

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

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



“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

sometimes need paid kinds of support. Finally, we all want to have influence on 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.”

Colin Allen has worked hard on his goals to lead a full and productive life.
Photo by L yNSEy WEAth ERSPoo N

Finding Faith in Life

The right environment makes a huge difference

by S h a N N o N T u r N e r

Colin Allen works part-time at a mobile coffee cart called Java Joy. He is a 19-year-old man with cerebral palsy and lives with his mom, Heather, in the Athens area.

Patiently waiting on the “short list” for about four years, Colin is hoping to receive services through the Medicaid waiver program. It took Colin and Heather a month to apply. Heather says her mother recently retired earlier than she’d planned simply so she could help out with Colin’s transportation and other needs. However, her mom is aging and she won’t be able to help that much longer.

“I’m not one to ask for stuff, but I need the waiver so he can have a full life,” Heather said. “I don’t want him to have to come home and stare at the four walls. He wants someone to hang out with. When he gets out of school, it’ll be crucial. I can’t stop working then. What am I going to do?”

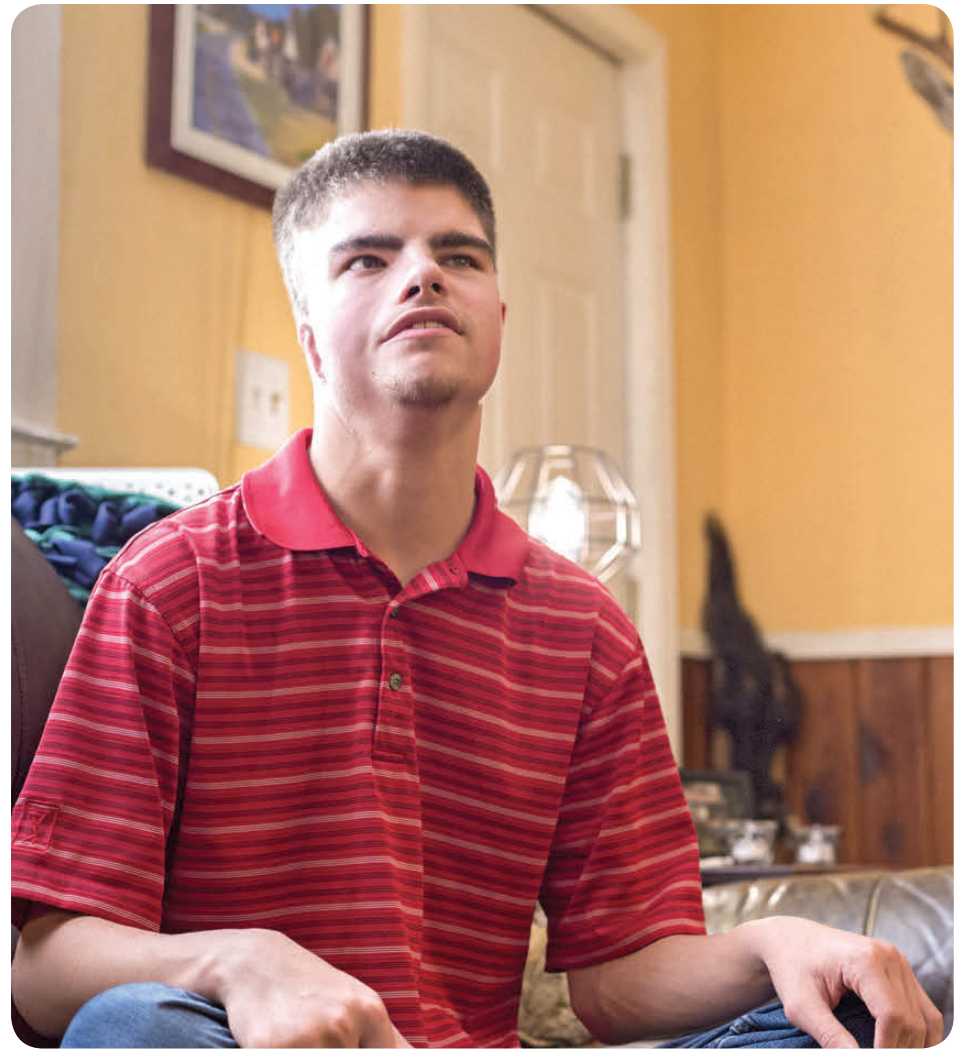
“He’s going to make a difference in the world. His life has meaning.”

Pastor Kay Dillard
Crossroads Community Church

Colin said he’d like to live on his own one day; he’s already got it all mapped out. He wants to live in an apartment with three of his friends when he graduates in two years. His mom noted that the transition may not be as fluid as he imagines, but she’s hopeful he’ll be able to find a place nearby so they can stay connected and he can also experience independence.

The Allens have been going to Crossroads, a non-denominational church just up the street from their home, for a large portion of Colin’s life. It’s their center point. He’s an active member of his youth group and loves to sing. “I have some pretty nice friends there,” Colin said, “and we worship the Lord together.”

Heather said they had to work to find a church home after Colin was born because he wasn’t always a typical reserved worshiper when he was young. Sometimes he would yell out or flail his arms or even say things back to the minister. This church was different, though, and she knew it immediately. They welcomed Colin and her whole family and made them feel right at home.



Administrative Pastor Kay Dillard comes to say hello as Colin gives a tour of his favorite spaces in the church. “There is no greater joy than to watch this young man enter into praise and worship,” she said.

Pastor Dillard has hopes for the young man’s life. “It reminds me of a quote I read the other day. It said, ‘Do not strive to be successful, but strive to be significant.’ I see that for him. He’s going to make a difference in the world. His life has meaning.”



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 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!)

Making Strides for Rights

Her case set a new standard for Medicaid recipients

by SHANNON TURNER

Callie Moore, a 22-year-old woman with a seizure disorder and cerebral palsy, is on a new journey towards independent living. It's a recent development resulting from her newly completed PATH.

PATH stands for "Planning Alternative Tomorrows with Hope." This process helps people of all ages and abilities realistically plan to reach their goals.

Pam Moore, Callie's mother, works for Georgia Options, which is an Athens-based nonprofit that supports people with disabilities to live in their own homes and to have typical life experiences. Previously a high school English teacher, Pam found that she was unable to support her daughter's medical needs, if nothing else, on a logistical level. "Callie was my unintended entrance into the disability world," Pam said.

Callie has a trailblazing and pioneering spirit. She's been the first in so many things, such as the first person in Madison County School District to have a

nurse accompany her to school.

Callie's biggest groundbreaking act is the lawsuit she won in 2008, *Moore v. Medows*.

Within six months after she started nursing services at the age of three, the Georgia Department of Community Health, the state's Medicaid agency, said she didn't need that much nursing care. Then, Pam contested that ruling. This became a biannual pattern. Every six months, the Moores received a letter saying that Callie needed less nursing care. The Moores had repeated mediations and hearings in state court. Every time, Callie won; but Georgia Medicaid continued to threaten

"This waiver system can make a huge difference in the quality of someone's life."

Callie Moore
Waiver recipient and trailblazing advocate



Callie Moore won an important court case that set a precedent for Medicaid recipients.

Photo by L yNSEy WEAth ERSPoo N

to decrease her services. Eventually, the Moores started meeting with the Georgia Advocacy Office.

When Callie was 12, the Moores got yet another notice that Georgia Medicaid officials were going to cut her hours. The Georgia Advocacy Office advised that it was time to let Callie's case provide some legal precedence. In the final ruling, the federal district court found that states participating in the Medicaid program do not have the discretion to

deny funding for treatments and services when prescribed by a treating physician for a Medicaid-eligible child. The case had implications for more than 700,000 children in Georgia who were eligible for Medicaid. It earned her name recognition throughout the disability community.

Callie now receives the COMP Medicaid Waiver, which started when she turned 21, and pays for all of her nursing supports.

"This waiver system can make a huge difference in the quality of someone's life," Callie said. "It can make life worth living."



WHAT DO HCBS WAIVERS MEAN FOR GEORGIA?

Home and Community-Based Service Waivers (HCBS) ...



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

Coping with Big Obstacles

by SHANNON TURNER



A WAY
TO WORK

Waiver helps family deal with expensive health issues

Gibson Williams is an eight-year-old boy from the Athens area born with single ventricular complex and heterotaxy syndrome. His heart does not have the usual four chambers, many of his organs are on the opposite side of his body and he was born without a spleen. He had multiple surgeries as an infant. He also had a stroke and seizures, which led to developmental delays.

Gibson has received the Katie Beckett waiver since he was six months old. His parents, Alison and David, explain that the renewal paperwork needs to be filled out annually within two weeks of receipt, even though it requires getting several doctors and specialists to complete sections. If it's not filled out absolutely correctly, the renewal can be denied. It's always a very stressful time in their year.

With training as a licensed clinical social worker, Alison said that she has lots of experience helping people apply for Medicaid and other government programs, yet applying for the Katie Beckett waiver is still very difficult and time consuming. She now helps other families fill out their applications and paperwork because she's learned so much about the process. "I know a family that got denied simply because one pediatrician checked one box wrong," she said.

The Katie Beckett waiver helps with co-pays and deductibles, physical therapy and speech therapy. Recipients must have



Gibson Williams has overcome a lot in his young life.

Photo by LYNSEY WEATHERSPORN

"A couple of times, we didn't know if he was going to survive."

Alison Williams
Mother and advocate

primary insurance; the waiver is an add-on. "It's good," Alison said, "because we meet our deductible, which is like \$3,000, by the end of January."

As she discussed the difficulties Gibson has encountered, Alison started to cry. "A couple of times, we didn't know if he was going to survive. It's hard."

Gibson had his last corrective heart surgery when he was five. The family has to be extremely cautious about potential infections. "We have to go on lock down in the winter because Gibson's immune system is so delicate," Alison said.

Gibson is in a special education

classroom in the local public school. Just to get him started at the school, they had to meet with the head of the special education department, the principal and the superintendent.

"There's not a lot of resources," David said. "It's difficult and it's expensive. People think, 'Oh, if you've got insurance, it'll cover everything.' But not if you're going to the doctor once a month, you've got therapies three times a week, and you need medicines. At one time, he was on 14 different medications. One of the co-pays was \$200."

"I would like the paths to service to be easier," he added. "It's literally jumping through hoops."

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.

Something to Write About

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

by Sha NNoN TuR Ner

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 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."

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

Kathryn
Mother and advocate



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

Photo by L yNSEy WEAth ERSPoo N



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!



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.

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**888-275-4233
www.gcdd.org**



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

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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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