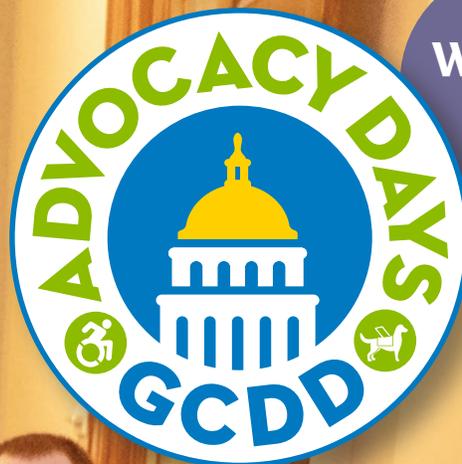


Making a Difference

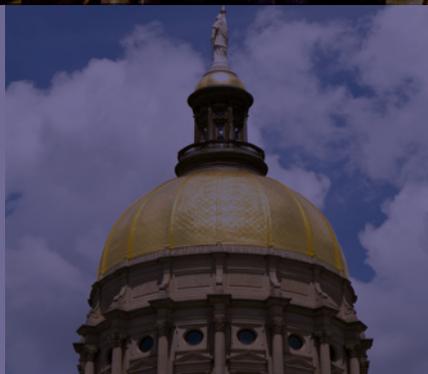


WINTER
2020



2020
ADVOCACY DAYS
ARE HERE!

gcdd.org



2020 Legislative
Preview - Getting
Ready to Advocate

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.

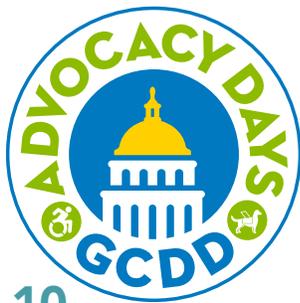
FEATURES



PUBLIC POLICY FOR THE PEOPLE 2020 Legislative Preview

by Alyssa Lee, PsyD

Georgia is about to kick off the 2020 legislative session! With it, GCDD welcomes a new public policy team – Dr. Alyssa Lee and Charlie Miller. Join us as we educate legislators about our legislative priorities and get involved in our advocacy network.



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2020 Advocacy Days are Here!

Join GCDD at the Georgia State Capitol in downtown Atlanta during the 2020 legislative session to learn about policies affecting people with disabilities, and join advocates from across the state in speaking with elected officials about these very important issues.



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The Fight for Gracie's Law

by Jennifer Bosk

Gracie's Law, written to avoid any organ transplant discrimination against people with disabilities in Georgia, will be introduced to the Georgia legislature in January 2020. While the Americans with Disabilities Act (ADA) denies discrimination based on any disability, there is still a lack of federal enforcement. Learn more about why GCDD will be advocating for Gracie's Law during its 2020 Advocacy Days.

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Making a Difference magazine is available online at gcdd.org in: English, Spanish, audio and large print. Previous issues are archived on the website as well.

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On the cover: GCDD gets ready to roll out 2020 Advocacy Days to teach advocates to speak to legislators about issues important to people with disabilities. Pictured are last year's attendees from Kennesaw State University's inclusive college program.



WELCOMING IN THE NEW YEAR

Hello, 2020! It seems like it was only yesterday when we were concerned about what would happen to our computers when the clock struck midnight of a new millennium in the year 2000.

As the Georgia Council on Developmental Disabilities (GCDD) moves into a new decade, we reflect on a dynamic end to 2019. In November, former Assistant Secretary of the Office of Special Education and Rehabilitation Services and international disability rights activist, Judy Heumann, visited Georgia to present at several forums. She spoke about where we have been, where we are and where we need to go. Her time here culminated with a discussion at the Georgia Disability History Symposium on the role of education in preparing students with disabilities for adulthood, college and career. Secretary Heumann's message was that each of us has value, that we must work together and that we should focus on the rights of people with disabilities to have a meaningful life in the community – just like all Americans.

Looking ahead, we are fortunate to experience new growth with the addition of two bright new public policy stars, Dr. Alyssa Lee and Charlie Miller. Already, Alyssa and Charlie are helping GCDD envision a public policy effort that examines issues that impact all Georgians, including legislation on

health, housing and transportation. They are also encouraging us to consider which parts of those pieces of legislation will support the independence, productivity and inclusion of people with disabilities. With their vision in mind, we look forward to the next level in advocacy and public policy.

As always, the winter edition of *Making a Difference* is dedicated to the 40-day legislative session that begins this month. Those 40 days are your chance to come to the Capitol and meet with your elected officials. It is a time to tell your story about what it takes to live a meaningful life. **My challenge to you is to join GCDD and your friends at one of five Advocacy Days, happening through March.**

For our part, GCDD will monitor legislative and budget issues that affect people with disabilities. Specifically, we will follow the progress of House Bill 511 that supports new transportation options in Georgia. We want to make sure that transportation is for all people, including those with disabilities. GCDD will also support the passage of Gracie's Law, a bill to end discrimination against people with disabilities who need an organ transplant. In



Eric E. Jacobson

addition, earlier this year, Governor Kemp asked most state agencies to reduce their budgets in order to prepare for slower economic growth and to fund his priorities, especially around education. We need to know how this impacts those waiting for services, as well as how it affects funding for inclusive post-secondary education. GCDD will monitor these issues and more with a pledge to keep you informed of what takes place.

MY CHALLENGE TO YOU IS TO JOIN GCDD AND YOUR FRIENDS AT ONE OF FIVE ADVOCACY DAYS, HAPPENING THROUGH MARCH.



Check out 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.

Eric E. Jacobson

Eric E. Jacobson
Executive Director, GCDD

ATHENS
● ●
DECATUR

Heumann Speaks with Disability Activists, Researchers & Students in Georgia

by H. M. Cauley

Judy Heumann is no stranger to the disability community. A rockstar in her own right, the disability advocate has led some of the nation's biggest conversations and movements for disability rights.

During a four-day visit to Georgia, Heumann shared her experiences and story as a disabilities and civil rights activist that spans more than 50 years. She was the keynote and lecturer at the Georgia Disability History Symposium and gave a guest lecture at the University of Georgia (UGA); and headlined an event in Decatur which brought together advocates and friends from across the state.

Now 72, Heumann was diagnosed with polio as a toddler. She recounted her own journey that began in New York, where her dream of becoming a city schoolteacher was short-lived because officials determined, since she uses a wheelchair, Heumann was a 'fire hazard' who couldn't assist students in case of emergency.

She went on to establish Disabled in Action, a Brooklyn-based advocacy organization, and to earn a master's in public health at University of California, Berkeley, where she helped set up one of the first centers for independent living in the country. Her journey led to jobs in the Senate on the staff of the Committee on Labor and Public Welfare and international positions that offered insight on how other countries address the concerns of citizens with disabilities.

At UGA, Heumann spoke with students in the class of Carol Britton Laws, PhD, on childhood and adolescent disability issues; and participated in the fifth annual Georgia Disability History Symposium.

Laws works for UGA, which is a University Center for Excellence in Developmental Disabilities (UCEDD) and directs its inclusive post-secondary education program, Destination Dawgs. She teaches the Disability Studies Certificate program at the undergraduate and graduate levels and instructs multiple service-learning courses that focus on disability issues across the lifespan.

Heumann's guest lecture to her class shared perspectives that continue to inform the work Laws is doing in the field of education.

THERE'S NOTHING LIKE HAVING SOMEONE RIGHT THERE WHO PARTICIPATED IN DISABILITY RIGHTS AND SOCIAL JUSTICE MOVEMENTS TO GET STUDENTS INSPIRED.

Students heard about Heumann's own struggles with isolation and inclusion, as well as the concrete examples of how those with disabilities are impacted. They learned about her continuing battle to have disability included in civil rights and legislation and were encouraged to keep the conversation going.

"To be honest, I think we were all a bit star struck," said Laws. "We had watched documentaries about Judy's rise to the top of the field as an advocate and policymaker. She spoke about her journey to becoming an advocate for people with disabilities; her work in national government; the importance of full inclusion in education and of belonging; and of the need for increased representation of people with disabilities in the media."

But she also focused on her career path that took her from Brooklyn, NY to California to DC to motivate the young advocates on what they can look forward to. "In some ways,



Keynote Speaker Judy Heumann

Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive Federal financial assistance from the US Department of Education (ED). Section 504 provides: “No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance”

I give you an overview of the work that I've done, particularly for younger people, as you never know what your life is going to give you.”

Heumann was also buoyed by her meetings with students. “It was clear they were eager to learn more about disabilities and their professors have them thinking about issues around disability and diversity.”

During her event in Decatur, she also pressed the audience to determine how they are working with their state and federal legislators to fund certain areas of importance.

“I think one of the most important parts of all of our work is we need to be living our lives and the work that we're doing with the premise that everything is urgent, that we live one life, and depending on when you acquire your disabilities, there are many different issues that one has to deal with,” she said.

Also the symposium's keynote speaker, Heumann reminded participants of the event's goal: to document the history of the disability community. UGA's Richard B. Russell Library for Political Research and Studies houses special collections from Georgia's history in that arena.

“The symposium is a way to let people know about the collections and to get them to make donations to it,” said Gillian Grable, the community outreach coordinator at UGA's Institute on Human Development and Disability. “It not only highlights parts of Georgia history; it also gets people thinking about actions they can take in their own communities. Judy did a historical review of inclusion over the decades and spoke about her own activist efforts to create inclusive practices.”

An organizer of San Francisco's 504 sit-ins, Heumann reflected that they “brought together people with all types of disabilities, different ages, including families who had children with disabilities, who were working on getting a set of regulations for Section 504, which is a part of the Rehabilitation Act of 1973.”

But, her most important contribution to the event was bringing that history to life, said Grable. “There's nothing like having someone right there who participated in disability rights and social justice movements to get students inspired.”

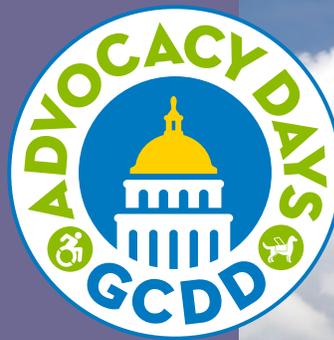
For Heumann, the visit provided insight into the work that still needs to be done around disability rights in Georgia.

“Through good discussions, I heard that people want more action, and they're actively engaged in getting the problems more effectively understood and finding solutions,” she said. “I found that people are frustrated by how the legislature is still not doing what it needs to advance the rights of people with disabilities in the state, but I was glad to learn that advocacy groups are working hard in that area.”



2020 LEGISLATIVE PREVIEW – Getting Ready to Advocate

by Alyssa Lee, PsyD, GCDD Public Policy Research & Development Director



Starting on Monday, January 13, 2020, the Georgia General Assembly will begin its race towards the finish line. The Georgia Constitution only grants the assembly 40 days to complete all its work. While the days do not have to be continuous, the assembly’s traditional deadline of late March or early April does not allow for much dawdling.

A GOVERNMENT OF THE PEOPLE AND FOR THE PEOPLE ONLY WORKS IF THE PEOPLE RAISE THEIR VOICE. WE AT GCDD ARE COUNTING ON YOU TO DO JUST THAT.



With that in mind, it is never too early to double check who your elected officials are at [Open States](#). Make sure to enter your entire home address, as multiple elected officials can represent the same ZIP code. You can also confirm their contact details and committee assignments at the official [Georgia General Assembly website](#).

Remember, your elected officials cannot represent your opinions if you have never taken the time to educate them on issues of importance to you. Whether you have new folks or old folks, be sure to take some time to

re-introduce yourself. Your elected officials work for you, so put them to work for your interests! A government of the people and for the people only works if the people raise their voice. We at the Georgia Council on Developmental Disabilities (GCDD) are counting on you to do just that.

For a quick recap on how a bill becomes a law in Georgia, be sure to check out Georgia Public Broadcasting’s short [video on the legislative process](#).

2020 Session Theme: Budget, Budget, Budget

As the Georgia General Assembly’s only required task, the passage of our state’s balanced budget is always a highlight of each year’s session. However, this year is sure to be one for the books as Governor Kemp, in early August, directed state agencies to propose massively impactful, 6 percent cuts to their fiscal year 2021 budget. To put that into perspective, the Georgia Department of Behavioral Health

and Developmental Disabilities (DBHDD) alone was tasked with finding areas to cut, totaling approximately \$56 million. Agencies submitted proposals in September, which provided us all with a preview of what to monitor during the upcoming session.

Although many of the cuts come from state agencies’ administrative and operational budgets, there are service areas that will likely be impacted. For example, DBHDD has proposed cutting approximately \$1 million from each of the following developmental disability service areas: Marcus Autism Center, family support services and assistive technology and research.

Also impacted by the governor’s directive will be DBHDD’s yearly proposal for new Medicaid NOW/COMP waiver slots. Typically, DBHDD requests additional funds for approximately 125 new waivers each year. In addition, they request funds to annualize approximately 250 waivers from the previous fiscal year. For the upcoming fiscal year, DBHDD only requested to annualize 125 waivers, and they are not requesting funds for any new NOW/COMP waivers.

GCDD’S PUBLIC POLICY TEAM



ALYSSA LEE, PsyD, GCDD Public Policy Research & Development Director



CHARLIE MILLER, GCDD Legislative Advocacy Director

Given the waitlist of over 6,000 people in Georgia for NOW/COMP waivers, GCDD is very concerned by this change.

Finally, although GCDD receives primarily federal funding to continue the great work being done around the state, GCDD does receive state funding for our fantastic IPSE programs. GCDD is particularly concerned that the 6 percent budget cut will mean that IPSE funding is scheduled for a \$50,000 cut for fiscal year 2021!

It is important to note that the changes are only proposed changes as of now, and cuts could be reorganized as the session progresses. Due to

the possibility of additional cuts to services we care about, GCDD will be relying on your strong advocacy skills throughout session. Following Governor Kemp's State of the State address in mid-January, the Governor's Office of Planning & Budget will officially release Kemp's budget recommendations. While ultimately the House of Representatives and the Senate decide what is included in the budget, the governor's recommendations usually serve as guiding light. Be on the lookout for many updates on the budget, including what you can do about the proposed changes. We will also be including budget updates in our public policy calls and newsletter.

QUICK FACTS



Governor Brian Kemp

Governor:

Brian Kemp (Republican)

Lieutenant Governor:

Geoff Duncan (Republican)

Secretary of State:

Brad Raffensperger (Republican)

56 State Senators:

(35 Republicans / 21 Democrats)

180 State House:

(106 Republicans / 74 Democrats)



GCDD'S 2020 PUBLIC POLICY DIRECTION: DISABILITY IN ALL POLICY!

The Georgia Council on Developmental Disabilities is governed by a 27-member board, appointed by the governor and comprised of at least 60 percent individuals with developmental disabilities and family members. Other members include policymakers that represent various agencies and organizations having a vested interest in persons with developmental disabilities.

Each year, the council comes together in the fall to formulate a legislative agenda to bring about social and policy changes that promote opportunities for persons with developmental disabilities and their families to live, learn, work, play and worship in Georgia communities. This year our council approved changes to our public policy department, which will allow GCDD to engage with legislators to ensure people with developmental

disabilities are considered in ALL policy. Our 2020 legislative priorities are as follows:

HEALTH AND WELLNESS

We are committed to advancing sound policies that improve the overall health (physical, mental, emotional and sexual) of people with developmental disabilities and their loved ones. The following topics will be highlighted in our health and wellness policy initiative:

- **DD Waivers**

We will always include eliminating the waiting list for NOW and COMP waivers in our policy initiatives until the waitlist in Georgia is ZERO. These waivers allow individuals with developmental disabilities who qualify for an institutional level of care to receive the supports they need to live healthy lives in the community. As of August

2019, 6,048 Georgians with developmental disabilities were on the waiting list for a NOW or COMP waiver. Our advocacy around this very important issue remains as crucial as ever.

- **The Shortage of DSPs: Workforce Crisis**

We believe that a competent, well-trained and caring workforce of direct support professionals (DSPs) is essential to the health and wellbeing of individuals with disabilities who utilize home and community-based services. We



Due to the possibility of additional cuts to services we care about, GCDD will be relying on your strong advocacy skills throughout session.

2020 LEGISLATIVE PRIORITIES

support strategies to address this crisis so people with disabilities can have the care they need.

- **Gracie's Law (Organ Transplant Discrimination)**

We support the Nobles family and Representative Williams in their efforts to ensure that people with developmental disabilities are not denied an organ transplant simply because of their disability status.

We believe it will be critical to be vigilant of any changes to budget line items that might impact people with developmental disabilities and their families.

EDUCATION

Inclusive education policies, starting with early childcare settings and continuing through postsecondary education, are necessary to assist Georgians with developmental disabilities in reaching their full potential. Currently, our education focus includes:

- **IPSE Programs**

We believe that all students, regardless of ability, should have access to postsecondary education programs in the state of Georgia. Inclusive postsecondary education (IPSE) programs provide students with intellectual and developmental disabilities access to education not otherwise available. Currently there are nine IPSE programs in Georgia serving approximately 139 students. They are Kennesaw State University's Academy for Inclusive Learning and Social Growth, University

of Georgia's Destination Dawgs, Georgia Institute of Technology's EXCEL, Georgia State University's IDEAL, Columbus State University's GOALS, East Georgia State College's CHOICE, Georgia Southern's Eagle Academy, Albany Technical College's LEAP and the University of West Georgia's Project WOLVES.

GCDD is committed to the growth and support of IPSE programs because we recognize their value in preparing students to live increasingly independent lives within their communities.

- **School-to-Prison Pipeline (StOPP)**

GCDD works to address the targeted disparity of African American and other minority students who are disproportionately identified in special education. They often end up in the Georgia Network for Educational and Therapeutic Support (GNETS) system or expelled from school, which leads to a higher probability of

incarceration. We support policy initiatives aimed at reducing the number of students being placed in the school-to-prison pipeline and look forward to the recommendations of the Senate Study Committee on Educational Development of African American Children in Georgia.

EMPLOYMENT

GCDD supports Georgia's vision for a public system that funds employment supports first. We will work to advance policies that improve competitive, integrated employment options for Georgians with developmental disabilities. Some policy proposals include:

1. Phasing out 14(c) certificates that currently allow people with disabilities to be paid subminimum wage
2. Increasing the budgets of DBHDD and the Georgia Vocational Rehabilitation Agency (GVRA) to assist the organizations in increasing the hourly rate of Georgia's supported employment services

HOW TO GET INVOLVED

- 1 **Attend GCDD's Advocacy Days:**
1/29, 2/6, 2/19, 2/27, 3/11
- 2 **Read GCDD's e-newsletter *Public Policy for the People*** 1/20, 2/3, 2/17, 3/2, 3/16, 3/30
- 3 **Participate in GCDD's public policy calls** at 9:30 AM on 1/13, 1/27, 2/10, 2/24, 3/09, 3/23
Dial-in #: 605-475-4063, Access code: 737-091
- 4 **Join GCDD's Advocacy Network**



DISABILITY IN ALL POLICY!

3. Reallocating funds from day habilitation program rates, which continue to be well *above* the national average, to supported employment rates, which continue to be well *below* the national average

TRANSPORTATION

Reliable transportation options are critical to ensure people with developmental disabilities are truly included in all aspects of their communities. GCDD supports policies that improve current transportation options, including [House Bill 511](#) (HB 511), which aims to create a state agency focused on transit. HB 511 also includes a committee whose purpose is to ensure vulnerable populations, including people with low income, people with disabilities and people who are aging, have access to

appropriate transit options. We believe this legislation will improve transportation for people with disabilities, particularly in the rural parts of our state.

HOUSING

GCDD supports policy solutions that provide the infrastructure and funding necessary to address the shortage of accessible, affordable housing options for people with developmental disabilities.

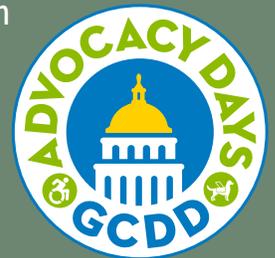
BUDGET

We believe Georgia's budget highlights our state's priorities, and GCDD strives to educate lawmakers on the importance on maintaining/increasing budget line items that impact Georgians with developmental disabilities. As described in our budget highlight, we believe it will be critical during 2020's session to be vigilant of any changes

to budget line items that might impact the supports and services on which people with developmental disabilities and their families rely. We will strive to keep each one of you updated on changes, and we know that you all will be ready to advocate when the time comes!

REMEMBER TO REGISTER for Advocacy Days 2020!

Choose from five days of advocacy (read more about it on pages 10-11).



FAQ

FREQUENTLY ASKED QUESTIONS:

Q How do I find out when legislative committees are meeting?

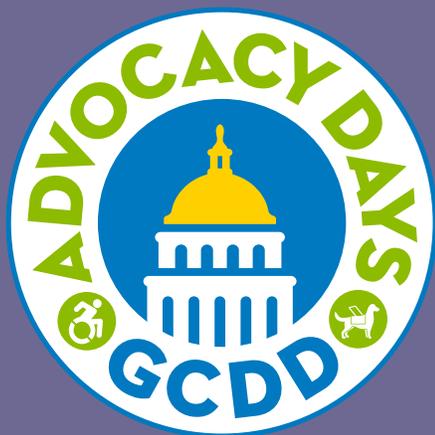
A You can find the schedule for the House of Representative online at the [State House calendar portal](#) and the schedule for the Senate at the [Senate calendar portal](#). If you plan to attend a committee meeting in person, plan to be flexible, as meeting times often change suddenly. Additionally, you can often watch committee meetings online. [View State House meetings here](#). [View State Senate meetings here](#).

Q How do I find the status of a bill?

A If you know the bill number, you can track it by visiting the [official Georgia General Assembly website](#). Or you can read GCDD's Public Policy for the People e-newsletter and participate in our public policy calls.

Q How can I help my school-aged child learn about the legislative process?

A Consider signing them up to be a page. Pages deliver messages to the senators and representatives when they are meeting in the legislative chambers. It is such an important job that there is even a Georgia law, [O.C.G.A. §20-2-692](#), that states "children who serve as pages of the General Assembly during the school year, either at regular or special sessions, shall be credited as present by the school in which enrolled in the same manner as an educational field trip, and such participation as a page shall not be counted as an absence, either excused or unexcused." To learn more about becoming a page, visit the [Senate page program site](#) and the [House page program site](#).



2020 Advocacy Days are Here!

Join the Georgia Council on Developmental Disabilities (GCDD) at the Georgia State Capitol in downtown Atlanta during the 2020 legislative session to learn about policies affecting people with disabilities, and join advocates from across the state in speaking with elected officials about these very important issues.

Each day will focus on a different topic that affects Georgians with disabilities.

January 29 - Gracie's Law (Organ Transplant Discrimination)

Gracie's Law, written to avoid any organ transplant discrimination against people with disabilities in Georgia, will be introduced to the Georgia legislature in January 2020. While the Americans with Disabilities Act (ADA) denies discrimination based on any disability, there is still a lack of federal enforcement. *(Read more about Gracie's Law on pages 12-13.)*

February 6 - Inclusive Post-Secondary Education (IPSE)

Inclusive college programs across the state offer students with intellectual and developmental disabilities (I/DD) a variety of experiences and opportunities for growth as they prepare for the next chapter of their lives. With IPSE, students with I/DD can now realize their dream of continuing their studies in a university or college setting with their peers.

February 19 - Home & Community-Based Services

GCDD will always include eliminating the waiting list for NOW and COMP waivers in our

policy initiatives until the waitlist in Georgia is ZERO. These waivers allow individuals with developmental disabilities who qualify for an institutional level of care to receive the supports they need to live healthy lives in the community. As of August 2019, 6,048 Georgians with developmental disabilities were on the waiting list for a NOW or COMP waiver. Our advocacy around this very important issue remains as crucial as ever given the proposed state budget cuts and the ZERO waiver slots recommended by DBHDD for Fiscal Year 2021.

February 27 - School-to-Prison Pipeline (SToPP)*

With advocates, GCDD will educate and inform lawmakers to develop and implement a plan to reduce the number of African American males in special education classes who are at risk of being pushed out of school and into the criminal justice system.

The school-to-prison pipeline is the funneling of children from the public schools into the juvenile and criminal justice systems, in part, due to zero-tolerance school discipline policies, disproportionate application of student suspensions, high-stakes testing and administrative practices that adversely affect children of color,



Geared at preparing advocates to take a leadership role at the annual advocacy event, team lead volunteers will learn how to navigate the Georgia State Capitol and support attendees in speaking with their legislators. Team leads will earn \$100 per each Advocacy Day for which they volunteer. Each individual must complete one training and fulfill all the responsibilities as determined by GCDD's public policy team.

Sign up to be a Team Lead.

poor children and children with learning disabilities. *(Read more on pages 18-19.)*

March 11 - Employment*

GCDD will work to advance policies that improve competitive, integrated employment options for Georgians with developmental disabilities. These include: prohibiting certificates that currently allow people with disabilities to be paid subminimum wage; increasing the hourly rate of Georgia's supported employment services; and reallocating funds from day programs rates to supported employment rates, which continue to be well below the national average.

**Topics for these Advocacy Days dates are subject to change, depending on developments during the legislative session.*

What to Expect Each Advocacy Day

Each day kicks off at 8 AM at the Central Presbyterian Church, across from the Gold Dome (201 Washington St SW, Atlanta, GA 30334), where leaders from GCDD and other organizations will train and teach advocates how to approach legislators, make a connection and discuss the topics that are important to you. After the interactive training, advocates and leaders will head over to the Gold Dome to meet with legislators. Event ends at 12:30 PM.

Agenda

8:00 AM – Check- In & Breakfast

9:00 AM – Welcome Remarks & Training

10:00 AM – Leave for Capitol

10:30 AM – 12:30 PM – Meet Legislators at the Capitol

Registration

All registrants should register on Eventbrite to attend the Advocacy Days of their choice. Organizations and agencies should complete the group registration option.

All registrants need to provide their home address so the GCDD public policy team can identify your district and legislators.

Frequently Asked Questions (FAQs):

From what to bring and where to park, GCDD has you covered. Check out the FAQs, and be prepared for a full day of advocacy.



MARK YOUR CALENDARS AND JOIN US!



Meet Charlie Miller, GCDD's New Legislative Advocacy Director

As the legislative advocacy director, Charlie Miller leads the Georgia Council on Developmental Disabilities (GCDD) in its community engagement and advocacy efforts in the state legislature. He also works alongside Georgians with disabilities and other stakeholders to build coalitions around issues important to the disability community.

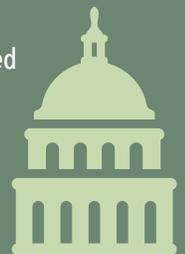
Charlie brings over 10 years of advocacy experience to the team. He joins GCDD from the Georgia Vocational Rehabilitation Agency, where he most recently served as the legislative liaison. Charlie began honing his skills in advocacy as a student at the Academy for Inclusive Learning and Social Growth at Kennesaw State University (KSU). While attending KSU, he served as an intern in the public relations and community engagement departments. In this role, Charlie collaborated with nervous students and their parents on navigating campus life, managing program expectations and more.

After completing his program at KSU, Charlie continued developing his expertise in leadership through community engagement. For example, he has enjoyed sitting on the boards for such organizations as the Statewide Independent Living Council and the Cobb County Transit System Advisory Board. Charlie is also a member of ADAPT, a national grassroots community that organizes disability rights activists to engage in nonviolent direct action; the Association of University Centers on Disabilities (AUCD), a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families and communities; and TASH, an international leader in disability advocacy whose membership is comprised of a community committed to positive and lasting change in the lives of people with significant disabilities.

To further engage with his community, Charlie is currently enrolled in a graduate-level program at Georgia State University (GSU). As part of GSU's Leadership Education in Neurodevelopmental Disabilities (GaLEND) program, he helps shape the futures of emerging leaders in the disability community.

"I'm thrilled to continue my work in advocacy at GCDD," said Charlie. "Being able to advocate for the many issues that affect the disability community – whether it's access to reliable transportation, inclusion in education or access to healthcare – is something I'm very passionate about."

Charlie lives in Decatur with his fiancé and two cats, Harper and Hugo. A Georgia native, he is the proud son of Butch and Teresa Miller and brother to Cole and Carey. When he's not in the office or at the Capitol, Charlie enjoys staying active by participating in marathons and obstacle-course races.



The Fight for Gracie's Law

by Jennifer Bosk

As far as gender reveals go, this was a simple one. No cupcakes with pink or blue centers, no boxes of helium-filled balloons. Erin and David Nobles had agreed to a genetic test, suggested because of her late-age pregnancy, but mostly because she knew it would be an easy way to find out if she was expecting a boy or girl.



Erin eagerly answered the doctor's office phone call about the test results only to hear an expressionless voice say, "It's a girl. She has Down syndrome." "There was no joy in the nurse's voice, it was flat, no hint of celebration," recalls Erin.

The Nobles promptly changed doctors, finding one who celebrated the impending birth of their baby, Gracie Joy. At 24 weeks into the pregnancy, the Nobles were told the baby had an atrioventricular (AV) canal defect – a large hole in the center of her heart. Approximately 45% of children born with Down syndrome have some form of a congenital heart defect.



Erin and David Nobles with children Walker and Gracie Joy

Born on March 9, 2019, Gracie Joy spent 17 days in the neonatal intensive care unit (NICU). A few weeks later it was time to have her heart surgery, and she entered the pediatric intensive care unit (PICU) at Children's Hospital of Georgia (CHOG). In total, Gracie Joy stayed at CHOG for eight weeks working to gain weight and fighting a bout of pneumonia, which delayed her heart surgery.

Eventually Gracie Joy had a successful surgery and was finally able to go home.

While spending a quiet evening at home, David and Erin were relaxing – watching TV, scrolling through their phones while their kids slept. Erin was reading more about Down syndrome and disabilities in general. Something caught Erin's eye, and she turned to David and read him information that shocked them both – people with disabilities do not receive equal consideration for organ transplants. "Do you realize if Gracie Joy needed an organ transplant, we would have had to fight to get her on a list?" said Erin.

"I was blown away! How is that even possible?" said David. "I didn't want to talk or even think about it. It's something we could easily have been faced with." At that moment,

the Nobles realized this was an opportunity to do something for their daughter and for all people with disabilities in Georgia.

Gracie's Law, written to avoid any organ transplant discrimination against people with disabilities in Georgia, will be introduced to the Georgia legislature in January 2020 by Representative Rick Williams (R – Milledgeville, District 145) and Senator Burt Jones (R – District 25). While the Americans with Disabilities Act (ADA) denies discrimination based on any disability, there is still a lack of federal enforcement.

EVEN WITH FEDERAL PROTECTIONS IN PLACE, CHILDREN AND ADULTS WITH DISABILITIES CONTINUE TO FACE AN UNFOUNDED AMOUNT OF DISCRIMINATION BY THE MEDICAL COMMUNITY. ”

"Even with federal protections in place, children and adults with disabilities continue to face an unfounded amount of discrimination by the medical community," said Rep. Williams. "For far too long, people with

disabilities have been denied organ transplants based on misconceptions about their quality of life, which consequently impacts their health care. This legislation seeks to change that stigma and ultimately save lives.”

Currently, only 12 states have laws in place to stop organ transplant discrimination: California, New Jersey, Maryland, Massachusetts, Oregon, Delaware, Kansas, Ohio, Pennsylvania, Washington, Louisiana and Indiana.



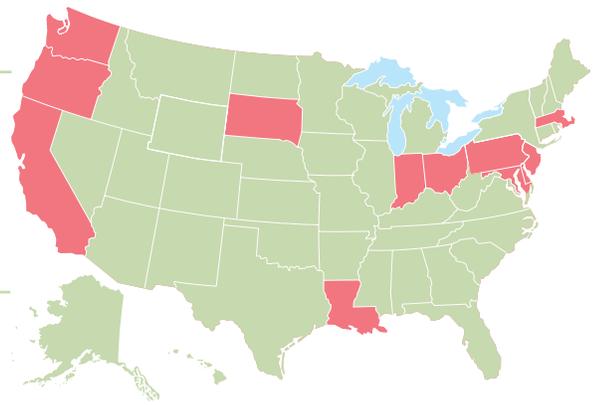
For far too long, people with disabilities have been denied organ transplants based on misconceptions about their quality of life, which consequently impacts their health care.

“It’s a very important issue, and it’s very emotional,” said Rep. Williams. “This is good legislation. It’s nonpartisan, and everyone is on board. Legislators have been coming up to me saying they are ready to sign it.”

Erin explains it is important to have a state law so that if there is an issue, it can be fought at the state level.

She paints the picture of someone with a very sick child with a disability having to find a lawyer to represent them at the federal level, filing with a federal court, waiting to get on the federal docket – all overwhelming, time consuming and expensive. “If you have a child with disabilities, get your boxing gloves on – you need to fight,” Erin said.

Currently, only 12 states have laws in place to stop organ transplant discrimination.



The Nobles also point out it is not simply the organ transplant center that is doing the denying. Many times, doctors treating patients with disabilities don’t even make a referral to a transplant center. Parents are told to take their child home and spend the remaining time with them. “We’re dealing with old mindsets, doctors assuming that children with disabilities are not eligible for organ transplants. That’s our biggest issue,” said David.

Gracie’s Law was written and submitted to the Georgia legislature quite rapidly. After the Nobles’ talk that Friday night about organ transplants for people with disabilities being denied, Erin reached out the following morning to Tami and Wayne Pearl in Louisiana who had already submitted their own request for a law to their state legislature called Evie’s Law, named for their daughter with Down syndrome. Wayne immediately sent his five-page bill for the Nobles to review and gave them advice on selecting the right member of the Georgia General Assembly to sponsor the bill, suggesting the Nobles find a legislator who aligned with their morals and beliefs.

Discussing their Georgia legislators, David, who works at the Georgia Department of Community Supervision in Milledgeville, recalled meeting Rep. Williams at several town meetings. “I knew the kind of person he is. He was definitely someone I could align with; my beliefs fit his beliefs.”

Rick reached out to Rep. Williams. “I went through my spiel, and he told me [to] send him what I had, and [he’d] be in touch.” Ten minutes later Rep. Williams called Rick to tell him that Gracie’s Law had been sent to the legislative council, and the following day Sen. Jones said he would submit the bill on the Senate side.

Looking back, David said, “When we got that phone call from the doctor’s office about Gracie having Down syndrome, it was like a funeral. We couldn’t even decorate the nursery. But that was a year ago, and we’ve made it through. Now we are introducing legislation to make a difference in our community and our state. Who would have thought this is where we would be?”

The Georgia Council on Developmental Disabilities will be advocating for Gracie’s Law alongside the Nobles family during its 2020 Advocacy Days. To learn more, visit www.gcdd.org.



Gracie Joy in the hospital



What's Happening in Washington?

Federal Disability Policy Updates

By Alison Barkoff and Erin Shea,
Center for Public Representation

It was another unpredictable year-end in DC. While the most visible Congressional activities were not related to passing legislation, we have continued to make progress on a number of priorities for the disability community.

Updates on Health Care Money Follows the Person:

In early December, Senate Finance Committee Leaders announced a bipartisan drug pricing agreement that would use cost savings to fund the first-ever proposed 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. Unfortunately, the budget passed by Congress in late December only extended MFP funding to May 22, 2020. However, we understand that Congress chose to pass a short-term extension of MFP (along with several other Medicaid programs) to create pressure to pass a larger healthcare package, including prescription drug reforms, before their Memorial Day recess. Had Congress passed a multi-year extension in the year-end budget, this chance for permanent reauthorization of MFP in May would not exist. We'll need everyone's help advocating for permanent MFP funding!

Drug Pricing: There is bipartisan support around drug pricing reform, and disability advocates are trying to ensure that any proposed legislation both lowers costs and meets the needs of people with disabilities. There are bills in the House (H.R. 3) and Senate (S. 2543, which was updated in December to permanently fund MFP); however only the Senate bill is bipartisan. Both bills create an out-of-pocket cap in Medicare and simplify the prescription drug benefit. Because of advocacy by disability groups, H.R. 3 now includes a ban on the use Quality Adjusted Life Years (QALYs), a way cost-effectiveness of treatments is determined that literally places a lower value on the lives of people with disabilities. As mentioned above, we expect there to be pressure to move on drug pricing before the Memorial Day recess.

Affordable Care Act Lawsuit:

On December 18, the Fifth Circuit Court of Appeals issued its decision in *Texas v. United States*, an appeal of the decision of a federal court in Texas to strike

There is bipartisan support around drug pricing reform, and disability advocates are trying to ensure that any proposed legislation both lowers costs and meets the needs of people with disabilities.

down the entire Affordable Care Act (ACA) in 2018, including provisions critical to people with disabilities and other pre-existing conditions. The Circuit Court ruled that the ACA's individual mandate is unconstitutional and sent the case back down to the same district court judge who issued the initial decision to determine whether the entire law should now be found unconstitutional. The case will undoubtedly be appealed to the Supreme Court, although the timing is unclear. In the meantime, the courts have "stayed" the decision – meaning the ACA remains fully in place during the appeals.

Public Charge Litigation:

As we described in our last column, five federal district courts issued decisions preventing the federal government from implementing

the new public charge rule, which would prohibit people who use or might use public benefits (including now Medicaid home and community-based services) from getting a visa or green card. Three of those courts issued decisions preventing the rule from going into effect anywhere in the country. The federal government asked the appeals courts to allow the rule to go into effect while the case is on appeal and so far, two of the three appellate courts have agreed to let the rule go forward and the third court will decide later in January. We will file an amicus brief explaining how the public charge rule illegally discriminates against people with disabilities in the appellate courts, as we did in the district courts. Remember, at this point, the rule is NOT in effect during the appeals.

Updates on Disability Employment

USCCR Hearing: On November 15, the United States Commission on Civil Rights (USCCR) held a hearing about civil rights issues related to paying subminimum wages to people with disabilities. Section 14(c) of the Fair Labor Standards Act allows employers to get special certificates to pay workers with disabilities less than the minimum wage (often pennies on the dollar) that are typically used in sheltered workshops, where workers with disabilities are segregated from their nondisabled peers. Alison testified about the federal government's role in protecting and advancing the rights of people with disabilities in employment, and Ruby Moore of the Georgia Advocacy Office testified about her experience helping people with disabilities

get competitive, integrated employment (CIE). The public also had an opportunity to give comments orally or in writing, and many self-advocates participated. We expect a report later this year.

Congressional Briefing:

We're continuing to build support for the Transformation to Competitive Employment Act, a bipartisan bill that would expand opportunities for CIE while phasing out the use of subminimum wages under Section 14(c) over six years. As part of that effort and in honor of National Disability Employment Awareness Month, we held a Congressional briefing in October, where panelists shared stories of successful transitions from sheltered workshops to CIE and state efforts to expand CIE.

WIOA Regulations: Disability groups continue to oppose the Department of Education's efforts to reopen regulations defining CIE, arguing it would roll back the progress made in expanding opportunities for people with disabilities to obtain CIE since Congress passed the Workforce Innovation and Opportunity Act in 2014. We sent a letter to the Department opposing the reopening of the regulations that was signed by over 200 groups representing a broad coalition of stakeholders across all 50 states (including GCDD, Georgia APSE, and the Georgia Advocacy Office).

Other Bills on the Horizon

As the congressional session progresses, top priorities include:

Keeping All Students Safe Act (KASSA): Disability groups are expecting the reintroduction of KASSA shortly, a bill from last Congress that would eliminate

seclusion and significantly limit the use of restraints in all schools that receive federal funding, including for students with disabilities, who are at particular risk.

HCBS Infrastructure Act:

Disability and aging groups have been working together on a bill to provide additional funding to states for infrastructure in their Medicaid-funded Home and Community-Based (HCBS) systems, including for housing, transportation, employment and workforce development. We hope the bill will be introduced in the coming months.

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.

Get More Information About:

- [Money Follows the Person \(MFP\) and MFP Advocacy](#)
- [Quality Adjusted Life Years \(QALYs\)](#)
- [Texas v. United States litigation](#)
- [The Public Charge Rule and the Litigation Challenge, Fact Sheet and Explainer](#)
- [Competitive, Integrated Employment](#)
- [Keeping All Students Safe Act \(KASSA\)](#)
- [United States Commission on Civil Rights \(USCCR\) Hearing Videos: morning, afternoon and open comment sessions.](#)

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 1/6/20



Welcoming Community Dialogue Summit Focuses on Inclusion

by Jennifer Bosk

“We’re here to talk about the foundation and elements of a welcoming community,” began Malaika Geuka Wells, community organizing coordinator for Global Ubuntu, as she kicked off the inaugural Welcoming Community Dialogue Summit on October 24 in Clarkston, GA, along with Clarkston Mayor Ted Terry and the Georgia Council on Developmental Disabilities (GCDD) Executive Director Eric Jacobson.

Nearly 90 participants attended the summit, including GCDD council member Lynn D. Walker (right) of the Georgia Department of Human Services.

The Welcoming Community Dialogue initiative is part of the Real Communities Partnerships (RCP), funded by GCDD and managed by Global Ubuntu. The goal of the RCP is to support community and civic engagement through the creation of inclusive and welcoming communities where people of all abilities are valued equally and are active participants in making the community better for everyone.

The nearly 90 individuals gathered for the day and participated in a collaborative dialogue centered around questions designed to be thought-provoking on what an inclusive and welcoming community should and could be.

Beginning with a presentation on the Universal Declaration of Human Rights by the United Nations, attendees focused on a foundation of law and order based on justice, fairness, truth, freedom and value for every human life, and on the principle of morality: value and practice justice,

equity, truth, love, compassion, fairness, freedom, forgiveness, reverence and respect.

“Everyone wants to be treated with dignity and justice. The discussion centered on how morality and society should bring out dignity and justice for people of all abilities. If we want to change our community’s narrative, it’s about human rights. If we want to offer radical hospitality, it’s about human rights. Each human right defined, and each element of the summit, coordinated,” said Sumaya Karimi, the project organizing director for RCP and founder and director of Global Ubuntu.

At the end of the summit, the five current communities working on changes to make them into official RCP Welcoming Communities – Athens, Augusta, Comer, Fort Gaines and LaGrange – committed to continuing their work and adding new issues to their focus. For example, LaGrange will work on its own summit to look at the intersection of developmental disabilities, racism and homelessness. Atlanta plans to review inclusiveness in the arts, and Comer will lead a dialogue on voting issues and accessibility. In addition, five new communities plan to apply for their cities to become RCP Welcoming Communities in 2020.

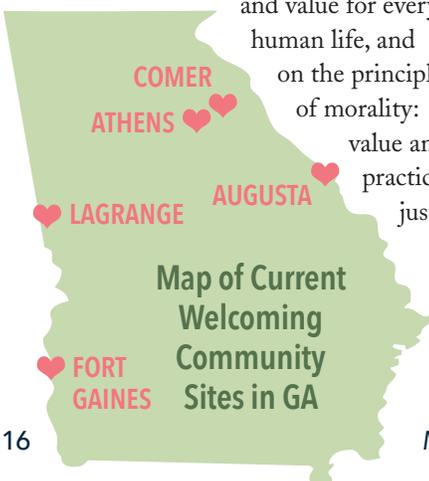
“For us, this summit set the tone and foundation of a movement but also showed us all what it is like to be welcoming. Ninety percent of participants left talking about how to bring this welcoming concept to their communities and to be more involved in making this shift happen,” said Karimi.

THE DISCUSSION CENTERED ON HOW MORALITY AND SOCIETY SHOULD BRING OUT DIGNITY AND JUSTICE FOR PEOPLE OF ALL ABILITIES.



Global Ubuntu explains the purpose of the dialogues, and the summit by extension, is to pave the way toward an equitable and just society – foundational of welcoming communities – where people across race, ethnicity, culture, class, socioeconomic background, educational status, abilities, gender and religion are treated with dignity and respect. It helps support the communities with technical assistance, financial support and discussion facilitation.

For information on this initiative, check out [Global Ubuntu’s website](#) or [GCDD’s Real Communities page](#).





Communicating with People First

People First Language (PFL) is a way of communicating that reflects knowledge and respect for people with disabilities by choosing words that recognize the person first and foremost as the primary reference and not his or her disability.

Geared towards everyday communication and for media outlets, the Georgia Council on Developmental Disabilities (GCDD) developed a People First style guide to promote the usage of People First Language that can be applied to everyday use by professionals and the general public.

In PFL, emphasis is placed on the person first, rather than the disability, thereby putting the focus and subject on the person.

The graphic on this page displays some simple ways to incorporate PFL in everyday use. For more information and the complete style guide, visit [GCDD's People First page](#).

Not all people with disabilities agree on which language or terminology is preferred. Individuals will vary as to how they refer to themselves and how they would like you to refer to them.

PEOPLE FIRST LANGUAGE

USED TO SPEAK APPROPRIATELY AND RESPECTFULLY ABOUT AN INDIVIDUAL WITH A DISABILITY



INSTEAD OF THIS ...



The disabled ...

Normal person ...

The blind ...

Crippled, lame, deformed ...

Has overcome his/her disability ...

TRY THIS ...



Person with a disability

Person without a disability

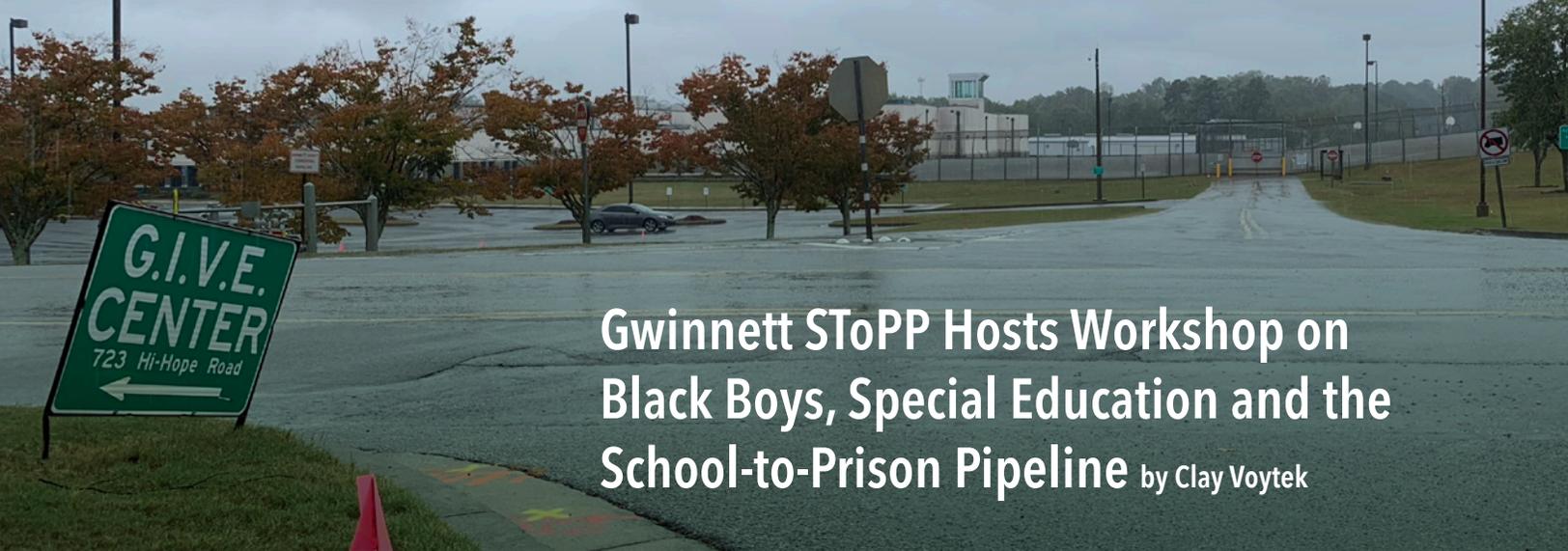
Person who is blind/visually impaired

Person with a physical disability

Person who is successful, productive

50 Million Americans Have a Disability

1 in 5 Americans is a Person with a Disability



Gwinnett SToPP Hosts Workshop on Black Boys, Special Education and the School-to-Prison Pipeline

by Clay Voytek

The GIVE Center East sits directly across from the Gwinnett County Department of Corrections.

After a pattern of behavioral misconduct, students in the Gwinnett County Public Schools system are often sent to the Gwinnett Intervention Education (GIVE) Center East. Located on Hi Hope Road just off State Route 316, the alternative school sits directly across from the Gwinnett County Department of Corrections.

Students enter through a metal detector with clear backpacks, the bell rings at 7:05 a.m. and they are dismissed at the end of the day one-by-one. Black boys with developmental disabilities are disproportionately represented in the center's [enrollment data](#).

A growing group of parents, advocates and students in Gwinnett say that the center is teaching kids how to go to prison.

The center is part of the Georgia Network for Educational and Therapeutic Support (GNETS) system. The 24 psychoeducational

programs – or GNETS – serve more than 3,000 students with

behavioral, intellectual and neurological

disorders. [An investigation by The Atlanta Journal-Constitution](#) shows that Georgia schools also send disproportionate numbers of African American students, especially those with behavior problems, to the programs.

In 2011, a [class action lawsuit](#) was filed in federal court alleging that the State of Georgia has discriminated against thousands of public school students with disabilities by providing them with a separate and unequal education via GNETS. The lawsuit stated that the schools were denying GNETS students the opportunity to be educated with students without disabilities, thus violating the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and the Fourteenth Amendment to the United States Constitution.

According to a [fact sheet provided by the Center for Public Representation](#), students in the GNETS program cannot access the basic credits they need to earn a diploma, resulting in a high school graduation rate of only 10% (compared to a statewide rate of 80%).

On a rainy Saturday in October, the [Gwinnett Parent Coalition to Dismantle the School-to-Prison Pipeline \(Gwinnett SToPP\)](#) hosted an interactive awareness



workshop at Georgia Gwinnett College as part of the [National Week of Action Against School Pushout](#). A group of over 30 community members, including high school students, a state house candidate for District 106, Rebecca Mitchell, and a former EMT training to become a special educator, spent the morning reckoning with schools' discipline policies and the inequity that has become a [clear national trend](#).



Gwinnett SToPP looks at the issue through a racial lens, including the way students with disabilities are singularly impacted.

Gwinnett SToPP formed in 2007 to lead a parent-driven, community-centered partnership approach to dismantling the school-to-prison pipeline in Gwinnett County. Its mission is to build and strengthen relationships with the community in two constructive ways – parent/

Attendees asked questions and heard answers from youth and experts at the workshop, which was part of a series of events called "From Lockers to Lockdown."



community advocacy training and policy-change facilitation.

The school-to-prison pipeline is the funneling of children from the public school system into the juvenile and criminal justice systems, in part, due to zero-tolerance school discipline policies and practices; disproportionate application of student suspensions; high-stakes testing; and administrative practices that adversely affect children of color, poor children and children with learning disabilities or learning differences.

Marlyn Tillman, executive director and co-founder of Gwinnett SToPP, likened the dismissal process at the GIVE Center to prison visiting hours. At the event, she explained that alternative schools and the removal from critical learning environments often have an adverse effect on children.

“We hate it,” said Tillman. “There are kids there who may need a different learning environment, but to put it in the words a student said, I don’t think it should be teaching kids how to go to jail.”

Attendees asked questions and heard answers from youth and experts at the workshop, which was part of a series of events called “From Lockers to Lockdown.” Gwinnett SToPP is fighting for equity in the county’s education system through data accountability,

advocacy and policy reform, with the help of a grant from the Georgia Council on Developmental Disabilities (GCDD).

The goal of this project is to expand and leverage the existing grassroots, community-based coalition, managed by Gwinnett SToPP and the Interfaith Children’s Movement (ICM), to develop and implement a plan to reduce the number of African American males in special education classes who are at risk of being pushed out of school and into the juvenile and criminal justice systems.

Because of its placement at a critical juncture of development and education, the upshot of the school-to-prison pipeline is especially harmful: affected youth find it harder to socialize, get jobs and live a fulfilling life. The over-representation of kids with developmental disabilities in the data compounds these issues.

It can be hard for parents to navigate school discipline and special education supports. And, these policies have a material effect on the children within the county school system.

Still, Tillman sees a unique cultural moment right now. America isn’t working for all of its citizens, and people are more cognizant of systemic problems. Her group looks at the issue through a racial lens, including the way students with disabilities are singularly impacted.

“That’s the foundation-level of our work with GCDD,” said Tillman, “That was how our white parents joined us so freely. The privilege dropped off for them.”

A GROWING GROUP OF PARENTS, ADVOCATES AND STUDENTS IN GWINNETT SAY THAT THE CENTER IS TEACHING KIDS HOW TO GO TO PRISON.

“It’s hard as a parent,” she said later. “I want to protect my baby. I want them to think the world is theirs.”

A group of four Grayson High School students, Isaiah Thompson, Faith Ebikeme, Mojola Oshikanlu and Goodness Dauda, participated in the workshop. In a group conversation, they agreed that their value in the eyes of administrators was conditional and noted that the lack of nuance behind zero-tolerance discipline policy is harmful to the development of their peers.

“I’m very appreciative of what Gwinnett has given me ... but at the same time you’re hurting students,” said Thompson, a talented 17-year-old student at Grayson who began working with Gwinnett SToPP last year and found a mentor in Tillman. “We’re trying to take all the information we get from this [event] and bring it back to our own school.”

Find out more about the School-to-Prison Pipeline on the [Gwinnett SToPP website](#) or [GCDD’s School-to-Prison Pipeline page](#).



"The Boys"

by Shannon Turner

Everyone in their family, and most other people who know them, refer to Todd and Alan Schatten as "The Boys." With an easy smile and an even easier manner, they are two of the nicest men you will ever meet.



Photographer: Haylee Fucini-Lenkey

The Schatten brothers have many claims to fame. They have countless medals for their participation in Special Olympics. They're accomplished equestrians. Also, Todd and Alan, along with their first cousin, Scott, have come to be known as the most famous Georgians with Fragile X syndrome. All three men were diagnosed at Emory Clinic Genetics on the same day. Fragile X-associated disorders (FXD) include a family of genetic conditions that can affect individuals in a variety of ways, including intellectual disability, behavioral and learning challenges and various physical characteristics.

On Sunday afternoon, Todd, 32, and Alan, 35, have equine therapeutic riding lessons at the Chastain Horse Park. Chastain

Horse Park has a Professional Association of Therapeutic Horsemanship (PATH)-certified program where people with developmental and physical disabilities can receive subsidized riding lessons from specially trained teachers. The Schattens have been coming here on scholarship for four years.

Their instructor, Gail, says, "Being able to ride and control a thousand-pound animal, and get them to do what you want, allows such confidence and freedom." Regarding the brothers, Gail gushes about their popularity. "Everybody loves 'The Boys.' They work so hard, and they come every single week. They have gone from not being able to get a horse out of a stall to being able to do it all themselves."

The Schatten brothers are extremely active in their community. Alan relays their list of regular activities: YMCA Happy Club, Special Olympics bowling and basketball, Jewish Community Center sports, synagogue and their own monthly "Friends Dinner Club," as well as a weekly Shabbat dinner with friends. Having an active community in Atlanta

is important to them and their mom, Janet. As their father passed away several years ago, Janet has since remarried and moved to Athens. She doesn't know what she'd have done if her sons didn't have the Medicaid waiver. Atlanta is their home, and the waiver allows them to live there even while Janet lives 90 minutes away. She Skypes in for the brothers' Friday night Shabbat rituals.

The Schatten brothers are accomplished equestrians and have won countless medals in Special Olympic competitions.



Todd and Alan both have COMP Medicaid Waivers. Thanks to careful and informative guidance from high school teachers, their parents were able to apply and get them on the waiting list without much difficulty. One thing that helped was that their cousin, Scott,

**BECAUSE OF THE MEDICAID
WAIVER, MY SONS CAN HAVE
A RICH LIFE THAT WE ALL
DREAM OF HAVING
OURSELVES.** ”

had been through the process a few years earlier. Janet says that she carefully followed the footsteps of her sister's parental advocacy efforts. As soon as the boys graduated from high school, their waivers kicked in. Says Janet, "I've never won anything in my life, but this is the lottery of a lifetime. It's great when you know that your kids have the chance to live as independent adults."



The COMP Medicaid Waiver has made it possible to have employees that support the brothers' independence.

The COMP Medicaid Waiver has made it possible to have employees that support the brothers' independence. Five years ago, Janet changed to a self-direct model and was able to hire a couple named Teresa and Mike, who live with her sons and serve as full-time employees. They also have full-time jobs elsewhere, but on opposite schedules, so Mike can be with the guys in the day, and Teresa takes the evening shift. Janet says that the Medicaid waiver really makes a difference because her sons are able to live independently and be part of the community: "The [employees] can step in and back out. It's a scaffolding process that's seamless."

Both brothers work as baggers at different grocery stores. When not working, Todd goes to Teamworks (Tools for Independence) at Jewish Family & Career Services to help two days a week. His participation in Teamworks is also paid for by the waiver. It gives Todd more work skills and allows him to bond with others.

Janet reflects on the system that has been so good to keep her sons living happily, healthfully and independently, but where thousands of others stay on the waiting list or don't even know how to apply. Speaking even more pointedly about the issue, Janet says, "Legislation needs to prioritize budgeting Medicaid waivers for individuals with disabilities because, as Alan and Todd have shown us, it provides a cornerstone for creating a vibrant, caring community where symbiotic relationships organically offer mutual support." She goes on to say, "I think future models should include mentorship from some of us who have had success with the waiver."

In the end, she believes it's a system that, when it works, works well: "When I was growing up, folks with developmental disabilities were put into institutions. Because of the Medicaid waiver, my sons can have a rich life that we all dream of having ourselves: good health, joy and contentment ... all who are in their sphere are happier."

Using a self-direct model, Janet Schatten was able to hire a couple named Teresa and Mike, who live with her sons and serve as full-time employees.



Telling Our Stories... GCDD GEORGIA COUNCIL ON DEVELOPMENTAL DISABILITIES

EVERYONE HAS A STORY TO TELL. READ OURS.

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](#).



COMMUNITY CALENDAR

JANUARY

January 14, 7:30 - 11:30 AM
Health Care Unscrambled 2020 - Atlanta, GA
[RSVP online](#)

January 21, 2 - 3:30 PM
Employment First and the ADA (Audio Series)
ADA Audio Conference Series
[Register FREE online](#)

January 21, 2:30 - 4 PM
Advancing Equal Employment Opportunities Webinar
[Sign up for webinar](#)

January 22, 10 - 11 AM
Computer 101 - The Basics
disABILITY LINK, 1901 Montreal Road, Suite 102, Tucker, GA
[Find more information online](#)

January 22, 10 AM - 12 Noon
Team Lead Training
GCDD Offices, Atlanta, GA
[Sign up FREE online](#)

January 25-26
Big Peach Slam Jam Wheelchair Basketball Tournament - Suwanee, GA
[Register online](#)

January 28, 1 - 2 PM
Tech Tuesday
disABILITY LINK, 1901 Montreal Road, Suite 102, Tucker, GA
[Find more information online](#)

January 29, 8 AM - 12:30 PM
Advocacy Day #1 - Gracie's Law (Organ Transplant Discrimination)
Atlanta, GA - [Register online](#)

January 30, 10 AM - 12 Noon
Team Lead Training
GCDD Offices, Atlanta, GA
[Sign up FREE online](#)

FEBRUARY

February 6, 8 AM - 12:30 PM
Advocacy Day #2 - IPSE (Inclusive Postsecondary Education)
Atlanta, GA - [Register online](#)

February 13, 10 AM - 12 Noon
Team Lead Training
GCDD Offices, Atlanta, GA
[Sign up FREE online](#)

February 19, 8 AM - 12:30 PM
Advocacy Day #3 - Home and Community-Based Services
Atlanta, GA - [Register online](#)

February 20, 10 AM - 12 Noon
Team Lead Training
GCDD Offices, Atlanta, GA
[Sign up FREE online](#)

February 20, 6 - 9 PM
ADA 30 - Nothing About Us Without Us - SILCGA, Atlanta, GA - [RSVP FREE Online](#)

February 25, 2:30 - 4 PM
Advancing Equal Employment Opportunities Webinar
[Sign up for webinar](#)

February 27, 8 AM - 12:30 PM
Advocacy Day #4 - STOPP (School-to-Prison Pipeline)*
Atlanta, GA - [Register online](#)

To find out about more events across the state, visit [GCDD's Calendar of Events](#).

REGISTER NOW FOR

ADVOCACY DAYS 2020



Join GCDD at the Capitol to speak with elected officials about policies affecting people with disabilities!

MARCH

March 4, 10 AM - 12 Noon
Team Lead Training
GCDD Offices, Atlanta, GA
[Sign up FREE online](#)

March 11, 8 AM - 12:30 PM
Advocacy Day #5 - Employment*
Atlanta, GA - [Register online](#)

March 23-25
2020 Disability Policy Seminar - Renaissance Hotel, Washington, DC
[Register online](#)

March 25-27
Year 2 Supported Employment Forum - sponsored by DBHDD, Callaway Gardens, GA
[Find more information online](#)

March 28, Noon - 4:30 PM
Autistic Women's Panel
Woodruff School of Nursing, 1520 Clifton Road, Atlanta, GA
[Purchase tickets online](#)

APRIL

April 16-17, 2020
GCDD Quarterly Council Meeting - Atlanta, GA
[Find more information online](#)

*Topics for these Advocacy Days dates are subject to change, depending on developments during the legislative session.