

Meet Us

Strong communities
include all of their
members!



Read
how people
are gaining better
access to educational,
employment and
financial opportunities
— and how that
benefits everyone!

MEET THE COUNCIL

Founded by federal legislation in 1971, the Georgia Council on Developmental Disabilities (GCDD) was tasked with making systemic change for the 158,000 people in Georgia who have a disability or who have a family member with a disability. Through advocacy and consensus building, its mission is to promote opportunities for everyone to live, learn, work, play and worship in Georgia communities.

To best implement positive change, GCDD focuses on **five key areas**:

- Real Careers
- Real Homes
- Real Learning
- Real Support
- Real Influence

GCDD further advances inclusion and self-sufficiency throughout Georgia by partnering with nonprofits, community and business leaders, which has had an impact on surrounding communities.

GCDD funds initiatives provided by nonprofits. It also promotes grassroots advocacy by encouraging state residents to contact their local legislators and be vocal about needed policy changes, getting everyone involved in the fight for inclusion!

We All Belong

BY THEA MARIE ROOD

Everyone has something to contribute to our community

If asked to describe our “ideal community,” we all might have different answers. Some of us may prefer the friendliness of a small town, while others may gravitate toward the hustle and bustle of a big city.

But no matter where someone calls home, there is one action that will help each place reach its full potential — welcoming all residents within a community.

“Everybody, regardless of who we are, wants to be part of our community ... and included in that community on the basis of our talents and gifts,” said Eric Jacobson, the executive director for the Georgia Council on Developmental Disabilities.

How do we make sure that happens?

“All of us — not just people with disabilities — need five things to be a productive member of our community,” he said.

“First, we need the opportunity for a career, a real job, someplace we go every day and earn real money. We also need a real home that we have the keys to, and our name is on the lease or we own it. And for someone with disabilities, that sometimes means it has to be accessible as well.”

The next three components are also universal.

“We all need to be able to go to school and get a real education,” Jacobson continued. “We all need real quality supports, but people with disabilities sometimes need paid kinds of support. Finally, we all want to have influence on



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Eric Jacobson
*Executive Director, Georgia
Council on Developmental
Disabilities*

what takes place around us.”

Society has made progress in including people with disabilities thanks to a focus on these five areas.

Particularly in employment and education.

“All people can go to work,” he said. “... We’re focused on going to a real job with real pay. Also, we are realizing students with disabilities can go to college and have a college experience.”

Jacobson credits many of these advancements to the Georgia state legislature.

“We need to acknowledge and thank the legislative champions who have been with us over the years and supported our advocacy issues,” Jacobson said. “Without them, we would not be making this progress — they are the ones who allocate funds and pass laws.”

But there is still more work to be done. Jacobson advised that even everyday interactions can make a big impact. These interactions aren’t ones that come through programs and supports for people with disabilities, but rather everyone else they come into contact with in their lives.

“Say you give someone a ride to church: That may be what they need to participate in that community, because they physically can’t get themselves there and that is the barrier to being included,” Jacobson said. “Sometimes ‘inclusion’ is as simple as that — just giving someone a ride.”

Matthew “Matty” Ladd has a better quality of life thanks to community programs like Social Saturdays.

PHOTO BY HAYLEE FUCINI-LENKEY

A Life of Purpose

Adults with disabilities thrive with interesting and engaging days

BY SHANNON TURNER



Once a month, Matthew “Matty” Ladd goes to Gwinnett County Public Library. There, he joins nine other adults in Social Saturdays, an event where participants read using assistive technologies and have sensory experiences related to the story: Matty smells bags of spice, feels the rush of leaves falling on his head and experiences wind in his face from a small handheld fan. This is one of his favorite activities.

Matty, now 23, was born with mitochondrial myopathy, a neurodevelopmental disease that is a type of muscular dystrophy. Matty experiences decreased vision and visual responses and is unable to walk or communicate via speech.

Matty “has a big personality,” said his mother, Anne Ladd. “He’s very chill, laid-back, always happy, has a good sense of humor.”

“Transportation is a big deal for families and, after that, just helping our people find a meaningful way to spend the day.”

Anne Ladd
Advocate and mother

Matty’s disability was not immediately diagnosed. By the time he was six months old, Anne and her husband, Paul, began to notice he wasn’t meeting developmental milestones. Matty’s pediatrician

disregarded her alarm and advised her not to compare him to his three-year-old brother, but not long after that, Matty’s grandmother confirmed Anne’s suspicion that Matty couldn’t see.

Then he began to have seizures.

It was a long road to diagnosis, which included a muscle biopsy, but

Matty’s family wanted to make sure they knew the genetic implications for future generations in their family.

Matty has used some form of Medicaid since he was 12. It initially took the family five years to get approved for Medicaid, a long time for the family to wait for much-needed support. The family still experiences challenges to find doctors who not only accept Medicaid

but are willing to work with people with disabilities.

“You’d think they’d be interested, fascinated even, with the opportunity to know someone like Matty,” Anne said.

Anne believes that better medical care and legislation is needed to ensure people like Matty can receive the support they need.

“Transportation is a big deal for families,” said Anne, “and, after that, just helping our people find a meaningful way to spend the day.”

Matty graduated from high school in 2017 and is an alumni of Oakland

Meadow School. Now Matty swims with Unique Therapy Services at the Roswell Recreation Center, goes for walks with his support staff and drums in drum circles.

Social Saturdays continue to be Matty’s favorite. Anne hopes that other adults with disabilities have access to similar programs in their own communities.

“It’s a big responsibility that we all have to care for these people,” said Paul. “You need to keep them in your view [as a community].”



WHAT IS A DEVELOPMENTAL DISABILITY?

The state of Georgia identifies a developmental disability as a disability that is severe, chronic, mental and/or physical. This disability becomes apparent before the age 22 and is expected to last a person’s lifetime.

People with developmental disabilities typically require supports in three or more of the following life activities: self-care, language, learning, mobility, self-direction, independent living and economic self-sufficiency.

Real World Community

Welcoming people with disabilities into schools and activities can change lives

BY SHANNON TURNER

On a rainy Sunday morning in Lawrenceville, Kyleigh Kramlich was relaxing at her family home. “I was watching some TV,” she spelled out one word at a time using an iPad-like device attached to the front of her wheelchair. After a robotic voice read each word aloud, she asked it to read the entire sentence back as a complete thought. It took about 30 seconds.

Kyleigh, 15, has cerebral palsy, likely from a uterine rupture that her mom, Christine, experienced during delivery. Both of them nearly died.

“It was a really treacherous situation for both of us,” Christine said.

Because she taught kids with developmental disabilities, Christine suspected some issues early on after bringing Kyleigh home. When Kyleigh was three months old, she had low muscle tone. At two years old, she was still not sitting up. Despite this, Christine had

to plead with Kyleigh’s doctors to get a diagnosis that would help them receive services.

“It was because of the nature of the injury,” she said. “No one wanted to point fingers at another practitioner.”

Kyleigh currently uses the Katie Beckett Waiver and the Community Care Services Program (CCSP) to help her family receive the support they all need, but these funding sources are not sufficient.

“It’s really hard to find support people ... [who] can manage physical needs as well as emotional and personal needs,” Christine said.

Kyleigh is on waitlists for both the COMP and NOW waivers and has been since she was five years old.

“The thing that is most important to me is being heard.”

Kyleigh Kramlich
Student



Kyleigh Kramlich leads a full life because she’s included in her own community.

PHOTO BY HAYLEE FUCINI-LENKEY

“Unless you call and follow up, you don’t ever hear anything,” Christine said. “It’s incumbent on me as the parent to keep calling and leaving messages on voicemails that are full.”

Still, Kyleigh has ambitions. She’d like to go to college, and the Kramlich family hopes Kyleigh will live independently one day.

“My life is hard because people don’t realize I am a person too,” Kyleigh said. “The thing that’s most important to me is being heard.”

Christine tells Kyleigh communication is important, so she can one day advocate for herself. For their community, Christine says including people with disabilities is critical.

“Being in [the real world] community, with her peers — that has been a primary goal for us and continues to be,” she said.

Kyleigh just transferred to Hebrom Christian Academy, which recently integrated students with disabilities into the same classes as other students.

Kyleigh also connects with other people through a Facebook group called “I Run 4.” Here, runners from all over the world “adopt” group members who can’t run themselves. Runners run for them in public events and trainings. A couple in Indiana started running for Kyleigh. They send her medals and write her letters, telling her she is the reason they enjoy their running practices.

Now, Kyleigh has a running wheelchair where someone runs from behind and pushes her. She went to a camp through the Kyle Pease Foundation where she deepened her understanding and appreciation of running. “Now, they run for each other,” Christine said. “Kyleigh is currently trying to qualify for the Peachtree Road Race.”

“I don’t care if we win or not,” Kyleigh said. “I love the wind in my face.”



WHAT IS A WAIVER?

Home and community-based waivers are sets of optional Medicaid services that states can choose to make available to people with disabilities that allow supports to be accessed right in their own communities — rather than being forced to receive them in a sequestered institutional setting. Waivers can help people find a home, job, caregiver or different therapies.

Here’s what else they can do:

- Help the more than 5,000 Georgians waiting for a waiver
- Create more jobs and pump money back into local economies
- Keep families out of crisis
- Save taxpayers money (on average, waivers cost less than institutional settings!)

Involved and Loving It

People with disabilities can bring important perspectives to their community

BY SHANNON TURNER

When Tira Harper, 35, walks into the small square building that serves as Lithonia's City Hall, everyone knows who he is. They joke and say, "Tira, you're the mayor!"

Tira, pronounced "Tie-ray," was born prematurely with cerebral palsy and an intellectual disability. He didn't walk until he was eight years old — and he has been making up for lost time ever since. He walks the same route most days of the week: from his home, to the Wayfield grocery store, to City Hall in the same parking lot then back home.

Tira graduated from Towers High School in 2004 and still lives in his hometown with his aunt and grandmother after his grandfather, mother and father all passed away. Even though Tira is legally his own guardian, his grandmother, Jo Ann Harper, supports him in making financial decisions.

Tira also receives additional support from his community living assistant, Barbara Branch, five days a week thanks to a COMP Medicaid waiver. The two of them go together to visit thrift stores, visit the library and to Wayfield Foods where Tira volunteers — his goal is to one day have a paid position there, and he advocates for having better employment opportunities for people with disabilities. Barbara also helps Tira fill out withdrawal

and deposit slips at his bank, pick out clothes and work in a community garden.

"It takes a lot of stress off of me," Jo Ann said. "We had him in another day program a while back ... [that] had him going out into the community, but it was also just a lot of 'no.' 'No' to this and 'no' to that. They didn't believe in him."

Tira is a busy guy, but his favorite role is the honorary position he serves in on the Lithonia City Council, created for him by Mayor Deborah Jackson. Tira goes twice a week to meetings to

share his thoughts and insights on disability issues at the Council level. One of the things he advocates for is better access to public transportation for people with disabilities, so Tira and others like him don't pay a physical toll for all the walking they do.

In fact, Tira has become an expert at riding the MARTA bus system, but he has a lot to say about how it could be better, particularly in terms of how long some of the routes take.

"I have to go all the way down to Five Points [for a transfer to downtown]," he said. "I have to spend the whole day doing that. We need something local, closer. Lithonia has a lot of empty buildings. MARTA should buy one."

"Tira,
you're the
mayor!"



Tira Harper makes a lot of contributions to his community, and he's not done yet.

PHOTO BY HAYLEE FUCINI-LENKEY



UNDERSTANDING SUPPORTED DECISION MAKING

All Georgians deserve to have control over their own lives. That's why the Georgia Council on Developmental Disabilities (GCDD) advocates for Supported Decision Making, a combination of supports that empower people to make their own decisions.

Too often, people with disabilities are presumed incapable of making or communicating their own decisions when it comes to their own health and safety. Many people are placed under guardianship when they don't necessarily need to be.

With Supported Decision Making, a person retains control of their own life and actions through the support of a small group of people they trust. **These supporters help that person:**

- Understand issues and choices
- Ask questions
- Receive explanations in a way they understand
- Communicate their own decisions to others

The Gymnastics of a Modern Family

Services people with disabilities require can be costly without help

BY SHANNON TURNER

Mornings can be hectic for a family with four boys. Now imagine that three of those boys are on the autism spectrum, and their mother recently had a yet unexplained epileptic event and is unable to drive for six months. That's what life is like for the French family. It's a lot to manage.

Still, the French family bustle along as they pursue Saturday activities in Sugar Hill. They start with bowling, which was the unanimous choice of Hunter, 12, and Jacob, 7. Next they'll go to gymnastics, which is what Andrew, 10, and Nathan, 6, love to do. Hunter, Andrew and Jacob all have autism.

Andrew first got involved in gymnastics three years ago after it was recommended by his occupational therapist. His mother, Stephanie, has seen significant improvement not only in his physical and motor skills, but also in his social skills.

"He waits his turn," Stephanie said. "And he's become very talkative. He's always very eager and excited to come."

Andrew uses the Katie Beckett Deeming Waiver, which helps his family pay for the therapies he requires and other medical expenses. Given the level of his need, those expenses can rack up quickly.

For example, getting 18-month-old Andrew diagnosed involved an evaluation with an expert in Norcross who was so sought after there was a six-month waitlist for a first appointment. That alone cost \$1,750. Andrew's father, Trey, who handles the family's finances, estimates they've spent an average of \$3,000 per month out-of-pocket over the last nine years for Andrew, Nathan and Hunter alone.

After gymnastics class ends, the family heads over to nearby E.E. Robinson Park so the boys can ride bikes, enjoy a picnic and generally burn off some steam. The boys take off, riding in zigzags all over the park's well-kept sidewalks, but staying in sight, while Trey watches

One day, Andrew wants to work at the car wash and he'd like to live on his own, but near his mom and dad. Andrew looks forward to growing up and growing old with his brothers.

"I love school, my family, gymnastics and playing outside."

Andrew French
Student and Medicaid waiver recipient

and cheers and Stephanie spreads out the food.

Today, Andrew is a happy ten-year-old who is easy to please.

"I love school, my family, gymnastics, and playing outside," he said.

Andrew also loves going to church and Bible class, and his family says it doesn't take much to make him happy. Even when happy, he does not like teasing humor because to him it feels the same as being made fun of.



Andrew French is a busy little boy, but needs a lot of help to make sure he stays healthy.

PHOTO BY HAYLEE FUCINI-LENKEY



A WAY TO SAVE

Saving money and being financially stable are not easy tasks for families whose members may have a developmental disability.

In 2017, the Georgia STABLE program launched to allow Georgians with disabilities and their family members to create tax-deferred savings accounts without needing to give up programs they desperately need, like Medicaid or Supplemental Security Income (SSI) benefits.

Grassroots advocacy and legislative action led to Georgia STABLE, which means people with disabilities and their families can use their STABLE accounts to invest and save. Learn more at www.georgiastable.com.



\$14,000: the amount people with disabilities or their families can put aside in savings thanks to STABLE accounts

Something to Write About

Student feels included on student newspaper in UGA's Destination Dawgs

BY SHANNON TURNER

An interest in journalism made Georgia the destination for Jordan, a 22-year-old man with Down syndrome.

This year, Jordan began attending University of Georgia through the Destination Dawgs full inclusion program. Its goal is for graduates "to gain new knowledge, skills and competencies that lead to a rewarding adult life."

Kathryn, Jordan's mom, says she's always believed in full inclusion, starting all the way back at kindergarten in Tennessee. She had to fight to get her son into a traditional kindergarten class. Year after year, she worked with Jordan's teachers to modify their curriculum to his needs.

When Jordan asked to go to college, and especially expressed his interest in

journalism, they did a thorough search. They considered several inclusive post-secondary education programs, but they weren't the right fit. "They just were keeping the students with disabilities mostly off to themselves, and that's just not what I want for Jordan," Kathryn said.

"We've been on this path of inclusion all our lives. Why would we stop now?"

With Destination Dawgs, there are student peer mentors who are part of the program at every step of the way, assisting him with participating in classes, going to the gym and working at the newspaper. These volunteers become cohorts, interested in the same academic and social things as Jordan.

Jordan does not have a Medicaid waiver, and that is something that deeply

"We've been on this path of inclusion all our lives. Why would we stop now?"

Kathryn,
whose son participates in Destination Dawgs



Jordan, who has Down syndrome, enjoys working on the University of Georgia student newspaper.

PHOTO BY HAYLEE FUCINI-LENKEY

impacts their lives on a daily basis. "Our number had just come up when we lived in Tennessee, but then we moved here to Georgia, so we had to start all over," Kathryn said.

When he wanted to go to college, Kathryn had to move to Athens with him and adopt the college lifestyle. "Fortunately, my job is entirely mobile," Kathryn said. "I can sit pretty much anywhere and work a full day. ... It isn't easy, but it's worth it to get him to a place where he's functional, living independently and working independently."

Currently, Jordan works at Rosati's pizza place in Cumming, 60 miles from Athens.

If any elected officials came to talk with him, Jordan would want them to know a few things. "I'm growing up," he said. "I would show them around campus. I would probably cook them something in my Crock-Pot at home — maybe chicken — because I'm becoming a very good cook. I would probably write about their visit in the paper."



EDUCATION FAST FACTS



144 students

are enrolled in the State of Georgia Inclusive College Programs in the 2018-2019 academic year



88% of students

graduate from their program



75% of students

become employed after graduation

We Are All Georgia



CONTACT YOUR LEGISLATOR TODAY!

If you are passionate about making your community a better place or just want to help more people be heard, the best place to start is by reaching out to your local legislator. Join the Georgia Council on Developmental Disabilities' Advocacy Network to:

- Track legislation
- Interact with elected officials
- Receive policy alerts
- Get guidance on how to talk to legislators

Visit <http://bit.ly/joinGCDD> to sign up!



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The Georgia Council on Developmental Disabilities (GCDD) is able to empower so many people with developmental disabilities and their families thanks to its network of partners. Together, these partners are known as Developmental Disabilities Network for the state of Georgia and collaborate to enact change and create new programs throughout the area.



Helps people with developmental disabilities achieve independent, self-determined, inclusive and productive lives by turning research into sustainable community practices.

**404-413-1289
www.cld-gsu.org**



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Works with and for individuals throughout Georgia who are oppressed and vulnerable and have been labeled as disabled or mentally ill. Advocates for these people and offers them protection.

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