

| 2026 |

Our STORIES

**A COLLECTION OF STORIES TOLD BY
INDIVIDUALS WITH DOWN SYNDROME
AND THEIR FAMILIES ABOUT
THE CHALLENGES THEY FACE**



**Down Syndrome Association
of Middle Tennessee**

To view the "Our Stories" participant video, use the QR code below.



Our STORIES

Dear Members of the Tennessee General Assembly,

Thank you for taking the time to read the stories in this booklet.

Each page reflects the lived experiences of Tennesseans with Down syndrome and the families who support them. These are not policy hypotheticals, they are real stories from parents, grandparents, caregivers, and self-advocates working every day to ensure safety, inclusion, education, healthcare, and opportunity.

Individuals with disabilities and their families care deeply about the policies that shape their lives, yet many do not feel equipped to share their experiences with policymakers. As a result, important perspectives are often missing from the conversation. This booklet is our effort to help change that.

At the Down Syndrome Association of Middle Tennessee (DSAMT), we believe empowering families and self-advocates to share their stories is essential to meaningful change. When policymakers hear directly from those most affected, it strengthens understanding and leads to more informed decisions.

Across these stories, common themes emerge: the need for meaningful inclusion, safe and appropriate education, reliable transportation, protection for vulnerable students, support for caregivers, and systems that are easier for families to navigate.

On behalf of the individuals and families whose voices are represented here, thank you for your service and for taking the time to listen. We look forward to continuing to work together to ensure individuals with disabilities can live, learn, work, and fully participate in communities across Tennessee.

In Celebration and Gratitude,



Tanya Chavez
Executive Director
DSAMT



Erin Richardson
Policy & Advocacy Director
DSAMT



Down Syndrome Association
of Middle Tennessee

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INDEPENDENCE REQUIRES ACCESS TO TRANSPORTATION

CALLI DAVIS (21 YRS) | LEBANON, TN



Transportation is more than just getting from one place to another, it is a key part of independence.

Hi, my name is Calli Jo Davis. I am an adult with Down syndrome, and I am working toward living a more independent life.

Transportation is very important to me. It helps me get to work, go to activities, and make it to appointments. When transportation is available, I can participate in my community and stay active in the things that matter to me; however, when transportation isn't available, it can make it very difficult to get where I need to go. Without reliable transportation, I miss opportunities to work, learn new things, and be involved.



Like many adults, I want to build a life that includes meaningful work, friendships, and independence. Having access to transportation makes those goals possible. It allows me to contribute to my community and continue growing as a person.

Transportation helps me work, participate in my community, and live more independently.

But right now, Tennessee needs to do a better job providing transportation options for adults with disabilities. Too many people want to work, participate in their communities, and live more independently, but they cannot do that without reliable ways to get where they need to go.

Transportation is more than just getting from one place to another, it is a key part of independence.

Thank you for listening to my story.

DSAMT 2026 Self-Advocate of the Year



When I have access to transportation, I have the chance to live a fuller, more connected life.

FINDING MY VOICE THROUGH READING AND ADVOCACY

WILL MCMILLAN (37) | NASHVILLE, TN

*When we lose our sense of reading,
we lose our inner voice.*



My name is Will McMillan, and I am 37 years old. I am a self-advocate, and over the years I have been involved in many advocacy events. I have helped organize events, present awards, and have traveled to Washington, D.C. for the National Down Syndrome Congress conference, along with other conferences focused on legislative advocacy. I enjoy meeting with legislators and sharing my perspective. I have gotten to know several of them, including my state representative, John Ray Clemmons.

I believe strongly that with the right supports and instruction, people with Down syndrome can absolutely learn to read, despite what some people may think. I know this from my own experience.

**I believe that when legislators hear directly
from people, they listen and learn.**

For anyone who wants to get involved in legislative advocacy, my advice is simple: dress to impress and always be on time.

One issue that is very important to me is reading. Reading gives people a voice and helps them understand the world. I know Vanderbilt recently closed its reading clinic, that concerns me because many people need specialized support to become strong readers. When we lose our sense of reading, we lose our inner voice. If you're not reading, you are not going to get a lot out of life.



I am part of a weekly book club, and right now we are reading Percy Jackson and the Olympians. I also attended the Next Steps program at Vanderbilt, where reading was a big part of the program and helped me build important skills.

Our STORIES



Today I work at the Nashville District Attorney's Office. During the week I live independently through Our Place Nashville, and on the weekends I spend time with my family. While I am proud of my work and my legislative advocacy, the most important role in my life is being part of my family as a son, a brother, and an uncle to my five nephews and one niece.



I share my story because access to education, reading instruction, and opportunities for independence matter.

When people with Down syndrome have the right support, we can learn, work, contribute to our communities, and speak for ourselves.

SEEKING STABILITY FOR OUR SON

**ALEXANDER BATSON (11 YRS)
ROYYA BATSON | ANTIOCH TN**

***We are asking for greater consistency, clearer communication,
and additional training for benefits administrators,
caseworkers, and eligibility staff.***



This is my son, Alexander, and I am Royya, a single mother raising a child with Down syndrome. We live in Antioch, Tennessee, with my parents, Alexander's grandparents, lovingly known as GransB and PaPa James. Our home is filled with love, laughter, and strong family support.

Alexander is 11 years old. He loves listening to music, playing basketball, swimming, and going to church. He is kind, funny, and incredibly smart. He approaches life with courage and curiosity, willing to try almost anything at least once.

Like many families raising a child with special needs, we have faced ongoing challenges navigating healthcare benefits.

We have experienced inconsistencies in coverage from changing determinations about which therapies are approved, to extensive waitlists, to limited access to specialized providers. We regularly encounter conflicting eligibility rules, redundant paperwork, and repeated assessments.

It is exhausting.

I am grateful to have a full-time job that provides private insurance. Even so, there have been times when Alexander was approved for additional health benefits through TennCare, only to be denied coverage six months later. The instability made it difficult to plan for his care.

At one point, I made the decision to keep Alexander solely on my private insurance plan because TennCare felt too unpredictable.

There have also been instances where I spoke with one benefits administrator and received one set of instructions, only to later receive completely different information from another administrator. Each conversation required us to revisit paperwork, eligibility requirements, and documentation, creating more confusion and delay.



Our STORIES

I understand that each case is unique and often complex. Families like mine respect that reality. What we are asking for is greater consistency, clearer communication, and additional training for benefits administrators, caseworkers, and eligibility staff.



When standards are clear and applied uniformly, families can spend less time navigating bureaucracy and more time supporting their children.

Alexander works hard every day to grow, learn, and contribute to his community. As his mother, I will continue advocating for the stability he needs to thrive.

Children and adults with special needs deserve systems that work with them, not against them.

The question we ask is simple: How can Alexander and I help create a system that is clearer, more consistent, and more supportive for families like ours?



Because when families are supported, our children can focus on what they do best: being extraordinary.

HIGH EXPECTATIONS CHANGE EVERYTHING

**ANEESA AHMED (11 YRS)
MOMINA AHMED | NASHVILLE, TN**

Ensuring that our children receive an appropriate and fair education has become a full-time job for many parents. It should not be this way.



My name is Momina Ahmed, and my beautiful daughter's name is Aneesa Ahmed. Aneesa is 11 years old and in 6th grade at Oliver Middle School in Nashville, Tennessee. She has Down syndrome. She is smart, hardworking, and deeply loving. Aneesa loves basketball, soccer, swimming, singing, and performing alongside her typically developing peers. She holds a blue belt in karate. She is extraordinary. She is loved by her teachers and her friends.

Aneesa dreams of becoming an actress, a social media influencer, and going to college. Through the years, however, any educators and others have underestimated her simply because she has Down syndrome.

It has been a constant battle with the school system to ensure Aneesa receives the services and supports she is entitled to.

We endured significant hardship in elementary school trying to get the school to follow her Individualized Education Program (IEP). The system often feels broken for children with special needs. Too often, schools apply a "one-size-fits-all" approach, even though the "I" in IEP stands for individualized, recognizing that every child is unique.

When Aneesa started kindergarten, she already knew her alphabet and letter sounds, just like her peers. However, because she has Down syndrome, the assumption was made that she could not learn at the same level. She was placed in a self-contained classroom where students watched television and worked on puzzles. She was not taught.

After a long and difficult fight, she was finally allowed to attend general education classes, but, by then, she had missed almost an entire year of learning in a regular kindergarten classroom. Even after that victory, the problems continued. I later discovered that she was frequently not going to her general education classroom because there was not a paraprofessional available to escort her. Instead, she remained in the special education classroom, in violation of her IEP.

It is heartbreaking when schools have low academic expectations for your child.

I had to fight for educators to believe that Aneesa was capable of learning to read, write, and do math. With support from the Down Syndrome Association of Middle Tennessee, and through constant vigilance on my part, Aneesa can now read, write, and do math.

Our STORIES

High expectations made the difference.

Another ongoing frustration was the lack of transparency. During elementary school, I rarely received homework or any meaningful information about what Aneesa was learning. When I asked for her work to be sent home so I could support her progress, I was told the materials were “district property” and could not be shared. Meanwhile, children without disabilities routinely receive homework to reinforce their learning. Parents cannot partner with schools if they are kept in the dark.

Middle school has brought some improvements, but new challenges as well. Inclusion remains inconsistent. This year, Aneesa was excluded from the school play in a way that felt deeply unfair. This was devastating for her, as she loved participating in school productions in elementary school. Bullying has also been an issue, and the response from administration has been inadequate.

Children with disabilities deserve protection from bullying.

They deserve inclusion in extracurricular activities.

Thank you for taking the time to read our story — and for working toward a system where children like Aneesa can thrive without their parents having to fight every step of the way.



They deserve to belong.

As a single mother working full-time, advocating for my daughter has been exhausting. I am fortunate that Aneesa does not have complex medical issues. Instead of focusing on nurturing her talents and helping her grow, I have had to devote enormous time and energy to fighting the system.

Ensuring that our children receive an appropriate and fair education has become a full-time job for many parents. It should not be this way. I ask you, as legislators, to consider families like ours when shaping education policy. Our children are capable. They are worthy. They deserve high expectations, meaningful inclusion, and accountability when schools fail to provide what the law already promises.



THE ROAD TO INDEPENDENCE

CALLI DAVIS (21 YRS)
NICKI DAVIS | LEBANON, TN

*Transportation is not a convenience,
it is the gateway to independence.*



My name is Nicki Davis. I am a single parent and caregiver to my daughter, Calli, who is 21 years old. I am here advocating not only for her, but for countless adults with disabilities across our state who are being left without one essential support: transportation.

Transportation is not a convenience, it is the gateway to independence.

Without reliable transportation, adults with disabilities cannot get to work, attend medical appointments, participate in educational programs, or engage in community life. The opportunities we talk about: employment, inclusion, and dignity, depend on something as basic as a ride.

In many areas of Tennessee, there are no realistic transportation options for adults who cannot drive or safely navigate public transit. Disability transportation programs often have long waitlists, limited service areas, and inflexible schedules that do not reflect real life. Work shifts don't always fit within narrow time windows. Medical appointments run late. Community activities happen in the evenings.

Life is not rigid, and transportation systems shouldn't be either.

As a result, adults with disabilities remain dependent, not because they lack ability or motivation, but because the infrastructure around them does.

This gap does not just affect individuals. It deeply impacts families.

Parents and caregivers are often forced to reduce work hours, turn down promotions, or leave jobs entirely to provide transportation. For single parents like me, that strain can be overwhelming. And as caregivers age, this arrangement becomes increasingly unsustainable and, at times, unsafe.

We speak often about independence and inclusion for adults with disabilities. We encourage employment. We celebrate community engagement, but without transportation, those goals are simply out of reach.

Our STORIES

If we truly believe in opportunity, then we must treat transportation as an essential support service, not an afterthought.

I am asking you to expand funding, improve availability, reduce waitlists, and ensure that adults with disabilities and caregivers have a seat at the table when transportation systems are designed and evaluated.



Transportation should never be the reason they are denied that chance.

Thank you for listening, and for considering how we can build a system that truly moves everyone forward.



Adults with disabilities want what every adult wants:
To work
To belong
To live with dignity.



When we invest in inclusion, we invest in the future of Tennessee.

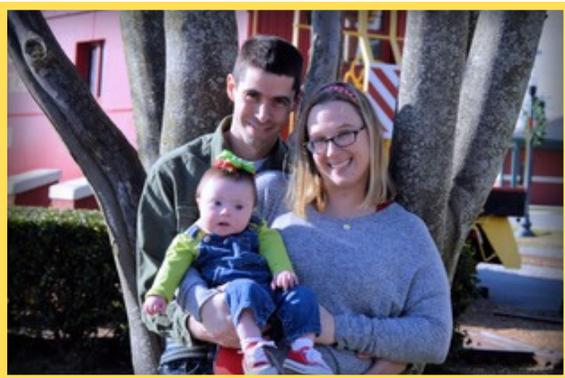
BE HER VOICE

CLARA WEST (11 YRS)
BRYAN AND JULIE WEST | COOKEVILLE, TN

Cameras protect students from potential harm, and they protect educators and school systems from false accusations. Most importantly, they provide transparency in classrooms.



We adopted our daughter, Clara. She was born in May 2014, and we finalized her adoption in October of that same year. Before Clara was born, we were told she had a 99% chance of having Down syndrome. The birth family gently asked if we still wanted to move forward with the adoption after receiving the diagnosis. We took a moment to process the news, but only a moment. We already knew the answer: yes. We knew Clara would still need a mama and a daddy. We knew she would still need someone to love her, protect her, and advocate for her. We wanted to be her voice.



That “yes” has led us on a remarkable journey. Today, Clara is 11 years old. She lights up every room she enters. She loves modeling for a local boutique and dreams big about her future. But like every child, she needs access to a quality education in a safe and supportive environment to make those dreams possible.

For those who know Clara, they know her joy is contagious. But there was a time when that joy began to fade.

We found ourselves in a painful battle with a previous educator. We were not the only parents who had concerns about what was happening in that classroom. We suspected emotional and verbal mistreatment, along with violations of Clara’s Individualized Education Program (IEP), yet we could never obtain clear proof to validate what we believed was happening.

We raised our concerns with the school principal, the Board of Education, and even the State Department of Education. Unfortunately, no one was able to witness the behavior firsthand. The educator could quickly shift demeanor when under observation, presenting one version in front of administrators and another when alone with students. Meanwhile, we watched our daughter deteriorate.

Clara’s light dimmed. Her love for school disappeared. It wasn’t just us who noticed—family members, friends, doctors, and even members of our community saw the change. She was not the same happy child.

Our STORIES

This was a classroom meant to serve students with limited verbal abilities, children who are among the most vulnerable. Many cannot clearly articulate what happens to them during the school day. They cannot advocate for themselves without being asked leading questions. They rely on adults to protect them.

We often wished we could place a camera on our child just to understand what she was experiencing, but doing so would have violated the parental code of conduct we were required to sign. Had there been cameras in the classroom, this situation might have been resolved much sooner, if not prevented altogether.

To this day, we may never fully understand the trauma Clara experienced. What we do know is that no child should feel unsafe at school, especially not in a special education classroom that is meant to nurture and protect them.

Thankfully, Clara has since moved to a different school. She now has a teacher who understands her past experiences and has helped create a supportive environment where she feels safe. While trauma responses still surface at times, her light has returned.



The joyful child who once loved school is thriving again. She is growing academically, emotionally, and socially. Under the previous educator, she had been stagnant and even regressing. Today, she is making remarkable progress.

But we still worry.

We worry about the students who may be in similar situations. We worry about parents who may not know how to advocate, or who may not be heard when they do. We worry about children who cannot speak up for themselves, which is why we strongly support the installation of cameras in special education classrooms.

This is not about distrust. It is about protection and accountability. Cameras protect students from potential harm, and they protect educators and school systems from false accusations. Most importantly, they provide transparency in classrooms serving some of the most vulnerable children in our communities.

Every child deserves to feel safe at school.

We said “yes” to Clara because we wanted to be her voice.

We will continue to say “yes” to protecting her, and children like her, every single day!

SAFETY FIRST FOR DJ

DARYL “DJ” DANIELS (10)
JANICE “JAN” DANIELS | LEBANON, TN



What we could not have predicted was that some of our most difficult challenges would come not from medical issues, but from the school system.

My name is Jan Daniels, and DJ has Down syndrome. He was diagnosed before birth, and by God’s grace, our family became part of the Down Syndrome Association of Middle Tennessee (DSAMT) community early on. We did not know then how much we would one day rely on that support.

My husband and I are raising DJ after the sudden and unexpected death of our daughter. Stepping into this role has been both a blessing and a heartbreak. We are his grandparents, but we are also his parents now.

DJ’s life has not been without challenges.

He has undergone open-heart surgery. He has relied on a feeding tube. He has participated in multiple therapies and countless medical appointments. Through it all, he has remained amazing: loving, sweet, smart, and funny. He brings joy wherever he goes.

What we could not have predicted was that some of our most difficult challenges would come not from medical issues, but from the school system.

DJ has a tendency toward elopement. When he runs, he runs fast, and he does so with very little warning. He does not always respond when his name is called. This places him at significant risk of getting lost, especially in busy or unfamiliar environments.

Both his primary care physician and his Down syndrome specialist strongly recommended that DJ wear a GPS tracking device for his safety. With his limited verbal ability, if he were to wander off and become lost, the consequences could be devastating.

The device was written into DJ’s Individualized Education Program (IEP) as a safety support. Yet despite that, his school principal decided DJ would not be allowed to wear the device while at school. Without my knowledge, DJ’s clothes were even changed into items from the school’s lost and found in order to remove the GPS device from his person.



Our STORIES

As his grandmother and guardian, that was heartbreaking.

We eventually had to retain an attorney and seek support from an advocate to address the issue. After significant effort and stress, DJ was finally permitted to wear his GPS device at school.

By then, however, my trust had been shaken. The device did not violate any district policy. It did not violate Family Educational Rights and Privacy Act (FERPA). It did not collect data on any child other than DJ. It was purely a safety measure. In light of several high-profile cases involving missing children with special needs, I could not understand why anyone would oppose something designed solely to protect him.



DJ deserves to be safe at school. All children do.

Families like mine should not have to fight to implement basic protections recommended by medical professionals and documented in an IEP.

We have faced many challenges raising DJ, ensuring his safety should never be one of them.

He is loved. He is valued. He deserves to be protected.

When policies and legislation are considered, especially those affecting students with disabilities, we ask that safety remain at the forefront.

INVESTING IN INCLUSION

GREER LEONE (2 YRS)

LAUREN & REED LEONE | EAST NASHVILLE, TN

At a time when special education and disability services face uncertainty at the national level, it is more important than ever for Tennessee to lead rather than retreat.

My name is Lauren Leone, and when I was 24 weeks pregnant, my husband Reed and I learned that we would be joining the Down syndrome community through our daughter, Greer. Like many parents in that moment, we didn't know what to expect. The diagnosis brought questions, uncertainty, and emotions we were still learning to process. Within hours of meeting Greer, something became very clear: She was no different from any other baby and she deserved the same opportunity to grow, learn, and belong.

As native Floridians, we moved to East Nashville after the pandemic, in what felt like a spontaneous decision at the time. Looking back, it feels providential.

We have been overwhelmed, in the best way, by the resources and programs available to support Greer's development.

Within weeks of her birth, we were connected to Tennessee Early Intervention Services (TEIS), which has been instrumental in coordinating therapies and helping offset the cost of specialists. At times, Greer has attended therapy sessions up to five times per week.



Living just minutes from the headquarters of the Down Syndrome Association of Middle Tennessee (DSAMT), as well as GiGi's Playhouse Nashville, has provided invaluable community and programming. We are also deeply grateful for the exceptional rehabilitative therapists at Vanderbilt and for Greer's enrollment at The Susan Gray School, where she learns alongside children both with and without disabilities.

These experiences have shown us what is possible when a community chooses to invest in inclusion. We do not take this for granted.

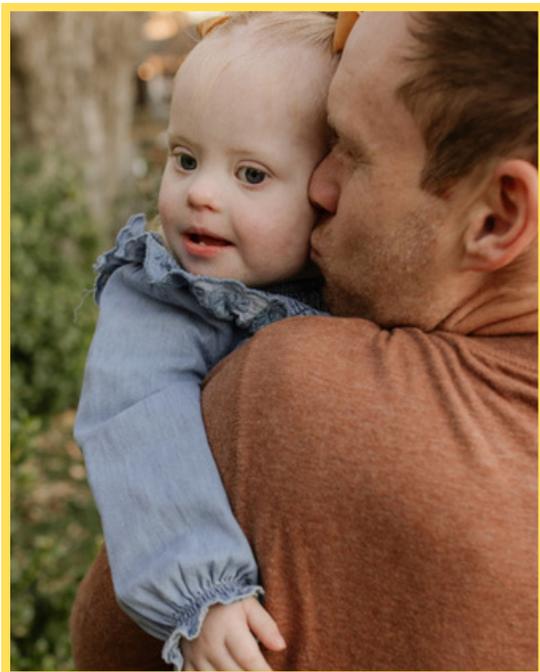
At the same time, our journey has made something equally clear: without these programs, our experience would look very different, and be far more difficult.



Our STORIES

Many families across Tennessee do not have easy access to these same resources. Others face overextended systems, long waiting lists, and overwhelming administrative hurdles. At a time when special education and disability services face uncertainty at the national level, it is more important than ever for Tennessee to lead rather than retreat.

We urge policymakers to continue funding and strengthening community-based programs. Expand, rather than roll back, special education services. Shape our cities, schools, and neighborhoods with accessibility and inclusion in mind.



These investments are not luxuries.

They are lifelines.



They make it possible for children like Greer, and families like ours, to fully participate in, contribute to, and strengthen our communities.

When we invest in inclusion, we invest in the future of Tennessee.

TRANSPARENCY BUILDS TRUST

**JULIETTE OLSON (7YRS)
AIMEE AND CARL OLSON | GALLATIN, TN**

If there had been cameras in her classroom, like the cameras already present on school buses and in many other school spaces, we could have observed what was happening.

We're the Olsons. We live in Gallatin, Tennessee. My husband, Carl, works as a network administrator for the school system. I work in the office at The Therapy Center of Hendersonville. I also volunteer as a county connector for the Down Syndrome Association of Middle Tennessee (DSAMT), serve on the board of directors for the Sumner County Special Needs Collaborative (SCSNC), and was selected as a parent advocate on the Sumner County Schools adaptive playground committee.

Our children were born and raised in Sumner County and attend Station Camp schools. Johnny is a senior this year, and Juliette is seven years old and in first grade.

Today, we are here for Juliette and to ask for your support of legislation that would allow cameras in special education classrooms. Juliette has a dual diagnosis of Down syndrome and autism. She has significant developmental delays. She receives nutrition through a G-tube, uses a walker or adaptive stroller for mobility, and communicates through sounds, signs, and assistive technology on her iPad.



She does not eat independently. She does not walk independently. She does not speak verbally.

And she is perfect. She is joy.

Because Juliette cannot verbally communicate what happens during her school day, even small changes in behavior can signal something important. During her first-grade year, she happily went to school each morning, until several months in, when something changed. Her teacher began reporting that once Juliette entered the classroom, she would cry, vomit, and then fall asleep. This became a near-daily occurrence.

When your child cannot tell you what is wrong, everything becomes a puzzle.

We exchanged countless emails. We scheduled multiple in-person meetings. We tried to analyze every possible variable to determine what might be causing the sudden distress.

To a parent of a typically developing child, this might not seem extraordinary. It might even seem excessive. For children like Juliette, triggers can be incredibly nuanced.

Our STORIES

She dislikes foliage, indoors or outdoors. A plant added to a shelf or a holiday decoration in the room could trigger distress. Objects with faces, certain dolls or stuffed animals, can overwhelm her, not all of them, just specific types. There is no simple checklist. As her mother, I have memorized every detail of my daughter, every subtle cue and pattern.

If there had been cameras in her classroom, like the cameras already present on school buses and in many other school spaces, we could have observed what was happening during those moments of distress. Access to that information would have saved enormous time and emotional energy for everyone involved: the teacher, the administrators, and most importantly, Juliette.

Cameras are not about mistrust. They are about partnership.

Cameras would allow families and educators to problem-solve more efficiently, would protect students who cannot speak for themselves, and would allow schools to document positive growth and meaningful successes that could be shared during Individualized Education Plan (IEP) meetings.



Transparency builds trust.

We understand that our children require extra support, extra attention, extra energy, and extra patience. Implementing classroom cameras may feel like an “extra” step, but for children who are medically fragile, nonverbal, and unable to report mistreatment or discomfort, that extra step can mean safety, accountability, and peace of mind.

As special needs parents, we believe this measure is not excessive. It is necessary.

Thank you for listening to our story.



We respectfully ask for your support of this legislation — so that children like Juliette are protected, and families like ours can partner more effectively with the schools entrusted with our children’s care.

CAREGIVING SHOULDN'T MEAN CHOOSING BETWEEN YOUR CHILD AND YOUR HOME

KEISTON FLOOD (16 YRS)
TAMECKA STRAWTHER | GALLATIN, TN



Families like mine often fall into the gap, earning too much to qualify for assistance, but not enough to sustain the extraordinary financial demands of raising a child with significant medical needs.

Keiston is 16 years old. He loves sports — especially flag football, basketball, and bowling. He participates in choir at our church and loves to worship God. He brings joy and energy into every room he enters. Keiston was diagnosed with Down syndrome at birth.

Over the past 16 years, he has undergone more than 20 surgeries. He has faced numerous medical conditions that require ongoing care, appointments, and constant attention. Through it all, he has remained strong and so have I.

As a single mother, my greatest and most consistent struggle has been financial stability.

Because of Keiston's complex medical needs, I have had difficulty finding and maintaining employment that can adequately support us. I have resigned from jobs, and have also been terminated, due to necessary absences related to his illnesses, hospitalizations, and doctor's appointments. These are not optional appointments, they are essential for his survival and well-being.

Every decision feels heavy.

Will I be able to keep my job?

Will I be able to pay the mortgage this month?

Will I have to choose between paying a bill and buying groceries?

I want to be present for my son's medical needs without fearing that doing so will cost us our home.

I am aware of Tennessee's Employment and Community First (ECF) CHOICES program and family caregiving supports through the Katie Beckett Waiver; unfortunately, we do not qualify.

Families like mine often fall into the gap, earning too much to qualify for assistance, but not enough to sustain the extraordinary financial demands of raising a child with significant medical needs.

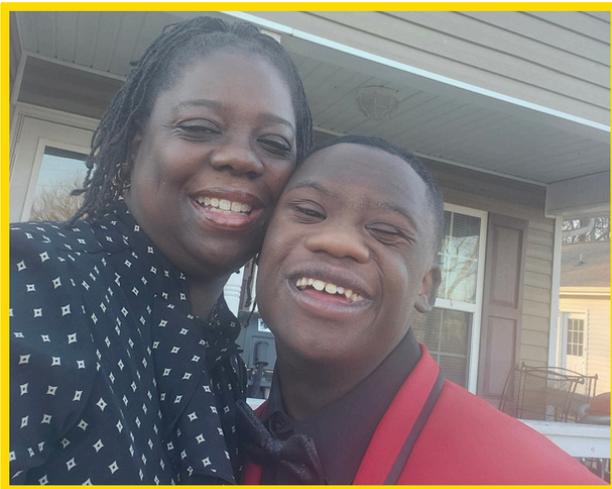
Our STORIES

Even when supports are available, restrictions on how funds can be used limit their practical impact. Most programs do not allow funds to be used toward mortgage payments, rent, or car notes, yet those are the very expenses that determine whether a family remains stable. Reliable housing and transportation are essential to getting a child to medical appointments and maintaining consistent care.

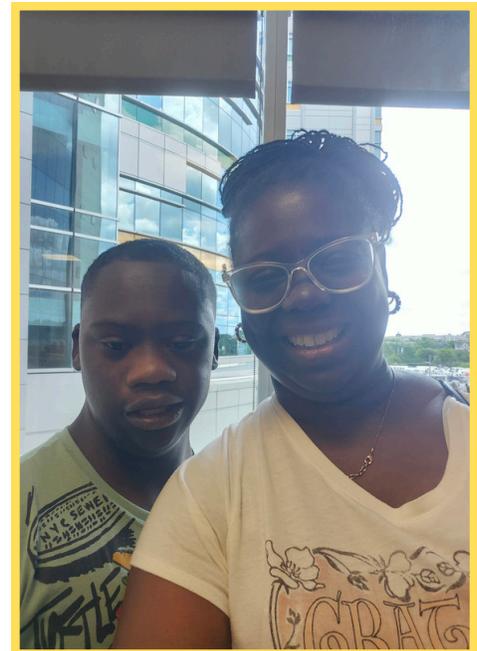
I would love to see expanded family caregiving support, that includes families like mine, and greater flexibility in how those funds can be used to stabilize households.

Caregiving is work. It is full-time work.

It often replaces the ability to maintain traditional employment.



Parents like me should not have to choose between being present for our medically fragile children and keeping a roof over their heads.



Thank you for taking the time to hear my story — and for considering policies that support families who are doing everything they can to care for their children.

ACCESS SHOULDN'T DEPEND ON EXHAUSTION

OWEN SCHAGREN (1YR)
KATHRYN SCHAGREN | MT JULIET, TN

Every child with a disability in our state should have equitable access to early intervention and support regardless of whether their parents have the time, expertise, or emotional bandwidth to navigate complicated systems.



My name is Kathryn Schagren, and this is my story about my son, Owen. Owen was born in April 2024, after an uncomplicated pregnancy. I was healthy and active throughout, and every ultrasound showed a growing little boy who was projected to be similar in size to his older brother. When Owen arrived, my husband and I had no idea about the surprise he was about to give us, or that we were stepping into an entirely new journey.

Within 24 hours of his birth, Owen was placed in the NICU for closer monitoring. Doctors noticed signs of a possible heart defect and physical features consistent with Down syndrome. Genetic testing later confirmed his diagnosis. Today, I am happy to report that Owen is a thriving 22-month-old who loves music, engaging with others, and cruising around our house now that he has mastered crawling.

Even with a professional background in special education, I quickly learned that a surprise birth diagnosis is not uncommon. While our family was surrounded by support from friends, relatives, and the Down Syndrome Association of Middle Tennessee (DSAMT), I also had to rapidly assess what it would take to ensure Owen had access to the care he needed to thrive.

By three months old, Owen was enrolled in Tennessee Early Intervention Services (TEIS) to give him an early start on developmental skills. In addition to regular pediatric appointments, we navigated specialist visits, applications for the Katie Beckett Waiver, and other disability-related programs.

Managing his care has been a full-time job.

I have the privilege of staying home with Owen to coordinate appointments, paperwork, therapies, and applications. I recognize that many families do not have that option. Accessing services often requires hours of phone calls, documentation, follow-ups, evaluations, and re-certifications. It requires flexibility with work schedules, transportation, and childcare.

While some of us refer to ourselves as “The Lucky Few” who get to parent a child with Down syndrome, the reality is that thousands of Tennessee families rely on government-supported programs to access essential therapies, medical services, and developmental supports.

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Strong support systems sustain strong families.

However, when entry into those programs depends heavily on the “sweat equity” of parents investing significant time, navigating complex systems, and advocating persistently true accessibility suffers. Families with fewer resources, less flexibility, or limited knowledge of the system may struggle to secure the very services designed to help them.

I have the privilege of advocating for Owen and other families because of the community and knowledge I possess, but not every family has that advantage.

Every child with a disability in our state should have equitable access to early intervention and support, regardless of whether their parents have the time, expertise, or emotional bandwidth to navigate complicated systems.



Access should not depend on exhaustion.



We know that early investment in children’s development leads to stronger long-term outcomes. I ask that you consider not only the financial cost of these programs, but also the social, emotional, and mental cost families bear in accessing them.



Thank you for taking the time to hear our story — and for considering how policy decisions shape the everyday realities of families like ours.

PROTECTIONS MATTER — BECAUSE OUR CHILDREN MATTER

**PENELOPE “PENNY” PLATTE (11 YRS)
AMELIA PLATTE | LEBANON, TN**



Laws such as the Individuals with Disabilities Education Act (IDEA) and the guarantee of a Free Appropriate Public Education (FAPE) are the framework that ensures Penny has access to the classroom, to services, and to opportunity.

My name is Amelia Platte, originally from Michigan. My husband Geoff and I moved to Lebanon, Tennessee in 2015. We are the parents of six children, ages 22 to 6. This is our 11-year-old daughter, Penelope, we call her Penny, and she has Down syndrome.

Penny loves her family. She loves summer camp, dancing, church, and school. She is joyful and social and thrives in the community. Like many families, our educational journey has included both meaningful support and significant barriers. Over the years, we have encountered assumptions about Penny's abilities and lowered expectations about what she can achieve. Those challenges intensified as she transitioned from a smaller, close-knit elementary school into middle school this past year.

**Our experience has not always been “bad.”
But it has often felt frustrating. We have felt
unheard.**

Someone once said to me, “Typical parents don't leave their child's school in tears.” That comment stayed with me because it felt painfully true.

After one particularly intense Individualized Education Plan (IEP) meeting, I told my husband that I was exhausted from feeling like I was arguing for my daughter's right to be there even in the small things: not arguing for extras, not arguing for special treatment, but simply arguing for her right to belong, to be included, and to receive an appropriate education.

The protections that exist today matter deeply to families like ours. Laws such as IDEA and the guarantee of FAPE are not abstract policy terms. They are the framework that ensures Penny has access to the classroom, to services, and to opportunity.

These protections were fought for by families who came before us. They provide structure, accountability, and recourse when things go wrong. They also give parents like us the ability to advocate, not from a place of desperation, but from a place of established rights.

We encourage legislators to preserve and protect these provisions. Please remember the faces and families behind the policies, remember Penny.

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When these safeguards remain strong, it relieves some of the burden families carry. It allows us to focus not only on navigating the system, but on building a long-term future for our children and their peers with Down syndrome and other disabilities.

We are not asking for more than what is promised.



We are asking that what has already been fought for remains in place.

Those protections are not theoretical.

They are personal.

They are Penny's future.



Thank you for listening to our story — and for protecting the rights that make inclusion and opportunity possible.

PROTECTING THE PROMISE OF EDUCATION

**SAWYER SHAFER (13 YRS)
SARAH SHAFER | DICKSON, TN**



Public education is not just important to my family; it is vital to countless families across our state.

My name is Sarah Shafer, and I am the proud mother of Sawyer, a 13-year-old boy with Down syndrome and autism. Sawyer is kind, intelligent, and full of potential, but he also has exceptional needs that require support, structure, and specialized education.

Placing the responsibility solely on the state raises serious concerns. States must have adequate funding, resources, and trained personnel to enforce these laws and protect our children. Without that, these rights risk becoming promises without protection.

Right now, my greatest concern is his right to a free and appropriate public education.

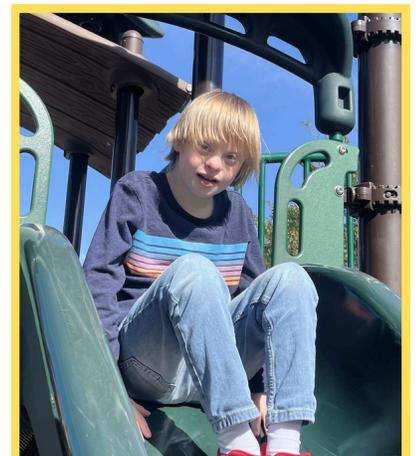
Some may suggest that families like mine should consider homeschooling, but that is not a fair or realistic solution.

The possibility of dismantling the federal Department of Education and shifting responsibility for the Individuals with Disabilities Education Act (IDEA) to the state level creates deep fear for families like mine. Laws like IDEA and Section 504 of the Rehabilitation Act ensure that children with disabilities have the right to attend their local public schools, just like any other child.



These protections are not optional. They are essential.

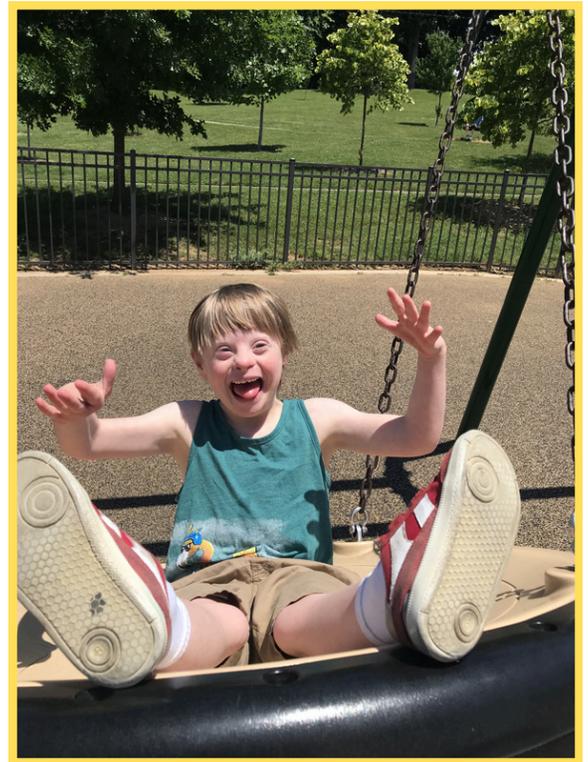
If the Office for Civil Rights is no longer able to effectively work alongside the Department of Education, how can we be confident that the hard-fought rights of individuals with disabilities will be upheld?



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I am not a trained educator, let alone a special education professional. I am not equipped to teach Sawyer the academic skills, behavioral strategies, or life skills he is learning in school. Just as importantly, he needs opportunities to socialize with peers both with and without disabilities. These interactions are critical to his growth, independence, and sense of belonging.

School vouchers in Tennessee present another challenge. Private schools are not required to accept students with disabilities or provide services under IDEA. In rural communities, like ours, options are even more limited. Why should I be expected to drive long distances to a private school that cannot meet my child's needs? What happens to our local public schools when funding is diverted away from them instead of being used to strengthen the system for all students?



Public education is not just important to my family—it is vital to countless families across our state.

We rely on special education services. We rely on 504 plans. Without these protections, our children risk falling through the cracks losing access to education, losing their civil rights, and ultimately losing opportunities to become active, contributing members of society.

Education is what prepares our children for adulthood. It gives them the tools they need to participate, contribute, and thrive.

We cannot afford to let these rights disappear.

Civil rights are human rights. And our children are human—just like yours.

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Thank you to the individuals who dedicated their time to share their stories to ensure that individuals with disabilities have the supports and access to lead meaningful, productive lives across the great State of Tennessee. To view the "Our Stories" participants telling their story in video format use the QR code below.



Down Syndrome Association
of Middle Tennessee