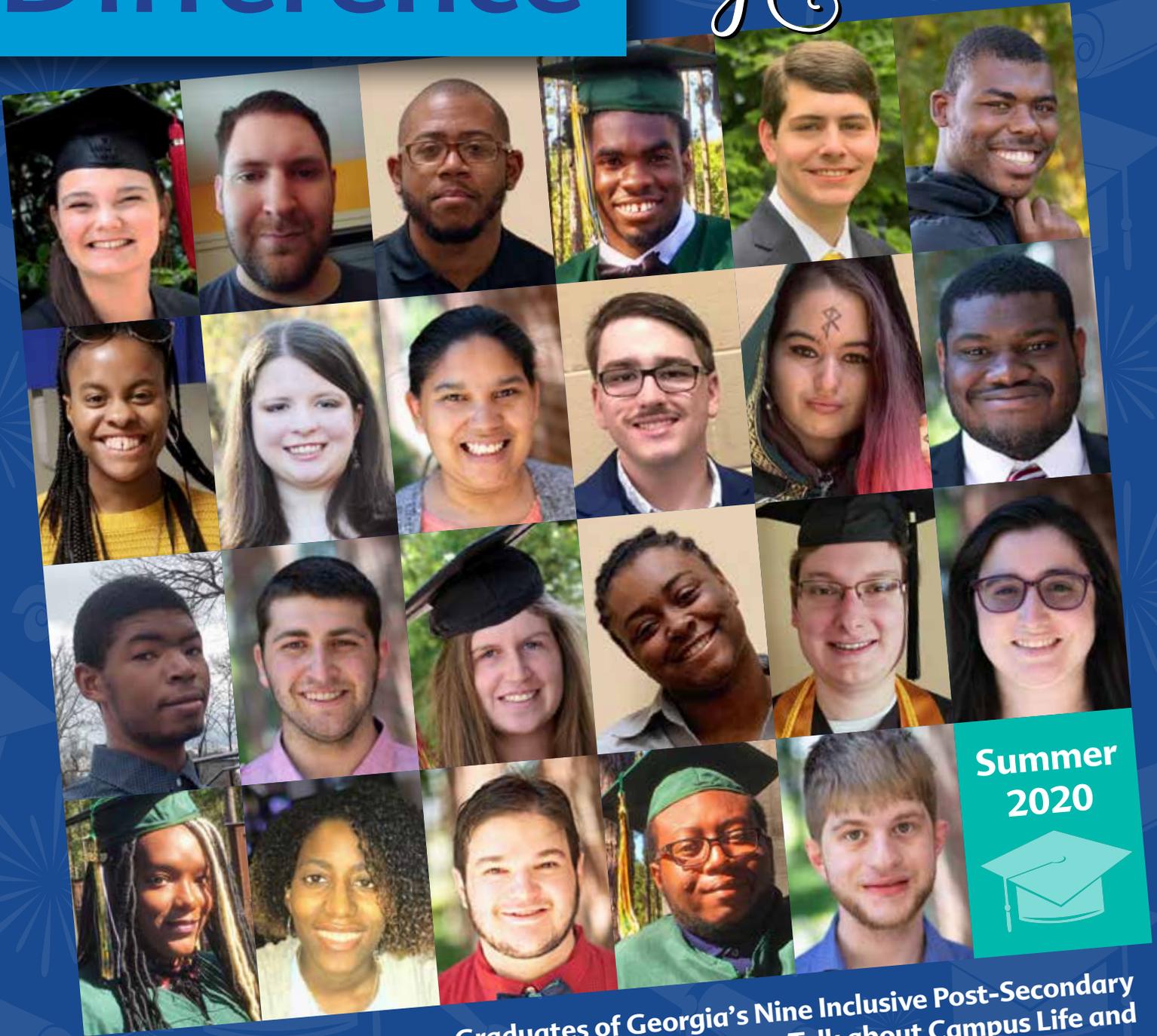


# Making a Difference

Congratulations graduates



Summer 2020



Graduates of Georgia's Nine Inclusive Post-Secondary Education Programs Talk about Campus Life and Give Advice to Incoming Students

[gcdd.org](http://gcdd.org)



**ADA30**  
Americans with Disabilities Act  
*La ley sobre estadounidenses con discapacidades*



Celebrating the 30th Anniversary of the ADA!  
July 26, 2020

# Making a Difference

A quarterly digital magazine from GCDD

VOLUME 21, ISSUE 1 SUMMER 2020

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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by Alyssa Lee, PsyD

*This session can only be described as a roller coaster, with plenty of highs and lows. No one could have predicted we would not have a recap until July due to pausing for COVID-19. Learn what happened in the 11 days when the legislature reconvened to pass the budget.*



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by Clay Voytek

*For students with developmental disabilities, there is rarely a smooth transition from high school to adulthood. Every day, families have tough conversations about aspirations and limitations. Learn from parents who have been there and students who have taken the next step into college and employment.*

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DEPARTMENTS



## JUSTICE AND EQUALITY

**I hope that you are all doing well during this time of great change. Not only have we dealt with a global pandemic, economic chaos and a state primary election riddled with criticism – but now we are witnessing people in the streets asking for justice and equity. Never in many of our lifetimes have we seen an outcry of this scale in the United States. Indeed, this week, this month and this year have been difficult. Still, the Georgia Council on Developmental Disabilities (GCDD) continues to stand in solidarity with those around the world who speak out against systemic racism.**

While I am not a person of color and have not experienced the same kind of oppression as many people in our state and country, I have listened and tried to learn and understand. Like many of you, we continue to fight for change. But how can we work toward meaningful change? Through dialogue, such as those supported by the GCDD Real Communities' Social Justice Dialogues. And through the ballot box and voting for those who are working toward a more peaceful and loving society. Even with the disorder Georgia experienced in June during the primary election, there were examples of people working together to make sure everyone in line was supported.

This edition of *Making a Difference* covers many of the issues discussed above. We continue to be involved in working to ensure people have information concerning COVID-19 through joining the Georgia Developmental Disabilities Network in hosting bi-weekly Zoom calls and compiling curated online resources. Over 1,100 people have signed up to join us to address how the virus is impacting their lives and the supports they need. If you have not been a part of these calls, it is not too late to join.

On the legislative front, because of COVID-19, the Georgia General Assembly did not complete its 2020 legislative session as planned. This means that state senators and representatives were unable to further discuss specific legislation and pass a budget by April, as they typically do. The only constitutional requirement of the General Assembly is to pass an annual budget, which needed to take place so the state could begin its fiscal year on July 1.

The General Assembly began its extended session on Monday, June 15 and held virtual appropriations meetings before then. Among the legislators' priorities was discussing how to cut agency budgets significantly. For people with developmental disabilities, these cuts affected funding for NOW/COMP waivers, family support services and other supports. Despite some reinstatements to the budget, we still believe the state should look at other sources of revenue, such as a tobacco tax increase, to cover this revenue deficit. (*Read more about the session in Public Policy for the People – Recap.*)

Finally, GCDD is about to undertake a five-year planning process. We need to determine the kinds of efforts we will support over the next five



Eric E. Jacobson

years. We need you to be involved. There will be a number of ways that you can provide input into the process over the next year. Make sure that your voice is heard. Check out GCDD's website, and join our advocacy network so that you can stay informed.

**FINALLY, GCDD IS ABOUT TO UNDERTAKE A FIVE-YEAR PLANNING PROCESS. WE NEED TO DETERMINE THE KINDS OF EFFORTS WE WILL SUPPORT OVER THE NEXT FIVE YEARS.** ”

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*

Eric E. Jacobson  
Executive Director, GCDD

# AROUND

# THE STATE



## Congratulations, Graduates!

It's graduation season! Across the state, young people graduated from high school and college throughout Georgia earlier this spring and last fall. *Making a Difference* magazine wanted to celebrate this milestone of the graduates across the nine inclusive post-secondary education (IPSE) programs in Georgia. Meet our grads as they share their favorite class or experience and their one piece of advice for incoming students or those considering attending an inclusive post-secondary education program.

### GEORGIA'S INCLUSIVE COLLEGE PROGRAMS

offer students with intellectual and developmental disabilities a variety of opportunities for growth as they prepare for the next chapter of their lives. These students are able to realize their dream of continuing their studies in a university or college setting with their peers.

- [Albany Technical College LEAP](#) (Albany, GA)
- [Columbus State University GOALS](#) (Columbus, GA)
- [East Georgia State College CHOICE](#) (Swainsboro, GA)
- [Georgia Institute of Technology EXCEL](#) (Atlanta, GA)
- [Georgia Southern EAGLE Academy](#) (Statesboro, GA)
- [Georgia State University IDEAL](#) (Atlanta, GA)
- [Kennesaw State University Academy for Inclusive Learning & Social Growth](#) (Kennesaw, GA)
- [University of Georgia Destination Dawgs](#) (Athens, GA)
- [University of West Georgia Project WOLVES](#) (Carrollton, GA)

[Read more about IPSE programs in Georgia.](#)



#### Abby Amatriain

University of Georgia

My favorite part about college was working out and staying fit.

My favorite part of going to class was working with people.

**My advice:** Work hard so you are prepared to find a good job.



#### Taylor Baker

Columbus State University

My favorite class was Narrative Illustration because it helped me to both improve my artistic skills and get back in touch with my inner child.

**My advice:** Failure is just the first step.



#### Isaiah Branford

Georgia State University

My favorite part of college was making a lot of new friends. My favorite class was Hip Hop and Politics because we got to talk about a lot of interesting stuff and learned about certain political issues. **My advice:** You will really enjoy the IDEAL program and it could make your dreams come true!



This video icon shown by some of the graduates indicates you can [access short videos about their college experiences on the GCDD website.](#)



**Martavious Carroll**  
East Georgia State College

My favorite part of college was having the opportunity to attend as well as meet new people. My favorite class was Public Speaking because I developed skills so that I could talk in front of crowds. **My advice:** Work hard and stay positive. Never get down on yourself. You can do anything that you put your mind to.

**Amara Hazzard**  
Georgia Tech

My favorite part of college was gaining independence, learning transportation, budgeting and meal prep. My favorite class was Abnormal Psychology because it talks about different mental illnesses. **My advice:** Make friends, then focus on getting a job. Have your own bank account and someone you trust to help.



**Tyler Crawford**  
Kennesaw State University

My favorite part of college was living on my own, being independent and making new friends. My favorite class was Culinary because I learned good cooking skills. **My advice:** Be all you can be and take pride in whatever you do.

**Jackson Hurst**  
Kennesaw State University

My favorite part of college was being able to actively go to college and take regular classes with other students. My favorite class was Earth from Above, which introduced me to the world of virtual mapping. **My advice:** Don't let your limitations hold you back.



**Johnique Davis**  
East Georgia State College

My favorite part of college was experiencing living on my own for the first time. My favorite class was Public Speaking because it helped me break out of my shell. **My advice:** Never be afraid to ask for help. The professors are willing to help.

**Lexi Johnston**  
Columbus State University

My favorite part of college was meeting new people. My favorite class was Art History because I like looking at different pieces of art. **My advice:** Find at least one person in each class and get their number so that if you miss one class you can get their notes.



**Nierra Dyer**  
Georgia State University

IDEAL at GSU was my favorite part of going to college. I enjoyed helping out with birthday cards and at my internship. My favorite class was Painting because it was so pretty and colorful and I learned about different colors.

**Ikenna Kamalu**  
Georgia Tech

My favorite part of college was making new friends; singing the National Anthem for GT football; and going on trips with Campus Christian Fellows. My favorite class was Stars, Galaxy and Universe, but I also liked American History. **My advice:** Get to know as many people as you can; making friends makes a big difference.



**Laura Funk**  
Kennesaw State University

My favorite part of college was living independently. My favorite class was Theater because I love to act. **My advice:** Be kind to others.

**Kaelen Knowles**  
Kennesaw State University

My favorite part of college was meeting people from around the world and learning different languages. My favorite class was Japanese 1001 because I really enjoyed the way my professor taught the basics of hiragana. **My advice:** Take your time and relax, don't act on your emotions and ask for help when it's needed.





### Michael Kurland

Georgia Tech

My favorite part of college was joining clubs on campus like Drama Tech because I got to hang out with friends. My favorite class was Theater Production because I got to set up and tear down the stage, stairs and lighting. **My advice:** Be open minded because you might enjoy things and people that you thought you wouldn't like.

### Gwenique Rountree

East Georgia State College

My favorite part of college was being around different people and growing into a better person. My favorite class was Public Speaking because it gave me the opportunity to express myself. **My advice:** Stay focused and organized.



### Malerie Moulder

University of Georgia

My favorite part of college was getting to live in Athens for my last year. My favorite class was Event Planning because this is one of my passions and something I love to do. **My advice:** Enjoy every minute and study the bus routes.

### Natalie Shaw

Kennesaw State University

My favorite part of college was being independent. My favorite class was Advanced Leadership and Career Development because it helped me get ready for the real world. **My advice:** Don't be afraid; there's a lot of support.



### Nadia Osbey

Georgia State University

My favorite part of college was that I already had friends at GSU. My favorite class was Acting because I figured out I have a lot of talents that I did not know I had. **My advice:** Focus on yourself and your work! Always make sure your work is turned in on time.

### Drew Schulman

Georgia Tech

My favorite part of college was making friends and getting to hang out with them. My favorite class was Earth Processes because it taught me more than I have ever been taught or thought I could learn about planet Earth. **My advice:** Do your best with time management, keep a calendar and don't be afraid to ask for help.



### Spencer Patterson

Kennesaw State University

My favorite part of college was making new friends and living on my own. My favorite class was Welding because I got to learn how to make several different weld joints. **My advice:** Only bring what you need, don't clutter the dorm room with electronics and talk to someone new every day.

### Antonio Smith

East Georgia State College

My favorite part of college was obtaining a college education. My favorite class was Criminal Justice because we got to do a lot of debates and fun activities. **My advice:** Always be on time.



### Jessica Rosen

Georgia Tech

My favorite part of college was making and keeping new friends, going to football games and Six Flags. My favorite class was PEERS Curriculum, which taught me a lot of social skills and rules to put into practice. **My advice:** Be yourself, figure out campus and have fun. You will make lifelong friends, just like me.

### Daniel Travis

Georgia Tech

My favorite part of college was meeting new people and making friends on my mentor team because we will be friends forever. My favorite class was Weapons of Mass Destruction because it was a new experience and it was unique and cool. **My advice:** Always be prepared for change – it forces you to be flexible.



# An Interview with Ron Wakefield

by Parker Glick, GCDD Council Chair

Georgia Council on Developmental Disabilities Chairman Parker Glick interviewed Ron Wakefield, director of the Division of Intellectual and Developmental Disabilities under the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) about the state of developmental disabilities services for Georgians with disabilities, the difference between state-funded services and Medicaid waivers and how people can connect with DBHDD.



**Parker Glick:** I'm the new Chair of the DD Council so I'm very excited to be diving into this as a young person.

**Ron Wakefield:** Awesome. Trust me, you are the future and it's always great to see young people getting involved, so thank you.

**Parker Glick:** Thank you. So, I'm going to jump right into it. The movement is comprised of a lot of alphabet soup, so would you mind sharing what DBHDD is and expanding that?

**Ron Wakefield:** Okay. So DBHDD, what a mouthful right? It's actually the Department of Behavioral Health and Developmental Disabilities. It's a state agency created in 2009. We provide treatment and support services for individuals with mental health, substance use disorders and intellectual and developmental disabilities (I/DD). DBHDD supports people who are uninsured, underinsured or on Medicaid.

**Parker Glick:** Wow. That is a lot to know, and of course that is for all of Georgia. And I know that's not all on you, so what specifically is your role over at DBHDD?

**Ron Wakefield:** I'm responsible for management of the entire I/DD services and systems for the state. So I oversee policy; I oversee the entire approval process from when somebody applies for eligibility all the way until they get into services, and also the management of the provider network that would provide services. So the

entire system is under my purview, and thankfully I am not the only one doing all this. I do have a tremendous team that works with me and for me.

**Parker Glick:** Awesome. How do you all work with the developmental disabilities community directly?

**Ron Wakefield:** We are actively involved and engaged. We have six regional offices across the state of Georgia, and in each region, we have staff that is actively engaged with individuals and families that are seeking services or who are in services. We have a central office in Downtown Atlanta at 2 Peachtree Street where I am located, and a number of my directors are located. We are able to oversee services across the state.

Families and individuals can interface with us directly through the central office or through field offices that are close to where they're living. So that's how we organize and ensure people have access to services and deliver our services and actually get involved.

**Parker Glick:** Awesome. Thank you. So one of the primary services that folks seek out in Georgia are the state waivers. Unfortunately, it's not an easy task to take on. Could you provide any insight as to how the state waivers operate and what families can do to navigate that more successfully?

**Ron Wakefield:** When we talk about waivers, there are a few things I would like to make clear. We do have what's called state-funded services (and I will come back to that in a second),

but when we mention waivers, we're talking about Medicaid waivers. We're speaking specifically of two: the new option waiver, which we popularly refer to as the "NOW" waiver, and the comprehensive waiver, which we refer to as a "COMP" waiver.

To be eligible for either one of those, there is a process. First there is a clinical process where people need to apply and we have psychologists who review the applications and review the person's clinical records, primarily their psychological, just to make sure that they meet the eligibility requirement. That's the very first step. The very first step is the application.

**If you're found pre-eligible, then you would get on what's called our planning list. When waivers are available - for this upcoming year the General Assembly approved 100 waivers - so we have 100 new waivers.**

Once you apply, a determination is made whether you are pre-eligible for services or not. If you're found pre-eligible, then you would get on what's called our planning list. When waivers are available - for this upcoming year the General Assembly approved 100 waivers - so we have 100 new waivers. We will do an assessment and base our decisions on who are the most

in need in terms of awarding those waivers. So that's typically the process.

State-funded services, we don't call those "waivers," it's different. Let me just mention that the waivers are funded both by the federal government and by the state. There is a state match along with the money that comes for those waiver services. With state-funded services, there is no federal match so that's all Georgia putting up money to provide state-funded services. With state-funded services, we try to mirror services that are in the waiver because we recognize that there are people who need services immediately and we have the availability to provide that.

There are also services and family support that we offer using state funds for people who are on the planning list while they wait to get into the waiver services.

**Parker Glick:** So, you mentioned while they're waiting, they can seek those state-funded supports while they're waiting on the waiting list?

**Ron Wakefield:** Correct.

**Parker Glick:** Would you mind expanding a little bit further on what those state funds are and how folks can approach those?

**Ron Wakefield:** So what I recommend to every single person who's interested in receiving services from DBHDD is go ahead and submit an application. As I said, once you do that and you're determined pre-eligible for our services you land on a planning list. While on the planning list, we do assessments once you apply for services and then annually to see what your needs are and if there are any changes in the level of needs. That's how we determine who are most in need of waiver services.

While you are on the planning list, you can work with what's called a Planning List Navigator and they will direct you based upon what your presented needs are at that time to apply for family support. That's the

way that you get into services while waiting – sorry, for waiver services.

**Parker Glick:** Excellent. Thank you. We mentioned earlier the state of DD services, and it's somehow connected. Can you explain what exactly state DD services for Georgia are?

**Ron Wakefield:** So, we have various services that are offered. There is community access which really means that somebody receives supports to be able to go out into the community and be involved. There are community living supports where somebody is living at home or in their own apartment but they need somebody to come in and provide some level of assistance during the day or evening.

There are also community and residential alternatives where somebody can no longer live with their family, but can no longer live on their own and they need 24/7 type services – so that's out of home services, out of their residential home. It's the type done in host homes, where somebody lives with an individual or family, and receives services that way or they live in what's typically called a group home. But we typically call it a community living arrangement with three or less other individuals who have similar needs. So staff would come in and provide support needs in that context.

I should also mention supported employment where somebody is interested in getting a job. There are supports in place to help that person receive the training they need and then transition into jobs in the community. So all the services that I just mentioned are both in waiver services and also in the state-funded services that I spoke about earlier.

**Parker Glick:** I personally am a person with a disability so I definitely appreciate the state waiver programs. I appreciate that I am able to choose where I want to live and then the supports come and meet me that way, and I hope that is something that reaches out to the entire community.

**Ron Wakefield:** I wish I could say we had unlimited resources, but we do not. That's probably the hardest part of my job, to know that this is the amount of resources that I have and these are the number of people that we need to serve and then try to make a determination for of all these people and this limited pot of resources. How can we best stretch to serve as many people as possible? That's probably the hardest thing that we do. That's the challenge now and that's the challenge going forward in the future. How can we maximize the resources we have? How can we help people to be as independent as possible?

How can we best stretch to serve as many people as possible? That's probably the hardest thing that we do ... How can we maximize the resources we have?

And their needs vary. There are some people who absolutely need a lot of resources just to be able to make it through the day because they have complex medical needs. So that person would need more resources than somebody who just needs some assistance navigating where they live. So we try to base our decisions on clinical assessments. And, we recognize that if people were not able to access these resources from us, I'm not sure where else they would get them. So I want everybody to understand how important that is to us and how seriously we take that. So our decisions are not made lightly. That's the context in which we plan for the future: how can we best maximize the resources that we currently manage?

**Parker Glick:** And reaching out for these resources is as simple as getting on your website or calling y'all? There is a number? How can folks reach out and acquire these resources?

**Ron Wakefield:** Absolutely. They can call the field offices, they can call the central office, and we just updated our website probably over a year ago. That is a great place to go. [Go to DBHDD and once you get on our website go to I/DD](#) and then you can navigate from there. You can call us, the field office, the central office. And something that we introduced over a year ago, for those who have access to a computer or even a cell phone, [you can access our website and you can now fill out an application online](#).

**Parker Glick:** Excellent. I am personally a firm believer in interdependence and so what can we as a community do to work with DBHDD to expand the resources that are not nearly enough?

**Ron Wakefield:** I recognize how families and how individuals view services. What I'd like people to be more aware of is we do have limited resources and we are trying to make that stretch as much as possible. For some folks who probably, years ago, received all kinds of services and, now, we have done another clinical assessment to determine that they don't need all of those services – it would be awesome if people who are in that situation recognize that, "You know what? I know there are others out there who need these services more than I do." I am not saying you step off the waiver. You stay on the waiver, you use the services that you really need, but others that you don't need, feel free to reach out to the field office support coordinator and tell us what you really don't need anymore. That would help.

When people are getting services, don't come with the mindset that, "I've got to get everything that I can because I don't know when I'll need more or not." What we're trying to do is create a system and a process where as you come in, we'll determine what you need and then we'll offer that.

As your situation or conditions change absolutely we will be flexible to try

and update what is allocated to you. It's really having people think carefully about their services and others because we're all in this together, and of course we would like to serve as many people as we possibly can.

**Parker Glick:** So how about the same question for stakeholders, larger entities that are working side-by-side with you towards supporting the disability community? Like us at GCDD, what are some things that we can do maybe legislatively?

**Ron Wakefield:** So I've really appreciated the partnership with GCDD and we are still going through a crisis because of the pandemic right now. So many things have needed to be adjusted during this time. Some things have changed. During times like this, our resources become even scarcer. What I've appreciated with partners and other stakeholders – not just GCDD, but I do want to give a shout out to GCDD – for instance, Eric Jacobson, we speak fairly frequently and Eric understands what message we want to give to people and so he's been able to assist us with that.

A few years ago, we did some work with our planning list. Some people were scared about what exactly we were trying to do. Limit resources for people? Take away resources from people? It was not that. We wanted to more accurately determine the needs of people on the waiting list. We typically call it the planning list because that's what we use it for. We use it to know who is on the list, assess their needs and plan for the future. But I know people outside of DBHDD consider it to be a waiting list.

Use the services that you really need, but others that you don't need, feel free to reach out to the field office support coordinator and tell us what you really don't need anymore. That would help.

What's significant about that is we try to find out exactly who is on the list and what their needs are, so we can better plan. We explained it to GCDD, and they were able to explain it to families and that is greatly appreciated. We are making sure that we are reaching all the right people who are in need of our services. So the partnership with stakeholders is absolutely critical.

And the same thing goes for when things change and we need to communicate or figure some things out, Having that dialogue with our stakeholders is also critical and essential for us to be able to meet changing demands.

**Parker Glick:** Excellent. Well I don't want to take too much of your day. I know that time is also limited. But I do want to thank you again for being with us and taking the time to answer our questions, clarifying DBHDD and your role, and thank you for the work you do not only in partnership with us but with our community.

**Ron Wakefield:** It's been great chatting with you and it's great to meet you. I'm looking forward to more conversations in the future. Thank you.

**Parker Glick:** Absolutely.

**VIDEO INTERVIEW:**  
Watch the captioned  
Interview of Ron  
Wakefield by  
Parker Glick.

**GCDD**  
GEORGIA COUNCIL ON  
DEVELOPMENTAL DISABILITIES

**EXPERT UPDATE**  
DIRECTOR RON WAKEFIELD  
Division of Developmental Disabilities  
Georgia Department of Behavioral Health and  
Developmental Disabilities

Interviewed by  
**PARKER GLICK**  
Chairman, Georgia Council on Developmental Disabilities

# OFFICIAL 2020 LEGISLATIVE RECAP

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



**Welcome to our official 2020 legislative recap. This session can only be described as a roller coaster, with plenty of highs and lows. For starters, no one could have predicted we would not have a recap for you all until July! Although our state session typically ends in April, it did not end until June 26 this year because of the pause that was required due to the COVID-19 pandemic. Please [read and/or listen to our previous recap](#) of all that took place this session before we had to suspend activity.**

When session officially resumed on June 15, we knew time was limited to get high-level legislation passed. There were only 11 days left to pass the fiscal year 2021 budget, which is required prior to its July 1 start date. When the session resumed, Governor Brian Kemp was proposing all state agencies rethink their budgets and provide 14% cuts instead of the 6% cuts that were proposed in the fall of 2019. You read that right. State officials had 11 days to pass a brand-new budget with deep cuts to all areas of services!

And not only did the budget have to pass, renewed pressure to pass a hate crimes bill had resurfaced after the killing of Ahmaud Arbery and the resulting protests after the murder of George Floyd. Georgia was one of the only states in the nation without a hate crimes law, having had previously passed a hate crimes law that was struck

down by the Georgia Supreme Court for being too vague. The Georgia House passed new hate crimes legislation during the 2019 legislative session, but the bill was sitting in a Senate committee with no signs of moving. The passage of this legislation quickly became top priority.

## BUDGET AND REVENUE

During the 11 days of session in June, we asked a great deal of our advocates, calling on you to advocate virtually through emails, calls and virtual visits with members of our General Assembly. Now that the budget has been officially signed by Governor Kemp ([HB 793](#)), we can say that our advocacy efforts paid off. Our biggest win came in the 100 new NOW/COMP waiver slots that were added to the budget. You all might remember that this was the first year since

the creation of the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) that the governor recommended no new waiver slots be included in the budget. We spent months advocating in January and February and were happy to see that 100 new slots were included in the House version of the budget. And then COVID-19 came along, which resulted in huge revenue losses in the state. New budget proposals were introduced, and again, there were no new waiver slots proposed. We had our work cut out for us because many services were being cut, and it was a long shot to think we could get services added during this time. But that is exactly what we did! We called, emailed, visited and were rewarded with 100 new slots. That totals over \$5 million dollars in new services for people with developmental disabilities. Y'all, that is the power of advocacy!

Not only were we able to secure new waiver slots, we also were successful in preventing the total elimination of the family support program. When DBHDD

## GCDD'S PUBLIC POLICY TEAM



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



CHARLIE MILLER, GCDD Legislative Advocacy Director

## BILLS PASSED that positively impact the disability community

**HB 426** – hate crimes legislation, which revises the criteria for punishment for crimes involving bias or prejudice and includes people with disabilities as a protected group

**HB 987** – increases protections for residents in assisted living facilities and personal care homes

presented their budget proposal with 14% cuts, the family supports program was completely eliminated. We were able to get most of that program reinstated in the budget and limited the cuts to 35% of the program. We recognize that these cuts will negatively affect families in Georgia, and we are prepared to advocate for full reinstatement of funds during the upcoming session.

Our other primary advocacy push focused on increasing our state's tobacco tax. We saw this as an opportunity to bring additional revenue to our state, and more money means more services. Our current tobacco tax is one of the lowest in the nation, and our legislators had an opportunity to raise millions of dollars to offset the budget cuts. Unfortunately, the tobacco tax increase stalled in the House and was not passed. We still have work to do to make sure our representatives understand our position on the tobacco tax. We will continue to push for this increase.

### BILLS

During the final 11 days, we had two main bills signed by the Governor that will positively impact the disability community, [HB 426](#) and [HB 987](#). The first is the hate crimes legislation, which revises the criteria for punishment for crimes involving bias or prejudice and includes people with disabilities as a protected group. The second is a bill to increase protections for residents in assisted living facilities and larger personal care homes.

**OUR BIGGEST WIN CAME IN THE 100 NEW NOW/COMP WAIVER SLOTS THAT WERE ADDED TO THE BUDGET. THAT TOTALS OVER \$5 MILLION DOLLARS IN NEW SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES.** ”

Unfortunately, with COVID-19 changing the course of the 2020 session, and many high-priority bills in the Senate Health and Human Services Committee (which is where Gracie's Law landed), we simply did not have the right set of circumstances on our side to get [Gracie's Law](#) over the finish line. We know that you all worked hard to get this introduced and passed in the House, and we have no doubt that our advocacy efforts will be just as strong in 2021 to get Gracie's Law passed and signed into law in Georgia!

This session was one for the record books, and we couldn't be prouder of Georgia's advocates. Thank you for all of your hard work. We can't wait to advocate alongside you during the 2021 session!



## FINAL LEGISLATIVE RECAP

Watch GCDD's public policy team's final recap video of the last 11 days of the session. (For the previous recap video of all that took place before activity was suspended due to COVID-19, [click here.](#))

# ADA 30: Celebrating the Americans with Disabilities Act

**Georgia Council on Developmental Disabilities (GCDD) Legislative Advocacy Director Charlie Miller interviewed Mark Johnson, renowned disability advocate and former director of advocacy at the Shepherd Center, on what it was like to advocate for the Americans with Disabilities Act, what the future holds and his advice for young advocates.**



**Q Charlie Miller:** What was your biggest “I can’t believe I lived without this” moment once the ADA got passed?

**A Mark Johnson:** Well, I got injured in 1971 and then, I got involved in Section 504 of the Rehabilitation Act in the late ‘70s, but none of them addressed or were as broad as the ADA. So back in those days when – I drive a modified or accessible van – you didn’t really have building codes that addressed access so there were a lot of physical barriers. You weren’t able to use public transit. There were just a lot of issues. You weren’t able to go down to Tybee Island and get on Beach Manning. You weren’t able to access power beach chairs in Orange Beach, Alabama, or Destin, [Florida]. You weren’t able to do all those things so you kind of did what you could do. So, I think the “aha” moment was when I was sitting on the White House lawn on July 26, 1990 with 3,000 other people in very hot weather.

You finally kind of got acknowledged as a person, you know? Not somebody to be treated differently or be



**Change takes time but now we have a new tool in the toolkit and that’s the ADA.**

discriminated against. It was like after all those years where people with disabilities were separated, isolated and discriminated against – it was like, okay change takes time, but now we have a new tool in the toolkit and that’s the ADA. So that one thing was just seeing that many people with that much history and understanding had started a new narrative.

**Q Charlie Miller:** I think it’s really important for us to highlight that, like you were saying, the ADA is there. But there are other laws and other things like the Olmstead decision that has really impacted our community.

**A Mark Johnson:** And think about that. [The Olmstead decision] didn’t come along till like nine years after ADA.

Well, I once had this theory, and I think I’ve told it to you before: “if common sense worked, we wouldn’t need laws.” So unfortunately, we had to pass the law, but sometimes they don’t go far enough. People who study history realized that the law itself should have been enough in 1990, but we had to go and sue the state of Georgia to enforce [the ADA] nine years later. And, if you look at the enforcement or implementation of Olmstead in places like Georgia, the home of Olmstead, we still have a long way to go. So

here we are: 30 years after the law, 30 years after the Supreme Court decision, and there is still a waiting list. What’s wrong with this picture?

**Q Charlie Miller:** Well, I think that brings me to my second question. You’ve seen ADA, you’ve seen Olmstead, you’ve seen the Rehab Act – all really instrumental laws and regulations to help people with disabilities. I was listening to one of Kate Gainers’ interviews and she was saying that she does not envy the younger generation because she sees so many new barriers coming up. It may not be a physical barrier, but it may be a new barrier. In your own knowledge, what do you think will be the next big barrier for the disability community?

**A Mark Johnson:** You still obviously have employment, underemployment. That one hasn’t gone away and it really hasn’t changed much since ADA passed. We still don’t have equal access to healthcare and look what’s happened with the pandemic. We still have a variety of systemic issues whether race injustices or whatever that needs to be addressed. So, you can look even within the disability community and say, “Okay, who tends to be forced into facilities and who tends to be not employed and who tends to have lack of housing?” And, you break that down demographic even more.

And then, we have the same old issues. Just because we say ADA required accessible buses in public systems, then you had to work with over the road coaches, and then you had to work with travel companies. Now you go, “Okay, can I go out to the local RV dealership and find an accessible RV?” When I rent a car or rent a van from a rental company, I have to go to a niche or specialty van company and pay a bunch more than I would have to pay if I would just rent it as a van from a rental company. If you look at Uber or Lyft, we don’t have the same level of access to those transportation modes as other people. I could go on. You asked me for one or two or three and I gave you eight or 10 really quick.

“So here we are 30 years after the law, 30 years after Supreme Court decision, and there is still a waiting list. What’s wrong with this picture?”

**Q Charlie Miller:** I totally agree with that. And I think you’re right. We’ve started a really good opportunity; we have really good laws behind us. And, now we’ve just got to make sure – to get the community to be involved to want to make it as accessible as possible because they see the value in making stuff accessible.

**A Mark Johnson:** Well you’ve always been good with people. You know. It’s easy for you to establish relationships with people. You’re not one to sit inside and not come in contact with people. When it’s all said and done the answer is relationships. You surprised your family; you surprised your family’s



friends. I would think they’re probably looking at access differently now that you’re a young man than they did when you were that kid who uses a wheelchair. “We’ll get him in,” versus now they’re asking, “Can he roll in?” Can he use my bathroom?” Maybe we don’t need to just drag him here or carry him there, but maybe we actually need to accommodate his disability. All of that changes with relationships and attitudes. When you get an attitude change, you get policy change.

**Q Charlie Miller:** So, our final question – and it’s an open-ended question. You’re welcome to spend as long as you want on it. Imagine you’re talking to a young advocate named Charlie. What is one piece of advice you would want to leave to that next generation to give them an understanding of what they are going to have to do and then what do you see as the next big push?

**A Mark Johnson:** At the end of last year, some of us were having a talk about what 2020 might look like. What are the opportunities for 2020, and of course, we were talking about more around this November? What would different outcomes look like? How would people respond based on who gets elected – not just as President but down-ticket? We said it’s going to be one of those transformative years, but that was before we had the pandemic or before we even had

some of the recent protests. And, that was before Gen Z recognized that they’re 10% of the voting population. I’m a Baby Boomer, then you’ve got your Millennials and Gen X, but Gen Z has woken up now and said, “Hey, we potentially control 10% of voters.” It is an opportunity. We’re learning things and we’re not going back.

**MAYBE WE ACTUALLY NEED TO ACCOMMODATE HIS DISABILITY. ALL OF THAT CHANGES WITH RELATIONSHIPS AND ATTITUDES. WHEN YOU GET AN ATTITUDE CHANGE, YOU GET POLICY CHANGE.**

So, it’s like that old Nike saying, “Just do it.” And then it’s like, just do it now. Understand that your personal experience makes you an expert. Nobody’s going to teach you that, and you don’t have to learn that first. Just know that your personal experience makes you an expert, so just go out and be an expert.



# Parents Navigate Georgia's K-12 Education Supports: Planning for the Future

by Clay Voytek

Joshua Williams with his mom Mitzi



When Joshua Williams walked the graduation stage with his peers in 2014, he received a standing ovation. He didn't know what the big deal was, his mother Mitzi Proffitt recalls. After returning for another year to complete a math credit and fighting to receive a diploma over a certificate, Joshua officially graduated from high school in 2015.

Williams, who turned 25 in April, celebrated at home when he graduated from Georgia Southern University in Statesboro this May. The moment was powerful for his family regardless. Amid the disruptions of the global COVID-19 pandemic, he has set up an internship with Georgia Southern's inclusive post-secondary education (IPSE) program, EAGLE Academy, in the fall.

"One day, he said, 'I'm finally proud of myself,'" said Proffitt,

who is also the former chair of the Georgia Council on Developmental Disabilities (GCDD). "That is huge. He finally realized that he has worth."

Williams underwent multiple rounds of interviews, and he didn't want to tell anyone until it was a sure thing. His internship is set to begin the second week of August, and there are no current plans to postpone it due to COVID-19. The job is a first step towards competitive, integrated employment.

For students with developmental disabilities, there is rarely a smooth transition from high school to adulthood. In Georgia, services vary by district and school; individual administrators and teachers are given wide latitude to implement policy. The result is a jumble of stories and experiences that reflect a complicated process. Every day, families have tough conversations about aspirations and limitations. Invariably, the best results require hard, thoughtful work.

**FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES, THERE IS RARELY A SMOOTH TRANSITION FROM HIGH SCHOOL TO ADULTHOOD. IN GEORGIA, SERVICES VARY BY DISTRICT AND SCHOOL.**



## Transition Plans and IEPs

The Individuals with Disabilities Education Act (IDEA) mandates that schools must incorporate transition planning into a student's individualized education plan (IEP) by the time they turn 16. A transition plan is not a separate document; it is one component of a student's overall IEP.

Elise James is a program specialist for transition outcomes at the Georgia Department of Education (GaDOE) with over 40 years of experience in special education. She explains that, according to IDEA, students' post-secondary goals must be guided by their own interests, preferences and gifts.

"It's really not our place to necessarily say, 'You can't do that,'" said James. "Our place is to provide [students] with the opportunities to see what is available and to experience it, so that they can make decisions based on their strengths."

Districts can encourage families to begin planning earlier, but they are not required to do so. The Georgia Vocational Rehabilitation Agency



Meet the graduates from Georgia's IPSE programs on pages 4-6.

(GVRA) services, specifically called Pre-Employment Transition Services, become available when a student turns 14 years old. The GaDOE does not monitor transition planning below age 14.

“Now, in terms of the actual paper itself, there is no set IEP nationally or even statewide,” James said. “Every district can design their IEP in whichever way they’d like.”

In Georgia, district administrators are responsible for presenting options to parents, and resources vary by location. School administrators and professionals have a meaningful impact on student outcomes. In addition to assisting with transition, teachers in special education conduct lessons, collect data and facilitate IEPs for every student on their list.



**Each student is different, so there is no one best path. As families and students plan for new circumstances, it can be especially difficult to manage their options, supports and the law.**

When students with developmental disabilities leave high school, they have a variety of options. Post-secondary plans can include internships, apprenticeships, tech school, college, IPSE programs, employment, Project SEARCH, or other pathways funded via GVRA, the Georgia Department of Behavioral Health and Developmental Disabilities or private pay. Each student is different, so there is no one best path. As families and students plan for new circumstances, it can be especially difficult to manage their options, supports and the law.

## Students’ Rights During and After Transition

The key difference between a student’s rights in high school and beyond is the responsibility of disclosure.

When students leave high school or turn 22 years old, the U.S. Department of Education’s Individuals with Disabilities Education Act (IDEA) no longer applies to them.

Additionally, the Free and Appropriate Education (FAPE) rule is also gone after high school, making it harder to ensure accommodations are met. Under FAPE, schools cannot discriminate. Without that protection in college, the burden is on the student to request and prove need for accommodations.

But their rights essentially remain intact. Through adulthood, people with disabilities are protected by Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA).

If a student chooses to go to college and passes the admission requirements, they have the right to receive accommodations under federal law, but they must self-disclose their disability.

In the public school system, it is the school’s job to identify and support students with disabilities. In college, a student must seek out and notify the university’s office of disability services. To receive certain workplace protections, people must also disclose their disability to employers.

Proffitt, the director of support services at Parent to Parent of Georgia (P2P), says that transition is when



Ryan Ramirez with his mom Stacey

all the disability entities begin to really weigh on a parent. For instance, it took her seven years to get a Medicaid waiver.

“You’ve got to be ahead of it,” she said. “It’s hard, but you’ve got to have a plan. The IEP teams have to have a plan. The parents have to have a plan. There have to be some options.”

The choice to pursue higher education is made on an individual basis, and transition plans are meant to be as personalized as the supports named in a student’s IEP. Most schools use career assessments to help determine a student’s goals. Then, school-level professionals are meant to be a main source of guidance and exposure to potential opportunities.

“That over-arching goal should really be based on data,” said Angel Snider, a transition specialist and district success coach with Marietta City Schools. “It should be based on some kind of interview with the student, or an assessment.”

## Navigating the Path

Despite federal and state guidelines, the process doesn’t always work as intended, and it has the potential to be a negative experience for both students and parents.

Stacey Ramirez’s son Ryan loves travel and calendars. Given a date, he can spout its exact day

of the week in under a minute. Before the coronavirus, he was visiting every state in the country – alphabetically. His cancelled trip to Idaho would have brought him one closer to finishing the “I” states.

“For Ryan, it’s travel, and it’s books; it’s being with people; its movies, and it’s animals,” Ramirez said.

When Ryan was in high school, his gifts weren’t factored into his IEP. Ryan is a person with autism, and Stacey recalls his time in school as a nightmare fraught with relocations and court battles. Ryan attended Harrison, Kennesaw Mountain and Hillgrove High School in Cobb County. After a series of traumatic experiences, he left school with a Georgia Alternate Assessment (GAA) certificate when he was 18 years old.

“One day, he came home sweaty and upset,” Stacey said. As a part of the school’s vocational program, he had been in the yard picking up trash on a hot day. In another instance, a parent called Stacey asking about Ryan’s new job as a janitor at the school. At 16, he was not employed or compensated in any way; he was providing free labor, though not by choice. Stacey says the issue wasn’t the status of the work, but the lack of consideration for who her son is as an individual and lack of relevance to his transition plan.

When he left high school, Ryan wanted nothing to do with an

IPSE program. He’s about to turn 26, and Stacey, who is the state director of the Arc Georgia, says the family is working to reconcile the post-traumatic stress of his high school experience to this day.

Until recently, Ryan worked at Zaxby’s. He liked the job, but he turned in his two weeks notice after they cut his hours. Stacey says life is more mundane in the pandemic. Still, she doesn’t miss the days of transition planning.

“The transition process is about the person,” said Stacey. “It’s about the student. It is not about what the school offers. The focus and spotlight have to continue to be on the student with a view of great capacity and community involvement. That’s not what’s being done now.”

Each family has its own experience. Not all are negative, but every story represents a winding path with its own anxieties. Ganesh Nayak recently wrote an editorial in the Atlanta Journal-Constitution about his son Ishan and life during the pandemic. Ishan, an 18-year-old with cerebral palsy, is a student at Pope High School in Cobb County. He’ll be in school until he’s 22, but the doors closed over two months ago due to COVID-19.

Since Ishan was 16, he has had a transition plan. It’s updated every year with his IEP after the family completes a lengthy questionnaire, and the school passes along transition-related information.

“They’re doing their bit, and it’s up to us to see how to consume that information,” said Ganesh, who is the co-chair of the State Advisory Panel for Special Education in Georgia. Views expressed are his own as a parent. “We know

the teacher very well because she lives in the neighborhood. That makes a big difference, actually.”

Ishan is a people person, and Ganesh says the primary focus of his schooling at the moment is more functional skills. The family still has time to figure out the specifics of Ishan’s plan, and they feel supported by his school. The Nayaks have looked into day habilitation programs, but there are no obvious fits in their area.

**EACH FAMILY HAS ITS OWN EXPERIENCE. NOT ALL ARE NEGATIVE, BUT EVERY STORY REPRESENTS A WINDING PATH WITH ITS OWN ANXIETIES.**



“Fortunately, we’ve had good teachers all along,” said Ganesh. “It makes a whole difference ... That relationship should always be one of trust and collaboration rather than being at odds.”

For now, the family deals with more immediate anxieties: the stream of breaking news, the risk of the virus and concern for their extended family in India. With the encouragement and assistance of his teachers, Ganesh says the stress of transition hasn’t yet come to the fore.

Despite the Nayaks’ positive experience with Ishan’s school, professionals can disappoint their students. When educators fail to center the child’s strengths and ambitions in transition planning, to consider them fully, they do more harm than good.



Ishan Nayak (center) with his parents Ganesh and Sitara.



**THE TRANSITION PROCESS** is about the person. It's about the student. It is not about what the school offers. The focus and spotlight have to continue to be on the student with a view of great capacity and community involvement.



Stacey & Ryan Ramirez

Stacey reflects on her experience for Ryan. “When I’m in the moment, of course it was hurtful and harmful ... for my child to be considered less than he is, but upon reflection, it’s just a lack of the ability to see more,” she said. “In my heart of hearts, I think they thought they were doing a good job, and they were doing the right thing for Ryan. How dare you not be realistic about your son’s outcomes? You know?”

Ultimately, all students are guaranteed the same protections under the law, but the reality of every family is different. At Marietta High School, Snider uses her own education philosophy based on inclusion and collaboration – rooted in her high school experience witnessing segregated basement classrooms for students with disabilities.

“Everybody has goals that they want to obtain whether they have a disability or not,” Snider said.



Martha Haythorn was an intern at the Arc Georgia.

“Everybody wants to have friends. Everybody wants to be successful. And success looks different for everybody. I think in order for us to function at our best, we need to include everyone in that plan. That just makes us better people.”

**Better Outcomes**

In the fall, Martha Haythorn will be among thousands of other incoming first years attending the Georgia Institute of Technology in Atlanta. The circumstances are less than ideal, but classes are expected to resume as scheduled. This spring, she graduated from Decatur High School. Haythorn received immense support from her family, teachers and mentors, but the accomplishment is her own. She is bubbly and confident, and she couldn’t be more excited for the future.

“They accepted me on the spot right after my interview,” Haythorn said. “There was a second of silence, and then there were tears coming down my face, real tears. I was so proud of everything that I’d worked for ... They really saw that I am capable of being a college student. Yes, I have Down syndrome, but I’m more than that.”

Haythorn successfully underwent the application process for Georgia Tech’s IPSE program, Excel. She loves to learn and is honored to be able to learn new, interesting material among her peers. Haythorn plans to study psychology and U.S. history.

Her dream is to work as an advocate or lobbyist in

Washington, D.C. to effect national change. She says all young people with disabilities should receive the same treatment and opportunities as their peers.

“It’s going to be a process,” said Haythorn. “There are certain steps you have to follow, but you will get there. It’s going to take time, but guess what? You’re going to be able to do it. You just need more time, and you will accomplish your dreams.”



**I was so proud of everything that I’d worked for ... They really saw that I am capable of being a college student. Yes, I have Down syndrome, but I’m more than that.**

Over the last year, she has worked three separate internships. Haythorn currently takes the MARTA blue line to her job as the policy intern for the Arc Georgia, where she’s found a mentor in Stacey. Haythorn says that with the help of parents, teachers or mentors, young people can find their true selves.

“I always feel like a real intern, doing something that is totally me,” Haythorn said about her work with Stacey and the Arc. “I love it because [Stacey] really sees my ability. And it shows that it doesn’t matter if you have a disability. What matters is you



have many abilities to do whatever you dream of, and whatever you dream can come true.”

“Talk about tapping into someone’s gifts and capacities,” Stacey said. “It’s hard to find a place where Martha’s not going to bloom.”

In the midst of the pandemic, Snider has warm stories from Marietta High School. As a transition specialist, she manages transition plans while working with students and referring them to agencies or programs. Through the school’s Check and Connect program, one mentor brought a student a birthday cake. Another student dropped out, only to re-engage with her mentor just recently.

Snider accompanied him to his training and helped out. Snider says she works hard to stay connected to local agencies and partners, including the parent mentor in her county, Susan Hand.

For parents who may be planning their own student’s transition at this moment, COVID-19 is a complicating factor. James notes that schools and the state are accountable to federal law, and the law remains the same.

“The requirements of transitioning students with disabilities did not get waived with the pandemic,” said James. “We’re still obligated to provide those services.”

After a delay due to COVID-19, the Marietta City Schools district is planning to start Project SEARCH in the fall of 2021. Since the coronavirus, Snider says she’s seen innovation and adaptability from professionals and advocates, as well as a willingness to share available resources virtually.

### **Vocational Rehabilitation, Other Resources and Paths to Employment**

In March, Stacey applied for a case for Ryan through the Georgia Vocational Rehabilitation Agency (GVRA). There is no age limit for GVRA services, but people with disabilities who want support in going or returning to work must submit an application to receive assistance. Once the agency determines eligibility, they assign a case worker and begin developing an individualized plan for employment, or work plan. They’ve been in contact, but Stacey says it may not be the time for Ryan to get a new job.

Lee Brinkley Bryan is the transition services director



**Planning for transition is a natural extension of the IEP process, and both can involve the same frictions. Dedicated professionals and devoted parents agree that collaboration and consideration of the individual are essential.**

at GVRA; she oversees hundreds of staff around the state. Bryan says services will continue through the pandemic, and she notes that anyone experiencing communication delays should call the customer care number on their website.

“The offices, like all other state offices, are closed, and people are teleworking. But our work continues,” said Bryan. “We are in uncharted territory with COVID-19 just like everybody else. We’re doing everything we can to continue to provide services.”

In the past, GVRA has been criticized by parents and advocates for a variety of reasons, from poor service to understaffing. Proffitt prefers to recommend other agencies to parents before GVRA. Bryan said that in some cases, clients are reassigned to new counselors, and she asks for feedback from any family with concerns.

“[GVRA] has faced some challenges over the last few years with our staffing and our ability to cover the schools as we would like to,” said Bryan. “But plans are in the works for increased staffing across the state ... I don’t

## **THE REQUIREMENTS OF TRANSITIONING STUDENTS WITH DISABILITIES DID NOT GET WAIVED WITH THE PANDEMIC. WE’RE STILL OBLIGATED TO PROVIDE THOSE SERVICES.**



“One of our students is doing work-based learning through the school, and he just started out doing an internship at an assisted living facility first semester,” Snider said. “He has a low-incidence disability: wonderful young man, hard worker, very dedicated. They hired him right before the pandemic hit. He’s actually been working in [the] assisted living facility this whole entire time.”

The student is comfortable with the circumstances, as is his family, and the facility takes precautions. When the student first got hired,

want [parents] to read these words and think we're describing a world they don't recognize. I want there to be hope."

There are other paths to employment beyond GVRA; everyone has their own potential. It might take a search, though. There are [many resources online](#), and parents can get support from local groups or agencies. Proffitt even suggests making the case directly to a business, taking direct initiative to secure the dream of gainful employment.

"My biggest thing is, nobody wants to go into companies and try to sell it to them," says Proffitt, Joshua's mom mentioned earlier. "Because all we ever hear is, 'Oh, your child's a liability. Oh, we don't want them to lose their services.'"

Transition councils are another resource for families of young people with developmental disabilities. Proffitt has sat on the Three Rivers Transition Council for the last few years. Councils are made up of teachers, parent mentors, advocates and agency representatives that collaborate to bring tools and resources to families. Council presence depends on location, but location and contact information can be found on the [P2P website](#).

Anne Ladd, a family engagement specialist at the GaDOE, says most parent mentors in the [Georgia Parent Mentor Partnership \(PMP\)](#) work on transition as well as K-12 education supports. Ladd says parent mentors bring different skill sets and dynamics to each district they serve.

"Parent mentors are also those go-to experts on family, school and community connections in

their school district or in their department," said Ladd. "They're the boots on the ground. It's a path they're going to have to go down."

Ladd's son Matthew graduated high school in 2017. Like many other parents' stories, things didn't go according to plan. Despite uncertainty, Ladd notes that they were able to pivot by connecting to community resources and developing strong relationships.

"Things did not go as we expected that they would," said Ladd. "You love to have everything laid out, and then, wham! It's not going to be that way. What was really important for us was the relationships and the connections that we had established."

### So, When Do Parents Start?

Many professionals and parents who have gone through the process recommend parents begin planning as early as possible. Exposure, encouragement and inclusion are essential building blocks of any transition plan. Seeds of possibility can be planted by educators and parents at a young age. Across the state, families are in different stages of the process.

"It's a tough conversation," said Nayak. "There's always the anxiety about the future. Because we are an immigrant family, we don't have any immediate family here, and that makes it that much more difficult when you think about what's next. What's after we go? Those are difficult questions, and we're still grappling with that."

Education protections and supports are constantly changing. James says even though federal law mandates transition planning by age 16, parents can't start the conversation too early.



Matthew Ladd with his father Paul and mother Anne

"The truth of the matter is that students are only going to know what they have been exposed to," said James. "You really have to start the day you put the pen to the paper to write the first IEP."

Planning for transition is a natural extension of the IEP process, and both can involve the same frictions. Dedicated professionals and devoted parents agree that collaboration and consideration of the individual are essential. Snider has children of her own. She recognizes her teachers know her daughter as a student, but that isn't everything.

"I know her in a different way," Snider said. "I know what helps her go to sleep at night, and what she likes in the morning when she wakes up. Things like that ... it needs to be a team approach. I think the earlier a parent gets started looking at things and talking about the future, the better."

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*This feature is Part 2 of GCDD's Education Series to help families and students navigate the IEP process in order to transition from high school into college or employment. [Part 1 covered education rights and the IEP process from primary years through high school and can be accessed on the GCDD website.](#)*

# LEARN THE LINGO Resource Guide

**ADA** – The Americans with Disabilities Act (ADA) is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.

**Check & Connect** – Check & Connect is a program offered at Marietta High School in Georgia that provides mentors to keep students on track toward graduation.

**FAPE** – Students with disabilities have a legal right to a Free and Appropriate Education (FAPE). The right is guaranteed by the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act.

**GAA** – The Georgia Alternate Assessment (GAA) is a key component of the Georgia Student Assessment Program which ensures that all students, including students with significant cognitive disabilities, have access to a general curriculum that encompasses challenging academic standards.

**GaDOE** – The Georgia Department of Education (GaDOE) administers Georgia's public school system. Its job is to identify and support students with disabilities from kindergarten through high school.

**GVRA** – The Georgia Vocational Rehabilitation Agency (GVRA) provides Pre-Employment Transition Services that become available when a student turns 14 years old.

**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.

**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.

**IPSE** – Inclusive Post-Secondary Education (IPSE) programs are inclusive college programs that offer students with intellectual and developmental disabilities a variety of experiences and opportunities for growth as they prepare for the next chapter of their lives.

**P2P** – Parent to Parent (P2P) 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.

**Project SEARCH** – Project SEARCH is a business-led, high school-to-work transition program, serving students with significant intellectual and developmental disabilities (I/DD). It takes place entirely at the workplace and the goal for each student participant is competitive employment.

**SECTION 504** – Section 504 of the Rehabilitation Act of 1973 requires that school districts provide a free appropriate public education (FAPE) to qualified students in their jurisdictions who have a physical or mental impairment that substantially limits one or more major life activities, regardless of the nature or severity of the disability.

## COVID-19 COMMUNITY CALLS NOW EVERY OTHER TUESDAY!

Please continue to join us every other Tuesday (beginning July 14) at 3 PM for our Zoom meetings to share your thoughts about COVID-19 and connect with others in the Georgia disability community. You must register in advance for each call.

## COVID-19 Resources

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

- Georgia-based agencies/ organizations
- Federal resources
- Global organizations
- Community organizations



# COMMUNITY CALENDAR

## JULY

July 19 - 20

**Camp To Be Independent 2020!** Camp Twin Lakes, Rutledge, GA  
[Register online](#)

July 20 - August 7  
**NCIL 2020 Annual Conference on Independent Living: Evolution of our Revolution (Virtual)**  
[Register online](#)

July 20, 4 - 5 PM  
**Community Strong! with Uniting for Change and Self-Advocates** Zoom Call  
[Register online](#)

July 21, 2 - 3 PM  
**Beginner's Zoom Tutorial**  
The Arc Georgia  
[Register online](#)

July 22, 12 - 1:30 PM  
**Disability & the Media: An ADA Anniversary Discussion**  
[Register FREE online](#)

July 27, 4 - 5 PM  
**Community Strong! with Uniting for Change and Self-Advocates** Zoom Call  
[Register online](#)

July 28 - 30  
**SEPSEA 2020 Virtual Conference** Zoom Call  
[Register online](#)

July 30, 3 - 4 PM  
**Taking Care of Your Home**  
[Link to video meeting](#)

## AUGUST

August 1, 9 AM - 3 PM  
**Special Needs Kids Day At The Lake** Lake Allatoona, GA -  
[Register FREE online](#)

August 3, 4 - 5 PM  
**Community Strong! with Uniting for Change and Self-Advocates** Zoom Call  
[Register online](#)

August 6, 12 - 1 PM  
**Windmills vs Walls Virtual Lunch** Synergies Work  
[Register online](#)

August 6, 7 - 8 PM  
**Lekotek of GA Parents Support Group** Zoom Call  
[Register online](#)

August 7, 1 - 3 PM  
**Path to Housing** Georgia Advocacy Office, Decatur, GA  
[To register for this FREE class, email \[cmitchell@thegao.org\]\(mailto:cmitchell@thegao.org\)](#)

August 10, 4 - 5 PM  
**Community Strong! with Uniting for Change and Self-Advocates** Zoom Call  
[Register online](#)

August 17, 4 - 5 PM  
**Community Strong! with Uniting for Change and Self-Advocates** Zoom Call  
[Register online](#)

August 21, 5 - 6 PM  
**Lekotek of GA Sibshop**  
Zoom Meeting  
[Register online](#)

August 24, 4 - 5 PM  
**Community Strong! with Uniting for Change and Self-Advocates** Zoom Call  
[Register online](#)

August 28, 3 - 7 PM  
**2nd Annual Disability Resource Fair** - NorthStar Church, Kennesaw, GA -  
[Order tickets FREE online](#)

August 31, 4 - 5 PM  
**Community Strong! with Uniting for Change and Self-Advocates** Zoom Call  
[Register online](#)

## SEPTEMBER

September 11 - 12  
**NADSP Annual Meeting and Conference: The Sixth One**  
Hyatt Regency Milwaukee, WI  
[Register online](#)

September 17, 7 - 8 PM  
**Lekotek of GA Parents Support Group** Zoom Call  
[Register online](#)

## OCTOBER

October 15-16, 2020  
**GCDD Quarterly Council Meeting** - Atlanta, GA  
[Find more information online](#)

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



# What's Happening in Washington?

## Federal Disability Policy Updates

By Alison Barkoff and Erin Shea,  
Center for Public Representation

Over the last few months, we've seen the devastating impact of COVID-19 on people with disabilities, who are struggling to get the home and community-based services (HCBS) they need to stay safe in their own homes and face a high risk of infection and death in institutions and other congregate settings.

We've seen discrimination in accessing care, a problem amplified for Black people with disabilities who have the highest rates of infection and hospitalization. And the recent police violence has laid bare the institutional racism that underlies the healthcare and criminal justice systems. The disability community is fighting tirelessly to get these disparities addressed and below, we detail some of that work.

### COVID-19 Response:

#### Congressional Response:

The COVID-19 crisis led to a flurry of Congressional activity in March that we summarized in our last column. While the three bills passed by Congress have provided some relief, the disability community's most urgent priorities – particularly dedicated funding for the HCBS on which people with disabilities rely – were not included.

On May 15, the House passed a fourth relief package, the HEROES Act (HR 6800),

that includes dedicated funding for HCBS, among other still-unaddressed priorities. The Senate has not yet taken up the bill for consideration; however, when the Senate does act, it is expected it will pass a much smaller bill than the one that passed in the House, meaning we will need your help to make sure the needs of the disability community are included in the final bill.

In addition to COVID-19 relief, Congress has just begun considering bills in response to calls for police reform across the country. An estimated one-third to one-half of people killed by police are people with disabilities, making the intersection of race and disability critical to these conversations. We will keep you updated as reforms move forward.

#### Federal Agency Response:

In March, Congress allocated \$175 billion to a provider relief fund being distributed by the Department of Health and

Many of these plans put people with disabilities at the back of the line for care, or even flat out deny them care.

Human Services (HHS). HHS has distributed significant sums to Medicare and hospital providers, but none yet to any Medicaid HCBS providers. Due to a huge push from disability advocates and members of Congress, HHS announced on June 9 that it would be distributing \$15 billion to Medicaid providers. While this funding is desperately needed, it is not a replacement for the dedicated HCBS funding in the HEROES Act, which will among other things help prevent cuts to HCBS as states (like Georgia) are reducing their state budgets.

With the attention on high infection rates and deaths in nursing homes, the Centers for Medicare and Medicaid Services (CMS) recently announced several nursing home initiatives. These have included requirements to report infections to residents and their families and share data with the Centers for Disease Control and Prevention (CDC), as well as the formation of a nursing

home commission to make recommendations about reforms. Disability advocates, however, have been pushing CMS to expand its initiatives to cover all people in institutional and congregate care settings, who are facing the same risks as people in nursing homes. In addition, we have urged CMS to expand initiatives to include strategies to divert unnecessary admissions and to transition people back to the [community](#). We'll keep you updated as these initiatives move forward.

**Medical Rationing:** [In our last column](#), we discussed the increasing concern of the disability community about discrimination against people with disabilities in access to care during the coronavirus pandemic and guidance issued by HHS' Office of Civil Rights (OCR) in response. Since then, there has been an increased focus on the Crisis Standards of Care that many states and hospitals are relying on during the pandemic to make decisions about how to allocate scarce medical resources like ventilators. Many of these plans put people with disabilities at the back of the line for care, or even flat out deny them care. CPR and partners have filed a number of [complaints](#) with OCR challenging states' discriminatory crisis standards of care, three of which have already been resolved and led to policy changes. In addition, CPR and partners developed an [evaluation framework](#) to assist stakeholders in evaluating Crisis Standards of Care plans in their states.

**Hospital Visitation Policies:** Around the country, hospitals and other health care facilities have enacted strict no-visitor policies to

contain the spread of COVID-19. While these policies often include some exceptions, like for parents of minors, for example, many do not include exceptions for people with disabilities who need support from family members or staff to have equal access to medical treatment.

HHS OCR's March [guidance](#), discussed in [our last column](#), makes clear that states and hospitals are legally required to provide equal access to treatment for people with disabilities, and that may include providing reasonable accommodations. In May, we filed the first OCR complaint about a state's hospital no-visitor policy, alleging that Connecticut's policy denied people with disabilities equal access to care. On June 9, OCR announced a resolution, setting a national precedent for the types of modifications hospitals and states must have in place for people with disabilities. To help stakeholders evaluate how well their state and local hospital or health care facility are complying, we released an [Evaluation Framework for Hospital Visitor Policies](#).

### Litigation Updates: [United States vs. Georgia](#)

**(GNETS):** [In our last issue](#), we updated you on a recent court decision allowing the lawsuit filed by the Georgia Advocacy Office, CPR and partners challenging the Georgia Network for Educational and Therapeutic Supports (GNETS) program to move forward. On May 13, a separate lawsuit filed by the Department of Justice (DOJ) challenging GNETS was also allowed to do so, meaning both cases can now move forward after sitting for almost [two years](#).

### Affordable Care Act Lawsuit:

The lawsuit challenging the Affordable Care Act (ACA) is before the Supreme Court. On May 13, CPR joined a "friend of the court" brief about the importance of the ACA to [people with disabilities](#).

### Get More Information About:

- [Disability-related provisions included in the COVID-19 relief packages passed by Congress](#)
- [HEROES Act \(list of what is and is not included\)](#)
- [HEROES Act advocacy and action you can take](#)
- [Advocacy to expand CMS' nursing home initiatives](#)
- [Medical Rationing resolutions: Tennessee - \[here\]\(#\) and \[here\]\(#\) Pennsylvania - \[here\]\(#\) and \[here\]\(#\) Alabama - \[here\]\(#\) and \[here\]\(#\)](#)
- [Medical Rationing federal and state advocacy](#)
- [Resolution related to Connecticut's hospital visitor policy - \[here\]\(#\) and \[here\]\(#\)](#)
- [GNETS litigation](#)
- [Affordable Care Act litigation](#)

These updates represent only a small portion of our work. For more, 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 6/30/2020*

# Keeping the “Welcome” in Welcoming Community Dialogues

by Jennifer Bosk

As the world deals with COVID-19, the typical way of gathering for day-long brainstorming and discussions, going out into neighborhoods and doing face-to-face contact, are no longer viable options.

Like many other groups and organizations, each of the Georgia Council on Developmental Disabilities’ (GCDD) Real Communities Partnerships worked diligently to find their new normal to carry on the work of their Welcoming Community Dialogues (WCD).

The Real Communities Partnerships, launched in 2010, equips community members with support to gather and focus on people with and without disabilities in a grassroots effort to make sure their neighborhood and local environment is workable and livable for all. GCDD assists these communities with technical assistance, training, popular education and financial support. All Real Communities Partnerships work to ensure the four commitments of the initiative.

Onnie Poe, the founder of Filling in the Gaps, LLC in Augusta, GA, recently organized a series of four *Authentic Dialogues & Virtual Deliberation* gatherings on Zoom, the online meeting platform. Topics covered were “Life in the Time of Corona,” “Mental Health: Reducing the Stigma,” “Finding Healing in Daily Lives” and “The Power of Empathy.”

Poe said she feels the best discussion was the one on mental health and mental wellness. “At the end of our discussion, I asked what next steps were going to be taken, and five of the participants said they would be seeking help with their mental health issues,” she said.

Each of the Authentic Dialogue sessions reached 15 participants, on average. Poe added, “I had originally planned to have just two dialogue sessions and expected 50 participants. But now that we’ve done four and expect to do more with less people, the ‘meat’ of the dialogue was much greater than I ever expected.”

The online dialogue series utilized the style of Living Room Conversations, which defines its talks as, “a conversational bridge across issues that divide and separate us.” A PowerPoint for each topic was sent to registered participants and provided a list of



questions allowing individuals to prepare their thoughts and answers ahead of the dialogues.

There are more dialogues being planned around the topic of people with disabilities to engage parents of children with disabilities.

“I want to do more to connect these families so all voices can be heard in a safe environment,” Poe said. These conversations will be offered in August with a back-to-school focus. Those interested should email Poe at [fillingthegaps831@gmail.com](mailto:fillingthegaps831@gmail.com).

Compassionate Atlanta partnered with Georgia Public Broadcasting to show the film Community First.

## Commitments of Initiative

1. People with developmental disabilities are active members.
2. Action focuses on making the community better for everyone.
3. Over time, the initiative builds up local capacity for collective action.
4. Participants take responsibility for sharing what they are learning.

**I WANT TO DO MORE TO CONNECT THESE FAMILIES SO ALL VOICES CAN BE HEARD IN A SAFE ENVIRONMENT.**



Global Ubuntu of Lilburn, GA, now provides oversight for the Real Communities Partnership. They began their relationship with GCDD’s initiative in 2019, growing the number of participating communities as well as providing opportunities for those representing the Real Communities to come together to share ideas and receive additional training.

Sumaya Karimi, founder and director of Global Ubuntu, says her organization will host their second annual Summit on September 26, bringing all the participants together to not only celebrate the

past 10 years of the initiative but to discuss what the next 10 years could and should encompass.

If you would like to read more about this initiative and the

organization providing oversight, please go to [GCDD Real Communities Partnerships](#) and [Global Ubuntu](#).

## Staying Connected During COVID-19

*There are multiple Welcoming Communities Dialogues taking place throughout Georgia and most have been able to stay active during COVID-19. Here's a snapshot of what some of those communities are doing to stay connected to those living and building inclusive cities and towns:*

### The Ark Refuge Ministries, Inc., LaGrange

This nonprofit is planning a series of WCD workshops starting in July and you can sign up for information by emailing [contact@arkrefuge.net](mailto:contact@arkrefuge.net). Organizers are looking at alternatives to virtual workshops, as many of their participants do not have access to the internet and electronic devices. One possibility is to conduct these in-person workshops outdoors in accordance with the Center for Disease Control's guidelines regarding social distancing. The workshops will focus on returning citizens and persons with disabilities who are experiencing financial, housing and employment hardships back into the community that [The Ark Refuge Ministries](#) serves.



### Colquitt County Arts Center, Moultrie

Normally, the Open Studio for All WCD is held at the Arts Center so community members can gather with one another, discuss community issues and create art. Since COVID-19, it has shifted to a virtual Open Studio.

Participants may still register online as usual and pick up their art materials, without contact, from the Colquitt County Arts Center drive through. Later on the pickup day, participants can log in to a virtual gathering for check-in, community discussions and short creative lessons.



Participants pick up art materials for Open Studio at the arts center drive through.



Graphic above was created by Claudia Lopez, Founder, On The Right Mind

### Compassionate Atlanta, Metro Atlanta

This organization is working on the intersection of gender, sexuality and disabilities and moved their discussion to a Zoom meeting with a small group who had experience in those areas. The next meeting on this topic will include allies, advocates and service providers. The group's other focus is on race and disability. They partnered with Georgia Public Broadcasting to show the film *Community First* and then hosted an online panel discussion on the challenges of affordable housing related to race, LGBTQ and disability. As more webinars and events are added, you will find them listed on the [Compassionate Atlanta](#) website.

### ConnectAbility, Dahlonega

Through its Meet Your Neighbor Dialogue, ConnectAbility has been hosting Family Fun Nights that have included a magic show, children's book illustrator and a puppet/comedy show all online due to COVID-19. It also hosted Small-Town Celebrity Story Time featuring stories read online by local resident celebrities; and Tuesday night concerts on Facebook Live to support local musicians and provide shared experiences. Plus, the group has created Kids Virtual Connections, a weekly Zoom call with themes such as scavenger hunts, a dance party, crafting activities, sharing jokes and dressing up. During April, the organization reached 22,000 people online. You can find out more about the Meet Your Neighbor Dialogue online.



Learning to make play dough during a Zoom meeting

# Georgia Advocacy Office Raises Awareness about Supported Decision-Making

by Jennifer Bosk



**From Toccoa to Macon to Savannah and points in between, the idea of supported decision-making as the best alternative to guardianship has turned people’s thinking 180 degrees.**

**Supported decision-making is defined as a series of relationships, practices, arrangements and agreements designed to assist an individual with a disability to make and communicate decisions about their life to others.**

In Georgia knowledge about supported decision-making is being spread through meetings, schools, agencies and by word of mouth throughout the state thanks to a project the Georgia Council on Developmental Disabilities (GCDD) funded with the Georgia Advocacy Office (GAO) and its Citizen Advocacy work, as well as through a partnership with the Center for Public Representation (CPR).

Now in its third year, the supported decision-making project continues to concentrate on raising public awareness about an alternative to guardianship. Guardianship, for decades, has been a near automatic intervention pathway selected when individuals with developmental disabilities reach adulthood to avoid the perceived risks of decision-making.

The project has taken the work in supported decision-making a step further by providing training on how individuals with developmental disabilities can use supported decision-making to take charge of their lives through methods other than guardianship and power-of-attorney. In addition, individuals with developmental disabilities can be paired with a citizen advocate for a one-on-one relationship to help both achieve a good life within their community.

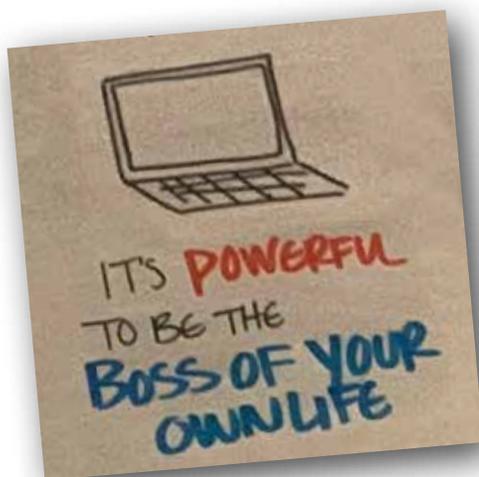
“It has to start with the individual with the disability who wants

supported decision-making,” explains Dana Lloyd, a protection and advocacy for individuals with developmental disabilities (PADD) advocate at GAO. “The individual must direct this from its inception to the result,” she added. Lloyd says so many people with developmental disabilities are seeking autonomy, choices and control – all of which supported decision-making provides.

**RESEARCH SHOWS THAT PEOPLE WITH DEVELOPMENTAL DISABILITIES WHO MAKE THEIR OWN DECISIONS HAVE BETTER HEALTH AND ARE MORE LIKELY TO BE WORKING WHICH IMPACTS A LONG-TERM DEFLECTION OF GUARDIANSHIP.**



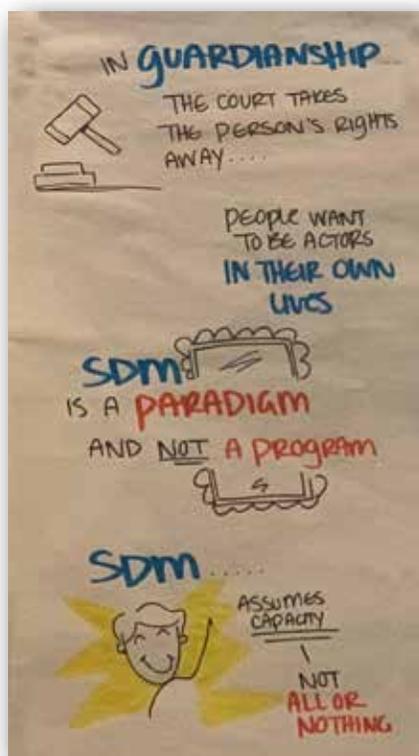
Besides providing skill training for people with developmental disabilities, GAO also assists in citizen advocacy pairings and this new way of thinking that is led by the person with the disability. GAO helps the citizen advocate to ask, “What would it take to solve issues and challenges?”



For example, one young man with developmental disabilities had to undergo a medical procedure that would take six hours. Working together, GAO and the medical staff were able to prepare him through videos, a visit to the medical office and some time sitting in the chair where the procedure would take place. By the end of the work to prepare for the procedure, the medical staff began to question the status quo themselves and decided the procedure, for people with developmental disabilities, could be adjusted to two three-hour sessions. Lloyd said, “My goal for supported decision-making is to help you think differently.”

In another instance, a young man with developmental disabilities was told he was going to have to move residences and was handed a list of three addresses and told to pick one. When GAO came on the scene to assist, advocates talked with the head of the current residence and asked, “What would you do? How would you make the decision?” This helped the person understand that anyone choosing would like to see each residence, judge its proximity to work and church, etc.

In the past two years of the project, GAO has hosted or presented about supported decision-making at over 35 workshops and seminars around the state of Georgia. In addition, Lloyd says they presented at a National Symposium on supported decision-making in Baltimore; collaborated with the South Carolina Center for Independent Living, Able South Carolina and Disability Rights Florida to enhance mutual projects; and hosted a



pre-conference workshop at the annual TASH conference in Phoenix. TASH an international leader in disability advocacy.

“We’ve even partnered with international experts to share information and learn from the growth of supported decision-making around the world,” Lloyd added.

One of the many organizations is the Center for Public Representation (CPR) in Washington, D.C. With funding from GCDD, and guidance from CPR, GAO has run a supported decision-making pilot since 2018.

The goals of the pilot are to:

- uphold the legal capacity of people with disabilities,
- disseminate knowledge of supported decision-making to stakeholders,
- utilize the structure of Citizen Advocacy relationships to develop supported decision-making arrangements, and

- prevent and overturn guardianships in favor of supported decision-making.

To continue its growth, GAO developed an advisory council composed of a diverse group of stakeholders, people with disabilities, parents, citizen advocates, a probate court judge, the directors of adult protective services, the Aging and Disability Resource Connection and the public guardian’s office. The council is instrumental in building a coalition of allies who are invested in ensuring supported decision-making is widely known as the first and preferred method of decision-making support for people with disabilities. Council representatives reside in Columbus, Atlanta, Athens, Fitzgerald and Roswell.

Lloyd says research shows that people with developmental disabilities who make their own decisions have better health and are more likely to be working which impacts a long-term deflection of guardianship. As the project enters year three, the focus will be on growing the network of people those with developmental disabilities can turn to for support with their decision-making.

If you would like to learn more about GCDD and supported decision-making initiatives, visit GCDD’s website.



Training sessions use visual storyboarding (these were created by Gabby Melnick) to work through the decision-making process and reflect key points gathered from the discussions.



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

**EVERYONE  
 HAS A STORY  
 TO TELL.  
 READ OURS.**



# Meet the People Behind "6,000 Waiting," GCDD's Forthcoming Documentary

After much hard work from the Friends of L'Arche project team, along with film producers, editors and directors, GCDD is excited to soon release its film, "6,000 Waiting."

Seasoned filmmakers Michael McDonald, Lexi Read and Zach Read came together and created a stunning look into the lives of Georgians with disabilities and their families. The film follows Ben Oxley, Nick Papadopoulos and Noah Williams and his mother Naomi as they navigate Georgia's daunting Medicaid waiver system. Storytelling team lead Irene Turner shares, "The film is not just a story about what has been ... it's the story of what has shaped the present and contains the pieces for renewed movement forward. Georgians with disabilities have the right to live full lives in their communities, and '6,000 Waiting' speaks to the urgency of making this a reality for all."

This documentary is the latest interpretation of the storytelling initiative, which began in 2018 to capture the stories of Georgians with intellectual and developmental disabilities (I/DD). Upon its release, the film will join [the catalog of written stories and photographs](#) and the first season of the [Hidden Voices podcasts](#).

GCDD looks forward to bringing this film virtually later this year and via in-person screenings when pandemic-related distancing recommendations are lifted. In the meantime, meet the people behind the stories.



**Ben Oxley**

Ben was born at 27 weeks and weighed only 2 lbs, 8.5 oz. He was placed in a neonatal intensive care unit for almost two months. Whether his cerebral palsy was caused by either too much oxygen – or too little – remains unknown to the family. After the reality sank in, Ben's father John, decided: "I want him to have as full of a life as we have."

The Oxley family gets going remembering some of Ben's adventures, one interrupting the other: "Remember the time we took Ben on a banana boat that bounced so hard? Or the time when he jumped out of a plane and parachuted to earth?"

After he graduated from high school in 2006 and watched his friends go off to college, Ben hit a slump. He went from being his extroverted and active self to being at home with not much to do. There were few resources that were a good match for him in his community, which is outside metro Atlanta.

After working at Publix for 10 years as a greeter, his mother Susie wanted to find other opportunities for Ben. They found that traditional "day programs" were too limited to meet Ben's abilities or interests and wouldn't stimulate his mind enough.

Then Susie found out about a training program called Partners in Policymaking. For nine months, Ben learned how to be an advocate, how to speak in public and interact with lawmakers. That led to Ben becoming an advocate with GCDD's Unlock! Campaign, which aims to get more funding for people with disabilities. The connections he made at Unlock! led to Ben learning about the Medicaid-

**I want him to have as full  
 of a life as we have.**

funded New Opportunities Waiver (NOW). Ben was one of the lucky ones who got his waiver after a nine-month wait.

The waiver allowed Ben to get out of the house and access more appropriate programs and resources. He took a weekend training with the Center for Leadership in Disability (CLD) at Georgia State University in 2016. The Center invited Ben back to become a trainer, and he volunteered to work with an HIV prevention group focused on reaching people in the I/DD community. He continues to work in both capacities with CLD.

And what are Ben's plans for the future? He wants to write a book, expand his YouTube channel, start a clothing line for people who use wheelchairs, do public speaking and train others to advocate for themselves and others. Ben has no shortage of dreams.

Thanks to the support of his family and the NOW waiver, he has every reason to believe he can achieve those dreams.

*Writer: Moira Bucciarelli,  
Photographer: Haylee Fucini-Lenkey*



**Nick Papadolopoulos**

Nick Papadolopoulos is a 40-year-old man with cerebral palsy and arthritis. Born six weeks premature, Nick used walking canes before the onset of arthritis in his knees in his late 20s. Shortly after that time, he began using a wheelchair for mobility. Currently, Nick lives in a nursing home facility in Royston, GA. "These places simply shouldn't exist," Nick says, with not a small amount of frustration.

It's deeply ironic that Nick has found himself in this precarious, isolating place with his own housing because his previous work had to do with advocacy

around this issue. While living in Athens around 2009, he worked for the Center for Independent Living, helping other people with disabilities explore their housing choices. It made him aware of the problems that Georgians are facing here and nationwide around housing options. When Nick first entered the nursing home, it was supposed to be for a state-required 90-day wait to qualify for housing assistance. That was more than two years ago.

Currently, Nick does not have a Medicaid waiver. That's why so many people are advocating with him. He'd like to be on the ICWP or COMP program and is on the waitlist for both. As long as he's in the nursing home, all waivers are off limits to him. The first step to him leaving is securing housing. When he gets into his own housing and his Medicaid waiver comes through, Nick would like to return to work as an advocate.

**THIS IS THE END OF THE LINE.  
WHY WOULD ANYONE WANT  
TO HAVE THIS PLACE BE HERE?  
THAT'S WHY IT'S IMPORTANT  
THESE WAIVER PROGRAMS  
DON'T GO ANYWHERE.** ”

Nick would say to legislators, "Quite honestly, I think these facilities should not exist." The staff have issues from being underpaid and overworked, which leads to their own aggressions and unhappiness. Nick feels lucky that he can speak up for those who cannot. Still, he shares a few horror stories of having to sit in



Ben Oxley  
with his  
family.

his own waste for more than an hour and a half because no one had time or the ability to change him. There are also frequent messes on the floor. “It’s a systemic problem. It’s like nitro and glycerin. By themselves, they’re harmless. Put them together, they’re harmful and destructive. It’s a powder keg.”

“This is the end of the line,” Nick says fervently. “Why would anyone want to have this place be here? That’s why it’s important these waiver programs don’t go anywhere. Because if they do, there’ll be a lot more instances like me.” He goes on to talk about people like himself who might be stripped from their homes, their choices and their lives. “People with disabilities are musicians, artists, bankers and scientists with dreams and ideas. They just require extra help. Without that extra help, those dreams won’t happen.”

*Writer: Shannon Turner,*

*Photographer: Lynsey Weatherspoon*



## Noah Williams & Naomi Williams

When Noah Williams was delivered, he immediately had to be revived. “They never expected him to live. He’s a fighter,” Noah’s mom, Naomi, says. Noah was born a “micropreemie” and now has cerebral palsy, a seizure disorder and cortical visual field impairment. Together, he and his mother are a team.

Noah is now eight years old and currently on the self-direct COMP Medicaid waiver, but he’s only been back on it very briefly. When Naomi’s father died, she inherited a small amount of money and her childhood home, which changed their financial circumstances, and Noah was no longer eligible for SSI. However, Noah’s medical needs are extensive. “I didn’t care about the check. It’s the insurance, the medicine, doctors’ appointments ...” Naomi explains.

They applied for the Katie Beckett waiver, and even though people are often turned down on the first application, they were approved. However, from beginning January until end of March, he had no SSI, no Medicaid and no insurance. “Nothing changed with him, nothing. That’s what’s so frustrating for me,” says Naomi.

“There’s no safety net for them.”

During that time Noah lost his slot with a speech therapist that he had been seeing for eight years. He’s been bumped down to the waitlist to see that practitioner again. Because there’s more demand than there are providers, if you lose a spot, you’re out of luck until someone leaves the system. The same thing would have happened for physical therapy and occupational therapy, but the providers were willing to work with Naomi to hold payment.

Noah got on the Katie Beckett waiver when he was four, and then moved to the COMP waiver when he was five years old. Naomi says they were discouraged from getting on the list because it was so long. A lot of families are discouraged, but people can’t ever get it if they’re not on it. “I’m a single parent,” Naomi says. “I thought, if something happens to me, what’s going to happen to him? And then, it seemed like I was going to have to quit my job. Then the state would have to take care of both of us. That makes no sense.”

**Don’t pity us, but don’t forget us. We are not going to hide in a corner or in the house.**

Naomi wants elected officials to know that disability doesn’t mean less. “Don’t pity us, but don’t forget us.” In her assessment, Georgia is not a disability-friendly state in terms of support or funding. Disability doesn’t go away when a person turns 18. “We are not going to hide in a corner or in the house,” she insists.



Naomi Williams with her son, Noah, who is currently on the self-direct COMP Medicaid waiver.