

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 and 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

Everyone has something to contribute to our community

BY THEA MARIE ROOD

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



“Everybody — regardless of who we are — wants to be part of our community ... and included in that community.”

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.”

Finding a Voice

With love, support and inclusion, children with disabilities thrive

BY SHANNON TURNER

Kristian Joseph Moses, 5, was clearly upset one day at school, so his teacher took him over to the iPad-type device he uses to help him speak and opened up the screen. He scrolled through the pages and icons until he found just what he needed: “My ear hurts.” While the potential ear infection wasn’t good news, the extraordinary thing was KJ was able to communicate what he was feeling.

KJ has Down syndrome and does not use traditional speech to communicate. His parents, Bob and Angela, learned of his diagnosis through an early scan during pregnancy. Although doctors painted a bleak picture of what raising a child with Down syndrome would be like, KJ’s parents feel he’s a delight, as do his two older sisters, Kristal, 13, and Annalese, 7.

Today, KJ is a happy, healthy kindergarten student at Nebo Elementary School in Dallas. Three 45-minute periods

a day, KJ goes to specialized, small-group instruction, where he works on things like reading and communication. The rest of the day, he is in a general classroom with other kids his age.

In fact, his classmates dote on KJ, hugging him as often as possible. (His sister Annalese is a popular guest reader for the class.) And as the school day comes to an end, students line up outside their classrooms to wait to be called for buses and car pick-ups. KJ walks down the hallway and each and every one of the children calls out “KJ!” and gives him a fist bump.

The Moses family also recently learned KJ’s Katie Beckett waiver is approved, after an 11-month application process Angela called “daunting and time-consuming.” But the waiver is life-changing: Before it kicked in, the family paid for professional evaluations and weekly speech therapy out of pocket.

“There’s been a lot of talk about Medicaid cuts,” said Angela. “All of these



cuts affect services that he receives. When you’re cutting those things, you’re cutting quality of life. You’re cutting therapy that allows him to progress closer to his typical peers.”

Bob also believes the health-care system has to change to better protect people, no matter what county or state they’re in. “Families can easily go broke, bankrupt with medical bills — it’s a fact,” said Bob.

This family is actually well-versed in speaking to legislators: They recently

traveled to Washington, D.C., where KJ’s two older sisters met with Rep. Tom Graves to advocate for a bill to protect benefits for people with disabilities. “I’m here to talk for my brother because he can’t talk yet,” Kristal told Graves.

In looking at the accomplishments KJ has made in these first years of his life, it is clear that he has many things to say and will be more than able to share them in the future.



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.

Moving to a Better Life

Inclusive opportunities exist here, but still there are challenges

BY SHANNON TURNER

Kelsey Gray moved from St. Louis to Acworth with her mom, dad and 12-year-old sister in November 2015. Kelsey is a 14-year-old student at Awtrey Middle School, where she is in a class with other students with significant disabilities. Kelsey is happy at school, where she takes classes in math, social studies, music and art.

In Missouri, Kelsey went to a school entirely for people with disabilities. At Awtrey, while she is in a class with other students with disabilities, Kelsey also interacts daily with kids who do not have developmental disabilities. They eat lunch and take extracurricular classes together. This is incredibly significant for Kelsey, and her family appreciates it, too.

Kids with developmental disabilities learn with kids who do not have them, and they are both enriched by the exposure and resources. Cammie, Kelsey's mom, and Terrell, Kelsey's teacher, both agree that visibility and inclusion are key. "You can tell a difference," Cammie said. "You don't get as many stares when you are out because the kids are used to seeing her every day."

Kelsey was born with Pallister-Killian mosaic syndrome. She

"If I could say one thing to my legislators, I would say they need to understand what our life is."

Cammie Gray
Mother and advocate



Kelsey Gray at home
PHOTO BY LYNSEY WEATHERSPOON

cannot walk or operate a wheelchair. She has seizures and is visually and hearing impaired. Kelsey's parents and teachers assist her with all her daily living activities. Kelsey's needs are expensive.

Her medication alone costs \$900 a month. This winter, the Grays bought a wheelchair-equipped van with a ramp and special safety belts. It cost \$30,000. It took a while to find an affordable rental house with zero steps or stairs, and room is tight, especially with Kelsey's special equipment.

Kelsey's medical costs are partially covered under her family's insurance, but that doesn't even begin to cover what she needs. A lot of her care and medications are covered by her Katie Beckett Medicaid waiver. Cammie recalled, "She had the Missouri equivalent ... when we lived there. It was so easy. Kids are automatically enrolled for the waitlist as soon as their diagnosis is confirmed.

We had a case manager walk us through the entire process."

Cammie wishes it was so easy in Georgia. They had to wait until they moved to reapply, which created an eight-month gap. No one helped them with the process. (The psychological developmental assessment is designed for someone who responds with their voice and has more physicality than Kelsey has.) Cammie said, "We never had the same point of contact, and they were always saying they couldn't find the forms we submitted."

The Grays persisted and got the waiver for Kelsey, but it was stressful. They have to renew the waiver every year, but they need it to care for Kelsey so they have no other option.

Cammie wants a more streamlined process for applying for Medicaid waivers, and she wants more flexibility in deciding how to use the funds, like she did in Missouri. "If I could say one thing to my legislators, I would say that they need to understand what our life is," Cammie said as she held Kelsey's hand. "Then they would understand why we scream for help."



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 6,000 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!)

A Solid Investment

Support for people with disabilities helps them and the local economy

BY SHANNON TURNER

Joe Grillo is a 16-year-old boy with spastic quadriplegia cerebral palsy, developmental delay and visual impairment. He was born three months premature at 26 weeks. Because it was her second pregnancy, and the first had gone smoothly, his mom, Jane, said she knew something wasn't right almost from the beginning. "I just didn't feel good the whole time I was pregnant with Joe," she recalled.

In fact, 2001 was a lousy year all around, she added. Jane's mom died eight days before Joe was born. They watched 9/11 happen while Joe was still in the NICU.

Currently, Joe receives the Katie Beckett and COMP waivers, which help pay for things like his \$9,000 wheelchair and special food supplements. His dad, Jerry Grillo, wishes people would see investment in Medicaid waivers as something that multiplies into more spending at the local level.

"For every dollar Joe receives, he hires assistants, goes places and invests

in other practitioners — he's the founder and chairman of JoeyCorps," Jerry said with a laugh. "Jane is the CEO. I'm the COO and CFO."

Jerry and Jane are also advocates for the disability community. Jerry has written articles and created a YouTube channel about their family to help normalize their experience for others. Jane works as a Parent Mentor for the White County School District, is a job coach at the high school, and also serves on statewide boards and commissions, including the Department of Behavioral Health and Developmental Disabilities and Parent to Parent of Georgia. Georgia is the only state in the country that has a parent

"For every dollar Joe receives, he hires assistants, goes places and invests in other practitioners."

Jerry Grillo
Father and advocate



Joe Grillo with his mother, Jane
PHOTO BY LYNSEY WEATHERSPOON

mentor partnership program. The Parent Mentor job is paid for by a federal grant through the Office of Special Education Programs.

None of this would be possible without Joe's assistant, Rebecca Obermeier. She works with Joe 18 hours per week in three six-hour shifts. She learned great note-taking skills from her previous work experience, so when their state support coordinator comes monthly

to review goal tracking and other tasks, they're always well prepared.

"She has a really great rapport with Joe," Jane said. "I think it's because she has brothers. She knows when to make a joke he likes, but she can also tell when he's uncomfortable or upset."

Rebecca agreed. "I also had a cousin who was (nonvocal), and I helped to take care of her," she said. "I don't put much stake in the words people say; it's their body language."



WHAT DO HCBS WAIVERS MEAN FOR GEORGIA?



Makes a small dent in the **6,000-plus Georgians on the waiting list** for a waiver



Creates jobs and pumps money back into local economies



Keeps families out of crisis through respite care and ensuring family members keep their jobs



Saves the taxpayer money, as HCBS waivers, on average, cost less than institutional settings

Gainful Employment

BY SHANNON TURNER



A WAY
TO WORK

A job training program can help people with disabilities find real jobs with good salaries and benefits

Timothy Massengill, 23, lives in Lafayette. He has autism. Because his dad, Randall, is a United Methodist minister, Timothy's family has moved around a bit over the course of his life. They've been serving this particular area and congregation for a little more than two years.

One day, Randall got a call from a parishioner who suggested a program called Project SEARCH, which became a turning point for Timothy and his family. It offered Timothy a job training program and placed him at Unique Fabricating, where a job coach worked with him as he learned his duties on the manufacturing line. Now, Timothy produces parts that are used in BMW bumpers and doors, neatly tying into his lifelong love of cars.

"Tim's been working with us for a while now," said Robert Bell, director of operations at Unique Fabricating-South. "He does a great job. He's very attentive to quality, safety and makes sure he's out there working on his job all the time. Timothy is what I call a stellar employee. He does everything right."

Like so many people with developmental disabilities, that precarious period right after high school left Timothy falling through the cracks. He had been volunteering for Meals on Wheels, but was underutilized. He also needed a salary and health insurance from an employer because he doesn't have a Medicaid waiver. He has some state funding for supported employment, but that's pretty much where it starts and stops.



Timothy Massengill on his way to work
PHOTO BY HAYLEE FUCINI-LENKEY

"Timothy is what I call a stellar employee. He does everything right."

Robert Bell
Director of operations,
Unique Fabricating-South

Timothy's parents applied for a waiver years ago but never received it, and they were also misinformed about

Timothy's Social Security benefits. "[Parents] need better communication [on resources]," said Mary Massengill, Timothy's mother. "Don't just assume that everybody knows what to do. We're all just out here asking other parents. A lot of these services, we had no idea Timothy was eligible for because it's not written somewhere where everybody can read it."

In addition to Project SEARCH, the family also has been referred to Lookout Mountain Community Services, which promotes independent living for people with disabilities. Lookout staff has helped them make an application for services through their agency.

In the meantime, Timothy is proud of his employment, where he is fully accepted as a member of the team. Timothy is one of several people with disabilities who works at the plant. He's been so successful, he's even helping to train new employees now.

"My life is great!" he said.

GCDD works to improve employment opportunities for people with developmental and intellectual disabilities in Georgia through their support of:

Project SEARCH - This high school transition program started in Cincinnati, Ohio. Project SEARCH prepares young people with disabilities for success in integrated, competitive employment. It is currently being replicated in 39 states and four countries. GCDD has helped organize a statewide Project SEARCH Initiative, which arranges for technical assistance and training for teams that would like to have Project SEARCH in their community. There are currently 13 Project SEARCH sites in Georgia and five others in the planning stages.

Advancing Employment - Dedicated to building a community for inclusive employment in Georgia, this program helps individuals with disabilities, their families, service providers and others interested in employment learn and connect with one another. We believe competitive integrated employment is possible for everyone.

Take Your Legislator to Work Day - This is an opportunity for employees with disabilities to invite their legislator(s) to visit them at work. The goal of this program is to show the far-reaching benefits to employers, employees and communities alike of hiring people with disabilities, as well as to create opportunities for Georgians with disabilities to form and nurture relationships with their elected officials.

A New Chapter

Supportive services can be life-changing for young adults with disabilities

BY SHANNON TURNER

Five months ago, Kelsey Payne started her new job at Shaw Industries Plant No. 52 in the MTO (Made-to-Order) Department. It was a significant moment in her life, representing a whole new chapter.

Kelsey is a 25-year-old woman with autism. She lives in Dalton, where she works as a “swatch handler,” pulling squares of material to send to people who are considering the purchase of carpet from the factory.

Kelsey’s job is significant. She had spent more than five years in what she and her mom, Pam, both call “a dark period.” When she graduated from high school in 2012, Kelsey had virtually no resources and no idea what to do, so she “went home and sat.” Kelsey and her mom lived together during those years with their four small dogs, while Kelsey’s dad, Tomas, was out knocking on doors, trying to get her some services.

Eventually, thanks to his unflagging persistence and advocacy, Kelsey got into vocational rehabilitation, where she was discovered by Project SEARCH. The program offered her a nine-month internship, with the No. 1 goal of obtaining competitive employment in the community. A job coach worked with Kelsey on her job skills and confidence and helped her make job applications.

Tomas also fought for seven years to get Kelsey a New Options Medicaid Waiver, something he applied for in 2012 and is only recently in place. Between this

and her salary and benefits from work, she is now highly independent.

Kelsey also has her driver’s license now. This is important because public transportation is not an option where Kelsey lives, and transportation services for people with disabilities had proven unreliable. “I was late to work because I was calling the transit bus over and over again and never getting a response,” Kelsey said, adding this is a common occurrence.

Pam is proud of her daughter, but also feels frustrated by the long gap she endured. “The word is lost — you don’t know what to do next,” she said. “If we’d had more information at the high school level, there’s no telling where she could have been. She could have been working years ago. Things could have been so different, and she wouldn’t have had to go through that dark, depressed phase.”

But mostly Pam is astounded at how far Kelsey has come. “This is somebody who didn’t talk very much a few years ago,” Pam said with a grin. “Now you can’t get a word in edgewise.”

“If we’d had more information at the high school level, there’s no telling where she could have been.”

Pam Payne
Mother and advocate



Kelsey Payne in her Dalton home
PHOTO BY HAYLEE FUCINI-LENKEY



HOME AND COMMUNITY-BASED WAIVERS

Home and Community-Based Waivers (HCBS) are known by different names, but they all support people with intellectual and developmental disabilities living in their own homes. They are also known as:

NOW/COMP:

The New Options Waiver/
Comprehensive Supports Waiver Program

ICWP:

Independent Care Waiver Program

SOURCE/CCSP:

Service Options Using Resources in a Community Environment/
Community Care Services Program

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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www.gcdd.org**

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 the 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**



Empowers people with disabilities to enhance their quality of life and achieve their highest capacities through education programs and outreach projects that touch every corner of the state.

**706-542-3457
www.fcs.uga.edu/ihdd**



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.

**800-537-2329
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