/MCO should specifically include "participating in the development of discharge plans for consumers being discharged from a State facility or other inpatient setting who have not previously been served in the community." *Id*.

The LME/MCO must help develop discharge plans, and must work with the facility and the individual on a plan for discharge beginning almost immediately upon admission. Careful, person-centered, community-based discharge planning for individuals with I/DD leaving state and private hospital settings would significantly decrease the potential for placement in an ACH. Several individuals included in this study likely could have avoided years in an ACH if they had been provided the level of support called for when they were discharged from inpatient settings.

Discharge planning from psychiatric facilities

Many people are discharged from North Carolina psychiatric inpatient treatment each year without meaningful discharge planning or follow-up. In the case of several people identified as part of this initiative, discharge from a psychiatric hospital immediately preceded and led to ACH placement. This was true for discharges from state-operated and private psychiatric hospitals. At least eight of the 15 individuals who were transitioned had a history of one or more psychiatric inpatient hospitalizations and were discharged directly to an ACH without adequate discharge planning. Some guardians reported they were told by hospital discharge planners that treatment would continue at the ACH, which the guardians later found did not occur. No evidence was found of MCO involvement in the discharge process for most participants. For the two participants who did have MCO involvement with discharge planning, those staff had no I/DD expertise and only focused on mental health needs, ultimately leading to additional hospitalizations and failed placements. Participants reported that they were not included in planning on their own behalf and that they felt no control over their environment or their future.

Living in an ACH

Loss of Independent Living Skills

Several of the individuals who were part of this project experienced mental and physical decline during their ACH stay. As their physical and emotional needs became greater, the availability of appropriate options for transition into the community diminished. Disability Rights NC has found through its work in many institutional settings that individuals who have been institutionalized and segregated are often fearful of living in the community and believe they cannot be successful outside of an institution. There is a need for more in-reach and education from LME/MCOs, service providers, and advocates to residents and those who influence them about community living options and supports that would lead to successful

Chloe - Loss of Independent Living Skills

Chloe is a 26-year-old woman who was living in an isolated ACH when she was identified by project staff. According to her most recent evaluation in 2015, Chloe has a Full Scale IQ of 61. Despite significant family challenges as well as a complicated trauma history, Chloe completed high school with a certificate, was attending community college classes, and held a part-time job in the food industry in the community. Unfortunately, she cycled in and out of psychiatric hospitals. According to her guardian, hospital discharge planners reported that there were no available placements close to home and "kept moving her farther and farther away."

When project staff met Chloe, she had been living in an ACH for a few years. She was drooling on herself, unable to sit on her own, and a wheelchair had just been ordered for her due to numerous falls. Staff were able to transition Chloe back into the community and only a 20-minute drive away from her family.

In her new home, she had a pharmacy review and a significant number of her medications were discontinued. While she no longer needs a wheelchair, she continues to struggle with relearning the basic independent living skills she lost while in the ACH.

living in integrated settings. As a consequence, many individuals are afraid to leave their institutions and feel they have no other choice. This held true for some of the residents who were part of this initiative.

Residents do not have the opportunity to learn independent living skills because the ACHs are designed to do those things for residents rather than to teach and support residents in doing things for themselves. For example, meals are provided to residents of an ACH. Residents do not have the opportunity to shop for their own meals or learn to cook.

Independent living skills are needed on a daily basis to promote independence, including self-care skills like eating, dressing, bathing, toileting, and grooming. They also include other skills like home management, cleaning, shopping, laundry, money management, and medication management. Even if ACH residents had some or all of these skills in the past, after spending years at an ACH, they are at risk of losing rather than gaining skills. Because it does not provide opportunities to learn, maintain, or re-learn independent living skills, our current system does not support the recognized best practice of moving to independent housing with appropriate supports immediately from an institutional setting.

Medical Care and Polypharmacy

While medical care was not seen as an issue that led to ACH placement for any of the people in this initiative, it was an issue for almost everyone once ACH placement occurred. Lack of adequate medical and dental care and overmedication were reported in numerous cases, which created barriers to transition.

Medication review for many ACH residents who were part of this initiative revealed significant reliance on prescription drugs. Most common were psychotropic medications, pain medications, muscle relaxers, and others that have drowsiness as a side effect. Some people were prescribed as many as 20 different medications. Disability Rights NC staff witnessed facility staff encouraging residents to take an "as needed" or "prn" medication when

Armando - Negligent Medical Care

Armando complained to the ACH staff for months about abdominal pain. The ACH staff gave him Tylenol for the pain and he was seen by the in-house medical provider who recommended the ACH schedule him an appointment to see a specialist. The ACH never made the appointment, so Armando continued to suffer pain. Within a few days of transition to a group home, the group home staff recognized he needed medical attention. He was taken to a doctor, who determined he needed gall bladder surgery.

Armando is not the only person to suffer pain without appropriate medical care at this ACH. In 2015, this ACH settled with the state and paid $10,000 in penalties for failure to administer medications as ordered by a physician. In 2016, penalties were issued in the amount of $23,000 for other medication and medical issues, not including Armando's.

agitated, instead of assisting the resident to work through the issue which led to the agitation. As noted previously, staffing ratios at ACHs do not allow for significant one-on-one interactions between residents and staff. Further, licensure rules do not require that staff have any training or knowledge related to I/DD or any of the other disabilities of residents. This has particularly serious potential consequences for residents with behavioral health needs that may result in overreliance on medication or criminal justice involvement for disability-related behaviors.

Failure to provide appropriate healthcare such as physical therapy was also an issue for some of the people who were part of this initiative. One woman with I/DD and a physical disability experienced a significant decline in physical ability because she was not provided necessary physical therapy while living at the ACH. This meant a higher level of care was needed for transition than otherwise should have been necessary had she received therapy. In another situation, a lack of appropriate health or sex education and other factors led to an unplanned pregnancy for one of the women supported through this initiative. She had little understanding of the physical and emotional aspects of her own pregnancy as it progressed which created

Josephina - MCO Did Not Follow Treatment Recommendations

In 2013, while living in a group home, Josephina had a comprehensive psychological evaluation. It outlined significant needs and included detailed treatment recommendations for her co-occurring mental health and I/DD diagnoses. None of the recommendations had been implemented or pursued by the MCO, corporate guardian, or ACH. In fact, the evaluation was not even available as part of her record at the ACH.

The following were some of the treatment recommendations not followed by the MCO, guardian, and ACH:

- Targeted case management services.
- Day activity services and vocational services.
- Treatment goals should focus on improving functional impairments.
- Psychiatric and psychotherapy services.
- Continued regular medical and dental services are recommended to maintain [her] health.
- Residential services are recommended. Treatment goals should focus on improving functional impairments.
- Developmental therapy services.

significant transition challenges.

Failure to administer medications, provide treatment, and refer residents to appropriate care and treatment were the top two issues most frequently cited by regulators of ACHs in the past year.

Vulnerable to Exploitation

ACH residents who rely on Social Security benefits, including all the people supported during this project, received $66 per month for personal expenses. That amount has to cover clothing, snacks, prescription copays, and any other personal expenses that come up. State regulators investigating an ACH where one person supported through the project lived documented in its findings that the ACH implemented a resident work program that was used as a tool for discipline and coercion and for which residents were not given fair or equitable compensation for work completed that benefited the facility.

Employment or Meaningful Day Activity

Employment is a critical measure of independent living. A real job for people with I/DD not only provides meaning to their day but leads to social and economic inclusion and independence. Having a job changes how the individuals with I/DD (or any disability) see themselves, and positively changes how people in the community perceive people with disabilities.

While planning for transition from an ACH to the community, a number of individuals with I/DD said they were interested in obtaining a job in the community. However, there were significant barriers to realizing this goal. It is unclear if challenges to meaningful employment were related to their placement in an ACH or are the same challenges facing many people with I/DD living in the community.

There are three funding sources that provide employment help for individuals with I/DD. In this context, a job is provided through a service called Supported Employment, which helps people with disabilities including intellectual disabilities, mental health diagnoses, and traumatic brain injury, among others, to obtain and maintain employment. The three funding sources are: Supported Employment as a B3 service; Vocational Rehabilitation (VR) Supported Employment; and Supported Employment for Innovations Waiver participants.

One individual with I/DD needed supported employment that was never authorized and another needed more supported employment support than could be authorized since the participant did not have Innovations funding.

Having a job was an important goal for one of the clients involved in the transition. Since he did not have a waiver slot, he was offered B3 Supported Employment. Under the B3 service definition, the supported employment service lasted only six months. Those supports were not in place long enough to assure skill development and long-term job supports that could have led to success. The LME/MCO denied a request for an extension, and he lost his job shortly after the six month Supported Employment ended.

There were other transitioning individuals in the project who received VR funded supported employment rather than B3 funded supported employment. They all experienced problems with the VR program. One person was excited to return to employment. To help him, his public guardian contacted the local VR office and was turned away when a VR employee told her that VR does not help people with disabilities. With encouragement from Disability Rights NC staff, the guardian contacted VR again and successfully referred

the individual. He was assigned to a contract provider, but his job search stalled. There were no jobs in his community that matched the exact position he desired, which is a specialty trade in construction. Without talking with him about broadening his employment goal to better match the job market, the VR counselor and provider indicated the lack of vacancies in this particular job as the reason the job search was ended. Another person who received services through a VR contract provider applied for a few jobs but has had no interviews to date. Other issues experienced by people transitioning out of ACHs included long delays in the receipt of services, and counselors providing them information in a manner that was not suited to their disabilities. This left them without the information they needed about the VR program and their rights with respect to VR.

Supported Employment: Eligibility and Service Definitions

B3 I/DD SE

- Service is available through LME/MCOs.
- Must be 16 or older, meet the ICF/ID level of care criteria, and not be eligible for VR or Innovations Waiver supported employment.
- Prior authorization for the service is required and reauthorization is required every 90 days.
- Job development, training, and support is available for up to 6 months with state funded long term (10 hours / month) funds available for follow up support. Authorization is required to exceed these limits.

Vocational Rehabilitation SE

- Service is available through local VR unit offices. Must be found eligible for VR services and develop an employment plan.
- Must have a significant physical or mental impairment that seriously limits three or more functional capacities (such as communication, interpersonal skills, mobility, self-care, self-direction, work skills, work tolerance), which causes a substantial impediment to employment. People who receive SSI or SSDI benefits are presumptively eligible for VR services.
- Job development, training, and support is available for up to 24 months with state funded long term funds available for follow up support. Authorization is required to exceed 24 months.

Innovations Waiver SE

- Service is available through LME/MCOs. There is a waitlist for Innovations Waiver services.
- Must demonstrate the need for supported employment.
- There is no time requirement limiting how long a recipient can receive job development, training, and support. There are budget and service hour limits.

Hard to Get Out: Barriers to Discharge Planning

Geographic Challenges

The individuals who participated in this project ranged in age from 18-51. Despite their young ages, many of the people with I/DD had already lived in several different ACHs before they became involved in this project. Some had been moved at their own request, and some were discharged because of behaviors that appeared to Disability Rights NC staff to be manifestations of their disability for which they had never received services. Some had been transferred to an inpatient-psychiatric program far away from their current home and then discharged to yet another ACH even further from their home, family, or other natural supports. Far away from home, the individuals' family and friends sometimes had difficulty visiting because of the distance. This distance also made it more difficult to transition the individual back to their home community.

Some of the transitioning individuals wanted to live in a county that was not part of their assigned MCO's catchment area. This created additional complications, due to travel distance for the MCO staff and guardians who needed to see the person and because the MCO did not have service providers as part of their network in the county where the person wanted to live. While there is a process for an MCO and

Brianna and Erica — Geographic Challenges

The disruptiveness of the living location changes that our current system creates is best illustrated by tracking the moves made by Brianna and Erica.

Brianna

866 miles in 24 months

From August 2014 to August 2016

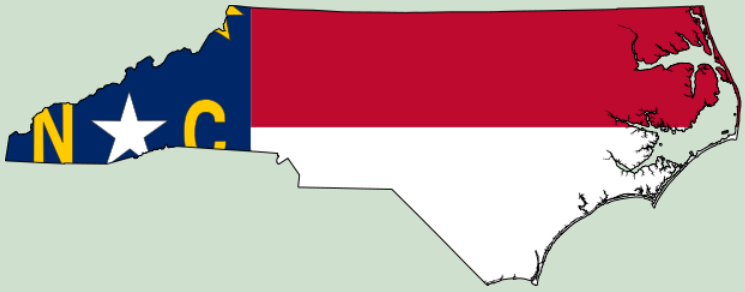
Living in ACH in Buncombe County
Moved 16 miles to hospital in Asheville
Moved 105 miles to housing in Lake Norman
Moved 45 miles to CMC in Randolph County
Moved 241 miles to hospital in Jacksonville
Moved 241 miles to housing in Charlotte
Moved 47 miles to hospital in Stanly County
Moved 36 miles to housing in Union County
Moved 48 miles to hospital in Charlotte
Moved 87 miles to community placement in Kernersville

Erica

678 miles in 25 months

From April 2014 to May 2016

Living in ACH in McDowell County
Moved 45 miles to hospital in Asheville
Moved 312 miles to ACH in Clinton
Moved 221 miles to ACH in Wilkes County
Moved 77 miles to community placement in Gastonia
Moved 23 miles to ACH in Charlotte



provider to execute a person-specific contract, that process did not work quickly enough to be useful for one person who experienced a substance use relapse while waiting for the contract to be executed.

Waiting to be Connected to Community Services

One person in this program, who had lived in an ACH for more than eight years, was eventually approved for an Innovations Waiver slot, helping make his transition to the community possible. Though he was not connected to the MCO when staff met him, MCO agreed to backdate his entry onto the waitlist by eight years, bringing him to the top of the list very quickly. Because of significant medical issues, another person needed to transition from an ACH to a hospital, and from there to a Skilled Nursing Facility, also known as a nursing home. A third person transitioned from an ACH to an Intermediate Care Facility (ICF). After some time, the people in the nursing home and ICF were eligible and approved for a program called Money Follows the Person MFP, which provides funding to help people both transition into the community and put them on a fast track to obtaining community services through programs like the Innovations Waiver or the Program for All-inclusive Care for the Elderly (PACE), an integrated health and case management/care coordination program for older adults.

However, the MFP program is not available to the people who live in ACHs. None of the remaining project participants could access Innovations funding because they did not qualify for ICF/ID level of care or because of the waiting list for Waiver services. It is important that any planning to support people with I/DD in ACHs to transition to the community consider that many people with I/DD do not meet the requirements of the Innovations waiver but still need supports to be successful in the community. Although transition plans were pieced together using other funding sources, these other funding sources were limited in intensity and duration, lessening their long-term benefit to the individual with I/DD. For some of the people, this had a negative impact on their quality of life and placed them at risk of readmission to an ACH or admission to a psychiatric hospital. One woman with I/DD became pregnant while still at an ACH, and while her MCO approved emergency housing and day support funding, those (non-Innovations) services did not offer true person-centered support, described by NC DHHS as "planning for services and supports that focuses on the strengths, interests, and needs of an individual." Person-centered planning is a central principle in recent I/DD service policies at the state and national level. Without person-centered planning, piecing together disconnected services and funding streams can be inefficient at best and dehumanizing at worst. Person-centered planning is not generally available at ACHs.

Overreliance on Professional Guardians

Many, but not all, of the people who participated in this project had a guardian. Of those with a guardian, all were under full guardianship, which covers all areas of decision-making. Guardians involved in this project included family and friends, a contract agency, and local DSS agencies. Guardians from a contract agency or a local DSS are referred to as "professional guardians." North Carolina's current system relies heavily on guardians to fill the gap where appropriate services, especially case management, are unavailable. Some clerks of court mistakenly believe that a guardian will have the ability and resources to substitute as a case manager for the newly assigned ward. However, even public and corporate guardians are frequently unaware of the complexities of the I/DD system or the needs of their wards with I/DD. As stated earlier, several misunderstandings held by guardians regarding the true nature of ACHs came to light during the project.

Initially, many family and professional guardians were hesitant to explore options for transition from ACHs because of an approach to guardianship that emphasizes safety over reasonable risk and does not facilitate the individual's involvement in making decisions that affect their lives. It was their belief that their wards

Each type of guardian has specific duties; however, all types of guardians must follow the same principles. All guardians must:

- Ensure that the guardianship is tailored to meet the actual needs of the individual ward.
- Make decisions that ensure the health and well-being of the ward, based on what the ward would decide if capable of making the decision.
- Seek information about the ward's value system, wishes, and needs from the ward, the ward's family, friends, or legal documents such as a Living Will.
- Involve the ward in all decisions to the extent possible.
- Allow the ward the opportunity to exercise rights that are within his/her comprehension and judgment, giving the ward the same possibility for error as a person who is not incompetent. This is a concept commonly called "dignity of risk."

would be safer in an ACH. For example, they were unaware that not only are resident to staff ratios high in ACHs, but in many instances the NC Division of Health Service Regulation (DHSR) cited the facilities their ward resided in for not even meeting these minimal requirements. In one facility where two of the people in this initiative resided, DHSR found that the facility failed to assure staffing met minimal requirements, which placed residents at risk for their personal care and supervision needs. Other examples of previously unreported incidents of resident abuse were found. For example, Disability Rights NC learned that five of the people who were part of this initiative—nearly one-third of the 18 people who became clients in this project — were victims of physical or sexual abuse while at the ACH. All incidents of abuse were reported to proper authorities.

Another factor leading to ACH placement, and reluctance of some guardians to support transitions to community settings, is case overload and a push for efficiency. Professional guardians are required to visit their wards at least quarterly. Many professional guardians carry caseloads of dozens, limiting the time available to each person they are responsible for supporting. As guardians of last resort, DSS must accept all new guardianships assigned by the Court, regardless of staff capacity. Professional guardians with overwhelming caseloads can make it more likely they will be able to meet their visiting requirements if they concentrate their wards in a small geographic area, sometimes placing multiple wards in the same ACH.

While one staff member is assigned to each guardianship case, rules allow any staff person from the agency to fulfill the quarterly visiting requirement, which makes it more difficult to establish trust and familiarity with a ward, both of which are necessary to provide a ward with appropriate support. It also makes it difficult for guardians to observe changes in the ward over time. Some professional guardians involved in the project expressed reluctance to move a ward to a different part of the state, even if it was a more appropriate setting, because it would make the quarterly required visits more difficult.

This is not to say that all professional guardians are biased toward institutionalization. Some professional guardians shared that they knew an ACH was not an appropriate place for their ward to live, but they were frustrated by the limited array of available, appropriate community-based placement options for their wards.

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During this project, project staff provided information to

James - Overprotective DSS Guardian

After being abused, neglected and exploited by a family member, James was assigned a DSS guardian who placed him in an Adult Care Home. He had been living in the ACH for several years when he learned about the project from another resident. At the first meeting with James and his DSS guardians in March 2014, his guardians said they were willing to work with project staff to explore options, but they expressed concern regarding independent living options because they believed James was at risk for exploitation. Disability Rights NC staff connected the guardian with local mental health professionals who explained the benefits of allowing this young man the opportunity to make his own decisions with the assistance of informal supports. Almost two years after staff began working with James, a psychologist assessed him and determined he was not only a good candidate for independent living, but also for restoring his competency. With Disability Rights NC's assistance, James petitioned for and received restoration of his competency and no longer had a guardian.

The staff pulled together a transition team consisting of representatives from the MCO and Vocational Rehabilitation. A few months later, he moved to a two-bedroom apartment with his girlfriend. He is employed as a dishwasher at Golden Corral and receives supported employment services to help him maintain that job.

Above: James signs papers after the Clerk of Court restored his competency.

both professional and family guardians about the possibilities for supports and services in the community, compared to the services inside the ACHs. During a housing planning meeting for one client, an MCO housing coordinator explained to a guardian the difference between ACHs and group homes: "[T]here is an emphasis on person-centeredness in a group home; staff tend to have higher qualifications; there is more oversight at these kinds of facilities and staff are more invested in the clients." In another situation, a strong, supportive family member, expressed dismay that neither she nor her brother had ever been told by anyone that he could be eligible for any services.

For some family guardians, financial barriers were significant. Wards were placed in facilities far away from their natural supports, and the guardians were unable to travel to the facility due to financial or work constraints. Many guardians did not see the facility before their family members were placed there, and visits following placement were infrequent.

At times, when contacted about participating in this project, guardians took months to sign and return the required documents, delaying the possibility of transition. In certain cases, Disability Rights NC staff conveyed concern about the safety and wellbeing of the individuals to various public agency staff, but the agency staff were limited by the reality of long waiting lists for services. It was common for public agency staff, in particular, to require several calls and/or emails over a period of weeks or months to prompt a response. This

It was common for public agency staff, in particular, to require several calls and/or emails over a period of weeks or months to prompt a response.

occurred with several public agencies, including local DSS offices and MCOs. Whether a limitation created by excessive workloads or a symptom of acceptance of slow responses as reasonable in those agencies, people in this project stayed in institutional settings longer than was necessary because of these delays.

Failure to respond to or even acknowledge communication was a common experience. In one case, a professional guardian admitted she had not read emails about her ward from Disability Rights NC staff for months because the emails were encrypted to protect confidential information, and she did not know how to open the emails; she never contacted the email sender to request assistance. Corporate, DSS, and family guardians also reported frustration with repeated attempts to contact staff in public agencies.

Service System Needs

The Impact of Ongoing Trauma

Nine of the 15 people with I/DD who completed a transition—over half—had a self-reported or medically-noted history of experiencing significant abuse, neglect, or exploitation, including events such as witnessing the murder of a parent, loss of a parent due to suicide, and being the victim of recurrent sexual and physical violence. The actual number may be higher since this information was based on record reviews or self-reports. These numbers are comparable to national data.[3]

At least seven of the people who participated in this project self-reported or had documented abuse and/or neglect as children but were not screened for trauma. Since they were not receiving appropriate treatment for abuse and neglect, some individuals experienced long-term effects, and were eventually diagnosed with post-traumatic stress disorder, anxiety, and depression. See Kara's story highlighted below for an example of the effects of long-term unrecognized and untreated trauma.

[3] See http://disability-abuse.com/survey/index.htm; also Hingsburger, Keynote in Reinventing Quality Conference, Baltimore, MD, 2012; National Association of State Mental Health Program Directors (NASMHPD), 1998; Hodas, 2004; Ryan, 2000; Beall & Warden, 1995; Charlton et al, 2004; White, Holland, Marsland & Oakes, 2003; Sobsey & Does, 1991; Sobsey, 1994; inter alia.

Kara - Never Treated for Trauma

Kara was 25 years old when Disability Rights NC met her. She has a diagnosis of a mild I/DD, seizures beginning at the age of two, and was repeatedly exposed to alcohol in utero. She experienced physical, mental and sexual abuse as a child, and witnessed a severe and disturbing crime prior to her 11th birthday. Even though Kara was diagnosed with Post-Traumatic Stress Disorder (PTSD) at that time, there is no evidence that she received any services directly related to the PTSD diagnosis. Instead, she was placed in an ACH at the age of 22 after seven hospitalizations related to depression and suicide attempts. It was only in 2015, twelve years after her first hospitalization and at the request of Disability Rights NC staff that Kara received a comprehensive psychological evaluation in which a clinician noted the importance of treating Kara for PTSD. The physician stated, "[Kara] has suffered from PTSD for a long time which remains unresolved. She has also developed Borderline Personality Disorder from her turmoil-filled past and evidenced by her current behavior patterns. If [Kara] can be introduced to a very stable, supportive and structured living environment, and be provided with a multitude of support services to manage her struggles, she may have a chance to become more independent."

Trauma

According to a study by Sobsey and Varnhagen regarding abuse, "the risk of people with disabilities is at least one and a half times as high as for other people. When only more severe forms of abuse are considered, that risk may be three or more times as high as the risk for people without disabilities." In addition, Sobsey & Doe report, "risk of abuse increases by 78% due to exposure to the disabilities service system alone." According to Dr. Karyn Harvey — a psychologist, national expert on trauma focusing on trauma and people with I/DD, and author of the book, *Trauma-Informed Behavioral Interventions: What Works and What Doesn't* — eight out of ten females who have developmental disabilities have been sexually abused more than once. For males, the number is six out of ten. Children with I/DD are more likely to be victims of abuse. Any type of disability appears to contribute to higher risk of victimization but intellectual disability, communication disorders, and behavioral disorders appear to contribute to very high levels of risk, and having multiple disabilities (e.g., intellectual disability and behavior disorders) result in even higher risk levels (Sullivan & Knutson, 2000).

Co-Occurring Diagnoses Resulted in Service Lapses

Every person who participated in this project had some co-occurring diagnoses including: mental health, substance use disorder, traumatic brain injury, or other diagnoses. The most common secondary diagnoses for the people in this project were mental health related, such as depression or borderline personality disorder. If any of the clients were receiving any services authorized through the MCO prior to Disability Rights NC's involvement, they were focused on mental health. There was never any focus on I/DD services until project staff brought it to the attention of the MCO. Services for these varying needs are often described as "siloed" because each area of expertise operates largely independently of the others. That creates additional barriers for people who fall into more than one "silo."

"[T]he division of responsibility between the mental health and I/DD service systems has resulted . . . in a denial of comprehensive care and treatment for individuals with I/DD."

I/DD and Mental Health Diagnoses

The experiences of the people with I/DD in this project demonstrated that the mental health and I/DD services silos were both a major factor leading to ACH placements and a major barrier to transitioning out of ACHs. The NADD, a national association for people with developmental disabilities and mental illness, states, "the division of responsibility between the mental health and I/DD service systems has resulted all too often in a denial of comprehensive care and treatment for individuals who have I/DD concurrent with a serious mental health problem."[4] Based on the experiences of Disability Rights NC's clients, this is true in North Carolina as well.

I/DD and Substance Abuse

Substance use, including alcohol, prescription drugs, and illegal substances, was reported as an issue for at least six of the 18 clients. One chose to transition from a large, isolated ACH to a family care home to be near his long-term girlfriend. The home was outside of his MCO catchment area, which created an

[4] http://thenadd.org/about-nadd/

Habilitative vs. Rehabilitative Services

Habilitation services focus on helping a person with I/DD or other disabilities attain, keep, or improve skills and functioning for daily living. Examples include therapy for a child who is not walking or talking at the expected age or teaching adults with developmental disabilities the fine motor coordination required to groom and dress themselves. Habilitation services may include physical, occupational, and speech-language therapy, various treatments related to pain management, audiology, and other services. The benefits of these therapies can include, for example, improved socialization skills, which reduces developmental delays for children with developmental disabilities. Adults and older people with certain disabilities can also benefit, for example, from therapies that prevent muscle loss and thus mobility, or that increase fine motor coordination so that independent living tasks such as dressing and bathing are made easier.

Rehabilitation services are intended to help regain function after an injury or illness and include acute clinical care in the hospital or treatment in a rehabilitation hospital or residential rehabilitation facility. Services might also include treatment from a day treatment program, outpatient clinic, other outpatient setting, or that a home health agency provides. Examples of covered services include physical, occupational, and speech-language therapy, cognitive therapy, recreational therapy, and psychological and behavioral evaluation.

administrative delay in accessing services. While waiting for service authorization, he experienced a relapse. He transitioned to a family care home in March 2016 and, as of November 1, 2016, he was still waiting for the MCO and provider to complete the administrative process for him to receive services.

Liam - Homeless

Liam, a 35-year-old participant, was homeless in the state of Ohio. His I/DD diagnosis became more complex when he sustained a TBI in addition to active substance use. He was not successful in finding supports in Ohio. According to Liam, he was given a one-way bus ticket to NC while he was panhandling. Still homeless in North Carolina, he was picked up by law enforcement and placed in a rural ACH.

Liam was identified through TCLI and transitioned to his own apartment. He was not given any services to address his TBI, I/DD, or substance use. After some time, Liam who felt like he could not manage on his own, checked himself back into the ACH. The MCO "blamed" Liam for his "failure" in the community and initially didn't see any point in working with him again until Disability Rights NC staff intervened.

Even when substance use disorder services exist, they are not designed to meet the needs of the individuals with I/DD who were involved in this initiative. For example, group meetings may be intimidating for people with intellectual disabilities, and written materials may not be linguistically accessible. For substance use disorder treatment services to be meaningfully accessible for people with I/DD, they must address the specific needs of people with I/DD.

I/DD and Traumatic Brain Injury

Of the 18 people with I/DD who sought to transition with support from project staff, four had a diagnosed or self-reported Traumatic Brain Injury (TBI). In at least one case, the client was diagnosed with I/DD prior to the incident that caused the TBI. While TBI at any age is included in the state statutory definition of a developmental disability in North Carolina, the Innovations Waiver qualification criteria is limited to people with TBI who meet the federal definition of I/DD, which includes only those

TBIs that have occurred before the age of 22. Two of the four people with a TBI had their injuries occur before age 22 and therefore are considered I/DD for purposes of Innovations Waiver eligibility. The Innovations Waiver provides only habilitative services, whereas TBI survivors often need long term rehabilitative services.[5]

Statewide Inconsistency in the Provision of Services

While the process for obtaining services is different for each MCO, each requires an updated assessment and/or evaluation to confirm eligibility for I/DD services. A lack of approved providers to complete the required assessments and/or evaluations led to significant delays for four people with I/DD participating in this project. In one case, there was only one approved provider in the county who could perform the evaluation required by the MCO, and that provider could not schedule the evaluation for four months. In another case, the MCO process for determining eligibility was delayed because there were no approved providers where the person lived. In both of these situations, it was quicker to help people transition to a smaller setting such as a group home or family care home in a different county without MCO involvement or funding so the evaluation could be scheduled faster and the individual could qualify for MCO services. In one situation the closest approved provider was 45 minutes away, and the provider would not travel to the facility to conduct the evaluation. The facility would not transport the resident. The resident had no family to help. The MCO gave contact information for Medicaid transportation providers in the county to the Disability Rights NC staff who contacted the provider to schedule accessible transportation.

Oversight and Accountability

Though all 18 of the people who became clients in this project had an I/DD, none of them were being served by an LME/MCO with any I/DD services when project staff met them. One individual moved into an ACH at the age of 18 and lived there for 34 years without any connection to his LME/MCO. Two of the 18 participants had received I/DD services in the past but had not been involved with their LME/MCO for years. Nine other project participants were receiving some mental health services when Disability Rights NC staff met them, though none were properly evaluated for additional services related to their I/DD diagnoses. Notably, none of the mental health services they received were provided by professionals with expertise in supporting people with I/DD.

Though all 18 of the people who became clients in this project had an I/DD, none of them were being served by an LME/MCO with any I/DD services when project staff met them.

In some cases, the lack of identification of an I/DD and/or provision of I/DD services meant years lost when they could have been making their way to the top of the wait list for services. It also meant they missed any opportunity for state funded or other services. Because these individuals had not been appropriately diagnosed, they were not able to receive necessary services as they moved between homeless shelters, ACH placements, and hospitalizations.

[5] Many people with TBI need rehabilitative services as they recover from the initial trauma of the brain injury. Consequently, the service needs for these individuals may be very different. In order to support individuals with TBI in the community, person-centered supports must be available and must be flexible enough to meet the changing needs of the individual. Currently only the Alliance MCO is providing specifically designed services through a new TBI waiver due to limits on funding.

TAC Statement

A 2012 report from the Technical Assistance Collaborative states " . . . the most vulnerable non-elderly adults in our nation [who rely on SSI] are often forced to choose between homelessness or placement in a segregated and restrictive institutional setting, such as an Adult Care Home, nursing home, or other congregate setting. Unlike the plight of chronically homeless people – whose dire circumstances are visible on the streets of our cities – people with disabilities 'housed' in institutional settings virtually disappear from the public eye." ("Priced Out in 2012: The Housing Crisis for People with Disabilities", TAC, 2012, available at http://www.tacinc.org/media/22484/PricedOut2012.pdf.)

Communication Challenges

Effective communication is essential to coordinate any successful transition. It is especially critical when developing discharge plans for individuals with I/DD and co-occurring diagnoses who are transitioning from an institution to a community setting. Yet at every stage of this project, there are documented examples of miscommunication, poor communication, and no communication. The communication challenges reinforce the mental health and I/DD services silos in the service delivery system and make appropriate transition planning difficult.

After project staff connected residents with their MCOs, the silos in the MCO system continued to be a major challenge. As noted earlier, none of these individuals received I/DD services while they lived in ACHs. Some, however, were identified as having a mental health diagnosis and were known to the Transitions to Community Living Initiative (TCLI) in-reach program through adult mental health services at the MCO. However, TCLI staff did not make any interagency referrals for I/DD services for any project participant prior to participation in this project. It is unknown why referrals were not made. However, this issue could be easily addressed by requiring and training TCLI staff to make I/DD referrals.

While several guardians stated TCLI program staff had contacted them in the past, they each refused to have the individual participate in the TCLI program because the TCLI program did not include services designed to address the individual's I/DD diagnosis and needs. In no case did a guardian report that TCLI staff had addressed their I/DD related concerns or indicate an opportunity for training to improve access to services. Until the TCLI program is modified to serve people with dual diagnoses, people with both I/DD and mental health needs living in adult care homes will experience unnecessary barriers to participating in TCLI because of their I/DD diagnoses.[6]

System Response Time

Throughout this project, project staff were required to follow up phone calls and emails with more phone calls and emails to get a single response. As advocates and attorneys, Disability Rights NC staff have much greater access to resources and providers; still there was tremendous difficulty in accessing the services

[6] As noted earlier, none of the people identified were known to the I/DD side of the MCO or receiving I/DD services. Nine were receiving mental health services such as attending the local Psychosocial Rehabilitation (PSR) program or Assertive Community Treatment Team (ACT) and 13 were on the Transition to Community Living Initiative (TCLI) list. Two of the 18 individuals had received I/DD services in the past, but were not actively receiving any meaningful I/DD services such as supported employment or habilitation services until identified by project staff. Because of Mental Health Reform and the consolidation of the former area mental health programs, current MCO staff could not locate medical records, social histories and other important information about the project participants, even though it was documented that some were served under the former system.

that are in place for people with I/DD because the gatekeepers for those services took many days and in some cases several weeks to respond to advocates. Project staff used their existing I/DD contacts at the MCO to make initial contact on behalf of the ACH resident, and in those situations where a previous relationship did not exist they made initial contact through the access line. In several situations, advocates had to call the supervisor's supervisor to get something done.

Chloe - Conflict in Roles

Chloe was physically assaulted at the ACH. Her guardian was alarmed when Chloe was taken to the hospital to receive stitches on her forehead, so the guardian called the local Adult Protective Services (APS) to investigate the incident. According to the guardian, DSS did not investigate the guardian's concerns. Instead, the APS investigator, who also served as the Adult Home Specialist (AHS) for DSS, asked the guardian to come to a meeting at the facility. When the guardian arrived, the AHS, who is responsible for ensuring the facility complies with all state laws and regulations, gave the guardian a list of all ACH facilities across the state and recommended that she find another place for the participant if she did not feel she was safe at this facility.

Within the context of this general non-responsiveness, the participants' compelling stories, along with their desperate desire to leave the ACHs, created a sense of urgency among both participants and project staff. For example, some participants were over-medicated to the point of drooling or falling repeatedly; others were depressed and expressed deep feelings of unhappiness and hopelessness. One participant had been sexually assaulted by a facility staff person, who was sentenced to prison for several years for this crime. Project staff found that guardians and the MCO staff responsible for authorizing services and facilitating transitions into the community did not share the participants' sense of urgency.

Conflicting Roles of DSS Adult Services

County Departments of Social Services provide various adult services, including three inter-related functions that pose an inherent conflict of interest with regard to individuals and potential placement in adult care homes.

- Adult Care Home Monitoring - The Adult Home Specialist (AHS) monitors the adult care homes in the county and investigates all complaints about those adult care homes. In other words, they are charged with ensuring the ACHs are in compliance with applicable regulations and laws.
- Adult Protective Services (APS) - The APS staff members investigate allegations of abuse, neglect and exploitation in the community or facilities within the county, and possess the authority to remove an individual from a dangerous setting. This creates the need for immediate availability of alternative housing.
- Guardianship - County DSS staff are appointed to serve as professional guardians, known as "public guardians," when a county clerk of court determines an individual is in need of a public guardian. Among other responsibilities, guardians are charged with ensuring their wards have housing and services.

In larger counties, staff are assigned to serve in only one of these functions. However, they may share a supervisor who may oversee two or three functions simultaneously. And in smaller counties, one staff member may perform more than one of these functions. Regardless, all three functions are housed in the same agency, and agency staff often rely upon one another.

Many public guardians have large caseloads that do not meet the National Guardianship Association's recommendations of weighting caseloads so that there is time to support each person individually including at least monthly in-person visits.[7]

In addition, case management was eliminated with the implementation of managed care and, as a result, North Carolina's complicated and confusing service system is more difficult to navigate. This means the professional guardians must spend even more time trying to access services for their wards. Professional guardians are required to physically visit their wards at least once a quarter, so placing an individual in an ACH creates an efficiency for the public guardian in several ways. First, the AHS already knows all ACHs in the county and has working relationships with facility staff. Second, when the DSS agency fills the role of AHS and guardian, it is more efficient for DSS to place the individual in a facility with which the AHS is familiar and visits regularly. There is an incentive to house multiple wards of the agency in the same ACH to make it more efficient to comply with quarterly visit requirements.

Three people with I/DD who participated in this project had direct interactions with DSS during adulthood. Two had DSS guardians at one point in time. All 3 had APS involvement. Two more had DSS guardians who refused to consent to their participation in the project. All people who participated in this project had indirect interactions with DSS because an Adult Home Specialist would have been responsible for monitoring, enforcing regulations, and ensuring safety of residents in the ACH.

Conclusion

The work of this project revealed a service system that fails to meet the needs of many people with I/DD; where even well-meaning professionals have high caseloads and insufficient training, and the necessary supports and services for people with I/DD are difficult to access even when they do exist. The resulting system burdens the rights of individuals with I/DD to choose to live in the least restrictive setting appropriate to their needs and enjoy the benefits of their communities. Staff successfully supported 15 people in transitioning from ACHs and, from that experience, offer recommendations for systemic changes and possible avenues of inquiry for the I/DD community in North Carolina.

[7] National Guardianship Association Standards of Practice, 2013, http://www.guardianship.org/documents/Standards_of_Practice.pdf. Weighting caseloads accounts for intensity of needs, geographic distance, and how well the guardian and ward know each other. Practically speaking that could mean single digit caseloads for very complex cases, but individual professional guardians reported believing that approximately 20 would be ideal for them.

A Blueprint for Transition

While each of the people served in this project had different needs, there were some common threads that can be used to create a blueprint for others and encourage investment in supports that will have the greatest impact on making such transitions possible. In every case of a successful transition, the linchpin was intensive case management. In this project, that support was provided by Disability Rights NC advocacy staff. In order to bring it to scale, intensive case management should be provided by an independent case management agency with staff trained in I/DD and co-occurring conditions, and who are familiar with the state's system of LME-MCOs, service providers, and housing resources.

However, even the most robust case management, standing alone, is not enough. A flexible funding source to cover the expenses inevitably associated with transition would help prevent small expenses from becoming major obstacles. A person with little or poor credit history typically must pay a substantial deposit in order to have utilities turned on. A $300 deposit with the power company can be a huge obstacle when you receive $66 per month. In addition, such a funding source would prevent Medicaid billing rules from getting in the way of the training and gradual service transitions that make success more likely.

And, of course, appropriate supports must be readily available in the community. For some people with I/DD that may mean an Innovations Waiver slot, but many, especially people with co-occurring mental health, TBI, substance use, or other needs either do not qualify for the Innovations waiver or the services offered under the waiver are inappropriate to meet their needs. They will need services that meet their needs in terms of mental health, TBI, and substance use, and also accommodate their developmental disabilities.

Though not by design, the elements discussed echo the practices of Money Follows the Person (MFP). MFP offers intensive transition coordination and case management, a fast track to access community services, funds for transition expenses including training staff who will provide community supports, and follow-up support as needed.[8]

MFP is not available to people living in ACHs, so it was not a resource that was considered for most of the people served in this project. Three people, however, did access MFP by first moving to an ICF or skilled nursing facility for 90 days, making them eligible for MFP. Such a two-step transition should not be necessary and can be counter-productive. Indeed, one of the times it was used in this project, the risks manifested in the client nearly being placed under a public guardianship and denied the opportunity to leave her current county to move to the community of her choice. Notably, MFP is also only available to people who are Medicaid eligible.

In MFP, transitions can be made from several types of institutional settings to a private home, including a home owned or rented by the person transitioning or by their family, or by a small group home. In this project, transitions were also made to family care homes, alternative family living arrangements, and others. Because of the lack of available integrated housing and services and the absence of a transition year funding source such as the one available under MFP, other options had to be considered. Transitions should be made to the least restrictive setting that meets the needs of the individual that the person is interested in living in.

[8] *See* What is MFP, https://dma.ncdhhs.gov/document/what-mfp.

Applying the principles in MFP (particularly intensive case management, shortcut access to community services, and flexible transition expense funding to people with I/DD living in ACHs) would substantially increase the ability of that population to transition to community living and thrive there. In addition, the community services themselves must be strengthened. They must be more widely available and be flexible enough to meet the needs of people with co-occurring diagnoses of mental illness, substance use disorder, and TBI.

In addition to adopting the practices and principles of MFP, the following recommendations would improve the ability of people with I/DD in ACHs to transition to the community:

Advance Integration

- Increase the number of Innovations Waiver slots to eliminate the waiting list for Waiver services, and consider the introduction of other waivers and state plan services that would meet the needs of this population and contribute to shortening wait times to receive services.
- Increase investment in state-funded services to fill gaps caused by HCBS waivers for those who do not meet eligibility for ICF/ID placement or ICF/ID Medicaid eligibility requirements.
- Amend the Medicaid State Plan options to include case management and other services to increase available supports for people with I/DD transitioning to the community.
- As they do with the Transitions to Community Living Initiative, MCOs must be responsible for ensuring that reliable transportation is available to people with I/DD living in ACHs so they can access necessary transition services such as assessments and evaluations, visits to potential housing options, etc.

Improve Accountability of MCOs

- Consistent with recommendations of the President's Committee for People with Intellectual Disabilities, create an independent ombudsman program outside of state government or any managed care entity to facilitate troubleshooting and navigation of the complex service system for people with I/DD, to include individual assistance, system monitoring and reporting, and consumer education and empowerment.
- Enforce requirements that MCOs ensure a reasonably prompt authorization process including performance standards for timeliness.
- Require MCO staff to provide technical support when providers have difficulty with the authorization process and include feedback from providers in measuring compliance.
- Utilize the MCOs' Community Guides to provide short term assistance with system navigation when a consumer is in urgent or emergent situations.
- Develop an authorization process for interim services in urgent or emergent situations.
- Require MCOs to establish a seamless system of response for people with co-occurring diagnoses, to include significant cross-training in mental illness, I/DD, substance use, and traumatic brain injury.
- Require MCO staff and their providers to attend Person-Centered Thinking training.
- Streamline the process of transferring Medicaid county of origin to a new county in a different MCO catchment area.

- Address the lack of provider capacity in rural areas, including new solutions, such as incentives for specialists to work in underserved communities.
- Require MCOs to have and identify an internal staff person with specific expertise in TBI and related services.

Improve ACH Admission/Screening to Identify and Track People with I/DD

- Prior to admission to an ACH, mandate the expanded use of the Level I and Level II PASRR program or another screening tool that assesses both mental health and I/DD related needs to include a focus on individuals with I/DD or suspected to have I/DD to ensure they are identified and MCOs are notified. Require prompt evaluations/assessments to confirm eligibility for and provision of housing and services in the community.
- For individuals admitted to ACHs prior to January 1, 2013, mandate the use of the Level I and Level II PASRR program or another screening tool that assesses both mental health and I/DD related needs for ACHs to include individuals with I/DD or suspected to have I/DD to ensure they are identified and MCOs are notified. Require prompt evaluations/assessments to confirm eligibility for and provision of housing and services in the community.
- Mandate a review of all existing PASRRs created since Jan. 1, 2013, to identify all individuals with I/DD or suspected I/DD, referral of all identified individuals to MCOs, and prompt evaluations/assessments to confirm eligibility for (and provision of) housing and services in the community.
- Use the existing infrastructure of MCOs' In-Reach of the state's Transitions to Community Living Initiative to identify people with I/DD in ACHs who would like to move or access I/DD services, including the development of a transition plan.

Improve Access to Services

- Create and ensure statewide access to best-practice therapeutic services specifically for individuals with I/DD and histories of trauma.
- Create and ensure statewide availability of best-practice services specifically for individuals with I/DD and substance use disorders. A particularly promising approach is that offered by the Alta California Regional Center's MHSA Substance Abuse Reduction Training Project.[9]
- Modify service definitions for relevant services to require training and experience in co-occurring I/DD, MH and SA dual diagnoses for an enhanced rate.
- Appropriate sufficient funding to ensure statewide availability and increase access to independent living skills training to for people with I/DD to prevent admission to and facilitate transition from institutional placements. This training must include information on sexuality and relationships.
- Expand capacity of NC START for adults; and fully fund NC START for children.

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[9] *See generally* http://www.altaregional.org/post/mhsa-substance-abuse-reduction-training-project and the presentation on this topic to the California UCED at http://www.uscucedd.org/component/jdownloads/send/18-dual-diagnosis-conference/156-slides-substance-abuse-in-people-with-intellectual-disabilities.

- Expand the B3 and state funded supported employment services in scope and duration for non-waiver participants.
- Expand the supported employment service definition to allow person-centered flexibility in duration and intensity for those who do not receive waiver funding.
- Implement intensive, targeted, independent case management services driven by person centered planning as people transition out of ACH.
- Implement targeted, independent case management for people with I/DD who demonstrate more intensive needs in care planning and system navigation.

Improve Medical Services to ACH Residents

- Implement a system of integrated care that includes physical health, dental health, mental health, developmental needs, and substance use disorder services consistent with the recommendations of the NCCDD's Medical and Health Home Initiative.
- Evaluate and address the causes of improper and/or excessive use of medications in ACHs, especially among people with I/DD as part of a medical/health home model.

Improve Guardianship Practices

- Provide Guardians, professional and family, with access to training on the needs of people with I/DD and co-occurring conditions and on navigating the publicly funded behavioral health system.
- Require professional guardians to review the publicly available regulatory surveys for an ACH prior to placement of a person they are supporting in the facility.
- Train professional guardians regarding the disabilities of the people they support, to include Person-Centered Thinking training.
- Train professional guardians on the requirements of the *Olmstead* decision regarding the least restrictive environment appropriate to the needs of a person with a disability.

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

In the nine years since it opened its doors as the North Carolina's protection and advocacy system for people with disabilities, Disability Rights North Carolina has become a leading voice in protecting the legal rights of people with disabilities in our State. It is the only nonprofit organization in the State dedicated solely to providing advocacy and legal services to people with all types of disabilities to protect their right to live independently with dignity in the communities of their choice. Its mission is to protect the legal rights of people with disabilities through individual and systems advocacy.

Its 38 staff members conduct a wide range of legal and advocacy services for people with disabilities, including (1) investigating complaints about neglect and abuse and suspicious or unexpected deaths in institutions; (2) representing individuals based on our target areas and case selection criteria; (3) educating people with disabilities about their many legal, civil and service rights; (4) providing technical assistance, training, publications, and advocacy support for North Carolinians with disabilities, their families, and representatives; (5) conducting outreach to traditionally underserved ethnic and disability communities; (6) working for changes in public policy to improve the lives of people with disabilities; and (7) bringing impact litigation and acting as amicus curiae in disability-related cases.

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