

## Making a Difference Magazine

A Quarterly Magazine of the Georgia Council on Developmental Disabilities

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On the cover: GCDD's Education Series helps families and students learn about their education rights and navigate the IEP process for a successful school experience.

The Georgia Council on Developmental Disabilities (GCDD) is driven by its Five Year Plan (2017-2021) goals of education; employment; self-advocacy; Real Communities; and formal and informal supports. The Council, charged with creating systems change for individuals with developmental disabilities and family members, will work through various advocacy and capacity building activities to build a more interdependent, self-sufficient, and integrated and included disability community across Georgia.

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## GCDD VIEWPOINT

### Keep Moving Forward

At the time of this writing, the world has come to a standstill because of COVID-19. Over 10,000 Americans have lost their lives to this illness, and hundreds of thousands are sick. People with disabilities who experience health-related issues such as heart, lung or kidney disease need to take extra precautions because they may be at increased risk of contracting COVID-19 and subsequently falling ill.

Throughout Georgia and across the country, people with disabilities are unable to get the supports they need and experience discrimination when they try to get a diagnosis or access medical care related to COVID-19. As a community, we mourn the loss of those who have passed away from this dreadful illness.

Together with our partners in advocacy, the Georgia Council on Developmental Disabilities (GCDD) penned [a letter to Governor Kemp and other state leaders](#) outlining concerns we believe should be addressed, including ensuring direct support professionals (DSPs) are deemed essential workers and receive the necessary protective equipment they need to be safe. The Department of Community Health has also submitted an [Appendix K to the NOW/COMP waivers](#), which would allow some rules to be waived in order to support individuals in their homes during this crisis.

We know much of this information can be overwhelming. To help be a resource for our community, GCDD has prepared a [dedicated COVID-19 page on our website](#) that outlines information relevant to the disability community in Georgia. Also, the Georgia Developmental Disabilities Network, of which GCDD is a member, is offering a [free, public webinar](#) every Tuesday at 3 p.m. to let people know what is happening in our state and what resources are available. Please join us.

While we continue to work, we also remember one of our champions. In early April, Georgia's disability community lost one of its legislative heroes in Senator Jack Hill (R-Reidsville), chairperson of the Senate Appropriations Committee. Sen. Hill was always available to us with advice and was responsible for making sure that funds were appropriated for the inclusive post-secondary education (IPSE) programs across the state. He also supported many other efforts impacting the disability

community. Sen. Hill will be missed, and our thoughts go out to his family.

Before Georgia shut down because of COVID-19, the legislative session happened, and there were many activities that impacted people with disabilities. Indeed, your advocacy helped to make this a successful legislative session. For more details, a full rundown of what took place during the General Assembly is available in this issue's Public Policy for the People.

Usually in the spring edition Making a Difference we cover education because this is the time when schools and families are preparing for the end of the academic year. However, schools across the state are closed and graduations canceled. We have provided you with resources to help plan for those meetings in the coming year.

Other issues we cover in this edition include recommendations for how to improve the conditions and quality of DSPs. We know there is a crisis in recruiting and retaining staff. Check out Expert Update for potential next steps and solutions.

Visit GCDD's [website](#) and join our [advocacy network](#) so that you can stay informed. We hope you enjoy reading this magazine, and we want to hear from you. Let us know your thoughts by writing to Managing Editor Hillary Hibben at [hillary.hibben@gcdd.ga.gov](mailto:hillary.hibben@gcdd.ga.gov).

Eric E. Jacobson  
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Tell us your thoughts about the magazine or what topics you would like to see addressed by emailing us at [hillary.hibben@gcdd.ga.gov](mailto:hillary.hibben@gcdd.ga.gov), subject line: Letter to the Managing Editor

## FEATURE STORY 1

[PUBLIC POLICY FOR THE PEOPLE: 2020 Legislative Session Recap](#)  
by Charlie Miller, GCDD Legislative Advocacy Director

This has been one of the most interesting legislative sessions we have seen in modern times. Between Governor Brian Kemp's first installment of recommended budget cuts and the threat of COVID-19, the Georgia Council on Developmental Disabilities (GCDD) has been responding through strong advocacy that empowers our community.

As you may know, this year's session got cut short due to the spread of the coronavirus and also because of the pause in session for budget negotiations. When the session began, we already knew the governor's recommended budget cuts were coming, as all state agencies and state-funded entities were asked to cut their spending.

From Medicaid waiver funding, to organ transplants for people with disabilities, to employment, many things were at risk for

the disability community. But Georgia's disability advocates were strong and spoke with one voice.

Here at GCDD, we believe in public policies that aim to advance the well-being of all Georgians with developmental disabilities, their families and all who love them. We do this by supporting and advancing policies that create and maintain true community inclusion.

Below we list each of GCDD's 2020 Advocacy Days, as well as various legislative highlights, under five different sections: state budget, health and wellness, employment, education and transportation.

## STATE BUDGET

Coming into this legislative session, we anticipated several interesting budgetary developments. Governor Kemp outlined in his State of the State address in January 2020 that he was looking to cut all state agencies' budgets by four percent this year and six percent next year in order to accommodate a pay raise for teachers, which would cost the state \$350 million.

After reviewing the governor's recommendations, GCDD was surprised to see they included no new waivers for home and community-based services (HCBS). This greatly impacts the disability community because, over the last 10 years, the governor's office has always recommended funding for new waivers – often as many as 125 slots per year.

In response, GCDD organized an Advocacy Day focused on HCBS funding. As part of that initiative, the Council recommended at least 100 new waivers be added to this year's budget to address the 6,000+ person waiting list in Georgia. We know these waivers are vital to helping people with disabilities live in their own communities and have real jobs and get the support they need to lead fulfilling lives. GCDD also worked with advocates around the state to prepare legislative testimony.

As a result, advocates educated and informed their lawmakers to include 100 new waivers in the House budget. And we are looking forward to advocating for more as soon as the session resumes and ensuring the budget improvements make it through the Senate!

## HEALTH & WELLNESS

Prior to 2020, Georgians with disabilities could be organ donors, but hospitals and donation organizations were legally able to deny people with disabilities the right to receive an organ transplant, based solely on that person's disability.

Spearheaded by the Nobles family from White County, [Gracie's Law is named after David and Erin Nobles' daughter](#) and would eradicate legal organ transplant discrimination based on disability status. Together GCDD, The Arc Georgia and the Down Syndrome Association of Atlanta worked alongside advocates across the state to educate legislators about this important issue. In fact, GCDD's first 2020 Advocacy Day

focused on organ transplant discrimination and Gracie's Law, also known as [House Bill 842](#).

Gracie's Law was introduced in the Georgia State House of Representatives by Rep. Rick Williams, who serves as the Nobles' representative. The bill flew through the House with a unanimous vote of 160-0. The last day of session, before COVID-19 mandated a break in the legislature, Gracie's Law was assigned to the Health and Human Services Committee in the Georgia State Senate and is waiting to be called for a vote. We are waiting for the session to reconvene so we can pass it out of the Senate and to the governor's office.

## EMPLOYMENT

For the past few years, Georgia has been considered one of the top states in which to do business. But sadly, the disability community in Georgia has been left out of the prosperity these businesses promise our state. While people without disabilities are employed at a rate of 73%, Georgians with disabilities are only employed at a rate of 34%. This means that while the majority of people with disabilities report that they want to work, unemployment for people with disabilities hovers between 65% and 70% nationally.<sup>1</sup>

The disability community has been garnering support from both the House and Senate around this issue, as we believe all people with disabilities have the right to go to work and get paid competitively. To further this support, one of our 2020 Advocacy Days was centered around creating a resolution in

the House to put pressure on the [Employment First Council, which was formed when Employment First officially became law in 2018](#). This entity is supposed to help guide the General Assembly on how to ensure Georgia becomes a state that truly implements “employment first” practices, including funding employment supports before and instead of segregated services.

The resolution would compel the [Employment First Council](#) to fulfill its mandate and hold public hearings that inform recommendations to the General Assembly regarding how to implement best practices, including how to eliminate the use of subminimum wages across the state. As of now, the plan for a resolution is on hold as the session has yet to reconvene.

## EDUCATION

On the education front, the governor’s proposed cuts impacted the budget allocation for inclusive post-secondary education (IPSE) programs in Georgia. Since some funding for IPSE is allocated as a line item in the state budget, it is subject to the governor’s budget cuts this year and next.

To address these concerns, GCDD worked with the Office of Planning and Budget to find a way to cover the cut this time. But legislators need to understand how impactful IPSE is to the disability community. To help show the impact to legislators, students, staff and supporters from all nine IPSE programs in Georgia joined GCDD at its IPSE Advocacy Day. Over 150 students, parents, professors and community advocates came

to the Capitol to educate and inform lawmakers about the importance of post-secondary education for students with disabilities.

In addition to IPSE, [Senate Bill 386](#) was introduced – but not without some concerning issues. This bill would expand the Special Needs Scholarship, which allows students to transfer to a private school in hopes that school can provide different supports. Specifically, it would expand access to the Special Needs Scholarship to students who have a 504 plan. A 504 plan is a plan developed to ensure that a student who has a disability is receiving the right supports and services needed to make them successful in school.

GCDD was concerned about certain aspects of the bill, namely the rights parents and students using the scholarship would be asked to relinquish. Families using the scholarship would lose their rights, provided under [Section 504 of the Federal Rehabilitation Act](#). These rights serve to protect against discrimination against a student with a disability. Essentially, this would allow discrimination and bullying based on disability.

The bill was voted favorably out of committee and passed in the Senate with a vote of 33-22. The Senate made some changes to the bill but did not correct the concerning language about relinquishment of rights. Fortunately, GCDD remained in close communication with the bill author and sponsors, who assured us that changes would be made to the bill while in the House. With the suspension of the session, no legislation can be

voted into law until our senators and representatives return after the pandemic.

## TRANSPORTATION

Just like all people, Georgians with disabilities use many different modes of transportation – from planes to trains to automobiles. In addition to these common modes of transportation, there are several other mechanisms that provide mobility, like elevators, that many of us may take for granted. Unfortunately, elevators are often broken, closed for repairs or otherwise inoperable, especially in high-use areas like public transit stations.

According to the laws in Georgia, all elevators should be inspected every six months. But a new bill coming out of the Senate is looking to change that. [Senate Bill 377](#), authored by Senator Burt Jones from Jackson, GA, aims to change mandatory elevator inspections to only every 12 months. GCDD researched other states and found that many states only inspect elevators every 12 months.

However, we wanted to use this opportunity to make necessary improvements to the way our elevators are maintained in Georgia. We know that many of our advocates rely on elevators to get around, and we also know firsthand how frustrating broken elevators can be. We worked with members of the state Senate to include language that organizations can be fined if their elevators break often.

## LOOKING AHEAD

Although the session is currently suspended due to COVID-19, the public policy department at GCDD is working around the clock to make sure that the needs of our community are identified and addressed. We are actively monitoring any news regarding when the session might restart and will make sure you all are in-the-know!

GCDD is standing by for the state legislature to reconvene for a special session, as is mandated by Georgia's state constitution. In the meantime, advocates can continue meeting with their legislators in their communities – especially since this is an election year. Policymakers should hear from the people they serve as frequently as possible. You don't need the legislature to be in session to advocate, so now is the time to write to, speak with and meet your elected officials about the issues important to you.

For resources and additional information related to COVID-19, please visit [GCDD's resource page](#). If, like me, you prefer your legislative updates in video format, check out our [2020 Legislative Recap Video!](#)

<sup>1</sup> Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J. (2018). StateData: The national report on employment services and outcomes.

## The Disability Vote Counts 2020 – It's Election Season!

It's election season again! In November, millions of Americans will head to the polls to vote in the 2020 Presidential and General Election taking place on November 3.

Like all elections this year's is important, and it is even more important for people with disabilities to head to the polls to make their voices heard.

### **The Primaries**

In a primary election, registered voters may participate in choosing the candidate for the party's nomination by voting through secret ballot, as in a general election.

Due to the COVID-19 outbreak, the Georgia primary was postponed to June 9, 2020. With many shelter-in-place orders in effect, Secretary of State Brad Raffensperger announced that [all ballots will be mailed to registered voters.](#)

While early voting was already underway, the primary election will feature the presidential candidates and the local and legislative primary races. The early voting for the June 9 primary will begin on May 18, 2020.

The candidates who are selected by voters will be on the ballot for the November General Election.

[Find out who is seeking election/re-election in Georgia.](#)

## **Who is up for election?**

- 14 Georgia representatives in the US House of Representatives
- 2 Senators in the US Senate

Also, many state senators and representatives, commissioners, judges, councilpersons and other regional and local seats impact how people with disabilities work, live and play in their communities.

## **MAKE YOUR VOTE COUNT**

[Did You . . . move, change your name or have any changes in the last one year? Make sure your information is up-to-date and current on the Secretary of State's website.](#)

[\*\*REGISTER TO VOTE BY MAY 11\*\* to vote in the rescheduled June 9 primary](#)

[All ballots will be mailed to registered voters due to COVID-19](#)

## **Dates to Remember**

May 11 – Deadline to register to vote in June 9 Primary

May 18 – Early voting begins

June 9 – Presidential Preference Primary, General Primary Election, Nonpartisan General Election and Special Election

October 5 – Deadline to register to vote in November General Election

November 3 – General Election

*Dates subject to change due to COVID-19*

## FEATURE STORY 2

### The Accessibility of the New Voting Machines

by Mary Welch

From the initial fact-finding process to the end result, leaders in the disability community are giving a big thumbs-down to the new Georgia voting booths as election season is here. While the Georgia primary election has been rescheduled to June 9 due to the COVID-19 outbreak; and the [Secretary of State \(SOS\) will be mailing absentee ballots to all registered voters for the primary;](#) the accessibility of the new machines will be an important factor in the general elections.

Not having the best, most accessible machines creates problems.

“There could be an effect on the actual vote count if votes are unconfirmed, or worse, inaccurate,” says Cheri Mitchell, an advocate for the Georgia Advocacy Office. “Aside from the impact on votes, however, voters with disabilities may start staying home instead of voting.”

Not only will their votes be marginalized or excluded, Georgia could slip further behind in terms of accessibility, threatening the participation of voters with disabilities in the future.

“There is no single definition of voter suppression, per se, but we can extrapolate the meaning of the term by looking at examples such as voter roll purges, ID requirements, restricting access to absentee voting and voter registration restrictions,” adds Mitchell.

All of these examples have the effect of making voting more difficult, and Georgia’s new voting machines will certainly do that for some. It may be unclear what the intention was in selecting the specific machines or not including certain accessibility features that would make the machines useable by all voters. Regardless, the impact is the same: the new machines will make it more difficult for people with disabilities to vote in Georgia.

The voting machines of yesteryear were challenging. “There had to be a better way,” said Robert Smith, president of the Decatur chapter of the National Federation for the Blind (NFB).

“The SOS’ office has a legitimate interest in making sure that the voting machines are secure, and protecting that interest means that Georgia is using these new machines. However, disability rights are no less important than voting security, and we have to be careful to avoid assuming that we can’t have both. We can and we must,” says Mitchell.

Voters with motor impairments or significant vision impairments are unlikely to be able to use the new voting machines independently.

Then-SOS Cathy Cox agreed and ordered new machines that were more sensitive to the needs of people with disabilities. “When Cathy Cox was in office, the blind said that we wanted to have a say, and we did,” said Smith.

Still there were issues, mostly over validation and technology. Governor Brian Kemp wanted new machines. “The office has made a big effort to try to make the voting as accessible as possible to people with any disability and have the voting be the same as everyone else,” says Walter Jones, communications manager for the SOS. “We went through a whole process and even had roundtable discussions with various disability organizations.”

At that meeting were senior members of current SOS Brad Raffensperger’s staff, including State Elections Director Chris Harvey, who said his mother also was a person with disabilities. “This is personal for me that we get out and serve people with differing abilities,” he said.

One of the sticking points is that Raffensperger brought them much later into the decision-making than Cox.

“We recommended the machines that Maryland uses, and they didn’t choose those,” says Dorothy Griffin, president of the NFB in Georgia. “It’s not an improvement. I liked the older machines better.”

Instructions on using the new machines are “very clear,” but Jimmy Peterson, executive director of the Georgia Center of the Deaf and Hard of Hearing, added that he wished, “all the amendments were in the [American Sign Language] version instead of the English version.” The new machines are almost the same as the old, except to print the ballot to vote. So, what’s the problem?

A big negative is check-in privacy. Poll workers can scan identification cards, but not a person’s party affiliation, so it must be given to the worker. “That’s not privacy,” says Griffin. Technology is another issue. “Using the headset is a bit confusing, and it repeats the instructions over and over again. It drives you a little batty,” says Griffin. Many, especially seniors, may not be comfortable with technology. Those with poor hand coordination could also be impacted, she adds.

Smith also questions whether poll workers might not be properly trained. “Is there enough training so the poll workers will know what to do right away if a person who is blind or visually impaired comes in?”

Jones says there is training as well as a video helping poll workers respect and aid people with disabilities.

There also are issues with validation. With the new system, a person will be given a paper copy of their ballot to ensure that it is correct and submitted. Of course, for anyone who can’t see, being given a piece of paper to read is a wasted effort.

Bringing smartphones, other artificial intelligence devices or magnifying glasses are a “Band-Aid,” says Gaylon Tootle, an independent living advocate and vice president of the NFB in Augusta.

Both Griffin and Smith want a scanner that, when you insert the ballot, will verbally read the vote so the person can approve. Smith says the state claims scanners are too expensive. “If I can’t read my ballot, a scanner is the next best thing. It puts us on equal footing. I want a paper trail as well as it being electronically recorded.”

By law, no one is allowed to bring smartphones with them into the voting booth. However, the voter election board held hearings to change that regulation.

In response, the SOS’ office will now allow voters with disabilities to verify their printed ballots before casting them. The system allows voters to make their choices on a touchscreen device and then print their ballot for review before casting.

According to a [press release from the SOS’ website](#), “the new system has the ability to adapt to various accessibility needs, from larger type fonts and altered contrast to audio instructions and sip-and-puff manipulation.”

It is every citizen’s right to vote.

“The people who are elected make decisions about equality, programs and services. We need equality, programs and services for all! That means ALL need to vote,” said Mitchell.

“Not only is it every person’s right to vote, every person has the right to vote privately in Georgia. If you are a person with a disability, your ability to read, mark or submit your ballot independently may be impacted. Accommodations like assistive technology (AT) devices are the only way that you can vote in private, just like everyone else.

Smith acknowledges the cost, “but we pay taxes.” Adding, “We’re going to keep pursuing it until it gets changed. We’re encouraging all people, especially in the blind community, to get out to vote.”

### **Voting Problems?**

If a person with a disability had trouble voting or was not treated properly, they can contact the [Georgia Advocacy Office](#) (GAO), which receives federal funding under the Help America Vote Act (HAVA) to advocate to ensure that people with disabilities have access to the voting process.

The GAO voting hotline on Election Day in November will be open: 7am to 7pm.

The phone number is 404-885-1234 or 1-800-537-2329.

There is also a complaint process on the [Secretary of State’s website](#).

## **Using Georgia's New Voting Machines**

1. CHECK IN AT THE POLLS. Upon verifying their eligibility status, voters receive a smartcard to begin the process.
2. MARK & PRINT YOUR PAPER BALLOT. A universal ballot marking device with accessible options, prints a paper ballot after voters mark and confirm their selections.
3. PLACE YOUR COMPLETED BALLOT INTO THE SCANNER FOR COUNTING. All paper ballots go into a secure lock box.

## FEATURE STORY 3

### [GCDD Hosts Record-Breaking Advocacy Days](#)

Over 650 disability advocates registered to attend the 2020 GCDD Advocacy Days at the Georgia State Capitol – making it the biggest series the DD Council has hosted since inception of the initiative.

Hosted by the Georgia Council on Developmental Disabilities (GCDD) in January, February and March, advocates met with their legislators to discuss the issues important to the disability community in Georgia.

Four different Advocacy Days focused on policies affecting people with disabilities and brought together advocates from across the state to speak with their elected officials. Topics included Gracie's Law, inclusive post-secondary education, home and community-based services and competitive, integrated employment. In addition to these four events, GCDD

planned a fifth Advocacy Day to focus on the school-to-prison pipeline. Unfortunately, the final event was canceled due to the COVID-19 pandemic that hit the United States in early March.

“All of our advocates – whether a self-advocate, a family member or a caregiver – were empowered to connect with their legislators to inform and educate them about issues that matter to them,” said Eric Jacobson, executive director of GCDD. “It was motivating to see advocacy in action and be at the forefront of positive change for people with developmental disabilities across Georgia.”

[View all the Advocacy Days photos posted on Facebook.](#)

### **Advocacy Days by the Numbers**

- 221 - were able to educate and inform their legislators about issues important to them
- 276 - felt better informed/ trained on issues impacting individuals with developmental disabilities
- 292 - plan on continuing to advocate on behalf of people with developmental disabilities

### **Quotes from attendees:**

“Everything was very well-organized and the team leaders were very knowledgeable and helpful.”

– Toni Franklin, Educator

“Best Advocacy Days ever! Thanks to our Team Lead Sophia Turner, we met our representative and senators!”

– Dawn Willis, Caregiver

“This event was great. I was able to use advocacy skills I acquired and advocate for Gracie’s Law.”

– Nina Martinez, Self-Advocate

## FEATURE STORY 4

Parents Navigate Georgia’s K–12 Education Supports: IDEA, IEPs and Students’ Rights

by Jennifer Bosk

Viviana Fernandez purchased a home in Snellville when her son, Cameron, was entering the first grade. Shortly after enrolling him at Britt Elementary, she received a call advising that he be moved to a separate school for kids with disabilities. The school continued to call her for minor behavioral issues, and she recalls feeling intimidated at her son’s first individualized education program (IEP) meeting.

“I cried, and I cried after I got out of there,” said Fernandez, now an advisory member of the Georgia Council on Developmental Disabilities (GCDD). “Most of the time, they were making it seem like I was crazy, that what I was asking for was totally crazy.”

After a two-year fight and dipping into her 401(k) to hire an attorney, Fernandez got her son the education he was legally entitled to. Cameron, now 18, was placed in an inclusive classroom, and he was the first student with Down syndrome to attend Britt Elementary School.

### [Navigating the IEP Process](#)

Fernandez is one of many parents navigating Georgia's K-12 special education supports. [Over 160,000](#) children in the state's education system have IEPs, or individualized education programs for students with disabilities. These plans, meant to ensure equity in access to education, are nationally mandated by the [Individuals with Disabilities Education Act \(IDEA\)](#).

IEP teams are made up of parents, school faculty and, optionally, the student and a neutral facilitator. A student's IEP is reviewed and updated at least once a year. According to resources from the Georgia Department of Education (GaDOE), parents receive written notice prior to IEP meetings outlining the agenda, location and time, but they can coordinate alternative times if necessary.

Parents can also request an IEP meeting in writing at any time to make changes or ask questions. At the end of a meeting, parents don't have to sign the documentation if they disagree with the program. However, the school will administer the IEP regardless, unless parents file for a due process hearing to stop the process.

“Many parents, especially in the Latino community, don’t know what kids’ rights are,” said Fernandez. “And I truly feel from the bottom of my heart that Cameron is who he is today because he was included from the very first day, first of all in our family ... and then after two years of a battle, in his elementary school.”

### Students’ Rights under IDEA

Parents and students are guaranteed certain rights under:

- [IDEA](#)
- [Section 504 of the Rehabilitation Act of 1973](#)
- [Family Education and Privacy Rights Act](#)

IDEA, the central piece of legislation, was last reauthorized in 2004 and last amended in 2015. Though each state uses different methods to determine guidelines and administer programs, the federal law must be followed.

“IDEA governs a lot of regulations, and the IEP process is just one of those regulations,” said Dr. Zephine Smith-Dixon, the state director of special education services and supports at the GaDOE.

Special education laws broadly afford protections to certain rights to children with disabilities, including a free and appropriate public education; the least restrictive environment for learning; additional support and services; and assessments to determine a child’s needs. To protect the parents’ and students’ rights, IDEA includes provisions for IEPs and a due

process hearing for dispute resolution involving an administrative law judge. The provisions are the same for rural and urban areas, though location determines the availability of certain GaDOE programs and community resources.

“It’s important to not think of the IEP as a paper; it’s really a process,” said Smith-Dixon. “You have to document how that process is implemented and how it benefits kids. The IEP team is the heartbeat of that process.”

Laws surrounding special education are complex and constantly evolving. Parents’ and students’ legal rights are outlined in IDEA, but without consulting outside resources or community supports to navigate the process, many parents struggle. “Parents should not have to go through that,” Fernandez said. “It exhausted me. I got gray hairs in [those] first years.”

### Resources for Understanding IEPs

Parents new to special education often need additional resources and support to understand the IEP process and their rights. During IEP meetings, parents are not always provided all the options available to their children by the school, but the GaDOE website has a wide array of resources available online, including a [glossary of special education terms](#), [sample forms](#) and a [list of parents’ rights](#). There is also a GaDOE phone help line. Parents or guardians receive a 20-page packet of rights at the start of their first IEP meeting, but the language is legalistic and tricky to parse.

“It’s very confusing, and it doesn’t really explain, not truly, what your rights are,” said Teresa Heard, a parent advocate and GCDD council member. “Unless you’re in the educational system, it’s almost like you don’t know what they’re talking about. Information is not volunteered to you necessarily; you have to know what to ask.”

### The Role of IEPs in GNETS Referrals

By making a calculated move from Dougherty to Lee County, Heard was able to get her son Derek out of the Georgia Network for Educational and Therapeutic Supports (GNETS) system, which has been [criticized by advocates](#) for its over-enrollment of black boys with disabilities and 10% graduation rate. Derek, a 19-year-old, graduated from high school after learning in a less restrictive environment, and he’s currently in an employment-transition program.

Per the GaDOE’s website:

GNETS is a program that “is comprised of 24 programs that support the local school districts’ continuum of services for students with disabilities, ages 3-21. The programs provide comprehensive educational and therapeutic support services to students who might otherwise require residential or other more restrictive placements due to the severity of one or more of the characteristics of the disability category of emotional and behavioral disorders (EBD). GNETS programs provide an array of therapeutic and behavioral supports as well as specialized instruction for students. These supports are designed to assist

the student to progress in the general curriculum and graduate ready for work or postsecondary studies. In addition, the GNETS program provides supports to families and works collaboratively with other agencies serving students. Students are referred by their local school districts through the Individualized Education Program (IEP) process.

GNETS is currently under litigation under a lawsuit filed by the United States Department of Justice versus the State of Georgia. “It really matters how the school is telling a narrative of the student,” said Leslie Lipson, founder and principal of Lipson Advocacy. Lipson led the coalition supporting a 2015 Letter of Finding issued by the Department of Justice detailing Georgia’s violations of the American’s with Disabilities Act by funding, implementing and supporting a statewide, segregated school system for students with disabilities.

If a student is having a problem in the classroom, and becomes known as a “behavior kid,” then the focus becomes on the behavior and tactics move to compliance rather than adjustment. The “compliance” can easily mean a referral into the GNETS program, which can digress away from the goals of the IEP if parents are not informed and empowered. “There is no comprehensive approach or look at the instruction, education or academic gain for the student,” says Lipson.

## Parent Strategies for IEPs

According to Lipson, parents should use positive strategies to direct and stay on task with the student's IEP and not transition the conversation to GNETS.

Three ways include: 1) the goals in the IEP should drive placements and supports, such as inclusive settings; 2) outline the strengths students display in the community or family gatherings; 3) make their kids become involved in their community through extracurricular activities, receiving mentorship and more.

Derek, Heard's son, has leadership roles in multiple organizations, and the school has been understanding about giving him excused absences for those kinds of opportunities. That relationship has developed over time, fostering efficient collaboration among Heard, her son and his teachers.

Heard, who works at Easterseals Southern Georgia and serves on Lee County's Parent Advisory Council, likes the principal at Lee County High School. She says it hasn't been easy to develop trust and rapport with her son's educators after his first few years of school, a crucial element to effective IEP administration. But, now, that relationship has developed into a supporting Derek's leadership and involvement in the community, while staying on track with his IEP.

## Finding a Parent Advocate

In 2016, Salman Panjwani, an active and involved student in Gwinnett County, experienced a sudden brain hemorrhage and stroke. Panjwani, who is now 22, was diagnosed with arteriovenous malformation (AVM), a condition that is found in less than one percent of the population.

“We really had a hard time,” said Sakina Jaffer, Panjwani’s aunt who is like a second mother to him. “Salman was a regular student at Parkview; he was in 11th grade. When he went back to school, they took him to Special Ed, and we had to start everything from scratch.”

After the diagnosis, Panjwani’s family got him into physical therapy. Panjwani is paralyzed in his right side, but writes with his left hand now. At the family’s first IEP meeting, administrators suggested Panjwani take part in ADAPT (Assisting Developing Adults with Productive Transitions), a functional life-skills program in Gwinnett County.

Jaffer and Laila Panjwani, Salman’s mother, said no. They believed, alongside the trusted family psychologist, that Panjwani should be in classes with his peers, a less restrictive environment. The family filed for a due process hearing and got connected to Fernandez, who helped advocate for them in subsequent IEP meetings.

Sitting in on his IEP meetings, Fernandez noticed disturbing similarities between Panjwani’s experiences and those of her

own son – years apart in the same county. Both children ended up where they belonged, in the environment most conducive to their learning ... but not without a fight.

“We think it would have helped him to be in the classes he’s in now earlier,” said Jaffer. “But we didn’t know.”

Panjwani’s family considers Fernandez a blessing. She came to their home, sat and talked with them. Fernandez told the family about supports the school never had, including moderate classes with appropriate supports and the Georgia Vocational Rehabilitation Agency. She gave them options.

“Give everybody a fair chance,” said Laila, Panjwani’s mother. “See what capability they have. It’s the thought that every child is important.”

Problems persist, especially for parents who aren’t accustomed to working with disability supports, but solutions are in constant development. There have been new initiatives in recent years meant to improve the process, and according to Smith-Dixon, the ultimate focus must be on the needs of the child.

“We don’t want this to become a distraction for the parent, where it becomes more about the parent managing a system, or paper or people,” said Smith-Dixon. “We want to focus on what’s really important – coming together and engaging to meet the needs of the student.”

## Student-led or Facilitated IEPs

Student-led IEPs (SL-IEP) are one of the ways that education professionals and advocates are trying to better the process for all the parties involved. An optional procedure not guaranteed by IDEA, SL-IEPs allow students to get involved in their own IEP process from an earlier age. The IEP doesn't change in the traditional sense, and the paperwork remains the same. Students, however, are more involved. Students with a disability have to be invited to the IEP process when they're 16 years old, according to the IDEA. They don't have to attend, but the planning components of an IEP are meant to reflect the individual student's interests and desires.

“The idea is that when they leave school, they won't be so reliant on other people telling them what they need,” said Elise James, a programs specialist for transition post-school outcomes for the GaDOE. “And they'll be more attuned to what their needs are and can express that, whether they go to college or when they're working.”

Georgia's SL-IEP initiative is called ASPIRE or Active Student Participation Inspires Real Engagement. James was the state lead on the project when it was piloted in the 2010-2011 school year with funding from a State Personnel Development Grant and GCDD assistance. According to James, the program is now self-sustaining around the state, and it's growing in popularity.

“There’s no place you can go in the state and talk about student-led IEPs, and people don’t know what you’re talking about,” said James.

Students’ engagement in their own education rose in popularity nearly two decades ago, but James says the state is now in a position to begin doing research on student outcomes. This year, the GaDOE also began implementing facilitated IEPs (F-IEP) in the state. IEP facilitation is an optional process not found in the IDEA, and parents and the school must agree to try it. F-IEP incorporates a neutral third party into the IEP meeting to advocate for the student. The process is meant to be a mechanism to collaborate and prevent disputes where there has been a history of disagreement and difficult interactions.

Anne Ladd, a family engagement specialist at the GaDOE’s Division of Special Education Services and Supports, shares why she welcomes difficult interactions with parents. “My philosophy is I’d rather have an angry parent than a parent that doesn’t show up,” said Ladd. “That anger or that hostility is because they care about their kid, and they’re trying to communicate something. ”

#### [Help from Parent to Parent](#)

In addition to these GaDOE IEP initiatives, there are in-school and community resources to help parents maneuver through the process. One of the organizations widely recognized for helping parents is [Parent to Parent of Georgia](#).

Parent to Parent of Georgia is not made up of lawyers or paid advocates; the organization is a training center for parents. They provide options and information like Fernandez did for the Panjwani family. Mitzi Proffitt, the director of support services at Parent to Parent of Georgia, says they will help in any way they can.

“If there’s no service, I’m going to be the first one to say we don’t have that here,” said Proffitt. “But we will teach them how they have to learn to advocate for services, which is where [GCDD] comes in.”

Parent to Parent doesn’t advocate for families, and they cannot give legal advice. They are there to simplify and enable parents to tackle the process. Proffitt underwent a due process fight for her son Joshua that went to federal court. She notes that there is a special education director for every county, and that person is responsible for every IEP in that system. She strongly suggests parents know who their director is.

“If the school is in the wrong, and we know that, we can never tell a parent what to do,” said Proffitt. “We can only make suggestions and give you processes. We will explain on the DOE website how you file a complaint. We will explain due process. But trust me, you’ll know when something’s not right.”

### Parent Mentor Partnerships

The [Georgia Parent Mentor Partnership](#) (PMP) is an in-school resource from the GaDOE that partners parents with other

parents who have shared similar experiences. The PMP is a voluntary process that districts can choose to participate in. Ladd works on the PMP, and she says there are about 80 districts throughout the state with mentors. There is a clear benefit to parents helping other parents work through the process.

“When you’ve been through a lot, you think, ‘Gosh, I’ve gone through all of this.’ I want to make someone else’s journey easier,” said Ladd.

The support PMP offers is dependent on location and available mentors. In smaller districts, mentors are able to attend individual IEP meetings, and in large districts, mentors are more likely to conduct training sessions and offer pre-meeting support. Like other resources and programs, the PMP is meant to make the process simpler and easier for struggling parents.

“Your emotions are high, and it’s your very special person,” Ladd said. “It’s daunting, and so we want to have had that experience. When we’re working with families, we have that empathy, and we have that shared, lived experience.”

The shared experience is vital to making a connection and materially improving outcomes. “As professionals we have to say, OK, this is not about me. This is about them, and their circumstances, and their kid, and we need to take that seriously,” said Ladd.

As a family engagement specialist and parent herself, Ladd says that when families get involved, things only get better for the student. [Research](#) shows that when families are engaged, students achieve more – higher test scores, better attendance and improved behavior – regardless of socioeconomic status, race or ethnic background and the parents’ level of education.

“What parent mentors are doing is helping districts understand how to be welcoming, how to grow leaders, and how to engage families so that they’re actively participating and contributing,” said Ladd.

### Still Progress to be Made

For Heard, who has been engaging with the IEP system for years, there is still progress to be made in terms of in-school supports.

“I wish there was more carryover into the school itself, instead of seeking it out outside,” said Heard. “GCDD funds a lot of programs that help with self-advocacy and leadership, so my son accesses these leadership opportunities outside the school system.”

In other words, if students had more opportunities to learn about leadership and advocacy with in-school supports, they may be better prepared to participate in their IEP processes and know how to advocate for what they need.

A full education and ample leadership opportunities allow young people to grow into their own. For four years, Panjwani was the manager of the Parkview track team, and he was involved with his mosque and various volunteering programs. Jennifer Newton, Panjwani's favorite teacher at Parkview High School, was going to appoint Panjwani the leader of SAVE SADD, or Students Against Destructive Decisions. He wasn't able to take the position after his brain hemorrhage, but now Panjwani is able to graduate this May with his peers thanks to the advocacy of Fernandez and his family. He hopes to attend Georgia Gwinnett College and become a psychologist.

"All children should be treated equally," said Laila, Panjwani's mother. "All children should be given the benefit that they are capable of education, that they have the right to learn. Give them the opportunity. They can shine, and they can have a better future."

## **FOCUS ON THE POSITIVE**

1. Goals in the IEP should drive placements and supports, such as inclusive settings.
2. Outline the strengths students display in the community or family gatherings.
3. Involve kids in their community through extracurricular activities, mentorships and more.

## **LEARN THE LINGO**

IDEA – The Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children.

GNETS – Georgia Network for Educational and Therapeutic Supports (GNETS) is comprised of 24 programs which support the local school systems' services for students with disabilities, ages five to 21. The programs provide comprehensive educational and therapeutic support to students with emotional and behavioral disorders (EBD).

IEP – Individualized Educational Program (IEP) is a written plan for each student with a disability developed by a team of professionals (teachers, therapists, psychologist, etc.) and the student's parents. IEPs are based on a multidisciplinary evaluation, describe the student's current level of academic achievement and how the student's disability affects involvement and progress in the general education curriculum.

F-IEP– Facilitated IEPs (F-IEP) incorporate a neutral third party into the IEP meeting to advocate for the student.

SL-IEP – Student-led IEPs (SL-IEP) allow students to get involved in their own IEP process from an earlier age.

P2P– Parent to Parent of Georgia offers a variety of services to Georgia families impacted by disabilities or special healthcare needs.

PMP– Georgia Parent Mentor Partnership (PMP) is an in-school resource from the GaDOE that partners parents with other parents who have shared similar experiences.

### **What to Do before the IEP Meeting: Use the power of Data!**

- Request a copy of evaluation results and new assessments.
- Call school psychologists before the meeting with questions to save time and give you the information you need.
- Bring information from private professionals that work with your child – tutor, occupational therapist, psychologists, etc.
- Be prepared and organized – have priorities organized and numbered. [Consider preparing an IEP binder.](#)
- Talk about strengths and weaknesses – shore up strengths to find the best approach for the child.
- Bring a video, written statement or photo of the student (or bring the student) so their voice is present. This allows your student to be involved in their IEP in all stages of the education.
- Write down a list of IEP goals for your student.
- When was the last time things went well and what did it look like?
- Ask for explanations, even if you know the answers. Drill down.

- Invite someone (advocate, relative or friend for moral support) and/or record the meeting so you remember what was discussed.

This feature is Part 1 of GCDD's Education Series to help families and students learn about their education rights and navigate the IEP process for a successful school experience. Part 2 will be released in July and will cover transitioning from high school into college or employment.

## WHAT'S HAPPENING IN WASHINGTON?

### Federal Disability Policy Updates

By Alison Barkoff and Erin Shea, Center for Public Representation

### COVID-19 Response:

**Congressional Response:** Congress has already passed three bills in response to the COVID-19 outbreak. The first was an emergency funding bill. The second bill, Families First Coronavirus Response Act ([H.R. 6201](#)), was an important first step in responding to the needs of people with disabilities. It included increased funding for states' Medicaid programs and federal nutrition assistance programs and provided emergency paid leave and free coronavirus testing.

The latest response bill, Coronavirus Aid, Relief and Economic Security (CARES) Act ([H.R. 748](#)) included some of the disability community's [priorities](#) as well. It ensured that direct cash

assistance to people during the crisis is available to all people (including people on SSI and SSDI) and won't count against means tested programs like Medicaid; and provided additional funding for education, housing, nutrition, Centers for Independent Living (CILs) and some aging programs.

However, many of our priorities were not included, such as additional grant funding for the home and community-based services (HCBS) on which many people with disabilities rely; paid leave for all caregivers; recognition of direct care workers as essential personnel; and additional funding for Medicaid, Social Security, and SSI. We are advocating for these priorities to be included in the next round of coronavirus relief legislation, which Congress has already begun developing.

**Medical Rationing Guidance:** We have seen increasing concern about disability discrimination in medical treatment during the coronavirus pandemic, particularly when it comes to accessing treatment and the quality of treatment provided. In response to extensive advocacy, including [complaints](#) filed by the Center for Public Representation (CPR) and partners, the US Health and Human Services Office of Civil Rights (HHS OCR) issued [guidance](#) on March 28 affirming that federal disability rights laws apply to decisions about access to care during the coronavirus pandemic. CPR and other national advocates have issued this document to assist state advocates working on this issue, and we are working hard to ensure the rights of people with disabilities are not violated when they seek treatment for COVID-19.

Updates on Medicaid Policies with Impacts for Georgia:

**Block Grant Guidance:** On January 30, the Centers for Medicare and Medicaid Services (CMS) announced new [guidance](#) that gives states the option to fund their Medicaid programs using block grants or per capita caps for certain populations through Section 1115 waivers. Block grants and per capita caps both provide states with a set amount of money, rather than funding for the actual cost of services provided, as Medicaid normally does. This pressures states to cut benefits, eligibility or both if they spend more than the set amount.

People with disabilities will be impacted by this new policy. Even though people who qualify for Medicaid on the basis of disability (for example, because they qualify for Social Security Disability Insurance) are not among the groups that the new policy can apply to, many people with disabilities on Medicaid are eligible for other reasons and are among the groups targeted by the guidance. Also, if these funding caps cause shortfalls in states' Medicaid budgets, all Medicaid participants could see their services cut.

Georgia has expressed interest in submitting an 1115 waiver under this new guidance. Georgia Council on Developmental Disabilities (GCDD) and CPR have created a [fact sheet](#) to help Georgians understand the potential impact. We will monitor those efforts and continue to keep you updated.

**Medicaid Work Requirements in Georgia:** On February 7, GCDD and CPR [submitted](#) joint comments opposing Georgia's application to CMS seeking an 1115 waiver to allow the state to, among other things, impose work requirements as a condition of expanding Medicaid. Work requirements have been shown to cause people to lose their healthcare. Georgia's work requirements proposal is particularly harmful because it does not even attempt to exempt from work requirements people with disabilities or their caregivers as other states have done (although even with exemptions, people with disabilities can still be impacted). It is likely that if Georgia's application is approved, it will be challenged in court, as other work requirements have been. We will keep you updated as CMS considers Georgia's application.

**HCBS Settings Rule:** As we've written about in this column before, Georgia is in the process of implementing their statewide transition plan to comply with the Medicaid Home and Community Based Services (HCBS) Settings Rule. The rule ensures that all people receiving HCBS have the full benefits of community living, including access to the broader community, opportunities for competitive, integrated employment and control over their daily lives. States have until March 2022 to fully implement the rule. In February of this year, Georgia put out for a 30-day public comment its final plan for complying. GCDD and partner organizations submitted comments raising concerns about the plan. Georgia will have to respond to those comments before it submits the plan to CMS for approval. We

will keep you updated as Georgia finalizes, and CMS considers the plan.

#### Litigation Updates:

**Affordable Care Act Lawsuit:** On March 2, the Supreme Court [agreed](#) to review the [lawsuit challenging the Affordable Care Act](#) (ACA). The lawsuit was brought by a group of states challenging the constitutionality of the ACA's individual mandate and argues that the entire ACA, including its protections for people with pre-existing conditions, should be struck down. A decision is not expected until next year because the court declined to expedite its review and hear the case this term. As we've noted previously, the ACA remains fully in place while the lawsuit is ongoing.

**Public Charge Litigation:** Disability and immigration advocates across the country continue to fight to overturn the federal government's new public charge rule. The rule prohibits people who use or might use public benefits (now including Medicaid HCBS) from getting a visa or green card, which disability advocates argue is illegal disability discrimination.

While advocates had initially succeeded in stopping the new rule while the lawsuits move forward, on January 27, the Supreme Court issued an [order](#) allowing the rule to go into effect while the litigation continues and on February 24, it went [into effect](#) nationwide. It is vital that people understand what it does and does not mean, and we encourage everyone to check

out our updated [fact sheet](#) and [explainer](#) to make sure they understand the rule.

Thankfully, in response to COVID-19, US Citizenship and Immigration Services (USCIS) [announced](#) last month that it “will neither consider testing, treatment, nor preventative care (including vaccines, if a vaccine becomes available) related to COVID-19” in making public charge determinations even if it’s paid for by federally-funded programs, like Medicaid. This means that immigrants can receive treatment without an impact on their immigration status.

**GAO v. Georgia (GNETS):** On March 19, a federal judge [denied](#) a motion to dismiss the lawsuit filed by the Georgia Advocacy Office, CPR, The Arc Georgia and other partners, that claims Georgia is illegally segregating students with disabilities in the Georgia Network for Educational and Therapeutic Supports Program (GNETS) in violation of the Americans with Disabilities Act, Olmstead and the US Constitution. The judge decided the plaintiffs had stated a claim for violations of federal law and that the case can now move forward. We’ll keep you updated as this case proceeds.

[Other Medicaid Updates:](#)

**Money Follows the Person (MFP):** As we noted in our last column, a bipartisan drug pricing agreement was [announced](#) in December that would use cost savings to fund a permanent reauthorization of the [Money Follows the Person](#) (MFP)

program, which helps people with disabilities and older adults move out of institutions and into the community.

MFP was ultimately only given a short-term extension in the budget Congress passed, which was intended to create pressure to pass a larger healthcare package, including prescription drug reforms, before their Memorial Day recess. However, because of the unexpected need for Congress to focus its energies this spring on responding to the coronavirus pandemic, MFP received another short term extension until November 30 in the CARES Act, which we discussed earlier. We will need your help later this year to help push for permanent funding for this important program.

**HCBS Infrastructure Improvement Act:** Disability and aging advocates have been working for over a year developing this new legislation, which we discussed briefly in our last column. It would provide additional funding to states to build up the infrastructure of their Medicaid-funded HCBS systems. On February 12, Senator Bob Casey (D-PA) [introduced](#) the Senate version of the bill ([S. 3277](#)), and we expect the House version, which will be bipartisan, to be introduced shortly. [Sen. Casey's office released a brief fact sheet on the Senate version](#) of the bill. [Find more information on that bill and the House version when it's released, along with other resources and media.](#)

These updates represent only a small portion of what we're working on. For more on our work, visit our [website](#) and connect with us on [Facebook](#) and [Twitter](#).

Alison Barkoff and Erin Shea work on policy and litigation related to community integration and inclusion of people with disabilities, including Olmstead enforcement, Medicaid policy, employment, housing and education.

Note: information current as of 4/8/20

#### Get More Information About:

- [CARES Act \(what was and was not included\)](#)
- [COVID-19, the Federal response & issues related to disability discrimination](#)
- [Block Grant Guidance](#)
- [GCDD-CPR fact sheet on 1115 Waiver](#)
- [Medicaid Work Requirements in Georgia](#)
- [HCBS Settings Rule](#)
- [Affordable Care Act litigation and what it means for people with disabilities](#)
- [Public Charge Rule and the litigation challenging it](#)
- [GAO v. Georgia \(GNETS\) Case](#)
- [Money Follows the Person](#)

#### GCDD IMPACT

##### Council Kicks Off Five Year Strategic Planning Process

This spring, the Georgia Council on Developmental Disabilities (GCDD) will kick off planning for its next Five Year Strategic Plan

that will lay the framework for the Council's work from 2022-2026.

The Five Year Strategic Plan determines how the Council will allocate funding to create systems change for individuals with developmental disabilities and family members through advocacy and capacity building activities.

"All GCDD efforts aim to ensure that people with disabilities are independent and interdependent, have greater economic self-sufficiency, are integrated and included in their respective communities and self-determined in their lives," said GCDD Executive Director Eric Jacobson.

The Council will reach out across the state to hear what people with developmental disabilities, families, caregivers and other stakeholders have to say about the issues most important to them when it comes to services and supports. GCDD will initiate this work with an online survey and statewide forums, and details of each will be announced soon.

"The Five Year Strategic Plan is the foundation of how the Council does its work across the state," said Jacobson. "We need to hear from individuals with disabilities, family members, caregivers, siblings and the community-at-large about what issues are important to them. This feedback will set the course of what the Council has to work on for the next five years."

Currently, the Council is working off the [2017-2021](#) plan that focuses on five goals: Education, Employment, Formal and Informal Supports, Real Communities and Self-Advocacy.

Driven by the plan, various projects emerged and were expanded by GCDD in partnership with organizations across the state. Through a grant from GCDD, [Sangha Unity Network](#) (SUN) is working to promote, create and sustain an advocacy movement for individuals with developmental and/or intellectual disabilities. With University of Georgia's Institute on Human Development and Disability, GCDD launched [Advancing Employment](#) to improve employment supports and outcomes for individuals with disabilities who want to work through a technical assistance center that supports Provider Transformation. Additionally, the [Supported Decision-Making](#) partnership seeks to lay the foundation for widespread adoption of supported decision-making as an alternative to guardianship in Georgia, among so many more.

“The strategic plan is the driver for the Council. We do our jobs by putting into action ideas that create [community impact](#) and ultimately change systems in ways that ensure the disability community has access to meaningful lives of their choice,” added Jacobson.

Learn more about [GCDD's Impact](#) in the state of Georgia.

[Sign up for our mailing list](#) to learn more about the next steps of the plan.

## REAL COMMUNITIES

### Real Communities Celebrates 10 Year Anniversary

by Jennifer Bosk

Ten years ago, the Georgia Council on Developmental Disabilities' (GCDD) Real Communities Partnerships began with a goal to partner with local groups that worked to support communities who welcomed all to the table and recognized and utilized everyone's gifts and skills.

Real Communities was focused to partner with local groups working to build more than just communities. "It was an intentional approach to improving communities by involving people with and without disabilities at the local, grassroots level to work together toward common goals to improve their community using person-centered supports, community-centered connections and persistent and reflective learning," said Eric Jacobson, executive director of GCDD.

Projects such as the [Mixed Greens Community Builders at the Forsyth Farmers Market](#) in Savannah, GA; or the [Open Studio for All](#) in Moultrie, GA; or the [Peacebuilders Camp at Koinonia Farm](#) in Americus, GA, have earned this project national acclaim by the [American Association on Intellectual and Developmental Disabilities](#) and the [National Association for the Advancement of Colored People](#).

Ten years later, the impact of this effort has expanded statewide and has developed into an additional initiative,

Welcoming Community Dialogue (WCD) groups – gatherings of community members representing many ethnicities, abilities and skills, who discuss and work towards a community that offers dignity and justice for all.

With five Georgia WCDs already up and running in Athens, Augusta, Comer, Fort Gaines and LaGrange, the initiative recently awarded grants to an additional four communities to expand this impact (see sidebar below).

When looking back over the 10 years of Real Community Partnerships, Project Organizing Director Sumaya Karimi celebrates the sustainability of the program, the investment by GCDD and how the initiative has scaled through the increase in the number of groups and communities participating throughout the state of Georgia.

Karimi is the founder and director of Global Ubuntu of Lilburn, GA, which provides oversight for this initiative by providing administrative and financial support, technical assistance, training and coaching.

Another of the initiative's successes was last fall's Welcoming Community Dialogue Summit held in Clarkston, GA, with 90 attendees. Karimi says Global Ubuntu is planning its next Welcoming Community Dialogue Summit on September 26, 2020 in Atlanta, GA, and expects a powerhouse of ideas and plans to result from the day.

“WCD groups give me a sense of hope and purpose in life knowing there are people who care about everyone and believe in the inherent dignity and equality of all human beings. I am hoping that together we create a movement for an equitable and just society. I understand it’s a long-term dream and commitment and we have no choice but to be committed if we want our kids and community to thrive in a healthy and peaceful environment,” explains Karimi.

Sidebar:

### New Welcoming Communities

- **Filling the GAPS, LLC in Augusta, GA**, plans to host two annual dialogues. Each dialogue will include a component that focuses on the need for mental health awareness in the African American community. The dialogue approach will be from the viewpoint of mental wellness as opposed to mental illness.
- **Abilities Discovered, Inc. in Warner Robins, GA**, notes that being willing to share time and space with people in order to find commonalities and to share ideas about how to make their neighborhood a more welcoming place for all people is vital. The community issues include transportation, lack of affordable housing, homelessness, as well as how religious groups relate to people with disabilities, those with socio-economic differences and people with varying lifestyles.

- **Diversified Enterprises in Tifton, GA**, will open dialogue with community leaders and individuals with affordable housing concerns to increase awareness, develop relationships and facilitate progress toward solutions in providing spaces for all community members to live and grow together. This group imagines the City of Tifton, as well as Tift County, where people from all walks and wheels of life ask, “How can we create affordable and accessible housing?”
- **Art, Music, Purpose (AMP) located in Rome, GA**, will bring individuals together to discuss social issues and get to know each other on a more authentic level than in traditional meetings. The plan is as people get to know each other through conversations in a safe, open and creative space, mutual understanding and empathetic connections will increase, trust will grow and individuals will realize that they have much more in common than what divides them.

For more details about this initiative and the Welcoming Communities Dialogue, please visit [GCDD's Real Communities website page](#) or [Global Ubuntu's website](#).

GCDD IMPACT

The Arc Georgia Celebrates the Completion of the Tomorrow's Leaders Pilot Program

By Clay Voytek

It's almost spring, and Martha Haythorn is trying to decide where to go to school. She's already been accepted to Georgia Tech, but she's waiting to hear back from Clemson University before making her decision.

"I am graduating and going to college," said Haythorn, a 20-year-old from Decatur. "I hope that everyone with a disability has the chance to do what I'm about to do."

On February 18, five young self-advocates came together from across the state to celebrate the culmination of Tomorrow's Leaders, a nine-month leadership development program for young people with disabilities organized by The Arc Georgia. At the top floor of the historic Hurt Building in downtown Atlanta, the leaders were joined by family, mentors and other advocates for the completion of the program's pilot run.

Haythorn was joined by Hannah Hibben, Ryan Lee, Otis Maffett and Ben Oxley to form the diverse first class. They applied to Tomorrow's Leaders last year and engaged with coaches and mentors for the duration to develop leadership, communication and advocacy skills.

"The intention of a mentor was to communicate and share your ideas with someone who didn't have a disability and was in the area of your interest," said Stacey Ramirez, the state director of The Arc Georgia. "So, we start to expand the abilities of people with disabilities outside the circle."

The program was run by Ramirez and funded largely through a grant from the Georgia Council on Developmental Disabilities (GCDD). The program also received funding from the American Association on Individuals with Developmental Disabilities (AAIDD). “Being a part of Tomorrow’s Leaders, I started sharing my gifts and talent with others,” said Maffett. “I didn’t force people or try to change them; I let my talent speak for itself.”

Tomorrow’s Leaders is the brainchild of Dawn Alford, the public policy director for GCDD who passed away last year. Participants remembered and thanked Alford throughout the event, and the leaders gave Eric Jacobson, the executive director of GCDD, a framed photograph of the group to say thank you.

“You have to know that Dawn is looking down upon all of us as we’re doing this because this was her dream – this was what she wanted,” Jacobson said. “Her desire to see young people with disabilities take over her job when you get to that place... that’s what she was inspired by, so I think this is a perfect tribute to her.”

Aged 20 to 32, the leaders are as unique and varied as the wider community of people with disabilities. In practice, Tomorrow’s Leaders was individualized for each participant. Haythorn works as a policy intern for The Arc Georgia, and Ramirez was her mentor throughout the process.

Maffett writes poetry to keep his mind occupied, and he performed a song he wrote during the event with beautiful vibrato. Lee works at a pizzeria in Alpharetta, but he's looking for a data-entry job. Hibben likes wrestling and tennis, and she gave a speech to the crowd at the event. Oxley has a sleeve of tattoos and recently took part in a documentary film. He brought his friend Jeremy Williams to the event, a musician and artist who spoke on representation in the media.

During the event, the five participants presented what they had learned through the program and took questions from the audience. Through Tomorrow's Leaders, they all grew as individuals and further developed their skillsets as advocates. "No one can tell you how to feel or what to feel. We can't turn our emotions off," Lee told Maffett after his presentation at the event.

"People treat us, as people with autism, like we don't have feelings," said Lee, who has written editorials for The Aspergian and Autism Speaks. "Just because you can't see something doesn't mean it's not there."

Before the celebration began, Maffett, Haythorn and Lee sat around a table and discussed prompts from conversation starter cards. One asked, "What would you do if you won the lottery?" Haythorn said she would go to Washington and offer to pay for Medicaid. Maffett said he would buy his mom a new house and cars for his brothers. Lee said he wouldn't tell anyone because that's the smart way to do it.

Tomorrow's Leaders enabled this group of young people to develop important skills, but it also allowed them to come together and connect with each other.

"GCDD supports people with disabilities to be true leaders," said Ramirez. "The intent was to have people with intellectual and developmental disabilities stand tall and be recognized as true leaders in their communities, and I really appreciate that." Through a partnership with GCDD, The Arc Georgia is continuing Alford's vision to go deeper in developing critical skills for young people with disabilities.

GCDD has approved funds for The Arc Georgia to implement a second year of Tomorrow's Leaders after the progress made by the first year's cohort.

The second year will continue with the original cohort, where they will build upon the skills they gained during year one by planning and implementing an inclusive community project.

"The hardest part is to help us be able to have this advocacy," said Haythorn. "I know it can be hard sometimes, but I'm telling you, when we do this, we are showing an impact in the world. We're here, we're alive and we're ready to show everybody that we are more than a disability."

[The Arc Georgia](#) supports people with intellectual and developmental disabilities (I/DD) over the arc of their lifetime.

## GCDD STORY COLLECTION

### Telling Our Stories

[GCDD's Storytelling Project](#) paints a picture of the complex systems of support that enable people with developmental disabilities to live their best lives.

Spanning Georgia's 56 state senate districts, these stories feature at least one individual who resides in each district – allowing this project to become a vehicle of advocacy for Georgians living with disabilities.

The stories highlight racial disparities, socioeconomic inequities and how a situation can play out in two different circumstances – one where people are or are not supported by the system.

### Podcast Series

The GCDD Storytelling Project has created a seven-episode podcast, called [Hidden Voices](#), spotlighting the stories of people with developmental disabilities.

The podcast explores issues that impact their lives such as Medicaid waivers, employment, housing, transportation, advocacy, adaptive technology and service animals.

Find GCDD's Hidden Voices on all streaming platforms, listen [via this Megaphone show page](#) or [use the player on our web page](#).

## Our Happy Place

by Shannon Turner, Photographer Haylee Fucini-Lenkey

Once or twice a week in the summer, Jack Clark's family loads up a couple of bags with ice water, pretzels and watermelon and heads down to the Little River Marine Center to hop on a boat rental and reconnect with their inner happy place on Lake Allatoona.

Jack is a 13-year-old boy with cerebral palsy and an intellectual disability. Because of his age, Jack only receives the Katie Beckett Waiver. But his mom, Chris, says that she plans to start the Medicaid waiver application this summer because the waiting list is so long.

She doesn't want him to have a gap in services when he "ages out" at 18.

The Katie Beckett Waiver pays for speech, occupational and physical therapy – but not music therapy, which is something Jack adores and would love to do. For several years, they were able to pay for orthotics that Jack needed out-of-pocket. The biggest thing that they do not currently receive, which Chris would very much look forward to with a waiver, is respite care.

Jack is getting to an age where, in other circumstances, he could possibly be left alone, but not in this case. Taking care of Jack can take a lot of time and energy, especially since Chris is also managing coursework as she continues her education.

After she graduates Chris would like to get back to work – something that would be difficult without respite care.

If a legislator came to talk to Jack, he would tell them, “I want to go to college. I want to live with friends. Play football. Work for Delta Airlines.” Chris says the first thing she would do is to learn more about that legislator’s understanding of or interaction with people with disabilities. She neither wants to talk down to them nor miss the opportunity to educate them about her family and perspective. She would tell them what Medicaid reform really means and where that money is going to come from. “I don’t think people have any clue how much more expensive it is or what would happen if they stopped supporting people with disabilities out in the communities and forced them back into institutions.”

What does she want for Jack’s life?

“I want more inclusive opportunities for Jack – for where he could live, for where he could work, for his future. I want him to be happy and challenged. If he wants to go to some college program, I’d truly welcome that, but we’d have to look for scholarship programs.”

Chris was in sales and marketing for many years, but adopting Jack has led her down a new path. After he exhibited signs of his cerebral palsy as a baby, they got into the Babies Can’t Wait program and had caseworkers. “They did okay, and had a little

checklist they went down. But they didn't do a good job of explaining what the program really is and how to navigate it. I had run sales for a \$20 million company, but I couldn't figure out all this involved."

Inspired by – or perhaps driven by – her family's experiences, she's due to graduate with a masters in social work next academic year.

Jack's father, Tim, a project manager in healthcare IT, has finished his last work call for the day. Since he's the family's assigned boat driver, his arrival means it's time to go out onto the open water.

After idling slowly past the buoys, he puts it into full throttle and cranks up some country music. Jack, who's been a bit sullen, immediately starts to smile and eases into a laid-back position on the boat's prow. He mimics a DJ spinning records and then settles back down and lets out a giant sigh. The family looks for a cove to jump into water and swim.

When they find their spot, Jack giggles with great delight, asking everyone to convince him to jump.

He's clearly found his happy place.

EXPERT UPDATE

## The Direct Support Professional Workforce Crisis

by Carol Britton Laws, PhD, MSW, FAAIDD

One of the most concerning issues affecting people with developmental disabilities, their families and communities right now is the state of the direct support professional (DSP) workforce, commonly called “the DSP crisis.” The Georgia Council on Developmental Disabilities (GCDD) is committed to providing solutions for the problems that most impact these communities.

To that end, GCDD contracted with expert Dr. Carol Britton Laws of the Institute on Human Development & Disability (IHDD) at the University of Georgia (UGA) to investigate and advise us on the state of the DSP crisis in Georgia and across the country.

Dr. Laws wrote a white paper titled [The Direct Support Professional Workforce Crisis: Challenges, State Approaches, and Opportunities for Georgia](#), that outlines the crisis and the approach Georgia and other states are taking to serve the disability community.

An excerpt from her white paper:

There is a growing demand for DSPs to support citizens with disabilities in home and community settings. DSPs are staff who are employed to provide a wide range of support services to individuals with intellectual or developmental disabilities (I/DD)

on a day-to-day basis, including habilitation, health needs, personal care, employment, transportation, recreation, housekeeping and other home management supports, so that these individuals can live and work in their communities and lead self-directed, community and social lives.

The direct support workforce is one of the fastest growing in America due to population growth, the increased life expectancy among persons with disabilities, the aging of family caregivers, and the mandated movement from institutional to community-based services.

This demand is outpacing the supply of available workers. Vacancy rates and voluntary turnover is high. Low wages and limited benefits, minimal training, ineffective supervision, and few opportunities for career growth, combined with the growing complexity of work, are barriers to creating a stable workforce. The crisis of care in home and community-based service settings is of high concern in Georgia. The annual turnover rate of direct support professionals is 45%. Only 64% of staff stays in their positions for more than one year. The average hourly wage is \$10.30 (below the national average of \$11.76 and far below the living wage for Georgia for one adult and one child of \$22.52). Only 16.3% receive any kind of paid time off, and health insurance is only offered to 43.9%.

The DSP crisis is extremely costly to the service system and to the individuals who need assistance. The DSP crisis puts people with I/DD who need assistance at great risk of harm,

contributes to unreasonably long waiting lists for services, and is leading many people to reconsider more expensive institutional models of segregated care outside their home.

Read [Dr. Law's white paper](#) and learn about the solutions Georgia and other states hope to implement.

**Dr. Carol Britton Laws, Associate Clinical Professor in Disability Studies, IHDD/UCEDD, College of Family and Consumer Sciences, UGA** coordinates the disability studies certificate program at the undergraduate and graduate levels. She also directs Destination Dawgs, UGA's first inclusive post-secondary education program for youth with I/DD.

Through the Living Well Georgia project, Dr. Laws leads efforts to enhance quality in home and community-based services and supports for adults with disabilities. She has worked in the disability field, in roles that range from direct support professional to state-level program design, for almost 20 years. She lives in Athens, GA with her husband, Jason. Visit Dr. Laws' webpage for additional information.

[COVID-19 Resources](#)

[COVID-19 Weekly Community Call](#)

Join us for an online session to share your thoughts about COVID-19 and connect with others in the Georgia disability community.

Tuesdays beginning April 7th | 3:00 PM - 4:30 PM | [Register today!](#)

The Georgia Developmental Disabilities Network, of which GCDD is a member, and its partnering organizations launched a weekly community call to address issues and concerns related to COVID-19. The goal of these weekly forums is to receive and provide guidance and resources to the people we support across the state. Together we can tune into a clear signal of facts and resources that stands out from the overwhelming noise of social media, email and 24-hour news outlets.

What we hope to accomplish:

- Provide a listening session to hear feedback on needs and wants regarding COVID-19 info and specific resources
- Crowdfund existing resources to share via a clearinghouse page
- Collect ideas and gauge where to focus our collective energy on new resources or advocacy efforts

Who can participate?

- People with disabilities and their family members
- Service providers
- Policymakers
- State and Federal human and social services agency leaders
- Media professionals and journalists

### Zoom meeting details:

Tuesdays from 3:00 PM - 4:30 PM

Register in advance for each meeting.

After registering, you will receive a confirmation email containing information about joining the meeting.

A maximum of 300 people can participate and registration is required. ASL/CART services are provided for all sessions. All sessions will be recorded and available for viewing on the following day.

[COVID-19 Resources on gcdd.org](#)

As a trusted resource for Georgians with developmental disabilities and their families, Georgia Council on Developmental Disabilities (GCDD) aims to continue educating and informing our community about available resources and information on the COVID-19 pandemic.

GCDD created a resources page on its website that includes regional, statewide, national and international information regarding the outbreak of COVID-19 from trusted sources in one central location. As more verified resources become available, they will be added to this list. For the most current national information contact the [Centers for Disease Control](#).

Visit GCDD's COVID-19 Resources for information from:

- Georgia-based agencies and organizations
- Federal resources
- Global organizations

- Community organizations

Our Community Calendar will return once the country has recovered from the coronavirus. In the meantime, follow protective measures and stay safe.