



August 6, 2025

Plaintiffs' Comments on Defendants' *Samantha R.* July 15, 2025 Quarterly Report

Below are Plaintiffs' comments on Defendants' July 15, 2025 *Samantha R.* Quarterly Report for the period January 1, 2025 – March 31, 2025. The parties met on July 24, 2025 to discuss Plaintiffs' questions and comments regarding the July 2025 Quarterly Report.

The Lives Underlying the Data

There are 18,950 people now on the Innovations Waiver waiting list, the number having grown steadily from the approximately 11,000 on the list when this case was filed in 2017. Because data points like this can become dry and disconnected from the day-to-day reality of the people affected, Plaintiffs' comments this quarter are accompanied by individual stories (attached). These stories were drawn from a collection published by the NC Council on Developmental Disabilities and give a glimpse under the data to those who are on the waiting list or unable to locate providers. The [full collection can be found here](#).

Many of these stories were also shared at a listening session on I/DD services. [Several videos from that event can be viewed here](#). Media coverage provides additional summary information about the stories shared, including a [Spectrum News story about Cheryl Powell](#), [an OpEd about Matt Potter written by his aging mother](#), and [an overview that touches on some of the thousands of other lives affected by lack of access to services](#).

One of the speakers at the listening session was Jon D'Angelo, who also wrote a piece for the Carolina Journal about his fear of institutionalization in the face of uncertainty while he waits for an Innovations Waiver slot. That can be found here: [Medicaid Innovations waiver can be difference between thriving and dying](#).

General Comments

Plaintiffs appreciate Defendants' continued transparency, openness, and willingness to accept comments with regard to the status of benchmarks and reporting requirements, as well as ongoing efforts by DHHS leaders to address reporting and service gaps.

The July 2025 Quarterly Report continues Defendants' practice of reporting on Consent Order requirements in a narrative format, followed by a chart for the benchmarks and data reportable pursuant to the Consent Order. As noted previously, this format does not make the relevant information easily accessible to the public, the parties, and the Court. Defendants have added data online in more digestible formats and have indicated an intent to add additional Consent Order reporting data to the online portal.

Benchmark Compliance

Benchmark 1.A requires the transition of 78 individuals from institutional settings to community-based services for the fiscal year ending June 2025. *Consent Order*, p. 9.

Defendants have updated the numbers for prior quarters and the current reporting quarter (through March 2025) using additional data sources. *July 2025 Report*, p. 10. One of those sources is the Transitions to Community Living (TCL) program, which is a program required by Defendants' settlement with the U.S. Department of Justice in a 2012 federal case. *Id.* TCL is designed to address *Olmstead* violations in the context of people with severe and persistent mental illness. Some of these individuals may also have co-occurring I/DD. At the parties' July 24 meeting, Plaintiffs objected to the inclusion of transitions that were required as part of a separate settlement agreement, and Defendants agreed to exclude TCL from the data. As a result, based on data share by Defendants at that meeting, 41 of the 97 transitions reported should be disregarded. The revised total is **56 individuals with I/DD transitioned** as of the end of March 2025, leaving **an additional 22 transitions needed in the final quarter** of the fiscal year. Defendants indicate that they nevertheless believe that they are on track to meet Benchmark 1.A by the end of June 2025.

Benchmark 1.B required the assessment of 3,000 individuals with I/DD for 1915(i) services by June 2024 and subsequent assessments within 90 days of request. *Consent Order*, p. 11. **Defendants have conducted the 3,000 assessments but have not tracked the 90-day timeline for additional assessments for this or prior quarters.** However, Defendants indicate that data is now being collected and will be reported in the future. *July 2025 Report*, p. 19.¹

Benchmark 2.A requires that Defendants ensure that the utilization rate for the Community Living and Supports (CLS) Innovations Waiver service is at least 82% by June 2024 and 85% by June 2025. *Consent Order*, p. 14. **While Defendants did not report or meet the June 2024 Benchmark, the available data suggest Defendants may meet the June 2025 Benchmark.** Defendants are reporting an average of 85.2% utilization rate across the four LME/MCOs for the quarter ending March 2025. *July 2025 Report*, p. 24. Two LME/MCOs are above 85%, and two are below. As noted in Defendants' Report and below, there are some discrepancies in the data that raise questions about the accuracy of some reporting. *July 2025 Report*, p. 24, fn. 13. For example, there were dramatic decreases in the units of CLS authorized from the first fiscal quarter to the second, which Defendants are investigating. See *July 2025 Report*, p. 25, Table 12.

¹ Benchmark 1.B also required, by June 30, 2024, the transition to 1915(i) services of individuals on the Innovations Waiver Waiting List who are receiving a specific category of services called (b)(3). *Consent Order*, p. 12. Defendants did not meet this aspect of Benchmark 1B but have since completed the transitions.

Reporting Compliance

1. Tracking Lack of Access to Providers

In the July Report, Defendants are reporting, for the first time, data on the units of CLS not utilized **due to lack of provider availability**. This data can be found on page 25, Table 12. One LME/MCO did not report data for the quarter. This data is a metric for assessing the availability of DSPs, which is as a primary concern with regard to access to services.

- Of the three LME/MCOs reporting all required data for the quarter ending March 31, 2025, there were 14,068,113 units of CLS authorized. Of those, 2,085,331 (about 14.8%) were unused.
- Defendants indicated that the data was derived from records of LME/MCOs that indicate the times in which substitute staff was not available or supplied to a beneficiary. In other words, if a DSP or other staff was scheduled to work but did not, and no appropriate substitute was found, the CLS units would be considered unused due to lack of providers. Plaintiffs raised the concern that this data, while helpful, may not capture situations where an individual simply cannot find staff to begin with – e.g. where services are not delivered because there is no provider at all.
- Although only required to report on the lack of available providers as a reason for unbilled hours, the Consent Order requires that Defendants “collect data showing the reason(s) for non-utilization.” *Consent Order*, p. 14. The lack of data collection as to other reasons for non-utilization creates doubt about the comprehensiveness of the reported data on non-utilization due to lack of provider availability.
- This data point is undermined by the use of a narrow metric and the failure to collect data on all reasons for non-utilization, as well as the lack of data from one of the four LME/MCOs.

2. Defining Eligibility for In-Reach and Diversion

Plaintiffs have previously noted that there was a need to better define who is “eligible for In-Reach” or “eligible for diversion” in the context of benchmarks and reporting requirements.

At the parties’ meeting on July 24, 2025, the parties agreed that any individual in an institutional setting is “eligible for in-reach.” The data on those eligible should therefore be roughly equal to the number of individuals institutionalized at the time of reporting. Defendants indicated that they have been working with the LME/MCOs to ensure consistency and completeness in the definition of “institution” being used. There was also discussion of compliance with the definition of In-Reach in the Consent Order. Data reported as In-Reach included telephone contact, which is not a compliant means of In-Reach under the terms of the Consent Order. Defendants estimated that half of contacts were by phone, and indicated that there would be follow up with LME/MCOs regarding compliance with the In-Reach definition.

With regard to who is “eligible for diversion,” Defendants have proposed a definition for use by LME/MCOs in reporting applicable data. Plaintiffs have provided feedback on that definition.

The July 2025 report data on diversions includes data from the TCL program. *July 2025 Report*, pp. 14-15. As noted above, the inclusion of data from the State's settlement with the U.S. DOJ is not appropriate, and Defendants have agreed to adjust reporting accordingly.

3. Measuring Unmet Need

As in prior quarters, there is a lack of measurement with regard to unmet need of those receiving services through 1915(i), which is a measure of the broader category of unmet need amongst those with I/DD who do not have Innovations Waiver services. *July 2025 Report*, pp. 19-23. Although Defendants consistently report on the number and percentage of individuals on the Innovations waiting list who are receiving some services, there remains no effective measure of unmet need.

- The Consent Order sought to identify the scope of unmet need by first assessing how much of the previous unmet need was addressed through 1915(i). The purpose was to inform future remedial orders to address the remaining gap once 1915(i) was in place.
- 1915(i) offers more limited support than the Innovations Waiver, making it necessary to ascertain the unmet needs of all those with I/DD who do not have an Innovations Waiver slot, including those receiving some 1915(i) services.
- Table 8 on page 21 of the July Report is labeled as being responsive to reporting on unmet need, but the categories of data do not appear to answer the question of the scope of unmet need. At the parties' July 24, 2025 meeting, there appeared to be agreement from Defendants that the data reported on Table 8 does not satisfy the need for direct information, which is also reflected in the comment on page 23 of the Report regarding the hiring of a contractor to design a means of assessing unmet need.

Some of the reporting gaps above appear to be due to the Department extrapolating data from pre-existing reporting rather than requiring LME/MCOs to directly report the required data.

Continued Concerns

Key takeaways from the July 2025 Quarterly Report:

- It is unclear if Defendants are on track to meet the transitions benchmark once the TCL data is disregarded.
- Defendants did not meet the June 2024 utilization rate benchmark but appear on track to meet the benchmark of a utilization rate of at least 85% for DSPs by June 2025.
- It is unclear whether Defendants have fully resolved the tracking of unused authorized services due to lack of available providers.
- Defendants are not tracking the unmet needs of individuals receiving 1915(i) services who still have unmet needs. This is core data, the lack of which will have implications for the next phase of the remedial process.
- As with prior quarters, the July 2025 Report indicates that there are ongoing efforts on improving (and in some cases initiating) data collection, but important gaps remain.

ATTACHMENTS

MEDICAID MATTERS



Jamishaele Symons, Hertford, NC

My four girls are ages 2-13, and they all have autism level 2-3.

The three older ones have been on the waitlist for Medicaid-funded services since 2020. The youngest was just added. The oldest would have been on it prior to 2020, but none of the medical providers or schools told us about it.

Knowledge of the waiver and waitlist is not readily available, or health professionals are poorly trained in services and needs of ID/DD people.

We get limit services while waiting, but there is very little staff, and staff are not fully versed in ID/DD needs.

We are in rural Northeast NC with very little access to any services or providers. Our options are to travel one hour or more north to Virginia (limited on NC Medicaid providers) or two hours south to Pitt County.

We need **more** waiver slots for the whole NE region as well as trainings for health care professionals, DSPs, and schools. We also need more community education on wandering, water safety to prevent drownings for DD/ID, and elopements.

We call every few months to inquire on waiver slots and always told it is up to a 20-year wait.

“We call every few months to inquire on waiver slots and always told it is up to a 20-year wait.”



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Jon D'Angelo, Raleigh, NC

I am an East Carolina University graduate. I work full-time with an insurance broker out of Atlanta. I am on the waiting list for the Innovations Waiver. Currently, 2/3rds of my care is done by my aging parents.

I have Spinal Muscular Atrophy type 2. I need physical assistance with most activities of daily living. I have CAP-DA, but it doesn't provide the hours needed to avoid a care crisis. If I go into a care crisis because of DSP pay or the waiting list, everything I've worked to achieve professionally and personally will be completely destroyed. Most 36-year olds with a Master's degree don't fear going into a nursing home, but I do, and it is something I've feared since my freshman year at ECU.



“Most 36-year olds with a Master’s degree don't fear going into a nursing home, but I do, and it is something I’ve feared since my freshman year at ECU.”

Medicaid means disabled people can live at home and age in place. Any cuts to Medicaid risks sending disabled people back to institutions.

710,000+ people with disabilities in the U.S. are on waiting lists in 2024 to access Medicaid services in their own homes and communities (HCBS).



The vast **MAJORITY OF U.S. VOTERS SUPPORT PROTECTING MEDICAID** from harmful cuts, and most would prefer to **INCREASE FUNDING FOR MEDICAID.**



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MEDICAID MATTERS



Jonathan Ellis, Murfreesboro, NC

For me and my family, Medicaid means...

I am a 52-year-old young man with Cerebral Palsy, which is a developmental disability. I am from Murfreesboro, NC and Hertford County. I am one of the few who is lucky enough to benefit from an Innovations Waiver system slot.

I have to depend on aging parents (my mother is 78, and my father is 79) when there is no staff coverage for my Innovations hours, and it takes both them to do what 1 Direct Support Professional could do in about 2 hours. Tasks could take up the entire day with my parents.

Even if my hours are covered by staff, my parents don't want me left alone for emergencies. What do I do when they are no longer here on this earth?

I am my own guardian, and I do not want to be placed in an intermediate care facility (ICF) or a group home for that matter. With the support of my direct support professional team that I have around me, I am able to go out to the community and to work and play and visit with friends. Without these wonderful people, I would be stranded in my own home.

“With the support of my direct support professional team that I have around me, I am able to go out to the community and to work and play and visit with friends.”



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Lisa Sullivan, Clayton, NC

Tom is 20 years old and has intellectual and developmental disabilities (IDD), autism, and mental health diagnoses. He was diagnosed at 2 years and 9 months, and I placed him on the Innovations Waiver waiting list when he was just 3 years old. When Tom finally received a waiver slot at age 10, we faced the heartbreaking challenge of being unable to find staff—ultimately leading to the loss of his waiver. During a crisis, I turned to our LME/MCO for help, and Tom was placed back on the waiting list.



Today, Tom receives 1915(i) services, which provide Community Living and Support (CLS) hours twice a week. Although he qualifies for 28 hours of support per week, we've only been able to secure staffing for 12. To supplement his care, he also attends a private-pay day program two days a week. With structured supports in place for four days a week, we've seen a remarkable improvement in his behaviors.

However, Tom has an even bigger goal—he dreams of living independently in the community. Without the Innovations Waiver, he lacks the essential supports to ensure his health and safety in a more independent setting. Recently, through advocacy, I secured 300 respite hours per year for him, but now we face the next challenge: finding staff.

Tom thrives when he has purpose and structure in his day. I remain hopeful that we can secure the support he needs to continue growing, gaining independence, and achieving his dreams. He deserves a chance to live a fulfilling life in the community—and that starts with accessing his Innovations Waiver Services slot.

This would not be possible without funding for Medicaid!

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Marjorie Serralles-Russell, Charlotte,

I am the mother of Spencer Russell, a 25-year-old with Autism and I/DD. Spencer aged out of high school in June 2022. As he has entered the adult service system, it has resulted in a major “cliff” of services because Spencer is on the Waiting List for the Innovations Waiver. This waiting list currently has 18,771 people on it, and it can take 10-15 years for those “waiting” to receive services. Spencer’s challenges have only been exacerbated, and he has greatly regressed because he is not receiving the help he needs. Being older parents, we worry about what will be a realistic future for our son.



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Ray Hemachandra, Arden, NC

Nicholas Hemachandra is a kind, loving, and entirely good man. He's 24 years old. We live together in an apartment in Arden in Buncombe County, and he is an example of the powerful difference the Innovations Waiver can make in the life of a person with IDD.

Nicholas is autistic and intellectually disabled. He has severe mixed expressive-receptive communication disorder. He is medically at-risk and immunocompromised—co-occurring conditions are common for people with IDD. He has severe ulcerative pancolitis, and he had a stroke. He had significant self-injuring behaviors as a child, behaviors that spiked when he was bullied in school by other children.

Nicholas began receiving the Innovations Waiver, which was then called a CAP waiver, in 2010. He's now had direct care workers who connect him to the community for 15 years. Having Medicaid also means his medical complications can be addressed appropriately.

Nicholas works part-time at Annie B's, a local ice cream shop; he volunteers at MANNA FoodBank and Asheville-Buncombe Community Christian Ministry. His volunteering expanded even more for 5 months after Hurricane Helene to help out his community and people in need.

He participates in Asheville City recreational programs and other social groups, swims and takes classes at the Y, and he has become a truly exceptional juggler. His Innovations support workers contributed to all of this.



“He is an example of the powerful difference the Innovations Waiver can make in the life of a person with IDD.”



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MEDICAID MATTERS



Shannon Bennett, Garner, NC

For me and my family, Medicaid means support, which provides us an opportunity to step out of survival mode and begin improving our quality of life and mental health with hopes of finding some sense of normalcy as defined by society.

Medicaid allows me to show up at my essential job with US Courts and maintain the federal benefits that save Medicaid money!

Medicaid means Lakelann [pictured] can stay with her family a little longer and prevent institutionalization, which is the path we are on due to lack of staffing and high turnover.



We are facing residential placement due to the staffing shortage. It is inevitable at this point that I am so burnt out as a single parent with other children and as a federal worker. It has gone on too long. This is the likely option ahead due to Lakelann's high medical needs, lack of qualified staffing and high turnover rate.

“Medicaid allows me to show up at my essential job with US Courts and maintain the federal benefits that save Medicaid money!”

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Susan Barner, Catawba, NC

For my son, Medicaid means...

Andrew is 16 years old. He is a very social, happy kid who loves to ride bikes, play outside and is an incredible springboard diver on a local dive team. Andrew also has Fetal Alcohol Spectrum Disorder—FASD. FASD is an intellectual and developmental disability that affects 1 in 20 children – and that statistic has probably grown since the pandemic. Yet it remains widely unrecognized and unsupported within our public systems.



My greatest fear is what happens when Andrew becomes an adult, and I am no longer there to advocate for him. He has so much potential—he can work, live independently, and contribute to society – but only if he has the right supports in place. Programs like the Innovations Waiver are not optional; they are essential. My son has been on the Innovations Waiver waitlist for 6 years now.

My son is also an example of someone who is not intellectually disabled but could not function without the support from the Innovations Waiver. Like many with FASD, his adaptive functioning is severely limited – he has extremely high impulsivity, which impairs his decision making, slow processing speed where he needs more time to think and process information, and low short-term memory, so he needs visual reminders and tasks broken down into a few steps at a time. Despite these challenges, Andrew is very capable IF he has the right interventions. This is why the Innovations Waiver is so important – it will provide Andrew with the right support that will allow him to reach his full potential.

“Programs like the Innovations Waiver are not optional; they are essential.”



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