

An Assessment of the North Carolina Department of Health and Human Services’ System of Services and Supports for Individuals with Disabilities

**Submitted to the North Carolina Department of
Health and Human Services**

By the Technical Assistance Collaborative and the Human Services Research Institute



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Executive Summary

In January 2020, the North Carolina Department of Health and Human Services (DHHS) engaged the Technical Assistance Collaborative (TAC), in partnership with the Human Services Research Institute (HSRI), to assist in the development and implementation of a comprehensive, effectively working plan to support people with disabilities in the most integrated settings appropriate to their needs as required under the landmark *Olmstead v. L.C.* United States Supreme Court decision.

This Phase One report is a foundation for development of the State's Olmstead Plan, and includes both an assessment and an analysis of how North Carolina DHHS's and other state agencies' systems, funding, services, and housing options function to serve people with disabilities in integrated settings. The report also provides a framework for subsequent phases of the initiative, specifically, Olmstead Plan development; technical assistance for implementation activities, as deemed necessary; and development and implementation of a system for performance evaluation and outcome measurement.

Approach and Methods

To conduct the Phase One system assessment and analysis, TAC conducted key informant interviews and stakeholder listening sessions, supplemented by an online survey; reviewed existing data summaries and reports; and analyzed both Medicaid and DHHS claims and encounter data. We summarized and presented both our findings and our recommended action steps for subsequent phases related to Olmstead Plan development, implementation, and quality measurement.

Key Findings

Demographics

The diverse rural, suburban, and urban geography of the state presents unique challenges to meeting the community integration needs of people with disabilities. According to one estimate, one-half of North Carolina's 100 counties have lost population since 2010, while the population of the state's urban areas is steadily increasing.¹ Approximately 9.4%, or 821,000 people, in North Carolina have a disability. Statewide, housing is less costly than the national average, but is out of reach for individuals with disabilities with the lowest incomes. Finally, the North Carolina state government is the state's largest employer, with over 81,016 employees, including individuals who work in state-operated healthcare facilities.²

¹ Doran, W. & Raynor, D. (2016, October 8). *NC economy a mixed bag*. *The News and Observer*. <https://www.newsobserver.com/news/politics-government/state-politics/article107009877.html>

² State of North Carolina (n.d.). *Jobs*. Retrieved March 25, 2021 from <https://www.nc.gov/jobs>.

Key State Agencies

The North Carolina Department of Health and Human Services (DHHS) has 15 divisions that administer the delivery of community- and facility-based health and human services for Medicaid-eligible and non-insured individuals of all ages who have intellectual/developmental disabilities (I/DD), physical disabilities, Traumatic Brain Injury (TBI), mental health disorders, substance use disorders (SUDs), or visual/hearing impairments.

Actions that Have Impacted State Improvement Efforts

North Carolina closed the Dorothea Dix State Psychiatric Hospital in 2003, and repurposed two state-operated Developmental Centers and a skilled nursing facility to neuro-medical treatment facilities in 2007. As a result, most patients were transferred to newly established, state-operated facilities rather than being provided with community-based service alternatives.

In the 2001-2002 budget, the legislature, in S.B. 1005, set aside \$47.5 million for the North Carolina Trust Fund and stated that one of the purposes of the fund was to facilitate the state's compliance with *Olmstead*. However, for a variety of reasons, very few resources from the Trust Fund were used to develop community services, and some funds were set aside for the development of specialized services at the institutions.³

North Carolina has experienced *Olmstead*-related investigations that have led to litigation, threats of litigation, and settlement agreements designed to enforce integration obligations, including a 2014 suit brought by Disability Rights North Carolina against DHHS regarding underfunding of services to children with complex needs; an investigation conducted by the Civil Rights Division of the United States Department of Justice (DOJ) for failing to afford many people with mental illnesses the opportunity to live in integrated settings, resulting in the 2012 settlement agreement that created the Transitions to Community Living Initiative (TCLI); and in 2017, another Disability Rights North Carolina suit alleging that thousands of people with I/DD are forced to live in institutions and that the state fails to provide many people with I/DD the services they need in order to live in and participate in their communities. The Court found on behalf of the plaintiff in this suit, and the state is working to implement remedies satisfactory to the court.

Since July 1, 2013, Local Management Entities/Managed Care Organizations (LME/MCOs) have been responsible for statewide management and oversight of the public system of mental health, developmental disabilities, and substance use disorder services at the community level. Their role is to provide coordination of Medicaid and state-funded behavioral health services and of payments for those services provided through a network of local community service providers that contract with and are monitored by the LME/MCOs.

³ National Council on Disability (2003). *Olmstead: Reclaiming institutionalized lives (full-length online version)*. Retrieved March 25, 2021 from <https://ncd.gov/publications/2003/Aug192003#NCarolina>

Assessment of Findings

TAC identified a range of issues that could be examined in greater depth to improve the overall system orientation to serve people with disabilities in integrated settings.

Strengths of Systems and Services

Stakeholders identified a number of strengths in North Carolina's service systems that support individuals with disabilities, including affording stakeholders opportunities to provide input regarding systems change, development of a broad array of services and supports, and honoring families' and individuals' choices in services.

Beyond those named by stakeholders, TAC identified additional systems and services strengths as a result of our analysis. The TCLI initiative has resulted in positive outcomes and improved delivery of services for many adults with serious mental illness (SMI) in North Carolina, and may act as a framework for serving other populations of individuals with disabilities. North Carolina leverages numerous federal resources to support individuals with disabilities, including Medicaid Home and Community-Based Services waivers, Money Follows the Person (MFP), the Children's System of Care model, and the development of affordable housing. North Carolina has made progress in providing opportunities for competitive, integrated employment for individuals with disabilities; Governor Cooper signed Executive Order No. 92, declaring North Carolina an Employment First state. State universities have created model programs and provide training and consultation in evidence-based practices. DHHS promotes evidence-based practices that support children, adults, and older adults with behavioral health disorders; individuals with I/DD; and individuals involved with the criminal justice system. LME/MCOs provide health-related services in addition to those in the approved NC Medicaid Plan. Finally, DHHS has entered into a contract with the Cherokee Indian Hospital Authority to support the Eastern Band of Cherokee Indians in addressing the health needs of American Indian/Alaska Native Medicaid beneficiaries, the first Indian managed care entity of its kind in the nation.

System Weaknesses and Gaps in Care

TAC also identified several weaknesses within the system and gaps in care that should be addressed in order to support integrated community living for people with disabilities. North Carolina spends a disproportionate amount of its resources on institutional and congregate care settings. The annual costs for state-operated health care facilities are increasing, while the number of individuals served in most facilities is decreasing. Too many community-based service providers do not have the skills necessary or incentives to serve individuals with complex needs or challenging behaviors, leaving state-operated facilities and costly, out-of-state psychiatric residential treatment facilities (PRTFs) as the only options for services for these individuals. North Carolina spends more to serve individuals in congregate care settings than it spends on community-integrated service options. Despite the settlement agreement, adults with SMI, as well as other disabilities, continue to live in adult care homes.

There are gaps in services that impede community integration. The supply of affordable, accessible housing is inadequate for individuals with disabilities. Additional community-based service options and capacity are needed for children, adults, and older adults with behavioral health disorders to reduce reliance on institutional and congregate care settings. Additional, appropriate services are needed to serve individuals with TBI and Autism Spectrum Disorder in community-integrated settings. More opportunities for socialization are needed to prevent individuals from returning to institutional and congregate care settings; individuals participating in TCLI and the MFP program have struggled with issues of loneliness, isolation, and boredom.

The penetration rates for mental health and substance use disorder services for children vary across LME/MCOs.⁴ Similarly, penetration rates for mental health services, SUD services, and I/DD services vary for both Medicaid/Waiver and state funding. In addition, there are different patterns of services authorized across the LME/MCOs that do not appear to impact the use of state psychiatric hospital beds. There are inadequate staff, including but not limited to direct support professionals, to serve individuals with disabilities, in part due to the discrepancy in wages between state-operated facilities and community-based providers. There are disparities in service delivery, with African-Americans disproportionately represented in state psychiatric hospitals and crisis services. Finally, DHHS lacks an organized data and performance improvement strategy to drive policy, decision-making, and funding across disability-serving systems.

Barriers to Care

A number of barriers inhibit both access to the services and supports that do exist and the development of additional services needed to support individuals with disabilities as integrated members of their communities. Individuals and families must wait for services and funding. The Registry of Unmet Needs exceeds 14,400 individuals with I/DD, more than the number of Innovations Waiver participants. More than one in ten North Carolinians lacks access to health care coverage and must rely on limited, shrinking state funding for community-based services, resulting in their use of crisis, emergency department, and state-operated health care services. Guardianship was identified as a consistent barrier to community inclusion, impacting individuals with all disabilities and of all ages.

Recommendations

TAC has organized its recommendations under themes, for review and consideration by the Olmstead Plan Stakeholder Advisory as the actual plan development phase begins.

⁴ Penetration rate is defined here as the percentage of the target population that has utilized a relevant service at least once during a specified time period.

Ensure that individuals with disabilities have access to the community-based services and supports they want and need to live as integrated members of their communities.

Recommendation 1: Build on the Strengths of the Current System

Use the components of TCLI as a framework for community inclusion and adopt lessons learned from the MFP program.

Recommendation 2: Increase the Use of Evidence-Based and Promising Practices

DHHS should target Medicaid and non-Medicaid funding to support best practices, promising practices, and evidence-based services, based on data that shows their effectiveness, and strengthen contractual language regarding the use of evidence-based practices in the Tailored Plans.

Recommendation 3: Eliminate Gaps in Community-based Services

Strengthen services for children with behavioral health disorders, enhance crisis response, improve services for adults with SMI, address issues with residential services for individuals with I/DD, improve services for individuals with autism, and provide coverage for services to meet the needs of individuals with traumatic brain injury.

Recommendation 4: Increase Access to Affordable Housing for Individuals with Disabilities

Increase the amount of funding for the Key Rental Assistance program; explore opportunities and eliminate service barriers to increase utilization of the available housing units in rural communities; increase the use of assistive technology in an effort to make housing units more fully accessible; and add housing indicators to the Tailored Plans performance criteria.

Recommendation 5: Increase Competitive, Integrated Employment Opportunities

Strengthen employment opportunities for youth, adults and older adults with disabilities; inform individuals and families about available resources and services.

Increase access to integrated housing and community-based services through new resources and repurposed funding from institutional and segregated settings.

Recommendation 6: Reduce Reliance on Institutional Settings

Define the role of institutional settings in the state's service array. Reduce state-operated health care facility capacity as supported by declining census. Promote diversion strategies. Repurpose existing funds to further expand community-based service capacity.

Recommendation 7: Request Targeted Bridge Funding

Identify the need for additional funding, based on an assessment of individuals' needs for services. Include a strategy for repurposed funding as part of request for additional funding. Commit savings from reduced institutional or congregate care settings to further expand community-based service capacity.

Recommendation 8: Reduce Reliance on Community-Based Congregate Care and Segregated Day Service Settings

Reduce reliance on congregate care settings. Phase out day service settings that segregate individuals with disabilities from the community.

Recommendation 9: Adopt Policy Strategies to Address Financing Challenges and Gaps

Increase access to affordable health care. Examine implications of transitioning from LME/MCOs to Tailored Plans to maximize the outcomes and efficiencies of the new approach, while mitigating disruptions in services. Enforce DHHS contract requirements. Introduce alternative payment approaches.

Address systemic challenges and eliminate barriers to accessing the services that can help individuals to live meaningful lives as integrated members of their communities.

Recommendation 10: Include Input from All Stakeholders

Support efforts to enhance meaningful participation and strengthen the roles of all stakeholder groups, targeting efforts to stakeholders that are currently underrepresented in the Olmstead planning process.

Recommendation 11: Create a Culture that Supports the Voices of Individuals with Lived Experience

Incorporate supported decision-making and person-centered planning into all applicable service definitions. DHHS should provide support to individuals and groups with lived experience for self-advocacy.

Recommendation 12: Address Workforce Capacity and Shortages

Utilize state staff expertise to strengthen community-based provider competencies. Promote the employment of individuals with lived experience. Incentivize employment through competency-based training of direct service staff and “professionalizing” these roles.

Recommendation 13: Use Data for Evaluation and Quality Improvement

Take measures to expand quality improvement efforts. Explore whether the Quality Assurance and Performance Improvement system designed to support TCLI can serve as a model for a statewide, cross-disability approach. Ensure that the Olmstead Plan’s outcome, performance, and quality measures align with Patient-Reported Outcome Measures (PROMs) and other relevant program measures.

Recommendation 14: Eliminate Barriers to Accessing Services

Reduce the number of people on the I/DD Registry of Unmet Needs. Right-size the Innovations Waiver waitlist. Expand the TBI waiver statewide while funding additional TBI waiver slots. Continue to assess all Medicaid authority options to further expand community-based service capacity. Rethink guardianship.

Conclusion and Next Steps

North Carolina is at a critical point in determining how best to meet the needs of its residents with disabilities. The state has a long history of providing institutional and custodial care, and of supporting practices proven ineffective by research.^{5 6} North Carolina invests a large amount of its limited state resources in sustaining institutional and congregate care settings that segregate individuals from their communities and from interacting with others who do not have disabilities.

DHHS has not received support from the administration or, for the most part, from the General Assembly, for past efforts to address this imbalance, and the state has faced litigation as a result, ultimately forcing the General Assembly to identify state resources needed to make the changes outlined in each settlement. Absent an Olmstead Plan and the resources that will allow the state to

⁵Cimera, R. (2011). [Does being in sheltered workshops improve the employment outcomes of supported employees with intellectual disabilities?](https://www.researchgate.net/publication/260781788_Does_being_in_sheltered_workshops_improve_the_employment_outcomes_of_supported_employees_with_intellectual_disabilities?) *Journal of Vocational Rehabilitation*, 35, pp. 21-27. Retrieved April 26, 2021 from https://www.researchgate.net/publication/260781788_Does_being_in_sheltered_workshops_improve_the_employment_outcomes_of_supported_employees_with_intellectual_disabilities.

⁶Lakin, K.C., Larson, S. A., Kim, S. (2011). [Behavioral outcomes of deinstitutionalization of people with developmental disabilities?](http://www.evidence-basedpolicy.org/docs/evidence-based_policy.pdf) (PDF). *Policy Research Brief*, 22(1). http://www.evidence-basedpolicy.org/docs/evidence-based_policy.pdf

incrementally implement the Plan, North Carolina will continue to face litigation and be left to the will of the courts to modify its systems that support individuals with disabilities.

Based on the goals and objectives that DHHS selects for incorporation into the plan, TAC is available to work with the Department to identify implementation strategies and provide technical assistance as needed to move the plan forward, inclusive of aligning Olmstead Plan activities with Medicaid Transformation and other key initiatives.

Chapter 1: Background and Approach

Background

In 2019, the North Carolina Department of Health and Human Services (DHHS) issued a Request for Proposals (RFP) to assist with the development and implementation of a comprehensive, effectively working plan to support people with disabilities in the most integrated settings appropriate to their needs, as required under the landmark 1999 *Olmstead v. L.C.* United States Supreme Court decision. The Technical Assistance Collaborative, Inc. (TAC), in partnership with the Human Services Research Institute (HSRI), responded to this RFP in November 2019 and was awarded a contract in January 2020.

Title II of the Americans with Disabilities Act (ADA) of 1990 established a mandate to public entities to ensure that people with disabilities live in the most integrated settings possible. The U.S. Supreme Court's *Olmstead* decision affirmed this civil right. In its ruling, the court strongly encouraged the development of 'Olmstead plans' to establish actionable strategies that would support integration and also serve as a defense for states facing allegations of violating the ADA's integration mandate.

According to the U.S. Department of Justice (DOJ), a comprehensive, effectively working plan must:

"...do more than provide vague assurances of future integrated options or describe the entity's general history of increased funding for community services and decreased institutional populations. Instead, it must reflect an analysis of the extent to which the public entity is providing services in the most integrated setting and must contain concrete and reliable commitments to expand integrated opportunities."⁷

This Phase One report is a foundation for development of DHHS' Olmstead Plan, and includes both an assessment and an analysis of how North Carolina's organizations, systems, funding, services, and housing options function to serve people with disabilities in integrated settings. The report identifies key information that was used to inform the assessment and analysis, including the array of services and living arrangements, available funding and how it is spent, people served in various settings, and the structures in place to organize and deliver services. The report also provides a framework for subsequent phases of the initiative, specifically, plan development; technical assistance for implementation activities, as deemed necessary; and development and implementation of a system for performance evaluation and outcome measurement. The proposed framework will align with the state's revised approach to transforming its health and human services system, including the implementation of Medicaid managed care.

⁷ U.S. Department of Justice, Civil Rights Division (2011). [Statement of the Department of Justice on enforcement of the integration mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.](https://www.ada.gov/olmstead/q&a_olmstead.htm) Retrieved March 25, 2021 from https://www.ada.gov/olmstead/q&a_olmstead.htm.

Our assessment and analysis are informed by Olmstead work in other states, and we used the DOJ definitions of integrated and segregated settings as a reference for the systems, services, and living options in North Carolina. While there are many factors that inform what an integrated or segregated setting is, the statement issued by DOJ in 2012 provides a definition that is useful to the framework for assessing programs, services, and living arrangement and the systems that support them:

Integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities. Integrated settings are located in mainstream society; offer access to community activities and opportunities at times, frequencies and with persons of an individual's choosing; afford individuals choice in their daily life activities; and, provide individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible. Evidence-based practices that provide scattered-site housing with supportive services are examples of integrated settings.

By contrast, segregated settings often have qualities of an institutional nature. Segregated settings include, but are not limited to: (1) congregate settings populated exclusively or primarily with individuals with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals' ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other individuals with disabilities.⁸

Approach

TAC's overall approach to accomplishing the tasks outlined in the Scope of Work of the RFP involved several components. In order to support DHHS' goal of building upon and unifying the work of the Transitions to Community Living Initiative (TCLI), Money Follows the Person (MFP), and related initiatives, TAC proposed that DHHS appoint a steering committee of decision-makers from the appropriate offices and divisions within DHHS to guide the Olmstead assessment and planning process. TAC consulted this group through formal and ad hoc meetings; presented to the group its initial findings and recommended action steps for subsequent phases; and sought the Steering Committee's decisions about how to incorporate and prioritize findings from the Assessment in the Olmstead Plan and its implementation.

Key strategies TAC used in developing and conducting the Phase One system assessment and analysis included collecting and synthesizing both qualitative and quantitative data:

1. We conducted key informant interviews and stakeholder listening sessions.
2. We conducted an online survey to facilitate additional stakeholder input.

⁸ U.S. Department of Justice, Civil Rights Division (2011). [Statement of the Department of Justice on enforcement of the integration mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*](https://www.ada.gov/olmstead/q&a_olmstead.htm)
https://www.ada.gov/olmstead/q&a_olmstead.htm

3. We reviewed existing data summaries and reports.
4. We requested individual Medicaid and Division of Mental Health/Developmental Disabilities/Substance Abuse Services (DMH/DD/SAS) claims and encounter data needed for the assessment and conducting related analyses.
5. We summarized and presented both our findings and our recommended action steps for subsequent phases related to Olmstead Plan development, implementation, and quality measurement.

Qualitative Data Collection

A significant part of the qualitative analysis involved engaging and interviewing a broad array of stakeholders.

Interviews

TAC conducted telephonic interviews with DHHS staff and other recommended stakeholders, supplemented by written survey responses. The purpose of these interviews was to gain perspective on the systems that support individuals with disabilities from people who work within those systems and oversee the delivery of services and supports. Staff were assured that their input would be kept confidential to encourage their open participation. Please see [Appendix B](#) for a list of agencies and stakeholder representatives that TAC interviewed, and [Appendix C](#) for sample interview questions.

Stakeholder Listening Sessions

TAC held a series of 15 virtual listening sessions with a variety of stakeholder groups, via Zoom, between August and October 2020 to inform our systems analysis for the development of North Carolina's Olmstead Plan. See [Appendix D](#) for a list of listening session dates by stakeholder group. A total of 341 stakeholders attended the listening sessions. Table 1 below shows a breakdown of listening session attendees of by stakeholder group.

Table 1. Listening Session Attendees by Stakeholder Group

Stakeholder Group	Number	% of Total
Aging Service Providers	16	4.69%
Coalition on Aging	30	8.79%
The Coalition	10	2.93%
Children's Service Providers	17	4.98%
Employment/Vocational Rehabilitation Service Providers	60	17.59%
Family members of those with Intellectual and/or Developmental Disabilities (I/DD)	17	4.98%

Stakeholder Group	Number	% of Total
Family members of those with Mental Illness and/or Substance Use Disorders (MH/SUD)	10	2.93%
Family members and individuals with Traumatic Brain Injury (TBI)	11	3.22%
Guardians (public and family)	13	3.81%
Housing Providers and Agencies	33	9.67%
LME/MCOs	38	11.14%
MH/SUD/SAS and TBI Service Providers	59	17.30%
Individuals with lived experience with MH/SUD	7	2.05%
Individuals with lived experience with I/DD	11	3.22%
Statewide Independent Living Council (SILC)	9	2.63%
TOTAL	341	100%

During each listening session, participants were asked similar questions regarding strengths, gaps, and challenges in the system for families and individuals with disabilities seeking services. They were also asked for their recommendations to strengthen the system. Due to the COVID-19 pandemic, TAC conducted the listening sessions virtually, using the polling feature of Zoom. Attendees were first asked to identify all responses that they determined applied to each topic or question area (strengths, gaps, etc.). Participants were then asked to prioritize their response for each area (i.e., their top strength, top gap, etc.) See [Appendix E](#) for the poll questions. After the polls were completed, TAC facilitators led open discussions, asking attendees to provide additional information regarding their responses. A summary of responses by stakeholder group can be found in [Appendix F](#).

Online Stakeholder Survey

In order to capture additional stakeholder input from those unable to attend a listening session, DHHS asked TAC to create an online survey using Survey Monkey, based on the same questions. The survey was open for responses from September 8 to September 22, 2020. There were a total 239 survey respondents. See Table 2, below, for a breakdown of respondents by stakeholder group.

Table 2. Online Survey Respondents by Stakeholder Group

Stakeholder Group	Number	% of Total
Advocacy Organizations	10	4.18%
Aging Service Providers	2	0.83%
Assisted Living Facilities (ALFs) and Acute Care Hospitals	3	1.25%
Children's Service Providers	2	0.83%
Employment/Vocational Rehabilitation Service Providers	7	2.92%
Family members of those with Intellectual/Developmental Disabilities (I/DD) or Mental Health/Substance Use Disorders (MH/SUD)	107	44.76%
Guardians	3	1.25%
Housing Agencies	0	0.00%
LME/MCOs	13	5.43%
Providers of I/DD services (including Supported Employment/WIOA)	38	15.89%
Providers of MH/SUD, TBI, and Rehabilitation Services	44	18.41%
Individuals with lived experience with a disability including MH/SUD and I/DD	9	3.76%
State agency staff	1	0.41%
TOTAL	239	100%

Responses from the listening session polls and the online survey were combined to find trends across all stakeholder groups and both data collection methods. This summary can be found in [Appendix G](#).

Review of Existing Data Summaries and Reports

TAC reviewed documents and literature from a variety of sources, including DHHS divisions as well as various stakeholders. The state provided numerous reports and policy, quality, and procedural documents for review. These documents offered details on system indicators and issues being tracked by the programs, and policy and quality issues identified and monitored by leaders in various state agencies as well as the Local Management Entities/Managed Care Organizations (LME/MCOs). A list of key documents provided or researched can be found in [Appendix H](#).

Quantitative Data Utilized

TAC and HSRI evaluated and utilized quantitative data to inform our findings and analysis.

HSRI obtained quantitative data for this report from the following sources:

- Medicaid claims data. These data include paid claims for which the primary diagnosis on the claim was a behavioral health condition, as well as claims for Innovations and (b)(3) waiver services, Community Alternatives Program for Disabled Adults (CAP/DA) and Community Alternatives Program for Children (CAP/C) waiver services, and claims with a diagnosis of traumatic brain injury (TBI). The data include both LME/MCO and fee-for-service claims for fiscal year 2017 through the first half of fiscal year 2020.
- Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMH/DD/SAS) claims data for which DMH/DD/SAS was the payor, for fiscal year 2017 through the first half of fiscal year 2020.
- North Carolina's Division of State-Operated Healthcare Facilities (DSOHF) provided information on DSOHF expenditures and numbers served. Demographic characteristics of people served and average length of stay were provided for some facility types, but not all. Because DSOHF does not have a shared data system, data elements across facility types were inconsistent. Data on the race/ethnicity of persons served was only provided for state psychiatric hospitals.
- Publicly available reports, including reports from the DHHS website (e.g., LME Annual Reports and monthly monitoring reports), the U.S. Substance Abuse and Mental Health Services Administration's (SAMHSA) Uniform Reporting System, National Core Indicators, the Residential Information System Project, and other publicly available reports containing data relevant to the populations of focus. When noted, we included some data from non-public reports that were available to DHHS.

TAC and its partner, the Human Services Research Institute (HSRI) used claims data to analyze numbers served, demographic characteristics of individuals served, service penetration rates, and expenditures for relevant services across the populations of focus. A discussion of data gaps and limitations is included in [Appendix A](#). One notable gap is the lack of data on the number of individuals with disabilities residing in adult care homes and nursing facilities.

Due to limitations in available data and to the broad scope of this assessment, this report surfaces several issues on data capacity and analysis that will require further attention by DHHS in order to ensure that DHHS is using data to drive decision-making on policy, program and service design, and funding.

Chapter 2: Summary of Key Findings and Relevant Information

This chapter presents findings based on available information across disability groups and key areas that were used to inform the analysis and recommendations offered in Chapter 4. The findings and relevant information are organized into the following topics:

- Demographics
- Key State Agencies Serving People with Disabilities
- Actions that Have Impacted System Improvement Efforts
- Services and Supports for Individuals with Disabilities

Demographics

The Technical Assistance Collaborative (TAC) reviewed various demographic data about North Carolina to provide context for our assessment of the system to support community integration for people with disabilities. North Carolina is the 28th largest and 9th most populous of the 50 United States. While much of the state is rural, the Charlotte metropolitan area, with an estimated population of 2,569,213 in 2018, is the 23rd most populous in the United States, and the largest banking center in the nation after New York City.⁹ The Raleigh metropolitan area is the second largest metropolitan area in the state, with an estimated population of 1,362,540 in 2018, and is home to the largest research park in the United States, Research Triangle Park.¹⁰ North Carolina comprises 100 counties; Mecklenburg County has the largest population, while Wake County has the second largest population.¹¹ The diverse rural, suburban, and urban geography presents unique challenges to meeting the community integration needs of people with disabilities.

Since 2000, there has been a division in the economic growth of North Carolina's urban and rural areas. Between 1990 and 2015, metro counties added nearly 739,000 jobs, while rural and small-town counties lost over 6,000 jobs.¹² The state's metropolitan areas have continued to grow, with an influx of white-collar jobs in the finance and technology sectors. However, many of the state's rural counties have suffered from job loss, rising levels of poverty, and population loss as their manufacturing base has

⁹ Roberts, D. (2018, November 15). [Charlotte regains its place as No. 2 U.S. banking center. Will it keep it?](https://www.charlotteobserver.com/news/business/banking/article221589840.html) *The Charlotte Observer*. <https://www.charlotteobserver.com/news/business/banking/article221589840.html>

¹⁰ Retrieved October 13, 2020, from <https://www.rtp.org/the-foundation>

¹¹ U.S. Census Bureau (2020, June 22). Annual estimates of the resident population for counties – April 1, 2010, to July 1, 2019. Urban 2 Point 0. Retrieved March 25, 2021.

¹² Webb, M. (2017, July 11). [Understanding North Carolina's urban-rural divide](https://urban2point0.com/2017/07/11/understanding-north-carolinas-urban-rural-divide/). Urban 2.0. <https://urban2point0.com/2017/07/11/understanding-north-carolinas-urban-rural-divide/>

declined. According to one estimate, one half of North Carolina's 100 counties have lost population since 2010, primarily due to the poor economy in many of North Carolina's rural areas, while the population of the state's urban areas is steadily increasing.¹³

The United States Census Bureau estimates that the population of North Carolina was 10,488,084 on July 1, 2019, a 9.99% increase since the 2010 Census.¹⁴ Approximately 9.4%, or 821,000 people, in North Carolina have a disability. According to 2019 Social Security data, there were approximately 211,329 people who were eligible for Social Security disability benefits, including 77,922 who were also receiving Supplemental Security Income (SSI).¹⁵ Individuals with disabilities who receive Old Age, Survivors, and Disability Insurance (OASDI) and/or SSI are most likely to need publicly supported disability services, although we did not crosswalk this data to DHHS data for this project.

Of the people residing in North Carolina, 56.41% were born in the state; 35.57% were born in another state.¹⁶ North Carolina ranks 9th nationally in individuals age 60 years and older and 10th nationally in individuals age 85 years and older. This trend is even more prevalent in rural counties.¹⁷ According to 2015-2019 American Community Survey, the state's racial composition is predominantly White (68.17%), followed by Blacks/African-Americans (21.5%) and Latinx/Hispanic Americans (9.8%).¹⁸ Concerns about access to community-based services and overrepresentation in institutional settings by race are noted later in the report.

Based on American Community Survey 2010–2014 data, North Carolina's median household income was \$46,693, ranking forty-first out of fifty states and the District of Columbia. North Carolina had the 14th highest poverty rate in the nation at 17.6%; 13% of families were below the poverty line.¹⁹ The cost of living in North Carolina is below the national average but varies based on location. Statewide, housing is less costly than the national average, but is out of reach for individuals with disabilities with the lowest

¹³ Doran, W. & Raynor, D. (2016, October 8). [NC economy a mixed bag](https://www.newsobserver.com/news/politics-government/state-politics/article107009877.html). *The News and Observer*.
<https://www.newsobserver.com/news/politics-government/state-politics/article107009877.html>

¹⁴ U.S. Census Bureau (2019). [QuickFacts North Carolina; United States](https://www.census.gov/quickfacts/fact/table/NC,US#). <https://www.census.gov/quickfacts/fact/table/NC,US#>

¹⁵ Social Security Administration (2019). [North Carolina, Table 3: Number of recipients in state \(by eligibility category, age, and receipt of OASDI benefits\) and amount of payments, by county, December 2019 \(PDF\)](https://www.ssa.gov/policy/docs/statcomps/ssi_sc/2019/nc.pdf). Retrieved March 10, 2021 from https://www.ssa.gov/policy/docs/statcomps/ssi_sc/2019/nc.pdf.

¹⁶ World Population Review. [North Carolina population 2021](https://worldpopulationreview.com/states/north-carolina-population). Retrieved April 26, 2021 from <https://worldpopulationreview.com/states/north-carolina-population>.

¹⁷ Author interview with the Division of Aging and Adult Services.

¹⁸ U.S. Census Bureau. [CEDSCI Profile: North Carolina](https://data.census.gov/cedsci/profile?g=0400000US37). Retrieved March 25, 2021 from <https://data.census.gov/cedsci/profile?g=0400000US37>.

¹⁹ USA.com. U.S. Population in Poverty Percentage State Rank Based on ACS 2010–2014 data. Retrieved March 25, 2021 from <http://www.usa.com/rank/us--population-in-poverty-percentage--state-rank.htm?hl=SC&hlst=SC&wist=&vr=9000&dis=&sb=ASC&plow=&phigh=&ps=>.

incomes. According to TAC's [Priced Out: The Housing Crisis for People with Disabilities](#) web page, a North Carolinian with a disability would have to pay 102% of their 2021 Supplemental Security Income (SSI) payment to afford a one-bedroom apartment at the federal fair market rent established by HUD.²⁰

North Carolina state government is the state's largest employer, with over 81,016 employees.²¹ The state is known for its agricultural products; however, emerging industries include aerospace and defense, automotive, biotechnology, and pharmaceuticals.²² According to the Bureau of Labor Statistics, North Carolina's unemployment rate was 6.2% in November 2020, slightly lower than the national average rate of 6.7%.

Key State Agencies

The North Carolina Department of Health and Human Services (DHHS) has 15 divisions, several of which are described below, that administer the delivery of community- and facility-based health and human services for Medicaid-eligible and non-insured individuals of all ages who have intellectual/developmental disabilities (I/DD), physical disabilities, traumatic brain injury (TBI), mental health disorders, substance use disorders (SUDs), or visual/hearing impairments. State agencies describe their role as including oversight of state and federal funding; program development; establishing and informing statewide policy; providing advocacy and protection for recipients; providing technical assistance on evidence-based and promising practices; and overseeing quality improvement.

Division of Aging and Adult Services

The Division of Aging and Adult Services works to promote the independence and enhance the dignity of North Carolina's older adults, individuals with disabilities, and their families through a community-based system of opportunities, services, benefits, and protections.

Division of Health Benefits (NC Medicaid)

The Division of Health Benefits (NC Medicaid) is responsible for providing access to physical and behavioral health care and services for over 2.1 million North Carolinians. Ninety to ninety-five percent of Medicaid recipients in North Carolina are children, people with disabilities, or elders. NC Medicaid manages the state's Medicaid and NC Health Choice programs, the implementation of Standard and Tailored Plans, pharmacy benefits, and behavioral health services. In addition, NC Medicaid oversees

²⁰ Technical Assistance Collaborative (2021). *Priced out: The housing crisis for people with disabilities*. Retrieved March 25, 2021 from <https://www.tacinc.org/resources/priced-out/>.

²¹ State of North Carolina (n.d.). *Jobs*. Retrieved March 25, 2021 from <https://www.nc.gov/jobs>.

²² North Carolina Department of Commerce (n.d.) *Key industries in North Carolina*. Retrieved April 26, 2021 from <https://www.nccommerce.com/business/key-industries-north-carolina>.

community alternative programs for children and adults with physical disabilities, I/DD, TBI, home health care, and helping people transition from nursing homes to live in their own communities.

Division of Mental Health, Developmental Disabilities and Substance Abuse Services

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) provides quality support to achieve self-determination for individuals with I/DD, and quality services to promote treatment and recovery for individuals with mental illness and SUDs, by infusing the service array with evidence-based practices supported by highly qualified trainers, ensuring that services are available, and establishing the expectation that providers and managed care organizations (MCOs) deliver high-quality services.

Division of Services for the Blind

The Division of Services for the Blind provides services to people who are visually impaired, blind, or deaf-blind to help them reach their goals of independence and employment.

Division of Services for the Deaf and Hard of Hearing

The Division of Services for the Deaf and Hard of Hearing works to ensure that all deaf, hard of hearing, and deaf-blind North Carolinians have the ability to communicate their needs and to receive information easily and effectively in all aspects of their lives, especially their health and well-being.

Division of Social Services

The Division of Social Services (DSS) provides guidance and technical assistance to agencies that provide direct services that address issues of poverty, family violence, and exploitation. DSS promotes self-reliance and self-sufficiency and works to prevent abuse, neglect, dependency, and exploitation of vulnerable individuals, children, and their families. County departments of social services administer the Special Assistance In-Home (SA/IH) program for adults, which gives cash supplements to low-income individuals who may be at risk for entering a facility.

Division of State-Operated Health Care Facilities

DHHS operates 14 health care facilities, of several types.

State Developmental Centers/Intermediate Care Facilities for Individuals with Intellectual Disabilities

The Division of State-Operated Healthcare Facilities oversees the Caswell, J. Iverson Riddle, and Murdoch Developmental Centers. All three facilities provide residential, medical, and habilitation services. The Murdoch and Caswell centers also provide some specialized services:

- *Murdoch Center*: Behaviorally Advanced Residential Treatment for adult males with an I/DD diagnosis and extreme behavioral challenges; Specialized Treatment for Adolescents in a

Residential Setting (STARS) for adolescents ages 13 through 17 who have dual diagnosis; Partners in Autism Treatment and Habilitation for children ages 6 through 16 with autism spectrum disorder and serious behavioral challenges; and Therapeutic Respite Addressing Crisis for Kids (TRACK) for children ages 5 through 17 with intellectual disabilities or autism spectrum disorders who have serious behavioral challenges and are in behavioral crisis.

- *Caswell*: Facility-based respite services to provide caregivers temporary relief based on bed availability, and a 10-bed program for males with a dual diagnosis of I/DD and mental illness (Intellectual Disability and Mental Illness program).

Admissions to state-operated developmental centers are voluntary and require consent of the individual or legal guardian if the individual is a minor or has been adjudicated incompetent. Of the 28 State Center admissions in fiscal year 2020, 14 admissions were to the Murdoch Center's TRACK program.

Neuro-Medical Treatment Centers

DSOHF also oversees three Neuro-Medical Treatment Centers — Black Mountain, Longleaf, and O'Berry — which are specialized skilled nursing facilities certified by the Centers for Medicare and Medicaid Services (CMS) under the Omnibus Budget Reconciliation Act long-term care regulations. These facilities serve adults with chronic and complex medical conditions that coexist with neurocognitive disorders often related to a diagnosis of severe and persistent mental illness or intellectual disability. The facilities serve individuals who need a skilled nursing level of care, and who may have a history of unsuccessful placement in community settings due to symptoms of their mental illness, neuropsychiatric disorder, or health and/or clinical treatment needs that exceed the level of care available.

State Psychiatric Hospitals

All state psychiatric hospitals provide treatment to adult, geriatric, and adolescent North Carolinians. Services include court-ordered Incapacity to Proceed (ITP) evaluations, treatment, and case management. Treatment may be acute or long-term. Rehabilitation therapies include advocacy, vocational therapy, pastoral services, art therapy, recreation therapy, speech/language therapy, and beauty/barber services. Statewide specialty services/programs are provided as follows:

- *Broughton Hospital*: Services accessible to individuals who are deaf
- *Central Regional Hospital*: Services for children ages 5 to 12, forensic services, electroconvulsive therapy, involuntary treatment program community screeners training
- *All Hospitals*: Health care technician training and certification programs

Alcohol and Drug Addiction Treatment Centers

Alcohol and Drug Addiction Treatment Centers provide inpatient treatment, psychiatric stabilization, and medical detoxification for individuals with substance use disorders and other co-occurring mental health diagnoses. The centers offer an array of specialized programs to meet the complex needs of their population, such as evidence-based treatment for trauma survivors, treatment for veterans, criminal diversion programs, and statewide perinatal and opioid treatment programs.

Residential Programs for Children

- The Wright School provides residential mental health treatment to North Carolina's children ages 6 to 12 who have serious emotional and behavioral disorders. The facility offers an on-campus school serving children and youth with special needs (K-8) in self-contained classrooms. Many children are referred to the Wright School because of problems with behavior and social skills. The highly structured, predictable program offers many chances for children to learn how they are doing as they go through the schedule of a normal day: school, chores, play, personal health, and homework. Teacher counselors provide direct instruction in anger management, problem-solving, and communication with other children and adults.
- The Whitaker Psychiatric Residential Treatment Facility is a secure, non-acute treatment program for males and females, ages 13-17, who have emotional and behavioral challenges and need secure residential care. Eligible youth must have a history of aggressive and/or self-injurious behavior and must have failed less restrictive forms of treatment or currently be placed in a secure residential setting such as a Youth Academy, psychiatric hospital, or detention center, with no expectation of improvement in the current setting.

State-operated health care facilities were described by DHHS staff as the “safety net” for individuals that local providers have been unable to serve successfully as they are “treatment refractory,” often behaviorally challenging, and have more complex needs. Many of the facilities serve a high indigent population.

Division of Vocational Rehabilitation Services

The Division of Vocational Rehabilitation Services (DVRS) assists people with disabilities to achieve their goals for employment and independence by connecting them to services and resources that help them to meet their goals. DVRS administers two core programs: Employment Services assists people with disabilities to find a job, keep working, or advance professionally by providing counseling, education, training, job placement assistance, assistive technology and many other services; and the Independent Living Rehabilitation Program which helps eligible individuals to live a more independent life as an alternative to living in a nursing home or other facility.

Actions that Have Impacted System Improvement Efforts

State Facility Capacity

In 2003, the North Carolina General Assembly passed legislation to close the Dorothea Dix state psychiatric hospital in 2007. The intent was for patients to be relocated to community-based programs

or to a newly constructed psychiatric hospital, Central Regional Hospital. Reportedly, most patients were transferred to other state hospitals rather than being relocated to the community.²³

In 2007, two of the state's five Developmental Centers, which had been in operation since 1988, were identified for closure with the intent of transitioning individuals to appropriate community-based settings. However, after strong opposition from family members and guardians, the facilities were not closed but instead repurposed, along with the Longleaf Nursing Facility, as the three current Neuro-Medical units that continue to house many of the previous state center and nursing facility residents.

Dedicated State Funding for Community Inpatient Care for the Uninsured

In the 2001-2002 budget, the legislature, in S.B. 1005, set aside \$47.5 million for the North Carolina Trust Fund and stated that one of the purposes of the fund was to facilitate the state's compliance with *Olmstead*. However, because of the state budget crisis at the time, the governor by executive action placed \$37.5 million from the Trust Fund in escrow, leaving only \$12 million available for bridge funding to support facility discharges to the community. The DMH/DD/SAS developed a utilization plan for reduced Trust Fund resources that included funding to support people's transition from state centers to the community; funding for transition planning; and \$3.6 million to leverage the development of community housing for people with mental illness or other disabilities. However, not all the resources from the Trust Fund were used to develop community services; some funds were set aside for the development of specialized services at the institutions.²⁴

In the 2017-2018 state fiscal year, in response to an "emergency department boarding issue," the General Assembly appropriated \$41,351,644 in recurring funds to increase access to psychiatric inpatient and substance use disorder treatment in community hospitals. Annual appropriations to DHHS continue and are used to purchase psychiatric and substance use inpatient care for individuals who are medically indigent, thereby diverting admissions to a state psychiatric hospital. As described later in this report, the impact of this funding appears to be limited absent increased access to community-based services necessary to support ongoing stabilization and recovery.

***Olmstead* Litigation and Settlement Agreements**

North Carolina has experienced *Olmstead*-related investigations that have led to litigation, threats of litigation, and settlement agreements designed to enforce integration obligations.

²³ Geary, B. (2010, December 8). [Closing of Dorothea Dix Hospital marks failure of state reforms](https://indyweek.com/news/wake/closing-dorothea-dix-hospital-marks-failure-state-reforms/). *Indy Week*.
<https://indyweek.com/news/wake/closing-dorothea-dix-hospital-marks-failure-state-reforms/>

²⁴ National Council on Disability (2003). [Olmstead: Reclaiming institutionalized lives \(full-length online version\)](https://ncd.gov/publications/2003/Aug192003#NCarolina). Retrieved March 25, 2021 from <https://ncd.gov/publications/2003/Aug192003#NCarolina>

Services to Children with Complex Needs

In 2014, Disability Rights North Carolina filed suit against DHHS, alleging that the state's mental health system for children was severely underfunded, preventing children with complex needs, including mental health disorders and developmental disabilities, from receiving the services they needed. DHHS entered into a settlement agreement with Disability Rights North Carolina, and committed itself to addressing gaps in services for children with complex behavioral needs, taking several specific actions, including: establishing a uniform process for identifying and assessing children with complex needs; ensuring these children receive appropriate services; and seeking funding from the General Assembly to increase the capacity of Systemic, Therapeutic, Assessment, Respite and Treatment (NC START), its community crisis support program for children and adults with I/DD and mental health needs. In response to the settlement agreement, DHHS established a children's assessment clinic at the Murdoch Center. An Order of Dismissal was issued in December 2018.

Transitions to Community Living Initiative

The DOJ Civil Rights Division of the United States Department of Justice (DOJ) conducted an eight-month investigation and concluded that North Carolina was violating the Americans with Disabilities Act (ADA) and the Supreme Court's 1999 *Olmstead* decision by failing to afford many people with mental illnesses the opportunity to live in integrated settings. According to the DOJ's letter of findings, published in July 2011, thousands of North Carolinians with mental illnesses remained in large, segregated adult care homes due to the state's failure to make supportive housing, Assertive Community Treatment (ACT), and other services available to enable these individuals to live independently.

As a result of a 2012 settlement agreement with the DOJ, the state created the Transitions to Community Living Initiative (TCLI) to help individuals with serious mental illness (SMI) living in large adult care homes to move into the community. With an annual base budget of \$52.3 million, in addition to ACT, Individual Placement and Support/Supported Employment (IPS/SE), community support teams, peer support, and crisis services, the settlement agreement stipulated that TCLI must provide in-reach; transition management/discharge planning services; assistance with guardianship and informed decision-making; and assistance with accessing supportive housing outside of adult care homes and state-run psychiatric hospitals. DHHS established a Barriers Committee that assists with planning for individuals with complex needs and challenges. The settlement agreement goal was to have 3,000 individuals housed by June 2021. The agreement has since been extended. As of the latest report on TCLI by DHHS to the state legislature, a total of 2,550 individuals have been provided permanent supportive housing (PSH) and supportive services. Local Management Entities/Managed Care Organizations (LME/MCOs) have helped 417 individuals receive bridge housing while awaiting PSH.²⁵

²⁵North Carolina Department of Health and Human Services (2021). *2019 - 2020 Annual report of the North Carolina Transition to Community Living Initiative NC General Statute 122C-20.15, Report to the Joint Legislative Oversight Committee on Health and Human Services*. Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf>.

Samantha R.

A lawsuit filed by Disability Rights North Carolina on May 24, 2017 against the State of North Carolina and DHHS alleged that North Carolina's system of care was fractured and inefficient, forcing thousands of people with I/DD to live in institutions. The suit also alleged that the state had failed to provide many people with I/DD the services they needed to live in and participate in their communities, leading to segregation and risk of institutionalization. The plaintiffs were five people with I/DD, including Samantha R., all of whom were allegedly subject to improper segregation or were at risk of segregation or institutionalization.

In February 2020, the court found that DHHS was in violation of NC General Statute §168 A-7(b), the North Carolina Persons with Disabilities Protection Act. The state is currently working with the court and Disability Rights North Carolina to provide relief to a named plaintiff and identify remedies satisfactory to the court.

Establishment of LME/MCOs

S.L. 2011-264 instructed DHHS to proceed with the statewide restructuring of the mental health, developmental disabilities, and substance use disorder services system by implementing its 1915 (b)(c) waiver statewide. Since July 1, 2013, LME/MCOs have been responsible for statewide management and oversight of the public system of mental health, developmental disabilities, and substance use disorder services at the community level. Currently, seven LME/MCOs operate in the state. Their role is to provide coordination of behavioral health services and of payments for those services. This is done through a network of local community service providers that contract with and are monitored by the LME/MCOs. LME/MCOs receive a monthly payment from DHHS' Division of Health Benefits (NC Medicaid) based on the number of Medicaid beneficiaries residing in the LME/MCO's catchment area. Medicaid beneficiaries receive mental health, substance use disorder, and I/DD services through the LME/MCO's authorization for services within their network. LME/MCOs are also charged by General Statute to serve the uninsured. Funding for the uninsured is supplied through Substance Abuse and Mental Health Services Administration (SAMHSA) block grants that require matching state funds as a "Maintenance of Effort." The state portion of non-Medicaid funding is appropriated by the General Assembly and referred to as "single stream funding."

A total of 375,574 clients were served by LME/MCOs during fiscal year 2020, representing only a slight increase of 2.43% since fiscal year 2011; 69% (258,307) had a mental health disorder, 4.73% (17,955) had a developmental disability, and 26.49% (99,497) had an SUD. Within each disability, the proportion of children (ages 0-17) served ranged from 0.33% (324) of individuals with an SUD, to 20.88% (3,710) of individuals with I/DD. Of people in the mental health category served, 12.46% (32,189) were children.²⁶

²⁶ North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, Data Operations Branch (2021). *North Carolina LME-MCO's annual statistics and admission report fiscal year 2020*. Retrieved 3/25/2021 from <https://files.nc.gov/ncdhhs/2020-LME-Annual-Report.pdf>.

Medicaid Transformation

In 2015, the North Carolina General Assembly enacted legislation which instructed DHHS to transition its Medicaid program and NC Health Choice from fee-for-service to Medicaid managed care. Under managed care, the state will contract with insurance companies, called Prepaid Health Plans. Approximately 1.6 million of the current 2.1 million Medicaid beneficiaries will transition to Medicaid managed care. Within Medicaid managed care, there are Standard Plans, which will provide integrated physical and behavioral health care for members with moderate to no behavioral health needs, and Tailored Plans, which will offer specialized and integrated services for members with significant behavioral health needs and I/DD.²⁷ The Tailored Plans will include individuals with serious mental illness (SMI), SUD, I/DD, and TBI. Both plans will offer long-term service and supports, with the Tailored Plan offering the current 1915(b)(3) and 1915(c) Innovations and TBI Waiver services.²⁸ The official launch of Standard Plans is scheduled for July 1, 2021 and Tailored Plans are scheduled to launch July 1, 2022.²⁹

Inventory of Services and Supports for Individuals with Disabilities

DHHS supports a wide array of services and programs to meet the needs of people with disabilities across the age span.

Aging, Adult, and Children's Services for Physical Disabilities

Services to this population are offered by three DHHS Divisions. The Division of Aging and Adult Services offers services for older adults and adults with physical disabilities. These services include: adult day services; coordination with the Area Agencies on Aging; care management for frail older adults; housing location services for older adults; family caregiver supports; in-home aides; options counseling; and transportation. Many of the goals, objectives and specific strategies of the *2019-2023 State Plan on Aging* speak directly to the expansion of home- and community-based services and supports, collaboration among stakeholders, and development of capacity within communities to promote the independence, safety, and self-direction of older adults with disabilities. The Division of Vocational Rehabilitation Independent Living Rehabilitation Program (ILRP) offers transition support, home modifications, Personal Assistance services and the provision of durable medical equipment and assistive technology. Additionally, the ILRP serves as the liaison for the Statewide Independent Living

²⁷ North Carolina Department of Health and Human Services, Division of Health Benefits (2019). [NC Medicaid fact sheet: Medicaid Transformation](https://files.nc.gov/ncdma/NCMedicaid-Provider-FactSheet-Medicaid-Transformation-Overview-20190925.pdf). Retrieved March 25, 2021 from <https://files.nc.gov/ncdma/NCMedicaid-Provider-FactSheet-Medicaid-Transformation-Overview-20190925.pdf>.

²⁸ North Carolina Department of Health and Human Services (2020, October 8). [DHHS to hold virtual mental health town hall meetings to hear from those receiving services](https://www.ncdhhs.gov/news/press-releases/dhhs-hold-virtual-mental-health-town-hall-meetings-hear-those-receiving-services). <https://www.ncdhhs.gov/news/press-releases/dhhs-hold-virtual-mental-health-town-hall-meetings-hear-those-receiving-services>.

²⁹ North Carolina Department of Health and Human Services, Division of Health Benefits. [Medicaid.ncdhhs.gov](https://medicaid.ncdhhs.gov/transformation). [North Carolina's transformation to Medicaid managed care](https://medicaid.ncdhhs.gov/transformation). Retrieved January 29, 2021 from <https://medicaid.ncdhhs.gov/transformation>.

Centers (SILCs) and Centers for Independent Living (CILs). The Division of Health Benefits supports elders, adults, children, and their families to choose community-based services rather than institutional care and includes the service arrays offered through the Community Alternatives Program for Disabled Adults (CAP/DA) and Community Alternatives Program for Children (CAP/C); options counseling; and the Money Follows the Person (MFP) program.

Community Alternatives Program for Disabled Adults Waiver

The CAP/DA waiver provides individuals 65 and older and adults with physical disabilities, ages 18 to 64, with: adult day health; in-home aide services; coordination of care/case management; financial management services; personal assistance services; chore services; community integration services; community transition; coordinated caregiving; equipment; modifications and assistive technology; meal preparation and delivery; non-medical transportation services; nutritional services; participant goods and services; personal emergency response services; respite services; specialized medical supplies; training/education; and consultative services. The waiver also offers a self-directed option allowing the participant to direct and hire their own personal care services.

Community Alternatives Program for Children Waiver

Administered by the North Carolina Division of Health Benefits, this 1915(c) waiver offers home- and community-based supports and services to children ages 0 to 20 who have a fragile or complex medical condition as their primary diagnosis and who are determined to require an institutional level of care. Waiver services include in-home care aide services; financial management; assistive technology; case management; community transition; home accessibility and adaptation; institutional and non-institutional respite; participant goods and services; pediatric nurse aide services; specialized medical equipment and supplies; training; education and consultative services; and vehicle modification. This waiver also has a consumer-directed option, allowing family or a designated representative to act as the employer of record to hire personal care staff. There are 4,000 slots for this waiver. Typically, there is a not a waitlist for this waiver.³⁰

Money Follows the Person

Since 2009, North Carolina has used the MFP demonstration to transition 369 older adults, 418 people with physical disabilities (under the age of 65) and 583 individuals with I/DDs from nursing facilities, hospitals, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs), and psychiatric residential treatment facilities (PRTFs). MFP benefits include immediate access to waivers (MFP has access to 68 waiver slots each year), transition services, move-in supports, home modifications, and staff training. The state contracts for transition coordination services with the DVRS Independent Living Program division, a selection of Area Agencies on Aging (AAAs), and some lead agencies that serve individuals on the CAP/DA waiver. AAAs are notified of individuals eligible for MFP,

³⁰ Complex Child Magazine. [KidsWaivers.org](https://www.kidswaivers.org). Retrieved March 25, 2021 from <https://www.kidswaivers.org/nc/>

based on referrals sent to them by nursing home Minimum Data Set Coordinators through the Section Q process of the Minimum Data Set, and referrals can be made by nursing facilities.³¹

Special Assistance In-Home Program

The SA/IH program provides cash supplements to low-income individuals who may be at risk for entering a facility. County-level case managers assess the individual's functional status and need for services; availability of natural supports (family, friends, neighbors); access to community-based services where they currently live; ability to pay for housing; and the array of safe/affordable housing in their area. A care plan is developed in collaboration with the person and their providers, and a plan is made for how the cash supplement can be used to keep the person housed in the community. SA/IH is provided as a monthly cash benefit. Average annual payments for participants range from \$4,100 to \$4,900. This program was developed in concert with TCLI to support individuals to live in the community as an alternative to institutions such as nursing facilities and adult care homes.³²

Statewide Independent Living Council and Centers for Independent Living

The North Carolina SILC is made up of members from the community with disabilities and is charged with overseeing the provision of independent living services by the statewide network of Centers for Independent Living (CILs). The SILC's mission is "to promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy, in order to maximize opportunities for individuals with disabilities and the integration and full inclusion of individuals with disabilities into the mainstream of society."³³ The goal for each CIL is to promote community inclusion, to employ staff, and appoint a board of directors who are people with disabilities as a support to people in the community. The SILC and CILs are key advocacy voices for independence for North Carolinians with disabilities across the lifespan.

Core services of CILs include advocacy; independent living skills; peer support; information and referral; and community integration, including transition-related services for those in facilities. Transitions include: Transition from nursing homes and other institutions; diversion from institutions; and transition of youth who were eligible for an Individualized Educational Plan to post-secondary life. As per each North Carolina CIL's service delivery definitions, CILs will provide, statewide, a minimum of:

- 1,000 units of information and referrals

³¹ North Carolina Department of Health and Human Services, Division of Medical Assistance (2018). [Money Follows the Person demonstration sustainability analysis: Transitioning beyond 2020 \(p.6\)](https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf). Retrieved March 25, 2021 from <https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf>.

³² North Carolina Department of Health and Human Services, Division of Aging and Adult Services (2017, July 1). [State/County Special Assistance In-Home \(SA/IH\) and Transitions to Community Living Initiative \(TCLI\)](https://policies.ncdhhs.gov/divisional/aging-and-adult/special-assistance-in-home-program/saih-5250.pdf). Transmitted by Change Notice 5250. <https://policies.ncdhhs.gov/divisional/aging-and-adult/special-assistance-in-home-program/saih-5250.pdf>

³³ [North Carolina Statewide Independent Living Council](https://www.ncsilc.org/). <https://www.ncsilc.org/>

- 24 advocacy and self-advocacy activities
- 24 peer support activities
- 24 independent living skills training activities
- 24 community integration activities
- 8 youth transition activities (from report attached)

CIL transition activities vary. Some CILs appear to provide robust transition-related services, which seem to be duplicative of MFP and DVRS-Independent Living efforts, while other CILs focus on transition-related services for the non-MFP target population.³⁴

Services for Individuals with Intellectual and Developmental Disabilities

Innovations Waiver

The 1915(c) Medicaid Innovations Waiver supports children and adults with I/DD who meet ICF/IID level of care criteria, or who are at risk of being placed in an ICF/IID, to live in the community. In collaboration with the North Carolina Division of Health Benefits, waiver services are administered by the LME/MCOs, which facilitate access to services and oversee a network of community-based service providers. The waiver offers the widest array of community-based services³⁵ in the state's system for individuals with I/DD and allows for individuals to live at home, in independent housing, or in a group living setting. Currently there are 13,138 individuals supported through the Innovations Waiver.

State-Funded (b)(3) and Medicaid Non-Waiver DD Services

Medicaid-eligible individuals on the waitlist for waiver services may qualify for (b)(3) Medicaid state-funded services, which are additional services not in the Medicaid state plan that focus on helping individuals remain in their homes or communities and avoid institutionalization or hospitalization.³⁶ Medicaid-eligible and uninsured persons may also qualify to receive non-waiver developmental disability services, outlined in Table 3 below, administered under the DMH/DD/SAS and contracted to the LME/MCOs. Neither the (b)(3) nor the DMH/DD/SAS-funded services are entitlements; access is limited by the availability of funds.

³⁴ North Carolina Department of Health and Human Services, Division of Medical Assistance (2018). *Money Follows the Person demonstration sustainability analysis: Transitioning beyond 2020*. Retrieved March 25, 2021 from <https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf>.

³⁵ Waiver services include: Assistive technology; community living and supports which include skills training for shopping and banking and with ADLs; community navigator and networking supports; community transition or pre-tenancy supports and supported living; crisis services; day supports; specialized consultation services which include PT, OT, and speech therapy evaluations; supported employment; vehicle modification; and respite services.

³⁶ Cardinal Innovations Healthcare. *Overview of (b)(3) services*. Retrieved March 25, 2021 from <https://www.cardinalinnovations.org/getmedia/8c397549-cde1-4cb1-8192-53f9ef9ab694/overview-of-b3-additional-services.pdf>.

State Funding to Promote Greater Independence for Adults with Down Syndrome

The General Assembly recently enacted legislation³⁷ that, beginning July 1, 2021, allocates a total of \$5,000,000 to DHHS, \$2,500,000 in nonrecurring funds for FY 2022 and FY 2023, exclusively to support programs that assist individuals with Down Syndrome and their families in developing opportunities for increased independence in adulthood. Funding is limited to providers with a proven record of providing at least one of the following services to adults with Down Syndrome: (1) Assistance with dignified integration into the community; (2) Housing assistance; (3) Job training, job placement, or both.

Table 3. Medicaid (b)(3) and Non-Waiver State Plan Services

Service	Medicaid (b)(3) Funded	Non-Waiver DD State Funded	Medicaid Fee for Service
Adult Developmental Vocational Program		✓	
Counseling/Therapy		✓	
Day Programs		✓	
Day Supports		✓	
Employment Supports	✓	✓	
Family Living		✓	
Group Living/Residential		✓	
Intensive In-Home Services	✓		
Peer Support*	✓	✓	
Personal Assistance		✓	
Personal Care Services	✓		✓
Respite	✓	✓	
Respite (outside the home, up to 24 days per year 38)	✓		
Supportive Housing	✓		

*In May 2019, Peer Support was approved as a State Plan service for individuals with SMI

³⁷ General Assembly of North Carolina, Session 2021. [House Bill 346: Funds for Down Syndrome Programs](https://www.ncmedsoc.org/hb-346-funds-for-down-syndrome-programs/). Retrieved April 26 from <https://www.ncmedsoc.org/hb-346-funds-for-down-syndrome-programs/>.

³⁸ Cardinal Innovations Healthcare. [b\(3\) Respite, children MH/ID/DD/SUD and adults with developmental disabilities Medicaid billable service, effective 04-01-07](https://www.cardinalinnovations.org/getmedia/92999F3F-035D-48BB-8453-B225680E99FF/b3-respite-children-mh-idd-sa-and-adults-with-developmental-disabilities.pdf). Retrieved March 25, 2021 from <https://www.cardinalinnovations.org/getmedia/92999F3F-035D-48BB-8453-B225680E99FF/b3-respite-children-mh-idd-sa-and-adults-with-developmental-disabilities.pdf>.

Other Programs and Evidence-Based Practices that Promote or Support Community Integration

Some organizations and LME/MCOs have developed programs to fill gaps or meet challenges for serving individuals with I/DD. In 2017, the North Carolina Council on Developmental Disabilities in collaboration with the state's MFP demonstration project and Vaya Health launched a Supported Living Learning Community. The initiative facilitated a learning collaborative of interested I/DD providers to examine how to better support individuals with I/DD to live in their own homes, providing technical assistance to providers and direct support staff on practices of the supported living model.

The Community Activity and Employment Transitions model, originally administered by the Mecklenburg County LME, promotes community integration, immersion, and independence in the community by assisting participants with developing social skills, exploring vocational options or volunteer opportunities, participating in wellness activities, and building skills for daily living. This model was developed as an alternative to sheltered workshops.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is defined by the Autism Science Foundation as a brain-based disorder characterized by social-communication challenges and restricted repetitive behaviors, activities, and interests. Individuals with ASD may communicate, interact, behave, and learn in ways that are different from those of most other people. Some individuals with ASD need substantial support in their daily lives; others need less. In the past, treatment for individuals under age 21 on Medicaid who had an ASD diagnosis was covered under Early Periodic Screening, Diagnosis and Treatment (EPSDT). In 2019, the Division of Health Benefits received approval of a State Plan Amendment to CMS to add research-based behavioral health treatment as a Medicaid-covered service for individuals under the age of 21.

LifeLong Interventions is a model that provides comprehensive treatment for children and adults with ASD. It is rooted in the principles of Applied Behavior Analysis and involves effective instruction using evidence-based practices to promote meaningful skills and behaviors in the home, school, and community. The services are offered in the Triangle, Wilmington, Asheville, Morganton/Asheville East, and greater Charlotte areas and may be accessed through the LME/MCOs. In addition, Rapid Response Clinical Consult (RRCC) is available for children and adults with a diagnosis of ASD throughout all 100 North Carolina counties, as the service is delivered via telehealth. RRCC is a short-term consultation service available to parents and caregivers that can assist with organizing and planning the day; provide quick tips/strategies to address social communication and other skill areas; and offer behavior intervention strategies. This service is not intended to address extreme forms of problem behavior or mental health crisis.

Adults with ASD can access I/DD services administered by the LME/MCOs and must compete for Innovations Waiver slots or state-funded supports.

Services for Individuals with Mental Health and Substance Use Disorders

Services for children with behavioral health disorders include comprehensive clinical assessment; outpatient therapies and medication management; multi-systemic therapy; intensive in-home services

for kids at risk of placement; day treatment; therapeutic foster care (level 2); residential treatment; and secure psychiatric residential treatment facilities. All services are covered by Medicaid and state funds as available; Children are Medicaid eligible as a family of one. Additionally, all LME/MCOs support High Fidelity Wraparound as an “in lieu of” service. DHHS is piloting youth peers, embedded in High Fidelity Wraparound teams with a case manager and a family partner. DHHS allocates federal block grant funds to support three first-episode psychosis programs, and is testing rural consultation.

Services available for adults with SMI include: ACT; community support teams; critical time intervention (CTI); Individual Placement and Support – Supported Employment (IPS/SE); crisis services via the North Carolina Crisis Solutions Initiative, mobile crisis teams, and the online behavioral health crisis referral system; peer support services; and transition management services via TCLI.

Services for adults with SUDs include hospital-based detox and residential treatment, outpatient therapies, medication-assisted treatment (MAT), and recovery supports. North Carolina has benefited from receipt of \$40 million in 21st Century Cures Act funding via State Targeted Response to the Opioid Crisis Grants to increase access to MAT and recovery supports.

A few LME/MCOs, such as Trillium and Alliance, are looking to expand best practices around SUD treatment. Healing Transitions, a provider within the Recovery Oriented Systems of Care model in Raleigh, helps people with SUDs with overnight shelter programs; non-medical detox; family services; and a structured, long-term recovery program. The program has an emphasis on motivational enhancement, job readiness, transitioning to permanent supportive housing, and teaching recovery to avoid emergency department visits and unnecessary hospital admissions.³⁹ Since October 2020, LME/MCOs, such as Alliance Health, have promoted service provision via telehealth, utilizing funding to purchase mobile phones and data plans for identified members to continue receiving services necessary to maintaining sobriety. By maintaining access to services through telehealth, they have provided needed services during the pandemic, reducing overreliance on emergency departments and inpatient hospital stays.

Crisis Services for Children and Adults with Mental Health and Substance Use Disorders include state-operated facility-based crisis (FBC) centers and behavioral health urgent care (BHUC) centers to serve as alternatives to hospital emergency departments and inpatient hospitalization for individuals who experience crises related to mental health, substance use disorder, or I/DD diagnoses. Eight BHUC facilities and 23 FBC facilities operate on a 24/7 basis. The FBC centers are licensed residential facilities, providing 323 beds to offer alternative treatment to inpatient hospitalization. Of the 23 adult FBC service sites, 11 are designated for the treatment of individuals who are under involuntary commitment. In addition, North Carolina is operating two child FBC service sites, with one of them designated for the treatment of individuals who are under either voluntary or involuntary commitment. Each child FBC service site has a 16-bed facility that provides services for children and adolescents, ages 6 through 17,

³⁹ Alliance Health Plan (2020, October 29). Alliancehealthplan.org. [LME/MCOs preserve healthcare access during COVID-19.](https://www.alliancehealthplan.org/general-news-announcements/lme-mcos-preserve-behavioral-healthcare-access-during-covid-19/)
<https://www.alliancehealthplan.org/general-news-announcements/lme-mcos-preserve-behavioral-healthcare-access-during-covid-19/>

who need crisis stabilization services and 24-hour supervision due to a mental health crisis, substance use disorder, or withdrawal from drugs or alcohol. Mobile Crisis Services are also available 24 hours a day, seven days a week, 365 days a year for individuals with Medicaid coverage as well as individuals who lack insurance. In FY 2019, 9,671 individuals were seen at a Tier IV BHUC.

Employment Support: IPS/SE and the North Carolina Collaborative for Ongoing Recovery through Employment Initiative

Since 2013, DVRS has utilized IPS/SE to assist individuals with SMI in finding competitive employment by providing counseling on benefits; support to help manage symptoms and behavioral health needs; and employment and peer support specialists who provide support to help maintain employment. IPS/SE services are funded via the Medicaid (b)(3) waiver or via a combination of Medicaid- or state-funded fee-for-service (FFS) payments and DVRS milestone payments. The FFS and milestone payments methodology has resulted in some providers being less clear as to how to bill services. In response, the state developed the North Carolina Collaborative for Ongoing Recovery through Employment (NC CORE) initiative. This innovative payment structure addresses the discrepancy between FFS and milestone payments by switching both the state and Medicaid FFS payments to milestones. The milestones align with the IPS/SE evidence-based practice and focuses providers on the quality of service they are delivering versus the quantity of service they provide. Most importantly, the approach ensures providers can seamlessly transition from state or Medicaid funds to DVRS funds, maximizing all funding streams.

Services for Traumatic Brain Injury

The current community-based system supports some individuals with TBI of all ages to access residential, personal care, supported employment, day supports, Critical Time Intervention, and other support services that support community inclusion and encourage integration into the most natural settings possible. Services for children/younger adults with acquired brain injury and adults over 22 with TBI in North Carolina are provided through LME/MCOs via state funds, via waivers or through the various agencies of DHHS. This includes:

- The NC Innovations Waiver: Individuals who sustained a brain injury before age 22 and who meet ICF/IID level of care may be eligible for this Medicaid waiver.
- NC TBI Waiver Pilot: The NC TBI Waiver serves adults who sustained their TBI on or after their 22nd birthday. Currently the pilot, administered by Alliance LME/MCO, serves 107 individuals in Wake, Durham, Johnston, and Cumberland counties. Additional services offered by the pilot waiver include Cognitive Rehabilitation, Life Skills Training, and Extended State Plan Allied Health Services.
- CAP/DA 1915(c) Waiver: The CAP/DA program allows older adults and adults with disabilities, including those with TBI ages 18 and up, to receive support services in their own home, as an alternative to nursing home placement.
- CAP/C: The CAP/C program provides services for medically fragile children, including those with acquired brain injury under age 21, who are at risk of institutional care.

- Medicaid-covered services include:
 - Personal Care Services
 - Residential supports
 - Supported employment
 - Community networking
 - Day supports
 - Resource facilitation
 - Specialized consultative services

- Medicaid behavioral health services
- Medicaid substance use disorder services
- Medicaid I/DD services – for children with acquired brain injury
- Physical therapy/occupational therapy/speech and language therapy⁴⁰

North Carolina was awarded a three-year grant from the federal Administration for Community Living to focus on the needs of individuals with TBI and the training and education needs of providers across the state. The grant is looking at a statewide action plan, including a plan to reapply for the current TBI pilot waiver which ends April 30, 2021. The application for the TBI Waiver extension will expand the waiver and supported living services statewide, allowing more individuals with TBI to live at home with supports.

⁴⁰ North Carolina Department of Health and Human Services (n.d.). *Traumatic brain injury*. NDDHHS.gov. Retrieved March 25, 2021 from <https://www.ncdhhs.gov/assistance/disability-services/traumatic-brain-injury>.

Chapter 3: Assessment of Findings

The Technical Assistance Collaborative (TAC) utilized qualitative and quantitative information about North Carolina to assess the state's public service delivery and support systems for people with disabilities. This chapter provides an assessment of many, but not all, aspects of North Carolina's system, based on the data that was available from various sources. In any given state system, there may be infinite strengths and weaknesses that could be identified to improve the availability of and access to quality, evidence-based services. During this assessment, we identified a range of issues that could be examined in greater depth to improve the overall system orientation to serve people with disabilities in integrated settings. The primary purpose of this system assessment is to examine the state's systems in the context of community integration, and as a result, we identify areas that should minimally be addressed in the development of an Olmstead Plan.

Strengths of Systems and Services

Stakeholder Feedback

Including Stakeholder Input

North Carolina invests considerable resources in outreach to stakeholders and in assessments that include broad-based stakeholder input. Examples include:

- Session Law 2015-241, Sec. 11.19(a) provided six agencies and institutions, joined by the Postsecondary Education Alliance and diverse community stakeholders, with an opportunity to effect system changes with pervasive effects on the lives of students and youth with intellectual and other significant disabilities. Though unfunded, the two-year effort brought together policymakers, advocates, interested stakeholders, students, youth, and families to form the Advisory for Education and Employment Opportunities for Students with Disabilities.
- DHHS held numerous statewide listening sessions to obtain input from a broad range of stakeholders, including Medicaid beneficiaries, to design initiatives under Medicaid Transformation.
- Even with the difficulties of the pandemic, the North Carolina Department of Health and Human Services (DHHS) fully supported TAC in proceeding with stakeholder engagement as a key component of this assessment, by conducting virtual listening sessions with 15 different stakeholder groups.
- Leaders from the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) held virtual Town Hall meetings throughout North Carolina to hear from consumers, families, and advocates about how the behavioral health system is working and how DHHS can assist in creating a system that improves health outcomes and promotes recovery for all North Carolinians.
- The Division of Health Benefits and DMH/DD/SAS initiated, and continue to hold, regular calls with beneficiaries and service providers to discuss and address the need for additional

flexibilities to serve individuals during the COVID-19 pandemic. These opportunities have been so successful that DHHS is proposing to continue them and broaden the focus post-pandemic.

When asked to identify the strengths of the systems and services that support North Carolinians with disabilities, stakeholder respondents most often identified these features:

- North Carolina offers a comprehensive array of treatment, therapeutic services, and supportive services.
- The preferences and choices in services of individuals, families, and caregivers are honored.
- Stakeholders have opportunities to participate in and contribute to systems change.

It’s relevant to note that some stakeholders did not identify a system strength, indicating that they did not view any of the options presented in the survey as a strength in North Carolina.

Array of Services and Honoring Choice

There appears to be a wide array of services and supports that *can* be available to individuals with disabilities in North Carolina. Through Enhanced Mental Health and Substance Abuse Services, 20 different services are available to children and adults for mental health and SUDs and are covered by Medicaid and state general funding. Please refer to Table 4 below for a list of Enhanced Services. Local Management Entities/Managed Care Organizations (LME/MCOs) determine eligibility and authorize the services based on person-centered plans. Medicaid waivers and litigation have also contributed to the service array for certain populations. However, access to this array of services and supports varies significantly, as described later in this report under “Barriers to Accessing Services and Supports.”

Table 4. Medicaid- and State-Funded Enhanced Mental Health and Substance Use Disorder Services

Mental Health Services	Substance Use Disorder Services
Diagnostic Assessment	Intensive Outpatient
Intensive In-home Services – Child	D&A Partial Hospital Program
Multisystemic Therapy – Child	Clinically Managed High-Intensity Residential
Day Treatment – Child and Adolescent	Medically Monitored intensive Inpatient
Partial Hospital Program – Child and Adult	Clinically Managed Low-Intensity Residential
Facility-based Crisis – Child	Ambulatory Detox
Mobile Crisis	Medication-Assisted Treatment
Crisis Residential – Adults	Medically Monitored Detox
Psychosocial Rehabilitation – Adults	Diagnostic Assessment
Assertive Community Treatment	Facility-based Crisis – Child

Mental Health Services	Substance Use Disorder Services
Community Support Teams	Crisis Residential – Adults
Targeted Case Management	
Peer Support Services	
Individual Placement and Support/Supported Employment	

DHHS leadership conveys a strong commitment to honoring choices and preferences in services. Family members and guardians confirmed this commitment; their choices have been honored for years, perhaps at the expense of individuals with disabilities themselves — also described later, under “Barriers to Accessing Services and Supports.”

Assessment of System Strengths

Beyond those identified by stakeholders, TAC identified additional systems and services strengths as a result of our analysis.

Transitions to Community Living Initiative

The Transitions to Community Living Initiative (TCLI) has resulted in positive outcomes and improved delivery of services for many adults with serious mental illness (SMI) in North Carolina. In fiscal year 2020, the number of individuals discharged from state psychiatric hospitals to TCLI and supported housing increased by 28% from fiscal year 2019, and the number of individuals referred to adult care homes (ACHs) decreased by 33%. Referrals to bridge housing and supported housing increased to 11.5% of the total state psychiatric hospital discharges, an increase of 3.2% of the total discharges from fiscal year 2019.⁴¹ Less than two percent (1.4%) of individuals had state psychiatric hospital admissions while housed in 2019.

In each full state fiscal year of TCLI, participants surveyed in follow-up interviews after 11 and 24 months in supportive housing have reported improvements in quality of life. They also reported more positive assessments of their life circumstances than did individuals who had not yet transitioned from congregate living facilities and other settings to supportive housing. These patterns are observed across LME/MCO catchment areas as well as over time.

⁴¹ North Carolina Department of Health and Human Services (2021). *2019 - 2020 Annual report of the North Carolina Transition to Community Living Initiative NC General Statute 122C-20.15, Report to the Joint Legislative Oversight Committee on Health and Human Services*. Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf>.

LME/MCOs increased their in-hospital care coordination presence, either through increases in the number of days on units, or through embedding care coordination at the state psychiatric hospitals, enhancing coordination and collaboration across, and at times, outside of an LME/MCO catchment area.

The TCLI includes:

- In-Reach and Transition services that provide or arrange for frequent education efforts and discharge planning targeted to individuals in institutional or congregate care settings.
- Diversion services that provide informed choice regarding housing options to individuals with disabilities considering admission to an institutional or congregate care setting.
- Housing, increasing the availability of and access to community-based supportive housing with tenancy supports.
- Supported Employment services that assist individuals in preparing for, identifying, and maintaining integrated, paid, competitive employment.
- Quality Management, using data to evaluate progress and outcomes.
- A Barriers Committee, establishing a process that regularly raises and addresses challenges and barriers to transitions.

TCLI also includes Assertive Community Treatment (ACT) for individuals with SMI to ensure that individuals transitioning from institutional and congregate care settings receive the intensity and frequency of services and supports they desire and need to be healthy and safe and live as fully integrated members of their communities.

While TCLI has resulted in positive changes for the system, challenges yet to overcome are described later in this report.

Use of Federal Resources

Medicaid Waivers

DHHS has a strong history of utilizing Medicaid waiver authorities to benefit individuals with disabilities. The Innovations Waiver, the Traumatic Brain Injury Waiver, the Community Alternatives Program for Disabled Adults (CAP/DA) and Community Alternatives Program for Children (CAP/C) waivers described earlier in this report cover a robust array of home- and community-based services and supports that allow thousands of individuals to live outside of institutional settings. Many stakeholders described the Innovations Waiver as “a Cadillac.” The Innovations Waiver serves 13,138 individuals with intellectual/developmental disabilities (I/DD); CAP/DA serves 11,534 adults with physical disabilities; and the CAP/C Waiver served 2,650 children with disabilities in fiscal year 2019, with the capacity to serve a total of 4,000. North Carolina administers the Innovations and TBI waivers, aligned with a 1915(b) waiver authority, allowing the LME/MCOs to administer the benefits. A strength of this approach is that the LMEs can offer 1915(b)(3) services in addition to State Plan benefits. DHHS includes a self-directed option for the Innovations, CAP/DA and CAP/C waivers, allowing recipients and their families to hire support staff and direct services provision.

In 2019, DHHS received approval from the Centers for Medicare and Medicaid Services (CMS) for an 1115 Medicaid demonstration waiver to support integrated health care. The waiver includes Healthy Opportunities pilots, which present an unprecedented opportunity for North Carolina to test and evaluate the impact of providing high-needs Medicaid enrollees with select evidence-based, non-medical interventions related to housing, food, transportation, and interpersonal safety. The federal government has authorized up to \$650 million in Medicaid funding for the pilots over the next five years. Pilot services are intended for Medicaid enrollees who meet at least one state-defined health criterion, including adults with two or more chronic health conditions and children (up to age 21) who may have experienced three or more Adverse Childhood Experiences (ACEs),⁴² and who have at least one state-defined social risk factor. Unfortunately, as a result of COVID-19, implementation of the pilots has been suspended.

Money Follows the Person

Money Follows the Person (MFP) is a federal demonstration program that supports state efforts to rebalance their long-term services and supports systems so that individuals have a choice of where they live and receive services. Since 2009, North Carolina has transitioned nearly 1,400 individuals from institutional settings to community-based living. Not only does MFP offer individuals the opportunity to transition to the community where they can receive home- and community-based services, but on average North Carolina saves \$2,600 per person per month compared to the cost of institutional care.

Children's System of Care

DHHS is committed to building an effective "System of Care," a comprehensive network of community-based services and supports organized to meet the needs of children, youth, and families who are involved with multiple service agencies, such as child welfare, mental health, schools, juvenile justice, and health care. The goal is for families and youth to work in partnership with public and private organizations, ensuring that supports are effective and built on the child's and family's strengths and needs. System of Care is not a service but an evidence-based model of working together with youth and families to achieve their desired outcomes, including reducing out-of-home placements. Youth and Family Teams are a key component of System of Care.

Housing

North Carolina has many federal and state resources that can support individuals with disabilities to live independently. Please refer to [Appendix I](#) for further information about the following resources.

Federal resources include:

- **45,220 Housing Choice Vouchers** that can assist very low-income families, senior citizens, and individuals with disabilities to afford decent, safe, and sanitary housing in the private market.
- **3,847 vouchers** targeted exclusively to people with disabilities

⁴² Centers for Disease Control and Prevention (2020, April 3). *Adverse childhood experiences (ACEs)*. Centers for Disease Control and Prevention. Retrieved April 22, 2021 from <https://www.cdc.gov/violenceprevention/aces/index.html>.

- **21,588 public housing units** administered by public housing agencies (PHAs)
- **556 Department of Housing and Urban Development (HUD) Mainstream Vouchers** awarded to 21 local PHAs, of which 15 are set aside for the TCLI settlement population
- **\$7,000,000 awarded to the North Carolina Housing Finance Agency (NCHFA) for HUD Section 811 Project Rental Assistance units** with about 188 apartments being targeted for individuals with disabilities transitioning from or at risk for institutionalization
- **HUD funds** — including Community Development Block Grants, the HOME Investments Partnership program, Housing Opportunities for Persons with AIDS, and Emergency Solutions Grants — targeted to reducing homelessness

At the state level, additional Housing resources and programs play an important role:

- The **NCHFA** has a strong history of implementing targeted efforts for housing development and has made targeting 10% of units for individuals with disabilities a Housing Credit Program threshold requirement and a requirement for all bond-financed development.
- The **Key Rental Assistance program** is funded through the General Assembly to make units from the Targeting Program affordable to individuals with disabilities who have incomes as low as Supplemental Security Income (SSI).
- The **Transitions to Community Living Voucher program** is a tenant-based voucher program operated by the LME/MCOs that provides support to tenants throughout the leasing process and a care team to support tenants after securing a unit. Tenants also have access to move-in funds, such as security deposits and utility assistance.
- The **Integrated Supportive Housing Program** fosters a collaboration among a local housing developer, DHHS, and the LME/MCO to increase the supply of integrated, affordable rental housing. This housing consists of independent rental units where no more than 20% of the units are required to be set aside for individuals with a disability. Prospective tenants are referred by DHHS and are anticipated to come with rental assistance and connection to supportive services. The program prioritizes TCLI participants.
- **Supportive Housing Development Program** financing is available to developments serving populations of homeless or non-homeless households with special needs who earn below 50 percent of area median income. Rent and utilities cannot exceed 30 percent of the targeted income, or 40 percent of the targeted income in developments that also provide food and transportation.
- **The North Carolina Housing Trust Fund** can finance home ownership and rental apartments, new construction, housing rehab, and emergency repairs. It provides the state's largest source of funds to finance supportive housing and emergency repairs/accessibility modifications.

To help the state meet the terms of its settlement agreement with the Department of Justice, HUD has approved the waiver request for a remedial preference for individuals with a serious mental illness (SMI) or severe and persistent mental illness (SPMI) who are living in an ACH or who are at risk of entry into an ACH for the North Carolina Commission of Indian Affairs/North Carolina Department of Administration. This will enable individuals with SMI/SPMI who are being diverted or discharged from an ACH to have priority access to a number of these newly created housing units.

Housing-Related Services and Supports

Community Support Teams (CSTs), transition management services, and permanent supportive housing (PSH) are available to promote community inclusion. DHHS has amended its service definition for CSTs, a component of TCLI, to include tenancy-sustaining services. CSTs can support individuals with SMI by helping to restore daily living skills; focus on money and benefits management; secure and maintain housing or other living environment; strengthen personal responsibility; assist with nutrition, menu planning, and grocery shopping; and attend to personal hygiene and grooming. One area of focus is on appropriate social and role functioning in various community settings and especially on understanding the roles, rights, responsibilities of tenancy. Other areas include accessing, renewing, and using appropriate public entitlements and resources such as Social Security and Section 8; and meeting requirements for securing and retaining affordable housing, transportation, and food stamps.

State-Funded Living Supports

North Carolina provides a unique state-funded program, the Independent Living Rehabilitation Program (ILRP), administered through the Division of Vocational Rehabilitation Services' (DVRS) 17 offices statewide. The ILRP helps individuals with disabilities integrate into the community. The ILRP offers an array of services that include, but are not limited to, counseling and guidance services, home modifications, equipment purchases, information and referral, and transition support. The ILRP prioritizes people in institutional settings; people who can be diverted from institutionalization; and individuals who need support to maintain community-based living. DVRS' Employment Section can close a vocational rehab case and transfer services to the ILRP until an individual meets the goals outlined in their service plan. The ILRP offers a self-directed Personal Assistance Service (PAS) plan that supports individuals by providing hands-on assistance. Currently, there are approximately 300 individuals served under the PAS program. Service to individuals in the PAS program is long-term.

The Division of Services for the Blind (DSB) administers the Independent Living Rehabilitation and Independent Living Older Blind programs. Training on assistive technology, such as voice-controlled smart speakers (e.g., Echo Dot or Google Home Mini), is available for consumers with visual impairments, enabling them to live independently. In 2019, these DSB programs provided services to several hundred North Carolinians:

- Served 1,109 eligible individuals (365 through Independent Living Rehabilitation and 744 through Independent Living Older Blind)
- Rehabilitated 445 eligible individuals
- Held 33 daily living skills classes, attended by 380 eligible individuals

Each year, DSB also serves individuals with vision and hearing loss through the Vocational Rehabilitation Program and its Independent Living programs. DSB has five deaf-blind specialist positions which serve all 100 counties in North Carolina. These specialists provide leadership in the provision of services to deaf-blind consumers by engaging in both direct services to consumers and serving as consultants to other staff. In 2019, deaf-blind specialists provided services to 148 qualified individuals.

Increasing Behavioral Health Inpatient and Facility-Based Crisis Beds via Dorothea Dix Hospital Property Fund Contracts

The General Assembly has appropriated funding from the sale of the Dorothea Dix State Hospital property to DHHS to establish state psychiatric hospital diversion services.⁴³ Funds have been allocated to convert existing licensed acute medical inpatient beds into licensed psychiatric or substance use inpatient beds or to create new licensed psychiatric or substance use inpatient beds, including in rural communities. In addition, funding was allocated to create new beds in a facility-based crisis program. At least 50% of the newly licensed beds are to be reserved for “(i) purchase by the Department under the State-administered, Three-Way Contract and (ii) referrals by local management entities/managed care organizations of individuals who are indigent or Medicaid recipients.”⁴⁴

Community-Based Service Pilots

The Community Behavioral Health Paramedicine pilot was originally funded by the state General Assembly in Session Law 2015-241, Section 12F.8, and has more recently received additional funding through an appropriation in Session Law 2017-57, Section 11G.1.(a). The intent of the pilot is “to use specially-training Emergency Medical Services (EMS) staff to intervene with patients experiencing behavioral health crises, and provide incentives for the participating EMS to either treat on-scene or route those patients not needing medical treatment to lower cost alternatives to hospital emergency departments (EDs).”⁴⁵ In SFY 2020, specially trained EMS workers in five counties in North Carolina (Forsyth EMS, Orange EMS, Stokes EMS, McDowell EMS, and Onslow EMS) responded to behavioral health emergencies, reporting 1,565 community behavioral health paramedicine encounters. Of those 1,565 emergency encounters, 380 were treated on the scene, and required no transport to a higher

⁴³ North Carolina Department of Health and Human Services (2020). *Funds for local inpatient psychiatric beds or bed days purchased in state fiscal year 2019-2020 and other department initiatives to reduce state psychiatric hospital use, Session Law 2020-78, Part IV-E, Section 4E.1*. Report to the Joint Legislative Oversight Committee on Health and Human Services and Fiscal Research Division, December 21, 2020. Retrieved April 26, 2021 from <https://files.nc.gov/ncdhhs/SL-2020-78-Section-4E.1-Funds-for-Local-Inpatient-Psychiatric-Beds-or-Bed-Days--Final-.pdf>

⁴⁴ Required by Session Law 2016-94, House Bill 1030, Section 12F.4.(b) and Session Law 2017-57, Senate Bill 257, Section 11F.5.(d) as amended by Session Law 2018-5, Section 11F.2.

⁴⁵ North Carolina Department of Health and Human Services (2016). *Final report on the Community Paramedic Mobile Crisis Management Pilot Program, Session Law 2015-241, Section 12F.8.(d)*. Report to the Joint Legislative Oversight Committee for Health and Human Services and the Fiscal Research Division, November 1, 2016. Retrieved April 26, 2021 from <https://files.nc.gov/ncdhhs/SL%202015-241%20Section%2012F%208%20d%20Community%20Paramedicine.pdf>

level of emergency response; another 159 encounters resulted in the individuals being transported to alternative emergency response facilities (e.g., behavioral health urgent care centers or facility-based care centers) instead of hospital emergency departments.⁴⁶

DHHS has also funded case management pilot programs developed by the Vaya, Trillium and Alliance LME/MCOs, intended to reduce emergency department visits and inpatient admissions.

Employment

North Carolina has several noteworthy accomplishments in supporting individuals with disabilities. In 2015, the North Carolina Council on Developmental Disabilities (NCCDD) released *Creating Productive Futures for Youth and Adults with Intellectual and Developmental Disabilities*, developed over three years by the Institute for Community Inclusion, University of Massachusetts Boston. This report identified several system strengths relative to the transition to postsecondary education and competitive employment outcomes by youth with I/DD:

- State agency staff have developed strong working relationships and understand the policies of each agency.
- The Postsecondary Education Alliance is one of the largest networks in the country to focus on expanding inclusive postsecondary options for students with an intellectual disability.
- Innovation and promising practices can be found throughout North Carolina. There are school districts, local partnerships, postsecondary education programs, and progressive community agencies helping people get their own jobs.
- Transition services for students with disabilities begins at age 14 in North Carolina, whereas many states do not begin offering transition services until age 16. The Department of Public Instruction tracks post-high-school outcomes through its State Performance Plan. Data collection is required for certain key indicators that are relevant to transition to postsecondary education and employment.⁴⁷

North Carolina General Statute 108A-48 extends the provision of foster care benefits to young adults between 18 and 21 years of age, giving youth additional, family unit assistance to enter postsecondary

⁴⁶ North Carolina Department of Health and Human Services (2020). *Funds for local inpatient psychiatric beds or bed days purchased in state fiscal year 2019-2020 and other department initiatives to reduce state psychiatric hospital use, Session Law 2020-78, Part IV-E, Section 4E.1*. Report to the Joint Legislative Oversight Committee on Health and Human Services and Fiscal Research Division, December 21, 2020. Retrieved April 26, 2021 from <https://files.nc.gov/ncdhhs/SL-2020-78-Section-4E.1-Funds-for-Local-Inpatient-Psychiatric-Beds-or-Bed-Days--Final-.pdf>

⁴⁷ North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, & Substance Abuse Services (2015). *Education Opportunities for Students with Disabilities Session Law 2015-241: Legislative Report, November 16, 2015*. Retrieved March 25, 2021 from https://files.nc.gov/ncdhhs/SL%202015-241%20Sect.%2011.19.%28a%29.%20Education%20Opportunities%20for%20Students%20with%20Disabilities%2011-16-15%20Final_0.pdf.

education or employment. This allows youth to live outside a licensed foster care facility in a college or university dormitory or other independent living arrangement. Expansion of foster care also allows young people who cannot complete educational or employment requirements due to a medical condition or disability to remain in foster care to age 21. This policy assists in providing youth with the family support they need to secure employment or enter postsecondary education.⁴⁸

The Workforce Innovation and Opportunity Act (WIOA) authorized a new category of transition services known as Pre-Employment Transition Services (PETS). These have potential to “expand and sustain postsecondary education and employment opportunities” for students and youth, ages 14-21, with disabilities. Under the WIOA, DVRS must allocate 15% of its federal Vocational Rehabilitation grant to the provision of PETS, to those students with disabilities who are eligible or potentially eligible for the DVRS program. DVRS estimates that the legislation expands its service footprint by increasing the Division’s youth population, ages 14 to 21, from approximately 24,000 youth served in 2015 to more than 64,000 youth.

In compliance with WIOA, North Carolina statute requires that if insufficient financial or staff resources cause a delay in the delivery of vocational rehabilitation services to all eligible service applicants, an order of selection for provision of services shall be implemented.⁴⁹ Unlike many other states, North Carolina has not had to invoke an order of selection.

Stakeholders expressed excitement about North Carolina’s becoming an Employment First state. In March 2019, Governor Roy Cooper signed Executive Order No. 92, recognizing that all citizens, including individuals with significant disabilities, are capable of full participation in competitive, integrated employment and community life.⁵⁰

In federal fiscal year 2019, DSB Vocational Rehabilitation Services were provided to 3,085 individuals with blindness or low vision. This was a substantial increase from the prior year of 2,770 consumers served.⁵¹

⁴⁸ North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, & Substance Abuse Services (2015). *Education Opportunities for Students with Disabilities Session Law 2015-241: Legislative Report, November 16, 2015*. Retrieved March 25, 2021 from https://files.nc.gov/ncdhhs/SL%202015-241%20Sect.%2011.19.%28a%29.%20Education%20Opportunities%20for%20Students%20with%20Disabilities%2011-16-15%20Final_0.pdf.

⁴⁹ [10A NC Administrative Code 63F.0502](https://casetext.com/regulation/north-carolina-administrative-code/title-10a-health-and-human-services/chapter-63-services-for-the-blind/subchapter-f-vocational-rehabilitation/section-63f-0502-order-of-selection-for-services). Retrieved March 25, 2021 from <https://casetext.com/regulation/north-carolina-administrative-code/title-10a-health-and-human-services/chapter-63-services-for-the-blind/subchapter-f-vocational-rehabilitation/section-63f-0502-order-of-selection-for-services>.

⁵⁰ State of North Carolina Executive Order No. 92, [Employment First for North Carolinians with Disabilities](https://files.nc.gov/governor/documents/files/EO_92.pdf). Signed by Governor Roy Cooper, on March 28, 2019. Retrieved April 26, 2021 from https://files.nc.gov/governor/documents/files/EO_92.pdf.

⁵¹ North Carolina Department of Health and Human Services, Division of Services for the Blind (2019). [Engage, empower, and employ! 2019 annual report](https://files.nc.gov/ncdhhs/documents/files/DSB%20Annual%20Report%202019.pdf), Department of Health and Human Services and the Workforce Innovation and Opportunity Act. Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/DSB%20Annual%20Report%202019.pdf>.

- DSB vocational rehab achieved 306 successful employment closures
- On average, successfully employed consumers earned \$13.83 per hour, a slight increase from the prior year.

Support from State Universities

Several university-based programs support individuals with disabilities in a variety of ways.

The University of North Carolina (UNC) Center for Excellence in Community Mental Health was established in 2009 to apply the expertise of UNC-Chapel Hill in addressing challenges faced by North Carolina's mental health system. Center clinics and programs provide diverse, multidisciplinary, evidence-based preventive and ongoing care for individuals with SMI, emphasizing recovery, support for independent living, and integration of medical and psychiatric care. The Center offers training and technical assistance for providers throughout North Carolina and is building broad collaborations with individuals served, their families, providers, state agencies, and advocacy groups. DMH/DD/SAS initiated a contract with the Department of Psychiatry, UNC School of Medicine, to develop, as part of the Center for Excellence in Community Mental Health, an ACT Technical Assistance Center, later rebranded as the Institute for Best Practices. Since 2013, the Institute has continued to offer coaching and consultation to facilitate the grassroots North Carolina ACT Coalition, and has facilitated and coordinated various DMH/DD/SAS-sponsored trainings.⁵²

The UNC Extension for Community Healthcare Outcomes for Medication-Assisted Treatment (UNC ECHO for Medication-Assisted Treatment) project is supported by DHHS, the U.S. Substance Abuse and Mental Health Administration (SAMHSA), and the Agency for Healthcare Research and Quality. It focuses on learning and collaboration across all 100 counties in the state, with health care networks and medical providers who want to understand the decisions associated with offering medication-assisted treatment (MAT.) The project began in January 2018. The ECHO for MAT project hosts live, web-based clinics and workshops. These present clinical cases and expertise, sharing best practices in the use of MAT.^{53 54} This model has been particularly effective in engaging rural community providers around concerns of advocates and stakeholders who note that MAT and adequate substance use disorder (SUD) treatment can be difficult to find in non-urban centers of the state.

Based at the UNC School of Medicine, the TEACCH Autism Project is made up of community regional centers that offer children with autism and their families clinical services, including referral, consultation, evaluation,

⁵² North Carolina Department of Health and Human Services (2021). *2019 - 2020 Annual report of the North Carolina Transition to Community Living Initiative NC General Statute 122C-20.15, Report to the Joint Legislative Oversight Committee on Health and Human Services*. Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf>.

⁵³ Newsome, M. (2021, January 29). *Project ECHO resounds through WNC*. North Carolina Health News. <https://www.northcarolinahealthnews.org/2021/01/29/project-echo-resounds-throughout-wnc/>

⁵⁴ *What Is UNC Echo?* University of North Carolina. <https://www.echo.unc.edu/unc-echo>

intervention services, and training. Parent support and education is a key service. TEACCH also offers consultation to schools and residential providers that serve children with autism.

Duke University's Child Development and Behavioral Health Clinic (CDBH) provides family-focused, diagnostic and treatment services for infants, children, and young adults (ages 0-24) with psychiatric, developmental, behavioral, and substance use illnesses in cooperation with other medical care providers, school systems, and social service agencies. CDBH faculty and staff include child psychiatrists, developmental pediatricians, child psychologists, a physician assistant, child psychiatric clinical social workers, and licensed substance abuse counselors. In addition to providing direct services, CDBH faculty members have assumed leadership roles in program development and service delivery systems at the local, state, and national levels in professional organizations and on advisory panels focused on promoting the emotional, behavioral, intellectual, and developmental well-being of youth.

Use of Evidence-Based and Promising Practices

As described under "Inventory of Services and Supports for Individuals with Disabilities," DHHS does offer several evidence-based practices (EBPs) to individuals who qualify for them.

Children, Adults, and Older Adults with Behavioral Health Disorders

EBPs for children include therapeutic foster care, multi-systemic therapy, high-fidelity wraparound, and piloting youth peer specialists.

- 7.3% of children served in North Carolina's behavioral health system receive therapeutic foster care compared to the national average of 0.7%.⁵⁵
- EBPs for adults include ACT, Individual Placement and Support/Supported Employment (IPS/SE), PSH, peer support specialists for adults with SMI; MAT for adults with SUD; and, in a DHHS pilot, peers (recovery specialists) in emergency department settings and detox.
- 6.8% of adults served in the state's behavioral health system receive ACT compared to the US average of 1.9%.⁵⁶

DHHS supports training in several evidence-based practices. In addition, DHHS requires fidelity reviews for ACT, permanent supportive housing (PSH), and IPS/SE; however, the reviews are performed through self-surveys.

⁵⁵ U.S. Substance Abuse and Mental Health Services Administration. [North Carolina 2019 Uniform Reporting System Output Tables](https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina). Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

⁵⁶ U.S. Substance Abuse and Mental Health Services Administration. [North Carolina 2019 Uniform Reporting System Output Tables](https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina). Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

Individuals with I/DD

Research-Based-Behavioral Health Treatments (RB-BHT) services are researched-based behavioral intervention services that prevent or minimize the disabilities and behavioral challenges associated with Autism Spectrum Disorder (ASD). RB-BHT demonstrates clinical efficacy in treating ASD; prevents or minimizes the adverse effects of ASD; and promotes, to the maximum extent possible, the adaptive functioning of service recipients.

Vaya Health collaborated with the NCCDD and the North Carolina MFP program on a supported living initiative. The partners engaged in a request for proposals process to promote best practices for individuals to live on their own and created a supported living guidebook and educational videos. Though this initiative ended, MFP is funding a new initiative to further expand the work resulting from the original collaboration.

The North Carolina State Treasurer's Office administers the Achieving a Better Life Experience (ABLE) Act, a federal law signed in December 2014 that allows individuals with disabilities and their families the opportunity to save for the future and fund essential expenses like medical and dental care, education, community-based supports, employment training, assistive technology, housing, and transportation. ABLE accounts provide North Carolinians with disabilities — including physical, developmental, and mental health or other conditions — with greater choice, independence, and opportunities to participate fully within their communities.

Individuals with Traumatic Brain Injury

The DMH/DD/SAS traumatic brain injury (TBI) program has strong partnerships with the Brain Injury Association of North Carolina, NC Medicaid, the Department of Public Instruction, DVRS, and the Division of Public Health. The program's accomplishments include consistency in TBI screening using the Ohio State University TBI identification method tool, claims data reviews to assist in determining the number of individuals with TBI currently receiving public services statewide, and the implementation of a TBI grant from the federal Administration for Community Living. The grant strives to improve the service array through training, TBI screening, improved information and referral, and enhancement of vocational rehabilitation services.

Individuals Involved with the Criminal Justice System

The North Carolina Department of Public Safety is piloting MAT in reentry centers for adults leaving incarceration.

In fiscal year 2020, NCCDD approved funding for a three-year reentry project to improve transition outcomes after incarceration for individuals with I/DD. The funding will be used to transition individuals into the community with the supports and services necessary for them to thrive, thereby reducing recidivism. The availability of housing and comprehensive services will be key to the project's success.

The Peer Justice Initiative is underway with support from the [Peer Voice of North Carolina](#) (described on page 92). The initiative brings together individuals with mental health system and criminal justice involvement histories. The current focus is on developing a forensic peer support service in the state,

including the credentialing criteria and process, training curriculum, and plan that will be necessary to implement the service.

Medicaid Managed Care(b)(3) Services and “In Lieu Of” Services

Section (3) of North Carolina’s 1915(b) Medicaid waiver enables DHHS to share cost savings with the LME/MCOs to provide health-related services in addition to those in the approved NC Medicaid Plan. Services are approved by CMS and include mental health, I/DD, and substance use supplemental services and supports. Services must be cost-effective and targeted to Medicaid-eligible people; these services are intended to decrease hospitalization and assist individuals to remain in their homes and communities when preferred, while appropriately serving the individuals. Services include:

- Intensive Recovery Supports
- Employment Supports
- Intensive In-home
- Personal Care Services
- Community Transition
- In-Home Skill-Building
- Transitional Living for Individuals with Co-occurring Mental Health and Substance Use Disorders
- Respite

In addition, LME/MCOs can present ideas for new services to DHHS for approval. These services are covered through “Alternative” or “in lieu of” service definitions. These services are not available in the traditional benefit plan and are provided at the discretion of the LME/MCOs. DHHS approves these new services for reimbursement under Medicaid, and in some cases with state funding. LME/MCOs have their own array of “in lieu of” services.

Tribal Health Initiative

DHHS and the Cherokee Indian Hospital Authority have entered into a contract to support the Eastern Band of Cherokee Indians (EBCI) in addressing the health needs of American Indian/Alaska Native Medicaid beneficiaries. This Indian Managed Care Entity is the first of its kind in the nation and will establish a new delivery system called the EBCI Tribal Option. The EBCI Tribal Option is a managed care option for federally recognized tribal members and other individuals eligible to receive Indian Health Services. The EBCI Tribal Option will manage health care for North Carolina’s approximately 4,000 Tribal Medicaid beneficiaries primarily in Cherokee, Graham, Haywood, Jackson, and Swain counties. The program will have a strong focus on primary care, preventive health, chronic disease management, and providing care management for high-need members. The option will reflect Tribal principles providing care coordination services in a culturally congruent system that leverages the collective strengths of a fully integrated health system, the Tribal community, and regional partners.

System Weaknesses and Gaps in Care

While TAC has identified many strengths within DHHS systems and services, our analysis also revealed weaknesses within the system that should be addressed in order to support integrated community living for people with disabilities.

In our stakeholder listening sessions, participants were asked about the effects of a lack of community-based supports for individuals with disabilities, including children, youth, adults, and older adults. Despite having an array of service options in North Carolina, respondents indicated that a lack of services and supports most often results in:

- Utilizing intrusive, intermittent, high-cost services such as emergency departments, crisis response, law enforcement, etc. as opposed to preventive care/primary care/routine care/wellness programs (65%)
- Living in congregate settings in the community, such as adult care homes, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs), or group homes; living with aging caregivers; living with people who jeopardize their recovery; couch-surfing; and living in under-resourced communities (60%)
- Spending time in segregated settings such as sheltered workshops, day programs (41%)
- Staying in state-operated health care settings for extended periods of time (41%)

Systemic Issues

Expenditures for Institutional and Congregate Care

North Carolina spends a disproportionate amount of its resources on institutional and congregate care settings. In the mental health population, 62% of expenditures are facility-based and 38% are for ambulatory, community-based services.⁵⁷ In the I/DD population, 63% of expenditures are for facility-based care and 37% are for community-based care.⁵⁸ The ideal ratio of community services to facility-based services is not established, but there is agreement that the current ratio for expenditures is too heavily dependent on institutional and congregate care for a very small portion of people served in the system.

As shown in Table 5, below, overall expenditures on state-operated facilities increased each year between fiscal years 2016 and 2019, as a result of staff salary increases and operational costs such as food, utilities, and medical supplies.

⁵⁷ U.S. Substance Abuse and Mental Health Services Administration. [North Carolina 2019 Uniform Reporting System Output Tables](https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina). Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

⁵⁸ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

Table 5. Expenditures on State-Operated Facilities by Type, Fiscal Years 2016 to 2019

Facility Type	FY16	FY17	FY18	FY19	% change FY16 vs. FY19
Developmental Centers	\$ 247,695,842	\$ 252,992,959	\$ 282,611,998	\$ 277,330,442	+12%
Psychiatric Hospitals	\$ 505,533,739	\$ 530,038,543	\$ 562,559,736	\$ 601,225,708	+19%
Neuro-Medical Treatment Centers	\$ 111,649,208	\$ 110,016,134	\$ 115,905,509	\$ 136,227,304	+22%
ADATCs	\$ 43,214,769	\$ 45,650,663	\$ 57,463,521	\$ 55,927,677	+29%
Wright School/Whitaker PRTF	\$ 7,925,243	\$ 8,687,280	\$ 8,764,330	\$ 8,781,145	+11%
TOTAL	\$ 916,018,801	\$ 947,385,579	\$ 1,027,305,094	\$ 1,079,492,276	+18%

Source: NC Department of State Operated Healthcare Facilities, data received upon request for this report.

Utilization of Institutional Care

Though the cost of state-operated health care facilities is increasing, with data indicating a 12% total increase between fiscal years 2017 and 2019, the number of individuals served in most facilities is decreasing as shown in Table 6, below. A total of 8,023 individuals resided in state-operated facilities in fiscal year 2019, down from 8,491 in fiscal year 2017, a 5% decrease across facilities.

Table 6. Numbers of Persons Served in North Carolina's State-Operated Facilities

State-Operated Facilities	State Fiscal Year 2017	State Fiscal Year 2019
Developmental Centers	1,156	1,137
Psychiatric Hospitals	3,110	2,750
Neuro-Medical Treatment Centers	644	595 [^]
ADATCs	3,496	3,476
Wright School	85	53
Whitaker PRTF		12 [†]
TOTAL	8,491	8,023

Sources: Fiscal year 2017 numbers are from the DHHS 2018 Strategic Plan for Improvement of Behavioral Health Services; Fiscal year 2019 numbers were provided by DSOHF, except for Whitaker PRTF which was derived from Medicaid claims.

[^]For one of the Neuro-Medical Centers (Longleaf), the number served is from calendar year 2020.

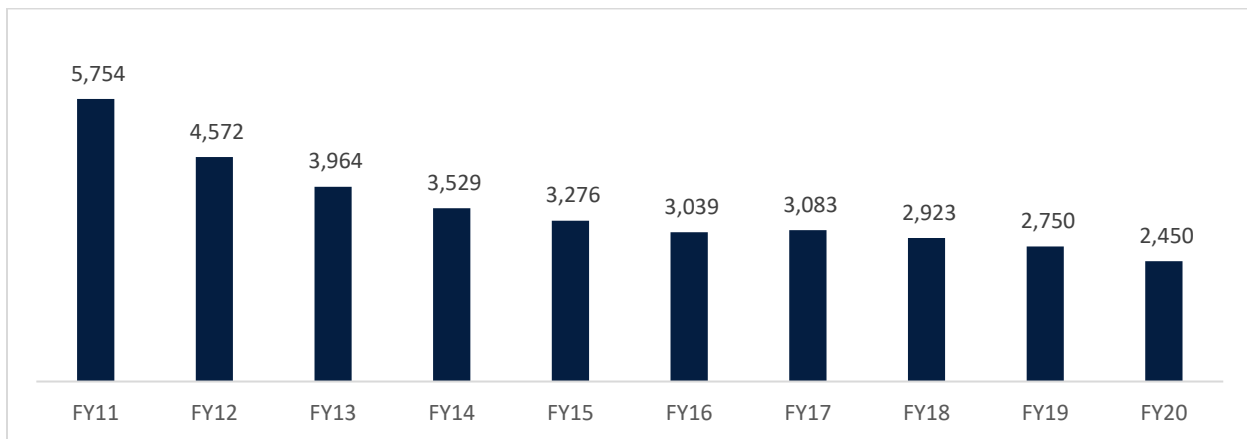
[†]The number served for Whitaker PRTF was derived from Medicaid claims data and may be an underestimate.

State Psychiatric Hospitals

There were 1,631 admissions to the state psychiatric hospitals during fiscal year 2020. The largest group of admissions 49.5% (807) were referred by general hospitals; 9.1% (148) were self-referred or referred by relatives, family, or friends; and law enforcement referred 22.1% (360). Involuntary admissions accounted for over 78.4% (1,278) of the total admissions for fiscal year 20, with 21.6% of total admissions being voluntary.⁵⁹

The number of individuals served in the state’s three psychiatric hospitals has decreased by 42.6% over the past decade, from 5,754 in fiscal year 2011 to 2,450 in fiscal year 2020.

Figure 1. Children and Adults Served in State Psychiatric Hospitals, Fiscal Years 2011-2020



Source: *North Carolina Psychiatric Hospitals Annual Statistical Report, FY2020*.
<https://files.nc.gov/ncdhhs/documents/files/2020-Psychiatric-Hospitals-Annual-Report.pdf>

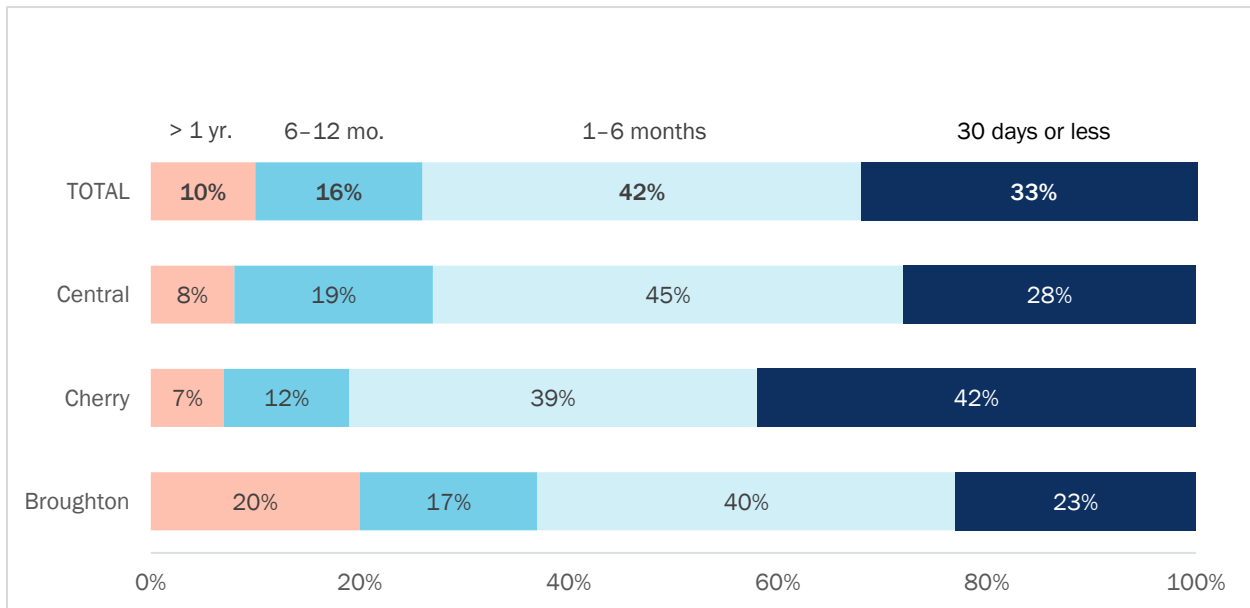
However, North Carolina’s use of state psychiatric facilities for children is more than double such use nationally. In 2019, 15.5% of individuals served in state psychiatric hospitals were children age 0-17 compared to the national average of 6.5%.⁶⁰

Figure 2, below, shows variation in the length of stay across facilities, which may be impacted by the differences in specialty services provided.

⁵⁹ North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, Data Support Branch (2021). *Annual statistical report, North Carolina psychiatric hospitals, fiscal year 2020*. Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/2020-Psychiatric-Hospitals-Annual-Report.pdf>

⁶⁰ U.S. Substance Abuse and Mental Health Services Administration. *North Carolina 2019 Uniform Reporting System Output Tables*, page 10. Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

Figure 2. State Psychiatric Hospital Discharges by Days in Hospital, Fiscal Year 2019



Source: *North Carolina Psychiatric Hospitals Annual Statistical Report, FY2020*: <https://files.nc.gov/ncdhhs/documents/files/2020-Psychiatric-Hospitals-Annual-Report.pdf>

In spite of the General Assembly’s allocation of state resources to shore up community inpatient behavioral health beds in an effort to alleviate pressure on the state hospitals, the state-operated facilities continue to experience short-stay admissions: 5.9% (102) of fiscal year 2019 discharges were for stays of 1 to 7 days, and an additional 10.1% (176) of discharges were for stays of 8 to 14 days.⁶¹ The state psychiatric hospitals are providing acute care that in many states would be provided in community inpatient beds or diverted to community-based services.

Though overall, state hospital utilization has declined, a significant number of individuals determined to need this level of care had to wait for admission, as shown in Table 7. On the positive side, the number of people awaiting admission is declining.

Table 7. Patients Waiting for Admission to State Psychiatric Hospitals in Fiscal Years 2019 and 2020, by LME/MCO

LME/MCO	Waiting for admission In Fiscal Year 2019	Waiting for admission in Fiscal Year 2020
Alliance	843	777
Cardinal	311	260

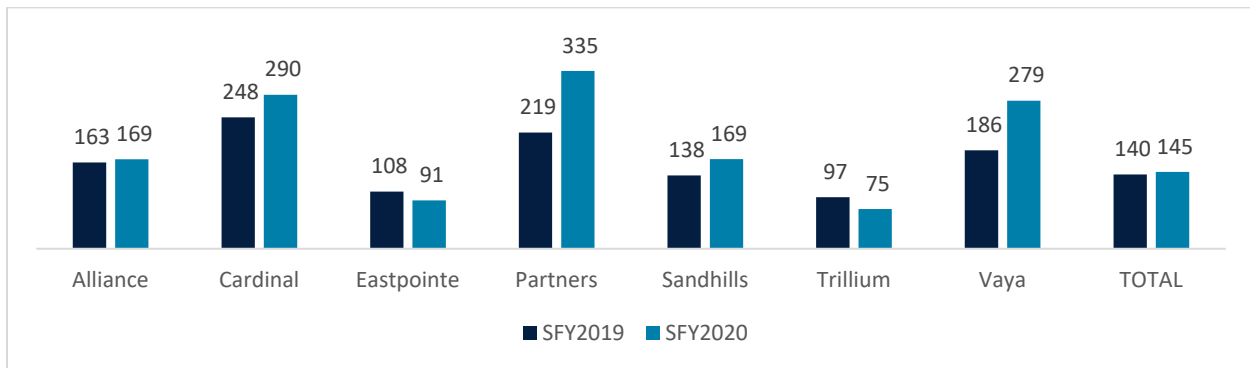
⁶¹ North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, Data Support Branch (2021). *Annual statistical report, North Carolina psychiatric hospitals, fiscal year 2020*. Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/2020-Psychiatric-Hospitals-Annual-Report.pdf>

LME/MCO	Waiting for admission In Fiscal Year 2019	Waiting for admission in Fiscal Year 2020
Eastpointe	360	294
Partners	101	53
Sandhills	276	215
Trillium	1,171	912
Vaya	205	135
TOTAL	3,267	2,646

Source: LME/MCO quarterly reports. *Fiscal year 2019*: <https://files.nc.gov/ncdhhs/LME-MCO-Only-Data-Quarters-1-4--FY-2019.pdf>; *Fiscal year 2020*: https://files.nc.gov/ncdhhs/documents/files/LME-MCO%20Only%20Quarters%201-4%20FY%202020_0.pdf

Not only have individuals had to wait for admission, but the average amount of wait time has also increased slightly, though with considerable variation among the LME/MCOs.

Figure 3. Average Wait Time in Hours for Admission to State Psychiatric Hospitals in Fiscal Years 2019 and 2020, by LME/MCO



Source: LME/MCO quarterly reports. *SFY19*: <https://files.nc.gov/ncdhhs/LME-MCO-Only-Data-Quarters-1-4--FY-2019.pdf>; *SFY20*: https://files.nc.gov/ncdhhs/documents/files/LME-MCO%20Only%20Quarters%201-4%20FY%202020_0.pdf

Forensic Services

The majority of individuals with a mental health disorder who are not capable to proceed with their legal case are referred to a state psychiatric hospital (SPH) for treatment and receive competency restoration during hospitalization. Individuals are court ordered and are required to meet SPH admission criteria. There are no community options to serve individuals involved in the justice system who are determined incompetent to stand trial. This leads to individuals under Incapacity to Proceed (ITP) status filling the psychiatric hospital beds, contributing to the lag in admissions from emergency departments. On average, an individual with ITP status has a length of stay nearly three times that of an individual

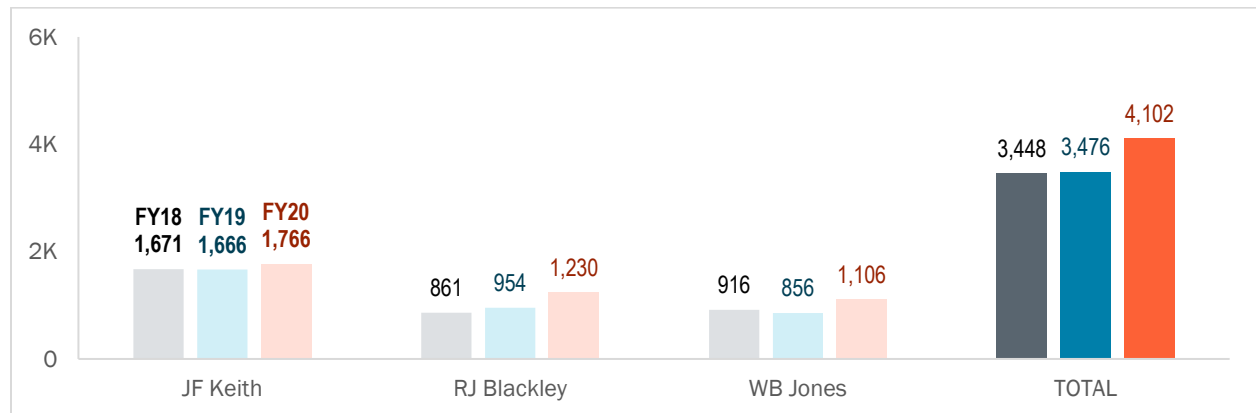
admitted civilly. In FY 2012, approximately 7.5% of all admissions were ITP; in FY 2017, the percentage of patients in SPHs with an ITP status rose to 13%.⁶² The number of admissions on ITP has increased, while overall admissions to the state facilities have decreased. This leads to a greater percentage of patients in SPH with an ITP status. Outpatient competency restoration, as used in several other states, would divert some of these admissions.

Alcohol and Drug Treatment Centers

Each Alcohol and Drug Treatment Center (ADATC) is accredited by the Joint Commission and certified by CMS as a psychiatric hospital but specializes in providing drug and alcohol detoxification and short-term treatment/stabilization to individuals age 18 years and older. ADATCs have evolved from 30-day treatment programs to 10 days; the mission has changed from offering short-term inpatient rehabilitation to short-term crisis stabilization and detox. All facilities also provide MAT. In addition, Walter B. Jones provides a statewide, high-risk, perinatal program for pregnant women seeking treatment during any trimester of their pregnancy. Length of stay varies based on individuals’ needs; an individual may stay beyond an LME/MCO authorization until appropriate discharge plans are in place. ADATCs accept individuals regardless of their inability to pay or lack of insurance; many community-based providers don’t accept Medicaid. The average daily per diem across all three Centers is \$923.

Refer to Figure 4, below, for the total served in state-operated ADATCs over the past three fiscal years; the number increased in fiscal year 2020 compared to the prior two years. The average length of stay in an ADATC was 9.04 days in fiscal year 2020.

Figure 4. Individuals served in State-Operated Alcohol and Drug Abuse Treatment Centers, Fiscal Years 2018–2020



Source: Data received from the North Carolina Division of State-Operated Healthcare Facilities.

⁶² North Carolina Department of Health and Human Services (2018). Study on the lack of capacity to proceed process: Recommendations for improvements to the incapacity to proceed (ITP) system in North Carolina Session Law 2017-147. Final report to the Joint Legislative Oversight Committee on Health and Human Services and the Joint Legislative Oversight Committee on Justice and Public Safety, March 29, 2018.

However, as evidenced in Table 8 below, the daily census is still well below capacity. It is worth noting that the census data was reported during the COVID-19 pandemic.

Table 8. Average Daily Census at Alcohol and Drug Abuse Treatment Centers, 7/1/2020 – 12/31/2020

ADATC	Total Beds	Certified Beds	Beds Staffed	State Fiscal Year 2021 Avg. Census through 12/31/20
Julian F. Keith	80	80	72	46
R.J. Blackley	80	80	60	30
Walter B. Jones	80	16	68	37

Source: DHHS 2021 Request for Proposals for Sustainable Business Model for the Alcohol and Drug Abuse Treatment Centers.

DHHS staff believe ADATCs are necessary due to the lack of treatment options in the community for the uninsured as well as for individuals who are homeless or unemployed, sex offenders, and those with medical and psychiatric comorbidities. Staff report that access to substance use disorder (SUD) treatment in the community has diminished, that the community-based system is very fragmented, and that emergency departments are overwhelmed by the number of individuals with SUD who present for detox and stabilization.

Despite these issues, the ADATCs face some challenges to their ongoing sustainability:

- A 10% reduction in state funding each year that will eventually result in no designated state funding for the ADATCs
- Lack of an electronic medical record
- Billing system limitations

Over the past five years, about 92% of ADATC revenues have come from the LME/MCOs for Medicaid recipients and uninsured individuals. Overall, receipts were about \$3,000,000 less in fiscal year 2020 than they were in fiscal year 2016. At the same time, expenditures have increased as a result of legislatively approved salary increases (7.5% cumulatively since fiscal year 2016); changes in approved positions; and changes in the mix of staff, overtime, and agency staffing. The increases in other spending, when combined with salary and fringe benefit costs, have contributed to increasing shortfalls in ADATC operations that have required reallocations of appropriation by DHHS in each year.⁶³

Intermediate Care Facilities for Individuals with Intellectual Disabilities

In fiscal year 2020, North Carolina operated three ICF/IIDs: the Caswell Developmental Center, J. Iverson Riddle Center, and Murdoch Center. The three state-operated facilities served a total of 1088 people in

⁶³ DHHS RFP citation

FY 2020. Of the total number served, 466 were age 60 or older. Based on the trend of increased costs to operate the centers, identified in Table 5, and the declining census at the Developmental Centers (shown below in Table 9), decreasing to 971 in fiscal year 2020, the average per-bed cost at these facilities continues to rise; the average daily per diem was \$804.78 as of May 2020.⁶⁴

Table 9. Persons Served at State-Operated Developmental Centers in Fiscal Year 2020

Developmental Center	Start of Fiscal Year 2020	Admissions in Fiscal Year 2020	Total Served in Fiscal Year 2020
Caswell	301	18	319
J Iverson Riddle	269	13	282
Murdoch	401	86	487
TOTAL	971	117	1,088

Source: Data received from the North Carolina Division of State-Operated Healthcare Facilities.

Table 10. Census at State-Operated Developmental Centers at Beginning of Fiscal Year, 2015–2021

Fiscal Year	Murdoch	Caswell	Riddle	TOTAL
FY15	460	347	297	1,104
FY16	446	340	286	1,072
FY17	439	328	284	1,051
FY18	435	329	280	1,044
FY19	417	314	278	1,009
FY20	401	301	269	971
FY21	379	284	269	932

Source: Data received from the North Carolina Division of State-Operated Healthcare Facilities.

All individuals served at the centers have a primary diagnosis of I/DD. Each center also serves a population with a secondary diagnosis of ASD, a fact that appears to support claims by some families of individuals with ASD that they prefer their loved ones to receive care in a State Center as opposed to the community. Murdoch Center has a higher number of children served; this center has adolescent mental

⁶⁴ Average rate of per diems provided during interview with DHHS staff.

health-I/DD and children’s autism programs, and is the only State Center that continues to admit children.

Table 11. Developmental Center Patients with a Secondary Diagnosis of Autism Spectrum Disorder

State Developmental Center	ASD as Secondary Diagnosis	Age range: 20 and younger	Age range: 21–40 years	Age range: 41 and older
Caswell	48	1	17	30
JR Riddle	55	3	26	26
Murdoch	79	26	15	38

Source: Data provided upon request by Division of State-Operated Healthcare Facilities staff.

Though the State Centers continue to admit individuals, all admissions to the Developmental Centers require that supports in the community have been exhausted. Since 2012, the Division has implemented a process to ensure that the centers are not long-term placements and are intended to provide time-limited services for individual stabilization while supports are sought in the community. As part of this process, DHHS requires a Memorandum of Agreement (MOA) between the center, the MCO, the individual being admitted, and their guardian, identifying the purpose and proposed length of stay for the admission. The MOAs have reduced the length of stay for newer admissions to the centers; however, within the current census, 85% were admitted prior to this requirement. Only 12% of the census at Caswell has an MOA, with 14% at Riddle, and 8% at Murdoch.

Individuals admitted to State Centers are reported to have significant behavior support needs. According to the Division of State-Operated Healthcare Facilities, 60 to 70 percent of admissions to the State Centers were receiving waiver services at the time of admission. Unlike community providers, State Center staff report their facilities neither refuse admission nor discharge an individual due to their behaviors.

Almost all individuals discharged from a State Center have access to MFP support to transition, with community-based services via the Innovations Waiver and/or (b)(3) services. These funding sources require state matching funds in order to draw down federal Medicaid revenue. Likewise, state funds are required for community placements and housing costs. DHHS staff observed that it would be a significant challenge for the state to come up with the resources necessary to place all long-term residents in a more integrated setting in the community, if they chose to transition to the community.

Neuro-Medical Treatment Centers

The Neuro-Medical units served 595 individuals in fiscal year 2019 at the following per diems: Longleaf, \$745/day; Black Mountain, \$602/day; and O’Berry, \$789/day. Two of these facilities were State Centers originally, converted to skilled nursing facilities to address the opposition to facility closures and community transitions from families and guardians, and to meet the growing needs of the aging State Center

population. DHHS needed to invest state resources to convert the centers into state-operated nursing facilities to address the complexity of symptoms and behaviors of the individuals, including development of an Alzheimer's disease/dementia unit. The Black Mountain unit was designed to provide up to a two-year stay, however resident representatives are often reluctant to have their family member transferred to community placement. Some of the residents have been there for many years, affording little movement since discharges typically occur due to people passing. The facilities have lengthy wait lists.

DHHS staff described the facilities as serving individuals whom community-based nursing facilities are not able or willing to serve. The Centers reportedly have second and third generations of staffing. Employee retention and quality of care were noted as key reasons that families trust the state facilities.

The Whitaker Center and Wright School

DHHS staff report that the Children's Centers have rigorous treatment plans that are lacking in the community; these facilities have the necessary resources to meet children's needs beyond the capacity of community-based providers. In fiscal year 2017, Wright School and Whitaker together served 85 youth. Wright School served 53 children in fiscal year 2019 and 36 children in fiscal year 2020. We did not obtain the number served in Whitaker from the Division of State-Operated Healthcare Facilities; although Medicaid claims showed 12 individuals in fiscal year 2019, this may be an underestimate. Since Whitaker psychiatric residential treatment facility (PRTF) serves older adolescents, DHHS staff noted that discharge planning can be a challenge due to the common absence of involved family and the system's reluctance to support transition-age youth.

Reliance on Residential Care and Congregate Settings in the Community

In fiscal year 2019, \$62,515,560 in state (non-Medicaid) funding was expended on I/DD services, supporting 5,588 individuals with I/DD at an average cost of \$11,187 per person. Three of the four highest total expenditures were for services in congregate settings, adult developmental vocational programs, group living, and group day activities.⁶⁵ During the same period, North Carolina spent \$568,064,638 to serve 4,011 individuals with I/DD in state-operated and community-based ICF/IIDs at an average cost of \$138,182 per person.⁶⁶

⁶⁵ MH/DD/SAS Claims data.

⁶⁶ Per DHHS staff, the state center rates include the costs for medical, dental, and pharmacy services though these costs are not included in community ICF/IID per diems.

Table 12. Expenditures for State-Funded Developmental Disability Services by Type, Fiscal Year 2019

State-Funded Development Disability Services	Expenditures	Percent of Total Expenditures
Adult Developmental Vocational Program	\$10,351,021	16.6%
Day Supports	\$2,325,089	3.7%
Day/Evening Activity	\$6,389,256	10.2%
Developmental Day (Child)	\$1,492,004	2.4%
Developmental Therapy - Medicaid	\$2,122,757	3.4%
MR/MI Independent Living	\$180,934	0.3%
Personal Assistance	\$5,375,373	8.6%
Residential - Family Living	\$1,199,972	1.9%
Residential - Group Living	\$21,609,761	34.6%
Residential - Supervised Living	\$5,908,515	9.5%
Residential Supports	\$1,945,627	3.1%
Respite	\$1,847,729	3.0%
Supported Employment	\$514,687	0.8%
Vocational Support	\$469,515	0.8%
Other	\$783,321	1.3%
TOTAL	\$62,515,560	100.0%

Source: Claims data from the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

Table 13. Per-Person Expenditures at Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs)

	Age 21 and younger	Age 22 and older	Total all ages
Recipients	475	3,636	4,111
Expenditures	\$50,422,014	\$517,642,624	\$568,064,638
Expenditures per person	\$106,152	\$142,366	\$138,182

Source: Data for fiscal year 2019 submitted by North Carolina to the Residential Information Systems Project data system. Report is anticipated for release in 2021.

Individuals with Mental Health Disorders in Congregate Living Settings

Stakeholders identified the lack of adequate independent living options as a significant gap in services for people with all disabilities, of any age — resulting in the ongoing reliance on congregate care settings. In fiscal year 2019, over 14,000 Medicaid beneficiaries with a primary mental health diagnosis received care in a congregate living setting, including 5,384 in assisted living facilities, 3,428 in skilled nursing facilities, 3,676 in nursing facilities, and 1,414 in group homes, as shown in Table 14. Note that this total does not include the number of individuals with mental health disorders who reside in an ACH.

Table 14. Persons with a Mental Health Diagnosis Served in Select Congregate Settings, Fiscal Year 2019

Setting	Individuals with MH Diagnosis Served
Assisted Living Facility	5,384
Custodial Care Facility	192
Group Home	1,414
Homeless Shelter	314
Intermediate Care Facility	54
Nursing Facility	3,676
Psychiatric Residential Treatment Center (Child)	1,161
Skilled Nursing Facility	3,428

Source: Medicaid paid claims with a primary diagnosis of a mental health condition, fiscal year 2019. Settings are based on the place-of-service code field except for Psychiatric Residential Treatment Center, which is based on presence of Revenue Code='0911' and/or provider taxonomy='323P00000X'. This table does not include adult care homes data.

Residential Services for Children

According to Disability Rights North Carolina, the state has increased its reliance on psychiatric residential treatment facilities (PRTFs) by 119% since 2010.⁶⁷ DHHS staff shared their perception that there is an overreliance on residential services for children with behavioral health needs, and that residential treatment facilities are viewed as a place for children to live, rather than as a level of treatment. Division of Social Services (DSS) staff shared that children involved with the Child Welfare

⁶⁷ [Disability Rights North Carolina \(n.d.\) Psychiatric residential treatment facilities](https://disabilityrightsnorthcarolina.org/what-we-do/our-advocacy-work/psychiatric-residential-treatment-facilities). Retrieved March 10, 2021 from <https://disabilityrightsnorthcarolina.org/what-we-do/our-advocacy-work/psychiatric-residential-treatment-facilities>

system sometimes remain in a PRTF long after a discharge plan is made because there is no identified placement available for them.

Community-Based Intermediate Care Facilities for Individuals with I/DD

According to the 2017 Residential Information Systems Project (RISP) data, North Carolina ranks eighth among the 50 states and the District of Columbia in the number of long-term services and supports (LTSS) recipients with I/DD who reside in a group setting of 16 or more beds: 6.8% of LTSS recipients in North Carolina resided in an “Institution for Mental Disease” setting compared to the U.S. average of 2.9%.⁶⁸ Perhaps more striking is that North Carolina ranks among the lowest five states (with available data) in the percentage of LTSS recipients with I/DD who reside in their own homes (0.8% compared to the U.S. average of 11.9%).⁶⁹

Data from the National Core Indicators (NCI)⁷⁰ shows that only 6% of NCI respondents in North Carolina reported being named on a lease or deed, compared to the NCI average of 19%.

Table 15. National Core Indicators Survey Respondents Named on a Lease or Deed

Statistics Source	Yes, Named On Lease or Deed	Yes, Named On Other Legally Enforceable Agreement	No	Don't Know	Number
North Carolina	6%	1%	85%	7%	640
NCI Average	19%	4%	67%	11%	18,449

There are an estimated 13 non-state-operated ICF/IID facilities in the state with 16 or more beds. These facilities served 685 individuals in fiscal year 2019 according to data submitted by LME/MCOs to the RISP system (data presented in the Congregate/Segregated Settings in the Community Section).

⁶⁸ University of Minnesota Residential Information Systems Project (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. Retrieved 12/28/20 from <https://risp.umn.edu/>.

⁶⁹ University of Minnesota Residential Information Systems Project (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. Retrieved 12/28/20 from <https://risp.umn.edu/>.

⁷⁰ National Core Indicators — National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute. In person survey (IPS) state report 2018-19, North Carolina report. Retrieved March 25, 2021 from https://www.nationalcoreindicators.org/upload/core-indicators/NC_IPS_state_508.pdf.

Table 16. Individuals served in community-based Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IIDs) in Fiscal Year 2019

Setting Size	Number of Facilities	Number of People Served
TOTAL	340	2,981
1–3 beds	4	Not available
4–6 beds	295	650
1–6 beds (includes 1–3 and 4–6)	299	1,775
7–15 beds	28	521
16+ beds	13	685

Source: Data for fiscal year 2019 submitted by North Carolina to the Residential Information Systems Project data system. Report is anticipated for release in 2021.

Utilizing community-based ICFs allows the state to draw down considerable federal revenues toward the cost of services, including room and board. Absent increased or repurposed state funding, the Department is limited in its ability to fund alternative living options in the community. However, these facilities are likely to have the characteristics of a “segregated setting.”⁷¹

Community ICFs maintain their own waitlists, allowing providers to select the individuals that they serve. DHHS staff reported that ICFs are not willing in some cases to admit children/youth with complex needs. LME/MCO representatives reported that ICF reimbursement rates are the same for individuals regardless of whether they are easier to serve or present with behavioral challenges or complex needs and that this lack of a rate differential creates a barrier to admission for individuals with higher needs. However, LME/MCOs do have the flexibility to enhance rates for services as necessary, though this does require an initial investment to cover the increase. LME/MCOs also reported that the criteria for admission to an ICF are not very strict. When providers accept referrals from families and request an authorization, LME/MCOs report feeling under pressure to approve the authorization. Finally, when a person is admitted to the community-based ICF there is no external oversight to determine their ongoing needs or their interest in living in another type of setting.

Stakeholders observed that if an individual is in an ICF in the community, the individual and their family have access to all services offered, which can exceed the array of services available via the Innovations

⁷¹ U.S. Department of Justice, Civil Rights Division (2011). [Statement of the Department of Justice on enforcement of the integration mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*](https://www.ada.gov/olmstead/q&a_olmstead.htm) Retrieved March 25, 2021 from https://www.ada.gov/olmstead/q&a_olmstead.htm.

Waiver. In addition, ICFs are viewed by families as “stable” providers capable of supporting their family members long-term.

An advocacy organization for individuals with I/DD in North Carolina is also a large provider of residential services, developing over 342 residences that include group homes, small apartment buildings, duplexes and condominiums, together serving more than 2,200 residents. Some stakeholders expressed concern that housing options for individuals with I/DD may be compromised when an agency known historically for advocating on behalf of the population is a provider with substantial investment in congregate residential services.

Adult Care Homes

North Carolina’s system relies on adult care homes to provide housing for people with disabilities. According to a 2017 State Long-Term Care Ombudsman report, there are 1,250 licensed ACHs with a total of 43,284 beds in North Carolina.⁷² This far exceeds the availability of integrated housing options for people with disabilities in North Carolina. Residences for adults with disabilities and older adults, ACHs provide 24-hour supervision and assistance with activities of daily living. For years, the lack of integrated community-based living options has resulted in reliance on the ACH industry to provide community-based care for individuals with mental health disorders. This reliance led to the State of North Carolina entering into a settlement agreement with the United States Department of Justice in 2012 to ensure that individuals with mental illness have the opportunity to live in their communities in the least restrictive settings of their choice. TCLI was designed to reduce reliance on ACHs by individuals with SMI; however, individuals with a mental health diagnosis continue to live in these settings. We were unable to estimate the number of people with SMI and with other disabilities living in the homes for this report.

Adult Developmental Vocational Program

North Carolina continues to provide state funding to support the Adult Developmental Vocational Program (ADVP). The service may only be provided in a licensed facility, often referred to as a “sheltered workshop” or an alternative facility approved by DVRS. Individuals spend their day interacting only with others with disabilities and are typically paid subminimum wages for their work. In fiscal year 2019, 27.7% of individuals receiving state-funded developmental disability services authorized by the LME/MCOs received ADVP, while only 1.1 % received supported employment.⁷³

⁷² North Carolina Department of Health and Human Services, Division of Aging and Adult Services (2017). [North Carolina State Long-Term Care Ombudsman Program 2017 annual report: Promoting quality of life and quality of care for long-term care residents](https://files.nc.gov/ncdhhs/2017-Ombudsman-AnnualReport.PDF). Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/2017-Ombudsman-AnnualReport.PDF>

⁷³ MH/DD/SAS data for state-funded services.

Gaps in Services

Lack of Affordable Housing

When asked to identify the most significant gaps in community-based services and supports, DHHS staff, as well as every stakeholder group, identified the lack of affordable housing as a barrier to community inclusion. More specifically, there is a gap in 1) the supply of housing that is affordable, and 2) the availability of rental assistance to support people with disabilities with low incomes to afford housing. It is difficult to provide Medicaid waiver Home and Community-Based Services without stable housing. Assistance in identifying housing options (or maintaining affordable housing — housing voucher, identifying appropriate roommates, etc.) while applying for or productively receiving Medicaid benefits is imperative for success. Yet, housing costs and unavailability are pushing individuals with disabilities into more segregated living arrangements like ACHs — or, worse, into homelessness. The issue is exacerbated in rural areas of the state where there are fewer services and transportation options.

Per North Carolina's Consolidated Plan, 200 Low Income Housing Tax Credit (LIHTC) units are set aside each year for individuals with disabilities. Subsidies are needed to make these units truly affordable for individuals with low income. North Carolina was recently awarded HUD Mainstream funding that will support approximately 150 new vouchers for individuals with disabilities each year. However, without additional subsidies, approximately 50 LIHTC units each year may not be affordable, and therefore not available, to individuals with disabilities.

North Carolina has one state-funded subsidy program which is disability neutral, Key Rental Assistance, which is funded in the amount of approximately \$5.5 million annually. On a yearly basis, the program currently serves an average of 2,400 households but is only funded to support 1,100 households, a trend that is not sustainable. Nineteen thousand households are currently on the waitlist for this assistance, underscoring the degree to which this program is underfunded.

The Special Assistance (SA) benefit has been expanded to offset the costs for individuals to live in independent settings. The maximum SA basic payment is \$1,228 (the SA basic rate of \$1,182 + a \$46 personal needs allowance). The appropriate payment may be less than the maximum allowable payment, based upon the assessment and service plan completed by the adult services case manager, who will determine the actual amount of the SA In-Home (SA/IH) payment. There is a limited number of SA/IH payments available by county.

There are subsidized housing units available for individuals with disabilities in rural communities, however these units are underutilized. Individuals with disabilities cite the lack of transportation in these communities as the primary reason for lack of interest in the units.

Stakeholders also identify the need for fully accessible units throughout the state.

Inadequate Access to Services and Supports

As described previously in this report as a system strength, stakeholders indicated that North Carolina offers a comprehensive array of treatment, therapeutic services, and supportive services for individuals

with disabilities. However, when asked about gaps in services, numerous stakeholders responded that services and supports or education about services and supports were not available in their county or geographic area. Specifically, respondents reported that there is a lack of:

- Services and supports in rural communities (60%)
- Adequate support services in all regions (54%)

Overall, respondents reported that there is a need to increase funding for best practice and evidence-based services, based upon data that shows their effectiveness.

These responses are consistent with data points included in TAC's analysis. In North Carolina's 2019 report to SAMHSA, community mental health services utilization per 1,000 people was 9.16%, well below the national average of 23.88%.⁷⁴ In the Strategic Plan for Improvement of Behavioral Health Services,⁷⁵ DHHS data suggests that:

- There is considerable unmet need in most parts of the state, particularly among uninsured individuals and in rural areas of the state.
- The amount of unmet need varies by county, disability and payer, with the uninsured being far less likely to receive services.
- The array of services currently available in North Carolina is inconsistently available.
- Most funding is spent on inpatient, institutional, residential and facility-based treatment as opposed to community-based treatment.

The Plan further elaborates that "there is significant unmet need for behavioral health services, especially among the uninsured. Over 475,000 people received services for a mental health disorder, an SUD, or an intellectual/developmental disability in FY17 from the public system, but the state's analysis estimates that close to 600,000 have these conditions and received no treatment. A lack of access to services, particularly among the uninsured, is a primary driver of this problem."⁷⁶

⁷⁴ U.S. Substance Abuse and Mental Health Services Administration. [North Carolina 2019 Uniform Reporting System Output Tables](https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina). Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

⁷⁵ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

⁷⁶ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

When stakeholders were asked about the effects of a lack of community-based services and supports for individuals with disabilities, including children, youth, adults and older adults, these were the results they most often indicated:

- Utilizing intrusive, intermittent, high-cost services such as emergency departments, crisis response, law enforcement, etc. as opposed to preventive care/primary care/routine care/wellness programs.
- Living in congregate settings in the community, such as adult care homes, ICF/IID, and group homes; living with aging caregivers; living with people that jeopardize their recovery; couch-surfing; and living in under-resourced communities.
- Spending time in segregated settings such as sheltered workshops, day programs.
- Staying in state-operated health care settings for extended periods of time.

Insufficient Services for Children with Behavioral Health Disorders

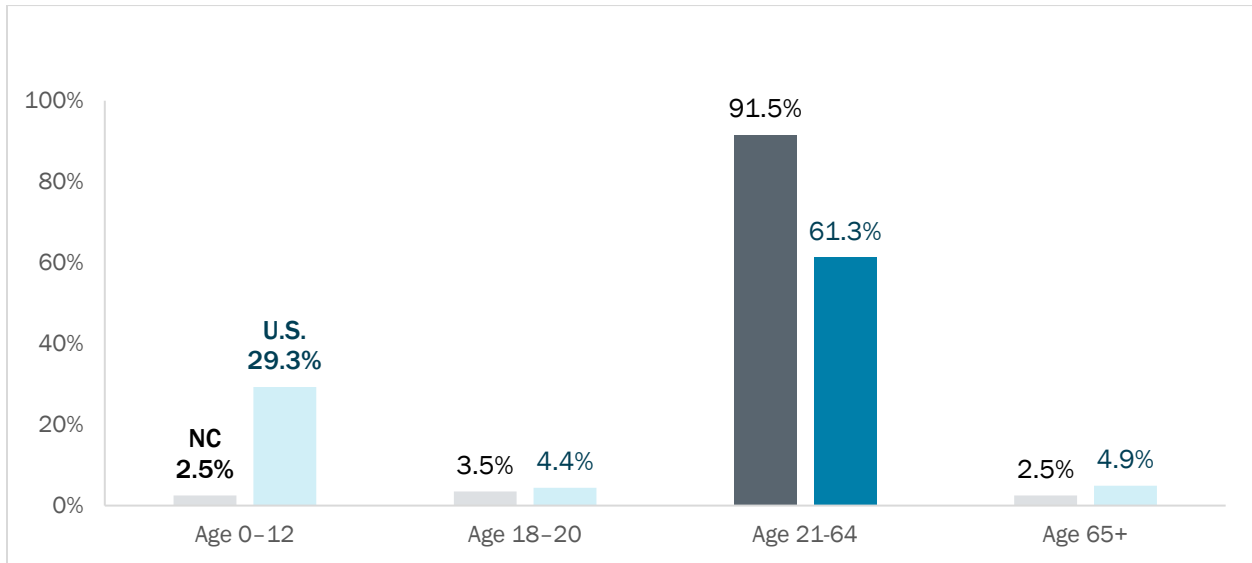
Both Table 17 and Figure 5, below, indicate that youth with serious emotional disturbance (SED), and especially youth under age 12, are severely underrepresented among people served by North Carolina's mental health authority. Nationally, 16% of youth ages 0-12 served by states' mental health authority are diagnosed with SED, while only 0.6% of youth served in this age group in North Carolina are diagnosed with SED. Among individuals with SMI or serious emotional disturbance (SED) served in community mental health programs in North Carolina, only 2.5% are ages 0-12 compared to 29.3% in this age group nationally (see Figure 5 below). It is important to note that the state's use of PRTFs has increased, and further work should be done to strengthen access to community-based services to reduce out-of-home placements.

Table 17. Children with Serious Emotional Disturbance served by a State Mental Health Authority – in North Carolina and Nationally, Fiscal Year 2019

	Total Served			Penetration per 1,000 Population		
	North Carolina N	North Carolina %	US %	State Penetration	South Penetration	US Penetration
Ages 0-12	4,499	4.2%	16.0%	2.7	16.9	25.0
Ages 13-17	6,882	6.4%	12.2%	10.4	34.6	48.0
Ages 18-20	4,885	4.6%	4.7%	11.4	23.2	30.2
TOTAL	107,091	100.0%	100.0%	10.3	18.2	24.8

Source: *North Carolina 2019 Mental Health National Outcome Measures (NOMS): SAMHSA Uniform Reporting System (URS)*, p.5, accessed at: <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>.

Figure 5. Adults with SMI and Children with SED Served in Community Mental Health Programs by Age, Fiscal Year 2019



Source: *North Carolina 2019 Mental Health National Outcome Measures (NOMS): SAMHSA Uniform Reporting System (URS)*, accessed at: <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>, p. 5.

It is a concern that only 2.8% of the individuals in North Carolina who are currently receiving evidence-based first episode psychosis services are children/adolescents, compared to 12.4% nationally.⁷⁷

Several areas for improvement were identified to increase access to services and to support the community-based needs of children and families.

Initial Assessment

DHHS staff observed that comprehensive clinical assessments need to be improved, especially for children with complex needs. Staff indicated that when children new to the behavioral health system receive an inadequate assessment and do not receive the correct services and supports to meet their needs, this perpetuates their ongoing involvement in the system. Stakeholders echoed this sentiment, saying that the needs of children/youth should be identified earlier to prevent deeper progression into their disorders and the need for additional systems intervention.

⁷⁷ U.S. Substance Abuse and Mental Health Services Administration. *North Carolina 2019 Uniform Reporting System Output Tables*. Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

Mobile crisis services

Reportedly, crisis response times can be up to two hours, which doesn't meet the need for timely intervention. Reportedly, families have stopped trying to access the service. There needs to be more immediate response.

Care coordination

Care coordination is insufficient. The service is telephonic and is not effective in supporting children with complex needs that cross many systems, requiring strong coordination.

Treatment for Co-occurring Disorders

The services system lacks the expertise to serve children adequately when they have co-occurring mental health and substance use disorders. Multi-systemic therapy attempts to meet this need but is reported to be inadequate. Likewise, stakeholders identified that community-based crisis teams are sometimes ineffective in stabilizing children and adolescents with I/DD and co-occurring mental health diagnoses. This can lead to the overuse of emergency departments and to referrals to state developmental centers, ICFs, or other residential programs.

Children with Autism Spectrum Disorder

Stakeholders in listening sessions noted that finding specialists and well-trained staff who can meet the needs of children with autism was a current challenge. Currently, Board Certified Behavior Analysts are not licensed in North Carolina and require oversight by a licensed psychologist, resulting in limited access to treatment and extensive waiting lists.

Children in the Social Services System

State staff report that children in foster care have difficulty accessing services, especially residential treatment. In addition, youth with SED in the juvenile justice system are reportedly treated as delinquent rather than as youth who need services and supports.

The Tax Equity and Financial Responsibility Act of 1984 allows Medicaid eligibility for individuals under age 22 in cases where a child has significant medical needs and the family has assets that inhibit eligibility; however, staff report that in North Carolina the child or youth must be in an institutional setting to be eligible.

Need for more Community-Based Services for Adults with Behavioral Health Disorders

As depicted in Table 18, most individuals receiving mental health services in North Carolina are receiving outpatient treatment, both Medicaid- and state-funded, 83.6% and 72.5% of individuals, respectively. Outpatient services are not prior-authorized by the LME/MCOs. Medicaid and state funds provided individuals with community-based behavioral health inpatient services, 13.7% and 17.9% respectively. Medicaid also funded emergency department visits for 12.3% of behavioral health service recipients. (Please refer to Table 4, earlier in this report, for all activities covered under Enhanced and Support Services.) Table 18 also depicts the penetration rates for SUD services.

Table 18. Medicaid-Funded Behavioral Health Service Penetration by Diagnosis, Fiscal Year 2019

Medicaid-Funded Service	Service Recipients with MH Diagnosis	Service Penetration for Recipients with MH Diagnosis	Service Recipients with SUD Diagnosis	Service Penetration for Recipients with SUD Diagnosis
Enhanced & Support Services	35,452	13.9%	24,703	68.6%
Supported Employment	1,394	0.5%	111	0.3%
Other Individual Supports (b)(3)	815	0.3%	77	0.2%
Outpatient	213,715	83.6%	19,079	53.0%
Residential Services	1,462	0.6%	694	1.9%
Emergency Room	24,229	9.5%	994	2.8%
Inpatient	20,945	8.2%	1,984	5.5%
TOTAL PERSONS SERVED (Medicaid)	255,540	100.0%	36,018	100.0%

Source: Medicaid (LME/MCO and FFS) paid claims, fiscal year 2019. The Residential Services category includes the residential services offered under Enhanced & Support Services.

Table 19. State-Funded Behavioral Health Service Penetration by Diagnosis, Fiscal Year 2019

MH/DD/SAS-Funded Service	Service Recipients with MH Diagnosis	Service Penetration for Recipients with MH Diagnosis	Service Recipients with SUD Diagnosis	Service Penetration for Recipients with SUD Diagnosis
Enhanced & Support Services	13,124	20.5%	22,834	55.2%
Outpatient	46,493	72.5%	27,745	67.0%
Supported Employment	1,706	2.7%	125	0.3%
Other Community Support	9,782	15.3%	8,538	20.6%
Residential Services	813	1.3%	3,709	9.0%
Inpatient	6,627	10.3%	3,166	7.6%
TOTAL PERSONS SERVED (MH/DD/SAS)	64,119	100.0%	41,399	100.0%

Source: North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services paid claims, fiscal year 2019. The Residential Services category includes the residential services offered under Enhanced & Support Services.

TAC concurs with DHHS' analysis in the 2018 Strategic Plan that "there also is an imbalance of community-based services relative to inpatient, residential, and institutional care for adults in North Carolina."⁷⁸ DHHS determined that the lack of robust community-based behavioral health care services resulted in individuals waiting until their conditions escalated and required visits to an emergency department, contributing to an emergency department "boarding" crisis.⁷⁹ DHHS also attributed the delay in discharges from state-run psychiatric hospitals to the lack of community-based behavioral health services, requiring people to wait in state hospital beds until the community services they needed became available. Delays in discharges from the state psychiatric hospitals result in delays in admissions to the hospitals, and ultimately people who are in crisis find themselves stuck in emergency departments throughout the state.

There is a need for improved services and access to care for adults with behavioral health conditions in several areas:

Assessments

There is a lack of comprehensive assessments for adults as well as for children. The Level of Care Utilization System (LOCUS) has been used in North Carolina for years, but the state should consider ways to ensure person-centered plans that align with specific services.

Crisis Response

Though mobile crisis teams have been implemented, the services are reportedly not available statewide, and some stakeholders question the true availability and quality of the service. The need to enhance and increase access to crisis response services was identified by the Task Force for Racial Equity in Criminal Justice.⁸⁰ DHHS staff expressed interest in a "no wrong door" approach for individuals in crisis, regardless of the service or system with which they initially interface.

Case Management

Stakeholders identified the need for reestablishing case management services, with more intensive, person-centered interventions than care coordination presently provides, for individuals with both mental health and substance use disorders. While ACT and CST services are to include intensive case management, stakeholders report that reimbursement rates "do not support" the intensity needed. The Tailored Plans will be required to provide more enhanced care management that includes some though

⁷⁸ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

⁷⁹ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

⁸⁰ North Carolina Task Force for Racial Equity in Criminal Justice (2020). [North Carolina Task Force for Racial Equity in Criminal Justice: Report 2020](https://ncdoj.gov/wp-content/uploads/2021/02/TRECREportFinal_02262021.pdf). Retrieved April 21, 2021 from https://ncdoj.gov/wp-content/uploads/2021/02/TRECREportFinal_02262021.pdf.

not all components of case management, but will be expanded to all eligible members and not limited to waiver recipients.

Peer Supports

Stakeholders report that systems partners would benefit from increased interaction with peer specialists as well as education on the roles of peers. Some providers reportedly use peers to function in place of the disbanded case management, as “go-fors” or unofficial Uber drivers. DMH/DD/SAS is using block grant funds to start up peer-run wellness centers, but will need state funds to sustain them. DHHS expressed interest in peers as a valuable addition to crisis teams, as well as older adult peer specialists.

Evidence-Based Practices

Though psychosocial rehabilitation is available, the service would be enhanced with the use of best practices. In addition, individuals would benefit from specialty ACT teams, including forensic and medical teams. Assessments should also reflect best practice, including standard criteria for services.

True Community Inclusion

Once people are placed, most providers don’t focus on involving them in non-paid activities, helping them build and sustain natural supports, or other important ongoing steps. But when people aren’t connected to the community, they often don’t want to be in independent housing. The experience with TCLI highlights that housing alone is not enough to maintain individuals in the community. DHHS has made progress in reaching milestones established for the Department of Justice settlement but continues to be challenged with supporting individuals apart from segregated settings. For example, while there was an increase of 140 individuals housed between May 31 and June 30, 2019, 63 of those individuals did not remain stably housed. Several TCLI residents expressed their desire to return to ACHS as a result of isolation and feelings of loneliness. The lack of community supports contributes to community and social isolation, a lack of personal support, and a lack of assistance from natural supports to prevent crises.⁸¹

Inadequate Recognition of the Specific Needs of Older Adults with Behavioral Health Disorders

DHHS staff reported that there is a full array of services and supports for older adults without behavioral health disorders in North Carolina, but some providers don’t understand or adapt service delivery to individuals with behavioral disorders or dementia. Older adults don’t qualify for the behavioral health system’s services that are designed for more significant mental health disorders, such as ACT and CST. Staff report that older adults often fall through the cracks. In addition, there are missed opportunities to identify behavioral health needs in older adults. Staff described scenarios where an older adult is dropped off at an emergency department and receives treatment for a presenting issue such as a fall,

⁸¹ Knisley, B. (2019). *Report of the Independent Reviewer in the matter of United States of America v. the State of North Carolina*. Retrieved March 25, 2021 from https://files.nc.gov/ncdhhs/documents/files/2019%20REPORT%20OF%20THE%20INDEPENDENT%20REVIEWER%2010_26_19.pdf.

but the cause of their fall, possibly an SUD, is not identified. Goal 2.1 of the *2019-2023 State Plan on Aging* addresses efforts to assess the needs of older adults and adults with disabilities, provide technical assistance to providers, and expand the availability of services and supports within communities.

Need for Appropriate Community-Based Services for Individuals with Traumatic Brain Injury

Stakeholders report a significant need for a community-based support system that addresses the unique needs of individuals living with TBI. Historically, TBI has been included in the state and federal definition of developmental disability but is more recently recognized as a unique disability. There are limited day programs and group homes that promote themselves as providing services for individuals with TBI, but there is no state licensure or credential specific to TBI; services would most likely meet the criteria for I/DD licensure. Core community-based service needs include cognitive rehabilitation, life skills training, and neuro-behavioral programming that is integrated into the systems that serve this population. Absent these appropriate services, the lack of coordinated assistance to access the limited options that are available and limited funding to support programming mean that North Carolinians with TBI often require the use of crisis-oriented and institutional services. Of the 36,068 individuals with TBI who received one or more behavioral health services during fiscal year 2018⁸²:

- 5,263 received crisis services
- 1,190 received 24-hour crisis service
- 1,280 resided in nursing homes
- 910 received facility-based care

Using a slightly narrower set of diagnostic codes to identify TBI, we examined claims for Medicaid beneficiaries where TBI was a diagnosis on the claim; the vast majority were for emergency department services. Overall, the number of North Carolina Medicaid beneficiaries with TBI indicated on a claim decreased between fiscal year 2017 and fiscal year 2019. As indicated in Table 20 below, this was true across LME/MCOs. The table is broken out by LME/MCO to show regional variation, though most claims with a TBI diagnosis were for emergency department services and covered by fee-for-service Medicaid and not reimbursed by the LME/MCOs.

Table 20. Medicaid Beneficiaries with a TBI-Related Medical Visit by State Fiscal Year

LME/MCO	Fiscal Year 2017	Fiscal Year 2018	Fiscal Year 2019
TOTAL	30,719	29,526	27,888
Alliance	3,542	3,537	3,366
Cardinal	7,271	7,391	6,815
Eastpointe	2,360	2,400	2,249

⁸² MH/DD/SAS TBI Data Updates – Claims Data, Abha Varma, Quality Management Analyst, December 11, 2019.

LME/MCO	Fiscal Year 2017	Fiscal Year 2018	Fiscal Year 2019
Partners	3,171	2,948	2,785
Sandhills	3,224	3,163	2,834
Trillium	3,564	3,372	3,267
Vaya	2,623	2,627	2,469
No LME/MCO	4,964	4,088	4,103

Source: Medicaid claims data (FFS and LME/MCO). TBI identified by presence of ICD-10 code S01, S02, or S06

According to the U.S. Centers for Disease Control and Prevention (CDC), an estimated 75% of all individuals diagnosed with a TBI will have a mild injury and are likely to recover. The remaining 25% will have a moderate to severe injury and may have long-term or lifelong effects from the injury. The consequences of severe TBI can affect all aspects of an individual's life, including relationships with family and friends, the ability to progress at school or work, doing household tasks, driving, and participating in other daily activities.⁸³ Using a conservative estimate, 1,394 individuals or 5% of the individuals identified in Table 20 above may have a severe TBI, and 20%, or 5,577 individuals, may have a moderate to severe injury that would benefit from TBI services. The TBI Waiver currently supports only 107 individuals residing in the Alliance LME/MCO catchment area.

DHHS staff report that \$2 million in state funding is allocated across the seven LME/MCOs to cover TBI services for people who do not have health care coverage for needed services; one LME/MCO receives only \$75,000 each contract year to serve its members. Staff also report that there is little turnover within the population of state-funded individuals, with the same 150 people receiving the state funding for years.

Data does indicate that individuals with TBI are receiving some Medicaid-funded services. DMH/DD/SAS conducted an analysis of claims data for 365,719 individuals who received behavioral health services in fiscal year 2018 (Medicaid- and state-funded) and found that 36,068 (10%) had a TBI diagnosis. The majority of individuals with a TBI diagnosis (N=34,420) were receiving Medicaid-funded services, and 3,919 (11%) received one or more services listed under the Innovations Waiver.⁸⁴

TAC did not identify a quantifiable target for TBI services expansion in this analysis; however, there is unmet need. Based on national trends, the lack of access to appropriate services and supports for North

⁸³ U.S. Centers for Disease Control and Prevention (2019, February 5). CDC.gov. [What are the potential effects of TBI?](https://www.cdc.gov/traumaticbraininjury/outcomes.html) Retrieved March 3, 2021 from <https://www.cdc.gov/traumaticbraininjury/outcomes.html>.

⁸⁴ Non-public data received from DMH/DD/SAS. PowerPoint file: "TBIDataUpdateDecember2019".

Carolinians with TBI is resulting in the admission or and readmission of individuals with TBI into out-of-state placements, state-operated health facilities, acute care hospital settings, or the prison system — and in homelessness for some individuals.⁸⁵

Lack of Community-Based Services for Adults with Autism Spectrum Disorder

Family members consistently identified the lack of community-based services for adults with ASD as the reason for admitting their loved ones to State Centers. Families observed that community-based providers do not have the expertise to support individuals with autism, and when committed staff are hired, they tend to leave for higher-paying jobs. The turnover in staff is especially difficult to tolerate for individuals with ASD, who do not respond well to change. Families reported that providers often do not manage behavioral outbursts well, sometimes resulting in individuals being dropped off at a hospital emergency department and left there with no place to which to return.

Insufficient Services for People with Disabilities who are Experiencing Homelessness

Individuals with disabilities who are homeless are at higher risk of being admitted to institutional settings due to lack of housing and poor access to services. Services for people with disabilities experiencing homeless are limited in North Carolina. The federal Projects for Assistance in Transition from Homelessness (PATH) grant that provides outreach, engagement, and services to adults who are living outside and have SMI or co-occurring SMI and SUD. PATH targets those individuals who are most in need and are not provided any services by homelessness or mental health provider agencies. DHHS contracts directly with provider agencies to manage and implement the PATH Program in four communities:

- WakeMed Health and Hospitals in Raleigh
- Supportive Housing Communities in Charlotte
- Interactive Resource Center in Greensboro
- Homeward Bound of Western North Carolina in Asheville

Statewide, stakeholders report that people experiencing homelessness do not receive needed outreach. Many are found outdoors, including a number of older adults. Many people experiencing homelessness also have significant mental health and SUD issues. To meet the eligibility criteria for TCLI, individuals experiencing homelessness must have serious and persistent mental illness and must either be facing discharge from a state psychiatric hospital or already have been discharged. Other services and housing supports available to assist people experiencing homelessness are driven at the local level with funding from HUD. The eligibility criteria and priorities for local homelessness systems' funding may not fully align with DHHS initiatives.

⁸⁵ U.S. Centers for Disease Control and Prevention (n.d.). *Traumatic brain injury in prisons and jails: An unrecognized problem*. Retrieved March 5, 2021 from https://www.cdc.gov/traumaticbraininjury/pdf/prisoner_tbi_prof-a.pdf.

Individuals Involved with the Justice System Need More Support

Stakeholders report that there are numerous adolescents and adults with behavioral health disorders, I/DD, and TBI who have committed minor offenses and are involved in the justice system. The Justice Team has workers who address individuals with developmental disabilities, for example, monitoring adherence to person-centered plans. When reentering their communities, individuals are to be connected with LME/MCOs using state funds, but these funds are often exhausted early in the year. Individuals with I/DD may be paroled from the prison system; however, individuals with TBI end up incarcerated for longer periods of time and reincarcerated due to parole violations. The NCCDD is supporting an effort to quantify how dollars are being spent to serve this population in the justice system. The new Director for the Division of Public Safety is advocating for better alternatives to serve individuals with I/DD outside of correctional settings. Additional services and supports are also needed to divert youth with behavioral health disorders from repeated involvement with the justice system.

Insufficient Competitive, Integrated Employment Opportunities

Despite the accomplishments noted earlier in this report, stakeholders reported that there are insufficient, competitive, integrated employment opportunities in North Carolina for individuals with disabilities. Some stakeholders identified the lack of community-based supports as often contributing to employment in segregated settings. These perceptions are consistent with the following TAC findings:

- Educational settings do not consistently promote employment for students with disabilities post-graduation:⁸⁶
 - Information about post-graduation opportunities for students with significant disabilities is not consistently available in schools.
 - Schools have not optimized opportunities to raise expectations for students with significant disabilities.
 - Department of Public Instruction data indicates that there is a gap in the graduation rate in North Carolina between students in the general population and those with an IEP.
- In the 2018-19 In-Person Survey, NCI respondents in North Carolina were significantly below the NCI national average in likelihood of having a paid community job (12% vs. 19%), and significantly above the NCI national average in not having a paid community job in spite of wanting one (58% vs. 44%).⁸⁷
- A significant number of North Carolinians with disabilities work at a wage below the federal minimum standard. According to the Department of Labor Wage and Hour Division, as of

⁸⁶ North Carolina Department of Health and Human Services (2007). *Role school counselors play in providing dropout prevention and intervention services to students in middle and high school, Session Law 2006-176*. March 2007, revised May 2007. Report to the Joint Legislative Oversight Committee on Health and Human Services and Joint Legislative Education Oversight Committee North Carolina Department of Health and Human Services, the Exceptional Children Division, Department of Public Instruction.

⁸⁷ National Core Indicators — National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute. [In person survey \(IPS\) state report 2018-19, North Carolina report](https://www.nationalcoreindicators.org/upload/core-indicators/NC_IPS_state_508.pdf). Retrieved March 25, 2021 from https://www.nationalcoreindicators.org/upload/core-indicators/NC_IPS_state_508.pdf.

July 1, 2017, North Carolina’s employers held 4,592 certificates issued under section 14(c) of the Fair Labor Standards Act and another 575 certificates for “patient workers” who are employed at the state-operated developmental disability centers, for a total of 5,167. The 14(c) certificates authorize the payment of subminimum wage to workers who have disabilities.⁸⁸

- The 2019 National Outcomes Measures report indicates that 33.5% of adults with mental health disorders in North Carolina were in the labor force, either employed or looking for work, lower than the national average of 46.7%.⁸⁹ However, 28% of adults with mental health disorders in North Carolina were reported as employed, which is higher than the national average of 21.7%.⁹⁰
- According to the 2019 report of the Independent Reviewer designated by DOJ to monitor North Carolina’s compliance with the TCLI settlement agreement, “the number of individuals in the TCLI target population receiving IPS/SE remains low and IPS/SE teams struggle to improve their performance. Data supports that there are many more individuals in the TCLI population who want the opportunity to go to work or back to work. There is a lingering belief that individuals in this target population cannot work even when the evidence shows many individuals want to work and can work.”⁹¹
- In fiscal year 2019, 58% of individuals served in ADATCs were unemployed or not in the labor force.
- MFP program staff identified that access to jobs would assist individuals served by MFP to be more successful in the community, observing that employment combats isolation and loneliness.

Individuals with disabilities in North Carolina want to work, and would benefit from the opportunity to seek and receive assistance to maintain competitive, integrated employment.

More Opportunities for Socialization Needed for Individuals with Disabilities

Individuals participating in TCLI and the MFP program have struggled with loneliness, isolation, and boredom. Social connections help to prevent isolation and the return to institutional settings and ACHs. One DHHS staff member observed that HCBS waivers cover “community navigation,” but the service doesn’t help individuals

⁸⁸ North Carolina Department of Health and Human Services (2015). *Education Opportunities for Students with Disabilities Session Law 2015-241: Legislative Report, November 16, 2015*. Retrieved March 25, 2021 from https://files.nc.gov/ncdhhs/SL%202015-241%20Sect.%2011.19.%28a%29.%20Education%20Opportunities%20for%20Students%20with%20Disabilities%2011-16-15%20Final_0.pdf.

⁸⁹ U.S. Substance Abuse and Mental Health Services Administration. *NC 2019 Uniform Reporting System Output Tables*. Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

⁹⁰ U.S. Substance Abuse and Mental Health Services Administration. *North Carolina 2019 Uniform Reporting System Output Tables*. Retrieved March 25, 2021 from <https://www.samhsa.gov/data/report/2019-uniform-reporting-system-urs-table-north-carolina>

⁹¹ Knisley, B. (2019). *Report of the Independent Reviewer in the matter of United States of America v. the State of North Carolina*. Retrieved March 25, 2021 from https://files.nc.gov/ncdhhs/documents/files/2019%20REPORT%20OF%20THE%20INDEPENDENT%20REVIEWER%2010_26_19.pdf.

to find friends. Service systems need to do better at connecting individuals with disabilities to faith-based communities, volunteer work, and natural supports, as well as to transportation.

Individuals in institutional and congregate settings have frequent human interactions, but these are typically confined to others with disabilities. As noted in the DOJ definition, however, settings that only provide for activities with other people with disabilities are a form of segregation and perpetuate unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.⁹²

Differences between LME/MCOs

Stakeholders consistently reported considerable differences in the provision of and access to services and supports among LME/MCOs. Each LME/MCO has the flexibility and responsibility to select the state funding array that it determines will meet the needs of its catchment area. The strength of this approach is that it allows each plan to address local needs. The weaknesses of this approach are that it does not ensure consistent availability of services statewide and that it undermines public perceptions about the commitment of LME/MCOs to provide evidence-based practices that meet the needs of service recipients. The data we analyzed from LME/MCOs provides several insights, however, DHHS should further evaluate the types of data collected; how it is used; the types of services needed based on the data; and how to work with LME/MCOs to ensure that local systems support integrated programs and services. This will be important as the state moves to implement the Tailored and Standard plans in the managed care environment.

LME/MCO Support to Children and Adults

Table 21, below, shows variation among LME/MCOs in mental health, developmental disabilities, and SUD services provided. While there is considerable variation in the percentage of youth among the total of members served with mental health disorders and developmental disabilities, the percentage of youth receiving SUD services is consistently very low in all plans, ranging from only 0.1 to 1.0 %.

⁹² US Department of Justice, Civil Rights Division (2011). [Statement of the Department of Justice on enforcement of the integration mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*](https://www.ada.gov/olmstead/q&a_olmstead.htm)
https://www.ada.gov/olmstead/q&a_olmstead.htm

Table 21. LME/MCO Behavioral Health Services Delivered to Youth and Adults

LME/MCO	Mental Health			Developmental Disabilities			Substance Use Disorders		
	Rec'd MH Service	% Adult	% Youth	Rec'd DD Service	% Adult	% Youth	Rec'd SUD Service	% Adult	% Youth
Alliance	75,872	92.9%	7.1%	3,808	78.0%	22.0%	14,371	99.9%	0.1%
Cardinal	49,426	83.1%	16.9%	2,994	89.6%	10.4%	12,635	99.6%	0.4%
Eastpointe	38,665	90.2%	9.8%	2,253	83.7%	16.3%	7,253	99.8%	0.2%
Partners	48,186	95.1%	4.9%	1,910	85.4%	14.6%	9,775	99.9%	0.1%
Sandhills	49,501	73.3%	26.7%	3,308	67.5%	32.5%	7,634	99.0%	1.0%
Trillium	37,370	77.4%	22.6%	1,927	67.4%	32.6%	10,793	99.3%	0.7%
Vaya	37,515	93.9%	6.1%	1,560	86.6%	13.4%	9,617	99.7%	0.3%
STATE TOTAL	254,961	87.5%	12.5%	17,760	79.1%	20.9%	93,302	99.7%	0.3%

Source: LME Annual Report FY2020 (reporting on FY19 numbers served): <https://files.nc.gov/ncdhhs/2020-LME-Annual-Report.pdf>, Table 5. The percentages above show the proportion of total served who were adults vs. youth.

Variation in Support for Individuals with Mental Health Disorders

Tables 22, 23, and 24 show penetration rates for behavioral services in the seven LME/MCOs. The Medicaid-funded services with the highest penetration rates among beneficiaries in fiscal year 2019 were: Outpatient treatment (average 83.6%); Enhanced and Support services (average 13.9%); and emergency department services (average 9.5%). Table 22 below does depict variation among the LME/MCOs. Penetration rates for supported employment and other individual support were very low across plans, ranging from 0.3% to 1%.

Table 22. Penetration Rates for Medicaid-Funded Mental Health Services by LME/MCO, Fiscal Year 2019

	Alliance	Cardinal	East-pointe	Partners	Sand-hills	Trillium	Vaya	State-wide
TOTAL NUMBER SERVED	33,530	62,087	18,271	27,884	24,980	31,278	27,433	255,540
Enhanced & Support Services	18.2%	14.9%	15.4%	15.6%	7.8%	14.9%	15.1%	13.9%
Supported Employment	0.7%	0.5%	0.5%	0.3%	0.6%	1.0%	0.3%	0.5%
Other Individual Support	0.2%	0.4%	0.2%	0.4%	0.2%	0.6%	0.3%	0.3%

	Alliance	Cardinal	East-pointe	Partners	Sand-hills	Trillium	Vaya	State-wide
TOTAL NUMBER SERVED	33,530	62,087	18,271	27,884	24,980	31,278	27,433	255,540
Outpatient	83.3%	82.9%	79.6%	85.3%	84.2%	82.6%	84.0%	83.6%
Residential Services	0.6%	0.6%	0.6%	0.6%	0.5%	0.6%	0.9%	0.6%
Emergency Room	7.9%	11.1%	11.5%	9.5%	9.1%	9.2%	7.5%	9.5%
Inpatient	8.3%	8.7%	9.0%	7.7%	7.8%	9.1%	8.0%	10.3%

Source: Medicaid paid claims, FY19. LME-MCO and FFS. Penetration rates are calculated as the number who received the service type divided by the total number served as shown in the 'Total' row multiplied by 100.

Table 23, below, identifies more significant differences in penetration rates among the LME/MCOs for state-funded behavioral health services. The penetration rate for Outpatient services was also highest among DMH/DD/SAS-funded services, ranging from 60.7% to 79.1%, with an average of 72.5%. This is followed by Enhanced and Support Services, ranging from 6.3% to 32%, with an average of 20.5%. Community Support services ranged from 3.2% to 34%, with an average of 15.3%. Like Medicaid, the penetration rate for Inpatient Services averaged 10.3%.

Table 23. Penetration Rates for DMH/DD/SAS-Funded Mental Health Services by LME/MCO, Fiscal Year 2019

	Alliance	Cardinal	East-pointe	Partners	Sand-hills	Trillium	Vaya	State-wide
Total Number Served	11,934	15,057	4,951	7,477	6,553	9,582	10,004	64,119
Enhanced & Support Services	17.4%	18.3%	19.1%	18.7%	6.3%	32.0%	25.1%	20.5%
Outpatient	79.1%	72.9%	78.9%	66.0%	74.5%	69.3%	60.7%	72.5%
Supported Employment	2.3%	3.0%	5.5%	1.1%	3.6%	2.2%	1.8%	2.7%
Community Support	14.8%	7.5%	4.0%	27.4%	14.9%	3.2%	34.0%	15.3%
Residential	0.9%	2.1%	0.9%	1.6%	2.0%	0.6%	0.5%	1.3%
Inpatient	10.3%	9.8%	8.3%	14.4%	13.6%	12.0%	6.8%	10.3%

Source: DMHDDSAS paid claims, FY19. Penetration rates are calculated as the number who received the service type divided by the total number served as shown in the 'Total' row multiplied by 100.

Finally, there is considerable variation in the use of state psychiatric hospitals by different LME/MCOs. However, there are not consistent correlations between services penetration and use of the state

psychiatric hospitals. For example, Trillium and Vaya have the highest penetration rates for Enhanced and Support Services; yet, Vaya is well below the statewide average penetration rate for state psychiatric hospitals and (community) Inpatient, while Trillium is just above the statewide average for these two services. Conversely, Cardinal's penetration rate for Enhanced and Support Services is below the statewide average, however Cardinal has the lowest state psychiatric hospital penetration rate of all the LME/MCOs, and a below-average penetration rate for (community) Inpatient. This is an area for further exploration; TAC would expect to see a correlation in the use of Enhanced and Support Services, (community) Inpatient, and state psychiatric hospitalizations.

Table 24. Rate of Persons Served in State Psychiatric Hospitals per 100,000 Population by LME/MCO in FY 2020

Alliance	Cardinal	Eastpointe	Partners	Sandhills	Trillium	Vaya	Statewide
33	15	54	16	18	24	16	23

Source: *North Carolina Psychiatric Hospitals Annual Statistical Report, FY2020*:
<https://files.nc.gov/ncdhhs/documents/files/2020-Psychiatric-Hospitals-Annual-Report.pdf>

Variation in Support for Individuals with SUDs

Medicaid-funded SUD service penetration rates, shown in Table 25 below, also reflected variation among LME/MCOs. Enhanced and Support Services rates were highest in all plans, from 61.9% to 81.3%, with an average of 68.6%. This was followed by Outpatient treatment, between 29.7% and 61.2%, with an average of 53%.

Table 25: Penetration Rates for Medicaid-Funded SUD services by LME/MCO, Fiscal Year 2019

	Alliance	Cardinal	East-pointe	Partners	Sand-hills	Trillium	Vaya	State-wide
Total Number Served	4,030	6,099	4,766	3,948	3,249	4,717	5,203	36,018
Enhanced & Support Services	61.9%	65.0%	81.3%	68.3%	75.8%	65.2%	67.4%	68.6%
Supported Employment	S	0.8%	S	S	S	0.4%	0.3%	0.3%
Other Individual Support	S	0.5%	—	S	—	0.8%	—	0.2%
Outpatient	61.1%	53.1%	29.7%	56.7%	46.9%	61.2%	56.6%	53%
Residential Services	2.2%	2.9%	0.3%	5.8%	1.8%	0.7%	S	1.9%
Emergency Room	2.9%	4.5%	1.7%	2.2%	3.1%	2.6%	1.8%	2.8%
Inpatient	5.5%	8.6%	2.6%	5.4%	7.0%	3.4%	5.3%	5.5%

Source: Medicaid paid claims, fiscal year 2019. LME/MCO and fee-for-service. Penetration rates are calculated as the number who received the service type divided by the total number served as shown in the 'Total' row multiplied by 100. S=suppressed; cell sizes less than 11 and corresponding percentages are suppressed for privacy purposes.

In state-funded SUD services, penetration rates (shown in Table 26, below) remained highest for Outpatient treatment, ranging from 55.4% to 76.4% and averaging 65.9%, and for Enhanced and Support Services, ranging between 25.6% and 66.5% with an average of 55.2%.

Table 26. Penetration Rates for MH/DD/SAS-funded SUD services by LME/MCOs, Fiscal Year 2019

	Alliance	Cardinal	East-pointe	Partners	Sand-hills	Trillium	Vaya	State-wide
Total Number Served	5,336	11,565	2,732	5,231	3,663	6,973	6,680	41,399
Enhanced & Support Services	62.6%	48.8%	57.0%	64.5%	25.6%	66.5%	54.9%	55.2%
Outpatient	71.2%	62.8%	63.9%	64.4%	55.4%	76.4%	67.0%	67%
Supported Employment	S	0.2%	2.0%	S	S	S	0.4%	0.3%
Other Community Support	27.7%	19.8%	5.6%	30.9%	26.6%	4.2%	27.4%	20.6%
Residential	5.3%	15.6%	3.1%	4.9%	27.1%	2.3%	2.9%	9%
Inpatient	7.1%	7.9%	8.2%	8.1%	12.3%	4.4%	7.2%	7.6%

Source: DMHDDSAS paid claims, fiscal year 2019.

S=suppressed; cell sizes less than 11 and corresponding percentages are suppressed for privacy purposes.

Since LME/MCOs do not authorize ADATC beds, TAC did not have access to ADATC penetration rates, as we did for the state psychiatric hospitals. However, DHHS staff did report differences. A DHHS director described one LME/MCO as “super invested, very involved with patients and providing two Peer Specialists onsite at the DHHS facility... while other LMEs/MCOs do not offer that level of support.”

Variation in Support for Individuals with I/DD

As shown in Table 27 below, penetration rates for Innovations Waiver services vary across LME/MCOs, with some particularly notable differences: Assistive Technology ranged from less than .1% to 22.4%, Community Navigator ranged between 1.2 and 56%, and Residential Supports ranged between 15.4 and 40.4%. Some of this variation could be due to differences between LME/MCOs in the service codes used for billing. Penetration rates across LME/MCOs were consistently higher for Community Living and Support and Respite services, and consistently low for Community Transition Services, Home and Vehicle Modifications, Employment Support, Natural Supports Education and Supported Living. DHHS is working with the LME/MCOs to enhance the use of Supported Living; these efforts will likely gain better traction as opportunities to increase access to affordable housing become available.

Table 27. Penetration of Innovations Waiver Services among Waiver Participants by LME/MCO, Fiscal Year 2019

	Alliance	Cardinal	East-pointe	Partners	Sand-hills	Trillium	Vaya	State-wide
Total Number Served	1,863	3,595	1,081	1,595	1,288	1,842	1,551	12,830
Assistive Technology	4.9%	8.6%	6.7%	S	10.1%	22.4%	S	7.9%
Community Living and Support	68.5%	65.8%	73.2%	63.5%	61.2%	71.8%	56.3%	65.7%
Community Navigator	12.0%	56.0%	1.2%	11.2%	30.3%	9.4%	12.1%	24.8%
Community Networking	29.8%	30.3%	19.2%	29.5%	30.7%	44.8%	40.5%	32.6%
Community Transition Services	S	0.3%	S	0.0%	S	S	S	0.2%
Crisis Services	1.2%	0.6%	S	1.1%	S	1.0%	0.8%	0.9%
Day Supports	42.7%	46.0%	41.5%	44.8%	49.2%	40.0%	38.0%	43.5%
Employment Support	15.8%	11.5%	3.2%	15.4%	10.9%	7.4%	16.0%	11.8%
Home/Vehicle Modification	2.3%	2.7%	2.5%	0.0%	4.8%	7.7%	0.0%	2.9%
Natural Supports Education	S	S	0.0%	0.0%	S	S	0.0%	0.1%
Residential Supports	30.4%	15.4%	26.2%	31.7%	35.8%	26.8%	40.4%	27.2%
Respite	50.2%	55.5%	54.8%	53.4%	48.8%	53.3%	43.6%	51.9%
Supported Living	1.9%	1.6%	S	2.8%	2.6%	1.8%	2.5%	2.0%
Other Waiver Services	25.6%	23.6%	3.1%	21.1%	18.8%	20.1%	17.8%	20.1%

Source: Medicaid claims data. 'Other waiver services' include specialized consultation services, employer supplies, financial support services, and individual goods and services.

S=suppressed; cell sizes less than 11 are not presented, and resulting percentages are suppressed for privacy purposes.

The statewide average penetration rates for state-funded I/DD services were highest for ADVP (27.7%), personal assistance (24.3%), and residential group living (14.9%). However, Table 28 below depicts wide variations among LME/MCOs in penetration rates for various services.

Table 28. Penetration Rates of State-Funded Developmental Disability Services by LME/MCO, Fiscal Year 2019

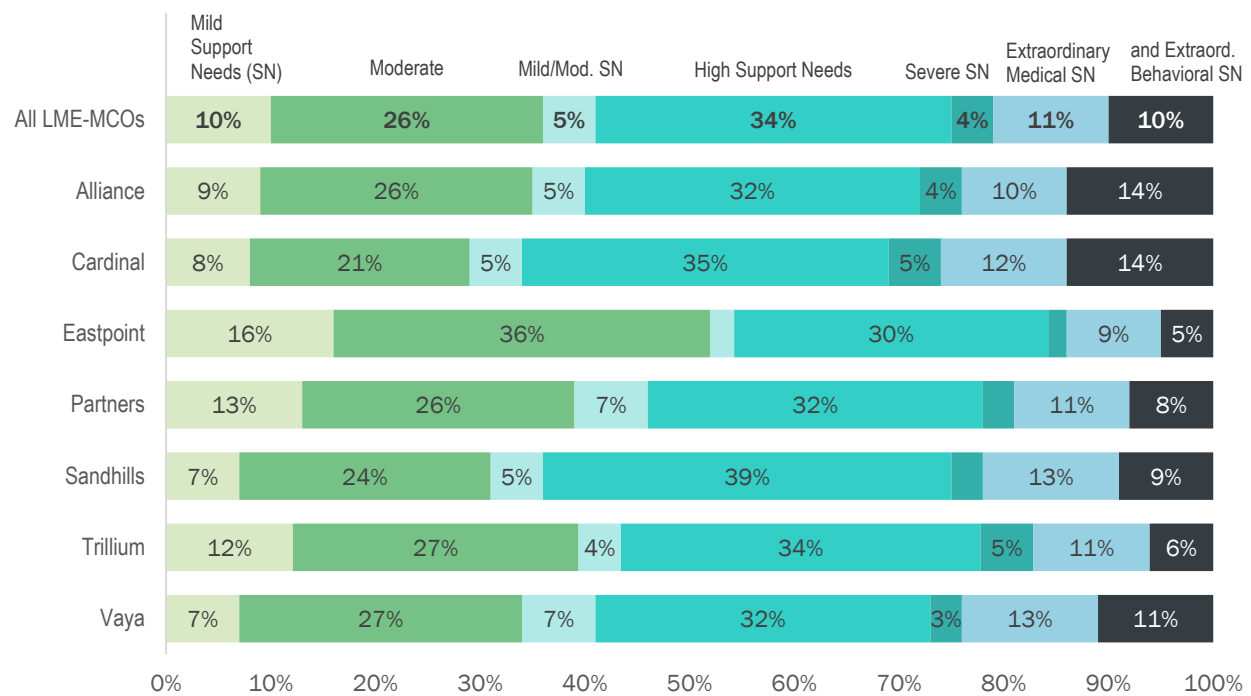
	Alliance	Cardinal	East-pointe	Partners	Sand-hills	Trillium	Vaya	State-wide
Total Number Served	1,204	1,143	584	522	798	842	500	5,588
Adult Developmental Vocational Program	22.2%	43.5%	55.3%	15.5%	23.1%	10.1%	22.4%	27.7%
Day Supports	0.0%	S	0.0%	32.6%	4.5%	0.0%	S	3.8%
Day/Evening Activity	4.5%	12.4%	5.0%	43.1%	12.3%	3.8%	0.0%	10.4%
Developmental Day (Child)	3.4%	1.1%	0.0%	0.0%	13.3%	6.1%	0.0%	3.8%
Dev. Therapy - Medicaid	21.6%	0.0%	18.5%	S	12.9%	26.1%	3.0%	12.7%
MR/MI Independent Living	S	0.0%	S	S	S	0.0%	0.0%	.2%
Personal Assistance	32.3%	10.8%	24.1%	8.0%	12.9%	25.4%	68.8%	24.3%
Residential - Family Living	S	1.0%	3.1%	4.0%	0.0%	S	2.4%	1.2%
Residential - Group Living	8.1%	32.3%	11.8%	25.1%	13.7%	2.7%	7.0%	14.9%
Residential - Supervised Living	6.0%	10.0%	3.6%	5.9%	7.1%	S	3.8%	5.7%
Residential Supports	0.0%	11.5%	0.0%	0.0%	0.0%	0.0%	0.0%	2.3%
Respite	4.7%	0.0%	2.2%	0.0%	2.8%	30.5%	10.6%	7.4%
Supported Employment	S	1.6%	0.0%	4.4%	1.5%	S	S	1.1%
Vocational Support	15.6%	6.6%	2.6%	S	20.7%	3.3%	4.4%	9.0%

Source: DMH/DD/SAS claims data. The penetration rates are calculated as the number of unique individuals who received the service divided by the total number served by LME/MCO (shown in the top row), multiplied by 100.

S=suppressed; cell sizes less than 11 are not presented, and resulting percentages are suppressed for privacy purposes.

Below, Figure 6 displays the percentage of individuals in each support level across the whole population of Innovations Waiver participants, and by LME/MCO. Support Level D (High Support Needs) is the largest percentage across all participants, at an average of 33.87% for all LME/MCOs except for Eastpointe, which has slightly more participants in Level B (Moderate Support Needs). Cardinal, Alliance, and Vaya appear to have more individuals with higher needs, with Cardinal serving the most people in Support Level E (Severe Support Needs) or higher.

Figure 6. Innovations Waiver Participants at Each Level of Support Needs, by LME/MCO



Source: Year 3 Assessment and Roster Management report, prepared by HSRI for DHHS in September 2019

Notes: Total n=12,545. Alliance n=1,811; Cardinal n=3,596; Eastpointe n=1,031; Partners n=1,445; Sandhills n=1,241; Trillium n=1,797; Vaya n=1,624. Reduced n due to missing level assignments for 111 people.

In reviewing waiver service penetration rates in Table 28 with the Support Level severity of needs seen in Figure 6, several points merit attention:

- Cardinal has the highest percentage of Innovations Waiver participants with Severe Support needs or higher, and the lowest percentage with Mild and Moderate Support needs. Cardinal’s penetration rates for Innovations Waiver services exceed the statewide average for Assistive Technology, Community Living and Supports, Community Navigator, Community Transitions, Day Supports, and Other Waiver Services. Cardinal’s penetration rates for state-funded services exceed the statewide average for ADVP, Day/Evening Activity, Residential Group Living, and Residential Supervised Living.
- After Cardinal, Alliance has the next highest percentage of Innovations Waiver participants with Severe Support needs or higher and 35% of participants with Mild and Moderate Support needs. Alliance’s penetration rates for Innovations Waiver services exceed the statewide average for Community Living and Support, Crisis Services, Employment Supports, Residential Supports, and Other Waiver Services. Alliance’s penetration rates for state-funded services exceed the statewide average for Developmental Therapy - Medicaid, Personal Assistance, Residential - Supervised Living, and Vocational Supports.

- Eastpointe has the lowest percentage of Innovations Waiver participants with Severe Support needs or higher, and the highest percentage of Mild and Moderate Support Needs. Eastpointe's penetration rates for Innovations Waiver services exceed the statewide average for Community Living and Supports and Respite. Eastpointe's penetration rates for state-funded services exceed the statewide average for ADVP, Developmental Therapy - Medicaid, and Residential - Family Living.

DHHS should determine whether service penetration rates are consistent with the Department's expectations for the assessed level of support needs among Innovations Waiver participants within each LME/MCO. We also suggest conducting an analysis of the Innovations Waiver program, given its extensive waiting list; a Medicaid State Plan amendment could provide coverage for some services, reducing reliance on the waiver. More than one-third (36%) of Innovations Waiver participants across all LME/MCOs were assessed to have Mild and Moderate Support needs. Finally, it is worth noting that the penetration rates for ADVP are high for plans with both the lowest and highest percentage of members with Severe Support needs.

Drawing from the data presented in Tables 17 through 24, it is evident that there are differences in mental health, SUD, and I/DD services penetration among the LME/MCOs, reinforcing stakeholders' perspectives that were shared during the listening sessions. Though there are differences, it's worth noting that there are consistently low penetration rates across the LME/MCOs for many services that promote community inclusion.

Lack of Formalized Advocacy by Individuals with Lived Experience

Of all stakeholders participating in the listening sessions and the online survey, individuals most impacted by the service system were least represented, despite efforts to solicit their participation.

- Only 2% of listening session participants self-identified as a person with mental illness or SUD lived experience.
- 3.2% of participants self-identified as a person with I/DD.
- 3.76% of online survey respondents identified as individuals with lived experience with a disability, including mental illness, SUD, and I/DD.

There was a significant imbalance of perspectives among family members. Very few families advocating for community integration participated in the sessions or the online survey, while some family members and guardians advocating for maintaining institutional placements participated. Most families and guardians represented individuals with I/DD, with very few families advocating for children or adults with behavioral health disorders.

Individuals with lived experience of mental illness do not have a statewide organized voice in North Carolina. Independent consumer organizations reportedly receive little to no funding from DHHS and may receive funding from an LME/MCO, but this varies. Reportedly, the voices of individuals with lived experience are only brought to the table in a token way and are not fully considered. The behavioral

health system continues to adhere to a paternalistic model and has not shifted to a system that embraces and supports recovery.

Some behavioral health advocacy groups do not promote a common message. The National Alliance on Mental Illness, the North Carolina chapter of the National Association of Social Workers, the American Health Care Association, owners of large group homes, and the North Carolina Psychological Association all have some advocacy voice, but each puts forward a different message, representing a competing interest. These interests do not necessarily reflect consumers' interests, making it even more difficult to present a united consumer/peer voice for advocacy.

There are efforts underway, such as those described below, to strengthen the voices of individuals with lived experience in North Carolina.

Youth Survey of Needs by NCCDD

As part of its five-year plan process, in September 2020, the NCCDD held statewide input sessions for self-advocates and youth (age 30 and under) to identify the issues that matter to them and the initiatives that NCCDD should work on to make North Carolina a more inclusive state for people with I/DD. TAC participated in the youth session, and though the number of participants was small, it was clear that young people with I/DD want to see greater opportunities for independent living and integrated education and employment in North Carolina.

Peer Voice of North Carolina

Peer Voice of North Carolina (PVNC) is funded by SAMHSA directly to the Promise Resource Network, a grassroots nonprofit in Mecklenburg County that uses the voices, experiences, and resilience of people who have overcome trauma, mental health, substance abuse, and related barriers to elevate recovery and wellness. PVNC is working to strengthen the peer voice by supporting people through recovery and providing a forum for them to have a voice and to influence mental health reform. Since 2016, PVNC has developed topic-based coalitions that are working to bring individuals with lived experience together in order to create change through legislative, policy, and systems change initiatives.⁹³

Centers for Independent Living

Centers for Independent Living (CILs) are consumer-controlled, community-based organizations that provide programs and services for people with disabilities and their families. The goal of CILs is to promote and support opportunities for people with disabilities to fully participate in an integrated community and to identify services and supports of their choice.

⁹³ [Peer Voice North Carolina: http://peervoiceenc.com/#](http://peervoiceenc.com/#)

Shortages of Staffing to Serve Individuals with Disabilities

Stakeholders were asked to identify the most significant challenges that providers face in supporting individuals with disabilities in North Carolina. Multiple challenges for providers were identified; however, 62% of all stakeholders identified staff turnover as a significant challenge. Family members of individuals with I/DD, SMI, SUDs, and TBI all ranked the lack of adequate and well-trained staff as a priority concern. Stakeholders also identified the lack of adequate, well-trained staff as a significant gap in the delivery of services and supports.

Stakeholders attributed the high rates of staff turnover to the low rate of compensation for direct service workers/direct support professionals (DSP). It is important to note the high level of skill, commitment, and compassion needed by this workforce, yet the hourly wage for these positions in community-based settings is reportedly less than the hourly wage at fast food restaurants in many areas of the state. The problem is exacerbated in communities where state-operated facilities are located. Direct service workers employed in State Centers earn \$15/hour while staff employed in community-based ICFs are estimated to earn between \$8/hour (only slightly better than the State's \$7.25/hour minimum wage) and \$12/hour. A direct service worker in North Carolina's disability system would need to earn \$14.86 per hour to afford housing.⁹⁴ Thus, much of the workforce cannot afford the basics if they stay in the field, and essentially compete for affordable housing with persons with disabilities.

State Center staff reinforced the observation that insufficient staffing and constant staff turnover, attributed to low wages for community-based services staff, can lead to increased State Center admissions. Similarly, private nursing homes reportedly do not offer the same pay scale or benefits that state-operated facilities do. State Neuro-Medical facilities report employing second and third generation staff. House Bill 488 was proposed in 2019 to increase the hourly rate for community-based direct service workers/DSPs to align with State Center staff wages, however the legislation was not adopted.⁹⁵

Nationally, states are looking to self-directed services options to assist with workforce shortages, by allowing individuals and their families to direct some or all their services. NCI data show that a significantly lower percentage of respondents with I/DD in North Carolina reported using a self-directed option compared to the national average: 2% vs. 12%. However, it is important to note that 24.8% of individuals on the Innovations Waiver in fiscal year 2019 received the self-directed Community Navigator service.⁹⁶ Self-direction is an option under the CAP/DA and CAP/C waivers as well, selected by 23% of CAP/DA participants and 38% of CAP/C participants.

⁹⁴ [National Low-Income Housing Coalition](https://reports.nlihc.org/oor/north-carolina) (n.d.). NLIHC.org. [Out of Reach 2020: North Carolina](https://reports.nlihc.org/oor/north-carolina). Retrieved March 25, 2021 from <https://reports.nlihc.org/oor/north-carolina>.

⁹⁵ General Assembly of North Carolina, Session 2019. [House Bill 488: An Act To Address The Staffing Crisis Impacting Intermediate Care Facility Group Homes For Individuals With Intellectual Disabilities And North Carolina Innovations Waiver Services](https://www.ncleg.gov/Sessions/2019/Bills/House/PDF/H488v1.pdf). Retrieved March 25, 2021 from <https://www.ncleg.gov/Sessions/2019/Bills/House/PDF/H488v1.pdf>.

⁹⁶ DHHS Medicaid Claims Data

Table 29. Use of Self-Directed Services Option in North Carolina and Nationally

State vs NCI	Average	N
North Carolina	2%	635
National Core Indicators (NCI)	12%	18,263

Source: NCI 2018-2019 In-Person Survey Report; [Data Brief on Self-Direction](#).

https://www.nationalcoreindicators.org/upload/core-indicators/Self-direction_508_IPS_18_19.pdf

In addition to issues with wages, North Carolina has acute behavioral health workforce shortages, presenting a barrier to improving the delivery of services and can also decrease access to services. The state has 103 Mental Health Care Professional Shortage Areas and is only able to meet 38% of residents' needs for a psychiatrist. Workforce shortages contribute to limited access to critical services, including crisis services, opioid/substance abuse comprehensive outpatient treatment, and child/adolescent day treatment.⁹⁷

Like their community counterparts, state-operated facilities are also experiencing staffing shortages. The Central Regional Hospital residency program has helped counteract difficulties with hiring psychiatrists and medical practitioners and increased the number of qualified medical professionals available to meet the needs of North Carolinians. The Division of State-Operated Healthcare Facilities is exploring creating residency programs at Broughton and Cherry Hospitals. While this may be viewed as a staffing solution by some, this practice also furthers dependency on institutional settings.

Disparities among Service Recipients

As described earlier in this report, Whites compose 70.6% of North Carolina's population, African-Americans compose 22.5% of the state's population and Latinx/Hispanics compose 9% of the population. However, the distribution of these populations across individuals served by publicly funded services varies and warrants intentional efforts to address disparities.

Mental Health Disparities

Tables 30 and 31 identify gender and racial differences in persons served by behavioral health services and in state psychiatric hospitals and ADATCs. Males compose less than 50% of individuals receiving mental health services in the community, but almost two-thirds of those who receive state psychiatric hospitalizations are male. African-Americans utilize 27% of community-based mental health services funded by DMH/DD/SAS and 32.4% of those funded by Medicaid, but represent 50.6% of all state psychiatric hospitalizations. African-Americans are also disproportionately represented in the utilization

⁹⁷ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](#). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

of crisis services, representing 30% of the population in some communities but 50% of all crisis contacts.⁹⁸ Conversely, Whites make up 64.2% of people receiving DMH/DD/SAS-funded community-based mental health services and 56.9% of people receiving Medicaid-funded mental health services. Notably, these individuals are only 45% of people who receive state psychiatric hospitalizations. The distribution of males and African-Americans served in the state psychiatric hospitals is disproportionate to their distribution in the broader population of people receiving publicly funded mental health services, and likely correlates to their limited access to community-based services.

Table 30. Gender and Race/Ethnicity of Individuals Receiving Behavioral Health Services, Fiscal Year 2019

	MH/DD/SAS-Funded Mental Health Services		MH/DD/SAS-Funded SUD Services		Medicaid-Funded Mental Health Services		Medicaid-Funded SUD Services	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Served	64,119	100.0%	41,399	100.0%	255,540	100.0%	36,018	100.0%
Gender								
Female	33,983	53.0%	14,374	34.7%	162,638	63.6%	21,936	60.9%
Male	30,134	47.0%	27,024	65.3%	92,899	36.4%	14,089	39.1%
Race/Ethnicity*								
Hispanic/Latinx	4,053	6.4%	1,203	2.9%	21,160	8.3%	1,002	2.8%
Asian or Pacific Islander	516	0.8%	168	0.4%	1,918	0.8%	111	0.3%
Black/African American	17,117	27.0%	10,067	24.5%	82,609	32.4%	12,332	34.3%
Native American	984	1.6%	749	1.8%	4,233	1.7%	1,393	3.9%
White	40,661	64.2%	28,848	70.3%	144,826	56.9%	21,138	58.8%

Sources: DMH/DD/SAS and Medicaid paid claims, fiscal year 2019.

*Individuals who are Hispanic/Latinx are counted only in that row; the other racial categories are Non-Hispanic/Latinx. A small percentage of individuals were missing information on race/ethnicity and are not included in the percentages, so the numbers served by race/ethnicity sum to less than the total served.

Waiver Disparities

Similarly, there are differences in gender, race, and ethnicity among individuals receiving waiver services.

⁹⁸ RI International. Data presented on March 17, 2021 on national stakeholders call for crisis services.

Table 31. Gender and Race/Ethnicity of Individuals Served by Waivers or on Waitlists, Fiscal Year 2019

	Innovations Waiver		Innovations Waitlist Receiving Services		CAP Waiver or Waitlist	
	N	Percent	N	Percent	N	Percent
TOTAL	12,830	100%	6,292	100%	15,684	100.0%
Gender						
Female	4,756	37.1%	2,284	36.3%	10,674	68.1%
Male	8,074	62.9%	4,007	63.7%	5,010	31.9%
Race/Ethnicity*						
Hispanic/Latinx	345	2.7%	485	7.8%	491	3.2%
Black or African American	4,078	32.4%	2,425	39.2%	6,796	43.8%
Indian/Native American	108	0.9%	44	0.7%	399	2.6%
White	7,912	62.9%	3,118	50.5%	7,596	49.0%

Source: Medicaid claims data, fiscal year 2019.

*Individuals who are Hispanic/Latinx are counted only in that row; the other racial categories are Non-Hispanic/Latinx. A small percentage of individuals were missing information on race/ethnicity and are not included in the percentages, so the numbers served by race/ethnicity sum to less than the total served.

Though males receive Innovations Waiver and waitlist services at twice the rate of females, this ratio is reversed for the CAP/DA Waiver. However, the gender distribution of Innovations Waiver participants is consistent with the state's population of adult I/DD service system consumers, 61% of whom are male, according to NCI data. Similarly, the racial distribution of Innovations Waiver participants is consistent with adult I/DD service users. For CAP/DA services, although we do not know the gender or racial distribution of individuals with physical disabilities on Medicaid, the fact that the percentage of individuals on the CAP/DA waiver/waitlist who are Black (44%) is greater than their representation in the general population (23% according to census data) suggests there is no disparity in waiver access; however, the percentage of CAP/DA waiver/waitlist participants who are Hispanic (3%) is smaller than their share in the general population (10%).

Geographical Differences in Services

When asked about gaps in the systems that serve people with disabilities, respondents to the survey and attendees at the listening sessions ranked the lack of services and supports in rural communities highest.

Stakeholders identified inequitable access to services throughout North Carolina. For example, stakeholders report that individuals in the eastern part of the state often must travel to Wilmington, Greenville, or the

central part of the state to access services for individuals with I/DD and complex behavioral needs. This includes seeking support from primary care physicians, psychiatrists, psychologists, and Board Certified Behavior Analysts. Since the TBI waiver is currently a pilot, only people living in the Alliance catchment area are eligible. That opportunity doesn't currently exist in the rest of the state.

Stakeholders report limited SUD treatment providers in rural communities. The lack of transportation inhibits the ability for many in need of SUD treatment to access providers in more populated areas. Stakeholders also identified the lack of competitive employment services in rural areas. Families expressed concerns that there are not enough jobs in rural areas to which individuals could transition if protected work environments/workshops are closed. Their family members fear individuals with disabilities will lose their current jobs with nowhere else to go.

In its strategic plan to improve behavioral health services, DHHS acknowledges that service penetration varies widely across the state. The percentage of individuals with a behavioral health diagnosis who received at least one service intended to respond to that diagnosis, relative to the estimated prevalence of behavioral health disorders, is different from county to county. For example, among the adult SUD population, Duplin County had the lowest penetration rate at 12% while Haywood County had the highest penetration rate at 58%, nearly five times higher.⁹⁹

Telehealth has been available in North Carolina for many years to assist with access to services in rural communities, but until the pandemic, accessing this service still required people to travel to a qualified center. Since the spring of 2020, opportunities to use telehealth have expanded significantly, increasing access to treatment and case management services. However, not all North Carolinians have internet access or a smart phone or laptop, and older adults are reportedly more reluctant to use technology, preferring instead to receive services in person.

Inability to Use Data to Assess Quality or Direct Improvement

DHHS lacks an organized data and performance improvement strategy to drive policy, decision-making and funding across disability-serving systems. The lack of timely access to comprehensive data presented challenges in conducting this assessment. This is a barrier to the state's ability to ensure quality, evaluate performance, and measure integration going forward. The key to success in designing, financing, implementing, sustaining, and evaluating an integrated system for people with disabilities includes an effective data collection and performance improvement system with an infrastructure to support these activities. While much of the responsibility for managing the system is delegated to the LME/MCOs, and ultimately to the Tailored Plans, DHHS itself must have an organized data and performance improvement strategy to ensure a high-quality, efficient system.

⁹⁹ North Carolina Department of Health and Human Services (2018). *Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.(a-d); Session Law 2017-57, Section 11F.6.(a-b)*. Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

DHHS

DHHS reports the inability to evaluate how well the behavioral health system is performing. Like many other health care organizations, DHHS reports that the agency has access to a large amount of data but has historically lacked the capacity to use the data to drive improvements in service delivery and value. Data is stored in many locations and formats; these are insufficiently integrated to allow a comparison of metrics among the Division of Medical Assistance, DMH/DD/SAS, and North Carolina's providers and facilities — or to aggregate disparate data sets into statewide numbers. Staff described the inability to compare North Carolina's data to existing metrics because the state's data is not integrated or isn't collected and codified in a consistent way.¹⁰⁰

State-Operated Health Facilities Data Limitations

The SOHFs census tracking and length of stay data are monitored through the Healthcare Enterprise Accounts Receivable Tracking System (HEARTS) data system and the NCTracks claims data warehouse. It's important to note that these systems are designed for billing rather than for data collection, reporting, and evaluation.

Assessing Quality of Service Delivery by LME/MCO

State Medicaid agencies that contract with Prepaid Inpatient Health Plans (PIHPs) are required to evaluate compliance with state and federal regulations. CMS protocols for external quality review of Medicaid MCOs and PIHPs include a desk review of documents, an onsite visit, compliance review, validation of performance improvement projects, validation of performance measures, validation of encounter data, an Information System Capabilities Assessment audit, and Medicaid program integrity review of the health plan. The external quality review focuses on compliance, with little attention to quality improvement.

DHHS's goal is to improve the health of North Carolinians through an innovative, whole-person-centered, and well-coordinated system of care and measurement of quality, which addresses both medical and non-medical drivers of health.

As North Carolina transitions to Tailored Plans, Behavioral Health I/DD Tailored Plans must¹⁰¹:

- Develop quality management and improvement programs, quality assessment and performance improvement plans, and at least three performance improvement projects

¹⁰⁰ North Carolina Department of Health and Human Services (2018). *Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.(a-d); Session Law 2017-57, Section 11F.6.(a-b)*. Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

¹⁰¹ NC Medicaid Division of Health Benefits (n.d.). *Quality management and improvement*. North Carolina Department of Health and Human Services. Retrieved April 26 from <https://medicaid.ncdhhs.gov/transformation/quality-management-and-improvement>.

- Achieve National Committee for Quality Assurance health plan accreditation with the LTSS Distinction for Health Plans by the end of Contract Year 3; and
- Report a wide range of quality metrics, including outcome metrics, with variations depending on whether the enrollee is receiving Medicaid- or state-funded services.

Barriers to Accessing Services and Supports

North Carolina offers a broad array of services and supports for individuals with disabilities. However, when asked about the availability of services and supports, stakeholders identified a number of barriers that inhibit access to those services. Barriers ranked as most significant in all stakeholder groups include:

- Waiting lists for services/funding (71%)
- Lack of coverage for needed services/supports (Medicaid, Medicare, private insurance, state funds) (54%)
- Lack of transportation (51%)

Waiting for Services/Funding

I/DD Waiver Waitlists

As of December 2019, there were 14,474 individuals on the Registry of Unmet Needs (RUN) for the Innovations Waiver,¹⁰² a number that exceeds the 12,830 individuals the waiver supported in fiscal year 2019. In 2017, North Carolinians waited on the RUN for an average of 9.5 years; the average wait time nationally was 5.5 years.¹⁰³ Given the growth in the RUN, wait times have likely increased. Families admitted during listening sessions that they have requested their loved ones be put on the RUN prior to needing waiver services out of concern over the wait time.

Factors contributing to the growing waitlist include:

- North Carolina's Medicaid state plan does not cover home- and community-based services for individuals with I/DD. Outside of the Innovations Waiver, there is insufficient funding to support the needs of individuals with I/DD; as depicted in Table 32, below, almost two-thirds of individuals on the waitlist do not receive services through the LME/MCOs.

¹⁰² 2019 LME/MCO Monitoring Report

¹⁰³ Musumeci, M., Chidambaram, P., & O'Malley Watts, M. (2019, April 4). [Key questions about Medicaid Home and Community-Based Services Waiver waiting lists](https://www.kff.org/report-section/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists-Appendix-tables/). Kaiser Family Foundation. Retrieved March 26, 2021 from <https://www.kff.org/report-section/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists-Appendix-tables/>.

- Individuals under the age of 21 are on the waitlist; 46% of individuals on the waitlist receiving some services are between the ages of 0 and 17.¹⁰⁴ Children/youth under age 21 should have access to any service covered under the U.S. Social Security Act's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program. This Medicaid benefit for children/youth may avert or delay the need for waiver services. Though many Innovations Waiver services are not covered under the Social Security Act (e.g., respite, home modifications, and all habilitative services), requests for services should be submitted to the LME/MCO's Utilization Management Department for consideration.

Senate Bill 350, the North Carolina Innovations Waiver Act of 2021, was introduced on March 29, 2021, proposing that the General Assembly provide the state match to fund an additional 1,000 Innovations Waiver slots across FY 2021-22 and FY 2022-23. The bill also requires the Department to convene a group of stakeholders to develop a ten-year plan to address the RUN. This bill is in the review process.

Table 32. Individuals on Innovations Waiver Waitlist on the First of the Month, December 2019¹⁰⁵

LME/MCO	Number on I/DD Waitlist	Percentage Waiting for Residential Services	Percentage Receiving State and/or (b)(3) Services	Percentage not Receiving any LME/MCO Services	Number Not Receiving any LME/MCO Services
Alliance	3,886	0%	21%	79%	3,070
Cardinal	3,989	5%	35%	65%	2,593
Eastpointe	548	1%	34%	66%	362
Partners	1,614	6%	34%	66%	1,065
Sandhills	1,941	2%	52%	48%	932
Trillium	1,148	0%	64%	36%	413
Vaya	1,348	4%	27%	73%	984
State Total	14,474	3%	35%	65%	9,408

Source: LME/MCO Administrative Functions Monitoring Report, December 2019. Accessed Nov. 2020 at: <https://files.nc.gov/ncdhhs/documents/files/LME-MCO-Administrative-Functions-Monitoring-Report-2019-12.pdf>

¹⁰⁴ DHHS Medicaid claims data for Innovations Waiver and waitlist.

¹⁰⁵ North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (2019). *Local Management Entities/Managed Care Organizations administrative functions monitoring report*. Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/LME-MCO-Administrative-Functions-Monitoring-Report-2019-8.pdf>.

Of the 14,000+ individuals on the waitlist, 5,066 were receiving at least one state-funded service or a Medicaid (b)(3) service through the LME/MCOs. The services most often provided were respite, community guide/navigation, and consultation. Other services provided but to a lesser degree include supported employment and personal care services.¹⁰⁶

Waitlist Management

Each LME/MCO manages its own waitlist, utilizing self-established policies and procedures. According to the Partners website: “Effective July 1, 2018, providers of intellectual and developmental disabilities State Funded services will be required to refer individuals receiving a State Funded Service to the Registry of Unmet Needs (RUN). This process is being implemented to ensure that all individuals currently receiving a State Funded service and who are potentially eligible for the Innovations Waiver are on the RUN and waiting for an Innovations slot to become available. This referral will be a prerequisite for obtaining an initial or continuing authorization of a state-funded service after July 1, 2018.”

This requirement is problematic for two reasons. First, as depicted in Table 32 above, the requirement is not substantiated by the plan’s own data; 66% of Partners’ members on the RUN are not receiving any LME/MCO-funded services. Second, this requirement is likely inflating the waitlist with individuals who have limited interest in or need for a waiver slot and are only registering because they are being required to do so.

Lack of Coverage for Needed Services and Supports

According to the American Community Survey 2015-2019, 11.3% of North Carolinians have no health insurance.¹⁰⁷ The lack of health care coverage or services funding was identified as a reason that individuals with disabilities do not have access to community-based services and supports and often end up in institutional settings. Community providers are not required to serve people who lack coverage. The LME/MCOs receive limited, insufficient funding to serve this population. State-operated facilities are the default “providers” that fill the need, at a high cost to the state.

Ineligibility for Medicaid

North Carolina is one of only nine states that has not yet expanded Medicaid under the Affordable Care Act (ACA).¹⁰⁸ There are currently an estimated 404,000 uninsured adults in North Carolina; 212,000 are in the “coverage gap,” meaning they are not eligible for Medicaid or for insurance through the

¹⁰⁶ Medicaid Claims Data for Innovations Waiver and Waitlist

¹⁰⁷ U.S. Census Bureau. *CEДСCI Profile: North Carolina*. Retrieved March 25, 2021 from <https://data.census.gov/cedsci/profile?g=0400000US37>.

¹⁰⁸ Kaiser Family Foundation (2021, March 26). KFF.org. *Status of state Medicaid expansion decisions: Interactive map*. Retrieved March 31, 2021 from <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.

Healthcare Marketplace.¹⁰⁹ Childless adults who have a disability, but whose condition does not meet the criteria for disability established by the federal government, are not eligible for Medicaid in North Carolina regardless of how low their income is.

There have been attempts by the Cooper administration to obtain legislative approval to pursue expansion, most recently in 2019. Governor Roy Cooper included Medicaid expansion in his state budget proposal for state fiscal year 2020, and subsequently vetoed the state budget passed by the Republican-controlled legislature when it did not include expansion. Senate Republicans were unsuccessful in securing the necessary votes for a veto override before the legislative session adjourned on October 31, 2019. This resulted in the state's operating without a new budget. Governor Cooper once again included Medicaid expansion in his fiscal year 2021 budget proposal.

Medicaid expansion would benefit North Carolinians with disabilities and address the disparities in access to services described earlier in this report:

- The state's portion of health care costs for those eligible under expansion would never exceed 10%, whereas North Carolina currently pays 100% of the cost for behavioral health services for the indigent, including services provided in state-operated health care facilities. The American Rescue Plan provided further incentives to states that have not yet expanded Medicaid eligibility; those incentives would offset any costs associated with expansion in the first two years.¹¹⁰
- State funding could be stretched farther for individuals with disabilities who would still not qualify for Medicaid, or for services not covered by Medicaid, to support community integration needs.
- Medicaid expansion would allow North Carolina to address disparities in health coverage, access, and outcomes among people of color.¹¹¹ People of color, particularly Black Americans, represent just less than one-third of North Carolina's population¹¹² and are disproportionately affected by the decision not to expand eligibility for Medicaid coverage.

Medicaid expansion would also increase the effectiveness of state-funded treatment, by, for example, in addition to outpatient therapies, individuals would have access to the psychiatric medications that are a

¹⁰⁹ Kaiser Family Foundation (2021, March 26). *KFF.org. Status of state Medicaid expansion decisions: Interactive map.* Retrieved March 31, 2021 from <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.

¹¹⁰ Kaiser Family Foundation. *Medicaid Provisions in the American Rescue Plan Act.* <https://www.kff.org/medicaid/issue-brief/medicaid-provisions-in-the-american-rescue-plan-act/>

¹¹¹ Guth, M., Artiga, S., & Pham, O. (2020). *Effects of the ACA Medicaid Expansion on racial disparities in health and health care.* <https://www.kff.org/medicaid/issue-brief/effects-of-the-aca-medicaid-expansion-on-racial-disparities-in-health-and-health-care/>

¹¹² Artiga, S., Orgera, K., & Damico, A. (2020). *Changes in health coverage by race and ethnicity since the ACA, 2010-2018.* <https://www.kff.org/racial-equity-and-health-policy/issue-brief/changes-in-health-coverage-by-race-and-ethnicity-since-the-aca-2010-2018/>

necessary part of ongoing treatment for individuals with mental illness and SUDs. ADATCs give individuals leaving treatment a seven-day supply of medications, but people without Medicaid or other health care coverage have no means to continue paying for these medications in the community unless they can get into a special program with the manufacturer. The discontinuation of medications is a primary cause for relapse that fuels repeated, avoidable admissions to psychiatric inpatient and SUD residential treatment settings, as well as homelessness and oftentimes incarcerations.

Reduced State General Funds

As a result of accruing what was viewed by the General Assembly as extensive fund balances, LME/MCOs saw their single stream allocations reduced in fiscal year 2017. However, the LME/MCOs were required to maintain the same level of non-Medicaid paid services provided during the 2015 fiscal year. Funded at slightly less than \$190 million, the LME/MCOs spent \$265 million in single stream funding in fiscal year 2017.¹¹³

Each month, LME/MCOs serve approximately 132,400 of the state's Medicaid recipients and 36,000 underinsured or uninsured North Carolinians.¹¹⁴ Through effective care coordination and active consumer education and outreach, LME/MCOs have achieved savings in Medicaid budgets. Reportedly, these Medicaid savings have been used to make up the shortfall in single stream funding in order to provide the same "level" of service offered in 2015. The 2017 cuts are problematic in several ways:

- There was no determination made regarding the efficacy of the services authorized in 2015.
- Ongoing funding shortfalls are not sustainable and have inevitably impacted service availability for both Medicaid and non-Medicaid members.
- These cuts have likely impacted the ability for LME/MCOs to provide "in lieu of" services to their members.

Reduced funding creates a disincentive for the LME/MCOs to invest in EBPs and services that are not contractually required, impacting the availability of the critical, yet voluntary, services that support community integration.

Guardianship

Per the *Olmstead* decision, unjustified institutional isolation "perpetuates unwarranted assumptions that individuals so isolated are incapable or unworthy of participating in community life and diminish[es]

¹¹³ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

¹¹⁴ CareforNC (n.d.). [#CareForNC Questions and Answers](https://www.carefornc.org/wp-content/uploads/2019/07/CareForNC-Questions-and-Answers.pdf). Retrieved March 25, 2021 from <https://www.carefornc.org/wp-content/uploads/2019/07/CareForNC-Questions-and-Answers.pdf>.

... everyday life activities ... including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”¹¹⁵

One of the most consistent barriers to community inclusion identified by state agency staff and by stakeholders, other than families of individuals with I/DD, was guardianship. Reportedly, guardians often oppose transition from institutional care to the community, overriding the wishes of individuals who want to transition. For example, there is a sizeable long-term population within each State Center that has not signed an MOA; the guardian may request that the individual *not* be considered for transition back to the community despite what the individual wants.

Staff report that paid guardians are especially unwilling to press the issue of transitions. Stakeholders also expressed concerns over how low the threshold is to establish guardianship in North Carolina. Data from the Administrative Office of the Courts reveals that of 4,860 incompetency petitions filed, 3,747 resulted in guardianship.¹¹⁶

Guardianship is a barrier to realizing the intent of *Olmstead*. Nationally, people with I/DD who do not have a guardian are more likely to:¹¹⁷

- Have a paid job
- Live independently
- Have friends other than staff or family
- Go on dates and socialize in the community
- Practice the religion of their choice

In North Carolina, guardianship impacts individuals with all disabilities and ages:

- DHHS staff report that when students with disabilities reach 16 years old, schools encourage guardianship.
- According to the NCCDD:¹¹⁸
 - Guardianship is the most restrictive option of legal substitute decision-making, and continues to increase in North Carolina, specifically for younger adults with disabilities.

¹¹⁵ *Olmstead vs. L.C.*, 1999, 527 U.S. at 600-01. Retrieved March 25, 2021 from <https://supreme.justia.com/cases/federal/us/527/581/>.

¹¹⁶ North Carolina Council on Developmental Disabilities (n.d.). *Rethinking guardianship: building a case for less restrictive alternatives*. NCCDD.org. Retrieved February 25, 2021 from <https://nccdd.org/guardianship.html>.

¹¹⁷ Nye-Lengerman, K., Narby, C., & Pettingell, S. (2017). *How is guardianship status related to employment status for people with IDD? Findings from the National Core Indicators Adult Consumer Survey*. ThinkWork! Institute for Community Inclusion, University of Massachusetts Boston. Retrieved April 26, 2021 from <https://www.thinkwork.org/how-guardianship-status-related-employment-status-people-idd-findings-national-core-indicators-adult>.

¹¹⁸ North Carolina Council on Developmental Disabilities (n.d.). *Rethinking guardianship: building a case for less restrictive alternatives*. NCCDD.org. Retrieved February 25, 2021 from <https://nccdd.org/guardianship.html>.

- Out of more than 5,000 adults served by a public guardian in North Carolina, nearly 3,000 (56%) are younger adults age 18-59 years old, the majority of whom (86%) have a primary diagnosis of I/DD or mental illness.
- Of older adults between the ages of 60 and 84, who are 37% of the adults served by public guardians in North Carolina, almost half (48%) have a primary diagnosis of I/DD or mental illness.
- MFP program staff report that guardianship impedes the ability of some eligible individuals to benefit from the program by keeping them in an institutional setting.

Stakeholders also expressed concern that existing guardianship laws, policies, and procedures do not receive uniform interpretation and implementation across the state. Clerks of courts, assigned the responsibility to determine if guardianship is warranted, may not fully understand disabilities, leaving assignment of guardianship dependent on each court's interpretation.

Lack of Transportation

When asked about the most significant challenges individuals with disabilities and families encounter in accessing services, slightly more than half (51%) of stakeholders identified the lack of transportation. Even a robust array of services and supports is of little benefit if individuals with disabilities are not able to access them.

Non-Emergency Medical Transportation (NEMT) is a covered service for North Carolinians enrolled in Medicaid. Transportation is available if the recipient receives a Medicaid-covered service provided by a North Carolina Medicaid-enrolled provider. Medicaid only pays for the least expensive means suitable to the recipient's needs. For beneficiaries enrolled in Medicaid managed care, health plans are required to provide NEMT services. Health plans may use transportation brokers to arrange and provide transportation, or contract directly with transportation providers. This resource is not available for individuals with disabilities to access non-Medicaid services or for individuals who are not eligible for Medicaid.

The expanded use of telehealth is being cited nationally as an effective strategy to increase access to services. The use of mobile services and co-locating behavioral health services with alternative types of providers, such as rural health clinics or Community Action Agencies, are approaches that may be viable options in addition to expanding transportation services.

Though not available statewide, there are also county-specific transportation resources. For example, Guilford County provides transportation for qualified individuals to access continuing education or employment, including work sites, work-related activities, job training, and job fairs.¹¹⁹ Individuals with disabilities may not be aware that this resource exists to support educational or employment goals.

¹¹⁹ County of Guilford, North Carolina (n.d.). *Services and programs*. Guilford County. Retrieved March 26, 2021 from <https://www.guilfordcountync.gov/our-county/human-services/transportation/services-and-programs>.

Funding and Program Policies

Through our analysis, TAC has identified funding and programmatic policies that create barriers to care.

Funding Policies

TAC identified concerns not only with the amount of funding for services for individuals with disabilities, but also with policies for how that funding is spent.

As described earlier in this report, the General Assembly prioritized state funding for community inpatient services to reduce admissions to state psychiatric hospitals; however, little funding has been appropriated to shore up services that would promote ongoing stabilization and recovery, essential for community integration. In addition to the funding prioritized for community inpatient beds, the LME/MCOs used single stream funding, appropriated by the General Assembly to pay for services to people without health insurance coverage, to purchase inpatient psychiatric and SUD treatment. LME/MCOs have also reported to DMH/DD/SAS that they have accessed local funding to purchase or supplement additional, psychiatric inpatient services in community hospitals.

In addition to LME/MCO-authorized Medicaid expenditures, fee-for-service (FFS) also covers a limited amount of mental health services.

Table 33. Medicaid Expenditures for Mental Health Services by Service Type, Fiscal Year 2019

Service Type	Medicaid LME/MCO	Medicaid Fee-for-Service	Medicaid Total	% of of Total
Enhanced & Support Services	\$274,605,195	\$4,363,554	\$278,968,749	24.9%
Supported Employment	\$4,704,119	—	\$4,704,119	0.4%
Other Individual Support (b)(3)	\$8,340,176	\$7,710	\$8,347,885	0.7%
Outpatient	\$176,954,478	\$19,215,179	\$196,169,657	17.5%
Residential Services	\$77,996,506	\$2,838,460	\$80,834,965	7.2%
Emergency Room	\$61,153,349	\$556,659	\$61,710,008	5.5%
Inpatient	\$448,791,826	\$38,955,732	\$487,747,558	43.6%
TOTAL	\$1,052,545,648	\$65,937,293	\$1,118,482,941	100.0%

Source: Medicaid paid claims, fiscal year 2019.

North Carolina spends in excess of \$1 billion for Medicaid-reimbursed mental health treatment in the community, of which 43% goes to inpatient treatment — yet all LME/MCOs report increasing wait times in emergency departments. An additional 12.7% of the funding is spent on residential and emergency department services, with just less than 25% spent on enhanced mental health and SUD services that

support community inclusion. TAC concurs with DHHS' own assessment that "there is inadequate investment in services that promote and support community inclusion."¹²⁰

Policies impacting LME/MCOs

LME/MCOs fund individual-level services based on the expectation that authorized services should decrease over time. This often results in service reductions as people become stable, without accounting for the possibility that services are the key to their stability. Service delivery and authorization that sustains stability and progress would decrease the amount of cycling in and out of intrusive, costly services and result in better outcomes for recipients and reduced costs to the system.

LME/MCO representatives reported that, under the current DHHS contracts, they are required to conform to an FFS payment system for provider reimbursement. FFS payment incentivizes the provision of services but does not encourage either greater efficiencies or provision of services that result in the most positive recipient outcomes. DHHS staff clarified that the LME/MCOs do have options for alternative payment approaches, such as bundled payments, and that the Department has committed to increasing value-based purchasing in the Standard and Tailored Plans.

Eligibility for the Medically Needy Program

North Carolina is a 1634 state with a medically needy program.¹²¹ Medicaid applicants who have income over the eligibility limit may still be eligible for services if they have high medical expenses relative to their income. "Excess income" (over the Medicaid eligibility limit) is used to cover medical bills, which may include insurance premiums, prescriptions, doctor visits, hospitalizations, and medical supplies. Individuals have six months to "spend down" their excess income to the Medicaid eligibility limit. Once the deductible is met, the individual will qualify for Medicaid for the remainder of the six-month period.

Under today's criteria, individuals remain in nursing facilities due to an inability to meet their deductible while also covering their costs to live in the community. This not only results in individuals being institutionalized unnecessarily, but also increases costs to the state. Currently, 44 states allow people whose functional needs require an institutional level of care to qualify for Medicaid under the Special Independent Living Program, thereby facilitating nursing facility transitions.¹²²

¹²⁰ North Carolina Department of Health and Human Services (2018). *Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.(a-d); Session Law 2017-57, Section 11F.6.(a-b)*. Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

¹²¹ Individuals who receive Supplemental Security Income in a 1634 state typically receive Medicaid automatically.

¹²² North Carolina Department of Health and Human Services, Division of Medical Assistance (2018). *Money Follows the Person demonstration sustainability analysis: Transitioning beyond 2020* (p.6). Retrieved March 25, 2021 from <https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf>.

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Chapter 4: Recommendations

In preparing this report, it is clear that North Carolina has many people and groups with good intentions of serving people in integrated settings. The state intends for its *Olmstead* Plan to be broad and comprehensive, and many of the findings and recommendations in this report will require bold actions over time to develop a system that prioritizes community integration. It is also important to recognize that an *Olmstead* Plan should be a document that is implementable, and will be revisited periodically to build from success, failure, and changing circumstances. Based on the information and data presented throughout this report, knowledge of best practices, and the Technical Assistance Collaborative's (TAC) experience with states and systems across the country, this chapter identifies a series of recommendations for the Department of Health and Human Services (DHHS) to consider in the development of an initial, comprehensive *Olmstead* Plan. As DHHS considers what recommendations to incorporate into its *Olmstead* Plan, the recommendations should be refined to be more specific.

Stakeholders were asked to identify their recommendations for improving the services and systems that support individuals with disabilities in North Carolina. The top three recommendations from stakeholder groups were:

1. Appeal to the legislature for more funding (73%)
2. Increase access to safe, decent, affordable independent living opportunities (70%)
3. Provide a more comprehensive array of community-based treatment, therapeutic services, and supportive services (62%)

Stakeholders also indicated their desire for the system to offer choice in and access to services in a robust, person-centered array, emphasizing the following improvements:

- Offer a choice in services to meet the unique needs of individuals with disabilities at various levels, including the choice of more restrictive settings such as supported workshops and state-run institutions.
- Continue to educate families and individuals with disabilities about *Olmstead* and about their choices for services.
- Ensure consistency across all services across the state.
- Target funding for best practice and evidence-based services, based upon data that shows their effectiveness.

TAC has organized its recommendations under three themes. These recommendations will be further informed by the *Olmstead* Plan Stakeholder Advisory (OPSA) as the actual plan development phase begins.

- Ensure that individuals with disabilities have access to the individualized array of community-based services and supports they want and need to live as integrated members of their communities.

- Increase access to integrated housing and community-based services through new resources and repurposed funding transferred from institutional and segregated settings
- Address systemic challenges and eliminate barriers to access to services to support individuals to live meaningful lives as integrated members of their communities.

Ensure that individuals with disabilities have access to the community-based services and supports they want and need to live as integrated members of their communities.

Recommendation 1: Build on the strengths of the current system

North Carolina has elements within its service systems that are vital to community integration. The key will be to fully implement those elements across the systems that serve individuals, regardless of their disability or their level of need, to create a strong foundation for transitioning to and living successfully in the community.

1A: Use TCLI as a Framework for Community Inclusion

TAC concurs with the observations offered in the latest Transitions to Community Living Initiative (TCLI) annual report to the state's Joint Legislative Oversight Committee on Health and Human Services¹²³ and other recommendations¹²⁴ that the services and housing strategies put in place as a result of the TCLI for individuals with serious mental illness (SMI) can serve as a solid foundation on which the state can build goals and objectives into its *Olmstead* Plan for other disability populations.

- DHHS should expand in-reach activities to individuals being discharged from psychiatric hospitals, skilled nursing facilities, state intermediate care facilities (ICFs) and Neuro-Medical units, community-based ICFs, and non-TCLI adult care homes (ACHs). This recommendation is consistent with requirements that will be incorporated into the Standard and Tailored Plan contracts.
- DHHS should expand the Referral Screening Verification Process (RSVP) to educate all individuals with disabilities about service options that are available as alternatives to an institutional or community-based, congregate setting.
- DHHS should expand the availability of pre-tenancy, transition, and tenancy-sustaining services beyond the TCLI population.

¹²³ North Carolina Department of Health and Human Services (2021). [2019 - 2020 Annual report of the North Carolina Transition to Community Living Initiative NC General Statute 122C-20.15, Report to the Joint Legislative Oversight Committee on Health and Human Services](https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf). Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf>.

¹²⁴ [MFP Sustainability Analysis Summary of Recommendations](#)

- DHHS should expand the housing supports and subsidies provided in the TCLI settlement to individuals with intellectual and developmental disabilities and other disability populations not covered by TCLI.

1B: Adopt Lessons Learned from the Money Follows the Person Program

- DHHS should ensure that transition-related activities currently covered under Money Follows the Person (MFP) are fully integrated into the Medicaid fee-for-service (FFS) program and into managed care Standard and Tailored Plans so that transition-related activities are imbedded into these programs when the MFP program ends.¹²⁵ Individualized support is essential for transition into the community, as individuals leaving an institution may not have the resources to cover furniture, security deposits, and other necessities.

Recommendation 2: Increase the Use of Evidence-Based and Promising Practices

Like many states across the country, North Carolina continues to use its limited resources to fund services and programs that lack efficacy. DHHS supports some degree of evidence-based and promising practices for individuals with disabilities but the support is not consistent across disability populations and is dependent on individuals' coverage.

- DHHS should target Medicaid and non-Medicaid funding to support best practices, promising practices, and evidence-based services, based on data that shows their effectiveness.
- DHHS should strengthen contractual language regarding the use of evidence-based practices (EBPs) in the Tailored Plans, incorporating research-based outcome measures and tying financial incentives and penalties to achieving benchmarks.

Recommendation 3: Eliminate Gaps in Community-Based Services

As described earlier in this report, North Carolina offers a robust service array, but addressing gaps in these services could reduce reliance on institutional care for individuals with disabilities.

3A: Strengthen Services for Children with Behavioral Health Disorders

DHHS must identify the factors contributing to low behavioral services penetration for children in North Carolina. DHHS staff have suggested that a timelier, comprehensive assessment would better identify a

¹²⁵ U.S. Centers for Medicare and Medicaid Services (2020, September 23). [CMS announces new federal funding for 33 states to support transitioning individuals from nursing homes to the community](https://www.cms.gov/newsroom/press-releases/cms-announces-new-federal-funding-33-states-support-transitioning-individuals-nursing-homes) [Press release].

<https://www.cms.gov/newsroom/press-releases/cms-announces-new-federal-funding-33-states-support-transitioning-individuals-nursing-homes>.

Note: NC Medicaid has had a written and CMS-approved sustainability plan since 2015 to continue MFP after the federal funding ended. With the latest continuation funding approved in December 2020, NC Medicaid signed the grant award to continue the program into 2027.

child's need for services and intervention at an earlier age, thereby preventing progression further into the behavioral health and juvenile justice systems.

- DHHS should identify and address the limitations of existing assessment tools and processes, identifying an alternative assessment if needed.
- DHHS should identify factors contributing to the high rate of child admissions to state psychiatric hospitals and create or expand community-based services capacity to eliminate the need for future admissions.
- DHHS should continue building its children's System of Care. Including families as system partners and building on their strengths helps to build trust; facilitates engagement; helps them to identify the resources, services, and supports they and their children need to avoid deep-end involvement in behavioral health services; and can reduce involvement in the social services and juvenile justice systems.
- DHHS should reach out to and engage with the Department of Public Instruction to increase local school districts' utilization of school-based behavioral health services.

3B: Enhance Crisis Response

In 2017, the National Association of State Mental Health Program Directors (NASMHPD) and the Substance Abuse and Mental Health Services Administration (SAMHSA) partnered in advocating for policy makers to consider what it would take to look "beyond beds" in state hospitals as a single solution to all the challenges of supporting individuals in the community. Instead, that paper pointed to building an infrastructure of mental health services and policies to ensure timely access to appropriate care that would address both serious emotional disturbance (SED) and SMI.¹²⁶

Effective crisis response and stabilization are key to preventing unnecessary reliance on institutional care. The National Association of State Mental Health Program Directors and SAMHSA have highlighted the need to prevent and manage crises in a way that offers a racially equitable, immediately accessible, interconnected, and effective array of crisis behavioral health services. An enhanced crisis response system meets community needs; saves lives with services that reduce suicides and opioid-related deaths; diverts individuals from incarceration and unnecessary hospitalization; and accurately assesses, stabilizes, and refers individuals with mental health, substance use, and other behavioral health challenges to appropriate follow-up services.¹²⁷

¹²⁶ Pinals, D. & Fuller, D. (2020, April 23). [Beyond beds: The vital role of a full continuum of psychiatric care](#). *Psychiatry Online*.

¹²⁷ Pinals, D. (2020). [Crisis services: Meeting needs, saving lives](#). Alexandria, VA: National Association of State Mental Health Program Directors.

Per SAMHSA's Crisis Toolkit¹²⁸, the core elements of a crisis system include:

- ✓ Regional or statewide crisis call centers coordinating in real time
- ✓ Centrally deployed, 24/7 mobile crisis
- ✓ 23-hour crisis receiving and stabilization programs
- ✓ Adoption of essential crisis care principles and practices

North Carolina has invested in Behavioral Health Urgent Care centers. The Sandhills Center Local Management Entity/Managed Care Organization's (LME/MCO) recent partnership with the Alexander Youth Network to provide facility-based crisis services for children and adolescents in Guilford County may serve as a model to replicate statewide.

- DHHS should continue to expand the crisis service array statewide to include minimally the core elements identified in SAMHSA's toolkit and to enhance child and youth expertise in all aspects of crisis services.
- DHHS should work with the LME/MCOs and, in the future, Tailored Plans to assess the quality of crisis services and outcomes for recipients.

3C: Improve Services for Adults with SMI

While the following description from the Independent Reviewer's Report pertains to the TCLI population, TAC's assessment is that the description is applicable to the adult mental health service system in general.

"The biggest challenge remaining is improving the focus, flexibility, and quality of services and supports. This requires making the array of needed services and supports available with the frequency and intensity necessary for successful transition to community living. This also requires assuring the duration of services and supports matches an individual's request and recovery needs. It requires that staff help individuals to increase their ability to recognize and deal with situations that may otherwise result in crisis and to strengthen and expand individuals' networks of community and natural supports. The TCLI target population is not a single homogenous group where one size of services fits all. Improving services requires a better understanding of needs, more intensive and frequent services, individualized

¹²⁸ U.S. Substance Abuse and Mental Health Services Administration (2020). Crisis services: Meeting needs, saving lives. Washington, DC: Substance Abuse and Mental Health Services Administration. <https://store.samhsa.gov/product/crisis-services-meeting-needs-saving-lives/PEP20-08-01-001>.

person-centered supports and services, flexibility, use of effective resources, a focus on recovery, use of natural supports, and use of data for decision-making.”¹²⁹

TAC developed and provided an initial series of trainings on best practice permanent supportive housing (PSH) services delivery to Community Service Team (CST) and Assertive Community Treatment (ACT) provider staff. The content of the trainings addresses several of the service concerns expressed by the Independent Reviewer. LME/MCOs are now required to provide or contract for the delivery of services on an ongoing basis.

- DHHS should ensure that the permanent supportive housing (PSH) training and refresher courses are provided on an ongoing basis.
- DHHS should further promote the principles of recovery in all aspects of the behavioral health system.¹³⁰ LME/MCOs and service providers would benefit from repeated training on recovery, especially training delivered by individuals with lived experience.
- DHHS should continue to identify and resolve the service-related issues that inhibit successful tenancy in independent living. The concerns identified in supporting TCLI participants are likely to be systemic.
- DHHS should examine the effectiveness of community-based crisis services/crisis planning with PSH residents and the adequacy of ongoing tenancy support services received while in PSH.

3D: Address Issues with Residential Services for Individuals with I/DD

It will take time to build additional affordable housing capacity for individuals with disabilities, including those with intellectual/developmental disabilities (I/DDs). Some individuals will continue to choose to live in an ICF if given the choice to live independently. If ICFs continue to be part of the community service array in North Carolina, DHHS should evaluate the institutional qualities of these facilities and promote person-centered approaches to increase community integration.

- Consistent with the TCLI approach, DHHS should provide In-reach to all ICF residents, insuring they are fully informed of their community-based living options.
- DHHS should promote and incentivize the development of Supported Living and other non-ICF, integrated community settings for individuals with I/DD.
- DHHS should reduce the size of any DHHS-funded facility with more than six beds and should consider reducing community-based settings to housing no more than three unrelated individuals.

¹²⁹ Knisley, B. (2019). *Report of the Independent Reviewer in the matter of United States of America v. the State of North Carolina*. Retrieved March 25, 2021 from https://files.nc.gov/ncdhhs/documents/files/2019%20REPORT%20OF%20THE%20INDEPENDENT%20REVIEWER%2010_26_19.pdf.

¹³⁰ U.S. Substance Abuse and Mental Health Services Administration (2012). *SAMHSA's working definition of recovery*. Retrieved March 25, 2021 from <https://store.samhsa.gov/sites/default/files/d7/priv/pep12-recdef.pdf>.

- All DHHS funded settings should be reviewed to assess and modify characteristics and practices that have qualities of institutions.

3E: Improve Services for Individuals with Autism

As described earlier in this report, families with adult members on the autism spectrum reported that the community-based service system does not have the capacity or the expertise to serve their loved ones. This results in institutional placements and extended stays that could be prevented or greatly reduced by building the capacity of community providers to support this population.

- DHHS should educate the General Assembly on the importance of supporting legislation allowing Board Certified Behavioral Analysts to provide services to children and youth with Autism Spectrum Disorder (ASD) without oversight from a licensed psychologist.
- DHHS should expand service approaches and pilot programs identified as best or promising practices for adults with autism.
- DHHS should continue efforts to resolve the discrepancy in salary and benefits of community-based direct service providers, reducing staff turnover that is so disruptive to supporting individuals with ASD.

3F: Develop and Provide Coverage for Services to Meet the Needs of Individuals with Traumatic Brain Injury

Data indicates that a significant number of individuals living with a traumatic brain injury (TBI) currently receive community-based services/supports in various existing service systems including, but not limited to, the Innovations waiver, the Community Alternatives Program for Disabled Adults (CAP/DA) waiver, the Community Alternatives Program for Children (CAP/C) waiver, single-stream-funded programs, substance use disorder (SUD) and mental health block grant programs. However, these programs may not reflect the needs of the TBI population.

- Policies, regulations, and contract provisions should include and reflect individuals with TBI as a population with distinct needs.
- DHHS should develop TBI-specific service definitions and therapeutic interventions that are congruent with effectively treating, serving, and supporting individuals with TBI in community settings.
- DHHS should incorporate service coordination for TBI into LME/MCO contracts and ultimately the Tailored Plans.

Nationally, TBI services are severely underfunded and North Carolina is no exception. Due to the lack of appropriate community-based services and supports, North Carolinians with TBI are being served through institutional care settings such as state hospitals, acute care hospitals, out-of-state placements, nursing facilities, and prisons.

- DHHS should expand the TBI waiver statewide as a strategy to support individuals in integrated settings.

Recommendation 4: Increase Access to Affordable Housing for Individuals with Disabilities

North Carolina's *Olmstead* Plan will need to include strategies to increase access to decent, safe, and affordable housing for individuals with disabilities. DHHS has contracted for a comprehensive assessment of need and development of a strategic housing plan for individuals across disabilities that will be incorporated into the *Olmstead* planning process when completed. Therefore, TAC is deferring comprehensive recommendations for increasing access to affordable housing for individuals with disabilities, pending recommendations that will be forthcoming in that strategic plan. However, TAC does offer the following strategies based on our current analysis:

- North Carolina should increase the amount of funding for the Key Rental Assistance program.
- DHHS and the LME/MCOs should explore opportunities and eliminate service barriers to increase utilization of the available housing units in rural communities.
- LME/MCOs should increase the use of assistive technology to make housing units more fully accessible for individuals with disabilities.
- DHHS should add housing indicators to the Tailored Plans performance criteria, including the number of individuals transitioned from institutional and congregate settings to independent living, and indicators of housing retention.

Recommendation 5: Increase Competitive, Integrated Employment Opportunities

5A: Strengthen Employment Opportunities for Youth with Disabilities

- DHHS should work with the NC Department of Public Instruction (DPI) to ensure schools inform youth and families of the benefits of the Division of Vocational Rehabilitation Services' (DVRS) offerings at Individualized Education Program (IEP) meetings when the student reaches the age of 14 and annually thereafter.
- DPI, DHHS (including DVRS), and the North Carolina Department of Labor should work with local school districts and local employers across the state to model and implement Employment First practices.
- DHHS should expand best practices in transitions such as Project SEARCH, a school-to-work transition program for students with disabilities in their final year of high school. Project SEARCH is based on a national model first piloted at Cincinnati Children's Hospital Medical Center in 1996 has developed into a comprehensive training and job development program that has been replicated with private and public employers at over 140 sites in 42 states, as well as the United Kingdom and Australia. It is based on a partnership between business, education and vocational rehabilitation and was created as a unique, business-led school-to-work program that takes place entirely at the workplace.

5B: Strengthen Employment Opportunities for Adults with Disabilities

Individuals who want to work must receive the opportunity and support to do so.

- DHHS should embark on a campaign to challenge the perceptions of families, service providers, employers, and individuals with disabilities themselves, about competitive employment.
- DHHS should ensure that it is modeling and implementing Employment First practices throughout the agency.
- DHHS should expand peer-operated services and supports.
- DHHS should continue to evaluate the newly applied business model for Individual Placement and Support/Supported Employment (IPS/SE) and provide technical assistance to providers that will support sustainability of their operations while improving service delivery under the Milestone reimbursement methodology.
- DHHS should apply the HCBS settings rule to all DHHS-funded vocational settings. The Adult Developmental Vocational Program (ADVP) is formalized in state statute which will need to be modified in order to eliminate the services. The Home and Community-Based Settings (HCBS) rule could be applied to reduce reliance on the settings, including state-funded programs.

5C: Strengthen Employment Opportunities for Older Adults with Disabilities

Nationally, older adults are increasingly viewed as a resource to expand the workforce. Some states, including Pennsylvania and New York, have Older Adult Peer Support initiatives, employing older adults with lived experience. Not only does this provide the benefits of employment for the peers, the service is also proven to benefit service recipients. Employment for older adults increases their social connectedness and improves health outcomes.¹³¹

- DHHS should promote employment for older adults with disabilities. The federally funded and operated Senior Community Service Employment Program is designed to provide job training and employment skill development to adults age 55+. Older adults not interested in competitive employment should be encouraged to participate in volunteer work or mentorships that allow them to contribute to their communities.
- DHHS should align the Medicaid 1915(b)(3) service definitions that cover employment and employment-related services with the Innovations Waiver and state-funded service definitions.

5D: Inform Individuals and Families about Available Resources and Services

TAC consistently hears the complaint in states across the country that individuals and families do not know about the services and supports that are available to individuals with disabilities, or how to access them. North Carolina is no exception. This may be a role assigned to “navigators,” but the individual in need still must find their way to the navigator. Too often, systems have more demand for their services than can be accommodated. Advertising is viewed as creating even more demand that can’t be filled; however, the lack of information prevents families and individuals from seeking services earlier in the

¹³¹ National Association of State Mental Health Program Directors (2017). *Older adults peer support: Finding a source for funding*. Alexandria, VA: National Association of State Mental Health Program Directors. Retrieved March 25, 2021 from https://www.nasmhpd.org/sites/default/files/TAC.Paper_.8.Older_Adults_Peer_Support-Finding_a_Funding_Source.pdf.

trajectory of their disability. Earlier identification of an emerging condition and early intervention can prevent further progression into the need for more intensive, costly services.

- DHHS should explore opportunities to educate individuals, families, and communities about the services and supports that are available for individuals with disabilities.
- DHHS should formalize the role of family navigators and peer support specialists in engaging and educating individuals and families.

Increase access to integrated housing and community-based services through new resources and repurposed funding from institutional and segregated settings

The strategy to rebalance a system that is structured to support community integration requires both new and repurposed resources. Stakeholders identified the need to approach the legislature for funding but expressed little confidence that the General Assembly would allocate the amount of additional funding needed to support community integration. This section identifies a multi-pronged funding strategy to make community-based services and supports readily available to support community inclusion. DHHS should also examine how new resources through the American Recovery Plan (e.g., through Medicaid expansion; enhanced Federal Medical Assistance Percentage (FMAP) for HCBS, mobile crisis and other services; and housing resources) could support the state's Olmstead Plan.

DHHS will need to take bold steps if it is to reduce reliance on institutional and segregated settings in favor of more integrated living options for individuals with disabilities. The most challenging of these involves shifting resources from institutional settings to integrated community-based housing and services.

Recommendation 6: Reduce Reliance on Institutional Settings

An increasing number of individuals with disabilities are being served in integrated settings in recent years, but the system is still structured in a way that serves too many people in institutional settings. North Carolina must establish a culture change that embraces community integration. The system must emphasize policy, financing, and programs designed to support individuals in integrated community-based settings, as opposed to pathways that lead toward institutional living.

6A: Define the Role of Institutional Settings in the Service Array

Historically, state-operated health care facilities have been viewed as the safety net in North Carolina, and a wide net at that. Through an *Olmstead* lens, if institutions continue to exist in some capacity, they must have a defined purpose within a service array. Institutions are not residences; their purpose, if deemed necessary, should be to provide specialized services that cannot be accessed in the community. Such services should be provided only as long as is necessary to stabilize individuals in order that they can return successfully to the community.

- DHHS should define and enforce the role for state-operated health care facilities (SOHFs) in each system of care.

6B: Reduce State-Operated Health Care Facility Capacity

DHHS cannot continue to devote more than 60% of its non-Medicaid resources to support institutional care that serves less than 10% of people with SMI, I/DD, and SUDs. As previously described in this report, there are new programs and funding mechanisms underway that are already reducing the need for some state-operated facility capacity, including state-operated ICFs and Alcohol and Drug Treatment Centers (ADATCs). Additional initiatives, such as Medicaid expansion, will further reduce the need for state-operated settings for the uninsured. If it is to build a viable system of community services and supports, North Carolina cannot sustain the level of state-operated capacity and infrastructure that is currently funded.

- DHHS should determine the most efficacious method(s) of addressing the changing need for SOHFs by considering options such as downsizing the capacity of existing facilities, consolidating facilities, or divesting of some services and facilities altogether.
 - **Downsizing the Capacity of Existing Facilities:** DHHS will achieve some cost savings using this approach as a result of reduced staffing costs and operational expenses. However, fixed costs that include physical plant maintenance and improvements, maintenance of the property, and administrative expenses will only increase with time. As the number of beds decreases and the costs for the facilities increases, the per-person cost will also increase, becoming even more cost-prohibitive. This option does not allow the state to achieve any revenues from sale of the property.
 - **Consolidating Facilities:** DHHS can explore consolidation in two ways, either by reconfiguring the areas served by regional facilities or by reducing in total the number of facilities within each region.
 - *Geographical Reconfiguration* — North Carolina is a large state, and its division into three regions has benefits. However, maintaining separate State Centers, psychiatric hospitals, Neuro-Medical units, and ADATCs in all three regions will become even more challenging to sustain. Reconfiguring the counties served by various facilities would allow for some facilities to be closed and their services moved to alternative locations. The operating locations could be staggered across the three regions to avoid any one region bearing the impact of all facilities closing. The plan to consolidate should be driven by multiple factors, including data on service utilization, alternative employment opportunities for staff, and options for disposition of the property. Given the size and geography of North Carolina, reducing from three regional facilities to one statewide facility for each state-operated service may generate too much opposition, though precedents are already set with the specialty programs operated.

- *Multiservice Campuses within Each Region* — DHHS could reduce the number of facilities operated by consolidating the services provided into fewer locations within each region. The state psychiatric hospitals could also provide alcohol and substance abuse treatment in discretely identifiable units or programs. Likewise, the ICFs and Neuro-Medical units could be operated as discrete units or programs sharing a campus. This would allow DHHS to benefit from the sale of properties and efficiencies in operations while maintaining some level of service capacity within each region.
- **Divestiture:** The Request for Applications recently released appears to promote the use of the ADATCs for the ongoing delivery of, though possibly alternative, state-operated substance use disorder treatment services. Divesting itself from operating the ADATCs is an opportunity for DHHS to consider. This option will be of even greater interest if Medicaid expansion is approved, providing more individuals with coverage for SUD treatment. While not all community-based providers currently accept individuals covered by Medicaid, reimbursement rates could be increased through contract negotiations and supported via a small amount of revenue the state will gain through divestiture. Many states meet the treatment needs of their SUD populations using private providers.

Some stakeholders may find divestiture of all state-operated health care facilities as the only acceptable strategy for *Olmstead*. This approach may not be practical for most services at this time and will not be until the community-based service system is adequately funded and able to support individuals in more independent living opportunities. Closing state-operated facilities without a plan and the funding needed to develop and sustain a strong system of community-based alternatives will only result in undesirable outcomes for individuals with disabilities including incarceration, homelessness, and further strain on local health care systems.

6C: Promote Diversion Strategies

Oftentimes, individuals are admitted to institutional settings without understanding the array of HCBS options available to them. Requiring a comprehensive assessment of an individual's needs and interests, and offering the individuals all available options prior to admission, promotes diversion and provides individuals the opportunity to make an informed decision about where their needs can best be addressed. This activity could be included in the functions of the "front door" to long-term services and supports and would be considered an administrative activity for federal financial participation (FFP).

As a result of TCLI, DHHS implemented RSVP for individuals being considered for admission to an ACH. RSVP replaces Pre-Admission Screening Resident Review (PASRR) for ACHs, providing a more streamlined and effective process to screen TCLI target populations.

- DHHS should expand RSVP or implement a similar process to ensure that all individuals with disabilities receive information about their service options and are able to exercise informed consent in choosing the best option for their needs.

The number of Incapacity to Proceed admissions is increasing, with some patients waiting for discharge well beyond their need for clinical stability. State psychiatric hospitals should not be the only or best option for individuals to receive capacity restoration unless they require inpatient hospitalization due to their clinical needs.

- North Carolina should establish community-based outpatient restoration capacity to divert individuals with low-level offenses from state psychiatric hospital admissions.
- DHHS should work with the Department of Public Safety, the Judiciary, and other leaders in the criminal justice system to develop policies and practices for such diversions.

6D: Repurpose Existing Funds

Historically, when DHHS has reduced the capacity of a state-operated facility, such as an ICF, or closed a facility such as the Dorothea Dix Hospital, DHHS used the resources to recreate an alternate state-operated facility. DHHS cannot continue this practice. North Carolina can correct its imbalanced expenditure of limited state resources by repurposing funding for state-operated health care facilities and increasing funding for individuals to be served in the community.

- DHHS should quantify the savings to North Carolina for those transitioned from institutional placement, in order to support the business case for community-based services.

Intermediate Care Facilities

Since State Center services provided to Medicaid recipients are eligible for FMAP, DHHS will realize modest savings in operational costs from facility downsizing or closures. Approximately 67% of funding for state-operated Developmental Disability Centers and community-based ICFs is federal, while about 33% of costs are funded by the state. The Innovations Waiver doesn't pay for room and board; if DHHS were to transfer all state matching funds to develop community-based services, there would still be a funding shortfall. However, repurposing funds that currently support institutional and congregate care to options that promote community integration will assist North Carolina in complying with *Olmstead* and reduce the likelihood of further *Olmstead* litigation.

- DHHS should continue to downsize ICF capacity and repurpose funds to enhance and support community-based services.

In addition, as with receipt of proceeds from the sale of the Dorothea Dix Hospital property, DHHS should realize financial benefit from the future sale of state property occupied by state facilities.

- DHHS should seek legislative support for receipt of at least a portion of revenues from the sale of any property that supported a state-operated facility.

Resources that Support Individuals in Adult Care Homes

An estimated 43,000 individuals reside in ACHs, many of which have the look and feel of a nursing home, resulting in a lack of opportunities to fully integrate into the community. North Carolina spends considerable resources to support individuals with disabilities in ACHs, including Special Assistance

Funding and the state share of Medicaid Personal Care Service. Since individuals can receive personal care services in their home, placement in an ACH is not necessary to meet these needs.

- DHHS should promote the use of Special Assistance funding and Special Assistance In-Home funding, which can be up to 100% of the amount an individual would receive if they resided in an adult care home, to be used for health, safety, and basic needs that will allow an individual to remain safely in their home as opposed to residing in a residential care facility.

Recommendation 7: Request Targeted Bridge Funding

In addition to repurposing existing funding, DHHS will likely need additional resources for start-up of new services and expansion of some existing service capacity. The request for additional funds should be based on the actual needs of individuals transitioning to the community. This not only provides a strong basis for the funding request but helps to ensure that the funding is used to support successful transitions. Initial success is important to build on.

- DHHS should identify the need for additional funding, based on an assessment of individuals' needs for services.
- DHHS should include a strategy for repurposed funding as part of the request for additional funding.
- DHHS should commit savings from reduced institutional or congregate care settings to continued expansion of community-based service capacity.

Recommendation 8: Reduce Reliance on Community-Based Congregate Care and Segregated Day Service Settings

8A: Reduce Reliance on Congregate Care Settings

- DHHS should allow the LME/MCOs to manage waitlists for all ICF beds, including community-based facilities. The state should reevaluate the use of a single portal as the entry point for services to allow for consistent application of admission criteria and use of beds. Absent a single portal, eligibility criteria should be further refined to confirm necessity for the service and ensure consistent application of eligibility criteria.
- LME/MCOs should provide care coordination for residents of community-based ICFs, to ensure that people do not move into ICFs and live there with no one advocating for their transition to a more independent setting.

8B: Phase Out Segregated Day Service Settings

Some stakeholders, most notably families of individuals with I/DD, oppose the reduction of ADVPs, stressing that their family members are “happy with the service” and that the program provides “socialization and the opportunity to earn a little money.” While these statements may be true, they are problematic.

- Individual preferences are being determined based on the experience that the individual *knows*, not what the individual *could experience*. An individual may find it even more enjoyable or rewarding to spend their day in an integrated setting or activity.
- Sheltered employment limits individuals with disabilities from exploring and realizing their full potential.
- In ADVPs, individuals with disabilities interact only with others who also have disabilities, contradictory to the *Olmstead* decision.

Eliminating ADVPs will require a change in statute and there will be opposition. Providing supported employment utilizes a person-centered approach that may be eligible for Medicaid reimbursement as an alternative to an entirely state-funded service.

- DHHS should use the Olmstead planning process to build stakeholder support for promoting supported employment and possibly eliminating ADVPs.
- DHHS should assess and apply the HCBS Settings rule to state-funded services, including ADVPs.
- DHHS should explore how to use ADVP staff expertise to provide TA to community-based employers and to provider organizations on training job coaches.

DHHS is to be commended for modifying the service definition for state-funded day programs to align with the Innovation Waiver service definition that complies with the HCBS settings rule.

Recommendation 9: Adopt Policy Strategies to Address Financing Challenges and Gaps

9A: Increase Access to Affordable Health Care

Implementation of the Affordable Care Act, including Medicaid expansion, would allow North Carolina to generate an estimated \$4 billion in federal dollars to increase access to health insurance for about 400,000 more people across the state, including an estimated 144,000 who have mental health and substance use disorders.¹³² Medicaid expansion will allow North Carolinians with behavioral health disorders to access needed services before their conditions evolve into crisis situations and require expensive emergency department and inpatient services.¹³³ Based on the national experience, TAC believes that Medicaid expansion in North Carolina will provide the opportunity to redefine a limited role for state-operated health care facilities, from providing indigent care to providing specialty services within the service system.

¹³² North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

¹³³ North Carolina Department of Health and Human Services (2018). [Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.\(a-d\); Session Law 2017-57, Section 11F.6.\(a-b\)](https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

9B: Examine Implications of Transitioning from LME/MCOs to Tailored Plans

TAC understands that DHHS is proceeding with conversion from LME/MCOs to Tailored Plans. Based on other states' experiences with integrated care, North Carolina should realize benefits for Medicaid recipients that include increased efficiencies, earlier identification of health and behavioral health conditions, increased use of preventive care, and reduced redundancies in care. However, it remains to be determined if implementing Tailored Plans will address many of the issues identified in this report and better support individuals in integrated community-based settings. DHHS should consider findings and recommendations in this report in the development of the procurement and implementation of the Tailored Plans and their responsibility to support individuals in integrated community-based settings.

9C: Enforce Contract Requirements

DHHS will be compromised in its ability to achieve its goals for Medicaid transformation if the Department "lacks staff capacity, expertise, or desire to enforce contract requirements." TAC consultants reviewed a DHHS LME/MCO contract in the past and observed that certain contractual requirements related to TCLI were not being enforced. These observations were reinforced in conversations with DHHS staff and the Independent Reviewer. Staff opined that DHHS was not always supported in previous efforts to correct deficiencies when the LME/MCOs elevated objections politically. Including stronger and more detailed expectations in the Tailored Plans is a good first step; however, these expectations must be clearly articulated in the contracts, closely monitored, and *enforced*.

9D: Introduce Alternative Payment Approaches

TAC fully supports DHHS in its efforts to expand pay for performance and value-based payment models to incentivize quality outcomes across both the plans and service providers.

- DHHS should include incentives or withholds for attainment of quality measures related to diversion, transition and the balance of services provided in institutional vs HCBS settings.¹³⁴

Address systemic challenges and eliminate barriers to accessing the services that can help individuals to live meaningful lives as integrated members of their communities.

TAC found additional systemic challenges and barriers that interfere with the ability of individuals to live in integrated settings. The following recommendations address several of these findings.

¹³⁴ North Carolina Department of Health and Human Services, Division of Medical Assistance (2018). [Money Follows the Person demonstration sustainability analysis: Transitioning beyond 2020](https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf) (p.6). Retrieved March 25, 2021 from <https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf>.

Recommendation 10: Include Input from Under-represented Stakeholders

Building on its rich history of seeking stakeholders' input in systems change, DHHS should provide and sustain opportunities for meaningful input from all stakeholders as the state moves forward with developing its Olmstead Plan.

- DHHS is already including stakeholders on the Olmstead Plan Stakeholder Advisory, including community co-chairs and committee members representing different disability populations and service systems. Stakeholders also chair and have been selected to serve on various subcommittees:
 - Children, Youth and Families
 - Community Capacity Building
 - Employment
 - Housing
 - Older Adults
 - Quality Assurance and Quality of Life
 - Transitions to Community
 - Workforce

Stakeholder participation varies, though, with little representation from past or present service recipients.

- DHHS should identify the reasons why some stakeholders are not fully participating in the planning process.
- DHHS should support efforts to enhance participation and strengthen the roles of stakeholder groups that are currently underrepresented to balance the perspectives and input provided for the Olmstead planning process.

Recommendation 11: Create a Culture that Supports the Voices of Individuals with Lived Experience

TAC commends DHHS for its recent efforts to promote supported decision-making, notably with Jonathan Martinis' presentation to OPSA and the North Carolina Council on Developmental Disabilities' (NCCDD) Rethinking Guardianship initiative.

- DHHS should incorporate supported decision-making and person-centered planning into all applicable service definitions.

DHHS staff involved with TCLI implementation collaborated with Medicaid's MFP program to develop an informed decision-making tool that supports the core principles of informed choice of setting in the *Olmstead* decision. The tool assists in identifying community living options, available resources, and services, and documents barriers to community living. LME/MCO In-reach staff began using the tool in September 2020. The TCLI report notes that this tool could become part of broader efforts in the state

to ensure that people have the information and experiences they need to make an informed decision regarding community living options.¹³⁵

- LME/MCOs, in collaboration with DHHS and the various TCLI Quality Assurance and Performance Improvement committees, should continue to review and evaluate the effectiveness of the informed decision-making tool, and consider adapting or revising the tool as needed to other disability populations.

Family members and providers are organized and resourced to advocate for their interests. Behavioral health consumers and individuals with I/DD are not. Providing leadership and funding to self-advocates will go a long way in garnering support for an Olmstead Plan, and can add meaningful input into DHHS programs and policies.

- DHHS should provide support to individuals and groups with lived experience across disabilities to promote self-advocacy and partnerships in policy making.

Recommendation 12: Address Workforce Capacity and Shortages

Addressing workforce capacity problems and shortages in direct services is a national problem that is particularly acute in rural areas. DHHS cannot resolve these issues alone, but there needs to be an intentional effort to increase the availability and capacity of the workforce to support integrated community programs.

12A: Utilize State Staff Expertise to Strengthen Community-Based Provider Competencies

This report identified the lack of expertise in supporting individuals with behavioral challenges and complex needs across community-based services as a factor contributing to reliance on state-operated services. Utilizing the nationally recognized Extension for Community Healthcare Outcomes (ECHO) model, state staff could provide case consultations and routine learning opportunities for community-based staff, thereby enhancing the community's capacity to serve individuals. The approach is especially effective in rural communities.¹³⁶

- DHHS should reduce reliance on state-operated health care facilities by utilizing the expertise of staff and deploying them to train and support community-based providers.

¹³⁵ North Carolina Department of Health and Human Services (2021). [2019 - 2020 Annual report of the North Carolina Transition to Community Living Initiative NC General Statute 122C-20.15, Report to the Joint Legislative Oversight Committee on Health and Human Services](https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf). Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf>.

¹³⁶ [Project Echo](https://www.rwjf.org/en/how-we-work/grants-explorer/featured-programs/project-echo.html). <https://www.rwjf.org/en/how-we-work/grants-explorer/featured-programs/project-echo.html>

12B: Promote the Employment of Individuals with Lived Experience

Certified Peer Specialists offer one example of expanding the workforce by employing individuals with mental health disorders, but additional opportunities exist. Individuals who have experienced homelessness or involvement with the criminal justice system, are in recovery from substance abuse, or have a physical, intellectual, or developmental disability are potential candidates to employ in direct service roles that serve and support people with disabilities.

- DHHS should develop additional training and employment opportunities for individuals with lived experience across the spectrum of community-based services.
- DHHS should increase its own hiring of people with disabilities.
- DHHS should continue to promote and support self-direction.
- DHHS can promote and encourage individuals age 55+ to enroll in the Senior Community Service Employment Program which serves older adults who experience barriers to employment due to having a disability or criminal justice involvement.

12C: Incentivize Employment

Increasing the hourly wage will go a long way to recruiting and maintaining direct service workers and direct support professionals (DSPs). However, increasing wages is not the only solution to addressing staffing shortages.

- DHHS should require that all direct service workers and DSPs receive initial training prior to employment and receive recognized, competency-based training throughout their employment. Staff with little experience are often put into situations they are not prepared to handle and terminate their employment out of fear and discomfort.
- Mastery of staff competencies should be rewarded with increased pay.
- DHHS should encourage providers to “professionalize” direct support roles. Direct support is often described as “entry level work” that is considered of little importance when, in reality, staff spend hours with individuals with disabilities and should be acknowledged, afforded a living wage, and shown respect for their work.
- DHHS should pursue enhanced FMAP for HCBS services that can be used to enhance pay for DSPs.

Recommendation 13: Use Data for Evaluation and Quality Improvement

Collecting, reporting, and using data for systems evaluation is an area for improvement in North Carolina. Matching recipient data across funding streams and services is a challenge. Certain state-operated facilities’ data requests for this report were not filled; data that could be provided required that each facility compile information to generate its own report. The centralized billing system used by the state-operated health care facilities to generate data is not adequate to assess service delivery across facilities.

- The *Olmstead* Plan must include a strategy to improve data collection and embrace a quality assurance and performance improvement system to inform progress toward a system that is integrated.
- DHHS should address the lack of standard reporting requirements and capabilities in state-operated health care facilities.

13A: Take Measures to Expand Quality Improvement Efforts

The TCLI Quality Assurance and Performance Improvement plan includes compliance and quality assurance data and processes associated with all aspects of TCLI and all substantive provisions of the state's settlement agreement with the U.S. Department of Justice. The plan outlines measures taken to implement the processes and meet the requirements associated with each provision; identifies relevant data systems and activities for compliance and quality monitoring of all TCLI processes; indicates the frequency of data collection and review and the parties responsible; specifies the formal reports used for tracking and communicating program progress; documents which program data and reports are compiled for TCLI Oversight Committee review; and incorporates the policies, guidelines, manuals, requirements, standards, plans, and other documents and communications that govern the implementation and execution of major TCLI functions and processes.¹³⁷

- DHHS should explore whether the Quality Assurance and Performance Improvement (QAPI) System designed to support TCLI can serve as a model for a statewide, cross-disability approach.

DHHS staff are working with Manatt to develop a set of Patient-Reported Outcomes Measures (PROMs) for both Standard and Tailored Plans. PROMS reportedly are intended to cover categories of health-related quality of life, symptoms, patient experiences, and health behaviors.

- DHHS should ensure that the *Olmstead* Plan's outcome, performance, and quality measures align with PROMS and other relevant program measures.

Recommendation 14: Eliminate Barriers to Care

Despite the array of services that exist for North Carolinians with disabilities, DHHS must address the sizeable barriers, described earlier in this report, for individuals to access these services.

14A: Reduce the Registry of Unmet Needs

DHHS can continue to request additional funding for Innovation Waiver slots; however, additional funding alone will not likely be enough to fully address the needs of individuals on the list.

¹³⁷ North Carolina Department of Health and Human Services (2021). [2019 - 2020 Annual report of the North Carolina Transition to Community Living Initiative NC General Statute 122C-20.15, Report to the Joint Legislative Oversight Committee on Health and Human Services](https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf). Retrieved March 25, 2021 from <https://files.nc.gov/ncdhhs/documents/files/GS-122C-20.15-Annual-NC-Supportive-Housing-Program-Report-2020--Final-1.21.21-final-report.pdf>.

- North Carolina should ensure that savings realized through any downsizing or consolidation of State Centers be allocated to fund additional waiver services.
- DHHS should explore pursuing a Medicaid state plan amendment as an option for addressing the Innovations Waiver waitlist.

14B: Right-Size the Waitlist

- DHHS should increase oversight of the Registry of Unmet Needs (RUN) and implement standards for a consistent waitlist management approach rather than allowing each LME/MCO to establish its criteria and process.
- DHHS should explore LME/MCO requirements for individuals to register for the waiver and its services. Such requirements may be inflating the waitlist.
- DHHS should ensure that individuals under the age of 21 who are on the RUN have access to services under Early Periodic Screening, Diagnosis and Treatment (EPSDT) that may improve the child's condition and prevent or defray the need for waiver services.

14C: Extend the TBI Waiver Statewide while Funding Additional TBI Waiver Slots

DHHS should identify individuals currently served in institutional settings who want community-based services; quantify the cost of services in these settings; and repurpose funding to support statewide expansion of the waiver and additional TBI Waiver slots to support integration into the community.

14D: Expand Eligibility for the CAP/DA Waiver

TAC concurs with a previous recommendation Mercer to DHHS: to add the Medicaid eligibility group available under 42 Code of Federal Regulations §435.217, along with special income level methodology to the CAP/DA waiver. This will allow individuals in institutional settings who have up to 300% of the federal benefit rate, and who would otherwise be Medicaid-eligible, to receive CAP/DA services.¹³⁸

14E: Continue to Assess All Medicaid Authority Options

The Centers for Medicare and Medicaid Services (CMS) continues to provide states with opportunities to refine and enhance their services that support Medicaid recipients. For example, states now can claim FFP for certain services within an Institution for Mental Disease. Services available under a 1915(i) State Plan Amendment would generate FFP for services that could reduce the need for 100% state-funded state psychiatric hospital and ADATC beds. Likewise, President Biden recently signed the American Rescue Plan Act of 2021 into law. This legislation includes a 10% FMAP increase for Medicaid Home- and Community-Based and other services effective April 1, 2021 through May 31, 2022. This increased FMAP provides DHHS the opportunity to enhance, expand, or strengthen HCBS and other programs in North Carolina.

¹³⁸ North Carolina Department of Health and Human Services, Division of Medical Assistance (2018). [Money Follows the Person demonstration sustainability analysis: Transitioning beyond 2020](https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf) (p.6). Retrieved March 25, 2021 from <https://files.nc.gov/ncdma/NC-Sustainability-Analysis-Report-2018.pdf>.

- DHHS should continue to explore all available Medicaid authorities and incentives to support North Carolina’s system transformation.

14F: Rethink Guardianship

- To provide individuals with disabilities the opportunity to explore community integration, DHHS should continue its support for Rethinking Guardianship, shifting emphasis from guardianship to assisted or supported decision-making.

Supported decision-making is a recognized alternative to guardianship that allows people with disabilities to use friends, family members, and professionals to help them understand the situations and choices they face, to make their own decisions without the “need” for a guardian.¹³⁹ While guardianship will continue to exist for some people, it should be sought and awarded only where documentation supports that an individual does not have any capacity to participate in decisions regarding their care and safety.

- TAC concurs with the long-term objectives of the Rethinking Guardianship initiative:
 - Continue to build a sustainable infrastructure to effect long-term changes in North Carolina’s guardianship system that respect the rights of individuals in a guardianship arrangement and those facing guardianship.
 - Secure North Carolina General Assembly amendments (NCGS 35A) that promote alternatives to guardianship, as appropriate. According to the National Guardianship Association: “Alternatives to guardianship, including supported decision-making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings.”¹⁴⁰
 - Provide educational resources to make individuals and families aware of the guardianship process and alternatives to guardianship.
 - Provide more individuals with I/DD, mental illness, and other disabilities greater capacity for supported decision-making and more control over their individual lives.

¹³⁹ Blanck, P. & Martinis, J. (2015). “The right to make choices”: The National Resource Center for Supported Decision-Making. *Inclusion*, 3(1), pp. 24-33.

¹⁴⁰ National Guardianship Association (2017). *Position statement on guardianship, surrogate decision making and supported decision making*. Retrieved March 25, 2021 from https://www.guardianship.org/wp-content/uploads/2018/09/SupportedDecision_Making_PositionStatement.pdf.

Chapter 5: Conclusion and Next Steps

North Carolina is at a critical point in determining how best to meet the needs of its residents with disabilities. The state has made progress over the years in creating an array of services designed to support people in integrated settings. However, the state's history of providing institutional and custodial care is slow to change. North Carolina still invests a large amount of its limited state resources in sustaining institutional and congregate care settings that segregate individuals from their communities and keep them from interacting with others who do not have disabilities. The development of an *Olmstead* plan can provide the framework, strategies, and actions to shift the system to one that supports community integration.

The Department of Health and Human Services needs support from the Governor's administration, and from the General Assembly, to address this imbalance. The state has faced litigation as a result of disability rights complaints, forcing the General Assembly to identify state resources needed to make the changes outlined in each settlement. Other resource allocations have been somewhat reactionary and were not based on research and best practices. Absent an *Olmstead* Plan and the resources that will allow the state to implement the plan incrementally, North Carolina will continue to face litigation and be left to the will of the courts to modify its systems that support individuals with disabilities.

Plan Development and Evaluation

After thoroughly reviewing and digesting this report, the Technical Assistance Collaborative (TAC) and the North Carolina Department of Health and Human Services (DHHS) will move on to the next phase of our engagement. TAC will pivot from assessing system capacity and performance to working with the Department to develop the *Olmstead* Plan. Together with the *Olmstead* Plan Stakeholder Advisory (OPSA) workgroups, we will review their work to date and crosswalk their observations and recommendations with this report. We will seek DHHS' support in our continued engagement with OPSA and other stakeholders. Based on the goals and objectives that DHHS selects for incorporation into the plan, TAC will work with the Department to identify implementation strategies and provide technical assistance, as deemed necessary, to move the plan forward. We'll also work with DHHS to align plan activities with Medicaid Transformation and other key initiatives.

As we have outlined earlier in the report, TAC recommends that North Carolina's *Olmstead* plan include a framework for quality improvement and evaluation. TAC will work with DHHS on the development and implementation of a system for performance evaluation and outcome measurement, with a focus on aligning the framework under design in the U.S. Department of Justice (DOJ) settlement with a broader, cross-disability Quality Assurance and Performance Improvement plan that can be modified as needed and incorporated into the *Olmstead* Plan for further implementation.

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Appendix A: Data Gaps and Limitations

There are numerous data gaps and limitations to the data available for this report. First, a notable gap in data is a complete number of individuals with disabilities residing in adult care homes (ACHs) or nursing facilities. We were able to glean some information from Medicaid claims for people with a mental health diagnosis served in assisted living facilities and nursing facilities, but these data were based only on the primary diagnosis on the claim, and likely underestimate the full number of beneficiaries with behavioral health conditions residing in such facilities. Furthermore, we could not capture from claims data the number of individuals with intellectual/developmental disabilities (I/DD) or physical health disabilities residing in ACHs or nursing facilities.

In addition, we did not obtain complete data for numbers served in North Carolina's state-operated facilities. The Division of State-Operated Healthcare Facilities (DSOHF) does not have a common data system or reporting mechanism for reporting numbers served across its facilities. We obtained numbers served for all facility types except Whitaker Psychiatric Residential Treatment Facility, which we derived from Medicaid claims data and may be an underestimate. There was some variation in how the data was reported; for example, one of the three neuro-medical facilities reported numbers served by calendar year rather than state fiscal year. Data on the race/ethnicity of individuals served in state-operated facilities was provided only for state psychiatric hospitals; this data was not provided for other facility types. Gender and age information was available for state psychiatric hospitals and provided by DSOHF for Alcohol and Drug Abuse Treatment Centers (ADATCs) and the Wright School, but not for the Developmental Centers.

There are also limitations with the claims data analyzed for this report. Due to privacy restrictions for substance use disorder (SUD) data from Title 42 of the Code of Federal Regulations (CFR) Part 2, claims related to SUD could not be linked to mental health claims for this analysis; therefore, we could not produce unduplicated counts or examine service penetration across mental health and SUD diagnosis types. In addition, the claims data we obtained could not be linked across funding streams (Medicaid and the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services) so we could not produce unduplicated numbers served. We cited data from the Local Managed Entity/Managed Care Organization (LME/MCO) annual reports which present unduplicated numbers across funding streams and disability types, but this data still underestimates the full population who receive mental health, SUD, or I/DD services; for example, the LME/MCOs are required to report unduplicated numbers served for all individuals receiving state- or Block-Grant-funded services, but only for Medicaid members receiving enhanced behavioral health or "managed" services. The 2018 Strategic

Plan cites a figure of 450,000+ individuals receiving behavioral health services, but the methods for arriving at this figure are not clear.¹⁴¹

For Innovations and (b)(3) waiver services received by individuals with I/DD, we were limited in our ability to tease apart Innovations Waiver and (b)(3) services that have the same procedure (CPT) code, due to having requested only a subset of claim modifier fields. For Community Alternatives Program (CAP) waiver services, we could not differentiate between individuals on the Community Alternatives Program for Disabled Adults (CAP/DA) waiver and those on the waitlist.

Finally, there may be differences between LME/MCOs in the use of billing codes that we did not account for in our analysis. Claims data are for administrative purposes, and have limitations with respect to measuring service use and access.

¹⁴¹ North Carolina Department of Health and Human Services (2018). Strategic plan for improvement of behavioral health services: Session Law 2016-94, Section 12F.10.(a-d); Session Law 2017-57, Section 11F.6.(a-b). Retrieved March 25, 2021 from <https://digital.ncdcr.gov/digital/collection/p16062coll9/id/338055>.

Appendix B: State Agencies and Organizations Interviewed

State Agencies/Representatives

DHHS

Office of the Secretary

- NC Council on Developmental Disabilities
- Office of the Senior Advisor on ADA – Olmstead and Transitions to Community Living Initiatives

Division of Aging and Adult Services

Division of Health Benefits (NC Medicaid)

- Medicaid Benefits and Services
- Money Follows the Person

Division of Mental Health, Developmental Disabilities and Substance Abuse Services

- Adult and Children’s Mental Health Services
- Developmental Disabilities Services
- Substance Abuse Services
- Traumatic Brain Injury Services

Division of Social Services

Division of State Operated Healthcare Facilities

Division of Vocational Rehabilitation

Stakeholder Organizations/Representatives

Patricia Porter, Ph.D., Past Director of State Administered I/DD Services

Employment Providers, Michael Maybee

LME/MCOs, Jesse Smathers

North Carolina Council on Developmental Disabilities, Youth Listening Session

North Carolina Families United

PACE Program

Promise Resource Network

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Appendix C: Sample Interview Questions

The following questions served as a guide for conducting interviews with state agency staff and organizational representatives. Questions were modified at times to align with the agency or organization being interviewed.

1. What is the role of the Division/your organization in meeting the needs of individuals with disabilities, including children, youth, adults and older adults?
 - Children and adolescents with a serious emotional disorder
 - Adults with a serious/persistent mental illness
 - Individuals with intellectual/developmental disabilities
 - Individuals with substance use disorders
 - Others?
2. What are the strengths of the community-based system in supporting individuals with disabilities, including children, youth, adults and older adults to live, work and enjoy activities in the community?
 - Children and adolescents with a serious emotional disorder
 - Adults with a serious mental illness
 - Individuals with intellectual/developmental disabilities
 - Individuals with substance use disorders
 - Others?
3. What are the greatest challenges for the community-based system in supporting individuals with disabilities, including children, youth, adults and older adults to live, work and enjoy activities in the community?
 - Children and adolescents with a serious emotional disorder
 - Adults with a serious mental illness
 - Individuals with intellectual/developmental disabilities
 - Individuals with substance use disorders
 - Others?
4. Are there additional services or supports that if available within the community-based system would reduce the need for admissions to state operated healthcare facilities or other segregated settings?
For-
 - Children and adolescents with a serious emotional disorder
 - Adults with a serious/persistent mental illness
 - Individuals with intellectual/developmental disabilities

- Individuals with substance use disorders
 - Others?
5. Are there certain populations or characteristics of individuals with disabilities who are not utilizing available community-based services and supports but are instead utilizing crisis-oriented services (e.g., inpatient and emergency departments) and/or encountering the criminal justice system or experiencing homelessness? What is the role of the LMEs/MCOs in addressing the needs of these individuals?
 6. Are there geographical differences in access to community-based services?
 7. Are there system coordination issues that may impact the ability for individuals with disabilities to live, work or enjoy activities in integrated, community-based settings? That create challenges for individuals to be transitioned from segregated settings to integrated, community-based settings?
 8. Are there key policies, regulations, contract provisions, and/or current and historic funding patterns that perpetuate facilities and programs that segregate people with disabilities or that inhibit the ability to serve individuals with disabilities in integrated settings? Do you have recommendations for how to address these concerns?
 9. From your perspective, how much does the lack of safe, decent and affordable housing impact the ability of Medicaid covered services to support individuals with disabilities to live successfully in the community?
 10. Are there any other issues you think would be important for TAC to consider or be aware of in conducting this assessment?

Appendix D: Olmstead Planning Listening Session Dates by Stakeholder Group

Table D-1. Listening Session Dates by Stakeholder Group

Zoom Listening Session Date and Time	Stakeholder Group	TAC Facilitator	OPSA Co-Conveners(s)
August 10, 6–8 pm	Family Members of persons with MH/SUD	Jennifer Ingle	David A. Smith and Benita Purcell
August 11, 10am–12pm	Children’s System providers and advocates	Sherry Lerch	Chandrika Brown and Michelle Hughes
August 11, 1–3 pm	Providers for those with MH/IDD/SAS	Sherry Lerch	Sara Potter, Karen McLeod and Wilson Raynor
August 12, 10am–12pm	Traumatic Brain Injury stakeholders	Jennifer Ingle	David Forsythe
August 12, 3–5 pm	Housing agencies and providers	Sherry Lerch and Jim Yates	Paul Kimball, Matty Lazo Chadderton and Janet Breeding
August 12, 1–3 pm	Statewide Independent Living Council	Jennifer Ingle	Melea Williams
August 12, 6–8 pm	Family Members of Persons with I/DD	Sherry Lerch	Kerri Eaker
August 13, 10am–12pm	LME/MCOs	Sherry Lerch	Leza Wainwright and Mike Bridges
August 14, 10am–12pm	Persons with Lived Experience with MH/SUD	Jennifer Ingle	Jeff McCloud, Kurtis Taylor and Cherene Caraco
August 14, 1–3 pm	Persons with Lived Experience with I/DD	Jennifer Ingle	Bryan Dooley, Matt Potter and Jeff Smith
August 18, 10am–12pm	Employment providers	Sherry Lerch	Bridget Hassan and Michael Maybee
August 20, 10:30am–12:30pm	The Coalition	Sherry Lerch and Jennifer Ingle	Betsy McMichael

Zoom Listening Session Date and Time	Stakeholder Group	TAC Facilitator	OPSA Co-Conveners(s)
August 21, 10am-12pm	Aging Services Providers	Jennifer Ingle	Jeff Horton, Lanier Cansler, Tim Rogers and Adam Sholar
October 1, 3pm-5pm	Guardians (public and family)	Sherry Lerch and Jennifer Ingle	None
October 23, 11:30am-12pm	Coalition on Aging	Sherry Lerch and Jennifer Ingle	Charmaine Fuller Cooper

Appendix E: North Carolina Olmstead Planning Listening Session Poll Questions

Demographics

Which best describes the area(s) you live in or serve (if a provider) in North Carolina? (Choose multiple if a provider or LME/MCO).

- Urban
- Rural
- Suburban

Which region(s) of North Carolina do you live or serve (if a provider)? (Choose multiple if a provider or LME/MCO).

- Eastern NC
- Central NC
- Western NC

Strengths

What are the strengths of the community-based systems that supports individuals with disabilities, including children, youth, adults and older adults, to live, work and enjoy activities in the community? (Choose multiple strengths).

- A comprehensive array of treatment, therapeutic services and supportive services
- A comprehensive array of residential/living opportunities
- Access to supported education/employment opportunities
- Access to community-integrated activities/social supports
- Individuals'/families preferences and choices in services are honored
- Services are readily available during days of the week and times that are convenient for individuals/families
- Services are accessible (interpreters, communication devices, physical plant accommodations)
- Stakeholders have opportunities to participate in/contribute to systems change

- Information about existing services and supports is readily available and easily accessible for individuals and families
- Other? Please type in the Chat Box.

What is the greatest strength of the community-based systems that supports individuals with disabilities, including children, youth, adults and older adults, to live, work and enjoy activities in the community? (Choose one strength).

- A comprehensive array of treatment, therapeutic services and supportive services
- A comprehensive array of residential/living opportunities
- Access to supported education/employment opportunities
- Access to community-integrated activities/social supports
- Individuals'/families preferences and choices in services are honored
- Services are readily available during days of the week and times that are convenient for individuals/families
- Services are accessible (interpreters, communication devices, physical plant accommodations)
- Stakeholders have opportunities to participate in/contribute to systems change
- Information about existing services and supports is readily available and easily accessible for individuals and families
- Other? Please type in the Chat Box.

Gaps

What are the gaps in services/supports that may result in individuals with disabilities/older adults being at greater risk of placement, employment, or spending time in a segregated setting? (Choose multiple gaps).

- Lack of adequate treatment options
- Lack of adequate support services
- Lack of adequate independent living options
- Lack of adequate options for crisis response
- Lack of supported education/supported employment opportunities
- Lack of community integrated activities/social supports
- Lack of services/supports in Rural communities
- Lack of adequate, well-trained staff
- Lack of culturally competent services
- Other? Please type in the Chat Box.

What gap in services/supports most likely contributes to individuals with disabilities/older adults being at greater risk of placement, employment, or spending time in a segregated setting? (Choose one gap).

- Lack of adequate treatment options
- Lack of adequate support services
- Lack of adequate independent living options
- Lack of adequate options for crisis response
- Lack of supported education/supported employment opportunities
- Lack of community integrated activities/social supports
- Lack of services/supports in Rural communities
- Lack of adequate, well-trained staff
- Lack of culturally competent services
- Other? Please type in the Chat Box.

Challenges for Families and Individuals with Disabilities

What are the greatest challenges for families and individuals with disabilities, including children, youth, adults and older adults to access services and supports that allow them to live, work and enjoy activities in the community? (Choose multiple challenges).

- Lack of coverage for needed services/supports (Medicaid, Medicare, private insurance, state funds)
- Waiting lists for services/funding
- Lack of transportation
- Lack of information about what services/supports are available and/or how to access them
- Services are not accessible (lack of interpreters, lack of technological devices, physical plant barriers)
- Services do not reflect individuals'/families' choices and preferences
- Services are not available during times that are convenient for individuals/families
- Lack of Care Coordination across services/systems
- Other? Please type in the Chat Box.

What is the greatest challenge for families and individuals with disabilities, including children, youth, adults and older adults to access services and supports that allow them to live, work and enjoy activities in the community? (Choose one challenge).

- Lack of coverage for needed services/supports (Medicaid, Medicare, private insurance, state funds)
- Waiting lists for services/funding
- Lack of transportation
- Lack of information about what services/supports are available and/or how to access them

- Services are not accessible (lack of interpreters, lack of technological devices, physical plant barriers)
- Services do not reflect individuals'/families' choices and preferences
- Services are not available during times that are convenient for individuals/families
- Lack of Care Coordination across services/systems
- Other? Please type in the Chat Box.

Challenges for Providers

What are the greatest challenges for providers in supporting individuals with disabilities, including children, youth, adults and older adults to live, work and enjoy activities in the community? (Choose multiple challenges).

- Policies that create barriers to serving individuals with disabilities in community-integrated services
- Regulations that create barriers for serving individuals with disabilities in community integrated services
- Staff turnover
- Increasing complexity of individuals' needs
- Lack of access to training/technical assistance
- Rates/reimbursement methodology
- Stigma (NIMBY, employers, landlords)
- Lack of coordination across state agencies/systems
- Other? Please type in the Chat Box.

What is the greatest challenge for providers in supporting individuals with disabilities, including children, youth, adults and older adults to live, work and enjoy activities in the community? (Choose one challenge).

- Policies that create barriers to serving individuals with disabilities in community-integrated services
- Regulations that create barriers for serving individuals with disabilities in community integrated services
- Staff turnover
- Increasing complexity of individuals' needs
- Lack of access to training/technical assistance
- Rates/reimbursement methodology
- Stigma (NIMBY, employers, landlords)
- Lack of coordination across state agencies/systems
- Other? Please type in the Chat Box.

Challenges for Employment Providers

Note: These questions were asked during the employment provider listening session only, in place of the provider challenge questions above.

What are the greatest challenges for Employment/Vocational Rehabilitation providers in supporting individuals with disabilities to work in community integrated/competitive employment settings? (Choose multiple challenges).

- Policies/regulations that create barriers to serving individuals with disabilities in community-integrated services
- Families/Guardians do not support employment outside of a sheltered setting
- Lack of timely referrals for available job training/employment opportunities
- Lack of adequate staff to support individuals with disabilities
- Increasing complexity of individuals' needs
- Stigma (Employers)
- Rates do not support high quality services
- Lack of coordination across state agencies/systems
- Other? Please type in the Chat Box.

What is the greatest challenge for Employment/Vocational Rehabilitation providers in supporting individuals with disabilities to work in the community? (Choose one challenge).

- Policies/regulations that create barriers to serving individuals with disabilities in community-integrated services
- Families/Guardians do not support employment outside of a sheltered setting
- Lack of timely referrals for available job training/employment opportunities
- Lack of adequate staff to support individuals with disabilities
- Increasing complexity of individuals' needs
- Stigma (Employers)
- Rates do not support high quality services
- Lack of coordination across state agencies/systems
- Other? Please type in the Chat Box.

Challenges for Housing Agencies/Providers

Note: These questions were asked during the housing provider listening session only, in place of the general provider challenge questions above.

What are the greatest challenges for Housing providers in supporting individuals with disabilities to live in the community? (Choose multiple challenges).

- Policies/regulations that create barriers to serving individuals with disabilities in community-integrated services
- Lack of timely referrals for available units
- Lack of provider response if there is a problem with a tenant
- Increasing complexity of individuals' needs
- Stigma (NIMBY)
- Lack of coordination across state agencies/systems
- Other? Please type in the Chat Box.

What is the greatest challenge for Housing providers in supporting individuals with disabilities to live in the community? (Choose one challenge.)

- Policies/regulations that create barriers to serving individuals with disabilities in community-integrated services
- Lack of timely referrals for available units
- Lack of provider response if there is a problem with a tenant
- Increasing complexity of individuals' needs
- Stigma (NIMBY)
- Lack of coordination across state agencies/systems
- Other? Please type in the Chat Box.

Results from Lack of Home and Community-Based Services

The lack of adequate community-integrated services and supports results in individuals with disabilities, including children, youth, adults, and older adults ... (Choose multiple results).

- Being admitted to state-operated healthcare settings
- Staying in state-operated healthcare settings for extended periods of time
- Utilizing intrusive, intermittent, high-cost services such as Emergency Departments, Crisis Response, Law Enforcement, etc. as opposed to Preventive care/primary care/routine care/wellness programs
- Living in congregate settings in the community, such as Adult Care Homes, ICF/IDD, Group Homes, Psychiatric Residential Treatment Facilities, living with elderly parents, living with people that jeopardize their recovery, couch-surfing, living in un-safe neighborhoods

- Spending time in segregated settings such as schools or classrooms for students with disabilities, sheltered workshops, day programs
- Interfacing with the Juvenile/Criminal Justice systems
- Experiencing Homelessness
- Other? Please type in the Chat Box.

The lack of adequate community-integrated services and supports most often results in individuals with disabilities, including children, youth, adults and older adults... (Choose one result).

- Being admitted to state-operated healthcare settings
- Staying in state-operated healthcare settings for extended periods of time
- Utilizing intrusive, intermittent, high-cost services such as Emergency Departments, Crisis Response, Law Enforcement, etc. as opposed to Preventive care/primary care/routine care/wellness programs
- Living in congregate settings in the community, such as Adult Care Homes, ICF/IDD, Group Homes, Psychiatric Residential Treatment Facilities, living with elderly parents, living with people that jeopardize their recovery, couch-surfing, living in un-safe neighborhoods
- Spending time in segregated settings such as schools or classrooms for students with disabilities, sheltered workshops, day programs
- Interfacing with the Juvenile/Criminal Justice systems
- Experiencing Homelessness
- Other? Please type in the Chat Box

Actions/Strategies to Improve Community Integration

What actions would provide North Carolinians with disabilities greater opportunity to live, work and enjoy activities as integrated members of the community? (Choose multiple actions/strategies).

- Provide a more comprehensive array of community-based treatment, therapeutic services and supportive services
- Increase access to safe, decent, affordable independent living opportunities
- Increase access to supported education/employment opportunities
- Increase access to community-integrated activities/social supports
- Ensure that services are accessible (interpreters, communication devices, physical plant accommodations)
- Provide opportunities for stakeholders to participate in/contribute to systems change
- Repurpose some existing resources from state-operated healthcare facilities
- Repurpose some existing resources from community-based settings that segregate individuals with disabilities

- Appeal to the Legislature for more funding
- Other? Please type in the Chat Box.

What strategy would you prioritize to provide North Carolinians with disabilities greater opportunity to live, work and enjoy activities as integrated members of the community? (Choose one action/strategy).

- Provide a more comprehensive array of community-based treatment, therapeutic services, and supportive services
- Increase access to safe, decent, affordable independent living opportunities
- Increase access to supported education/employment opportunities
- Increase access to community-integrated activities/social supports
- Ensure that services are accessible (interpreters, communication devices, physical plant accommodations)
- Provide opportunities for stakeholders to participate in/contribute to systems change
- Repurpose some existing resources from state-operated healthcare facilities
- Repurpose some existing resources from community-based settings that segregate individuals with disabilities
- Appeal to the Legislature for more funding
- Other? Please type in the Chat Box.

Strategies — Employment Providers

Note: These questions were asked during the employment provider listening session only, in place of the general strategy questions, above.

What are some strategies that you feel would increase access to community integrated/competitive employment for individuals with disabilities? (Choose multiple strategies).

- Educate individuals/families about the benefits of competitive employment
- Provide opportunities for stakeholders to participate in/contribute to systems change
- Increase resources for pre-employment activities/job training
- Increase resources for Supported Employment
- Repurpose some existing resources from community-based settings that segregate individuals with disabilities
- Appeal to the Legislature for more funding
- Increase support service/vocational staff training
- Increase employer engagement activities/incentives to hire individuals with disabilities
- Streamline the process to identify eligible referrals for job vacancies
- Other? Please type in the Chat Box.

What strategy would you prioritize to increase access to community integrated/competitive employment for individuals with disabilities? (Choose one strategy).

- Educate individuals/families about the benefits of competitive employment
- Provide opportunities for stakeholders to participate in/contribute to systems change
- Increase resources for pre-employment activities/job training
- Increase resources for Supported Employment
- Repurpose some existing resources from community-based settings that segregate individuals with disabilities
- Appeal to the Legislature for more funding
- Increase support service/vocational staff training
- Increase employer engagement activities/incentives to hire individuals with disabilities
- Streamline the process to identify eligible referrals for job vacancies
- Other? Please type in the Chat Box.

Strategies — Housing Providers

Note: These questions were asked during the housing provider listening session only, in place of the general strategy questions above.

What are some strategies that you feel would support access to community-based housing for individuals with disabilities? (Choose multiple strategies)

- More affordable units that are in safe neighborhoods
- More Rental Assistance
- More Accessible units
- More support services available
- More support service staff training
- More Landlord engagement
- Streamlined process to identify eligible referrals for units
- Other? Please type in the Chat Box.

What strategy would you prioritize to support access to community-based housing for individuals with disabilities? (Choose one strategy).

- Create more affordable units that are in safe neighborhoods
- Provide more Rental Assistance
- Create more Accessible units
- Increase support services
- Increase support service staff training
- Conduct more Landlord engagement
- Streamline the process to identify eligible referrals for units
- Other? Please type in the Chat Box.

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Appendix F: Olmstead Planning Listening Session Themes by Stakeholder Group

Family Members of Persons with Severe Mental Illness/Substance Use Disorders — August 10, 2020

Systems' Strengths/Best and Promising Practices

- There is an array of mental health services in urban communities including Raleigh, Charlotte and Asheville.
- The state is working hard to get information out to parents.
- There are peer specialists supports.

Gaps in Services

- Mental health services, such as therapy and community mental health services, are extremely limited, fragmented, and difficult to find, particularly in rural communities.
- There are shortages for specialists and well-trained provider staff for children with co-occurring mental health and intellectual and developmental disability (IDD) diagnoses (i.e. autism and developmental delays).
- There are also Direct Service Workers (DSW) shortages across the age span (children and adults) in the mental health and substance use disorder services system.
- There is a lack of group homes for adults with SMI/SUD due to funding cuts. The remaining group homes cherry pick easier clients instead of accepting clients coming from institutions who they perceive are more difficult to serve.
- Providers lack training on family centered approaches for children with co-occurring mental illness and developmental disabilities.
- The state lacks support services once someone moves to independent living/housing. Often people are isolated in their apartments with few supports, which does not support success in the community.
- Coverage for weekend hours for substance use disorder services are limited.
- Affordable housing options are lacking for persons with SMI/SUD.
- Transportation across the state is inadequate.
- There is a lack of providers that serve individuals with Autism Spectrum Disorder (ASD).

Systems Challenges

- Families lack information on local services and providers for MH/SUD. Providers do not always share the most up to date information with family members or parents.
- Eligibility requirements are often not clear.
- There is poor communication and coordination between providers across levels of service/levels of care.
- Coordination of services and housing are difficult with LME/MCOs from one catchment area to another. If a client wants to receive services outside of their Local Management Entity/ Managed Care Organization's (LME/MCO's) designated area, the authorizations for services do not automatically follow.
- Hospital beds are at a premium. There are often difficulties getting authorization for inpatient beds for more than a few days. Local Management Entity (LMEs) are quick to deny services for extended treatment.
- Some families are hesitant to move their family member to the community.
- Some families feel that working with long established providers in the community is the only option for community-based services even though they may not be the best quality providers.
- Apartment complex managers, Managed Care Organization (MCOs) and providers do not understand the Fair Housing Laws.
- Each LME/MCO implements the Systems of Care model differently.
- Often providers over medicate children with mental health/intellectual and developmental disabilities (MH/IDD) versus using behavior supports.
- Gaps and challenges above lead to people being placed in institutions.

Recommendations/Priorities

- Increase ongoing education on the Olmstead Decision and rights for families.
- Increase use of Evidenced Based Practices.
- Redirect funds to community-based services and increase programing for substance use disorders. ER visits and jail are far more expensive than proactive treatment.
- Increase education and outreach to local Clerks of Courts to get information on guardianship.
- Provide/increase incentives for local businesses to employ individuals with disabilities.
- Increase Mental Health Parity.

The Children's Systems Listening Session — August 11, 2020

Systems' Strengths/Best and Promising Practices

- Families do have opportunities to provide input into systems change.
- There are examples of Best/Promising Practices including:
 - The Project ECHO (Extension for Community Healthcare Outcomes) initiative,
 - Family Navigators pilot with Trillium, and
 - Some schools work well with/have good programs for students with special needs and their families.

Gaps in Services

- There is a lack of specialists for children which results in them being over medicated by primary care physicians.
- Case Management is a large gap in children's services.
- There are not enough services for children with Autism Spectrum Disorder (ASD) and Traumatic Brain Injuries.
- There is a need for more Youth Peers and Family Support Specialists in the system.

Systems Challenges

- Often families are relied upon to identify best practices/innovation; families are too busy being care-takers to drive the system.
- Variability in services/access across regions and Local Management Entities/Managed Care Organizations (LME/MCOs) creates inconsistent service delivery across the state.
- Identification of needs occurs too late in age; instead, children are quickly labeled as 'behavior problems' and end up in high end services or the juvenile justice system.
- There is a heavy reliance on Medicaid. There is a need for private insurance to cover additional services not under Medicaid as well for many families with children with disabilities.

Recommendations/Priorities

- Ensure consistent service array and access to them statewide.
- Shift the focus from families to the LME/MCOs and providers to identify solutions for better services.
- Review current practices and policies for assessment in order to provide earlier identification of children's needs.
- Consider submission of an Autism Spectrum Disorder (ASD) Waiver.
- Cover self-directed programs in order to pay families as caregivers.
- Expand Peer Supports and Family Support Services.

Mental Health/Substance Use Disorder/Developmental Disability Service Providers Listening Session — August 11, 2020

Systems' Strengths/Best and Promising Practices

- Adults with a serious and persistent mental illness (SPMI) have greater access to services/supports as result of the Settlement Agreement.
- Individuals with Intellectual/Developmental Disabilities and Traumatic Brain Injury are supported by Care Coordinators who advocate for clients; services are person-centered.
- There are examples of best/promising practices though they are not available statewide.

Gaps in Services

- There is the need more funding for everything!
- A lack of affordable housing options limits access to the community.
- There is a need for enhanced housing support services for individuals with SPMI
- Employment supports are lacking.
- Need a more effective crisis response system.
- There is a need formalized Case Management again, funding for this was cut.

Systems Challenges

- Inadequate funding/ongoing cuts creates gaps in services and care.
- Waiting lists for services leaves people in services placements not matched to their needs.
- There is a lack of services in rural areas.
- Individuals and families are often unaware of the services and supports that exist.
- Lack of information sharing across systems and by the LME/MCOs creates silos in care.
- Fee-for-service reimbursement is administratively burdensome.
- There are a lot of requirements for data reporting, yet data is not used to drive decision-making and improve services.

Recommendations/Priorities

- Appeal to the Legislature for more funding.
- Downsize State Operated Centers, not just community-based Intermediate Care Facilities.
- Fund best practices based on data.
- Create incentives for landlords to rent to people with disabilities.
- Increase service capacity in rural areas, including transportation, housing, and internet connectivity.
- Create alternative payment approaches.

Families and Individuals with Traumatic Brain Injury — August 12, 2020

Systems' Strengths/Best and Promising Practices

- There are passionate and dedicated brain injury service providers.
- The Brain Injury Association of North Carolina (BIANC) provides virtual camps, support groups for individuals with TBI and their families, and conduct trainings that they have shared with LME/MCOs.
- Support groups are a strength where they exist, but there is a need for more across the state.
- Recent grant funding has provided additional TBI related training to providers.

Gaps in Services

- TBI waiver slots are limited, and the waiver is not available statewide. The waiver is currently a pilot in the Alliance catchment area.
- There are limited residential program options for those with TBI and those that do provide services are not trained well to accommodate the behavioral changes that often come with TBI.
- There are limited case management services and navigator services. Families and individuals tend to be left on their own to navigate the services system and they may miss key programs or services as a result.
- Transportation is designed county by county. This is very challenging for individuals living in rural/suburban communities to get to urban centers where medical specialists are located.
- Affording reliable transportation is an issue. If the person with a brain injury becomes employed, they may not be able to afford private funded transportation and sometimes lose their employment as a result.
- Many Licensed Independent Practitioners (LIPs) don't have expertise to provide services for TBI.
- There is a need for more trauma informed care training for providers to understand aggressive behaviors and more training on dual diagnoses interventions (TBI/SMI).
- Veteran's Administration and state services are siloed for military service members with TBI.

Systems Challenges

- Accessibility, comprehensiveness, accommodations, and simplicity of connecting to TBI services are all challenges.
- Not qualifying for services due to financial eligibility is a barrier.
- Often people with TBI are not correctly diagnosed. For those who are diagnosed it can be hard to get medical documentation from doctors or other providers to show proof of TBI.
- Agencies are reluctant to screen for TBI because there are limited services, so individuals' needs go unmet.

- Those with more severe TBIs, who need activities of daily living/instrumental activities of daily living (ADL/IADLs) services (i.e. toileting), are not eligible for some day or community programs leaving them with limited community-based services options.
- Persons with TBI are not well served by either the behavioral health/mental health BH/MH or the intellectual/developmental disability (IDD) systems. Gaps in services and supports lead to interactions the criminal justice system.
- Individuals with TBIs only qualify for the Innovations Waiver if their injury occurred before age 22. Those over 21 may apply for the waiver but it is not available statewide.
- Trying to form support groups in rural areas is a challenge given that people/families are spread out.
- In most cases, people receive initial rehabilitation following a TBI and are sent home with just family to help care for them.

Recommendations/Priorities

- Many individuals with TBI live in rehab or skilled nursing facilities because they do not have access to the services and supports that would allow them to live in a more independent setting. There is a need for additional in-reach into facilities to help individuals to transition to the community.
- Take lessons learned and data on prevalence rates of TBI from the waiver pilot in order to design an effective statewide waiver.

Housing Listening Session — August 12, 2020

System Strengths/Best and Promising Practices

- Supported Living is covered under the Innovations Waiver which includes:
 - 4 levels of acuity and,
 - Services that are not attached to the residence which offers flexibility.
- Transitions to Community Living Initiative (TCLI) recipients receive housing subsidies
- Mainstream Vouchers/recent 811 Project-based Rental Assistance award has helped create more affordable housing.
- The state's focus on Social Determinants of Health includes Housing
- There are examples of Best/Promising Practices in housing which include:
 - Reinvestment Partners converting old hotel into housing for the Homeless
 - University of North Carolina – Tiny Home Village and,
 - First in Families Standard Plan pilot

Gaps in Services

- There is a lack of affordable housing options. The current shortage is 200,000 units.
- There are not enough innovative approaches to support individuals in independent living.
- Providers and staff need more training about housing options.

Systems Challenges

- Housing is costly/unaffordable without a subsidies or vouchers.
- The state lacks a Statewide Housing Agency.
- There is a lack of coordination among state agencies that each have a role in housing.
- Criminal background checks create barriers for individuals with disabilities, especially for those with substance use disorders, to obtain housing.
- Guardians of those in more restrictive settings often oppose moving their family member with a disability to independent living options.
- People with different needs should have access to different types of living arrangements. There is a need for an array of housing options as one size does not fit all. Currently there is a lack of data to quantify needs for various types of living arrangements.

Recommendations/Priorities

- Increase collaboration across agencies with housing options.
- Create a statewide Housing Authority.
- In addition to Transitions to Community Living Initiative (TCLI) for persons with SMI, provide rental assistance to others with disabilities.
- Increase provider and staff training on supporting people to move to and remain in independent living.
- Increase support for an array of residential models such as Alternative Family Living, Intermediate Care Facilities for children, and smaller (3-4 bed) group homes for individuals with Intellectual/Developmental Disabilities.

Statewide Independent Living Councils (SILC) Listening Session — August 12, 2020

Systems' Strengths/Best and Promising Practices

- Person Centered Planning is a strength; the system has been moving to a whole person care approach.
- The T-step model at the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) and the Ignite program at the Autism Society of NC both help with training in independent living skills.
- The NC Assistive Technology Center has a lending library for communication devices.

- Centers for Independent Living (CILs) provide training for families.
- The Innovations Waiver Consumer and Family Advisory Committee (CFAC) group does advocacy work to get the legislature's attention about waitlists.

Gaps in Services

- The state needs better data collection methods to see where the gaps are for people who use the SILCs and all other state funded services.
- There is a lack of providers across the state and a lack of culturally competency for existing providers in communities of color.
- Mental health services for children is a large gap. There is also a lack of preventative mental health services for adults as well. Crisis services are the norm.
- Transportation is good in some areas but is not across the state.
- Closed captioning and sign language are not available across the state in all venues (i.e. movies) and there are not enough sign language interpreters in health care (i.e. primary care offices) for the deaf and hard of hearing (DHH). North Carolina is 20 to 30 years behind in services for the DHH population compared to other states.

Systems Challenges

- Direct Support Workers (DSWs) cannot make a living wage with current reimbursement rates.
- There are an increasing number of people who are uninsured.
- Stigma and lack of awareness is a problem for persons with mental illness.
- The waitlists for Innovations waiver services are a long-standing problem. The average wait time is 12 years; many are on the waitlist from the time they are born.
- Independent Living Centers (ILCs) advocate for diverting those with physical disabilities and those with mental health and substance use disorders from institutional care to HCBS/independent housing. However, this is often challenging to move people out of institutions given housing shortages and guardian hesitations.
- The wait time for Vocational Rehabilitation funded housing modifications is very long.
- The state has a high number of guardianships; they are overused.

Recommendations/Priorities

- Apply for modifications to waivers to include a self-directed option that will allow people to hire their own staff.
- Reallocate some of the surplus funding at the Department of Vocational Rehabilitation to the 7 Independent Living Centers (ILCs) across the state so that they may do more home modifications and fund more durable medical equipment (DME) equipment.
- Move disability systems to assisted decision-making models and away from guardianships to move more people from institutions to the community.
- Develop more "in-lieu of" services to get people off waiver waitlists.

- Increase use of assisted technology to meet the needs of people living at home and who want to move to the community.
- Revise policies to increase emphasis on early intervention in school-based services.
- Increase the use of telehealth and extend the CMS flexibilities for telehealth under COVID after the pandemic to continue to meet people’s needs, especially in rural areas for all disability populations.
- Implement Medicaid expansion in order to get care and services to the large numbers of those that are uninsured in North Carolina.

Family Members of Persons with Developmental Disabilities Listening Session — August 12, 2020

Systems’ Strengths/Best and Promising Practices

- Sheltered workshops are needed for adult children to work.
- State Centers provide a better array and quality of services as they are better funded.

Gaps in Services

- There is a need for more group homes across the state for persons with intellectual and developmental disabilities, in some cases LME/MCOs may need to place people 4 hours away from their family.
- They pay for respite care workers is inadequate. There is a lack of all direct support staff due to inadequate salaries as well.
- The Registry of Unmet Needs continues to grow.

Systems Challenges

- The legislature has continued to cut funding for services over time.
- The state promotes one-size fits all approach to services instead of flexible and individualized services.
- There is variability in the service array and access to services across regions and across each LME/MCO.
- There is a lack of transportation options.
- Planning and coordination across systems is not prevalent.
- Family members of persons with I/DD need a stronger voice at the table with the state.
- Most medical providers and specialists don’t understand or are not trained to work with people with I/DD.

Recommendations/Priorities

- Create and maintain an array of living arrangements and employment opportunities. Use empty buildings on the grounds of State Centers to create housing for persons with I/DD.
- There is a need to educate Legislators about the importance of funding community-based services.
- Develop a consistent message about funding needs across all stakeholder groups.
- Work to address salary increases for direct support staff.
- Develop strategies to address the lack of transportation options across the state.
- Increase the requirements for training of medical professionals who treat persons with I/DD.

Local Management Entity/Managed Care Organizations (LME/MCOs) Listening Session — August 13, 2020

Systems Strengths/Best and Promising Practices

- The system needs more of everything. No strengths were identified.
- Best Practices of the system that were identified included:
 - The Community Inclusion pilot,
 - Family Navigators,
 - Peer Specialists and,
 - LME/MCOs Provider Summits to support their networks.

Gaps in Services

- There is a need for more funding for all services and housing.
- The funding of the system needs to be consistent to build networks and sustain quality services.
- There are not enough slots supported by the Money Follows the Person (MFP) program to move more people from restrictive settings.
- A lack of in-reach into facilities for individuals with I/DD leaves more people in restrictive settings.
- The array of residential options for children with co-occurring mental health and IDD is inadequate to meet the needs of children and families. Children are often get placed in Psychiatric Residential Treatment Facilities which is not an appropriate setting for them.
- There is a need for a fuller array of residential living options.
- Persons with disabilities need more and better options for meaningful day activities.

Systems Challenges

- Inadequate funding and ongoing budget cuts are a big challenge.

- LME/MCOs are required to pay the state a set per diem for State Operated Facility beds. These rates increase each year, but fewer people are served. “People in State operated facilities are not sicker than others, but they have the resources to better serve them.”
- State facility staff believe people leaving an institution must “graduate” from more intensive to fewer intensive levels of care in order to be successful in the community.
- The Innovations Waiver waiting list contributes to state center admissions as there are few community services beyond the waiver and then people end up in crisis and then admitted to state centers.
- Community-based Intermediate Care Facilities each keep their own waiting lists.
- Service definitions are population specific which creates confusion and administrative complexity.

Recommendations/Priorities

- Continue to appeal to the Legislature for more funding and consistent funding.
- Allow the LME/MCOs to negotiate rates for State Operated facilities.
- Change policy to allow the money from all state facility discharges to follow the person into the community as is done in the MFP program.
- Allow LME/MCOs staff to provide in-reach at State Centers for persons with I/DD.
- Expand Peer Support specialists to other populations aside from persons with SMI/SUD.
- Revise service definitions to cover people across all disabilities.

Persons with Serious Mental Illness/Substance Use Disorders Listening Session — August 14, 2020

Systems Strengths/Best and Promising Practices

- The Department of Vocational Rehabilitation (VR) supports have helped some individuals with internships that have led to peer specialist positions.
- Trillium (MCO/LME) is looking at supporting Healing Transitions, a provider and service model in Raleigh, which provides peer supports, detox and other serious mental health and substance use disorder (SMI/SUD) supports.
- Some Managed Care Organizations (MCOs), such as Alliance, are purchasing phones for members to do telehealth appointments with folks with SUDs during the pandemic to help bridge gaps in services. This has been helping to reduce no-show rates and connect people to peer supports. Alliance also provides family specialists to provide service navigation.

Gaps in Services

- There is a lack of information about services to persons who need services. There is a need for more community support liaisons to help find services.
- Providers who can cover service after 5pm are lacking across the state.
- There is a gap in childcare services to help people keep appointments.

- Transportation is lacking, especially in rural communities.
- There is a need for additional SUD peers across the state.

Systems Challenges

- Provider reimbursement rates are low however, they have high administrative/documentation burdens.
- There have been increases in Opioid Use Disorder crises and deaths with COVID-19.
- Most people with SUDs services are not Medicaid eligible. The MCOs are trying to fill this gap in SUD services but this remains a challenge.
- Vocational Rehabilitation funds Supported Employment services for MH/SUD services but requires supervision of a clinical professional at the provider. This is difficult with provider shortages across the state. Another challenge is that providers are only reimbursed for services if person remains employed for 3 months.
- Job coaching services are available via (b)(3) state funding, but these funds have diminished in recent years.
- The peer support service definition is restrictive; it does not allow for long-term service flexibility.
- State funding cuts have made it difficult to keep services consistent across the state for all MH/SUD providers.
- Maintaining fidelity with the TCLI supported employment (SE) model is difficult given the Evidenced Based Practices (EBP) service definitions. The rates do not support SE EBPs and the model does not always fit people's needs.
- Individuals with high needs are "stuck" in restrictive residential placements due to a lack of other community-based programs to meet their needs. There are not enough community providers for high needs individuals.

Recommendations/Priorities

- There is a need for more flexibility in service definitions for individuals with higher levels of need.
- For those transitioning from child to adult placements/services there is a need for more longer-term community-based programs.
- When transitioning adults with SMI/SUD from more restrictive setting to the community, there is a need to have longer-term extended transition services in order to help the individual be successful in the long term.
- There is a need for greater emphasis on Social Determinants of Health in SMI/SUD services, such as Housing, Food, Health and Safety for those moving to the community.
- Additional funding to increase MH peer specialists' rates and to keep peers involved in care during and after transition to the community.
- Increase the use of telehealth. This includes telehealth for peer supports to reach rural communities (given transportation issues) and providing more support during the pandemic.

- There is a need to move away from AA and NA group supports. More and more persons with SUDs are rejecting these groups given emphasis on God and religious undertones.
- The data at VR on employment and VR practices are out of date. The state needs to think more outside the box and current models to help people get work.
- There is a need to improve coordination between MH/SUD services and health care integration.
- The state could benefit from looking at other states' best practices around MH/SUD services, particularly around peer supports.

Persons with Intellectual and Developmental Disabilities Listening Session — August 14, 2020

Systems' Strengths/Best and Promising Practices

- The system is so difficult to navigate that it is hard to see the strengths.
- ABLE accounts (Achieving a Better Life Experience, tax-exempt savings accounts for qualified disability expenses) help with income for those with ID/DD who qualify.

Gaps in Services

- There are 14,000 people on the Innovations waiver waitlist, who get few, if any, services while waiting. This leaves parents providing a lot of the care, which is difficult as their adult child with I/DD ages and as parents age.
- There is a need to create "in lieu of" services for individuals while on waitlist. There is a gap for many who are waiting as only those who are eligible for Medicaid get (b)(3) services. Institutions are often the only option for waitlisted individuals.
- There is a lack of competitive employment services and job options in rural areas for persons with I/DD. There are not enough jobs or job creation services in rural areas to transition individuals from protected work enclaves/workshops if they are closed in the future. Individuals in enclaves/workshops fear losing their current jobs with no other job opportunities in rural areas.

Systems Challenges

- Community Rehabilitation Programs continue to be threatened with closure and told that they can no longer provide a protected work environment to the people who want to be there.
- There is an over-reliance on institutions for harder to serve individuals. The state has not funded enough additional home and community-based services to serve higher needs individuals to keep harder to serve persons out of institutions.
- Policies and funding are based on the expectation that services should decrease over time. Services often are reduced when the person stabilizes. The state does not recognize that consistent services are keeping the person stable. Inconsistent services are bad for the individual and expensive for the system.

Recommendations/Priorities

- Repurposing existing funds to support home and community-based services (HCBS) from institutional setting would help with funding more HCBS without having to request more from the legislature.
- There is a need to improve staff rates for HCBS. Staff can earn higher wages in institutions currently. The state needs to shift the culture to HCBS by moving jobs from institutions to the community.
- Incentivize and educate businesses on the benefits of hiring people with disabilities in order to create more volunteer and internship programs to help reduce fears about hiring persons with disabilities and build relationships with businesses.
- Develop micro-enterprises/companies to create more jobs for persons with disabilities.
- The state could benefit from reviewing policies that potentially jeopardize benefits related to job income and financial stability over time.
- The state should promote choice in employment services including protected work environments/workshops.

Employment Services Listening Session — August 18, 2020

Systems' Strengths/Best and Promising Practices

- The Transition to Community Living Initiative (TCLI) focuses on Supported Employment for people with Serious Mental Illness.
- There are examples of Best/Promising Practices which include:
 - Vaya (MCO) supports the Community Activities and Employment Transitions (CAET) approach in Mecklenburg County and
 - The Easter Seals Sensible Snacks Food Truck supported employment initiative.

Gaps in Services

- There are gaps in funding for long-term supported employment (SE) services.
- Supported Employment services for individuals not covered by the Transitions to Community Living Initiative (TCLI) or Waivers are lacking.
- There is a lack of case management services to help families navigate service options.
- Alternative career pathways such as mentorship programs and apprenticeships are lacking.

Systems Challenges

- Local Management Entities/Managed Care Organizations (LME/MCOs) vary in their support of employment/integration into a persons' care plan.
- There is a disconnect/lack of communication between some school districts and Vocation Rehabilitation (VR) offices.

- There are high rates of Vocational Rehabilitation staff turnover and vacancies. Rehabilitation Services Administration (RSA) requirement for Vocational Rehab counselors can be a challenge as well.
- The focus for employment is strictly on the Supported Employment model (SE); some families don't view that as an option. Families are then expected to identify innovative approaches that meet their loved ones' needs.
- There is no mandate for systems to work together for individuals aged 22+ years old.

Recommendations/Priorities

- There is a need to support an array of employment models/approaches from sheltered workshops to self-employment models with supports.
- Provide education to families on various services/approaches that are available nationally and in other states.
- Re-instate Case Management services to navigate the employment system and the broader system.
- The state could partner with Community Colleges, in all 100 counties in the state, to develop skills/career paths for individuals with disabilities.
- Provide longer-term funding for SE services.

The Coalition Listening Session — August 20, 2020

Systems' Strengths/Best and Promising Practices

- Stakeholders have opportunities to provide input into systems change.
- Some examples of Best and Promising Practices include:
 - Peer-lead providers and services and,
 - The University of North Carolina Homeless Prevention Team funded by a Substance Abuse and Mental Health Services Administration grant that includes an Occupational Therapist (OT)

Gaps in Services

- There is a lack of Case Management services. There is a lot of Care Coordination, but it does not provide the same level of individualized service that Case Management.
- There is a lack of small, black-owned providers who have contracts with managed care companies.
- Access to Occupational Therapy and Physical Therapy (PT) is a gap as they not covered under the waiver or by Local Management Entities/Managed Care Organizations (LMEs/MCOs).
- There is a lack of affordable housing options

Systems Challenges

- There is inadequate funding and ongoing cuts for services. The states' emphasis on reducing costs has resulted in:
 - High staff turnover rates (50% each year). Providers invest \$3,500 - \$6,500 per new hire for recruitment, training, etc.,
 - Unstable and inconsistent services which impacts the individual to receive the needed to services and supports to live independently and creates distrust of the system by families,
 - The need for far more expensive services given that community-based services have been inadequately funded and,
 - Hardships for families who end up serving as caregivers and self-funding services for their children with I/DD.
- A lengthy Innovations Waiver Wait List is a large challenge that creates gaps in care. Wait times result in premature referrals that can over-inflate the list as well as people giving up and not even trying to get on the list.
- The Mental Health System relies too heavily on forced treatment including:
 - The use of involuntary mental health commitment to reduce risk and liability, and
 - The use of Law Enforcement to provide transportation to emergency services.

Recommendations/Priorities

- The state could benefit from shifting their focus from cutting costs to sustaining consistent, comprehensive, and high-quality services.
- To ensure high quality community-based services, the Department of Health and Human Services should focus on building provider capacity and staff training.
- DHHS could explore alternative options to the Innovations Waiver (e.g. – a Supports Services waiver or TEFRA Waiver).
- Use the move to Standard Plans and Tailored Plans under Medicaid expansion as an opportunity for true integration of physical and mental healthcare and not just viewing it as a different mechanism for paying for services.

Aging Providers Listening Session — August 11, 2020

Systems' Strengths/Best and Promising Practices

- Money Follows the Person (MFP) has helped transition people from institutions.
- The Transitions to Community Living Initiative (TCLI) in-reach process has been good.
- Access to transportation is available for older adults.

Gaps in Services

- There is a lack of coverage for Medicare services.

- Specialists across the state are lacking.
- There is a general lack of consistent high-quality care for all disability populations across the state.
- Providers need additional training to work with adults and those aging with autism spectrum disorder and other IDD.
- There is a need for additional family peer groups or family navigators so families can learn about services and resources, such as groups at the Autism Society of NC and First in Families.
- Services offered under the Community Alternatives Program for Children (CAP/C), Community Alternatives Program for Disabled Adults (CAP/DA) waivers, and the Program for All Inclusive Care for the Elderly (PACE) Program are inadequate and lead to institutionalization.

Systems Challenges

- As people with I/DD age, they do not have a good transition to aging services because aging and I/DD services and providers are siloed.
- There is inadequate Care Coordination to prevent institutionalization.
- Reimbursement structures do not allow for enough occupational, physical and speech language therapy (OT/PT/SLP) services for persons with I/DD.

Recommendations/Priorities

- The state could benefit from expansion of in-reach services like those of the Transitions to Community Living Initiative (TCLI) to other disability populations. Increase outreach to Skilled Nursing Facilities (SNFs) and Adult Care Homes (ACHs) to find out who would like to try to transition back into the community.
- Work to implement prevention programs through the National Home Builders Association to learn about mobility and prevention of falls and other incidents that put people in more restrictive care.
- The state could benefit from adopting the Medical Home model to provide preventive care for elders.
- Use data more effectively to make informed decisions across the state and across populations.
- Address issues related to the ability to recruit, retain, and train staff with strong rate systems to reduce staff turnover.
- Continue to shift financial resources into community-based services and away from institutional settings.

Legal and Public Guardians Listening Session — October 1, 2020

Systems' Strengths/Best and Promising Practices

- Guardians have opportunities to participate in and contribute to systems change.
- Guardians noted that state operated healthcare facilities such as Murdoch and Caswell provide good care for children with I/DD. State centers/facilities provide more services and higher quality services for individuals with challenging behaviors as they are better funded. There is less

staff turnover because staff are paid better than community-based provider staff and they have benefits.

- The Carolina Living and Learning Center TEACHH program is a best practice program for individuals with autism.

Gaps in Services

- Many community-based providers are not trained to serve individuals with autism. It is not unusual for group home staff to drop individuals off at emergency departments where they spend days or weeks.
- There is a need for more community-based supports for people with all disabilities.
- The state needs a more complete array of service options.

Systems Challenges

- Community provider staff lack sufficient training to adequately care for people across a spectrum of needs.
- Providers are not adequately trained to understand and serve people with autism.
- State facilities are viewed as negative options for people. State centers require guardians of new admissions to agree that the stay is “time-limited.”

Recommendations/Priorities

- Allow individuals whose families want their child to stay in state operated facilities to remain there.
- Increase options for and the quality of community-based services and supports.
- Address the inadequate salaries of community-based direct support staff.
- Replicate the Carolina Living Center TEACHH model in every county of the state.

Aging Coalition Listening Session — October 23, 2020

Systems’ Strengths/Best and Promising Practices

- There are opportunities to participate and give feedback about systems change.
- There are an array of state plan and waiver services.

Gaps in Services

- There is a lack of community-based living options for older adults with ID/DD.
- There are not enough crisis services, especially in rural communities.
- Well-trained staff to serve older persons with disabilities, particularly those aging with I/DDs, are inadequate.

Systems Challenges

- There is not one system for people with disabilities to access making multiple systems difficult to navigate.
- There are many older persons with I/DD that are on the Registry of Unmet Needs and the Innovations waitlist. The waitlist remains a problem.
- There are not enough transportation services statewide.
- Gaps in care often exist due to the lack of coverage for services between Medicaid, Medicare, state-funded and private insurance.
- Gaps in care result in the use of crisis services and ED visits which then often results in people living in more restrictive settings as there is not enough community-based programming.
- There is a need for more service coordination across systems of care for those with I/DD who are aging.

Recommendations/Priorities

- There is a need for a better variety of quality services for people with disabilities across settings.
- There is a stigma or belief in North Carolina that people with disabilities and elders cannot adapt to new settings which is a key barrier to getting people into the community.
- More funding is needed to bridge the gaps in services and to provide more community-based options. Reallocating funding from state operated facilities could help to bridge the gap for funding for more community-based services and supports.
- Additional funding and programs are needed for additional affordable housing units and vouchers for persons with disabilities to live in the community

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Appendix G: Olmstead Planning Listening Session Poll and Survey Results

Data from the Listening Session polls and the online survey were combined to find trends across all Stakeholder groups and both data collection methods. Listening Sessions attendees and survey respondents were able to skip questions if they wished not to answer or did not have input regarding specific questions. Therefore, the trends presented below show overall percentages for those who answered questions across the sessions and in the survey.

Demographics of Respondents

Respondents were asked what type of community they lived in or which types of communities they served (if a provider) and in which part of the state they lived or provided services. Forty percent (40%) of those who answered this question were from rural areas, 38% from suburban communities and 33% in urban areas. Fifty-one (51%) lived in or served people in Central North Carolina, 31% in Western North Carolina and 30% in Eastern North Carolina.

Strengths

The top three areas identified by all respondents when asked to identify the multiple strengths of the systems that support people with disabilities in North Carolina were:

- 44% - A comprehensive array of treatment, therapeutic services and supportive services
- 42% - Individuals/families/caregivers preferences and choices in services are honored
- 40% - Stakeholders have opportunities to participate in/contribute to systems change

When asked to identify the top strength of the systems the three areas, the same strengths were identified. (Note, percentages vary from the multiple-choice question above as some participants skipped this question and that this was a forced choice question)

- 25% - A comprehensive array of treatment, therapeutic services and supportive services
- 16% - Individuals/families/caregivers preferences and choices in services are honored
- 16% - Stakeholders have opportunities to participate in/contribute to systems change

Stakeholder Group Differences Regarding Strengths

Most stakeholder groups rated the comprehensive array of services as the top strength on both the multiple-choice question and prioritized question. Those who chose a different strength as their top choice(s) are described below along with any other differences in data that are noteworthy.

- Persons with I/DD and SMI and or SUD across both the survey and listening sessions rated the opportunity to participate in/contribute to systems change as their top strength for both the multiple choice and forced choice question.
- Family members of persons with SMI/SUD also rated the opportunity to participate in systems change as their top strength for both the multiple choice and forced choice question.
- A noteworthy difference regarding the family member stakeholder group (including family members of persons with SMI/SUD, IDD, and TBI) as compared to other stakeholder groups, was that a higher portion of people chose the Other option in the survey and poll. Many stated that they did not view any of the options as a particular strength in North Carolina or noted that services and support or education about services and supports are not available in their county or area and therefore did not feel they could identify a strength based upon their lack of interaction with the services system.

Gaps

When asked about multiple gaps in the systems that serve people with disabilities, the following were the most highly ranked across all respondents to the survey and attendees at the listening sessions.

- 60% - Lack of services/supports in rural communities
- 59% - Lack of adequate independent living options
- 56% - Lack of adequate, well-trained staff
- 54% - Lack of adequate support services

When ranking the top gap to prioritize, answers changed slightly from the multiple-choice question results, as follows. (Note, percentages vary from the multiple-choice question above as some participants skipped this question and that this was a forced choice question)

- 19% - Lack of adequate support services
- 16% - Lack of adequate independent living options
- 15% - Lack of adequate, well-trained staff
- 14% - Lack of services/supports in rural communities

Stakeholder Group Differences Regarding Gaps

Most stakeholder groups chose the lack of services and supports in rural areas (multiple choice) or a lack of adequate support services (prioritized choice) as their top gap in the system. Family members of those with IDD, SMI/SUD and TBI ranked the lack of adequate and well-trained staff as a top choice for the multiple choice question and when asked to prioritize their top gap lack of adequate staff was tied

with lack of support and services in the community, which was the third choice in the overall survey results.

Challenges for Individuals with Disabilities and Families

Respondents were asked to choose multiple challenges that they identify for individuals with disabilities and their families. The following were the most highly ranked challenges.

- 71% - Waiting lists for services/funding
- 60% - Lack of coverage for needed services/supports (Medicaid, Medicare, private insurance, state funds)
- 51% - Lack of transportation

When asked to prioritize the challenges the top three choices for those that answered the questions were as follows:

- 36% - Waiting lists for services/funding
- 25% - Lack of coverage for needed services/supports (Medicaid, Medicare, private insurance, state funds)
- 9% - Lack of information about what services/supports are available and/or how to access them

Stakeholder Group Differences Regarding Challenges for Individuals and Families

The only stakeholder groups for which the top challenge was not waitlists, were aging providers and family members of those with MH/SUD, who rated the lack of coverage for needed services/supports (Medicaid, Medicare, private insurance, state funds) for both the multiple choice and prioritized question as their key challenge.

Challenges for Providers

Multiple challenges for providers were identified. The top 3 answer choices when asking about multiple challenges included:

- 62% - Staff turnover
- 57% - Rates/reimbursement methodology
- 50%- Lack of coordination across state agencies/systems

The top 3 challenges for providers when respondents were asked to prioritize one option were:

- 22% - Rates/reimbursement methodology
- 25% - Increasing complexity of individuals' needs
- 19% - Staff turnover

Stakeholder Group Differences Regarding Challenges for Providers

Employment and vocational rehabilitation providers were asked about their greatest challenges. Answer options for these providers differed from others in the survey. (See [Appendix C](#) for all answer options).

The top challenges for the multiple-choice questions were:

- 85% - Policies/regulations that create barriers to serving individuals with disabilities in community-integrated services
- 71% - Lack of coordination across state agencies/systems
- 57% - Stigma by employers
- 57% - Rates do not support high quality services

When asked to prioritize which challenge was most difficult when supporting individuals with disability to work in the community, the top 3 choices of employment providers were:

- 42% - Lack of timely referrals for available job training/employment opportunities
- 28% - Rates do not support high quality services
- 14% - Increasing complexity of individuals' needs
- 14% - Lack of coordination across state agencies/systems

LME/MCO respondents rated the rates and reimbursement methodologies as their top challenge just slightly above staff turnover which was the most popular choice for the multiple-choice question overall. There was a tie for the prioritized challenges with rates and staff turnover as the top choices for LME/MCOs.

Children's providers and Aging Services providers rated staff turnover as their second most often seen challenge but rated the increasing complexity of needs as their top challenge when asked to prioritize their single biggest challenge.

Segregated Settings

Respondents were asked about the effects of a lack of community-based supports for individuals with disabilities, including children, youth, adults and older adults. Top answers to the multiple-choice question included:

- 65% - Utilizing intrusive, intermittent, high-cost services such as Emergency Departments, Crisis Response, Law Enforcement, etc. as opposed to Preventive care/primary care/routine care/wellness programs
- 60% - Living in congregate settings in the community, such as Adult Care Homes, ICF/IDD, Group Homes, living with elderly parents, living with people that jeopardize their recovery, couch-surfing, living in un-safe neighborhoods
- 41% - Spending time in segregated settings such as sheltered workshops, day programs
- 41% - Staying in state-operated healthcare settings for extended periods of time

When asked to choose which effect of the lack of community-based supports was seen most often respondents answered similarly with a slight change between the 3rd and 4th top choice.

- 31% - Utilizing intrusive, intermittent, high-cost services such as Emergency Departments, Crisis Response, Law Enforcement, etc. as opposed to Preventive care/primary care/routine care/wellness programs
- 26% - Living in congregate settings in the community, such as Adult Care Homes, ICF/IDD, Group Homes, living with elderly parents, living with people that jeopardize their recovery, couch-surfing, living in un-safe neighborhoods
- 9% - Staying in state-operated healthcare settings for extended periods of time
- 8% - Spending time in segregated settings such as sheltered workshops, day programs

Stakeholder Group Differences Regarding Segregated Settings as a Result of the Lack of HCBS

For the multiple-choice question, family member stakeholders (including of persons with I/DD, SMI/SUD and TBI) most often answered that living in congregate settings in the community, such as Adult Care Homes, ICF/IDD, Group Homes, living with elderly parents, living with people that jeopardize their recovery, couch surfing, and living in unsafe neighborhoods, was the result of a lack of community-integrated options which was different than the top answer overall. When asked to prioritize which settings were most prevalent as a result of a lack of community options, family members answered most often that “utilization of intrusive, intermittent, high-cost services such as Emergency Departments, Crisis Response, Law Enforcement, as opposed to Preventive care/primary care/routine care/wellness programs” were used as a the result of the lack of community based options. This choice was followed closely by “living in congregate settings in the community, such as Adult Care Homes, ICF/IDD, Group Homes, living with elderly parents, etc.”

Aging service providers, aging advocates and LME/MCO stakeholders most often chose “Utilizing intrusive, intermittent, high-cost services such as Emergency Departments, Crisis Response etc.” response choice in the multiple choice question but when asked the prioritize which setting was seen most often as a result of lack of community based options the aging stakeholder group chose “Living in

congregate settings in the community, such as Adult Care Homes, ICF/IDD, Group Homes, Psychiatric Residential Treatment Facilities Living with elderly parents etc.”

Actions/Recommendations

The multiple actions to help persons with disabilities gain additional access to community integration recommended by respondents were:

- 73% - Appeal to the Legislature for more funding
- 70% - Increase access to safe, decent, affordable independent living opportunities
- 62% - Provide a more comprehensive array of community-based treatment, therapeutic services and supportive services

Priorities for actions and recommendations included:

- 31% - Appeal to the Legislature for more funding
- 24% - Provide a more comprehensive array of community-based treatment, therapeutic services and supportive services
- 14% - Increase access to safe, decent, affordable independent living opportunities

Stakeholder Group Differences

Children’s providers, aging providers/advocates and other disability advocacy organizations (including The Coalition) ranked increasing access to safe, decent and affordable independent living opportunities/housing above appealing the to the legislature for more funding in the multiple-choice question. These same stakeholder groups also ranked increasing a comprehensive array of community-based treatment, therapeutic services and supportive services above appealing to the legislature for more funding when asked to prioritize which strategy they would recommend.

Listening Session Open Discussion and Other Answers from the Survey

Attendees of the Listening Sessions were asked to provide additional feedback regarding their answers to the questions asked in the polls via open discussion and survey respondents were asked to add answers in an ‘Other’ category to capture additional qualitative data that was not represented in the poll/survey questions. Feedback that emerged are organized by high-level themes below.

Emphasis on Choice and Access across a Continuum of Services

- A choice in services across the continuum is key to meet the various needs of persons with disabilities at various levels, including the choice of more restrictive settings such as supported workshops and state-run institutions.
- Continue to educate families and persons with disabilities about Olmstead and about their choices for services
- Ensure consistency across all services across the state

Services and Evidenced Based/Best Practices Expansion

- Participants suggested a need to fund more best practice and evidenced based services based upon data that shows their effectiveness. Service expansion and best practices recommendations for replication included:
 - Care coordination and navigation
 - Cover self-directed care/pay families as caregivers
 - Micro-enterprises and more partnerships with local business to create jobs
 - Partner with Community Colleges, in all 100 counties, to develop skills/career paths for individuals with disabilities
 - Increase peer supports and family support services across all disability populations
 - Mental Health Parity
 - Create a statewide Housing Authority
 - Increase self-directed options in waivers to allow people to hire own staff
 - Expand Transitions to Community Living Initiative (TCLI) in-reach across populations. Implement the Referral Screening Verification Process (RSVP) Process through Adult Care Homes (ACHs).
 - Adopt Medical Home model to provide prevention care
 - Work on implementing prevention programs through National Home Builders Association to learn about mobility and prevention.
 - Expand High Fidelity Wraparound services and provide more education to stakeholders and families on System of Care
 - Increase Crisis and Respite services hours and access
 - Improve behavioral health services for youth with dual diagnosis of MH and IDD by training more providers to serve this population
 - Replicate ECAC in more counties across the state
 - Fund more early intervention services
 - Increase telehealth for rural areas and advocate for permanency in telehealth post-pandemic

Policy, Financing and Process Strategies to Meet Challenges and Gaps

- Expand Medicaid
- Align policies and services authorization similarly across all LME/MCOs

- Expand pay for performance and value-based payment models to incentivize quality outcomes across providers
- Develop more “in-lieu of” service definitions and services package for those on the waiver waitlists
- Move from guardianships to assisted decision making model by partnering with the courts
- Better coordinate housing and support services to ensure successful community placements
- Better coordinate Vocational Rehab and school-based services for youth with disabilities
- Increase provider/staff training on supporting people in independent living
- Create career advancement pathways for direct support workers to retain them
- Increase outreach to Skilled Nursing Facilities (SNFs) and Adult Care Homes (ACHs) to find out who would like to try to transition back into the community.
- Increase education and outreach to local Clerks of Courts to get information on guardianship.
- Need more flexibility in service definitions for individuals with high needs
- Use empty buildings on the grounds of State Centers to create more community-based living options and employment opportunities
- Repurpose existing funds to support home and community-based services (HCBS) without requesting more from the legislature.
- Change policies that potentially jeopardize benefits related to income and financial stability

Appendix H: Key Documents Reviewed

- 2016 Update to the Task Force on Co-location of Populations in Adult Care Homes.
- 2019 Profile of Older Americans; Administration for Community Living.
- 2019 - 2020 Annual Report of the North Carolina Transition to Community Living Initiative NC General Statute 122C-20.15, Report to the Joint Legislative Oversight Committee on Health and Human Services By North Carolina Department of Health and Human Services February 1, 2021
- DHHS, Division of Services for the Blind, 2019 Annual Report
- Education Opportunities for Students with Disabilities Session Law 2015-241, Section 11.19.(a). Report to the Joint Legislative Oversight Committee on Health and Human Services and Joint Legislative Education Oversight Committee North Carolina Department of Health and Human Services November 27, 2017.
- Money Follows the Person Demonstration Sustainability Analysis, Transitioning Beyond 2020. Mercer Government Human Services Consulting, May 2018.
- NCI In-Person Survey (IPS) Sate Report 2018-2019 for North Carolina.
- North Carolina 2019 Mental Health National Outcome Measures (NOMS): SAMHSA Uniform Reporting System
- North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services Local Management Entities/Managed Care Organizations Administrative Functions Monitoring Report December 2019
- NORTH CAROLINA LME-MCO's ANNUAL STATISTICS AND ADMISSION REPORT FISCAL YEAR 2020.
- North Carolina Medicaid Fact Sheet: Medicaid Transformation. May 2019.
- NORTH CAROLINA PSYCHIATRIC HOSPITALS ANNUAL STATISTICAL REPORT FISCAL YEAR 2020
- North Carolina State Action Plan for People with Traumatic Brain Injury.
- Olmstead vs. L.C.*, 1999, 527 U.S. at 600-01.
- REPORT OF THE INDEPENDENT REVIEWER In the Matter of *UNITED STATES OF AMERICA v. THE STATE OF NORTH CAROLINA*. Submitted By: Martha B. Knisley, Independent Reviewer October 26, 2019.
- Report to the Joint Legislative Oversight Committee on Health and Human Services and Joint Legislative Education Oversight Committee North Carolina Department of Health and Human Services, the Exceptional Children Division, Department of Public Instruction.
- Rethinking Guardianship: Building A Case For Less Restrictive Alternatives
- STRATEGIC PLAN FOR IMPROVEMENT OF BEHAVIORAL HEALTH SERVICES Session Law 2016-94, Section 12F.10.(a-d) Session Law 2017-57, Section 11F.6.(a-b).
- Study on the Lack of Capacity to Proceed Process Recommendations for Improvements to the Incapacity to Proceed (ITP) System in North Carolina Session Law 2017-147. Joint Legislative Oversight Committee on Health and Human Services and Joint Legislative Oversight Committee on Justice and Public Safety by North Carolina Department of Health and Human Services March 29, 2018.
- Supporting the Mental Health and Emotional Well-being of Students in North Carolina Schools, September 2019.

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Appendix I: North Carolina Housing Resource Scan

Introduction

Technical Assistance Collaborative (TAC) reviewed the current array of housing resources available to individuals with a disability who wish to live more independently and integrated in the community. Below is a scan of the various affordable housing resources for people with a disability to help inform the need of additional housing resources and understand the current resources that can be leveraged and built upon for this population.

Federal Resources

Public Housing Authorities

Public housing agencies (PHAs) are public agencies overseen by a board of commissioners that is either elected or appointed by the city, town, or governor to develop, own, and manage public housing under contract with the U.S. Department of Housing and Urban Development (HUD) and/or the state. PHAs can administer Housing Choice Vouchers, conventional public housing programs, or both, as well as numerous other affordable housing programs.

The State of North Carolina does not operate, own, or manage any public housing units. In North Carolina, Public Housing Authorities (PHAs) in the larger suburban and metropolitan areas own and manage public housing developments.

Housing Choice Vouchers

The Housing Choice Voucher (HCV) program is the major federal program for assisting low-income families, the elderly, and people with disabilities to obtain decent, safe, and affordable housing in the community. Vouchers are commonly referred to as tenant-based rent subsidies because they are provided to eligible applicants to use in private market rental housing of their choice that meets the HCV program requirements. The HCV household pays a portion of monthly housing costs that is based on the income of the household. The household's portion is usually, but not always, equal to 30-40% of its monthly-adjusted income. This subsidy is based on the cost of moderately priced rental housing in the community and is provided by a PHA under a contract with HUD.

At the present time, there are 65 active PHAs in North Carolina with Housing Choice Vouchers. The PHAs in North Carolina administer a total of 45,220 tenant-based vouchers.

Special Purpose Vouchers

In addition to regular Housing Choice Vouchers, there are special purpose vouchers that have been appropriated by Congress exclusively for people with disabilities. Because of various requirements imposed on these vouchers by law and by Congressional appropriations language, these vouchers are an invaluable resource for meeting the housing needs of people with disabilities since they must continue to be set aside for people with disabilities even when they turnover and are re-issued. There are 45,268 Housing Choice Vouchers administered by PHAs in North Carolina. Approximately 8% (3,847 vouchers) are targeted exclusively to people with disabilities through the following programs:

- **Five-Year Mainstream Housing Opportunities for Persons with Disabilities**
Five-Year Mainstream vouchers are set aside exclusively for people with disabilities. These vouchers are funded through the Section 811 tenant-based rental assistance program (25% of the program's appropriations have been used for tenant-based rental assistance) and PHAs received five-year annual contributions contracts.
- **Rental Assistance for Nonelderly Persons with Disabilities ("NED" Vouchers)**
Over the past decade, HUD has awarded over 55,000 other vouchers targeted to nonelderly people with disabilities, now referred to as NED vouchers.¹⁴²
- **Rental Assistance for Non-Elderly Persons with Disabilities ("NED" Category 2 Vouchers)**
In 2011, HUD awarded another category of vouchers targeted to non-elderly persons with disabilities currently residing in nursing homes or other healthcare institutions who want to transition into the community. These vouchers are now referred to as NED Category 2 vouchers.

On May 12, 2020, HUD released a [Notice](#) announcing additional funding allocations through the CARES Act to PHAs awarded in the 2017 and 2019 competitions. Additionally, on September 8, 2020, HUD released a [Notice](#) announcing a non-competitive round of funding availability. The additional tenant-based vouchers from these opportunities are included in the totals found in Table I-1 below.

¹⁴² NED vouchers include those vouchers previously known as Designated Housing vouchers, Certain Developments vouchers, Project Access vouchers, and 1-year Mainstream vouchers.

Table I-1. PHAs in North Carolina with NED or Mainstream 5-Year Vouchers¹⁴³

PHA	Mainstream ¹⁴⁴	NED	NED Cat 2
Asheboro Housing Authority	—	25	—
Brunswick County General Fund	—	—	—
Carteret (Coastal) Community Action ¹⁴⁵	—	50	—
Chatham County Housing Authority	26	50	—
City of Hickory Public Housing Authority	73	—	—
Eastern Carolina Human Services Agency, Inc. ¹⁴⁵	75	—	—
Fayetteville Metropolitan Housing Authority	62	—	—
Franklin Vance Warren Opportunity, Inc. ¹⁴⁵	—	150	—
Gastonia Housing Authority	52	100	—
Housing Authority of Graham	—	—	—
Housing Authority of Laurinburg	—	—	—
Housing Authority of Lexington	—	50	—
Housing Authority of the City of Asheville	37	75	—
Housing Authority of the City of Charlotte	72	275	—
Housing Authority of the City of Concord	—	—	—
Housing Authority of the City of Goldsboro	20	—	—
Housing Authority of the City of Greensboro	200	400	—
Housing Authority of the City of Greenville	40	—	—
Housing Authority of the City of High Point	148	—	—
Housing Authority of the City of Lumberton	—	—	—

¹⁴³ [Data](http://www.tacinc.org/knowledge-resources/vouchers-database/) from: <http://www.tacinc.org/knowledge-resources/vouchers-database/>

¹⁴⁴ Data includes the most recent awards announced in [PIH Notice-2020-22](#).

¹⁴⁵ Private non-profit organization that manages special purpose vouchers.

PHA	Mainstream ¹⁴⁴	NED	NED Cat 2
Housing Authority of the City of Wilmington	37	50	5
Housing Authority of the City of Wilson	4	—	—
Housing Authority of the City of Winston-Salem	278	378	—
Housing Authority of the County of Wake	13	100	—
Mid-East Regional Housing Authority	38	—	—
Monroe Housing Authority	39	—	—
Mountain Projects, Inc. ¹⁴⁵	75	—	—
North Carolina Commission of Indian Affairs ¹⁴⁶	39	—	—
Northwestern Regional Housing Authority	110	64	—
Rocky Mount Housing Authority	39	—	—
Sandhills Community Action Program, Inc. ¹⁴⁵	39	—	—
The Housing Authority of the City of Durham	33	200	—
Western Piedmont Council of Governments	246	—	—
Town of East Spencer Housing Authority	—	50	—
Western Carolina Community Action ¹⁴⁵	—	30	—
TOTAL	1,795	2,047	5

On June 14, 2011, HUD published [PIH Notice 2011-32](#), a critical document for ensuring the effective utilization of all the NED vouchers described above. All PHAs should now be clear that, upon turnover, those vouchers must continue to be provided ONLY to nonelderly disabled households.

HCV Utilization Rates

Data related to the utilization of Special Purpose Vouchers by household type in 65 PHAs in North Carolina is in Table I-2. As illustrated below, the utilization rate by *non-elderly disabled individuals* in 39 of the 65 PHAs that administer housing choice vouchers in North Carolina was lower than the national

¹⁴⁶ State agency that manages special purpose vouchers.

rate of 20%. For elderly households, the utilization rate by *elderly disabled individuals* was less than the national rate of 18% for 35 of the 65 PHAs that administer vouchers in North Carolina.

Table I-2. Housing Choice Voucher Utilization Rates (Tenant Based Vouchers Only) by Nonelderly Disabled and Elderly Disabled Individuals¹⁴⁷

PHA	% Nonelderly individuals with disabilities	% Elderly individuals with disabilities
Albemarle Dept of Public Housing	14	15
Asheboro Housing Authority	27	23
Asheville Housing Authority	26	22
Bladenboro Housing Authority	16	10
Brunswick County Housing Authority	22	26
Caswell County Housing	15	16
Chatham County Housing Authority	12	17
Choanoke Area Development Association, Inc.	19	13
Coastal Community Action, Inc. ¹⁴⁸	22	23
Columbus County Housing Authority	23	21
Concord Housing Authority	9	12
Durham Housing Authority	19	16
East Spencer Housing Authority	13	30
Eastern Carolina Human Services Agency, Inc.	22	22
Economic Improvement Council, Inc. ¹⁴⁸	14	15
Fayetteville Housing Authority	17	14
Four Square Community Action, Inc. ¹⁴⁸	31	28
Franklin-Vance-Warren	19	23

¹⁴⁷ Data from: [HUD Resident Characteristics Report on December 31, 2020](https://www.hud.gov/program_offices/public_indian_housing/systems/pic/50058/rcr): www.hud.gov/program_offices/public_indian_housing/systems/pic/50058/rcr

¹⁴⁸ Private nonprofit organization that manages Housing Choice Vouchers.

PHA	% Nonelderly individuals with disabilities	% Elderly individuals with disabilities
Gastonia Housing Authority	20	13
Goldsboro Housing Authority	18	17
Graham Housing Authority	23	16
Greene County Public Housing Agency	18	12
Greensboro Housing Authority	27	20
Greenville Housing Authority	16	16
Hickory Housing Authority	20	18
High Point Housing Authority	17	15
Housing Authority of the County of Wake	15	15
Isothermal ¹⁴⁸	21	19
Johnston County Housing	22	19
Kinston Housing Authority	17	18
Laurinburg Housing Authority	19	9
Lexington Housing Authority	28	25
Lincolnton Housing Authority	23	19
Lumberton Housing Authority	21	18
Macon Program For Progress ¹⁴⁸	35	33
Madison County Housing Authority	19	23
Mid-East Reg Housing Authority	11	8
Monroe Housing Authority	11	7
Mountain Projects Inc. ¹⁴⁸	34	18
Nash-Edgecombe Econ Dev, Inc. ¹⁴⁸	13	13
NC Commission of Indian Affairs ¹⁴⁹	18	13

¹⁴⁹ State agency that manages Housing Choice Vouchers.

PHA	% Nonelderly individuals with disabilities	% Elderly individuals with disabilities
Northwestern Regional Housing Authority	25	17
Orange County Housing Authority	25	29
Pender County Housing Department	19	14
Piedmont Triad Regional Council	29	18
Raleigh Housing Authority	17	19
Roanoke-Chowan Reg Housing Authority	16	16
Rockingham Housing Authority	20	22
Rocky Mount Housing Authority	21	10
Rowan County Housing Authority	14	9
Sandhills Community Action Program, Inc. ¹⁴⁸	7	6
Sanford Housing Authority	15	18
Southeastern Community & Family Services, Inc. ¹⁴⁸	16	10
Statesville Housing Authority	16	12
The New Reidsville Housing Authority	22	19
Thomasville Housing Authority	13	14
Twin Rivers Opportunities, Inc. ¹⁴⁸	15	16
Wadesboro Housing Authority	14	8
Washington Housing Authority	11	16
Western Carolina Community Action, Inc.	29	26
Western Piedmont Council of Governments	34	21
Williamston Housing Authority	13	15
Wilmington Housing Authority	18	22
Wilson Housing Authority	13	19
Winston-Salem Housing Authority	14	9

PHA	% Nonelderly individuals with disabilities	% Elderly individuals with disabilities
STATE AVERAGE	20	17
NATIONAL AVERAGE	20	18

Public Housing Units

In addition to the numerous Housing Choice Vouchers in North Carolina, there are currently 80 active PHAs in North Carolina with Public Housing units. The PHAs in North Carolina administer a total of 21,588 public housing units. Table I-3 below shows the PHAs with public housing units.

Table I-3. PHAs in North Carolina with Public Housing Units¹⁵⁰

PHA	Units
Albemarle Department of Public Housing	189
Andrews Housing Authority	46
Asheboro Housing Authority	190
Beaufort Housing Authority	93
Benson Housing Authority	163
Bladen Housing Authority	75
Bladenboro Housing Authority	74
Brevard Housing Authority	161
Burlington Housing Authority	352
Chapel Hill Department of Housing	271
Concord Housing Authority	156
Durham Housing Authority	1,087
East Carolina Regional Housing Authority	723
Edenton Housing Authority	96

¹⁵⁰ Data from: [HUD Resident Characteristics Report](https://www.hud.gov/program_offices/public_indian_housing/systems/pic/50058/rcr) on December 31, 2020: www.hud.gov/program_offices/public_indian_housing/systems/pic/50058/rcr

PHA	Units
Elizabeth City Housing Authority	308
Fairmont Housing Authority	48
Farmville Housing Authority	169
Fayetteville Housing Authority	736
Forest City Housing Authority	142
Goldsboro Housing Authority	1,155
Graham Housing Authority	167
Greenville Housing Authority	679
Hamlet Housing Authority	211
Hendersonville Housing Authority	21
High Point Housing Authority	842
Hot Springs Housing Authority	59
Housing Authority of the County of Wake	310
Kings Mountain Housing Authority	236
Kinston Housing Authority	707
Lenoir Housing Authority	153
Lincolnton Housing Authority	239
Lumberton Housing Authority	526
Madison County Housing Authority	35
Madison Housing Authority	43
Mars Hill Housing Authority	46
Marshall Housing Authority	46
Mid-East Regional Housing Authority	173
Monroe Housing Authority	193
Mooresville Housing Authority	106
Morganton Housing Authority	239

PHA	Units
Mount Airy Housing Authority	286
Mount Gilead Housing Authority	30
Mount Olive Housing Authority	19
Murphy Housing Authority	17
New Bern Housing Authority	100
North Wilkesboro Housing Authority	190
Northwestern Regional Housing Authority	79
Oxford Housing Authority	248
Pembroke Housing Authority	240
Plymouth Housing Authority	183
Raleigh Housing Authority	1,389
Randleman Housing Authority	71
Roanoke Rapids Housing Authority	239
Roanoke-Chowan Regional Housing Authority	308
Robersonville Housing Authority	100
Robeson County Housing Authority	286
Rockingham Housing Authority	172
Rocky Mount Housing Authority	739
Rowan County Housing Authority	171
Roxboro Housing Authority	166
Sanford Housing Authority	158
Selma Housing Authority	164
Shelby Housing Authority	172
Smithfield Housing Authority	193
Spruce Pine Housing Authority	75
Star Housing Authority	26

PHA	Units
Statesville Housing Authority	522
The New Reidsville Housing Authority	96
Thomasville Housing Authority	249
Troy Housing Authority	76
Valdese Housing Authority	121
Vance County Housing Authority	74
Wadesboro Housing Authority	166
Washington Housing Authority	366
Waynesville Housing Authority	97
Whiteville Housing Authority	53
Williamston Housing Authority	143
Wilmington Housing Authority	717
Wilson Housing Authority	461
Winston-Salem Housing Authority	1,361
TOTAL	21,588

Public Housing Utilization Rates

According to data from HUD, as of December 31, 2020, 15% of the public housing units owned and operated by PHAs statewide were occupied by *nonelderly individuals with disabilities*, which is lower than the national utilization rate of 16%. *Elderly disabled individuals* occupied 14% of public housing units in North Carolina, which is lower than the national utilization rate of 17%.

Table I-4 below shows public housing utilization rates by nonelderly individuals with disabilities and elderly individuals with disabilities.

Table I-4. Public Housing Utilization Rates by Nonelderly Disabled and Elderly Disabled¹⁵¹

PHA	% Nonelderly individuals with disabilities	% Elderly individuals with disabilities
Ahoskie Housing Authority	16	16
Albemarle Dept of Public Housing	12	20
Andrews Housing Authority	11	22
Asheboro Housing Authority	9	12
Ayden Housing Authority	16	22
Beaufort Housing Authority	16	12
Belmont Housing Authority	15	6
Benson Housing Authority	13	17
Bladen Housing Authority	16	3
Bladenboro Housing Authority	9	14
Brevard Housing Authority	18	11
Burlington Housing Authority	12	3
Chapel Hill Department of Housing	10	8
Concord Housing Authority	9	6
Dunn Housing Authority	16	13
Durham Housing Authority	14	18
E Carolina Reg Housing Authority	19	12
Edenton Housing Authority	16	9
Elizabeth City Housing Authority	16	10
Fairmont Housing Authority	31	8
Farmville Housing Authority	8	12
Fayetteville Housing Authority	14	13

¹⁵¹ Data from: [HUD Resident Characteristics Report](https://www.hud.gov/program_offices/public_indian_housing/systems/pic/50058/rcr) on December 31, 2020:
https://www.hud.gov/program_offices/public_indian_housing/systems/pic/50058/rcr

Forest City Housing Authority	4	5
Goldsboro Housing Authority	17	15
Graham Housing Authority	7	7
Greensboro Housing Authority	11	11
Greenville Housing Authority	15	16
Hamlet Housing Authority	10	17
Hendersonville Housing Authority	24	10
High Point Housing Authority	22	15
Hot Springs Housing Authority	17	14
Housing Authority of the County of Wake	17	14
Kings Mountain Housing Authority	18	11
Kinston Housing Authority	15	7
Lenoir Housing Authority	11	9
Lincolnton Housing Authority	15	12
Lumberton Housing Authority	17	14
Madison County Housing Authority	0	5
Madison Housing Authority	11	7
Mars Hill Housing Authority	13	26
Marshall Housing Authority	15	17
Mid-East Reg Housing Authority	15	19
Monroe Housing Authority	12	8
Mooresville Housing Authority	16	12
Morganton Housing Authority	9	7
Mount Airy Housing Authority	20	16
Mount Gilead Housing Authority	13	17
Mount Olive Housing Authority	0	5
Murphy Housing Authority	4	7

N Wilkesboro Housing Authority	16	10
New Bern Housing Authority	13	10
Northwestern Regional Housing Authority	10	6
Oxford Housing Authority	13	10
Pembroke Housing Authority	15	14
Plymouth Housing Authority	8	14
Raleigh Housing Authority	10	20
Randleman Housing Authority	14	24
Roanoke Rapids Housing Authority	13	21
Roanoke-Chowan Reg Housing Authority	15	11
Robersonville Housing Authority	12	22
Robeson County Housing Authority	14	13
Rockingham Housing Authority	13	11
Rocky Mount Housing Authority	10	9
Rowan County Housing Authority	16	6
Roxboro Housing Authority	15	6
Sanford Housing Authority	26	20
Selma Housing Authority	13	9
Shelby Housing Authority	17	22
Smithfield Housing Authority	18	16
Spruce Pine Housing Authority	15	5
Star Housing Authority	0	15
Statesville Housing Authority	15	12
Tarboro Housing Authority	11	11
The New Reidsville Housing Authority	10	4
Thomasville Housing Authority	12	11
Troy Housing Authority	19	8

Valdese Housing Authority	22	14
Vance County Housing Authority	5	9
Wadesboro Housing Authority	18	18
Washington Housing Authority	13	25
Waynesville Housing Authority	11	9
Whiteville Housing Authority	17	11
Williamston Housing Authority	10	8
Wilmington Housing Authority	17	18
Wilson Housing Authority	17	20
Winston-Salem Housing Authority	22	14
STATE AVERAGE	15	14
NATIONAL AVERAGE	16	17

Resources Administered by State and Local Community Development

Each year, Congress appropriates billions of dollars that go directly to all states, most urban counties, and communities “entitled” to receive federal funds directly from HUD. Before states and communities can receive these funds, they must have a HUD-approved Consolidated Plan (ConPlan). A list of the [HUD-approved Consolidated Plans from North Carolina, along with contact persons](https://www.hudexchange.info/consolidated-plan/con-plans-aaps-capers/) can be found online at <https://www.hudexchange.info/consolidated-plan/con-plans-aaps-capers/>

The ConPlan must outline a plan for the use of federal housing funds including:

- Community Development Block Grant (CDBG)
- HOME Investment Partnerships Program (HOME)
- Housing Opportunities for Persons with AIDS (HOPWA)
- Emergency Solutions Grant (ESG)

Table I-5 below are the points of contact for the State of North Carolina’s federal housing funds included in the ConPlan.

Table I-5. FY 2020 Consolidated Plan Administer Agencies for State of North Carolina¹⁵²

CDBG	ESG	HOME	HOPWA
<p><u>Iris Payne</u> Programs and Compliance Section Chief Department of Commerce, Rural Economic Development Division</p> <p>4346 Mail Service Center Raleigh, NC 27699-4346 919-814-4663 ipayne@nccommerce.com</p>	<p><u>Joseph Breen</u> Homeless Programs Coordinator Health and Human Services, Division of Aging and Adult Services</p> <p>2101 Mail Service Center Raleigh, NC 27699-2101 919-855-3435 joseph.breen@dhhs.nc.gov</p>	<p><u>Barbara Waring</u> Compliance, Policy and Reporting Policy, Planning and Technology</p> <p>P.O. Box 28066 Raleigh, NC 27611 919-877-5706 bwaring@nchfa.com</p>	<p><u>Robert Winstead</u> HIV Care Program Manager Department of Health and Human Services</p> <p>225 N. McDowell Street Raleigh, NC 27699 919-755-3122 robert.winstead@dhhs.nc.gov</p>

Table I-6 below are the communities that receive Community Planning and Development (CPD) funding, including the funding allocated through the CARES Act, across North Carolina by program and award.

Table I-6. FY 2020 CPD Funded Communities¹⁵³

Administration Area	Program Name	Award Amount
Asheville, NC	CDBG-CV1	\$ 615,934.00
	CDBG-CV3	\$ 889,456.00
	CDBG	\$ 1,047,092.00
	HOME	\$ 1,335,301.00
Burlington, NC	CDBG-CV1	\$ 277,455.00
	CDBG-CV3	\$ 344,077.00
	CDBG	\$ 471,648.00
Cary, NC	CDBG-CV1	\$ 408,652.00
	CDBG-CV3	\$ 720,175.00
	CDBG	\$ 694,670.00
Chapel Hill, NC	CDBG-CV1	\$ 245,693.00

¹⁵² [Data](https://www.hudexchange.info/grantees/contacts/) from: https://www.hudexchange.info/grantees/contacts/

¹⁵³ [Data](https://www.hudexchange.info/grantees/allocations-awards/) from: https://www.hudexchange.info/grantees/allocations-awards/

Administration Area	Program Name	Award Amount
	CDBG-CV3	\$ 290,902.00
	CDBG	\$ 417,655.00
Charlotte, NC	CDBG-CV1	\$ 3,514,923.00
	CDBG-CV3	\$ 4,919,487.00
	CDBG	\$ 5,975,046.00
	ESG-CV1	\$ 1,765,572.00
	ESG-CV2	\$ 6,866,990.00
	ESG	\$ 512,016.00
	HOME	\$ 3,241,207.00
	HOPWA-Formula	\$ 2,860,489.00
	HOPWA-Formula-CV	\$ 416,283.00
Concord, NC	CDBG-CV1	\$ 400,339.00
	CDBG-CV3	\$ 604,865.00
	CDBG	\$ 680,540.00
	HOME	\$ 1,304,995.00
Cumberland County, NC	CDBG-CV1	\$ 509,194.00
	CDBG-CV3	\$ 435,210.00
	CDBG	\$ 865,583.00
	HOME	\$ 398,574.00
Durham, NC	CDBG-CV1	\$ 1,202,601.00
	CDBG-CV3	\$ 1,513,616.00
	CDBG	\$ 2,044,310.00
	ESG-CV1	\$ 602,383.00
	ESG-CV2	\$ 2,060,285.00
	ESG	\$ 174,691.00
	HOME	\$ 1,165,206.00

Administration Area	Program Name	Award Amount
	HOPWA-Formula	\$ 483,344.00
	HOPWA-Formula-CV	\$ 70,340.00
Fayetteville, NC	CDBG-CV1	\$ 902,653.00
	CDBG-CV3	\$ 943,468.00
	CDBG	\$ 1,534,426.00
	HOME	\$ 905,172.00
Gastonia, NC	CDBG-CV1	\$ 386,391.00
	CDBG-CV3	\$ 484,878.00
	CDBG	\$ 656,830.00
	HOME	\$ 805,905.00
Goldsboro, NC	CDBG	\$ 206,554.00
	CDBG	\$ 220,749.00
	CDBG	\$ 351,137.00
	HOME	\$ 237,076.00
Greensboro, NC	CDBG-CV1	\$ 1,329,635.00
	CDBG-CV3	\$ 1,611,310.00
	CDBG	\$ 2,260,258.00
	ESG-CV1	\$ 675,621.00
	ESG-CV2	\$ 1,880,847.00
	ESG	\$ 195,930.00
	HOME	\$ 1,820,790.00
	HOPWA-Formula	\$ 533,970.00
	HOPWA-Formula-CV	\$ 77,708.00
Greenville, NC	CDBG-CV1	\$ 575,301.00
	CDBG-CV3	\$ 589,258.00
	CDBG	\$ 977,960.00

Administration Area	Program Name	Award Amount
	HOME	\$ 545,511.00
Hickory, NC	CDBG-CV1	\$ 194,604.00
	CDBG-CV3	\$ 274,226.00
	CDBG	\$ 330,809.00
High Point, NC	CDBG-CV1	\$ 552,706.00
	CDBG-CV3	\$ 588,651.00
	CDBG	\$ 939,549.00
	HOME	\$ 544,069.00
Jacksonville, NC	CDBG-CV1	\$ 219,446.00
	CDBG	\$ 310,803.00
	CDBG	\$ 373,037.00
Kannapolis, NC	CDBG-CV1	\$ 230,437.00
	CDBG-CV3	\$ 264,857.00
	CDBG	\$ 391,721.00
Lenoir, NC	CDBG-CV1	\$ 86,056.00
	CDBG-CV3	\$ 88,397.00
	CDBG	\$ 146,288.00
	HOME	\$ 1,145,874.00
Mecklenburg County, NC	CDBG-CV1	\$ 467,087.00
	CDBG-CV3	\$ 857,608.00
	CDBG	\$ 794,006.00
Morganton, NC	CDBG-CV1	\$ 87,803.00
	CDBG-CV3	\$ 106,060.00
	CDBG	\$ 149,257.00
New Bern, NC	CDBG-CV1	\$ 152,252.00
	CDBG-CV3	\$ 194,483.00

Administration Area	Program Name	Award Amount
	CDBG	\$ 258,814.00
North Carolina	CDBG-CV1	\$ 28,517,231.00
	CDBG-CV2	\$ 28,363,678.00
	CDBG-CV3	\$ 23,037,981.00
	CDBG	\$ 48,537,754.00
	ESG-CV1	\$ 18,423,179.00
	ESG-CV2	\$ 35,948,234.00
	ESG	\$ 5,342,722.00
	HOME	\$ 18,171,161.00
	HOPWA-Formula	\$ 3,610,021.00
	HOPWA-Formula-CV	\$ 525,361.00
	Orange County, NC	HOME
Raleigh, NC	CDBG-CV1	\$ 1,878,051.00
	CDBG-CV3	\$ 2,672,436.00
	CDBG	\$ 3,192,514.00
	ESG-CV1	\$ 950,338.00
	ESG-CV2	\$ 3,503,113.00
	ESG	\$ 275,598.00
	HOME	\$ 1,464,643.00
Rocky Mount, NC	CDBG-CV1	\$ 309,806.00
	CDBG-CV3	\$ 328,242.00
	CDBG	\$ 526,640.00
	HOME	\$ 579,250.00
Salisbury, NC	CDBG-CV1	\$ 168,950.00
	CDBG-CV3	\$ 200,221.00
	CDBG	\$ 287,229.00

Administration Area	Program Name	Award Amount
Surry County, NC	HOME	\$ 571,230.00
Union County, NC	CDBG-CV1	\$ 518,322.00
	CDBG-CV3	\$ 539,180.00
	CDBG	\$ 881,099.00
Wake County, NC	CDBG-CV1	\$ 1,258,790.00
	CDBG-CV3	\$ 1,619,695.00
	CDBG	\$ 2,139,826.00
	ESG-CV1	\$ 626,800.00
	ESG-CV2	\$ 1,709,995.00
	ESG	\$ 181,772.00
	HOME	\$ 965,130.00
	HOPWA-Formula	\$ 911,546.00
	HOPWA-Formula-CV	\$ 132,656.00
Wilmington, NC	CDBG-CV1	\$ 612,032.00
	CDBG-CV3	\$ 883,609.00
	CDBG	\$ 1,040,399.00
	HOME	\$ 692,384.00
Winston-Salem, NC	CDBG-CV1	\$ 1,300,830.00
	CDBG-CV3	\$ 1,375,863.00
	CDBG	\$ 2,211,290.00
	ESG-CV1	\$ 660,748.00
	ESG-CV2	\$ 2,047,257.00
	ESG	\$ 191,617.00
	HOME	\$ 1,323,652.00

Table I-7 below shows highlights of investments in rental housing and services that could support people with disabilities outlined in community ConPlans in North Carolina.

Table I-7. Consolidated Plan Highlights¹⁵⁴

Jurisdiction	Timeframe	Investment Highlights
Durham	2020–2024	<ul style="list-style-type: none"> HOME investments in Multifamily rental new construction, Multifamily rental rehab, and TBRA HOPWA investments in TBRA to assist 75 households and housing for 5 households Goal of rehabilitating 66 rental units and constructing 63 rental units with CDBG and HOME investments
Fayetteville	2020–2024	<ul style="list-style-type: none"> HOME investments in Multifamily rental new construction, Multifamily rental rehab, and TBRA; goal to construct 350 rental units CDBG investment in housing education with goal of assisting 250 households, tenant-based rental assistance/rapid rehousing with goal to assist 400 households
Gastonia	2020–2024	<ul style="list-style-type: none"> Goal of constructing 30 rental units and assist 250 households with tenant-based rental assist through CDBG and HOME investments
Goldsboro	2020–2024	<ul style="list-style-type: none"> HOME investments to increase affordable rental housing options by constructing 156 rental units.
Greensboro	2020–2024	<ul style="list-style-type: none"> CDBG investments in housing and public services HOME investments in Multifamily rental new construction, Multifamily rental rehab, and TBRA HOPWA investments in permanent housing, supportive services, and TBRA ESG investments in rental assistance Goal to increase the supply of decent affordable housing by constructing 300 rental units, rehabilitating 5 housing units, and assisting 670 households with tenant-based rental assistance
Greenville	2018–2022	<ul style="list-style-type: none"> CDBG investments in housing and public services; goal to provide supportive services for special needs to 2,500 persons HOME investments in Multifamily rental new construction, Multifamily rental rehab, and TBRA Goal to construct 10 rental units and rehabilitate 10 units
Hickory	2020–2024	<ul style="list-style-type: none"> CDBG investment in housing and public services but no

¹⁵⁴ [Consolidated Plans](https://www.hudexchange.info/programs/consolidated-plan/con-plans-aaps-capers/) can be found at <https://www.hudexchange.info/programs/consolidated-plan/con-plans-aaps-capers/>

Jurisdiction	Timeframe	Investment Highlights
		clear investments in rental housing or supportive services for people with disabilities
Morganton	2020–2024	<ul style="list-style-type: none"> CDBG investment in public services for non-homeless special needs
New Bern	2019–2023	<ul style="list-style-type: none"> Goal of constructing 2 rental units with CDBG
North Carolina	2016–2020	<ul style="list-style-type: none"> Goal to construct 1776 rental units HOPWA investments in tenant-based rental assistance for 1,294 households and housing operations for 75 units ESG investments in rental assistance
Orange County	2020–2024	<ul style="list-style-type: none"> HOME investments to construct 15 rental units and assist 25 households with tenant-based rental assistance CDBG investments in supportive services to assist 250 households
Rocky Mount	2018–2021	<ul style="list-style-type: none"> Investments primarily in homeownership
Union County	2016–2020	<ul style="list-style-type: none"> CDBG investment in public services for homeless and non-homeless special needs to assist 4,000 persons
Wake County	2020–2025	<ul style="list-style-type: none"> CDBG and HOME investments to construct 200 rental units and rehabilitate 25 rental units CDBG, HOPWA, and ESG investments to support vulnerable populations in accessing affordable housing with tenant-based rental assistance and services
Wilmington	2017–2021	<ul style="list-style-type: none"> Goal to construct 100 rental units CDBG investments in education and supportive services for non-homeless special needs populations
Winston-Salem	2018–2022	<ul style="list-style-type: none"> CDBG investment to rehabilitate 260 rental units and construct 250 rental units

Community Development Block Grant

Authorized by Title I of the Housing and Community Development Act of 1974, the Community Development Block Grant (CDBG) Program is one of the longest continuously run programs at HUD. The funds are a block grant that can be used to address critical and unmet community needs including those for housing rehabilitation, public facilities, infrastructure, economic development, public services and more. Since 1974, it has invested \$144 billion in communities nationwide and each year approximately 95% of funds are invested in activities that primarily benefit low- and moderate-income persons.

HUD determines the amount of each grant by using a formula containing several measures of community need, including the extent of poverty, population, housing overcrowding, and age of

housing. The annual CDBG appropriation is allocated between states and local jurisdictions called "non-entitlement" and "entitlement" communities, respectively. Entitlement communities consist of central cities of Metropolitan Statistical Areas (MSAs); metropolitan cities with populations of at least 50,000; and qualified urban counties with a population of 200,000 or more (excluding the populations of entitlement cities). States distribute CDBG funds to non-entitlement localities not qualified as entitlement communities.

Each grantee receiving CDBG funds is free to determine what activities it will fund if certain requirements are met. Each activity must be eligible according to HUD regulations and meet one of the following national objectives:

- Benefits persons of low- and moderate-income;
- Aids in the prevention or elimination of slums or blight; or
- Meets an urgent housing/community development need¹⁵⁵ that the grantee is unable to finance on its own or with other funding sources.

Many states and communities use CDBG resources to support essential public services such as operating homeless shelters, providing support services to special needs populations, and making accessibility modifications to housing for people with disabilities. North Carolina received \$201,204,693 in CDBG funds in FY 2020.

CDBG-CV Funding

In response to the coronavirus pandemic, Congress passed the Coronavirus Aid, Relief, and Economic Security (CARES) Act which appropriated supplemental funding to CDBG entitlement communities. The first round of funding was released to communities in April 2020, and the second and third rounds released in May 2020. While the funds are administered through the CDBG Program, on August 10, 2020, HUD released the [CDBG-CV Notice](#) outlining additional flexibilities and limitations on the use of CDBG-CV funding.

The State of North Carolina received a total of \$79,918,890 in CDBG-CV. Other communities in the state also received supplemental funding amounting to \$201,533,464. Supplemental funding amounts by community can be found in Table I-6 above.

HOME Investment Partnerships Program (HOME)

The federal government created the HOME Investment Partnerships Program (HOME) in 1990. The HOME program is a formula grant of federal housing funds given to states and localities (referred to

¹⁵⁵ Urgent development is defined as posing a serious and immediate threat to the health or welfare of the community in the past 18 months.

as “participating jurisdictions” or PJs). North Carolina received approximately \$37.6 million in HOME funds in FY 2020.

HOME funds can be used to:

- Build, buy, and renovate rental housing;
- Finance homeownership opportunities;
- Repair homes, including making buildings physically accessible; or
- Provide rental subsidies to eligible households.

Specifically, HOME resources can be used to cover the cost of acquiring land and buildings, renovating properties, as well as constructing new rental housing. However, HOME funds cannot be used to fund ongoing housing operating costs. Funds can be provided for projects developed by both for-profit and nonprofit developers and can be made available in the form of grants or loans, which are designed to ensure affordability. Sometimes HOME funds are used to cover costs incurred to determine if a project is feasible, such as architect and engineering fees.

The rental housing developed using HOME funds can take on many forms. The units can range in size from Single Room Occupancy (SRO) units or efficiencies (studios) to multi-bedroom apartments. HOME-funded rental housing can be as small as a single-family home or as large as an apartment complex with hundreds of units.

All housing developed with HOME funds must serve low- and very low-income individuals and families. For rental housing, at least 90% of HOME funds must benefit families whose incomes are at or below 60% of AMI; the remaining 10% must benefit families with incomes at or below 80% of AMI. However, the fact that HOME funds cannot be used to subsidize the operating costs of rental housing can be a barrier to using the program for people with extremely low- incomes (i.e., below 30% of the AMI).

Housing Opportunities for Persons with AIDS (HOPWA)

HOPWA funding provides housing assistance and related supportive services by grantees who are encouraged to develop community-wide strategies and form partnerships with area nonprofit organizations. HOPWA funds may be used for a wide range of housing, social services, program planning, and development costs. These include, but are limited to, the acquisition, rehabilitation, or new construction of housing units; costs for facility operations; rental assistance; and short-term payments to prevent homelessness. HOPWA funds also may be used for health care and mental health services, chemical dependency treatment, nutritional services, case management, assistance with daily living, and other supportive services.¹⁵⁶

¹⁵⁶ [Data](https://www.hudexchange.info/hopwa/) from <https://www.hudexchange.info/hopwa/>

HOPWA funds are awarded through the Consolidated Plan as a block grant to states and larger metropolitan areas based on the incidences of AIDS in these areas and competitively through an annual Notice of Funding Availability (NOFA). North Carolina has five HOPWA recipients through the formula process and received over \$9 million in FY 2020.

HOPWA Formula-CV Funding

In response to the coronavirus pandemic, the CARES Act appropriated additional HOPWA funding. In April 2020, HOPWA recipients in North Carolina received supplemental funding amounting to \$6,761,229. Supplemental funding amounts by community can be found in Table I-6 above.

Emergency Solutions Grant (ESG)

On May 20, 2009 President Obama enacted the Homeless Emergency and Rapid Transition to Housing (HEARTH) Act of 2009. The HEARTH Act provides communities with new resources and better tools to prevent and end homelessness, including revamping the ESG program. The key changes that reflect this new emphasis are the expansion of the homelessness prevention component of the program and the addition of a new rapid re-housing assistance component.

The current ESG program provides federal grants to states and localities based on a formula. To receive ESG funds, each state/entitlement community must submit a Consolidated Plan to HUD describing how the ESG resources will be used to meet local needs.

Under HEARTH, ESG eligible components include:

- Street Outreach
- Emergency Shelter
- Homelessness Prevention
- Rapid Re-Housing
- Homeless Management Information Systems (HMIS)
- Administration (up to 7.5% of ESG allocation)

North Carolina has seven ESG recipients who received a total of \$82.5 million in FY 2020.

ESG-CV Funding

In response to the coronavirus pandemic, Congress appropriated significant supplemental funding to the ESG Program. The first round of funding was released to communities in April 2020 and the second round released in June 2020. While the funds are administered through the ESG Program, on September 1, 2020, HUD released the [ESG-CV Notice](#) outlining additional flexibilities and limitations on the use of ESG-CV funding.

North Carolina as a State Recipient received \$18,423,179 in Round 1 and \$ 35,948,234 in Round 2. All seven recipients received a total of \$84,083,692. Supplemental funding amounts by community can be found in Table I-6 above.

Continuum of Care

In 1987, Congress passed the first federal law specifically addressing homelessness. The Stewart B. McKinney Homeless Assistance Act of 1987, later renamed the McKinney-Vento Homeless Assistance Act, provides federal financial support for a variety of programs to meet the many needs of individuals and families who are homeless. The housing programs it authorizes are administered by HUD's Office of Special Needs Assistance Programs.

HUD designed the Continuum of Care planning process to promote the development of comprehensive systems to address homelessness by providing communities with a framework for organizing and delivering housing and services. The overall approach is predicated on the understanding that homelessness is not caused merely by a lack of shelter, but involves a variety of underlying, unmet needs: physical, economic, and social.

As an entity, a Continuum of Care serves two main purposes:

- To develop a **long-term strategic plan and manage a year-round planning** effort that addresses the identified needs of homeless individuals and households; the availability and accessibility of existing housing and services; and the opportunities for linkages with mainstream housing and services resources.
- To prepare an **application** for McKinney-Vento Homeless Assistance Act (McKinney-Vento) competitive grants.

These resources are invaluable in providing housing and supportive services for people who are homeless. These funds are made available through a national competition announced each year in HUD's Notice of Funding Availability (NOFA). Applications should demonstrate broad community participation and identify resources and gaps in the community's approach to providing outreach, emergency shelter, and transitional and permanent housing, as well as related services for addressing homelessness. An application also includes action steps to end homelessness, prevent a return to homelessness, and establishes local funding priorities.

According to the 2019 Housing Inventory Count which collects data from CoCs at a point in time in January, there were 1,673 total rapid rehousing beds and 5,798 total permanent supportive housing beds in North Carolina. Table I-8 below shows the amount of permanent housing by program component for the 11 CoCs in North Carolina. According to the 2019 Housing Inventory County, there was total of 1,673 rapid rehousing beds and 5,798 permanent supportive housing beds in North Carolina.

Table I-8. Permanent Housing in North Carolina CoCs (HIC, 2019)

Continuum of Care	Rapid Rehousing	Permanent Supportive Housing
NC-500 Winston-Salem/Forsyth County CoC	73	343
NC-501 Asheville/Buncombe County CoC	28	493
NC-502 Durham City & County CoC	188	332
NC-503 North Carolina Balance of State	336	1,720
NC-504 Greensboro, High Point CoC	34	486
NC-505 Charlotte/Mecklenburg County CoC	550	1,256
NC-506 Wilmington/Brunswick, New Hanover, Pender Counties CoC	30	202
NC-507 Raleigh/Wake County CoC	333	517
NC-509 Gastonia/Cleveland, Gaston, Lincoln Counties CoC	99	144
NC-511 Fayetteville/Cumberland County CoC	—	155
NC-513 Chapel Hill/Orange County CoC	—	88
NC-516 Northwest North Carolina CoC	2	62
TOTAL	1,673	5,798

On January 29, 2021, [HUD announced funding](#) to renew grants of existing CoC projects in lieu of a releasing a competitive FY20 NOFA. [A list of awards by state](#) can be found at https://www.hud.gov/program_offices/comm_planning/coc/fy20-funding-report.

National Housing Trust Fund

The Housing and Economic Recovery Act of 2008 established the Housing Trust Fund (HTF) which is administered by HUD as a block grant, giving states the ability to decide use of funds to support local housing needs. Under the program, 90% of the funds must be used for the production, preservation, rehabilitation, or operation of affordable rental housing and up to 10% may be used to support homeownership activities for first-time homebuyers, such as producing, rehabilitating, or preserving owner-occupied housing, as well as providing down payment assistance, closing costs, and interest rate

buy-downs. The North Carolina Housing Finance Agency (NCHFA) administer the National Housing Trust Fund resources for the State of North Carolina.

State-Specific Information

North Carolina's latest Annual Action Plan outlines goals for using Housing Trust Funds to help finance loans through NCHFA's Rental Production Program (RPP) and Integrated Supportive Housing Program (ISHP), which are used in conjunction with Low Income Housing Tax Credits (LIHTC), state-appropriated funds, and other private and local funding. The [Annual Action Plan](#) is available online at: https://files.nc.gov/nccommerce/documents/Rural-Development-Division/CDBG/2020-NC-AAP_FINAL-HUD-Submission-6.30.2020.pdf

Table I-9. National Housing Trust Fund Awards to North Carolina

Year	HTF Award
2016	\$ 3,280,235
2017	\$ 4,433,361
2018	\$ 5,874,191
2019	\$ 5,259,160
2020	\$ 7,251,897

State Resources

North Carolina Housing Finance Agency

The North Carolina Housing Finance Agency (NCHFA) finances and support a significant amount of housing for people with disabilities. NCHFA, a statewide housing finance agency administers federal funding, such as the Low-Income Housing Tax Credit Program, and state appropriations to fund housing.

North Carolina Housing Trust Fund

NCHFA administers the [North Carolina Housing Trust Fund \(Trust Fund\)](#) which is funded through annual appropriations. The NC General Assembly creates the Trust Fund in 1987 using \$19.8 million from a legal settlement the state received due to oil company overcharges. The North Carolina Housing Partnership provides oversight, sets policy, and allocates funds for the Housing Trust Fund.

This flexible resource can finance home ownership and rental apartments, new construction, rehab and emergency repairs. It provides the state's largest source of funds to finance supportive housing and emergency repairs/accessibility modifications.

Since its creation, the Trust Fund has helped finance \$1.6 billion in housing construction and rehabilitation and financed 38,810 homes and apartments.¹⁵⁷ On March 24, 2021, Governor Roy Cooper released a FY2021-2023 budget proposal that increases the Trust Fund to \$15.4 million per year, doubling last year's allocation.¹⁵⁸

Supportive Housing Development Program

Supportive Housing Development Program financing is only available to developments serving populations of homeless or non-homeless households with special needs, including:

- Homeless persons
- Persons with mental, physical or developmental disabilities.
- Persons with substance use disorders.
- Children in foster care.
- Youth aging out of foster care.
- Adults released from correctional facilities.

Supportive housing developers can access up to \$700,000 in interest-free loans. The housing must serve individuals and families who earn below 50 percent of area median income. Rent and utilities cannot exceed 30 percent of the targeted income. Developments that provide food and transportation cannot exceed 40 percent of the targeted income.

Section 811 Supportive Housing for Persons with Disabilities Program

The Section 811 program funds the development of supportive housing for people with disabilities between the ages of 18 and 62. Historically, the program created group homes and congregate living situations for persons with disabilities. In January 2011, President Obama signed into law the Frank Melville Supportive Housing Investment Act of 2010, legislation to revitalize and reform the Section 811 program. The "traditional" option remains authorized within the reformed Section 811 program. However, the program includes two new approaches to creating integrated permanent supportive housing: the Modernized Capital Advance/Project Rental Assistance Contract (PRAC) multifamily option, and the Project Rental Assistance (PRA) option. Only nonprofit organizations were eligible to apply competitively through HUD for Section 811 PRA funding.

¹⁵⁷ Data provided by [NCHFA's Investment and Impact Report](https://2020.housingbuildsnc.com/#scene-1): <https://2020.housingbuildsnc.com/#scene-1>

¹⁵⁸Information provided by [North Carolina Housing Coalition's policy update](https://nchousing.org/policy-update-3-25-21/): <https://nchousing.org/policy-update-3-25-21/>

State-Specific Information

Until recent, North Carolina was not a recipient of Section 811 PRA program funds. In August 2020, North Carolina was awarded approximately \$7 million to fund rental assistance on approximately 161 units through the Section 811 PRA Program.

More information about Section 811 PRA can be found at:

<https://www.hudexchange.info/programs/811-pra/>

Low Income Housing Tax Credits

The federal government created the Low-Income Housing Tax Credit (LIHTC) program to encourage the development of new mixed-income rental housing that would benefit low-income households. The program is not administered by HUD, but by the Internal Revenue Service (IRS) within the US Department of Treasury. Housing developed under the program must be maintained as affordable rental housing for at least 15 years. Eligible types of rental housing include:

- Multi-family rental housing;
- Mixed-use projects that include both rental housing and commercial space;
- Single Room Occupancy (SRO) housing; and
- Scattered-sites that can be “bundled together” as one project.

According to the LIHTC program guidelines, the minimum number of affordable units required in each LIHTC property is determined by the following federal formula:

- For a LIHTC project targeted to assist households at 50% of AMI and below, at least 20% of the units in the project must be affordable; or
- For a LIHTC project targeted to households between 50-60% of AMI, at least 40% of the units in the project must be affordable.

States can choose to require deeper affordability standards, such as a requirement that a certain number of units be affordable to people with incomes at 30% of AMI.

In addition, newly constructed or substantially rehabilitated properties financed with LIHTC are required have 5% of the units accessible to people with mobility impairments and an additional 2% of the units accessible to people with sensory impairments. Because of the accessibility standards and the opportunity to create more deeply subsidized housing, the LIHTC program is a valuable housing resource for people with disabilities.

A Qualified Allocation Plan (QAP) is the strategic planning document that the LIHTC program requires states to develop describing how the LIHTC program will be utilized to meet the housing needs and housing priorities of the state. This plan must be submitted to the Department of Treasury/IRS each year for the state to receive its LIHTC allocation from the federal government.

State-Specific Information

The latest Qualified Allocation Plan (QAP) for North Carolina is available online at: https://www.nchfa.com/sites/default/files/page_attachments/QAP21-FinalQAP.pdf. To find LIHTC properties financed in NC, you can use the LIHTC Database: <https://lihtc.huduser.gov/>

Transitions to Community Living Initiative

In several programs, NCHFA partners with North Carolina’s Department of Health and Human Services (DHHS) to provide housing and services to people with disabilities living in the community. The following programs are efforts of the Transitions to Community Living Initiative which provides eligible adults living with serious mental illnesses the opportunity to choose where they live in North Carolina. Table I-10 below shows the active tenancies through the Transitions to Community Living Initiative by LME/MCO and subsidy. The Initiative currently supports 2,706 individuals in their community living.

Table I-10. Active Tenancies in TCL Initiative

LME/MCO	TCLV Program	Key Program	Other
Alliance Behavioral Healthcare	254	122	6
Cardinal Innovations Healthcare	566	135	15
Eastpointe	196	19	12
Partners Behavioral Health Management	234	68	13
Sandhills Center for MH/DD/SAS	251	47	10
Trillium Health Resources	321	86	17
Vaya Health	195	104	35
TOTAL	2,017	581	108

Targeting Program

The [Targeting Program](#) aims to increase access to LIHTC developments for individuals with disabilities and individuals experiencing homelessness. After several years of implementing various targeting efforts, NCHFA has now made targeting 10% of units for individuals with disabilities a Housing Credit Program threshold requirement and a requirement for all bond-financed development.

Approved service providers refer individuals through a process managed by DHHS to lease these units and rental assistance to subsidize the units comes from a variety of funding, including the Key Rental Assistance Program and federal HUD funding.

Table I-11 shows the Targeting Program households by subsidy source, with a total of 2,753 households.

Table I-11. Targeting Program by Subsidy Source

Subsidy Source	Targeted Households	Average Housing Assistance Amount
Key Rental Assistance Program	2,246	\$391.72
No Assistance	88	\$0.00
Other Assistance	13	\$434.05
Public Housing Operating Subsidy	4	\$146.42
RHCDS (FMHA Rental Assistance)	47	\$402.93
Section 8 Moderate Rehabilitation	1	\$765.27
Section 8 Project Based assistance	137	\$583.15
Section 8 Project Voucher	41	\$535.52
Section 8 Voucher	168	\$485.03
Transitions to Community Living Voucher (TCLV)	8	\$391.79
TOTAL	2,753	\$413.59

Table I-12 below shows the Targeting Program properties by county, with a total of 846 properties. As demonstrated in Table I-22, Wake, Mecklenburg, Guilford, and Cumberland Counties have the largest number of properties.

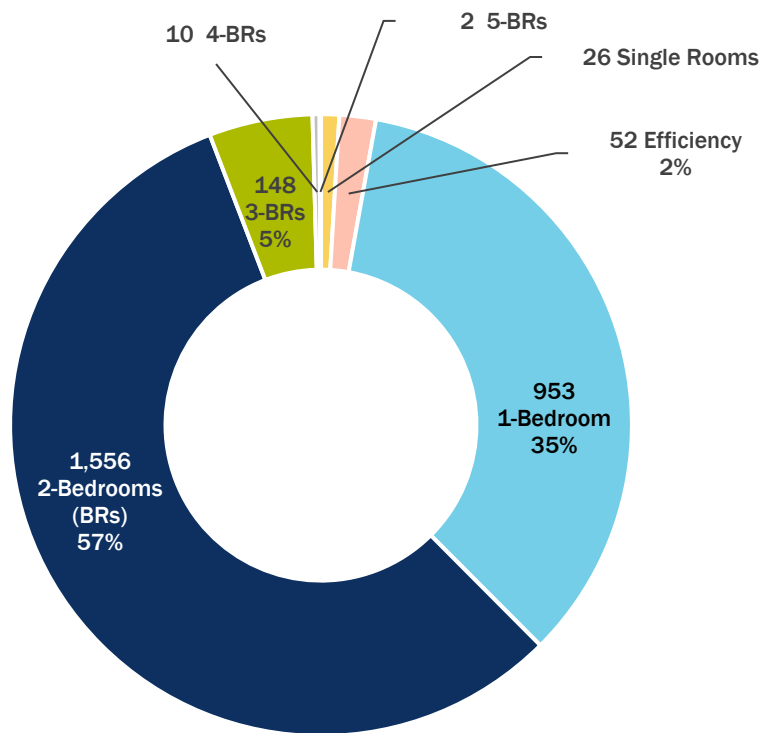
Table I-12. Targeting Program Properties by County

County	Props.	County	Props.	County	Props.
Alamance	11	Granville	4	Pasquotank	6
Alexander	4	Greene	1	Pender	1
Anson	3	Guilford	48	Person	3
Ashe	2	Halifax	11	Pitt	20
Avery	1	Harnett	10	Polk	1
Beaufort	5	Haywood	4	Randolph	9
Bladen	2	Henderson	8	Richmond	9
Brunswick	10	Hertford	4	Robeson	17
Buncombe	26	Hoke	8	Rockingham	16
Burke	8	Iredell	9	Rowan	10
Cabarrus	13	Jackson	3	Rutherford	6
Caldwell	11	Johnston	21	Sampson	2
Carteret	10	Jones	1	Scotland	6
Catawba	11	Lee	10	Stanly	7
Chatham	7	Lenoir	8	Stokes	3
Chowan	6	Lincoln	2	Surry	7
Cleveland	13	Macon	3	Transylvania	3
Columbus	10	Madison	1	Union	3
Craven	12	Martin	4	Vance	8
Cumberland	39	McDowell	3	Wake	91
Dare	1	Mecklenburg	62	Warren	3
Davidson	6	Montgomery	1	Washington	1

County	Props.	County	Props.	County	Props.
Davie	6	Moore	7	Watauga	1
Duplin	1	Nash	8	Wayne	13
Durham	24	New Hanover	17	Wilkes	4
Edgecombe	3	Northampton	2	Wilson	15
Forsyth	24	Onslow	13	Yadkin	3
Franklin	2	Orange	8	Yancey	2
Gaston	23	Pamlico	1	TOTAL	846

Figure I-1, below, shows the distribution by unit size of households in targeting units. The figure shows 1,556 households in two-bedroom units, which is 57% of all targeting program households. The average household size in the program is 1.8 individuals.

Figure I-1. Targeting Program Households by Unit Size.



Key Rental Assistance Program

In 2004, NCHFA and DHHS created the [Key Rental Assistance Program](#) to make units from the Targeting Program affordable to individuals with disabilities who have incomes as low as Supplemental Security Income (SSI). Since 2006, the NC General Assembly has funded reoccurring appropriations to DHHS for the program. The funding is used as rental assistance to subsidize the Targeted Units, specifically to pay the difference between the tenant's rent share and the Key Payment Standard directly to property management. The Key Program may also serve as a bridge subsidy to other ongoing, permanent rent subsidies like the local Housing Choice Voucher program.

As of January 31, 2021, there are 2,266 Key Program participants residing in units among 643 developments. The locations of these developments are outlined in Table I-13 below.

Table I-13. Key Program Properties by County

County	No.	County	No.	County	No.	County	No.
Alamance	8	Davie	6	Lee	9	Richmond	7
Alexander	3	Duplin	1	Lenoir	8	Robeson	12
Anson	3	Durham	17	Lincoln	2	Rockingham	12
Ashe	1	Edgecombe	3	Macon	3	Rowan	8
Beaufort	4	Forsyth	13	Madison	1	Rutherford	5
Bladen	2	Franklin	1	Martin	1	Sampson	2
Brunswick	8	Gaston	17	McDowell	3	Scotland	4
Buncombe	22	Granville	3	Mecklenburg	35	Stanly	7
Burke	7	Greene	1	Montgomery	1	Stokes	2
Cabarrus	10	Guilford	31	Moore	7	Surry	6
Caldwell	9	Halifax	9	Nash	5	Transylvania	2
Carteret	7	Harnett	9	New Hanover	12	Union	1
Catawba	9	Haywood	3	Onslow	11	Vance	5
Chatham	5	Henderson	8	Orange	6	Wake	80
Chowan	2	Hertford	2	Pamlico	1	Watauga	1
Cleveland	12	Hoke	6	Pasquotank	6	Wayne	9
Columbus	9	Iredell	7	Pender	1	Wilkes	4

County	No.	County	No.	County	No.	County	No.
Craven	8	Jackson	2	Person	2	Wilson	11
Cumberland	35	Johnston	16	Pitt	17	Yadkin	2
Davidson	5	Jones	1	Randolph	7	TOTAL	643

Transitions to Community Living Voucher Program

The Transitions to Community Living Voucher (TCLV) Program is a tenant-based voucher program operated by the state’s Local Management Entities/Managed Care Organizations (LME/MCOs). The program provides support to tenants throughout the leasing process and tenants have a care team to support them after securing a unit. Tenants also have access to move-in funds, like security deposits and utility assistance.

The TCLV program also provides risk mitigation funds to incentive landlords to accept voucher holders. Landlords with tenants in the TCLV program can access reimbursement for the following:

- Unpaid damages after a tenant moves out
- Unpaid tenant portion of rent and late fees
- Vacancy due to tenant abandonment of the unit
- Successful eviction costs

The TCLV Program currently provides rental assistance for 2,017 individuals. Table I-11, above, shows the average monthly housing assistance amount provided to TCLV holders in the Targeting Program is \$391.79

Integrated Supportive Housing Program

Integrated Supportive Housing Program (“ISHP”) fosters a collaboration between a local housing developer, DHHS and the LME/MCO to increase the supply of integrated, affordable rental housing. This housing consists of independent rental units where no more than 20% of the units are required to be set aside for persons with a disabling condition. Prospective tenants will be referred by DHHS and are anticipated to come with rental assistance and connection to supportive services. The program prioritizes participants in the Transitions to Community Living Initiative.

Table I-14 below shows the ISHP properties across the state showing a total of 253 set aside units. Currently, 12 properties are operational and offering integrated PSH opportunities. Maple Crest and Amaranth are expected to be completed and leased up during the summer 2021. As of March of 2021, completion dates for Park Court and Abbington Square are still being determined.

Table I-14. Integrated Supportive Housing Program Properties

ISHP Property	City	Set-Aside Units ¹⁵⁹
Amber Spring	Raleigh	8
Cascade Garden Apartments	Mooresville	10
Eagle Market Place	Asheville	12
East Haven Apartments	Swannanoa	19
Mezzanine at Freedom Park	Charlotte	29
Prosperity Ridge Apartments	Kannapolis	9
Quarry Trace	Raleigh	20
Rivergate Greene	Charlotte	15
The Arbor at Cotton Grove	Lexington	16
The Reserve at Hickory Commons	Winston-Salem	13
Vermilion	Durham	12
The Village at Washington Terrace	Raleigh	17
Maple Crest	Asheville	32
Amaranth	Candler-Asheville MSA	14
Park Court	Goldsboro	10
Abbingdon Square	Raleigh	17
TOTAL	ALL CITIES	253

Department of Health and Human Services Resources

In addition to the programs DHHS provides in partnership with NCHFA, DHHS also operates several service-oriented programs to support individuals with disabilities to live in the community, lessening the pressure on housing resources developed and targeted for individuals with disabilities.

¹⁵⁹ Set-Aside units consist of Targeting Units and additional ISHP Units made available through ISHP loan awards. All set-aside units operate under ISHP rules.

Independent Living Rehabilitation Program

The Independent Living (IL) Rehabilitation Program provides services, directly and through coordination of community resources, to support participants choosing to live more independently in alternatives to a nursing home or other facility.

Eligibility for IL services include having a significant disability that severely limits your ability to live independently and the services will improve the ability to live independently.

Table I-15 below shows the number of clients served through the IL Rehabilitation Program from SFY 2015-16 through SFY 2019-20. The number of clients served through the program has generally decreased each year, except for a small increase between SFY 2016-17 and SFY 2017-18.

Table I-15. Clients Served in the Independent Living Rehabilitation Program by SFY of Payment Date

	SFY 2015-16	SFY 2016-17	SFY 2017-18	SFY 2018-19	SFY 2019-20
Service Account Category	# Clients with Services by SFY of Payment Date				
IL Consumer Managed Personal Care	233	226	261	322	318
IL Diagnostic & Assessment	502	463	491	545	502
IL DPP	432	452	384	380	271
IL Housing & Community Integration	72	75	77	58	42
IL Rehab Tech & Assistive Devices	1,478	1,376	1,436	1,474	1,175
IL Restoration Services - Med	731	684	644	520	498
IL MFP	40	46	63	71	71
TOTAL	3,488	3,322	3,356	3,370	2,877

Table I-16 shows the average cost per client in the IL Rehabilitation Program from SFY 2015-16 through SFY 2019-20. There was a notable increase in average cost across service accounts between SFY 2015-16 and SFY 2016-17, and again between SFY 2018-19 and SFY 2019-20. In SFY 2019-20, the average cost per client was \$4,221.

Table I-16. Average Cost per Client in the Independent Living Rehabilitation Program by SFY Payment Date

	SFY 2015–16	SFY 2016–17	SFY 2017–18	SFY 2018–19	SFY 2019–20
Service Account Category	Average Cost Per Client by SFY of Payment Date				
IL Consumer Managed Personal Care	\$13,262	\$13,819	\$13,299	\$13,252	\$15,229
IL Diagnostic & Assessment	\$67	\$52	\$90	\$109	\$77
IL DPP	\$5,210	\$5,384	\$5,263	\$5,609	\$6,075
IL Housing & Community Integration	\$1,037	\$1,040	\$1,336	\$1,390	\$1,576
IL Rehab Tech & Assistive Devices	\$2,313	\$2,628	\$2,445	\$2,503	\$2,931
IL Restoration Services - Med	\$1,222	\$1,250	\$1,199	\$1,321	\$1,619
IL MFP	\$1,996	\$2,135	\$2,462	\$1,904	\$2,041
AVERAGE COST PER CLIENT	\$3,587	\$3,758	\$3,728	\$3,727	\$4,221

Community Alternatives Program for Disabled Adults

The Community Alternatives Program for Disabled Adults provides home and community-based services to adults with disabilities who are at risk of institutionalization by waiving certain NC Medicaid requirements. The program is intended to support households who have no other person that can meet their medical, psychosocial, and functional needs. The services support the individual to remain in their primary private residences.

Money Follows the Person Program

Medicaid-eligible North Carolinians who live in inpatient facilities can move into their own homes in the community with supports through the Money Follows the Person (MFP) project. North Carolina received the MFP grant from the Center for Medicare and Medicaid Services (CMS) in 2007 and the grant was extended through 2020 under the Affordable Care Act. The annual budget is approximately \$10 million, including \$5 million per year for five years of supplemental funding for capacity building.

- [The MFP Program](#) states the following as its objectives:
- Increase the use of home and community-based services (HCBS)
- Eliminate barriers that prevent or restrict Medicaid-eligible individuals from receiving long-term care in the settings of choice
- Ensure continued provision of HCBS to those individuals who choose to transition from institutions
- Provide quality assurance and continuous quality improvement of HCBS with supports

Program participants receive supports through one of the four Medicaid waiver programs¹⁶⁰ and access to financial assistance for security deposits, utility startup, furniture, and accessibility modifications. Each beneficiary can access up to \$3,000 for start-up funds and the average use per beneficiary is about \$1,800.

The MFP program has capacity to serve 68 individuals with intellectual/developmental disabilities, five individuals with traumatic brain injuries, and 100 individuals under the Community Alternatives Program for Disabled Adults per year. Approximately 1,389 individuals have been served through MFP since 2009.

¹⁶⁰ The four Medicaid waiver programs include Community Alternatives Program for Disabled Adults (CAP/DA), Community Alternatives Program for Children (CAP/C), NC Innovations, and Program of All-Inclusive Care of the Elderly (PACE).

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Appendix J: Medicaid and DMH/DD/SAS Claims Service Categories

Table J-1. Medicaid and DMH/DD/SAS Claims Service Categories

	Medicaid-Funded Services	DMH/DD/SAS-Funded Services
Enhanced & Support Services	This category includes the services on North Carolina's fee schedule for Enhanced MH/DD/SA services such as ACT, peer support, psychosocial rehab, community support teams, partial hospitalization, and mobile crisis. Residential Services from this fee schedule are not included here but counted in the 'Residential' service category.	Same services as funded by Medicaid but paid for by the state.
Supported Employment	Medicaid-funded Supported Employment	DMH/DD/SAS-funded Supported Employment
Other Individual Supports (b)(3) (Medicaid only)	Services provided under the (b)(3) waiver that are not captured under Enhanced & Support Services, such as personal care services and supported housing	Not applicable
Other Community Support (MH/DD/SAS only)	Not applicable	Community-based services that are funded only by the state, including personal care services, individual supports, day supports, and personal assistance, as described in State-Funded MH/DD/SA Service Definitions, 2019 .
Outpatient	Psychotherapy, psychological testing/assessment, evaluation & management, and other outpatient service codes where the primary diagnosis on the claim is a behavioral health condition	Same services as funded by Medicaid but paid for by the state.
Residential Services	Substance abuse residential services, psychiatric residential treatment facility	State-funded Family Living, Group Living, Supported Living, and Residential Supports
Emergency Room (Medicaid only)	Hospital emergency department claims identified by procedure code, place of service, and/or revenue codes for ER	Not applicable
Inpatient	Inpatient claims identified by bill type or procedure codes for inpatient consultations. For expenditures, this category includes the cost of room & board and inpatient consultation, but does not include all costs that might be part of an inpatient stay (testing, labs, etc.)	State-funded inpatient, all-inclusive

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Appendix K: Abbreviations Used in this Report

ABA – Applied Behavior Analysis therapy	EBP – Evidence-Based Practice
ACH – Adult care home	EPSDT – Early Periodic Screening, Diagnosis and Treatment
ACT – Assertive Community Treatment	FBC – Facility-based crisis center
ADA – Americans with Disabilities Act	FFS – Fee for service
ADATC – Alcohol and Drug Addiction Treatment Center	HCBS – Home- and Community-Based Services
ADVP – Adult day vocational program	HCV – Housing Choice Voucher
ASD – Autism Spectrum Disorder	HSRI – Human Services Research Institute
CAP/C – Community Alternatives Program for Children	HUD – U.S. Department of Housing and Urban Development
CAP/DA – Community Alternatives Program for Disabled Adults	ICF – Intermediate Care Facility
CDBG – Community Development Block Grant	ICF/IID – Intermediate Care Facility for Individuals with Intellectual Disabilities
CIL – Center for Independent Living	I/DD – Intellectual and other Developmental Disabilities
CMHC – Community Mental Health Center	IPS/SE – Individual Placement and Support/Supported Employment
CMS – U.S. Centers for Medicare and Medicaid Services	ITP – Incapacity to Proceed
CST – Community Support Team	LIHTC – Low-Income Housing Tax Credit
CTI – Critical Time Intervention	LME/MCO – Local Management Entity/Managed Care Organization
DHB – North Carolina Division of Health Benefits	LTSS – Long-Term Services and Supports
DSDHH – Division of Services for the Deaf and Hard of Hearing	MAT – Medication-Assisted Treatment
DHHS – North Carolina Department of Health and Human Services	MCO – Managed Care Organization
DMA – North Carolina Division of Medical Assistance	MDS – Minimum Data Set
DMH/DD/SAS – North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services	MFP – Money Follows the Person
DPI – North Carolina Department of Public Instruction	MIL – Money for Independent Living
DSB – North Carolina Division of Services for the Blind	MST – Multisystemic Therapy
DOJ – U.S. Department of Justice	NC Medicaid – North Carolina Division of Health Benefits
DSS – North Carolina Division of Social Services	NCCDD – North Carolina Council on Developmental Disabilities
DVRS – North Carolina Division of Vocational Rehabilitation Services	OPSA – Olmstead Planning Stakeholder Advisory
	PHA – Public Housing Agency/Authority
	PRTF – Psychiatric rehabilitation treatment facility
	PSH – Permanent supportive housing
	PSR – Psychosocial rehabilitation

RISP – Residential Information Systems Project

RRCC – Rapid Result Clinical Consult

RUN – Registry of Unmet Needs

SA/IH – Special Assistance/In-Home Program
for Adults

SAMHSA – Substance Abuse and Mental Health
Services Administration

SED – Serious Emotional Disturbance

SFY – State Fiscal Year

SILC – Stateside Independent Living Council

SMI – Serious Mental Illness

SOHF – State Operated Healthcare Facilities

SPH – State Psychiatric Hospital

SSI – Supplemental Security Income

SUD – Substance Use Disorder

TAC – Technical Assistance Collaborative

TBI – Traumatic Brain Injury

TCLI – Transitions to Community Living Initiative

WIOA – Workforce Innovation and Opportunity Act

Appendix L: Glossary

ABLE ACT and Accounts – The North Carolina’s State Treasurer’s Office administers the Achieving a Better Life Experience (ABLE) Act, a federal law signed in December of 2014, that allows individuals with disabilities and their families the opportunity to save for the future and fund essential expenses like medical and dental care, education, community- based supports, employment training, assistive technology, housing and transportation. ABLE accounts are tax-exempt savings accounts for qualified disability expenses.

Autism Society of North Carolina – The society’s mission is to improve the lives of individuals with autism, supports their families, and educates communities.

Behavioral Health Disorders – Refers to mental health disorders, substance use disorders and co-occurring mental health and substance use disorders.

Coalition on Aging – The NC COA Coalition’s mission as a coalition is to improve the quality of life for older adults through collective advocacy, education, and public policy work. They work to develop programs for children with autism, advocate and help families navigate services and education state policy makers on the needs of children with autism.

CAP/C Waiver – The waiver provides services for medically fragile children under 21 who are at risk of institutional care. By providing in home nursing care, case management, and other supports, CAP/C can help these children stay at home with their families

CAP/DA Waiver – This waiver program provides a cost-effective alternative to institutionalization for a Medicaid beneficiary who is medically fragile and at risk for institutionalization if home- and community-based services approved in the CAP/DA waiver were not available. These services allow the beneficiary to remain in or return to a home and community-based setting.

Competitive, Integrated Employment – Defined by the Rehabilitation Act as work that is performed on a full-time or part-time basis for which an individual is: (a) compensated at or above minimum wage and comparable to the customary rate paid by the employer to employees without disabilities performing similar duties and with similar training and experience; (b) receiving the same level of benefits provided to other employees without disabilities in similar positions; (c) at a location where the employee interacts with other individuals without disabilities; and (d) presented opportunities for advancement similar to other employees without disabilities in similar positions.

Community Activity and Employment Transitions – The CAET program is administered by the Mecklenburg County LME/MCO, promotes community integration, immersion and independence in the community by assisting participants with developing social skills, exploring vocational options or volunteer opportunities, participating in wellness activities, and building skills for daily living.

Direct Support Professional – staff who work one-on-one with individuals with disabilities with the aim of assisting them to become integrated into the community or the least restrictive environment.

ED Boarding – Emergency Department boarding is the process of holding patients in the Emergency Department after the decision is made to admit the patient due to a lack of inpatient beds.

IGNITE Program at Autism Society of NC helps with training in independent living. IGNITE is a community center in Davidson, North Carolina for young adults with high functioning autism or Asperger's syndrome transitioning into adulthood.

"In Lieu Of" Services – Alternative MH, SUD, or IDD services that are not included in the state Medicaid plan or managed care contract but that are clinically appropriate, cost-effective alternatives for the state plan services. These services are not required and are provided at the discretion of the LME/MCOs.

Innovations Waiver – This Medicaid waiver supports children and adults with I/DD to live in the community who meet ICF-IDD level of care criteria or are a risk of being placed in an ICF-IDD

Lifelong Interventions (LLI) model – This approach is comprehensive treatment program for children and adults. It is rooted in the principles of Applied Behavior Analysis (ABA) and involves effective instruction using evidence-based practices to promote meaningful skills and behaviors in the home, school, and community.

Money Follows the Person – The MFP program helps Medicaid-eligible North Carolinians who live in inpatient facilities move into their own homes and communities with supports. North Carolina was awarded its MFP grant from CMS in May 2007 and began supporting individuals to transition in 2009.

NC CORE – North Carolina Collaborative for Ongoing Recovery through Employment Initiative an innovative payment structure that addresses the discrepancy between FFS and milestone payments by switching both the State and Medicaid FFS payments to milestones for Supported employment services.

NC Health Choice – The North Carolina Health Choice (NCHC) Health Insurance Program for Children is a comprehensive health coverage program for low-income children.

Olmstead v. L.C. – The *Olmstead* Decision is a United States Supreme Court case regarding discrimination against people with mental disabilities. The Supreme Court held that under the [Americans with Disabilities Act](#), individuals with mental disabilities have the right to live in the community rather than in institutions if, in the words of the opinion of the Court, "the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

Project SEARCH – Is a one-year school to work transition program for seniors in high school focusing on the school to work transition process. Project SEARCH is based on a national model first piloted at

Cincinnati Children's Hospital Medical Center in 1996 has developed into a comprehensive training and job development program.

Serious Emotional Disorders – Conditions experienced by children, birth to 18 years old, determined by DSM-IV Diagnosis and moderate to severe impairment in functioning. Also referred to as Serious Emotional Disturbance.

Serious and Persistent Mental Illness – A mental illness or disorder (but not a primary diagnosis of Alzheimer's disease, dementia, or acquired brain injury), experienced by a person who is 18 years of age or older, that is so severe and chronic that it prevents or erodes development of functional capacities in primary aspects of daily life such as personal hygiene and self-care, decision-making, interpersonal relationships, social transactions, learning and recreational activities; or satisfies eligibility for Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) due to mental illness.

Social Determinants of Health – Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

Systems of Care (SOC) – is a philosophy supported in North Carolina where providers work together in a coordinated network of community services and supports that are organized to meet challenges of persons with disabilities.

Transitions to Community Living Initiative (TCLI) – The State of North Carolina entered into a settlement agreement with the United States Department of Justice (DOJ) in 2012. The purpose of this agreement was to make sure that persons with mental illness can live in their communities in the least restrictive settings of their choice. DHHS have worked to develop in-reach, transition, and community-based services to support those with SMI moving from facilities to the community.

Treatment and Education of Autistic and Related Communication Handicapped Children – TEACCH is an Autism Project at the University of North Carolina School of Medicine, made up of a set of community regional centers that offer children with autism their families a set of clinical services including referral, consultation, evaluation, intervention services and training. Parent support and education is also a key service.

Workforce Innovation and Opportunity Act – WIOA was signed into law on July 22, 2014, is designed to help job seekers access employment, education, training, and support services to succeed in the labor market and to match employers with the skilled workers they need to compete in the global economy.