## Making a Difference

## Advocacy Days Go Virtual!



WINTER 2021



Georgia's 2021 Legislative
Session: What We Can Expect
and Gearing Up for 2021
Advocacy Days

gcdd.org

A quarterly digital magazine from GCDD

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.

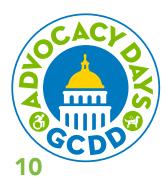


#### PUBLIC POLICY FOR THE PEOPLE

#### Georgia's 2021 Legislative Session: What We Can Expect

by Alyssa Miller, PsyD

Last year, GCDD introduced a legislative agenda that focused on "disability in ALL policy" for the first time during the legislative session. GCDD plans to continue these efforts to incorporate disability perspectives, focusing on three key areas: waivers, education and employment.



#### Gearing Up for Virtual 2021 Advocacy Days

by Charlie Miller

With the start of a new session, due to COVID-19 considerations, we have decided to re-develop our Advocacy Days this year. Changes include fewer, more focused events and interactive, virtual initiatives. Tentatively scheduled from 10 a.m. to 3 p.m., we will have more time for breakout sessions and opportunities to speak with our legislators.



#### **Coalition of Family Advocates** Newest Initiative to Kick Off 2021

by Jennifer Bosk

When family members of people with disabilities join forces, they work to promote and protect the best interests of their loved ones, making sure their voices are heard and their rights are protected. Find out more about our new advocacy initiative.

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Making a Difference magazine is now available online in an expanded website experience at <a href="https://magazine.gcdd.org/">https://magazine.gcdd.org/</a> in: English, Spanish, audio and large print. Previous issues are archived on the website as well.

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Hello 2021!

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On the cover: Advocacy Days go virtual this year due to the continuation of the pandemic (See pages 10-11).



#### GCDD VIEWPOINT

#### **HELLO 2021!**

I am sure we are all happy to see 2020 leave and a new year begin. We have seen a virus take over our daily lives. Many Americans protested in the streets as Black men have been murdered by the police. People lost their jobs as restaurants and shops closed. And we experienced the most divided presidential election ever. It was a year of unprecedented strain, and I, for one, am glad it is over!

At the Georgia Council on Developmental Disabilities (GCDD), we look forward to 2021. As you'll notice, we're kicking off the new year with a brand-new magazine platform! We heard from you all that you're loving the interactive elements, videos and more that we're producing in *Making a Difference*, and we hope this new site lets you enjoy our content in even more dynamic and accessible ways.

We're excited to work alongside you during the legislative session to address a growing waiting list; to make sure inclusive postsecondary education programs continue to thrive and grow; and to encourage legislation that allows people with disabilities to live in their own homes, with jobs and with the supports necessary to have great lives. We hope that you will connect with your legislators and attend our Advocacy Days. You can read more about the legislative session and Advocacy Days in this edition of our reconceptualized magazine.

In addition to preparing for statewide advocacy, Georgians are also welcoming new faces to the US Senate. All eyes have been on Georgia as we completed the race for the runoff, and Rev. Raphael Warnock and Jon Ossoff have been elected to represent us at the federal level. Read more about what that means for Georgians with disabilities in our legislative preview.

In 2021, GCDD will unveil its new five-year strategic plan. The plan will tell you what GCDD council members and staff will work on for the coming years. Don't worry: GCDD will continue many of the great programs we lead. But this is also an opportunity to think toward the future and what we can do together to create a state where all people are welcome and supported to have the best life.

You will read in this edition about a new coalition of families that will work together to discuss issues and advocate for positive change. You will also read about Uniting for Change that brings together self-advocates to discuss what is happening in their lives and are working to change the system of services.

We also look forward to telling your story through our Storytelling Project. This includes the debut of the GCDD-produced documentary film, "6,000 Waiting." This film tells the story of three people who are on the waiting list for home and community-based services. We will let you know where you can view the film, and make sure to share it with your friends, family and legislators.

Most important to us at GCDD is that we hope to see you in person during 2021. We know that COVID-19 has left many of us



Eric E. Jacobson

isolated, unable to visit friends and family. Until the vaccine is readily available, make sure to join with GCDD and our partners every month on Zoom to talk about how COVID-19 is impacting your life. For more information, check out GCDD's website and join our advocacy network so that you can stay informed.

IN 2021, GCDD WILL UNVEIL ITS NEW FIVE-YEAR STRATEGIC PLAN. THE PLAN WILL TELL YOU WHAT GCDD COUNCIL MEMBERS AND STAFF WILL WORK ON FOR THE COMING YEARS.

From the members and staff at GCDD, we wish you a happy 2021. 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 <a href="hillary.hibben@gcdd.ga.gov">hillary.hibben@gcdd.ga.gov</a>.

Eric E. Jacobson
Executive Director, GCDD



Dr. Toni Franklin, co-director of Columbus State's GOALS program, is flanked by proud graduates Shawna and Shirin. Photo provided by Dr. Greg Blalock.

Some of these students have intellectual or developmental disabilities (I/DD), and they're staying connected however they choose while participating in the Guidance and Opportunities for Academic and Leadership Success (GOALS) Program at Columbus State University (CSU).

During the fall 2020 semester, there were two students in the program.

While one student chose to take classes online, and the other completed his coursework on campus, both students participated fully in the college experience. Dr. Greg Blalock, an associate professor of special education in the College of Education and Health Professions, says they worked to create personcentered plans by discussing the available course options: hybrid, online and face-to-face.

"One-hundred percent of the classes that students within the GOALS program take are what we call ... fully integrated classes, so that means GOALS students take the same classes that any other student might take," Blalock said. "They also have a greater number of online options for them this fall."

Blalock began at CSU in 2008, and he says the <u>COVID-19 pandemic</u> has brought new challenges and opportunities. The adjustment has forced administrators and professors

## Columbus State Helps Students with I/DD Reach GOALS

by Clay Voytek

Amid the pandemic, college students in Columbus, GA still need to connect. One might be playing Dungeons & Dragons on a Zoom call, another exercising independently during a group FaceTime.

to think creatively about providing college-life experiences for their students, even in an online format. Blalock says this may include meeting at a park for socially distanced frisbee golf or hosting a virtual movie screening.

There are nine inclusive postsecondary education (IPSE) programs throughout the state. GOALS has been at CSU since 2015, and it offers a two-year certificate and access to internships in a student's areas of interest.

After completing the program's initial two-year stretch, students participate in Columbus State's graduation ceremony, walk the stage alongside their peers and receive a university completion certificate, which documents what they accomplished. For students who wish to continue, the GOALS program offers the option to return for a more advanced certificate that builds on the skills of the first one.

"Both certificates utilize a combination of academic work; employment; training and career development skills; and social skills development," Blalock says. "But the second certificate is much more focused on the world of employment and being out in internships — internships of choice, importantly."

When a student arrives at Columbus State's GOALS program, Blalock

says they begin a conversation about their career ideas and choices. From there, staff begin to reach out to the community. He says one recent student had an interest in working in retail gaming and books, so they arranged an internship with a local shop. Another was interested in art, so they coordinated an opportunity at the city's museum.

Blalock recommends prospective students take a tour of the school's main campus and downtown Columbus campus. That way, students and their families can get a feel for the university and how it might fit into their plans.

"I think the one thing that is most important is that families and students themselves understand that university-college life is something that's now an option for them," Blalock said. "I would encourage any students with a developmental disability, whether they're in middle school or high school, or maybe they're done with high school, to call us – and they can contact me directly – and schedule a visit to the university. And we can do a virtual visit, or we can do an in-person visit."



# SELF-ADVOCACY SPOTLIGHT

## How Self-Advocates Build Relationships with Legislators

by the Uniting for Change Collective Leadership Team

<u>Uniting for Change</u> continues to grow the self-advocacy movement in Georgia by staying connected during the pandemic and learning more about how to build relationships with legislators so that our voices are heard.

Strength means being strong no matter what comes my way.

Since the pandemic,
Uniting for Change has
worked through many barriers
to stay connected virtually through
Zoom and other technologies.
Community Strong has been a
wonderful way for us to gather each
week for fun, learning and staying
strong. During a recent Community

Strong gathering, advocate Ratiel Shepherd said, "Strength means being strong no matter what comes my way." We would love for this to include all self-advocates across the state, and we look forward to meeting more.

This COVID-19 experience has also provided us opportunities to learn how to use technology to connect with each other in ways other than having to drive long distances to meet with folks. This will be helpful as we rise up and speak out during the legislative session starting in January. It is important that we all know who our legislators are

and that we introduce ourselves by writing to them or calling them. We can let them know what is important to us and what we need in waiver services so that we can live our lives the way we want.

It is important that we all know who our legislators are and that we introduce ourselves by writing to them or calling them.

Uniting for Change is a statewide self-advocacy network committed to advocating, organizing, showing up and being heard. Uniting for Change envisions a community where all people belong and are heard – a place where people are involved, speak out, make their own choices, are seen as equal and stay true to their destinies! We are united. We want change!

To join us and expand self-advocacy across Georgia, sign up for our online mailing list.





### Georgia's 2021 Legislative Session: What We Can Expect

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



As many of you might remember, the Georgia Council on Developmental Disabilities (GCDD) introduced a legislative agenda that focused on "disability in ALL policy" for the first time during Georgia's 2020 legislative session. Our idea for this type of legislative agenda is to ensure that people with disabilities and their families are considered in all areas of legislation.

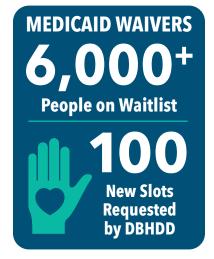
#### GCDD'S LEGISLATIVE PRIORITIES:

Last year, our public policy team worked with numerous organizations and legislators to make sure that the perspectives of people with disabilities were being considered. This included any policy area from school choice to elevator compliance. As a result, the voices of the disability community are being represented in new and innovative spaces.

GCDD plans to continue our efforts centered around "disability in ALL policy" during the upcoming 2021 session. In addition to our efforts to incorporate disability perspectives across all policy areas, we will be focusing on three key priority areas, which will be highlighted during our 2021 Advocacy Days (read more about Advocacy Days logistics here).

HCBS Medicaid Waivers

GCDD continues our commitment to highlighting the waiver waitlist, comprised of over 6,000 people, and we will work to ensure that all Georgians with developmental disabilities and their families receive the supports and services they require to be fully included in their chosen communities. Medicaid waivers are necessary components of this work. Last year, GCDD worked with advocates across the state to make sure that new waiver slots continued to be funded, even during significant budget cuts across most state agencies. Although the governor's office originally recommended zero new waiver slots, the disability community was successful in advocating for the addition of 100



new waiver slots once the final budget was passed and signed by Governor Brian Kemp.

This year, the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) has asked for 100 new waiver slots in the upcoming budget. We are glad to see a request for additional slots but remain concerned that these low requests will do little to address the waiting list. For the past few years, a limited number of slots have been funded, which has resulted in no major changes in our large waitlist. Because of this, people with disabilities and their families continue to wait years for needed services. GCDD was encouraged by the creation of DBHDD's multi-year plan, finalized in 2018,

## DISABILITY IN ALL POLICY

to address the waitlist, and GCDD would like to advocate to ensure DBHDD is receiving enough funding from the General Assembly to reach their goals and objectives. Based on the goals outlined by DBHDD, they would like to be serving 1,950 newly admitted waiver recipients by the summer of 2021. You can find DBHDD's multiyear plan, as well as an appendix document outlining specific target numbers, here. To further shine a light on the waiver waitlist problem in Georgia, GCDD will also officially premiere its documentary "6,000 Waiting" during the upcoming legislative session. We hope these powerful stories of Georgians with disabilities will further highlight the need for additional funding for waivers.

## Inclusive Postsecondary Education (IPSE) Programs

about the documentary here.

You can find out more information

For the past decade, IPSE programs have grown and developed into nine different programs across Georgia. These programs provide inclusive learning opportunities for college students with intellectual disabilities. These students typically would not have the option to attend college, as many do not receive a traditional high school diploma or have difficulty with the competitive admission standards; however, IPSE programs were designed to deliver the true college experience, while preparing students for successful careers post-college. In fact, the employment rate of

54%

STANSIE OF STANSI

IPSE students is about 54 percent, compared to just 34 percent for Georgians with disabilities. The employment rate drops to only 24 percent when discussing Georgians with a cognitive disability. You can learn more about Georgia's IPSE programs here, and you can view more specific employment data for Georgians with disabilities here.

Given the effectiveness and importance of IPSE, GCDD has focused its advocacy efforts on improving the support and funding for the programs during previous legislative sessions. This year, we plan to focus on the 16-percent cut that was made to the programs' budgets during the last legislative session. Due to COVID-19's impact on our economy, many services saw budgets cut, but IPSE received a higher cut than many. In addition to the state cuts, IPSE programs have also been negatively impacted by the Georgia Vocational Rehabilitation Agency's (GVRA) decreased funding model for student support, as well as GVRA's removal of academic transition teacher (ATT) funding. We plan to advocate to reinstate those funds to ensure the success and sustainability of the programs throughout Georgia.

#### Competitive, Integrated Employment

As mentioned above, Georgia's rate of employment for people with disabilities is very low, even when compared to the national average, and only about 16 percent are working in competitive, integrated employment. This means that only 16.3 percent of Georgians with developmental disabilities have jobs that pay at least minimum wage and are in a workplace in the community, alongside their peers without disabilities, that is not owned or managed by a provider of support services. GCDD is committed to

increasing the rate of Georgians

who participate in competitive,

integrated employment, and we

are excited that DBHDD has

also committed to this goal.

COMPETITIVE, INTEGRATED EMPLOYMENT

ONLY 16.3% of Georgians with Developmental Disabilities Participate

DBHDD has acknowledged the importance of competitive, integrated employment and has presented a goal to triple the rate of Georgians with developmental disabilities who participate in competitive, integrated employment from 16.3 percent to 48.9 percent by 2025. To read more about DBHDD's employment goal, check out Commissioner Judy Fitzgerald's blog post here. Join GCDD in helping DBHDD reach that goal by advocating for policies that support and advance competitive, integrated employment in Georgia, while transitioning away from subminimum wage policies!

#### OTHER POLICY PRIORITIES TO WATCH

The 2021 legislative session will be the first year of the next biennial session in Georgia. As many of you might know, Georgia has a biennial session that takes place for a two-year period. The 2020 session was the second year of the previous biennial, meaning we are starting fresh with a new two-year period. In addition to the election

of each representative and senator, all the bills previously introduced in the last two years will have to be reintroduced if a representative or senator is interested in continuing to pursue the policy priority.

Because we are just now at the beginning of the biennial, the only way we can figure out what bills we might want to watch is by visiting the prefiled legislation list on the General Assembly's website. This list starts to develop

in November before session and gives us our first look at what we might expect. GCDD continues to monitor the introduction of new legislation and can highlight a few areas now; however, the current prefiled list is small and certainly not a complete representation of what the session might bring.

If you would like to monitor what bills have been prefiled, you can find the <u>House prefiles here</u> and the <u>Senate prefiles here</u>.

#### **BILLS TO WATCH**

Here are just a few of the prefiled bills\* we will be monitoring:

HB 7 Higher Education Access and Success for Homeless and Foster Youth Act

HB 7, introduced by Representative Sandra Scott, aims to assist youth experiencing homelessness and youth in the foster care system in achieving higher education. Given the disproportionately high rate of children with disabilities in the foster care system, we believe this bill could have an impact on our community.

HB 28 Each Statutory Board and Commission Reflect General Population

HB 28, introduced by Representative Dar'shun Kendrick, aims to improve the diversity of boards and commissions by requiring all statutorily created boards and commissions to reflect the general population. We have previously discussed the underrepresentation of people with disabilities in most settings where important decisions are made, and we think this bill could improve the representation of the disability community, which includes almost 25 percent of Georgians.

HB 34 Audiology and Speech-Language Pathology Interstate Compact

HB 34, introduced by Representative Dave Belton, aims to improve the availability and access of audiology and speech-language services by entering into an interstate compact. Given the frequent use of these services by Georgians with disabilities, we believe this bill will likely impact the services received in the disability community.

\*Based on prefiles available as of 12/4/2020

Although no voting or election bills were prefiled at the time of this writing, we can likely expect a renewed focus on voting and election matters, as these topics have been frequently highlighted in the news since the general election on November 3. We have already had meetings of the Senate Government Oversight Committee and a Sub-Committee of the Senate Judiciary Committee, during which legislators expressed interested in policies that would further strengthen the security of our elections. GCDD will be monitoring these proceedings as the 2021 session progresses.

In addition to the priorities listed, GCDD is committed to monitoring the budget process to ensure there are no cuts to the supports and services that are critical for Georgians with disabilities and their families. The impact of COVID-19 resulted in significant cuts during last session, even as we were able to successfully advocate to minimize some of the cuts. State agencies, at the request of Governor Kemp's office, presented a neutral budget based on their funding from fiscal year 2021. This means there are no new cuts we currently anticipate; however, the neutral budget also means that state agencies are continuing to fund services at the funding level impacted by deep cuts during the 2020 session. As budget meetings take place, and the budget priorities become clear, GCDD will make sure to keep advocates updated on any areas of concern!

#### Impact of COVID-19 on the 2021 Session

Although COVID-19 might make in-person advocacy difficult during the 2021 session, there are plenty of ways we can still take part in the process. One great way to stay involved is to take advantage of the live streaming of the floor sessions and most committee meetings. Throughout the week during session, the House and Senate calendars will be updated to show which committees are meeting, when they are meeting and what they are meeting about. This information is critically important in helping us stay inthe-know about the happenings under the Gold Dome, even when we can't be in-person. You can find the House calendar here and the Senate calendar here. Once you've

Join us during our virtual Advocacy Days this session to learn all about advocating in a virtual world!

decided on the meetings you would like to watch, you can access live streaming by visiting Georgia's General Assembly website.

And as always, GCDD's public policy team is here to help with any virtual advocacy questions you might have! Make sure to join us during our virtual Advocacy Days this session to learn all about advocating in a virtual world!

resulted in significant cuts during last session, even as we were able to successfully advocate to minimize some of the cuts.

#### The Race for the Runoff: Election Updates

As we all have been aware, based on the numerous commercials, text messages and mailers we received over the past two months, we recently ended the two most expensive senate races in US history.

On January 6, 2021, both races were officially called for the Democratic senate candidates

Reverend Raphael Warnock and <u>Ion</u> Ossoff, and the two Democratic candidates have officially accepted the results and claimed victory. Both men were endorsed by **Disability** Action for America, and you can view thencandidate Warnock's



**Rev. Raphael Warnock** 



Jon Ossoff

response to the endorsement here.

As of the writing of this update\*, both races appear outside of the 0.5-percent margin required for a candidate to be able to request a recount. Senator Kelly Loeffler has officially conceded the race to Senator-elect Raphael Warnock. David Perdue has also conceded his race to Senator-elect Jon Ossoff.

\*Information current as of January 8, 2021

#### **GCDD'S PUBLIC POLICY TEAM**



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



CHARLIE MILLER, GCDD Legislative Advocacy Director

## Gearing Up for Virtual 2021 Advocacy Days

by Charlie Miller, GCDD Legislative Advocacy Director





Hello, advocates! We are so excited to be preparing for another legislative session. Slated to begin on January 11, the session will go for 40 non-consecutive days, which marks the start of a new biennial legislative session.

Advocates meet with Nikema Williams, recently elected US Representative to Georgia's 5th District (formerly held by John Lewis).

#### **What's New**

With the start of a new session, it's time to get ready for GCDD's Advocacy Days! And per COVID-19 considerations, we have decided to re-develop our Advocacy Days this year. Some of the changes include fewer, more focused events and interactive, virtual initiatives. With the start of a new biennial, we are excited to see all the new bills and legislation.

Our three Advocacy Days are tentatively scheduled for the following dates (note: each of the Advocacy Days will have a policy or budget focus):

- Wednesday, January 27: Advocacy Day #1
   Topic: Home and community-based services (HCBS) Medicaid waivers
- Tuesday, February 16: Advocacy Day #2
   Topic: Inclusive post-secondary education (IPSE)
- Tuesday, March 2: Advocacy Day #3
   Topic: Competitive, integrated employment/supported employment

These dates are subject to change based on the calendar of the 2021 legislative session, which is released in segments across the 40-day session. So please keep an eye out for any updates!

Another exciting change this year includes going all virtual! We are planning to have a more robust schedule that will allow for participants to come and go based on their availability and interest in the agenda items. We have also totally revamped our agenda. We are tentatively scheduling our virtual days from 10 a.m. to 3 p.m. With

longer Advocacy Days, we are excited to have more time for breakout sessions and opportunities to speak with our legislators.

We also want to celebrate you and your advocacy with a virtual awards ceremony on April 15! We will share more details, including how we're honoring some longtime legislative advocates, so stay tuned.



Charlie Miller engages with advocates at the 2020 Advocacy Days.

#### **How to Prepare**

We cannot wait to advocate with you during the legislative session. But before we start advocating, we need to make sure we are prepared to speak with confidence to our legislators.

One of the most important steps we can take ahead of Advocacy Days is to look up our legislators, see what committees they are on and find out how they have voted on issues we care about. With the website **Open States**, constituents can find bills they are interested in and also search for their legislators. To find your legislators' voting records, we recommend searching for them on **Ballotpedia**. Both of these sites are great resources for any advocate to be properly informed.

Once we become informed on the issues and our legislators, we can better advocate for ourselves during the session and beyond. But Advocacy Days are not the only opportunity to advocate! In fact, there are year-round opportunities. Once you have found who represents you and how they vote, feel free to reach out to them on social media or connect with them via email or phone before each Advocacy Day. Make sure to let them know you are a constituent in their district. Each legislator has an important voice in their chamber, and they want to hear from their communities.

One thing we must remember is that these state lawmakers are our friends and neighbors. A lot of these legislators know some information about a lot of different things, so be prepared to educate them on issues you care about. If you are planning to come to our Advocacy Days, feel free to invite them to join you!

#### **Who To Know**

Georgia's 2021 legislative session will be moving at a quick pace, and we want to make sure that you know how to stay most up to date with all the goings-on under the Gold Dome. One of the ways we can do that is by sharing some of our great partners in policy:

#### Georgians for a Healthy Future

Focus includes bringing healthcare to Georgia's communities with increasing care, as well as working on expanding Medicaid; also works alongside GCDD to address the waiver waitlist

#### Georgia Council on Aging

Advocates with and on behalf of aging Georgians and their families to improve their quality of life; often works with GCDD to educate and advise legislators on making recommendations for Georgians who are aging and/or have disabilities

#### Voices of Georgia's Children

Advocates for all of Georgia's children, particularly those whose location, family income, race or family/community circumstances leave them most vulnerable; currently works alongside GCDD to better understand disability issues and how they can exist in all laws, policies and actions to improve the lives of children

#### Georgia Association of Persons Supporting Employment First

Working on a robust legislative agenda focusing on employment issues for people with disabilities; also focusing on furthering its organizational mission to "advance employment equity for people with disabilities"



GCDD Council member Nandi Isaac meets with Rep. Dale Washburn (R-141) at 2020 Advocacy Days.



We look forward to the session starting on January 11 and for our advocacy to get underway. But until then, please keep a lookout for any updates about our Advocacy Days and bills to watch during Georgia's 2021 legislative session.

Like always, Georgia, let's keep advocating!

Sen. Mike Dugan (R-30) meets with advocates during 2020 Advocacy Days.



It's been a busy few months, with ongoing advocacy with Congress and federal agencies while simultaneously preparing for a new administration and Congress that begins in January. Below we provide a few key updates and lay out expected priorities for the coming year.

#### **UPDATES:**

**Congress:** On December 27, the Consolidated Appropriations Act was signed into law, which includes both general government funding and coronavirus relief provisions. While the coronavirus relief provisions include some urgently needed aid, they do not address the most pressing disability community priorities, like dedicated funding for home and community-based services (HCBS). HCBS funding is urgently needed to help people with disabilities and older adults live safely in their homes during this pandemic. Additional stimulus checks are also provided, but adults with disabilities who qualify as dependents are once again excluded.

- More on the priorities that did and didn't make it into the bill can be found here.
- Find additional section-by-section summaries of the bill and one page summaries here.

 A comparison of the Consolidated Appropriations Act and other recent coronavirus relief proposals can be found here.

The bill does, however, extend funding for the Money Follows the Person (MFP) program for three years, along with spousal impoverishment protections. While we have been advocating for permanent funding of MFP and will continue to do so, this will provide states with longterm funding at a time when transitions are more crucial than ever. It also includes important changes to the program, including lowering the number of days someone has to spend in an institution before qualifying for MFP from 90 days to 60.

It also, importantly, did not include the liability shields Republicans have long been pushing for, discussed in previous columns, which would waive civil rights and workplace protections and For more information on why funding Money Follows the Person (MFP) matters, check out our fact sheet.

shield businesses, nonprofits, schools and medical providers from liability related to COVID-19 in most circumstances. We will continue to fight efforts to include similar provisions in future coronavirus relief legislation.

Vaccine Allocation: The disability community has been heavily engaged around allocation of coronavirus vaccines. We have been advocating for the needs of people with disabilities to be prioritized in the national framework being developed by the federal government, including with the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices (ACIP).

National disability groups released principles for vaccine allocation, which include, among other things, prioritizing people in all congregate settings and who receive home and community-based services (HCBS) and of workers in those settings; ensuring that both the information and the means of distribution are accessible; and

For a comprehensive list of federal frameworks, state plans and related resources regarding COVID-19 vaccine allocation, visit our website.

ensuring compliance with federal civil rights law and guidance. We have also been working with state advocates as they review their states' plans for vaccine allocation and will continue to keep you updated on this fast-moving issue.

#### Priorities for the New Administration and Congress:

Disability advocates have been preparing for the new administration and Congress. Through our coalition work, we have developed congressional and federal agency priorities in a range of areas that impact people with disabilities. We also have been meeting with the transition teams that will be working with new agency leadership on priorities. Below we highlight some areas where we expect to focus our advocacy:

#### **COVID-19:**

#### **Administrative Priorities:**

The Biden-Harris administration has already said that addressing COVID-19 will be its top priority. President-elect Biden has established a COVID-19 Advisory Board and a White House position focused on healthcare equity. Disability advocates sent a letter to and met with the COVID-19 Advisory Board about our top priorities, including ensuring people with disabilities are prioritized in vaccine distribution; fighting against discriminatory

medical rationing; expanding mandatory COVID-19 reporting and testing to all Medicaid-funded congregate settings; ensuring all providers and program participants – both institutional and HCBS – have access to needed personal protective equipment (PPE); and implementing a national strategy to assist people in transitioning from high-risk institutional and congregate settings to safer community settings.

- More on the disability community's priorities for vaccine allocation, as well as federal resources and state plans can be found here.
- Find out more about our advocacy in congregate settings during COVID-19 here.

#### **Congressional Priorities:**

We will be urging Congress to pass additional coronavirus relief that meets the needs of the disability community. Our top priority has been additional funding for HCBS. Other priorities include additional funding for Medicaid; housing; education and nutrition assistance; hazard pay for direct service providers and other essential workers; and recovery rebates. We will also continue to oppose the liability shields discussed earlier.

- For more on passed and proposed legislation, see our COVID-19 legislation page.
- Find the latest on advocacy and action that you can take on our COVID-19 page.

#### **Community Living:**Administrative Priorities:

The Biden-Harris administration has said that expanding and strengthening the "caregiving infrastructure" - including HCBS for people with disabilities and older adults - is a key priority as part of its economic recovery plan, as well as crucial to addressing COVID-19. We will be advocating with federal agencies about the many ways to expand HCBS, including strong implementation of the HCBS Settings Rule, strengthening the workforce and working with states as they unwind COVID-19 emergency waivers to permanently incorporate positive changes, like expanded telehealth.

- For more on the HCBS Settings Rule, check out the HCBS Advocacy Coalition.
- For more on COVID-19 emergency waivers, check out our web page.

#### **Congressional Priorities:**

We expect to see legislation to expand access to HCBS, including reintroduction of the HCBS Infrastructure Investment Act, which provides a grant program for states to strengthen their HCBS systems. Legislation to address long waitlists and Medicaid's institutional bias and to expand long-term care outside of Medicaid is also possible. Advocates will also continue to push for permanent reauthorization of MFP, as discussed above.

#### **Disability Employment:** Administrative Priorities:

Then-candidate Biden made strong commitments to expand opportunities for competitive,

#### WHAT'S HAPPENING IN WASHINGTON?

integrated employment (CIE) and to work to end subminimum wages to people with disabilities under Section 14(c) of the Fair Labor Standards Act. We will push the new administration in these areas. We also have emphasized that any COVID-19 recovery focus on displaced or unemployed workers must include people with disabilities.

#### **Congressional Priorities:**

We expect re-introduction of the Transformation to Competitive Employment Act (TCEA), a bipartisan bill that would expand opportunities for CIE while phasing out the use of subminimum wages under Section 14(c) over six years. The Raise the Wage Act, which eliminates the payment of subminimum wages to people with disabilities, is a top Democratic priority as well and will likely be one of the first bills passed by the House.

#### **Other Priorities:**

**Healthcare:** Based on the priorities of then-candidate Biden, we expect the administration to quickly rescind policies that weaken Medicaid, like permitting states to condition Medicaid eligibility on work requirements or to block grant funding. Advocates will also

EQUITY AND RACIAL JUSTICE
IS AN IMPORTANT PRIORITY
THAT CUTS ACROSS ALL AREAS,
INCLUDING HEALTHCARE,
EDUCATION, EMPLOYMENT,
POLICING AND
CRIMINAL JUSTICE.

#### **What You Should Know**

- Congress has passed a government funding bill that provides three years of funding for Money Follows the Person (MFP). It also includes some coronavirus relief but leaves out the disability community's most pressing priorities.
- As priorities and logistics for distributing coronavirus vaccines are being developed, advocates continue to meet with decision-makers to ensure people with disabilities and their needs are prioritized.
- The country will soon welcome a new presidential administration and Congress. Some of the topics on which advocates will collaborate with federal-level leaders include COVID-19, community living and disability employment.
- In addition, advocates will work to elevate issues related to healthcare, inclusive education and racial justice and equity.

work with the administration to rescind the public charge rule, which prohibits immigrants who use or may use healthcare programs, including Medicaid HCBS, from entering the country or getting a green card. We also expect efforts to strengthen the Affordable Care Act (ACA), and there are many competing healthcare proposals that will likely be introduced or reintroduced in Congress. However, it is unlikely that a huge healthcare bill will pass in the 117th Congress unless the ACA is struck down.

#### **Inclusive Education:**

Priorities for the Department of Education include strengthening implementation of rules related to racial disproportionalities in special education; stronger enforcement by the Office of Civil Rights; and reinstating guidance around discipline and positive behavioral supports. In Congress, we expect to see reintroduction of the Keeping All Students Safe Act, which would eliminate

seclusion and significantly limit the use of restraints, including for students with disabilities, who are at particular risk.

#### **Racial Justice and Equity:**

Equity and racial justice is an important priority that cuts across all areas, including healthcare, education, employment, policing and criminal justice. It is critical for the disability community to identify intersectionalities and address the systemic barriers that people of color with disabilities face. President-elect Biden has identified racial equity as a top priority, and we expect that all federal agencies will be incorporating it into their work. Congress also will likely introduce legislation focused on equity and racial justice in a range of areas.

These updates represent only a small portion of what we're working on. For more on our work, visit our <u>website</u> and connect with us on Facebook and Twitter.

Note: information current as of 1/5/2021

## Coalition of Family Advocates Is Newest Initiative to Kick Off 2021

by Jennifer Bosk

When family members of people with disabilities join forces, they work to promote and protect the best interests of their loved ones, making sure their voices are heard and their rights are protected.

Seeing more and more families become active in advocating, the Georgia Council on Developmental Disabilities (GCDD) noted their efforts would be more powerful if they came together with one voice.

To achieve that unified effort, GCCD will work with <u>Claritas Creative</u> to create a new coalition of parent and family advocates within the disability community. The initiative, "Building a Coalition of Family Advocates," will make an impact both by advocating at the legislative level and through developing and teaching advocacy skills to not only self-advocates but also to parents, siblings and family members.

#### The objectives for building the coalition include plans to:

Conduct an environmental scan for practices that best promote inclusive and proactive advocacy within family circles.

Identify family advocacy groups that have experience with policy and political advocacy.

Develop a strategic plan for how to engage key stakeholders in the community.

Gain an understanding of what families are most concerned about within their communities.

Create a curriculum for educating parents and family members.

The early goals of the initiative will include a comprehensive curriculum for training parent advocates, a strategic plan that delineates statewide issues of priority to the developmental disability community and how the Coalition of Family Advocates will tackle these, as well as a list of need-to-know family member groups that should be involved in the coalition.

"This group will not be parents talking *for* their family members with disabilities but rather *with* them, a true collaboration," explained Charlie Miller, GCDD's Legislative Advocacy Director.

Stay tuned for more details and the work being done as this initiative gains momentum in 2021. If you are interested in being a part of this work, you can reach out to Claritas Creative at <u>Advocate@</u> <u>ClaritasCreative.com</u>.





THIS GROUP WILL NOT BE PARENTS TALKING FOR THEIR FAMILY MEMBERS WITH DISABILITIES BUT RATHER WITH THEM, A TRUE COLLABORATION.



## How COVID-19 Affected People with Disabilities and Direct Support Professionals

Featuring Erin Rachel Vinoski Thomas, PhD, MPH

Erin Rachel Vinoski Thomas, PhD, MPH, Director of Health and Wellness at Georgia State University's Center for Leadership in Disability, sat down with *Making A Difference* to share the findings of her research on how COVID-19 affected people with disabilities and direct support professionals.

In March, at the beginning of when we started to understand what the pandemic looked like, what COVID-19 was looking like and what it might develop into, we started to see a lot of information come out about how people with disabilities would be disproportionately at risk.

The research that we conducted had two major components. The first was an online survey. We conducted an online survey of 61 people with intellectual and developmental disabilities (I/DD) and 76 direct support professionals (DSPs) in May of 2020. Most of the people who participated in the survey represented the state of Georgia. There was some representation of people outside of Georgia, but it was mostly people from the southeastern region of the US.

#### **QUALITY OF LIFE AREAS:**

- 1. Personal Life Satisfaction
- 2. Work Competence & Productivity
- 3. Empowerment & Independent Living
- 4. Belonging & Community Integration

What we did in that survey is called a retrospective pretest. So, usually if we want to measure change, we would give a questionnaire or a survey before the thing happened, then the thing happens and we give them that same survey after the thing happens. Then we're able to look at the numbers to figure out if there was a shift in whatever the thing that we're measuring is from before the thing to after the thing.

The survey that we used is called the Quality of Life Questionnaire. It has 10 questions in four different areas – including personal life satisfaction, work competence and productivity, empowerment and independent living and belonging and community integration. Those are the four really broad areas of quality of life that we're exploring.

We found that both people with I/DD and DSPs experienced statistically significant declines in all four of those areas of quality of life that we measured. In general, surveys do a really good job of giving a quick snapshot of what's going on. But surveys don't always do a great job of telling us why something is happening. To understand why things are happening we really have to talk to people themselves. We need to understand their perspectives. We need to understand their experiences and their day-to-day especially in a pandemic situation where things really do change hour to hour, day to day.

Using Zoom or another virtual conferencing platform, we conducted interviews with eight people with I/DD and 10 DSPs. We did those interviews at two time points – the first was in July and the second was in September.

We asked people to very generally tell us "what are you experiencing right now; how is your quality of life; what is quality of life to you; and how has it changed?" We also asked people how their relationships have changed with people that support them or people that they support during the pandemic, and what actions they're engaged in to help sustain quality



of life during this time together. We also asked people about resources that they have used, so anything that they've found that's been a helpful resource. Then we also asked people what resources they felt like they've needed but have not been able to find.

#### **SURVEYS SHOWED:**

Both people with I/DD and DSPs experienced statistically significant declines in all four areas of quality of life we measured.

From the interviews, we found that people with I/DD really described, above and beyond anything else, experiencing isolation. That was really the main takeaway. They described dealing with the effects of major changes in their life routines and changes in those relationships with their support providers. Jobs may have shifted, right? DSPs may be working a whole lot more hours or they may be working a whole lot less hours depending on what their situation is. They may be spending more time with their support providers, or they may be spending a lot less time with their support providers and getting less of the support that they need. Some people described instances in which their direct support providers have gotten sick, have gotten COVID-19, and how that had impacted not only the support provider but also impacted the person themselves.

The last main finding for people with I/DD is a real sense of fear

and feelings of uncertainty about the future. There were people who said "I just want someone to tell me when this is going to be over, how long this is going to go, because I need to be able to understand when I'm going to get back to that routine, or when I'm going to be able to see my family again, or have access to those supports that I had before the pandemic that have now changed."

The most substantial decreases in quality of life in people with I/DD occurred in the domain of work competence and productivity, and then in belonging and community integration. I thought the finding for people with disabilities related to work competence and productivity was particularly interesting.

What we saw in the quantitative data that matched the qualitative data was that there were a lot of people with disabilities who just weren't working anymore. They had jobs before the pandemic, and then their jobs were either gone because the entire business was shut down or their hours were cut. So people didn't have that sense of being productive at work because they didn't have jobs anymore. Those were two specific areas where we saw real steep decreases in quality of life for people with I/DD.

The DSPs that we interviewed talked about a lot of the same themes. By and large, people are experiencing the same things regardless of who they are. But specifically, DSPs experienced overwhelming burnout. That shouldn't be a surprise to anybody. They also described a constant pressure weighing on them, not only to keep themselves safe just for their own health's sake, but also to keep themselves safe so that they could keep other people safe. This idea that not only is my safety my responsibility, but someone else's safety is also my responsibility – and I have to keep that in the forefront of my mind.

The other major finding among DSPs, and particularly among DSPs who are members of populations that have been historically excluded on the basis of race or ethnicity, is extreme emotional distress that was related to living and working as a DSP during COVID-19 – given the ways that it has been

racialized and the ways that it's been discussed as a racial or an ethnic virus – as a "Chinese Virus," was a quote that was provided by one of the DSPs.

Also, the ways that the timing of this pandemic has intersected with what one of our participants called a "dual pandemic," a pandemic of racial violence and racial tension in our country, given that COVID-19 has disproportionately impacted communities of color who are also simultaneously being impacted by violence and racial tension in our country. We didn't directly ask questions about that, but as people started to talk about it, then we started to ask more questions about it. That is the beauty of qualitative research - the ability to ask more questions over time as you gain understanding of an issue.

For DSPs, the two areas that we saw the most substantial decreases in were personal life satisfaction and also belonging and community integration. The fact that the DSPs didn't have that substantial decrease in work competence and productivity to me goes along with the idea that these are things that are just always present; they're persistent. Burnout is persistent, and yes, it may be heightened during times of pandemic and in the time of COVID-19, but the decrease we saw at least in the numbers was not as substantial as other areas.

I do think that the aspects that we discussed about racism and the racialization of COVID-19 probably played into that substantial decrease in personal life satisfaction that people reported, and then again, belonging and community integration. We talked to DSPs in the interview phase of the study that mentioned again if they're living in the place that they're working, they weren't leaving because it was

#### **VIRTUAL INTERVIEWS:**

- What were they experiencing?
- How did their relationships change with people that support them or that they support?
- What resources did they use and what did they need but did not find?

dangerous. It was dangerous to them, and then by being dangerous to them, it was dangerous to the people that they were supporting. They didn't have a sense of belonging and community integration because they weren't seeing their communities. They weren't being a part of their traditional community outside of work that they had previously had access to.

There is an importance of including people with disabilities in research, even when research is not necessarily focused on people with disabilities. Even if it's a more general research study about COVID-19, people with disabilities need to be represented in all research. I encourage people to continue to fight for representation in all areas of life and that includes research. If there's any research studies that are being done in the state around COVID-19 that aren't including representation from people with disabilities and their families, and direct support professionals, continue to advocate for that because that is how we understand what's going on, and that's how we can really make a difference.

VIDEO INTERVIEW:

Watch the captioned presentation by Erin Rachel Vinoski Thomas, PhD, MPH.



## Statewide Disability Organizations Form New Network

The Georgia Developmental Disabilities Network (GDDN) is a consortium of 15 Georgia disability-focused organizations that are committed to connecting people with resources during the COVID-19 pandemic.



Launched at the beginning of the pandemic in Spring 2020, GDDN has hosted monthly phone calls to support individuals with disabilities, parents and family members, caregivers and other stakeholders to share COVID-19 challenges.

Additionally, the monthly webinars provide resources for Georgians with disabilities and other stakeholders that offer guidance on navigating various topics such as Medicaid waivers, employment, Appendix K and more.



Susanna
Miller-Raines,
Operations
Coordinator at
Georgia State
University's Center
for Leadership in
Disability (CLD),
spearheaded

the formation of GDDN. She spoke to *Making a Difference* about the network and how it plans to continue advocating for Georgians with disabilities.

#### How did GDDN come about?

Many of us have worked together for years and many organizations already had relationships. Georgia State's CLD, <u>University of Georgia's Institute on Human Development and Disability</u>, the <u>Georgia Council on Developmental</u>

<u>Disabilities</u> (GCDD) and the <u>Georgia Advocacy Office</u> are already a part of the <u>DD</u> <u>Network</u>. And then, by working with other organizations, we have all developed relationships throughout our work.

We all have different roles and responsibilities within the community, and we all serve different groups of people. We got full support and pulled everyone together to provide different perspectives based on our mandates and work in the community.

#### Who does the GDDN aim to serve?

The pandemic presented specific challenges that affected the disability community at a different level and gave individuals and families different things to think about when it came to services, medical appointments, employment and so much more. We wanted to specifically serve people with intellectual and developmental disabilities (I/DD) and their families.

The pandemic presented specific challenges that affected the disability community at a different level.

## Tell us about GDDN's webinars. What kind of information do they cover?

The <u>network's webinars</u> started with some of the basics of DD services such as understanding Appendix K, getting medical services and more. Then, we started to survey our audience and brought experts to address the topics that were also important to our callers.

IT HAS BEEN EMPOWERING TO PULL TOGETHER AND MOBILIZE A GROUP OF POWERFUL ORGANIZATIONS THAT ARE SHARING THE KNOWLEDGE AND EXPERTISE OF THEIR RESPECTIVE WORK.

Many wanted to learn about access to financial resources, for example understanding how the stimulus checks works, who gets it, how is someone who is a dependent going to get it, etc. We also had many discussions on mental health and dealing with isolation. Attendees did an idea swap that allowed everyone to share how they might be solving this problem.

We also did a webinar on education that featured the state director of special education who shared the master plan for students with disabilities and guidance for districts. Parents also learned about their rights and how to serve students who might not be getting services like speech therapies.

Other topics included assistive technology, employment, access to food banks and updates on COVID-19 from a source from the Centers for Disease Control (CDC).

#### Are there future plans for the network among other issues that are important to the disability community?

Absolutely. We have a whole new level of connectedness. At this point, we all know each other, and we have also invited organizations that are new to the network. We now have a platform that we can spring into action around other issues that matter to the disability community.

## What has been a rewarding experience of seeing this network grow and support the community?

It has been empowering to pull together and mobilize a group of powerful organizations that are sharing the knowledge and expertise of their respective work through the webinars and reaching individuals with I/DD and their families during a time of crisis.

While GDDN continues to provide information on COVID-19 updates, the network is now expanding its webinars to discuss legislative advocacy and how to advocate with legislators as the Georgia General Assembly's 2021 session is underway.

The webinars are now held monthly, and all recordings, transcripts and information are available on GCDD's website.

#### **GDDN PARTNERS**

- Adult Disability Medical Healthcare
- The Arc Georgia
- Bobby Dodd Institute
- Center for Leadership in Disability at Georgia State University
- Department of Public Health Georgia
- Down Syndrome Association of Atlanta
- FOCUS
- The Fragile X Association of Georgia
- Georgia Advocacy Office
- Georgia Council on Developmental Disabilities
- Institute on Human Development and Disability at the University of Georgia
- Parent to Parent of Georgia
- Spectrum Autism Support, Education and Resources
- Tools for Life Georgia's Assistive Technology Act Program
- Uniting for Change

In the beginning, these calls were so important as a way to connect and also to find out how others were approaching the challenges. They have continued to serve as a great way to get information and to hear the voices of individuals speaking on behalf of themselves. The self-advocate voice is impactful.



GEORGIA DEVELOPMENTAL DISABILITIES NETWORK







CENTER FOR Leadership in Disability





















## Real Communities Transitions to Welcoming Community Movement Fund

by Jennifer Bosk

Ten years ago, the Georgia Council on Developmental Disabilities (GCDD) launched its Real Communities Partnership (RCP) initiative to equip community members at the local, grassroots level to work together toward common goals to improve their community.



Now being led by Global Ubuntu, RCP is transitioning and expanding its reach by becoming the Welcoming Community Movement Fund (WCMF). This change will allow it to address the urgent issues many individuals with and without disabilities are now facing in society and across the state of Georgia.

The fund's goal is to build and sustain a movement where the culture shifts from one of hate, unfairness and dehumanization to one of love and belonging. It supports seven local initiatives throughout the state of Georgia, including:

- Peacebuilders Camp
   (Americus, GA) provides
   transformative learning
   experiences in summer camp
   and post-camp settings that
   empower a diverse community
   of youth to work toward peace,
   justice and human rights.
- Mixed Greens (Savannah, GA) is implementing health equity and community conversation programs to improve the lives of Black and Brown people and individuals with disabilities within their community. The initiative aims to empower participants to take control of their own wellness.

- Inspire Positivity
  (LaGrange, GA) is creating
  a program that will include
  welcoming community
  dialogues that specifically
  address the social issues and
  concerns of persons of color
  with disabilities, as well as the
  creation of public gatherings
  that will encourage better
  community involvement
  and support of persons with
  disabilities in disenfranchised
  communities in LaGrange
  and Troup County.
- New Neighbors Network (Comer, GA) recently purchased <u>The Perch</u> and is planning to develop the building into a gathering space for those who have historically been excluded and sidelined in their community.
- Compassionate Atlanta (Atlanta, GA) will create a steering committee with individuals who are representative of different identities of marginalization, including Black people and those with disabilities, especially in low-income communities. This group will work together to discuss issues that are most obstructive in moving towards a more equitable society.

Georgia Research
 Environment Economic
 Network (Savannah, GA)

will focus on documenting the social justice concerns of marginalized groups in the Savannah community and establish a Community Action Team to come up with measurable solutions.

• Filling the Gaps (Hephzibah, GA) will offer individuals within local communities a safe place to have authentic, real dialogue around topics that are timely and relevant to their current societal issues within a safe, judgment-free environment.

In addition to the seven initiatives, three coaching organizations will work alongside Global Ubuntu to support the Welcoming Community Movement. Mattie J.T. Stepanek Foundation (Americus, GA), The SEMANCO Team (Smyrna, GA) and Taproot (Atlanta, GA) will provide expertise on think tanks, inclusion, sustainability, restorative justice and healing.

The coaches will have the capacity to help the local initiatives research and organize around a diverse range of policy issues; to form multi-disciplinary collaborations



in their communities; and to provide resources and share the latest innovations in community organizing, advocacy and community-building practices for sustainable change.

THE FUND'S GOAL IS TO BUILD AND SUSTAIN A MOVEMENT WHERE THE CULTURE SHIFTS FROM ONE OF HATE, UNFAIRNESS AND DEHUMANIZATION TO ONE OF LOVE AND BELONGING.

Those involved will empower and stand beside leading agents to provide the necessary support in making the dream of the Welcoming Community Movement a reality. Global Ubuntu believes dialogue and advocacy are poised to shift culture and attitudes so that everyone can regard others with empathy and compassion, and so people feel welcome and develop a sense of belonging.

"We are excited about this movement, the dialogue, the education and change that is bringing restorative healing into all the work this initiative is doing. What's ahead now is to bring action into communities to all while including local government, churches, doctors, etc.," explained Sumaya Karimi, the project organizing director for RCP and WCMF. Karimi is also founder and director of Global Ubuntu.

According to Malaika Geuka Wells, community organizing coordinator for Global Ubuntu, the next step for WCMF "is to support community minded people across Georgia to be involved in creating deliberate

and intentional welcoming spaces, so all feel seen and valued."

For more information about the Welcoming Communities Movement and its fund, please visit Global Ubuntu's website. Additional details about the Real Communities Partnership initiative through GCDD can be accessed here.



#### The Mayor of Lithonia

by Shannon Turner, Photographer: Haylee Fucini-Lenkey

When Tira Harper walks into the small, square building that serves as Lithonia's City Hall, everyone knows who he is. Even before he gets there, when Tira tells his colleagues he's going, they joke and say, "Tira, you're the mayor!" Tira, pronounced tie-ray, has a circuit he walks many days of the week – from home to the Wayfield grocery store and city hall, which share the same parking lot, and then back home.

His community living support assistant, Barbara Branch, says she wishes he wouldn't cross the road exactly where he does because there's no crosswalk, but he's been doing it all his life.

Tira serves on the Lithonia City Council in an honorary position created for him by Mayor Deborah Jackson. The two knew each other previously, and she invited him to serve in this capacity to represent disability issues at the council level. Tira goes twice a week to meetings to share his thoughts and insights. Some of the things he advocates for include access to MARTA public transit for people with disabilities, among other accessibility issues.

Born with cerebral palsy (CP) and an intellectual disability, Tira is a 35-year-old man who has lived in the Lithonia area his whole life. He lives with his

Lithonia
BLUEPRINT
Progress
2017

aunt and step-grandmother, who was the wife of his grandfather. His grandfather, mother and father have all passed away. Tira is legally his own guardian, and his step-grandmother, Jo Ann Harper, helps to direct some of his financial decisions. Barbara helps Tira communicate with others, serving as a sort of translator. Tira says there are many people in his life who understand and help him communicate in this fashion, including his uncle, step-grandmother and cousins.

Having worked in the field over 30 years in three states, Barbara has been with KES, the service provider Tira uses, for four years and has been working with Tira for two. Tira has a COMP Medicaid waiver, which allows him to have Barbara's support 94 hours a week. The two of them go out into the community together in many capacities, including stopping by KES a few times a week for an hour or two, going to work at Wayfield, going thrift shopping and going to the library at multiple locations. Before they leave Tira's home each day, Barbara helps Tira pick out his outfits and makes sure he's working on his matching. Barbara doesn't work with Tira on the weekends. He is very independent when he's at home on the weekends.



Regarding the Medicaid waiver and how it helps to bring Barbara's presence in Tira's life, Jo Ann says, "It takes a lot of stress off of me. We had him in another day program a while back. The other program had him going out into the community like KES does, but it was also just a lot of 'no.' 'No' to this and 'no'

Tira Harper stands proudly in front of the Lithonia City Hall where he attends meetings as a member of the City Council.

IF A GOVERNMENT OFFICIAL
CAME TO TALK TO TIRA DIRECTLY,
HE WOULD TELL THEM WE NEED
MORE JOBS FOR PEOPLE WITH
DISABILITIES - AND DEFINITELY
MORE ACCESSIBLE
MARTA OPTIONS.

#### **GCDD STORYTELLING**



to that. They didn't believe in him like KES does. KES has been trying to teach Tira how to count money, which is great. There's no stopping Tira."

If a government official came to talk to Tira directly, he would tell them we need more jobs for people with disabilities – and definitely more accessible MARTA options. Tira speaks about having to go downtown to the MARTA headquarters and how long it takes. "That's crazy! I have to go all the way down to Five Points. I have to spend the whole day doing that. We need something local, closer. Lithonia has a lot of empty buildings. MARTA should buy one," he says.

Given how much Tira likes to walk, he also talks about how his community has too few crosswalks.



Just a week ago, he had to go to the doctor because he was having problems walking. CP can lead to joint problems and inflammation. The doctor put cortisone shots in Tira's hip and gave him some pills, which led him to be temporarily unable to walk and to feel generally lousy. However, his 35th birthday was the following week, so things were definitely on an upswing.

**Telling Our Stories** paints a picture of the complex systems of support that enable people with developmental disabilities to live their best lives. Spanning Georgia's 56 state senate districts, these stories feature at least one individual who resides in each district – allowing this project to become a vehicle of advocacy for Georgians living with disabilities. The stories highlight racial disparities, socioeconomic inequities and how a situation can play out in two different circumstances – one where people are or are not supported by the system.

#### GCDD's Storytelling Project

GCDD's Storytelling Project is the culmination of many works funded by the Georgia Council on Developmental Disabilities (GCDD) and managed by Friends of L'Arche, a self-advocacy organization, that share the stories of Georgians with disabilities and

their families. "6,000 Waiting," the project's movie, is a compelling short film that tells the stories of three Georgians with developmental disabilities whose lives are significantly impacted by the staggering lack



and complexity of state Medicaid waiver funding. With persistence, courage and self-determination, they fight to access the resources they desperately need to live life on their own terms.

Friends of L'Arche has contracted with film distribution company <u>Sound Off Films</u> to lead the charge in bringing the work to audiences. Currently, "6,000 Waiting" is being viewed via private virtual screenings and will premiere this January to the public. Those wishing to learn more about the project, watch the trailer and inquire about hosting a private screening can do so by visiting <u>www.6000waiting.com</u>.



A Part of the Storytelling Project

Participants are also being interviewed and accepted for the Over the Wire virtual story collection project. This digital collection vehicle of our Storytelling Project invites Georgians with disabilities to record themselves sharing their stories and submit it to the team. The video submissions will be turned into short social media clips featured on GCDD's social media channels. Learn more on the Over the Wire website.

Stay tuned to <u>GCDD storytelling page</u> for more details on all of these Storytelling Project opportunities.

To find out about more events across the state, <u>visit</u> GCDD's Calendar of Events.

#### **-JANUARY**

January 19, 3 - 4:30 PM COVID-19 Monthly Call Georgia DD Network

Register for Zoom call online



GEORGIA
DEVELOPMENTAL
DISABILITIES
NETWORK

Join our Monthly Zoom calls online

January 21, 7 – 8 PM Lekotek's Virtual Parent Support Group

Email lekotek.georgia@gmail. com to register for Zoom link

January 23, 7 AM - 4:30 PM

Southern Conference on Children: Navigating Our New Normal Virtual Conference

Register online

January 25 to February 6
Assistive Technology
Industry Association 2021:
AT Connected event

Register online

January 27, 10 AM - 3 PM

GCDD Virtual Advocacy Day #1 - Home and Community-Based Services (HCBS) Medicaid Waivers

Find more information online

January 28, Reg Deadline

Supported Employment ACRE Training for SW Georgia (Region 4)

Information and registration

#### FEBRUARY

February 4, 7 – 8 PM

Focus + Fragile Kids

Stockbridge Share Group

Pre-register & get Zoom link

February 9-12, 12 -1:15 PM Virtual Release of the Annual Disability Statistics Compendium Webinars Register FREE online for

all four (4) webinars

February 16, 10 AM – 3 PM GCDD Virtual Advocacy Day #2 – IPSE (Inclusive Postsecondary Education)

Find more information online

February 16, 3 – 4:30 PM **COVID-19 Monthly Call Georgia DD Network** *Register for Zoom call online* 

February 25, 7 – 8 PM **Lekotek's Virtual Parent Support Group** 

Email lekotek.georgia@gmail. com to register for Zoom link

#### **MARCH**

March 2, 10 AM – 3 PM
GCDD Virtual Advocacy Day
#3 – Competitive, Integrated
/ Supported Employment
Find more information online

March 16, 3 – 4:30 PM **COVID-19 Monthly Call Georgia DD Network** *Register for Zoom call online* 

#### **APRIL**

April 15 **GCDD Virtual Awards Ceremony** - Atlanta, GA <u>Find more information online</u>

April 15-16

GCDD Quarterly Council Meeting - Atlanta, GA Find more information online

April 20, 3 – 4:30 PM **COVID-19 Monthly Call Georgia DD Network** *Register for Zoom call online* 

