



2025 North Carolina Medicaid & Advocacy Stories



Adam Strom Wake Forest, NC

Adam Strom is a vibrant and joyful young man with **Fragile X Syndrome**, a genetic condition affecting his learning, behavior and social interactions; he experiences cognitive and developmental delays requiring lifelong support, including sensory sensitivities and socialization difficulties due to Fragile X and Autism. He enjoys singing with his favorite music videos, weekly workouts at the gym with a personal trainer, and playing Bingo on Zoom with friends from across the country. He stays in touch with his friends with disabilities through bi-weekly virtual meet-ups to strengthen and build a sense of community. His infectious enthusiasm and hugs delight everyone he meets.

Through the North Carolina Innovations Medicaid waiver, Adam benefits from essential supports that help him with daily activities such as bathing, dressing, household chores, and employment and is developing independent living skills for the future.

At age 28, Adam lives with his parents, who are in their 60s. He will need continuous support over his lifetime as he faces these challenges alone. His parents are deeply concerned about his transition to independent living while also managing their own financial challenges related to retirement and healthcare costs. Adam's parents envision a future where he fully and independently lives his best life in his own place, supported by paid caregivers, professionals, friends, and his faith community. They want him to continue his competitive integrated employment at Cambridge Village of Apex, where he is respected and valued. All of this is made possible through Medicaid funding which is essential for Adam's care and support.



Adam thrives on connecting with people and is affectionately known as a serial hugger.

Alisa, Tony and David Ginyard
Durham, Durham County
Alisa@RealityMinistries.org
301-922-1185



- I'm the mom of David "the Cartoonist," who is on the Autism Spectrum, and the wife of a patient man named Tony. We named our son David after the giant slayer in the Bible, and he himself happens to be a giant of a human, 6' 3" with a size 14 foot. He was officially diagnosed with Autism at age 4.
- Through Medicaid support services, my son David is with a wonderful Direct Support Provider (DSP). I work at Reality Ministries, and I hear the voices of other parents and caregivers who are lovingly carrying sons, daughters, siblings and grandkids with I/DD...and this is often very heavy.
- We never even wanted to consider government resources at that time; nobody could accuse us of living "off of the system" when we were supposed to handle our own. When our son was around 13 years old, he started having rages, smashing his fist into walls and the glass shower door, even into my arm a few times. Thank God the extreme version of this stopped after around age 27 but left him with effects from medications and some residual anxiety.
- We are so grateful to have support for him with workers who act as job coaches, take him to activities and help him to work on life skills that were not developed during the hard years. Having someone steadily with him has helped his anxieties to lessen as well. We hope that this DSP won't leave, we have lost so many because the pay for this work is not high enough, we hope this changes.
- David was added to the Innovations Waiver waitlist in 2016; we have a ways to go, but we're hopeful that on the waiver he will have strong supported living services when we are no longer here.



Annette and Ben Smith
Cary, NC
919-280-9944
nettersmith@yahoo.com

- My son Ben is 36; he has received Waiver services since he was 8. My husband and I were a team, ensuring Ben had continuous services and DSP workers while we both worked. It was tough but manageable.
- My husband's name was John Smith, “an extraordinary man with a very ordinary name.” Our world changed drastically in 2001 when John was diagnosed with breast cancer. He died at age 54 when Ben was only 16. After John died, we were left with enough Social Security Survivor funds to help our children trust us to take care of them.
- We parents trust that Social Security and Medicaid will do the right things. We received notification that because Ben was not 18 and he did not have SSI, that he would have to pay back his survivor benefits monthly for the remainder of Ben’s life, leaving only \$292 a month! These 30-year-old laws that impact our families need to be updated.





Anthony and his mother, Lether Young, for whom he was a caregiver until she passed away December 2024.

Anthony Young Franklinton, NC

I am an African American man, self-advocate, and caregiver, the third of five children. I was born with cerebral palsy. My two older siblings have passed away; now I serve in the role of big brother to my two younger siblings. After our mom had a major stroke four years ago, I moved home to help take care of her, until her passing in December 2024. That was needed because my two younger siblings were not able to retire early, and we did not want our mom to go into an assisted living facility.

I have watchful eyes and listening ears that focused on mom's every move. I drove her to medical appointments, church, Walmart, and anywhere else she wanted to go. I use a walker, and she used a rollator! We were quite the pair! I was her protector, advocating for her whenever necessary. I wash dishes and take out the garbage. When Mama was still living, I even had the chore of hanging out and bringing in her laundry (yes, on the clothesline outside!). Life is interesting. Growing up, my mom was my biggest advocate and motivator, and for several years, I got to be hers!

When time allows, I advocate for accessibility and reliable transportation for people with disabilities. I am a member of the Strategic Involvement Committee (SIC) for the Greensboro Transit Authority (GTA). We gather monthly to discuss how to better serve the paratransit community. These are such critical issues in the I/DD community.

I dabble a little in politics too, encouraging African Americans as well as the I/DD community to register and vote. I remind them that many people gave their lives just so we'd have the right to vote. And I let them know that their vote really does count! In years past, I've even chauffeured people to the polls.

I enjoy attending conferences, like the in June 2024 where I learned more about Medicaid Expansion. In sharing this information with others, one of my high school classmates was able to apply, and now she has health insurance!

Medicaid is so very important for our disability community! We must have it funded!

Beverly Christian

L'Arche North Carolina, an intentional community
Durham, NC
beverly@larchenc.org



At L'Arche NC, we believe that true care is built on relationships. Our home is more than just a place to live—it's a community where people with and without intellectual and developmental disabilities (IDD) share life together. But finding the right people to support this vision has never been harder.

The ongoing Direct Support Professional (DSP) shortage has made staffing a constant challenge. We already strive to pay above the average hourly rate, recognizing the immense value of this work. But even with competitive wages, recruiting and retaining dedicated assistants is difficult. The reality is that many skilled candidates are drawn to industries with better pay, benefits, or less demanding work. And yet, the work we offer isn't just a job—it's a calling.

Every day, our team at L'Arche NC sees the profound impact of relationships built in community. When the right assistants join us, they don't just provide support; they become part of something greater—a family of belonging, growth, and mutual care. But without enough staff, the weight of responsibility falls heavier on those who remain, making burnout a real risk.

The DSP crisis isn't just about wages; it's about recognizing and valuing the essential role of caregivers in our society. At L'Arche NC, we remain committed to fostering a workplace where assistants feel supported, appreciated, and inspired. But we can't do it alone. It takes a community—a collective effort to advocate for better pay, policies, and recognition for those who make inclusive living possible.

Despite the challenges, we press on, believing that the right people will come. Because when they do, they don't just change lives—they become part of the heart of L'Arche itself.



Bryan Dooley, NCCDD Chair

155 Conrad Circle
Lewisville, NC 27023
336-529-8647
bryan@sicilnc.org

- I am Immediate Past Chair of the North Carolina Council on Developmental Disabilities. I was appointed by the Governor in 2022, and I served until the end of 2024. I also work as an inclusion specialist at Solutions for Independence In Winston-Salem.
- I am currently experiencing difficulties due to the Direct Support Professional (caregiver) workforce shortage. I am on the Innovations Waiver.
- My mother passed away in 2021, leaving my Grandparents now as my main family caregivers. My grandfather died in 2024 at age 89, and my grandmother is still one of my primary care providers at age 87. I had a big scare in 2024 because my only Direct Support Professional, who had been with me for years, retained a better paying job. I couldn't find any Direct Support Professionals because the pay is so low, and it came down to the last week before I found some people to work with me.
- If I don't have Direct Support Professionals, then I can't get out of bed, I can't go to work, and I could even face having to go into a nursing home or institution to live. This is much more costly than living at home.

The top policy education priorities for NCCDD are:

- Maintain Medicaid funding!
- More Innovations Waiver slots.





Cameron Kempson
Asheville, NC
centeredresources.com
cameron@centeredresources.com

At 20-years-old, I entered the disability sector as a camp counselor with Camp New Hope (Autism Society of NC) in Chapel Hill, North Carolina. That summer changed the trajectory of my life, and now, 35 years later, I'm still deeply committed to this work. Over the decades, I've walked alongside families navigating the often-complex Medicaid waiver system—helping them secure funding for assistive technology, direct support professionals, and access to their communities. I always knew this work mattered, but five years ago, it became personal. When my sister began her own journey with disability, I stepped into a new role—not as a professional, but as a family member and advocate.

Neither of us could have anticipated this path, but we've chosen to walk it together with intention and resolve. Medicaid has been our anchor. It enables my sister to remain in her home, receive the medical care and daily support she needs, and continue living a life of autonomy—all without placing a crushing financial burden on our family or her community of care.

I have experienced Medicaid from two powerful vantage points: as a professional and as a sister. In both, it has been nothing short of transformative. Medicaid is not just a funding stream—it is integral to ensuring people with disabilities have access to healthcare, housing, employment supports, and direct services. It sustains lives, fosters dignity, and makes inclusion possible.



Landon excited to play baseball!

Carly Oberle
letsincludelandon@gmail.com
Waxhaw, NC
Parent/disability inclusion/loves
playing baseball



I am passionate about disability inclusion. Both of my boys love sports, especially baseball. My older son, Landon, has Williams Syndrome, which is a deletion of genes on the 7th chromosome. He grew up watching his cousin play. When he finally started playing, he was embraced by our local baseball community. I love nothing more than being out playing baseball with my boys.

I believe that every child deserves to play sports together with their peers. This does not mean their peers are helping the kid with a disability, it means they are playing with them on the same team -- learning how to be successful together. If we teach our kids to change their perceptions, then we can change what kids with disabilities can achieve. Everyone needs to be given opportunities to be on a team, have a best friend, be invited to birthday parties, be part of their school, and have a place in their community.

Carol Conway and Paul Conway
carol.ann.conway@gmail.com
Chapel Hill (Orange County)

- My name is Carol Conway, and I live in Chapel Hill with my husband and son, Paul. Our son is 37 with a rare genetic disorder that comes with low cognitive capacity. He is mostly nonverbal, can't manage his toileting, needs his bedding changed in the middle of the night, is prone to tantrums and self-injury, and sometimes goes manic without sleeping for 2 or 3 days at a time.
- Paul is one of at least 30,000 developmentally disabled adults who have exceptionally high support needs. You almost never hear about the needs of people like my son. Medicaid is so important to provide the care that my son needs through a DSP, Direct Support Professional.
- DSPs need to get to know each person and each family deeply. They need to know how to manage difficult behaviors—which makes community excursions possible. They need to know how to spot medical problems in a nonverbal person before it gets serious. Treating DSPs as professionals pays off.



Cathy Hatcher
cathymidgett@gmail.com
Poplar Branch, NC

Given the area of Currituck County and the complexity of my son's caregiving, the staffing has been a situation or lack of staffing has always presented a problem here.

We will have staff for a short time several months at the most, and then they move on to a higher-paying job.

This means we have to train new staff often.

The top policy education priorities for NCCDD are:

- Keeping Medicaid
- Increase Innovations Waiver slots
- Increase Direct Support Professional (caregiver) Wages





Caroline Dempsey (aka, Liney Dee, Artist)

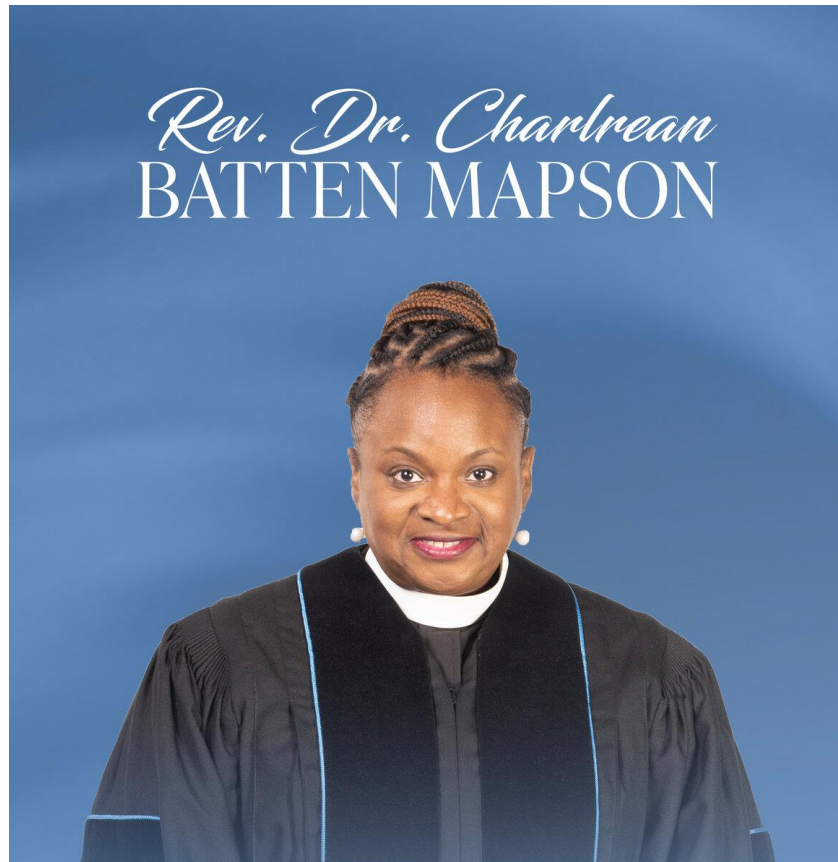
carolined11@icloud.com

Facebook: <https://bit.ly/3N7bY7E>

Raleigh NC 27604

- Hi, I'm Caroline. I'm an artist. I like to paint with acrylic paint on canvas, and I love lots of bright colors.
- I like to share my art at festivals, and I like when I make sales. I've also had art exhibits at Atlanta Library, Rome-Floyd Library (GA) and Georgia State University.
- This photo is me at an art sale in Chapel Hill in May 2023.
- I love my family and friends. I enjoy making people feel welcome and happy.
- I have a job at a very popular bakery near my house. My job coach supports me in my work.
- I have some support (8 hours a week) through Medicaid 1915(i).
- I moved to North Carolina in January 2022 with my mom, Pam, and my dog, Moses.
- I want to make new friends, do a good job at work, and keep making lots of amazing art.

Rev. Dr. Charlrean Mapson
Wilmington, NC
nccdd4cbm@gmail.com
Mom to Jadon, age 20



I am in my first term as a Governor-appointed Member of the North Carolina Council on Developmental Disabilities.

A Wilmington resident, I am employed by the African Methodist Episcopal (AME) Zion Church, currently serving as the pastor at Evergreen AME Zion Church in Delco, outside of Wilmington. I hold a Bachelor of Science in Chemistry and Engineering from Clark Atlanta University, a Master of Divinity from Hood Theological Seminary (where I graduated Magna Cum Laude), and a Doctor of Ministry from Duke Divinity School where my thesis was titled "Inclusion of the Autism Population in Churches, Schools, and Communities." I currently serve on the New Hanover County Smart Start Board.

I am a mother of a son with Autism. There is a need for more parent advocates, as we experience a lack of resources and supports for us as parents.

If my son did not have Medicaid, he would not currently receive his services that he needs at home and in the community; furthermore, he would not receive assistance with coverage for his health care needs. Both of these are vitally important to our household.

<https://open.spotify.com/show/3PGoSbAhRZYBk24XdwYUDG>



Cheryl Powell

cpowellbsw@gmail.com

910-757-9012

Wilmington, NC (New Hanover County)

My name is Cheryl. I'm married to the love of my life, Billy, and I have Cerebral Palsy. I am responding as a self-advocate, not just for myself but for so many people with disabilities across North Carolina who deserve the chance to live with dignity. Right now, there are over 18,700 people on the Innovations Waiver waitlist while there are only 14,000 who have a Medicaid Innovations Waiver slot. Being on the waitlist can last years, even decades, holding us back from accessing vital services that promote independence and respect. These waivers aren't just red tape or a line on paper; they are lifelines. They provide personal care, job supports, community integration—services that allow people like me to live meaningful lives. But for many this waitlist feels like being told their lives are on hold or worse.

We need to discuss the direct support professionals (DSPs) who make these supports possible. I have over ten years of experience working as a DSP so I am quite familiar with the role. They are the backbone of our system, supporting people with disabilities every single day. Too often, they are overworked, underpaid, and lack proper training—and in some cases, adequate respect.

Ensuring funding for the Innovations Waiver waitlist and investing in DSPs are not just moral imperatives—they are investments in the future of our communities. When people with disabilities can lead fully productive lives everyone benefits. But to get there, we need action, funding, and commitment.

Together, we can build a future where everyone, regardless of ability, is truly supported.



Dave Owen

336-575-6359

David.Owen@vayahealth.com

- I am now an I/DD Transition and Inreach Coordinator with Vaya Health.
- I am the former Direct Support Professional for NCCDD Chair, Bryan Dooley.
- I was Bryan Dooley's Direct Support Professional for 6 and a half years. It was one of the best jobs of my life and allowed me to grow and learn exponentially. I absolutely adored working with Bryan. He is, hands down, one of our state's best advocates. He needed my help with getting in and out of bed, with bathing, with eating, and with other basic activities of daily living. My support helped him to do his work and his vital advocacy.
- In 2023, I decided that I needed to take another job because the pay for DSP was just too low, and the new position came with benefits. My work now is actually a lot like Bryan's. I am helping individuals with disabilities transition out of institutions and back into the community.

The top policy education priorities for NCCDD are:

- Keep Medicaid funding!
- Increase Innovations Waiver slots.
- Increase Direct Support Professional (caregiver) wages to have a strong workforce.



David Ingram
4006 Brown Place
Raleigh, NC, 27604
DHIngram@gmail.com

I am David Ingram. I was born and raised in Raleigh, NC.

I have an 11-year old daughter who enjoys dancing and a receiving a wonderful public school education.

Healthcare is important to me and those I love, including two aging parents and an immunocompromised partner.

I am particularly interested in seeing Medicaid funding preserved so that as more people living with disabilities get the services and supports they desperately need.

Deja Barber
dejabarber94@gmail.com
Raleigh, NC

Medicaid means independence to me because I am able to be have freedom without worrying about financial and medical concerns and I can work. I have a great job!

My top policy priorities are:

- Increasing the amount of work income I can make while having social security.
- Being able to work.
- Keeping Medicaid.





Demi Eckhoff

Cell: (205) 807-1587

Email: demileckhoff@gmail.com

Durham, NC



I was born with a rare form of congenital muscular dystrophy. I rely on a non-invasive ventilator throughout the day as well as a feeding tube for all hydration and supplemental nutrition.

I moved independently from Alabama to North Carolina in 2016 to receive my master's in public health-registered dietetic training at UNC - Chapel Hill.

Currently, I serve patients with eating disorders and other chronic health issues as a part-time dietitian. I pay taxes now and am a productive and influential individual in my community. In the fall, I will be attending John's Hopkins University online, working towards my Doctor of Public Health with a concentration in Health Equity and Social Justice.

Through Medicaid, I received an Innovations Waiver after having to hospitalize myself in order to get it. You may say that this is a drastic measure, but this is what it takes in order to receive equitable, independent care for someone with a significant disability.

It costs Medicaid more money for me to be hospitalized than it is for me to live and thrive in my community independently. If my services were stripped away from me, due to these proposed budget cuts, I would be forced into a Long-Term Acute Care Facility due to my ventilator. This would cost taxpayers significantly more money than keeping me in the community.

I urge you to preserve funding for Medicaid.

Donna Beckmann
Parent and guardian to a young man with Down syndrome
Durham County, North Carolina
donnabeckmann@gmail.com
919-880-4644

- My 24-year-old son Thomas has been on the Registry of Unmet Needs (RUN) since July 2012. The time it takes a child to complete elementary, middle and high school.
- I recently left my job to provide support to my son.
- Thomas was approved for 1915(i) services and supports in summer 2024. First direct support staff worked for two weeks in February 2025 before quitting for another job.
- On the first day with the 1915(i) direct support staff, staff worker was able to get Thomas to complete a task he continually refused to do for me, his mother.
- I cannot help but think how far along Thomas would be with independent living skills, communication, safety, etc. if he had had direct support staff all these years.
- For my family, Medicaid means Thomas might have more opportunities and choices in life as a 24-year-old man...who at this point is reliant on his parents for many things a typical 24-year-old would be doing independently. Thomas can use power tools but cannot manage money. What will his future look like when his parents are no longer able to care for him?
- Thomas works three days a week from 9:00am-3:00pm. With more support, he might have been able to work longer hours or more days. However, transportation is an issue regardless of the amount of hours he works.
- Thomas loves life and participates in Special Olympics golf, swimming, and for the past year, powerlifting. In addition, he kayaks, does woodworking, rides his bicycle, and finds ways to be useful at home and at his father's business. He is a hard worker and very independent – to a point. He does not always stay on task or move on to the next task as planned.
- Thomas is a huge Durham Bulls Baseball fan. He knows all the players (current and former), what team they came from, and who is moving up and down from the Tampa Bay Rays. Thomas has met many of the players and has a nice camaraderie with the players.
- There is much to know about Thomas and how his life is impacted by Down syndrome and the lack of services and supports. I am happy to share our experiences to better educate you on the impact that policies have on Thomas's and our family's life.





Donna Spears, NCCDD Council Secretary

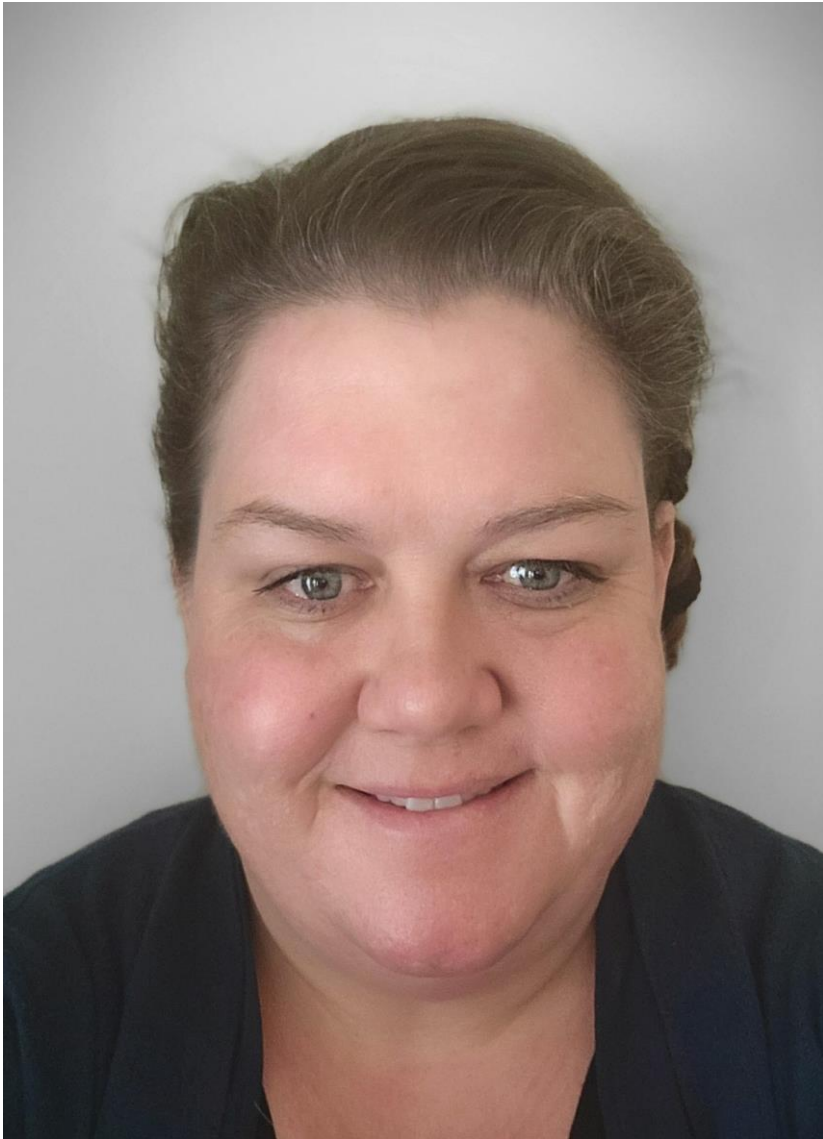
259 Sweet Gum Lane

Richlands, NC 28574

337-368-8370

donnaspears1966@aol.com

- I am a member of the North Carolina Council on Developmental Disabilities and serve as Co-Vice Chair of the Council. I was appointed by the Governor in 2019.
- I have the CAP-DA Medicaid Waiver and have a Direct Support Professional who supports me with activities of daily living.
- I serve on the Advisory Board for the state Subminimum Wage to Competitive Integrated Employment grant.
- I am particularly concerned about the workforce shortage for Direct Support Professionals (caregivers), the Innovations Waiver waiting list, and competitive integrated employment.
- **The two top policy education priorities are:**
 - Increase Innovations Waiver slots. We have 18,770 people waiting for waiver services in NC!
 - Increase Direct Support Professional (caregiver) Wages. We need a strong care support workforce.



Holly Connor
hconnor2111@gmail.com
Jacksonville, North Carolina

I am a parent advocate with training from COPAA and other advocacy groups. I volunteer in various groups - Family Support Network of the Crystal Coast, Special Education Alliance for Eastern North Carolina, Exceptional Families Military Program Advisory Board, Onslow IDD representative for the Trillium Health Resources Southern Regional Consumer and Family Advisory Committee (CFAC), and as a board member for the Down Syndrome Network of Onslow and Carteret Counties.

I believe in the concept of utilizing families' firsthand accounts and their lived experience in order to learn from them and build a network of supports through that knowledge! I have been pleased to be a part of the pilot program to build Family Navigator as ILOS (in lieu of service) and now I am working within ICS as a Program Supervisor.

Medicaid is important to me and my family. We waited 11 years to get an Innovations Waiver slot. It's called the golden ticket, but it changed very little due to the staffing crisis. Finding people willing to work with our son is challenging.

Lack of understanding, lack of education of what I/DD is, lack of exposure to our disabled population, and treating the position as if it is not an important role are all a problem.

Having someone in your home caring for the needs of individuals who has I/DD and ensuring a meaningful day is hard work. As of right now our family is utilizing relative as employee. This means my husband and other son are providing the services. I know firsthand the effort being made to hire people as I work for an agency that does this valuable work. The Innovations Waiver is not a golden ticket if you still face the same challenges with or without it.

Jadon Mapson

Wilmington, NC

Hi, my name is Jadon. I am 20 years old. I live in Wilmington. I'm still in high school, making plans for what comes next.

Recently, I received my very first voter registration card! I have had the opportunity to vote in two elections! When it was time for me to vote, Mommy took me to a building, and I marked my choices on a piece of paper. When I was all done, my sheet was placed in a machine, and my vote was counted, then I got a sticker. It was all okay, and I was very happy to vote.

When I get sick, Mommy takes me to the doctor, and Medicaid helps me to get the care that I need.

I have Innovations Waiver Funding that provides Respite services to give my Mommy a break, and Community Living support where spend time in my community and learn about life, I'm glad to have Medicaid waiver funding now after I spent eleven years on the Waiting List!

Read more about Jadon here - <https://nccdd.org/news-media/highlights-hot-topics/1446-february-2024-highlights-and-hot-topics>



Jamishaelle Symons and my husband, Mark Symons

Jami.symons@gmail.com

mark.c.symons@gmail.com

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.
- **The top policy education priorities are:**
 - Keep Medicaid.
 - Increase Waiver slots.
 - Increase (caregiver) Wages.





Jeffrey Olander
jeffrey.olander@gmail.com
501 Driewood Ct., Raleigh, NC 27609
Education /employment: Physics PhD from UNC-CH / Researcher, Assistive
Technology Inventor and Consultant
Hobbies/interests: 3D Printing and Gaming

I have been a participant in the Medicaid Private Duty Nursing (PDN) program for my entire adult life—20 years. I am not just someone navigating the system, but I am also someone who is struggling against its failure.

For years, I have fought an impossible battle to secure the skilled nursing care I need to safely remain in my home. I require 12 hours of care every night, seven days a week, yet despite working with three different staffing agencies in the last five years, not a single nurse has joined my case. Instead, I have watched my care team dwindle. Today, I have just one nurse left—someone who has been with me since 2016. If he were to leave, I don't know what I would do.

I live with my single, elderly mother, who, despite her love and dedication, can no longer perform most of my daily care. To fill the growing gaps, I have been paying out of pocket for unskilled caregivers (CNAs), just to survive. But this is not a sustainable solution. I fear that without access to the nursing staff I am entitled to, my health will be put at serious risk, or worse—that I will be forced into an institution simply because I cannot get the care I need at home.

I am not asking for special treatment. I am asking for action—for policies that ensure Medicaid PDN recipients can actually access the care the program promises. Without immediate reform, people like me will continue to fall through the cracks. Please help me stay in my home, maintain my dignity, and live as full a life as possible.



Jon D'Angelo, NCCDD Council Member

4753 Sharpstone Lane

Raleigh NC 27615

252-732-6811

jdangelo0725@gmail.com

- I am a member of the North Carolina Council on Developmental Disabilities. I was appointed by the Governor in December 2022. I currently serve as Chair of the Council.
- 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.
- **The two top policy education priorities for NCCDD are:**
 - Increase Innovations Waiver slots. 2,000 additional slots each year for the next 8 years is needed to end the waiting list.
 - Increase Direct Support Professional (caregiver) Wages to Ensure a Sufficient Workforce.





Jonathan Ellis

Sutje14@gmail.com

Murfreesboro, NC (Hertford County)

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.



Dr. Josh Gettinger
Asheville, NC
Joshua.Gettinger@mahec.net
NCCDD Council Member

I am Joshua Gettinger, member of the NCCDD as the parent of an adult child with Down Syndrome. I teach Family Medicine at MAHEC in Asheville, North Carolina. I am a member of the American Public Health Association's Disability Section, and Mental Health Section. As a former rural practitioner in East Tennessee, I am aware of the mental health crisis confronting our small towns, and the difficulty many people have accessing health care. Rural populations, individuals with developmental disabilities or mental health diagnoses are especially prone to face difficulty accessing the health care and services they need.

My policy priorities include:

- The recent bipartisan Medicaid expansion in North Carolina has been a boon to many. We need to increase access to health care in general, and primary care in particular, by maintaining and perhaps expanding Medicaid coverage.
- Addressing the "DSP Crisis."
- Better support for primary care as the cornerstone of the medical system.
- Support for integrated behavioral/medical care (IBH) to become the standard model for delivering healthcare to all Americans.

Joshua Gonzales Fuquay-Varina, NC

- My name is Joshua. I live in a house with two roommates. This is called Alternative Family Living (AFL).
- I have a job that I like, and I have worked there for 6 years.
- The Medicaid Innovations Waiver program funds my AFL staff and support. My disability payments help pay for my rent.
- Medicaid and Medicare help me pay for doctor, dental, vision, and therapy visits. They also help me pay for medications and a gym membership.
- I love LEGOs and model trains, and I play baseball with The Miracle League and basketball with The Spirit League.

- **The two top policy education priorities for NCCDD are:**
- More pay for DSPs.
- More money for home and community-based waivers.



Karen Carlton and Joey Tucker

Karen: 5132 Kenwood Rd.

Durham, NC 27712

919-923-3193

karenacarlton@gmail.com



I (Karen) have spent a good part of my career as an advocate for people with disabilities and now I work for a private foundation on the philanthropy side of the nonprofit arena. I have a Bachelor of Arts in Psychology and Sociology from Meredith College. In my spare time, I love to hang out with a young man with Down Syndrome, who crawled into my heart over 30 years ago. In early 2025, I became his guardian.

Joey is 34 years old. He's funny, charming, strong willed, and the most amazing person I know. What you can't immediately see is that Joey has received Medicaid waiver services most of his life—services that have allowed him to greet everyone he meets in store aisles, attend our public schools' arts performances, volunteer at local nonprofits, learn to cook, participate in a handbell choir, play on a baseball team, take ballet and Zumba classes, and thrive in our community rather than an institution.

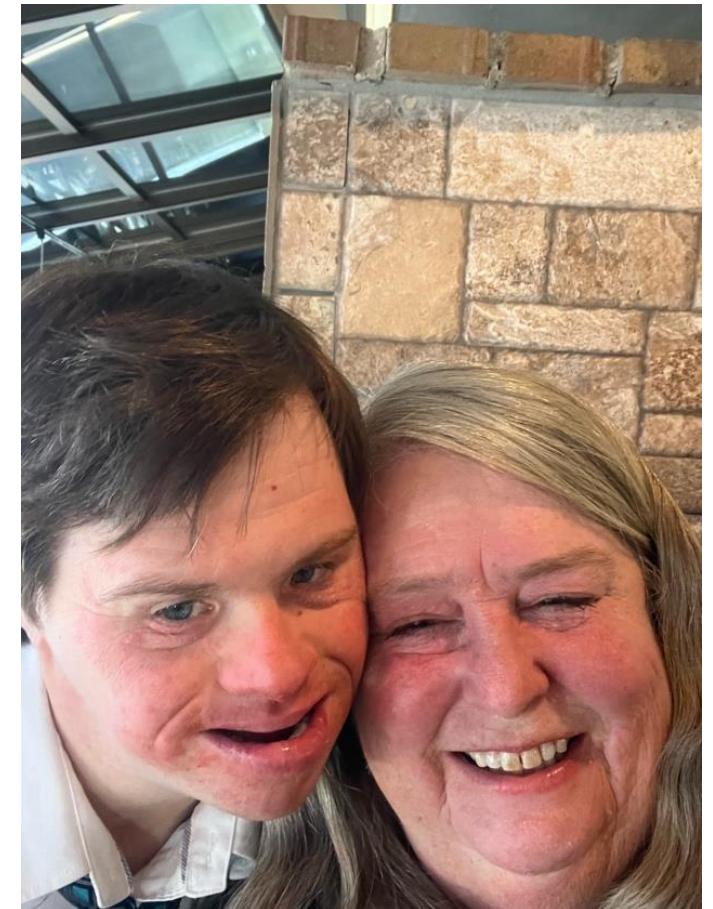
At just 20 months old, Joey faced placement in a nursing home when his mother stepped forward to foster and then adopt him. Because of Medicaid waiver services, she could provide him a loving home while continuing to work. I've seen how beautiful his life has been because I've known Joey since he was 3 ½ and became one of his direct support staff when he was 5.

On December 21st 2024, tragedy struck when the car Joey and his mother were in was hit head on by an impaired driver. Joey sustained serious injuries and sadly, his mother did not survive. I rushed to the hospital and remained with Joey during his stay. After discharge, Joey came home with me, and I am now his legal guardian. I will never replace his mother. I'm his "KK," and I am doing my best to honor her legacy of loving and advocating for him.

Here's what I want you to understand: Without Medicaid waiver services, Joey would have faced state care and placement with strangers during the most traumatic time of his life. Instead, he lives with someone he's known and trusted for over 30 years, maintaining his routines with familiar caregivers and continuing to thrive while I keep my full-time job.

While we both grieve deeply for his mother, we're building a new family together. This transition was possible because of continued access to these critical services.

Because of Medicaid waiver services, Joey has lived a dignified life in a vibrant community of family and friends who love him deeply. As you make budgetary and policy decisions, I urge you to protect and strengthen these programs. For you, they may be just line items; for Joey, they are a lifeline.





Kay McMillan

Executive Director, Youth LEAD NC

kay@youthleadnc.org

I am a graduate of NC State University with a bachelor's degree in Political Science and minors in Accounting and Nonprofit Studies. I live in my own apartment in Cary, NC. In my spare time, I enjoy playing bocchia ball every Sunday.

I want to be able to create change for individuals with disabilities, and I saw joining the Council as another way that I could make positive change for people with intellectual or other developmental disabilities (I/DD) and their families.

I am the co-founder of a small nonprofit, Youth LEAD NC, that equips young people with disabilities in North Carolina with the skills they need to lead full and independent lives.

I believe it is crucial that individuals living with I/DD have the self-determination to make decisions regarding their own lives as much as possible. Any initiative that promotes the autonomy of people with disabilities and encourages collaborative decision-making is a step in the right direction.

For me, having services through Medicaid allows me to live in my own apartment, have a job that I love, and participate in activities in my community! I rely on Medicaid.

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!

Lisa Sullivan & Thomas Sullivan
Clayton, NC (Johnston County)

919-523-8170

Peaceandquiet123@hotmail.com



Maria dreamed of working in a bakery. Rochel Groner of ZABS Place, with funding from an NCCDD Initiative, discovered the Whisk + Wood Bakery in Charlotte in a local café and reached out to the owner, Christina Morita, to thoughtfully share how the skills Maria honed while working in the ZABS Placing job training program would add value to the bakery. Maria's abilities and the work experience that she gained at ZABS Place aligned well with a Bakery Assistant position, so Whisk + Wood hired Maria to join their team.

Christina was amazed at the diligence that the ZABS Place team put forth to empower Maria during the training process. Maria's job coach guided Maria until she was able to execute her tasks confidently and professionally. Maria has assisted the bakery by peeling and weighing bananas to be used to bake banana bread for the Charlotte area, and she said folding boxes is her favorite part of the job.

Christina appreciates how efficient the onboarding process was for Maria with ZABS Place and how they "worked tirelessly to empower her to achieve her unique dreams."

When she's not working, Maria loves to dance and watch superhero shows, including her favorite, "Wonder Woman." Her next dream is to sail away on a Disney cruise.

Maria *(last name withheld) working at Whisk + Wood Bakery Charlotte, NC





Marjorie Serralles-Russell
NCCDD Vice Chair and Policy Education Chair
Charlotte-Mecklenburg County
704-806-0044 • serrallesrussell@me.com

- I am a member of the North Carolina Council on Developmental Disabilities and serve as the Vice Chair and the Policy Education Committee Chair.
- I am the mother of Spencer Russell, a 24-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.
- **The two top policy education priorities for NCCDD are:**
 - Increase Innovations Waiver slots. Create a long-term plan to fund at least 2,500 additional slots over 8 years each year to be able to properly address this backlog.
 - Increase Direct Support Professional (caregiver) wages to ensure the needed trained workforce becomes available."



Matt Potter

Pfafftown, NC

pottmm5@gmail.com



I am employed as a Consultant with Centered Resources, (formerly, Community Bridges Consulting Group). I consult primarily on stakeholder engagement and advocacy, and I regularly serve as a speaker and trainer. Born with Cerebral Palsy, I decided very early on to rise above my challenges and help others to do the same. Having been a public speaker and advocate for people with disabilities for over 20 years, I have been a tireless, sought-after trainer and advocate for the I/DD Community, both in NC and nationally.

Additionally, I am employed as an E-Badge Reviewer for the National Association of Direct Support Professionals (NADSP).

I have a Bachelor of Arts in English from Wake Forest University and I am 2011 graduate of North Carolina Partners in Policymaking, among other professional and advocacy development certifications.

I am currently receiving CAP-DA services, and I am on the NC Registry of Unmet Needs and have been since 2009. The current services that I receive are imperative for me to continue to work and contribute to my community. If not for these Medicaid-funded services, I would likely end up in a congregate living setting. My being in an institutional care setting would not only reduce my value to the community, but it would also cost the State more money to maintain.



Michele Torres Valladares

Pfafftown, NC (Forsyth County)

mkbeev@gmail.com 786-273-2586



- I am MOM to three special children. My son Emmanuel had a pyloromyotomy surgery at three weeks old and became septic in 2005. For nineteen years he has had PT, OT, Speech therapy. It took months for him to learn to suck and swallow, three years to learn to crawl, then walk; however, he cannot speak, he has severe IDD and is legally blind. In addition, he has ASD and UC. He has been on the waitlist for 10 years.
- My son Elijah has Autism Spectrum Disorder, Language and Speech disorder and UC and is currently going through the process of being added to the Medicaid Waiver Waiting list.
- My daughter has stage 3-4 liver fibrosis, NASH (non-alcoholic steatohepatitis), diabetes, and Graves disease.
- Just trying to get a statement together for today has been a challenge because I often find myself all over the place.
- I homeschool the children, manage dietary restrictions, work on therapy at home, keep medical appointments, perform infusions at hospital and have my own medical issues. As a single parent, I am worried that if I were to die today what would happen to my children.
- Receiving the services will not only benefit my boys but will also save on the long-term care costs, both in living arrangements and medical costs.



Nancy and Jerry Baker
Asheville NC (Buncombe County)
Nbaker0620@gmail.com
828-242-4177

I'm Jerry's mom. This is a photo of Jerry meeting NASCAR
Driver Josh Berry!

- I am a 76-year-old mother of a son with IDD by the name of Jerry Baker. He is now 56 years old and lives in a group home in Rutherford County.
- Jerry was lucky and got Innovations Waiver at an early age. We soon learned that because of Jerry's love for NASCAR, we would be able to teach him his colors and his numbers as long as they were connected to Dale Earnhardt.
- Jerry attends 3 races a year and enjoys every minute that he is there. Jerry says that the 2 most important things in his life are Dale Earnhardt and macaroni and cheese.
- As Jerry continues to age, we are seeing more health issues that require more support.
- With Jerry aging and becoming a senior citizen, for him to be able to get the services and support that he will need to have a life worth living will depend upon Medicaid.
- I would also like to thank you for the great support that you are giving us in Western North Carolina after the devastation from Helene.





Nicholas Hemachandra and Ray Hemachandra

rayhemachandra@gmail.com

360-393-1361 mobile

Arden, Buncombe County

- 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.

I'm a fulltime student working on a second graduate degree. I enjoy gardening; walks in the park with my dog, Moses; cooking; and riding my bicycle. I am learning to practice yoga and loom knitting. I'm also the proud mother of three amazing daughters. My youngest daughter, Caroline, is 28 and has Down syndrome. She lives with me. She hopes to live on her own with support one day. She has a job that she enjoys very much, and she receives support from a job coach. She will begin to receive 10 hours of community living support (when a new Support Staff person starts work in early May, her fifth Support Staff person in eight months) with fund from Medicaid 1915(i), and that is very helpful. Otherwise, all of her support comes from me.

When I accepted my job with NCCDD, we moved from another state and left behind Medicaid Waiver funding for Home and Community-based Services to move to NC. My daughter has applied for services and has been placed on a waiting list with over 18,770* other people with intellectual and developmental disabilities.

People with intellectual and other developmental disabilities have gifts, strengths, and talents that the whole community misses out on when they are not supported to live fully in their own community doing what they love.

Medicaid means healthcare coverage for my adult disabled daughter, support from a job coach, and community living support from a trained Direct Support Professional.

*(Source: <https://www.ncdhhs.gov/about/department-initiatives/inclusion-connects/innovations-waitlist-dashboard>)



Pam Hunter Dempsey
NCCDD Systems Change Manager
pamhd1@hotmail.com
Raleigh, North Carolina



Rebecca and Erica Conway

Candler, NC (Buncombe county)
Mobile: 580-678-3972

- Erica has been on a journey of recovery from a severe TBI she survived in 2006 at the age of 16. She continues to be my greatest teacher, in part, because she is dually diagnosed with I/DD and Mental Health support needs.
- Erica has success in daily life with adequate supports around her. Supports are provided through her emergency Innovations Waiver slot that she received in March of 2020, and she now has one-on-one support at her day program to meet her physical and behavioral support needs as they arise.
- She received support to meet the extraordinary needs caused by Hurricane Helene. Her program was able to send support to even help Erica do her laundry and take a shower at available community sites. They even took time to play cards with her and ease some of the stress and strain from the disaster. So thankful this was available and provided for her!
- In 2022, because no other direct support professional (DSP) could be located, it became necessary for me to quit my job that had full benefits to be available and provide care for Erica myself. I am her DSP now, along with being her Mom.
- I am certain that individuals who depend on others for their personal care will still have needs to be met. I call for us to meet these needs and support their success.

Dr. Rebecca Putnam
rebecca.putnam@mahec.net
Family Medicine Physician in I/DD Clinic
Sibling of adult brother with I/DD who relies on Medicaid
Asheville, NC

I am a mom of two; I love to hike in Western North Carolina. I believe strongly that everyone deserves access to healthcare. Most importantly, my passion is for people with intellectual disabilities. On July 1st, 2021, I was appointed to the North Carolina Council on Developmental Disabilities.

I work at a residency clinic (MAHEC, Mountain Area Health Education Center) teaching the next generation of doctors. While teaching residents, I also serve as the Director for the Adult I/DD Consult Clinic and am the Medical Director of the Acute Care Clinic. We know that physicians across the country do not get training on how to care for adults with intellectual disability. I'm trying to teach these resident physicians how to take better care of people like my brother.

Medicaid expansion has been life-changing for so many of my patients with and without disabilities. It has helped many families of people with disabilities take care of their health needs so that they can take care of their loved ones.

I've had so many people in my office crying about the possibility of losing their Medicaid. During Hurricane Helene, so many people in Western NC lost their jobs, homes, and livelihoods related to Helene, but the ability to at least get healthcare through Medicaid is very important.



Ryan Rotundo
Weaverville, NC

North Carolina Council on Developmental Disabilities, Council Member

Sibling to Nicole Rotundo, adult with Down syndrome
National Down Syndrome Society (NDSS), Director of Programs

I am a member of the North Carolina Council on Developmental Disabilities, appointed by the Governor in 2018, and I serve on the Financial Asset Development Committee.

I am the younger brother of Nicole Rotundo, a 41-year old woman with Down syndrome. Siblings are the longest relationship that someone with I/DD will have in their life. Siblings will be an integral part of the long-term support for someone with I/DD.

Nicole is very active in her local community in Asheville, enjoying Open Hearts Art Studio, dancing with friends, making jewelry, and more. Having support during Hurricane Helene was critically important for Nicole as she, like all of us, dealt with the trauma and destruction from the disaster.

In my work with NDSS, I talk with people often who are concerned about maintaining funding for Medicaid. This funding is vitally important for healthcare coverage, for home and community-based support services, for employment support, and more.

My top policy priorities for people with intellectual and developmental disabilities are:

- Increase Innovations Waiver slots.
- Increase pay for Direct Support Professional (caregiver) so that there is not so much change in staff, and they can afford to continue working longer.





Sam Henning

heningfamily@gmail.com

252.469.1093

Raleigh, NC

For me, Medicaid means I get to have a great life! I have big dreams. My Mom and Dad support me to reaching my dreams and goals.

I attended UNC-Greensboro in the Beyond Academics program. I got an Innovations Waiver slot during that time after I was on the waiting list for TEN Years.

I have two part-time jobs. I love my jobs! I never miss work. I have about 12 hours of support from a direct support person. I love music and working out. I am the biggest Wolfpack fan around.

I feel valued in my community. I love living on my own – with my wife. I am glad I have a support person. We cook and clean and do all sorts of things together.

Please let more people get on the Innovations Waiver. Some might need “just a little bit” of support, and it will really help them to live more independently.

Sarah Potter
Pfafftown, NC
spot1050@gmail.com



I'm a mother of two adult sons, one of whom has Cerebral Palsy and lives with me. My son, Matt, has been on the Waiting List for 15 years. He receives services through CAP-DA which gives him 25 hours of support services each week; I fill in the remainder of his support hours myself. I pulled out of the workforce early as a mother to meet the support needs of my children, knowing that I must be available. Additionally, because of the real-life expertise that I have gained, I am a full-time advocate now, volunteering to various advocacy groups.

We sacrificed for our son for many years, and we ultimately learned that we could no longer afford private insurance, making Matt reliant upon Medicaid for his health care coverage.

Matt also relies on Medicaid waiver funding for support to remain at home and to continue to be employed. I want my son (who has dedicated his **life** in service to his community) to live his best life!

On a daily basis, I see the larger I/DD Community that is impacted by Medicaid, and my concerns are amplified much beyond me and my family. Our DSPs make such low wages that they rely on Emergency Departments for their healthcare, on supplemental food and housing voucher benefits, and other types of assistance.

Medicaid is essential. It is a lifeline to the heart and the rest of the parts of the body. People must understand the impact that it has on millions! Yes, it comes with a price tag, but there is also a price to be paid for taking away necessary resources from people who need it! Every human being has the right to be an active member of their community!

Shannon Bennett, Mom to Lakelann
securry2000@gmail.com
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 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.





Stacy Watson
sawatson@hbmhs.com
Kings Mountain, NC

Medicaid is important to me because...

My son joined the waiting list for IDD services in 2013. My recent call to Partners Behavioral Health Management, I was informed that Partners was currently working on individuals who joined the wait list in 2011. With the expected 14-15 year wait, I would expect 2027 will be our year. The issue is my son is 20 years old and eager to move forward with his own independent life. It's frustrating to have to wait so long for services and only currently have the option of the minimal services of the 1915(i).

> After waiting four months, my son's 1915(i) ISP is expected to start at the beginning of May. Partners is taking time to assess my son and evaluate his support needs. We have been waiting for 1915(i) now for four months.

- **My two top priorities for people with intellectual and developmental disabilities are:**
 - More funding for Innovations Waiver slots.
 - Higher pay for staff so that there is not such a long wait.

Susan Barner
with my son, Andrew (age 16)
(856) 816-0389
susan.barner@gmail.com
Catawba, NC - Catawba County

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.



Tiffany Williams. LMSW

Boone, NC

Contact: tteate@gmail.com , 803-604-6174

When you are a parent, you are usually forced to surrender some expectations little by little as your children grow up. Maybe they chose to play soccer when you thought they'd play football, or Duke instead of UNC. When you're a parent of child with a disability, you are forced to surrender your expectations all at once, and over and over. When you get a prenatal diagnosis, it starts before they arrive. We drop our expectations early. But that is not to say we don't have hope. We have a lot of hope. In fact, our hopes probably still look similar to other parents. We want our children to be able to have a job they like, a partner they love, a home they're happy in, and hobbies they're excited about. And when we hope for and dream about these things, we want to know there is scaffolding making it possible for these dreams to come true.

Our daughter June is a great example. We just funded her 529 for this year, along with her brother's—we're hoping she goes to college, and we think that she will. Our hopes, clearly, are high. And we're doing our best to financially support her and make sure she has social supports in place to make that good life possible. We want to also be able to count on Medicaid for her healthcare needs and for support to live in a community, not an institution.

We live in Boone, and I think Helene showed everyone in the high country that you can't plan everything, and your safety net can be washed away. With one storm, we watched our neighbors lose their homes and life savings to try to recover what was lost. The security and peace of mind it would give parents of kids with disabilities that they would have the bare minimum supports to succeed in place are priceless. And when people with disabilities have the resources to thrive and contribute to their community, everyone wins. I am hopeful that when you are considering what to fund this session, that you will remember my daughter June, who loves preschool and wants to be a dentist, or maybe an astronaut. And keep Medicaid funded.





Tony Hall
Raleigh, NC
halton88@pct.edu
Triangle Disability and Autism Services

I have a passion for advocating for adults and children with disabilities, like myself.

Outside of work, I enjoy trying new recipes, playing with my dog, participating in adaptive recreational activities, attending and participating in poetry events, and spending time with friends.

For the disability community, Medicaid is the difference between being able to receive necessary medical care and having those needs go unmet.

For people with I/DD and many of the job seekers whom I support, Medicaid is critical for funding community-based support services.

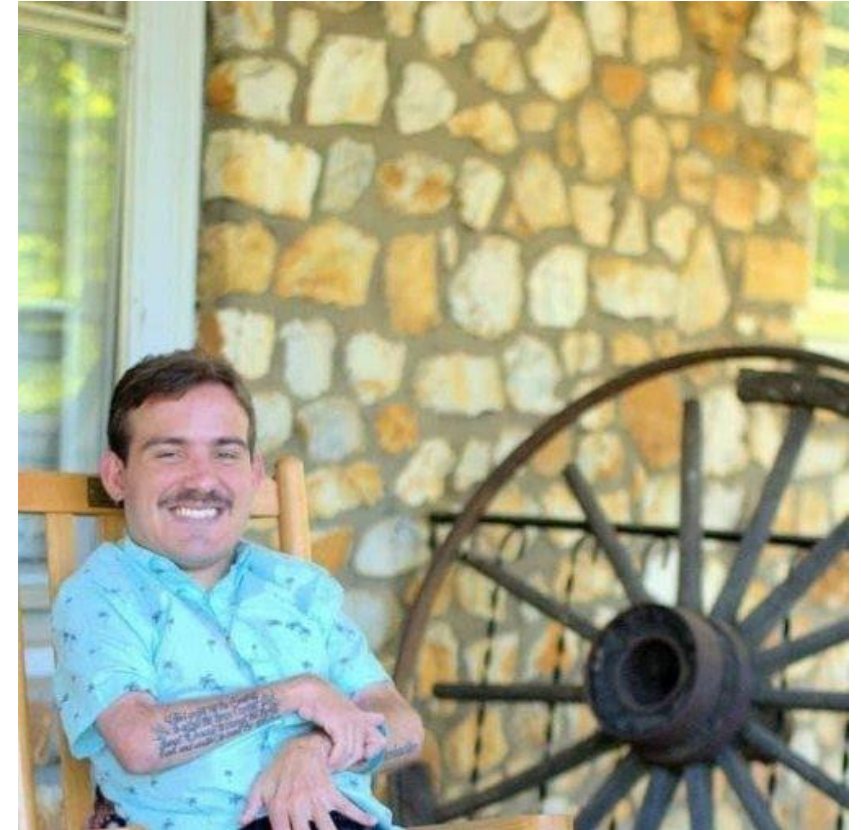
See my YouTube video for Developmental Disabilities Awareness month here:
<https://www.youtube.com/watch?v=-DZLiNa9XgA>

Tylor Freeman

Apex, NC

tylor.freeman@gmail.com

- For me/ for my family, Medicaid means I can have the care and support that I need.
- I have been dealing with caregiver shortage for many years and ended up in the hospital for 9 months due to my housing situation and the lack of caregiver support.
- “My mission is to help other people with disabilities because we all deserve a voice.”
- Read more about my story here:
<https://www.northcarolinahealthnews.org/2024/06/20/stuck-in-a-hospital-hoping-for-a-place-of-his-own/>





Yvonne Bell
byvonne06@gmail.com
Charlotte, NC
Person with I/DD / Self-Advocate

I moved into my current apartment in April 2021. I rented a room that was part of a residence and moved four times in two years while waiting to find a permanent place to live. I was on many housing waiting lists as well. Finally, I received help from someone at the Disability Rights & Resources Center for Independent Living in Charlotte. He was a true angel!

I'm into history, politics, current events, psychology, weather, astronomy, disability advocacy, all things British, and random trivia. I advocate on the Autism Advisory Board of the Autism Society of North Carolina and participate in Think Tank (an autism group) meetings. I also participate monthly in NCCDD's Self-Advocate Discussion Series.