Medicaid Flexibilities in Action: North Carolina Member Testimonials

Compiled by Shannon Dowler and Talley Wells

Introduction

The COVID-19 pandemic led to a large number of temporary Medicaid flexibilities allowed under state and federal authority waivers. Decisions about what to continue into permanent policy were influenced by many factors, but perhaps the most important was the actual impact on the lives of the members receiving Medicaid services. Listening to stakeholders is an important role of state policymakers. Specific to the federal Appendix K flexibilities, we are including some testimonials from recipients receiving Medicaid via the NC Innovations Waiver to demonstrate the impact for those with lived experience.

"My brother receives Mom's Meals as a result of the waiver and the flexibilities. These meals have helped him tremendously these past three or so years. I work an eight-hour day job and he is able to utilize these meals for breakfast and for packing his lunch daily while with this day worker. We were never worried about him going without food or stressed about stopping and getting him money for his lunch. The meals are very convenient and so simple that he takes pride in preparing his own meals, even though it is just microwave meals.

However, with Appendix K sunsetting, his meals will go down to one meal a day. This leaves me with a hard decision of which meal is more important to him, breakfast or lunch. I know things aren't meant to be taken advantage of, but when you are as busy as myself, rushing to get out the door first thing in the morning and constantly struggling to even find time for yourself to eat, it is reassuring to me to know that my brother has these meals to eat. That took a lot of worry off me."

— K.F.

"Definitely allowing a guardian or family member to be paid for providing all authorized hours ... has been the most critical. I also liked having CFAC [Consumer and Family Advisory Committee], DSP [direct support professional] workgroup, PACID [Parent Advocates for Adult Children with Intellectual and/or Developmental Disabilities], ISP [Individual Service Plan] meetings, etc., on Zoom, which allowed me to participate/advocate. My daughter would not tolerate in-person meetings and I had never had consistent enough care to commit to participating, but I need to advocate on her behalf since she is unable to speak for herself.

The non-family-caregiver was a problem for me long before COVID, because my daughter's need is higher than the average waiver recipient; they called us an 'outlier.' I was constantly bringing on unskilled, young, non-committed people and sinking so much time and effort into training them only to have them leave. I became paid staff 10 years ago to fill all the gaps; under managed care, they only looked at claims as data of service used and never considered that unused service was due to lack of available or appropriate staff. Paying family as qualified, trained, skilled support staff is critical moving forward until many DSP issues around pay, training, retention, proper insurance, paid time off, etc., are worked out. It however is not a permanent solution for those of us in our 60s."

— D.C.

"My daughter is 20 years old and has IDD [intellectual or developmental disability]. She has been on Medicaid since 2022. She has benefited from being able to have evaluations done virtually and from telehealth. Continuing to offer virtual/remote services is so beneficial for both her and the providers. She attends high school full time, in-person speech and occupational therapy weekly, and attends Special Olympics practices weekly. If we had to do evaluations for the 1915(i) services and her genetics clinic in person, we would have had to miss some of the above. As a parent who works part time, I try and arrange her therapies on the two days that I do not work. I hope this flexibility will continue."

— M.K.

"If it had not been for the telehealth calls with Dr. Gordon Schneider, we would have lost Jerry totally with his loss of reality during the COVID shutdown."

— N. B.

"Allowing family members to serve as direct support professionals ensured ongoing care for my autistic son and provided the opportunity for his sibling to gain work experience. She took the job very seriously. Similar flexibility would be useful now

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due to the ongoing shortage of direct support professionals.

Flexibility in location and televisits were also useful. Van interacted with one provider by internet and spoke much more than he would have in person because he likes computers and dislikes talking to people in person. Providing ongoing flexibility would be extremely valuable to individuals with I/DD and their caregivers."

— Amy Fowler, MD, MPH, Pediatrician,
Chapel Hill Children's Clinic

"I have two adult children receiving services through the Innovations Waiver. I began self-directing their services as an employer of record in 2021. And then in 2022, I began working as a RADSE (relative working as a direct support employee) and was able to give them much greater continuity of services whenever we were without staff.

Being without staff happened fairly frequently and for prolonged periods of time. If I hadn't been able to step in and work the hours, they would've been without services. This definitely would've impacted their quality of life. Both of my kids are very challenged and upset by changes in their routine.

Being able to work as a RADSE has also greatly benefited our family financially. I have been unable to work a consistent job outside of the home due to the needs of my kids. So, working as a RADSE has allowed me to contribute significantly to the family income."

— Eileen Rice