RESEARCH FINDINGS AND POLICY SOLUTIONS TO ADDRESS THE NORTH CAROLINA REGISTRY OF UNMET NEEDS

CCR
Strategic Research and Consultation

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Executive Summary

Medicaid program Home- and Community-Based Services (HCBS) Waivers fund long-term services in community versus institutional settings and one means for States to achieve compliance with the 1999 U.S. Supreme Court *Olmstead v. L.C.* decision. The waivers have been shown to increase quality of life and address unmet needs for people with intellectual and/or developmental disabilities (IDD). In North Carolina, Innovations Waiver services include: assistive technology; community living and support services; community navigator services; community networking; community transition; crisis services; Day Supports; respite services; financial support services; home modifications; individual goods and services; natural supports education; residential supports; specialized consultation services; supported living; supported employment; and vehicle modifications. Unfortunately, in North Carolina only 22% of Medicaid beneficiaries with intellectual disabilities or autism are enrolled in the Innovations Waiver. It can take an individual as many as 12 years to receive a slot after being placed on the waiting list, which is called the Registry of Unmet Needs (RUN). This report summarizes research interviews from eight States including North Carolina, NC LME/MCO interviews, and NC stakeholder focus groups. We found variability in Waiver-eligible populations, administrative oversight, and waiting lists across States and among NC regions. However, most states have a waiting list for the valuable home- and community-based services covered by the Innovations Waiver. Recommended strategies and long-term solutions include increasing the number of Waiver slots with sustainable federal and State match funding; outreach and education to potentially eligible individuals and their families; streamlining and centralizing the application process; enhancing supported employment; and increasing Direct Support Professional wages to ensure access to services for individuals enrolled in the Waiver. Without increased Waiver capacity, a large segment of the IDD population and their families will remain unsupported or only partially supported and Medicaid beneficiaries with IDD will be at risk for unnecessary institutionalization.

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Methodology

We used a multiprong strategy to generate the findings identified in this report. Under a one-year contract with the North Carolina Council on Developmental Disabilities, CCR worked with Duke University researchers to design a survey instrument, conduct interviews with a national sample, and evaluate states' historical and current practices, gaps, and solutions to ensuring access to Medicaid Home-and Community-Based Services (HCBS) Waivers for individuals with intellectual and developmental disabilities.

We interviewed 10 Developmental Disabilities Council Directors and Department of Health and Human Services (DHHS) leaders representing eight states: Georgia (GA), Louisiana (LA), Maryland (MD), North Carolina (NC), Tennessee (TN), Texas (TX), Washington (WA), and Wisconsin (WI). CCR and Duke University researchers met with both DHHS and NCCDD representatives to seek approval of the best list of States that appeared to have similarities to North Carolina in terms of population size or geography or political party composition in the State's legislative body. The researchers also considered whether States of interest had made recent changes to address their waiting lists or had unique policy experience to share regarding HCBS IDD waivers. The semi-structured interview guide is provided in **Appendix A**.

Via email, telephone calls, and virtual face-to-face meetings we also surveyed the seven North Carolina Local Management Entity / Managed Care Organizations (LME/MCOs) that administer IDD, behavioral health (BH), and substance use disorder (SUD) services under Medicaid managed care for all 100 North Carolina counties. The survey questions are provided in **Appendix B**. We also met with eight stakeholder groups to present information about the project and gather feedback. Stakeholders included: NC Council on Developmental Disabilities members; the Developmental Disabilities Consortium; the *Olmstead* Community Capacity Committee; the Cardinal Innovations Healthcare LME/MCO IDD Stakeholder Group; Money Follows the Person beneficiaries; the IDD committee of a statewide provider association for IDD, BH, and SUD services (the North Carolina Providers Council); the NC Waiver Action Team; and the State Consumer and Family Advisory Committee.

Key Findings

State Interviews

We gathered qualitative data during live interviews that lasted an average of 68.5 minutes each (range 53 – 92 minutes). While North Carolina has one IDD waiver serving 13,138 people and has 15,187 people on the RUN (note that these are point-in-time statistics that change monthly), states on average have 3.6 waivers serving almost 20,000 people. Other states' waiting lists have an average of 27,000 people who wait for about 9.1 years for a slot. One exception, WI, has eliminated its waiting list. Conversely, TX has 159,000 people on the waiting list and a wait time of 12-15 years.

Some states construct waivers to cover services throughout an individual's lifespan, while other states use separate child and adult waivers or some combination. Numerous states (including NC) follow a first come, first served approval process for available slots, while some open needs-based slots. One state, TN, prioritizes individuals who are seeking employment, are transition age youth, and are in crisis status [e.g., therefore eligible for reserve slots]. For individuals who are waiting and not enrolled in Medicaid, there are few options for supportive services. However, States do have mechanisms for informing individuals about those services. Nonetheless, there may be insufficient outreach and education, care management or funding for those services.

To be eligible for the North Carolina Innovations Waiver, an individual must:

- Meet the requirements for Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID) level of care
- Live in an ICF-IID or be at risk of being placed in an ICF-IID
- Be able to stay safe, healthy and well in the community while using NC Innovations Waiver Services
- Need and use NC Innovations Waiver services listed in their person-centered plan at least once a month
- Want to use NC Innovations Waiver services instead of living in an ICF-IID

Interviewees in States that implement a first come, first served approach to Waiver placement acknowledged that inequities to access can arise when the most well-informed, well-resourced, or most proactive families sign up first or find ways to access open slots first. Each of the state interviewees expressed concerns about inequities in waiver distribution; however, they have not formally studied the issue. Every interviewee also stated that it is not easy for families to understand information published by State Medicaid agencies or to sign up for the waiver. Most states refer to their waiting list by an alternate name because federal law technically prohibits the existence of a waiting list. Interviewees reflected that Medicaid agencies do not publish their waiting list data.

"It is very confusing to families. . . we get calls all the time. . . a parent said to me once – it'll always stick with me – 'It's like going into a room of curtains and if one is pulled back all you see is the next curtain.'"

Most interviewees reported additional unmet service needs such as supported employment (available via Vocational Rehabilitation and (b)(3) in NC), low direct support professional wages, and lack of self-determination and choice. Specific underserved subpopulations include rural populations, historically marginalized populations, LGBTQ+, children, transition age youth, aging individuals, and dual-diagnosed individuals.

States have employed different strategies to address their waiting lists and the unmet service needs of the individuals on the waiting lists. Strategies have included a tiered waiver system (tiered funding corresponding with tiered categories of service needs) and advocacy through cross-sector partnerships. Most interviewees reported being dependent on legislative action to increase the number of Waiver slots and corresponding State match funding. That is the case in North Carolina. Future strategies suggested to improve Waiver access include increasing the number of slots with sustainable funding; educating potentially eligible individuals and families and streamlining the application process; enhancing supported employment; and increasing direct support professional (DSP) wages.

Table 1 summarizes key interview findings by State.

Table 1: Summary of State Findings

State Interviewed	Waiver program characteristics	Waiting list status	Strategies for reducing or eliminating the waiting list	Policy recommendations
GA Waiver Programs | Georgia Medicaid	Implemented in the late 1980s and up for CMS renewal/at end of five-year cycle, but concerns about proposed changes (e.g., self-directed supported employment at risk) Two Waiver categories, each one with expenditure caps: 1) supports waiver for HCBS/limited supports; and 2) comprehensive waiver for residential and other intensive supports. There is a separate, independent care waiver for individuals with ASD or TBI but services are "a mishmash" and there isn't a waiver	Currently serve 13,464 individuals with a $719 annual budget There are approximately 7,000 individuals on the planning list; average wait time is 10 years; Six regional offices of the State Department of Behavioral Health and Developmental Disabilities manage Waiver funding and slot allocation; the process is not standardized, although the Department is working on a set of standardized criteria	Produced a film titled, "6,000 Waiting" that highlights stories from Waiver-enrolled and waiting list individuals in each Senatorial district Relies on other resources & payors such as the education system, GA Pediatric Program, Autism State Benefit Plan, or Division of Family and Children's Services can cover services. Initial (within 14 days) and annual assessments completed for *pre*-eligible individuals to ensure that circumstances and prioritization remain current on the planning list; also calls to individuals on the planning	Ensure access to adequate provider networks and services in both urban and rural areas Don't just survey providers about system gaps and service needs; include enrollees and families Need models that address waiting lists with needs-based prioritization versus models that allocate Waiver slots to the "squeaky wheels" or the most connected or influential families Need a streamlined application process that is not difficult for families to access or complete Need outreach and education for eligible individuals / their families regarding the Waiver and the application process (GA estimates 10,000 additional individuals eligible to apply) Need to address needs outside of IDD services such as affordable housing and crisis intervention for dually diagnosed individuals Need adequate Medicaid reimbursement rates for Waiver providers Need adequate hourly wages for DSPs Encourage self-directed plans and mobilize community resources and coordinators for

	focused on children Consideration for individuals most in need facilitates the prioritization of the planning lists. Evaluation includes priorities related to health and safety and caregiver support systems. Needs assessments tools are Determination of Need – Revised and Behavioral Health and Medical Needs assessments. Scores allow those with the greatest unmet need to move to services more quickly. Operating under a DOJ Settlement Agreement and still have institutional beds to eliminate		list quarterly to update them on their status Although not the goal for the GA Council on DD, rather than appropriating more money for the Waiver, the GA legislature wants to cut services for existing Waiver enrollees or give fewer slots to minors as a means of saving money and creating more slots The GA Council on DD advocates for recurring appropriations via a 20 year-old “waiting list campaign;” see approximately 125 new Waiver slots added annually GA has a bill (not enacted) to require elimination of the waiting list within five years	community integration for individuals with IDD End sub-minimum wage and Day Programs and foster supported employment; use provider reimbursement rates that incentivize supported employment

LA Medicaid Waiver Services | Louisiana Department of Health	Four diverse HCBS waivers targeting different age groups and service needs; BUT applying soon to CMS for one, 4-tiered waiver LA does not consider the tiered waiver to be *needs*-based since an assigned tier may not be dependent on the severity of an IDD. Could be dependent on emergent circumstances such as caregiver availability, risk for incarceration, losing [aging out of] EPSDT, etc. No Group Homes; only ICF-IIDs with 4-6 beds	Reduced a 2015 waiting list of approximately 40,000 with a wait time of 10-14 years Current waiting list has 13,200 individuals	Worked with the legislature to invest State funding and add 600 slots per year LA has statutorily dedicated funding (12% of General Fund surplus) for the Waiver Also consider, where feasible, earmarking a percentage of “sin taxes” and lottery or sports wagering State profits as statutorily dedicated funding to sustain Waiver slots	Don’t rely solely on the SIS; use diverse screening tools Need more person-centered planning such as Charting the Life Course Consider a tiered waiver and assess individuals for both “urgent” and “emergent” service needs Need more supported employment services Educate beneficiaries and case managers and make the application process transparent and accessible Increase direct care wages via legislation and facilitate workforce opportunities with community colleges, nursing schools

MD DDA Medicaid Waiver Programs | Maryland Department of Health	Established in the 1980s One Community Supports Waiver and one Family Supports Waiver, each serving 300 individuals. Previously capped at $25K and $15K respectively, but no longer capped under the recent renewal. One Comprehensive Waiver serving 16K individuals, and 600 individuals on the waiting list receive case management Minimum eligibility age for Waiver services in a residential setting is 21 years One ASD Waiver with 1400 slots through Dept. of Education for individuals under 21	4,000 individuals on a needs-based waiting list (SIS included among screening tools) but an estimated 24,000 – including children in the state – are potentially eligible. Four regional DDA offices collect and track waiting list data	State Cabinet agencies collaborate to help transitioning youth with disabilities (funding for the fiscal year in which they turn 21) The legislature meets annually with stakeholder groups (the Arc, DD Council, providers groups) to conduct a fiscal analysis of Waiver funding and service utilization Advocates work with the legislature to protect/sustain existing State match funding, but it has been difficult to *increase* funding for the past 12 years No specific initiatives to address the waiting list, but the legislature sets aside annual funding to assist 48 waiting list individuals with crisis resolution and 168	Need meaningful ways to advance supported employment in this employment first state Need a family friendly application process; "Make it easier to get on the list and make it easier to get the services." Need to evaluate and potentially broaden the Waiver service definitions Need to increase the long-stagnant provider reimbursement rates to improve and ensure access to covered services Need statewide outreach and education to capture diverse populations who may be eligible / to eliminate disparities

			individuals with crisis prevention Implementing an initiative to reach underserved minorities by training and funding Cultural Brokers	
NC NC Innovations Waiver | NC Medicaid	Established in the 1980s but demand grew primarily in the 1990s; most recent CMS renewal was in 2020 Same eligibility criteria for ICF-IID and HCBS waiver services is problematic RUN shift to a Waiver slot is 'first come, first served' versus needs-based or tiered Operating under a DOJ Settlement Agreement	13,138 approved and funded slots in NC ($135K annual budget per enrollee) Approximately 15,000 on the RUN; wait up to 12 years Seven Local Management Entity Managed Care Organizations manage regional RUNs and funding for available slots	Advocacy for General Assembly appropriations of additional State-funded services for individuals on the RUN Enrolling RUN and non-RUN individuals with IDD into Medicaid managed care to improve access to non-Waiver services	Some people may be accessing more services than they can use Need to evaluate the system and ensure person-centered planning Need parity in wages for DSPs in both institutional and HCBS settings; today institutional wages (in State institutions in particular) are higher Fund Supported Employment and post-secondary education It isn't advisable to continue to run parallel public and private ICF-IID facilities Need centralized and periodic collection of beneficiary/family/guardian survey data re: service needs for RUN individuals Need to evaluate racial, ethnic, and socioeconomic disparities among RUN individuals with IDD and individuals with IDD within the general population

TN 1915(c) HCBS Waivers | Division of TennCare	Has one Employment and Community First Choices waiver for individuals with IDD; includes 7,000 individuals from legacy "high need, high cost" developmental center programs TN also launched a Katie Beckett program in 2019 for children who don't qualify for Medicaid Has a centralized referral list enrollment Web page that categorizes needs-based versus first come, first served based eligibility criteria (needs based can include aging caregiver or multiple complex needs while first come, first served can include employed individuals in	Approximately 10,000 enrolled in the Waiver and approximately 5,000 on the referral list Communication and management across four different agencies	Tennessee's newly passed TennCare III program (branded as a "block grant" by some) is poised to overhaul funding and create a windfall of new federal funding that the state has suggested, but not committed, will go to eliminating the waiting list.[*] The legislature appropriates funding for approximately 200 new slots some years, but not consistently; has been annual since 2016 15 year-old TN Disability Pathfinder Service via Vanderbilt University with a toll-free information line & searchable database of more than 3,000 services; working to modernize with an app and more Two years ago the Governor	Need providers training to provide respite care for minor children, particularly in the age of COVID Need adequate support and hourly wages for DSPs; training isn't enough Person-centered planning and supported employment are important and employment needs to be meaningful, age-appropriate, and integrated in the community; not separate workshops. Need outreach and education for eligible individuals and families regarding the referral list Need clear language in materials and videos. Need an assessment process that leads to *meaningful* person-centered planning Need better case management to help people on the referral list access services; there are local funding stipends up to $4K in TN for e.g., respite and vehicle modifications

	need of support and youth of transition age); the State reserves some slots in the first come, first served category for adult individuals who have a planned transition from home (e.g., due to aging caregivers) or who want to sustain a family living arrangement with supports.		was committed to cutting the referral list in half by supporting legislated funding, but that never went through when COVID hit	
TX Intellectual or Developmental Disabilities (IDD) - Long-term Care | Texas Health and Human Services	Have 10 HCBS waivers so it's challenging to educate families about the nuances of each waiver so they can choose	Approximately 160,000 on the interest list; wait 12-15 years	Numerous, diverse waivers and a strong voice for individuals with IDD Important to have a legislative champion	Need eligibility screening and consistent administrative oversight of the waiting list Consider a reduction in individual allocations to serve more people Find a means of addressing gaps and providing timely access to services for individuals on the waiting list

WA Home and Community Based Waivers (HCBS) | Developmental Disabilities Administration	5 waiver programs including a Core Waiver (highest support level) and an Individual and Family Support Waiver and one for intensive supports for children "silver tsunami" concern as individuals on the waiting list are 40-50 years old, live with aging/elderly caregivers – what will happen to the individuals if they don't get a Waiver slot? Non-eligible populations include ASD individuals First come, first served in terms of getting on the waiting list, but essentially becomes needs-based	150,000 people with DD in the state; approximately 50,000 have Waiver or State service supports Approximately 15K who are eligible but waiting to receive services Approximately 500 individuals living in institutions and Labor Union is opposed to closing	No State income tax so it is difficult to adequately fund systems and services and expand the number of Waiver slots Legislative advocacy is the means to expanding funding and the number of slots, but there aren't any current initiatives in place. Have pushed for "case load forecasting" for the IDD population but the legislature has not agreed to it Ongoing work with the Protection and Advocacy agency and other associations to monitor and oppose bills that could be detrimental to the IDD population's access to services Expand to statewide the successful 'transition from	Capped waivers for individuals who don't have the highest level of service needs can help share existing resources among more people; at least gets them into the system with a case manager. Need equitable means of applying for and accessing slots (including LEP educational materials) instead of most educated, non-minority, or most persistent families Need to educate all families about the Waiver consistently at time of birth if IDD known Need to educate consumers about Medicaid entitlement services and Aging and Long Term Supports Administration services available during the wait for a Waiver slot Need to cover dual services such as community inclusion and supported employment; don't exclude services if Waiver enrollees get employment Need an *Olmstead* commission in WA

	once an individual is on the waiting list		school to work' programs. Employed individuals with IDD may be more likely to get a Waiver slot.	
WI Children's Long-Term Support Program | Wisconsin Department of Health Services	Statewide managed care with four statewide plans with robust benefits	***No Waiting List*** as of February 2021	When WI went to Medicaid managed care, grassroots programs held out for a State commitment to ending the waiting list – Waiver slot must be treated as an entitlement. But it took years. Today, the waiver is an entitlement for all Medicaid-eligible individuals; no one will wait for a slot. WI has a *Survival Coalition* comprised of >20 statewide disability organizations that focus on policy, services, and voting.	Public rate bands that managed care plans can charge for enrollee services Need fewer Day Programs and more integrated employment Focus on the intersection of disabilities and racial disparities. Consider the incidence and prevalence of disabilities versus only racial composition of the population. Don't just use satisfaction surveys; assess service needs. There's a challenge to discuss what a person wants and needs versus what the system (and providers) are offering.

[*] *Note: As of 9/30/2021, this TN program approved under the Trump Administration is posted for public notice and comment under the Biden Administration and CMS approval is at risk for being retracted.*

LME/MCO Surveys

The total number of individuals reported on the RUN in January 2021 across all seven LME/MCOs was 15,187. That's a 6% increase from the 14,295 reported on the RUN across all seven LME/MCOs in a December 2019 *Administrative Functions Monitoring* report to DHHS. The average number of individuals on the RUN per region was 2,169 with the smallest waiting list in the Eastpointe catchment (597) and the largest waiting list in the Alliance Behavioral Health catchment (3,996).

The waiting time on the RUN ranges from five to 15 years. The wait time varies by slot type and by county within any given LME/MCO catchment area. LME/MCOs reported assigning Waiver slots on a first come, first served basis and then on a per capita basis within catchment area counties. The CMS-approved Innovations Waiver requires North Carolina to maintain "reserve capacity" – literally a reserved portion of the total Innovations Waiver slots available – for the following categories of eligible Medicaid beneficiaries:

- Community Alternatives Program for Children (CAP/C): To transition individuals when they age out of the CAP/C waiver.
- Military Transfers: participants who were on a comparable 1915(c) waiver in another state whose family was transferred to North Carolina for military service or who were receiving Innovations waiver services prior to their family transferring to another state and have now returned to North Carolina.
- Emergency needs in which an individual is at risk of imminent, significant harm.
- Money Follows the Person (MFP): To transition individuals out of institutional settings using the Money Follows the Person (MFP) federal grant.

Although all Medicaid beneficiary demographic data are available at the State level in the NCTracks Medicaid Management Information System, some LME/MCOs reported not having the ability to generate reports regarding sociodemographic or other trends within their RUN lists. Because individuals do not have to be Medicaid-eligible to qualify for the RUN and because RUN lists are managed at the LME/MCO level, NCTracks demographic data may not include all non-Medicaid individuals on the RUN. Four of the seven LME/MCOs reported monitoring RUN enrollees' age, race, ethnicity, and county of residence. One LME/MCO collects the demographic information on applications but does not analyze or report it. Three LME/MCOs analyze the race and ethnicity of their RUN population. One LME/MCO, Vaya Health, provided its RUN race and ethnicity data with the survey responses. However, researchers did not request the data, so this report does not include a comparison across all seven LME/MCOs. The actual survey question as shown in **Appendix B** was, "Do you know the racial breakdown of the RUN list?" Please see **Table 2** for the Vaya Health data and a comparison column with race and ethnicity statistics from the 2020 U.S. Census general population report for North Carolina.

Table 2: Comparison of NC Population and Vaya Health LME/MCO RUN Population by Race and Ethnicity

Race and Ethnicity	**NC General Population [2020 U.S. Census]**	**LME/MCO RUN Population**
American Indian/Alaska Native	1.6%	12 (0.9%)
Asian	3.2%	11 (0.82%)
Black or African American	22.2%	87 (6.49%)
Native Hawaiian and other Pacific Islander	0.1%	3 (0.22%)
Two or more races	2.3%	4 (0.3%)
Unknown		47 (3.51%)
White	70.6%	1,176 (87.76%)

Sources: U.S. Census Bureau QuickFacts: United States; Vaya Health LME/MCO

The researchers recommend statewide collection and analysis of these data under the new, multi-year grant project to ensure that systemic biases are not posing barriers to access for any race or ethnicity within any LME/MCO (future Tailored Plan) region. A Duke-Margolis Center for Health Policy literature review regarding racial and ethnic disparities and IDD diagnoses yielded findings that statistics relate historically marginalized racial and ethnic groups and disability to poverty, and poverty to disability. Furthermore, preterm birth and low birth weight are associated with both IDD and Black parental race. According to a February 2020 *National Health Statistics Reports* publication included on the **Resources** page, from the years 2015 through 2018 the prevalence of any developmental disability among children aged 3–17 years was 17.8%, but the prevalence was 19.8% among children living in rural areas as compared with 17.4% among children living in urban areas. Another study reviewed by Duke-Margolis Center for Health Policy researchers concluded, "Compared to non-Hispanic White students, non-Hispanic Black students were overrepresented in the ID classification and underrepresented in the ASD classification across urban and rural areas. Indicators of low resource availability were also associated with higher probabilities of ID versus ASD classification."

For the LME/MCOs that collect and analyze the data about their RUN enrollees, the data inform the following:

- In lieu of Medicaid service needs and definitions to assist beneficiaries while they are on the RUN
- State-funded service needs and definitions to assist beneficiaries while they are on the RUN
- In-reach efforts
- Children with complex needs service needs
- Behavioral health and substance use disorder service needs
- Provider contracting and quality management activities
- (b)(3) services offerings

Survey responses revealed that LME/MCOs neither manage their RUN lists nor communicate with RUN enrollees in a standardized manner. For example, some LME/MCOs accept RUN self-referrals via both telephone lines and online portals, while some offer telephone access only. One LME/MCO has a toll-free line dedicated to RUN inquiries but most LME/MCOs process RUN self-referrals through their general access lines. In general, beneficiaries or their authorized representatives must call a designated telephone number and participate in an intake interview and an assessment and provide supporting documentation. LME/MCOs then work with care coordinators (some have care coordinators dedicated to RUN enrollees) and community-based resources including North Carolina System, Therapeutic, Assessment, Resources, and Treatment (NC START) to connect individuals on the RUN with services that are available. One LME/MCO proactively reassesses the service needs of individuals on the RUN quarterly, while some LME/MCOs assess the service needs of individuals annually. Four LME/MCOs reported updating individuals' information when contacted by the individual or their authorized representative. Three LME/MCOs reported proactively seeking updated information from RUN enrollees only as the enrollees approached receiving a slot.

The number of days for the application process before an appealable RUN eligibility decision is made can range from three to six months. However, many LME/MCOs use the date of the initial Web-based or telephone inquiry as the date for placement on the 'first come, first served' RUN. There is currently a dearth of information about the Waiver application process on the NC DHHS Website. It says, "How to Apply - If you are eligible, your LME-MCO can help you get services. There are only a certain number of NC Innovations Waiver slots. If the slots are full, your name will be added to the Registry of Unmet Need." This information does not contain a direct link to the Department's LME/MCO Directory, so there is no point of contact with which to begin. At a minimum, a directory of LME/MCO Innovations Waiver enrollment telephone numbers ["access lines"] and online portals, where applicable, could be posted on this NC DHHS Web page to facilitate access to information. Ultimately, a statewide, centralized toll-free enrollment help line may best serve the individuals who need Innovations Waiver services.

Regarding community outreach and education to increase awareness of the Innovations Waiver and the application process among potentially eligible individuals, the LME/MCOs have diverse approaches. Some only post information on their websites, while others maintain online information but also distribute fliers at community events such as health fairs. Some LME/MCOs are more proactive and have Member Services or Care Coordination staff who work with local pediatric offices, schools, Child Development Service Agencies, Consumer and Family Advisory Committees, and local Department of Social Services offices.

For both Medicaid-eligible individuals and non-Medicaid individuals who qualify for the RUN, there *are* some services available during the wait for an Innovations Waiver slot. Those services are State-funded only and "(b)(3)" funded. Section 1915(b)(3) of the federal Social Security Act authorizes State Medicaid programs to use cost savings within a Medicaid managed care delivery system to provide non-Medicaid services. In North Carolina, the General Assembly authorizes and appropriates all State-only funding that LME/MCOs may receive within a budget year (the North Carolina budget year is July 1 through June 30). Both State-only funding and (b)(3) funding are available to provide IDD, behavioral health, and substance use disorder services administered by the LME/MCOs. Therefore, there is often not enough funding to provide all services to all individuals who need or request services. However, LME/MCOs did report covering State-funded and (b)(3) funded services to individuals on their RUN lists. Examples of State-funded services that LME/MCOs reported covering for individuals on the RUN include Developmental Day Programs, Respite, Personal Assistance, and Supported Employment. Examples of (b)(3) services that LME/MCOs reported covering for individuals on the RUN include Respite, Community Navigator, Supported Employment, and Applied Behavior Analysis Therapy. The LME/MCO survey questions in **Appendix B** did not yield a means of documenting a) how many individuals on the RUN, by LME/MCO, request State-funded or (b)(3) services; b) how many individuals on the RUN, by LME/MCO, access or use the services available; or c) whether any LME/MCOs do not have enough State or (b)(3) funding to provide all of the services requested by individuals on the RUN. The researchers recommend statewide collection and analysis of these data across all LME/MCOs under the new multi-year grant project.

Stakeholder Input

The stakeholder groups that advocate for NC Registry of Unmet Needs Waiver slots work toward a common goal despite their diverse perspectives and approaches. The nine stakeholder groups shared meaningful feedback regarding their concerns *and* their suggested solutions.

Table 3: Stakeholder Considerations, Concerns, and Solution Strategies for the NC RUN

Considerations and Concerns	Corresponding Solution Strategies
Awareness of the Waiver and the application process among potentially eligible individuals	Personalized outreach and education – a request to not simply direct individuals to a website
Individuals who *are* aware of the Waiver have low motivation to sign up for the RUN because they are aware of the long waiting time	Consider implementing multiple Waivers for different groups and funding allocations per person or a tiered Waiver
Individuals with IDD see the NCGA and the State making investments in select programs, but not the RUN	Advocate for annual, recurring funding to add a predicable number of Waiver slots each year and to fund the system and workforce capacity to serve individuals enrolled in the Waiver
Individuals on the RUN experience high frustration and a lack of hope while on the RUN	Individuals with IDD are aware that people are *talking about* the inherent challenges of the RUN, but what are people *doing* about the RUN? Need to reduce the waiting list
Individuals on the RUN do not receive regular updates about their status	Invite members of the RUN to share their perspectives and to help improve the system
Schools and providers need more education about how to make a referral to the RUN	Invite members of the RUN to be present at relevant State and local Board and Commission meetings in addition to CFAC meetings
Individuals on the RUN feel unseen among the State's residents	Need "one voice" of a statewide advocacy group and need to use media outlets (all forms, including social media) to raise awareness with individuals' vignettes

Policy Recommendations

The research project findings prompt policy recommendations to shorten Waiver waiting lists and address waiver awareness and accessibility inequities. Investment in a centralized database to maintain accurate eligibility and demographic data would inform next steps and has already helped some states shorten their waiting lists.

North Carolina State officials have discussed but not yet implemented a centralized, State-administered "unified RUN." We understand that the forthcoming American Rescue Plan Act (ARPA) funding associated with the 10% Federal Medical Assistance Percentage for HCBS will facilitate this effort. Additional States interviewed are also relying on an influx of ARPA funding to facilitate legislatures' actions to reduce Waiver waiting lists. With the most complex multi-payor Medicaid managed care system that North Carolina has implemented to date, a unified RUN at NC DHHS will be critical. In 2022 there will be six LME/MCOs, four statewide commercial plans, a Tribal Option Plan, and one regional, provider-led plan. Furthermore, the possibility of "churn" of beneficiaries across delivery systems (fee-for-service Medicaid Direct) and Plans (Tailored Plans, Standard Plans, the Tribal Option, and a future state Foster Care Plan) will also make it important to centralize the RUN. Otherwise, this could be one more component of the Medicaid program where beneficiary data are at risk for not being transferred or updated timely. Beneficiaries could be at risk for not receiving updates and notifications about their status on the RUN. Individual Plans could be at risk for inadvertently incorrectly recording individuals' chronological placement on the first come, first served list.

We learned from the survey of LME/MCOs that RUN management differs across Plans. A unified RUN can be populated with standardized and real-time reporting from each Plan, but NC DHHS can oversee the data quality and accuracy and beneficiary updates. NC DHHS can also communicate directly with RUN enrollees on a more frequent basis (e.g., we recommend quarterly versus annual updates; most LME/MCOs conduct only annual updates). Some States interviewed also implement at least annual reassessments of all individuals on the waiting list to ensure continued eligibility for the waiting list and also to ensure that emergency needs or other service needs are documented and addressed.

Additional Waiver administration solutions may include a streamlined application and more widespread efforts to educate and refer the public to the Waiver. There is a consensus among State interviewees that potentially eligible individuals and their families need information about the Waiver *and* helpful guidance for the application process. Education and referrals could be coordinated with applicable hospital departments, pediatricians, local Departments of Social Services and Health Departments, primary care providers, schools conducting transition planning for children with Individualized Education Programs (IEPs), specialized therapy therapists and other specialists, psychologists and social workers, and NC's Area Health Education Centers. Individuals and families not only need to know how to apply for the Innovations Waiver and the Registry of Unmet Needs, if applicable; they need to understand what services the Waiver will cover, and what non-Waiver services they may be eligible for while they wait on the RUN. Furthermore, State Developmental Disabilities Council representatives recommend educational materials that are both in writing and available via videos, in simple language that is not bureaucratic, and translated for individuals with Limited English Proficiency.

Perhaps most importantly, sustainable State and federal appropriations are needed to increase the number of Waiver slots and to support the workforce infrastructure to meet the need. The North Carolina General Assembly's 2021 proposed State budget includes provisions to increase the number of Innovations Waiver slots by 1,000, to increase Group Home funding, and to increase IDD provider agency reimbursement rates and Direct Support Professional hourly wages. Without increased Waiver capacity, a large segment of the IDD population and their families will remain unsupported, and people with IDD will be at risk for unnecessary institutionalization. Adequate State funding to the LME/MCOs (future Tailored Plans) is also needed to allow LME/MCOs to cover the aforementioned State-funded services for the thousands of individuals on the North Carolina Registry of Unmet Needs. We acknowledge that increasing the number of Waiver slots without an adequate provider network and DSP workforce would be problematic. We work with LME/MCOs, provider agencies, and advocates across the State, and we know that lobbyists have met regularly with DHHS officials and NC General Assembly Members to address the direct support professional workforce crisis for both existing and new Innovations Waiver slots. The North

Carolina General Assembly 2021 proposed State budget provisions include a newly established Home- and Community-Based Services Fund (using federal American Rescue Plan Act funding) to increase provider agency reimbursement rates and bring the hourly wage for Home- and Community-Based Direct Support Professionals to $15. At the time of the publication of this report, there is no enacted State budget for fiscal year 2022. However, we should soon know how much funding the General Assembly appropriates to address the current workforce crisis and any future needs for staffing capacity to serve existing and new Innovations Waiver slots.

Finally, when advocating in *any* State for additional Waiver slots and corresponding appropriations, it is advisable to involve Waiver waiting list members in the legislative process to literally give a "face" to the issue. Legislators should not hear from only the Executive branch agencies administering Waiver services or the providers who render the services. Legislators need to hear all stakeholder perspectives, including those of waiting list members and their advocates.

LME/MCO Policy Recommendations:

1) Greater regulation of the RUN process either within the Waiver (which has the force and effect of administrative rule pursuant to NC Statutes) or within the LME-DHHS contracts;

2) DHHS-led, regular LME/MCO Executive Leadership meetings to facilitate standardized RUN oversight and management;

3) NCGA appropriations for additional Innovations Waiver slots;

4) NCGA appropriations for greater State supports for children with developmental disabilities whose families do not qualify for Medicaid, but for whom private insurance co-payment or private payment for supports is a financial hardship;

5) NCGA and CMS authorization and appropriations for broader Medicaid supports, including medical and non-medical drivers of health, and in-lieu-of services for individuals on the RUN;

6) A Statewide, DHHS-operated RUN database to increase administrative efficiency and accuracy and to centralize the oversight of slots, including eligibility determination and slot allocation;

7) Authorization to fill vacant slots in real time versus at the beginning of a new waiver budget year when a slot is vacated for a permanent reason such as death, a move out of state, a permanent move to a medical facility, or voluntary termination;

8) Consumer and family education about the RUN and the Innovations Waiver and assistance with referrals to other community support services available;

9) More staff designated to work with RUN applicants and to evaluate applicants for the Social Determinants of Health;

10) A meaningful feedback loop between each LME/MCO (or the State, if operations become centralized) and each individual on the RUN to include annual, but preferably quarterly, communication regarding RUN status; and

11) Standardization around individuals moving from one RUN to another LME/MCO RUN if the individual has moved out the catchment area.

Conclusion

Policy Recommendations for The North Carolina Innovations Waiver:

- Increase the number of Waiver slots so more individuals with IDD will be fully included, respected, valued, and supported in their communities.

- Increase direct support workforce capacity and wages to ensure adequate support for existing and new Waiver slots.

- Centralize the Registry of Unmet Needs database within NC DHHS to ensure accurate data and timely and periodic (quarterly) notifications to beneficiaries on the RUN.

- Offer an online portal via NC DHHS (or consider amending the Enrollment Broker contract) for beneficiaries to read about, self-refer, and apply for the RUN.

- Institute and centralize a RUN enrollment telephone line.

- Collaborate with the North Carolina Institute of Medicine (NCIOM) on a year-long Task Force and report that would yield recommendations to the North Carolina General Assembly. The task force could include representatives from the LME/MCOs (future Tailored Plans), the State Medicaid agency, consumers and their families, Disability Rights North Carolina, care management agencies, and State vendors.

- Develop educational content for potentially eligible individuals - including new North Carolina residents - and consider Limited English Proficiency needs and outreach strategies for Historically Marginalized Populations within all communities. Include education about what services individuals can expect to receive on the Waiver and what non-Waiver services may be available during time on the RUN.

- Coordinate with community-based stakeholders such as clinical practices, local DSS offices, and local schools to disseminate written education and outreach materials about the Innovations Waiver.

- Work with stakeholders who can lobby the North Carolina General Assembly to support new slots *annually* with recurring funding and adequate State funding for non-Medicaid services.

- Institute annual reassessments of individuals on the RUN to ensure that their service needs are accurately documented and to facilitate any care management that may help them access non-Waiver services.

- Expand the scope of data collected from RUN applicants to track the number of individuals on the RUN who are using one or more other services each month, and the service lines that they are using.

- Consider moving North Carolina away from a first come, first served RUN model and shifting to a needs-based placement with tiered enrollment and annual Innovations Waiver slot budget levels like those proposed in the 2021 Session Senate Budget bill.

- Consider standardized LME/MCO (future Tailored Plan) tracking of the numbers of individuals on the RUN who are receiving one or more *other* services per month and track those services by State-only versus Medicaid (b)(3) funding [*Note: in 2022, NC DHHS anticipates replacing (b)(3) services with a new NC Medicaid 1915(i) Waiver*]. Those service utilization data and initial and periodic assessment data could inform the strategic management of the RUN.

In August of 2021 the North Carolina Department of Health and Human Services, in collaboration with the Technical Assistance Collaborative, circulated an online Strategic Housing Plan survey for review and feedback about housing experiences regarding affordability and supportive housing from individuals with disabilities, their family members, and providers. The Housing Plan will inform NC DHHS policies and resource allocation for creating and maximizing community-based housing opportunities for people with disabilities who are experiencing homelessness, living in an institution, or at risk of institutionalization over in the next five years. In addition to the online survey, DHHS will engage stakeholders in focus groups, individual housing surveys, and in-person planning sessions.

In August of 2021 the Division of Health Benefits in the North Carolina Department of Health and Human Services sent Joint Communication Bulletin #400 to the LME/MCOs to "Reiterate Olmstead Obligations and Address Department's Current Initiatives and Planning." The Bulletin stated, "North Carolina has an obligation under *Olmstead*, the Americans with Disabilities Act, and the North Carolina Persons with Disabilities Protection Act to provide appropriate opportunities for people with disabilities to become fully integrated into the community if they choose to do so. This is more than a legal obligation—it is a moral imperative."

In September of 2021, the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services in the North Carolina Department of Health and Human Services posted a structured list of resources for accessing Intellectual and Developmental Disabilities (including Autism) and Traumatic Brain Injury services in NC. The resource list includes information about the Innovations Waiver Registry of Unmet Needs and other Waivers of interest (e.g., CAP-C and CAP-DA); how individuals can access services even if they are not Medicaid beneficiaries; and how individuals can access services while they are on the Registry of Unmet Needs.

We sincerely hope that the research findings and policy recommendations included in this report will inform and contribute to the success of the NC DHHS *Olmstead* plan in North Carolina and future policy and programming strategies to address the "15,000 Waiting" in North Carolina.

Appendix A: State Interview Questions

Part 1: Questions about History and Process of State's HCBS IDD Waiver Program

1. We would like to begin by learning more about the history of your State's Home and Community-Based Services (HCBS) IDD waiver program.
    a. When was the first waiver cycle approved by CMS and how was it shaped over time?
    b. When was it last amended and in what ways?
2. How well do you believe your state's HCBS IDD Waiver is meeting the needs (e.g., habilitative services, housing, supportive employment, respite, etc.) of the IDD population in your state?

    Additional Prompts:

    a. What are strengths of the current HCBS program?
    b. What are areas for improvement?
    c. Do you survey waiver enrollees or their parents or guardians regarding unmet needs?
        If yes: When? (e.g., annually, when Person-Centered Plan is updated, other)
    d. Do you review State Waiver data annually to assess waiver funding, service utilization, etc.?
3. When individuals are approved for a HCBS IDD waiver, is this done on 1) a first-come, first-serve basis, 2) a needs-based strategy, or 3) a different or hybrid approach?
    a. How many waiver slots does your state have?
    b. How many potentially eligible individuals does your State Medicaid Program estimate your state has? [particularly adults / who is on the radar]?
4. Can you describe how easy or difficult it is for families to sign up for the HCBS IDD waiver?
    a. What barriers are present that make it harder to sign up for the IDD Waiver?
    b. What components of the process are in place to make it easier for someone to sign up for the IDD Waiver?"

Part 2: Questions about Waiting List

5. Does your state currently have a waiting list for the IDD waiver?
    - If yes:
        a. Are you aware of how many are on the waitlist? Is this current information publicly available?
        b. What is the average length of time on the waiting list (months or years)?
        c. Is data tracked regarding the composition of the waiver wait list (e.g., age, race/ethnicity, gender, geography
            - If so, who tracks this data?
            - Are there any disparities noted (e.g., among those who are receiving, on waiting list, in placement priorities)?
        d. Are there other service definitions or programs that are available to individuals on the waitlist through the in lieu of service definition or other mechanisms that you have found helpful for individuals with I/DD on the HCBS waiver waitlist in your state?

Appendix A: State Interview Questions (cont'd.)

- If no:
  a. Can you share more about what you think that means? Does that mean everyone that needs it has some access to services?

  b. Is data tracked regarding the composition of the waiver recipient list (e.g., age, race/ethnicity, gender, geography)?
    - Are there any disparities noted (among those who are receiving, on waiting list, in placement priorities)?

6. If your state wanted to increase the number of waiver slots, would that be done through legislative action or is there another mechanism?
7. What has your state done to lower or intervene on the waiting list for the IDD population?

Part 3: Questions about Other Unmet Needs and Ideas to Improve HCBS IDD Waiver

8. As a DD Council, are you currently implementing or considering implementing strategies to help address unmet needs for the IDD population? If so, are any of these strategies, specifically related to reducing or controlling the waiting list?
   a. Are you collaborating with Protection and Advocacy agencies?
   b. Are you collaborating with Medical-Legal partnerships?
9. Will you describe any subpopulations and their needs that your DD Council is currently focused on?
10. Within your state, do children stay on the same waiver or do you have a waiver for children and a waiver for adults?
11. Next, will you share about any efforts targeted on the transition from adolescent to adulthood period at this time.
12. What ideas do you have on ways to improve the allocation and quality of HCBS IDD waivers?
13. Is there anything else you would like to share that we have not yet discussed?
14. Lastly, are there any other DD Council Directors in other states you think we should ensure we speak to?

Appendix B: North Carolina LME/MCO Survey Questions

1. How many individuals are currently on the RUN?
2. What is the average length of time for being on the RUN?
3. What is the process for being placed on the RUN?
4. Do you know the racial breakdown of the RUN list?
5. How often do you confirm the individual information?
6. Have you developed marketing strategies to educate the public about the RUN?
7. How are you utilizing the data from the RUN within the LME/MCO?
8. Do you share the RUN information with the BOD, CFAC, IDD Stakeholders, Provider Network, etc.?
9. What services and/or supports do you offer individuals on the RUN? (State-funded, Medicaid, B3, etc.)
10. Do you have a plan, or have you implemented strategies to improve supports for individuals on the RUN?
11. Please describe your process in awarding innovation slots to individuals on the RUN.
12. Do you have families who would share their stories from being on the RUN?
13. Based on your knowledge of managing the RUN, please provide recommendations that you would like to share with the NCCDD.

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