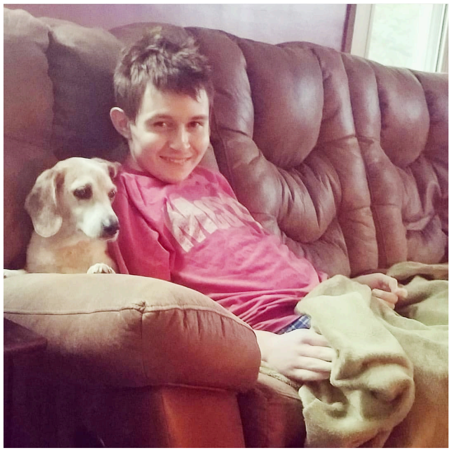
NICK'S WORLD IS SELF-DIRECTED

In Nick's world, he has the power to choose—when to wake up, when to watch TV, and how to engage with his community. He experiences the everyday freedoms that so many take for granted.

This could all change if the Maryland General Assembly votes to approve the proposed cuts to the DDA.

SAVE OUR SERVICES!
RESTORE THE FUNDING!

Nick Gregory is 31 years old and diagnosed with LGS, a form of epilepsy that comes with developmental delays.



February 26, 2025
Appropriations Committee
House of Delegates
Testimony: HB350 Budget Bill (FY26)

120 Taylor House Office Building
121 Taylor House Office Building
Annapolis, Maryland 21401

Councilmember Michele Gregory
(443) 669 3483
mgregory@salisbury.md
709 Parkway Ave.
Salisbury, MD 21804

Honorable Delegates,

It is 6:00 AM as I write this. I’ve rewritten this piece countless times, each version growing too long, too in-depth, likely losing readers along the way. So I scrap it and start again—throwing it at the wall until something sticks.

That’s what it feels like the state and Governor Wes Moore’s administration have done with these budget cuts. But before we get into that, let me tell you how my family ended up here.

Our eldest son, Nick, is profoundly disabled. His condition was so rare that we didn’t receive a real diagnosis until he was 18. He always had global developmental delays—he's non-verbal with a skills range equivalent to 6-36 months—but it wasn’t until he suffered a breakthrough tonic-clonic seizure at school that we got answers. He was admitted to the hospital with a diagnosis of encephalopathy with global developmental delays and discharged with one for Lennox-Gastaut Syndrome—a complicated, treatment-resistant form of epilepsy that will forever shape his daily life.

At the time, he still had a few years of school left, and we were blessed with a wonderful teacher. But when the dreaded “transition” period arrived, it terrified us. We had little trust in the system or others to care for him properly. In fact, for the first year after high school, he stayed home with me while I worked 11-hour days running a childcare business. It was stressful, but the hardest times were when he got sick and had to be hospitalized. His dad had to take time off work because I, and my clients, couldn’t afford for the daycare to close four or five times a year, sometimes for weeks. He burned through his sick leave, flex time, and vacation days within the first six months of each year. We hoped and prayed we wouldn’t end up without paid leave when we needed it. Vacations? Nonexistent. Every day off was spent on Nick’s care.

Eventually, we tried enrolling him in a day program. His schedule ran from 7:00 AM to 2:30 PM, four days a week. Transportation was provided by a staff-driven car. But we quickly realized this setup wasn’t healthy for him. Waking up unnaturally early triggered more seizures, leading to aspiration pneumonia, then hospital stays. The cycle repeated.

We also discovered that his dedicated staff was frequently reassigned, meaning they were still paid from his budget while caring for other clients—or, as the system cynically calls them, “consumers.” It frustrated us endlessly, but we were powerless in the face of limited options.

In 2017, we finally took a vacation. For the first time, Nick lived on his own schedule—and the results were stunning. Two weeks, seizure-free. It felt like a miracle.

A few months later, at his annual health department review, we had yet another new coordinator—so new that his supervisor attended our meeting to train him. I mentioned how much better Nick did on his own schedule but explained that I had no choice but to work.

The next day, the supervisor called with news of a program that would allow us to do just that. We immediately applied. The wait was long—much longer than promised—but eventually, we got in, and I became Nick’s paid caregiver.

The impact was almost immediate. His seizure frequency dropped dramatically, from several dozen per day to about a dozen. That meant fewer hospital visits—down from every few months to just once or twice a year—saving the state tens of thousands of Medicaid dollars annually. And for the low cost of 40 hours of weekly pay, he received 24/7 care from his own mother.

As Nick has grown older, his needs have become more complex. New medications have further reduced his seizures, but every injury he sustains sets him back. Skills are lost, and his needs increase. We applied for his father to become a caregiver as well. After years of rejections, we finally got approval. His dad left his career as a cable technician to help with Nick’s daily care. Now, Nick has two caregivers working a combined 80 hours a week—still far less than the 168 hours of care he requires. This setup has worked for years. It’s not always easy, but it’s undoubtedly the best for Nick. His health has improved, and he receives the best care possible, in the comfort of his home. It’s Nick’s world—we just live in it and facilitate it.

Nick loves Mickey Mouse and Bluey. He’s an avid Ravens fan, though he’ll watch any football game just for an excuse to shake his fist at the TV. He’s a familiar face at community events like Third Friday downtown. He loves the loaded fries at Roadie Joe’s Bar, and thanks to our caregiver salaries, he just got a brand-new accessible van to cruise around town in search of the best milkshakes.

Which brings me to my final point: The budget that pays our salaries does far more than just compensate his caregivers. It pays for the roof over his head, the car that allows him to be part of the community, the ramp that lets him leave the house, and the wheelchair without which he would never experience the world outside our home. Every one of these things has been paid for out of our pockets—at no additional cost to taxpayers. And let’s not forget the unpaid labor we provide: being on call 24/7, every single day, without breaks. The alternative—placing him in full-time institutional care—would cost the state hundreds of thousands more per year and greatly reduce the quality of that care in the process.

As a member of the Salisbury City Council, I know firsthand how tough budget decisions can be—especially now. But these cuts won’t just fail to save money; they will create even greater costs down the line. And worse, they won’t just cost dollars—they will cost lives. Lives that are every bit as vibrant and full as anyone else's, all thanks to a program that could vanish for thousands if the current budget moves forward with your vote.

As an elected official and a visible advocate in the developmental disability community, I hear from families who are terrified for their loved ones' futures. I receive constant messages and calls—pleas for guidance, cries for hope. But for every voice you hear today, hundreds more remain unheard, their desperation and fear echoing again and again.

I urge every legislator to reject these cuts for the 2026 fiscal year. Find another way. This isn’t trimming fat—it’s cutting families like mine to the bone.

Sincerely,

Councilmember Michele Gregory
709 Parkway Ave.
Salisbury, MD 21804
443-669-3483
mgregory@salisbury.md