

Making a Difference

Summer
2021

Back to School



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What Going Back to School
Will Mean for Georgia
Students with Intellectual/
Developmental Disabilities

Making a Difference

A quarterly digital magazine from GCDD

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Focus on Education

by Alyssa Miller, PsyD

In this Education edition, we will be focusing on the Georgia Department of Education's plans to spend the dollars provided to the state's educational system through the American Rescue Plan Act. A key area of emphasis, included as a requirement to accept the funds, is supporting learning loss that has taken place during the pandemic.

Treasure Maps: The Georgia Storytelling Roadshow 2021

This pop-up, interactive, outdoor theatre traveled to six Georgia cities in June and July to creatively showcase 10 Georgia storytellers' personal viewpoints into what it's like living with intellectual/developmental disabilities.

What Going Back to School Will Mean for Georgia Students with Intellectual/Developmental Disabilities

by H. M. Cauley
As the new school year approaches in August, teachers, administrators, parents and students are pondering many of the same questions about what a return to "normal" will look like. If there is one element of certainty, it's this: No one has all the answers.

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SUMMER 2021

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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On the cover: As students head back to school in August, GCDD focuses on education and what face-to-face learning will be like in a post-COVID world.

SUMMER
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OUR NEW COUNCIL LEADERSHIP TEAM

This edition of *Making a Difference* will introduce you to our council leadership team. You will note that GCDD Chairman Nick Perry has co-written this letter with Executive Director Eric Jacobson. This will be a regular column. Nick was appointed to GCDD in November 2020 and elected chairman in January 2021.

This change coincides with the Georgia Council on Developmental Disabilities' (GCDD) efforts to elevate the voice of those with intellectual/developmental disabilities (I/DD) and their families. We believe that you will see this kind of collaboration in the new efforts that GCDD will undertake in the coming years.

First, let us congratulate those of you who have gotten their COVID-19 vaccine. This is your ticket to going out and visiting with friends and family. It is the time to start seeing each other at meetings and conferences. We want to encourage those who have not gotten their vaccine to do so.

The DD Network and the Aging Network are working to make sure every Georgian gets a vaccine. We recognize that some may be hesitant to get the vaccine, and we want to be able to answer any questions you might have.

Second, every five years, the United States Administration for Community Living requires that DD Councils submit a strategic plan describing how they will use

federal dollars to address issues of importance to people with I/DD and their families. We thank those of you who participated in this process over the last year. We listened to you and with your encouragement are proposing bold, risk-taking efforts. GCDD is excited to begin work on this new plan that will focus on Systems Change, Self-Advocacy and Diversity. While there are many details to be decided upon, we know that our readers and others will be key to our success. GCDD will continue to be leaders in advocacy, communications and supporting projects that will improve the lives of people with I/DD and their families.

Finally, after a year with kids being home and learning online, we want to help prepare for the return to schools. We have heard from parents, siblings and students in elementary school, high school and college. There are many questions about what happens when summer is over and school begins in the fall. *Making a Difference* has the answers for you. What do I as a parent need to know about schools opening in the fall? Will my child be required to have a vaccine? What happens if my child has regressed during the year; will there be extra help?



Nick Perry



Eric E. Jacobson

What about my child's sibling who has struggled and may need mental health supports? We have reached out to leadership at the Department of Education and with educators and parents to talk about what schools will look like in the fall.

MAKING A DIFFERENCE HAS THE ANSWERS FOR YOU. WHAT DO I AS A PARENT NEED TO KNOW ABOUT SCHOOLS OPENING IN THE FALL? WILL MY CHILD BE REQUIRED TO HAVE A VACCINE?

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We hope you enjoy reading this magazine, and we want to hear from you. Let us know your thoughts and comments about the magazine by writing to maria.pinkleton@gcdd.ga.gov.

Eric E. Jacobson
GCDD Executive Director

Nick Perry
GCDD Chairman

Students Excel at Georgia Tech

by Clay Voytek



Elliott Smith has known he wanted to work with children since the seventh grade. After starting as an intern, Smith now works 35 hours a week as a teacher's assistant at the Phase Family Learning Center in Alpharetta.

"It's a good amount of work, but I still really enjoy it," Smith said.

He started making progress on his career goals while completing the Expanding Career, Education and Leadership (Excel) program at the Georgia Institute of Technology.

Excel is an inclusive post-secondary education (IPSE) program designed for students with intellectual and developmental disabilities (I/DD). Founded in 2014, the four-year program approaches post-graduation employment from multiple angles. Graduates receive two separate certificates in academic enrichment and social growth.

Smith is one of 12 students who graduated from the program this May. Amid the ongoing pandemic, 83% of the 2021 graduates currently have employment, according to Nathan Heald, a lecturer and the assistant director of Excel.

To get there, students are required to complete seven internships over the course of the program. They work on campus for the first two

years, in addition to completing courses with other Tech students.

Heald says the program's career development course allows students to develop their interests and capacities over four years. The program works with students to build proficiency in seven key areas of transition: social and leadership development, health and wellness, technology and communication, housing, finances, transportation and employment.

Eventually, students transition to off-campus internships, and they work between 15 and 40 hours per week. The Excel program has 39 active internship partners and a total of 135, including Trees Atlanta, the Centers for Disease Control and Prevention and the National Center for Civil and Human Rights.

Before starting his current job, Smith also interned at the Elaine Clark Center and the Frazer Center, both inclusive child development and learning centers in Atlanta.

"I felt like with everything I was just growing and growing each new moment," Smith said. "The future is looking really, really good to me. I try to think about that a lot."

Ken Surdin, the director of Excel, says the program is constantly growing. Surdin says he would tell the state legislature that Georgia

could do more to help individuals with I/DD lead independent and productive lives.

"In the 2019 Case for Inclusion, it was noted that Georgia had just 12% of working-age individuals with I/DD in competitive employment – which is significantly less than the national average of 17.9%," Surdin said. "IPSE programs in Georgia are an excellent investment."

True Rafferty is another recent graduate with a competitive job. Randall Brothers, a lumber company in Atlanta, recently hired Rafferty as a full-time forklift operator. He received his certification after completing courses in supply chain and logistics.

Rafferty enjoys working and says he appreciated the chance to explore his options through Excel.

"I've tried some internships that I thought would be a good fit for me, but it turned out they weren't," Rafferty said. "I think it's good that I realized that early on instead of after graduation."

"A lot of people struggle after they leave college," he added, "but Excel will help make that struggle a little less complicated. A little bit easier, if you will."

Georgia Tech  **Excel**
Expanding Career, Education and Leadership Opportunities

Essay Forty-Six

by Michelle Simon, poem by Susan Berch

I would like to share with you a message from my dear friend and use her message as a conduit for my own. We have known each other for a while but have become extremely close during COVID-19. She is 52 has an intellectual disability. When everything shut down, she needed me and, of course, I was there for her. What I did not know was how much I needed her.



Susan Berch

Michelle Simon

I never took our friendship for granted; I just didn't realize what great times we had together and how genuinely real and meaningful they were. When it was time to choose our "quaranteam," we agreed we would be part of each other's, and the rest is history. We have had adventures and conversations that ended up being highlights of my last year. Instead of only running errands and taking care of things, we were able to do some unique explorations, and I was able to introduce her to my family.

As part of her challenges, she does not speak very loud or clearly, but I could always understand her and relished in what she had to say. She often told me that she knew she was difficult to understand and, like our nation's poet laureate Amanda Gorman, who also had a speech impediment, she preferred to write down her thoughts. She shared the following poem with me about her experiences during COVID-19, and I would like to share it with you.

Regardless of whether you can speak or just write, regardless of whether you have an IQ of 160 or 60, we all have something to say that is worth hearing, and I know firsthand that the world is a better place when we all are listening to each other. Please just open your heart to those you may perceive as different. I promise during this time and always, you will be surprised by the voids that can be filled.

Susan Berch is very involved in the Uniting for Change Leadership Collective and has worked at Jewish Family and Children's Services for 28 years.

*At the beginning of this Pandemic, I didn't know what we were in for
I didn't know how long this would last
How long we would all be isolated
Why did this virus occur in the first place?
Not being able to see our family, friends, loved ones
Celebrate special occasions, being there in person for one another
I feel sad each time I hear someone has COVID or another illness
I know for a fact that we have all experienced loneliness, anxiety, depression, being afraid, etc.
We ask ourselves when will this ever end?
None of us know
This is what I do know
I know that we will overcome this somehow
We all have to believe & hope that it will get better
Praying helps
This could be a whole lot worse
Thank goodness we all have each other
Many people have no one
We have a roof over our heads
Several people live on the streets
Many of us are healthy, but a majority of us are dealing with health issues
I feel very fortunate that we recite the Misheberach prayer every night. It has healed many, others not.
There are several family members that are in the hospital, recovering from surgery going for treatments, etc.
Still, we have to be grateful for what we have
No one said this was going to be easy
As hard as this has been for everyone, it has had many perks
We have Mindful Moments, Minyan, Shabbat Services, classes, etc.
We can take walks & enjoy the sunshine, spend time with the family & friends we have
Take road trips, play games, go through your closets & throw out stuff we no longer need
Cook new dishes, watch movies on Netflix
We have a new President & Vice President
I try to look at the bright side of things
I know not everyone can do that & that's ok.
I wish for the best for everyone
I want y'all to know that I feel very blessed to know all of you
We all have to stick together. Amen.*

Regardless of whether you have an IQ of 160 or 60, we all have something to say that is worth hearing.

This Self-Advocacy Spotlight was reprinted with permission. The original essay by Michelle Simon and poem by Susan Berch ran in 2020 Hindsight, a book published in May 2021 by the Jewish Women's Fund of Atlanta.

Focus on Education

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

In this Education edition of *Public Policy for the People*, we will be focusing on the Georgia Department of Education (GaDOE)'s plans to spend the dollars provided to the state's educational system through the American Rescue Plan Act.

These funds are the third installment of federal dollars intended to assist states during the COVID-19 pandemic. The first two installments came through the Coronavirus, Aid, Relief & Economic Security (CARES) Act and the Coronavirus Response & Relief Supplemental Appropriations (CRRSA) Act. These funds came during the height of the pandemic with the primary aim to prepare schools to respond to the COVID-19 pandemic

through prevention methods, as well as focus on transitioning to online learning. In addition, teachers and many school staff members were also allotted a one-time bonus.

The most recent installment of federal funds will be coming to Georgia after the passage of the American Rescue Plan Act in March of this year, and it is the largest relief installment yet at almost \$4.3 billion dollars. Georgia's statewide office, as well as Local Education Agencies, have been putting plans together regarding how they propose to spend the funds. This process included a public comment period in May where the

public were able to weigh in with their recommendations and ideas for how the funds should be spent. Although the final spending plans are not due until July 9, there are some highlights that we can share.

Georgia's State Plan will focus on three priorities: accelerate learning, personalize supports, and promote opportunity. The list of activities the state plans to invest in is quite long, which is no surprise considering the massive funding stream coming to the state.

A few highlights include:

- increase school-based health clinics,
- invest in the rural sparsity programs, social-emotional learning (SEL) and mental health formula grants to Local Education Agencies,
- support for the Whole Child Model (including a school nurse, social worker and wraparound specialist), and
- a large investment into teacher retention for IDEA programs, given the difficulty Georgia's educational system experiences with recruitment and retention of special education teachers.

A key area of emphasis, included as a requirement to accept the funds, is supporting learning loss that has taken place during

Georgia's State Plan will focus on three priorities: accelerate learning, personalize supports, and promote opportunity.

the pandemic. Georgia intends to invest approximately \$85 million of the funds for summer and afterschool learning.

The GaDOE is partnering with the [Georgia Statewide Afterschool Network](#) to administer grant opportunities for organizations through the Building Opportunities in Out-of-School Time (BOOST) grants.

With all of these new and enhanced educational opportunities, this is a very exciting time for those invested in our education system. As advocates, we should continue to work closely with our Local Education Agency, as well as the GaDOE, to ensure the needs of students with intellectual/developmental disabilities (I/DD) are considered when developing and improving upon the highlighted activities. In addition, when the BOOST grants become available, we would strongly encourage organizations with an emphasis in supporting students with I/DD to apply. In addition, you can track the funding levels and spending plans by state [HERE](#).

GCDD'S PUBLIC POLICY TEAM



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[Watch the trailer here.](#)

- Columbus - Friday, June 18
- Savannah - Friday, June 25
- Macon - Saturday, June 26
- Athens - Wednesday, July 7
- Dahlonega - Friday, July 9
- Atlanta - Saturday, July 10

It included live-local hosts, film screening, installations and interactive activities, all under safe social distancing practices. The roadshow feature is a film screening of "Treasure Maps," the movie featuring Georgians who share about their lives, their challenges and their communities. [Watch the full show here.](#)

Shannon M. Turner, creative director of the project, said, "We want to provide a virtual stage for the important stories of people with I/DD. But an equally important component is to provide education and advocacy to the general population and legislators around the Medicaid waiver, a vital funding structure which supports the lives of people with I/DD so they can live independently."



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What Going Back to School Will Mean for Georgia Students with Intellectual/Developmental Disabilities

by H. M. Cauley



As the new school year approaches in August, teachers, administrators, parents and students are pondering many of the same questions about what a return to "normal" will look like. Factors around physical spaces, classmates and schedules are under scrutiny, as are ways to figure out where students stand academically after months of being at home due to the COVID-19 pandemic.

If there is one element of certainty, it's this: No one has all the answers.

Experienced psychologists and teachers know there's a lot of ground to cover. School districts around the state have been looking at ways to make the transition as smooth as possible particularly for students with intellectual/developmental disabilities (I/DD), while also preparing to juggle the inevitable curveballs the fall term is sure to send their way. But it's a challenge to predict what face-to-face learning will be like in a post-COVID world.

"That's the million-dollar question," said Nicole White, the director of special education and psychological services for Gwinnett County Public Schools. "We are thinking carefully about how our students will be when they return."

Rebuilding Relationships

The state's largest school district, Gwinnett has almost 180,000 students, 23,000 of whom utilize

special education resources. In the last 15 months, some of those with I/DD have experienced varying levels of face-to-face learning.

"We have been very fortunate that many of our students who receive special education services took advantage of that opportunity to return to school," said White. "But there are also those who have been out since last March [2020], and we anticipate that our teachers will reach out in July to re-establish those relationships with students."

For teachers of special education students, the social aspects of school often play as important a role as the actual learning. "We recognize that students have been impacted by some level of trauma," said White. "We're thinking closely about how teachers will need time to rebuild those relationships that are usually very different in person rather than the digital environment. Teachers will need to take time to reintroduce themselves and get to know

If there is one element of certainty, it's this: No one has all the answers.

who the students are. We're also discussing the emotional learning factors that might prevent students from having social interaction."

Back in the Building

Marlena Wragg, director of compliance for Gwinnett's public schools, has been conversing with parents who recognize the benefits of having their students back in the building. One of the best ways to bolster their children's

Returning To School During COVID-19



By Heather Androsoff

Click the image above to download the social story.



experience, she tells them, is to start preparing well ahead of time.

"We're encouraging parents to talk to students, to have them think about school over the summer and to prepare them for fall," said Wragg. "We've also offered parents the chance to come into the schools during the summer so students can see the building and become familiar with it again before the first day. Most of our schools will be open on certain days, and if the parent talks to a local administrator, they can do that. They can also just drive to the school and talk about what going back will be like, even if they can't go inside. And we always encourage parents to come to the open house to meet the teachers. For students who have cognizant deficits, having that social story about the first day is a fantastic idea."

White adds that having a set schedule and re-establishing routines makes the transition easier for many of these students.

Wragg suggests, "Parents can also think about what their schedule at home will be like. Start working through getting up in the morning, preparing lunch – whatever pre-COVID routines can be part of the new normal can begin prior to the start of school."

Relearning the Routine

Andy Roach, an associate professor of counseling and psychological services in Georgia State University's College of Education and Human Development, is a former elementary school teacher who expects this school year to be one of the most challenging. But he agrees with Gwinnett's approach that families can do practical activities to manage the

resocialization and stress before that first bell rings.

"It's going to be difficult for all students to get back into and relearn that routine," he said. "And it will be particularly challenging for students with I/DD. If I were a parent, I'd be thinking about things like getting up at a regular hour.

Many of us have enjoyed working in sweatpants all day, and that will be a transition for our kids, too. It's a good idea to ramp up and practice all those things we need to do to build back a routine."

Roach also notes that students with I/DD often require specific instruction, accommodation and support. Those are the three areas where schools should put the emphasis when the year begins, and he offered specific insights into them.

Beginning with academics, he recognizes that the efforts of teachers during the pandemic have been nothing short of "heroic. But there's probably no doubt that online instruction in a lot of places hasn't been optimal, especially for students with I/DD," he said. "It's possible students will be returning with gaps in their reading and math skills after a year's-plus work of virtual learning. I often talk to my [Georgia State University] students about how students with I/DD are very instructionally sensitive, so when the instruction isn't optimal, it's particularly difficult for them to make progress."

Riding the bus will be different



a covid-19 related story

© Autism Little Learners



Because of Coronavirus (or COVID-19), riding the bus will be a little different this year.

© Autism Little Learners

Fulton County created a series of social stories designed to help students understand rules around in-person learning, such as wearing a face mask, riding the bus and sneezing.

While those gaps are not the fault of the students, their families or educators, Roach believes extra efforts do need to be made to ensure students are making progress. One way is to offer an environment conducive to learning.

WE'RE ENCOURAGING PARENTS TO TALK TO STUDENTS, TO HAVE THEM THINK ABOUT SCHOOL OVER THE SUMMER AND TO PREPARE THEM FOR FALL.

“

"They're coming back to a learning environment they're not used to," he said. "As a former elementary school teacher, I find myself thinking of all the classroom expectations around behavior that kids haven't been living with. For instance, you don't normally just get up and walk out of the classroom when you're tired of doing stuff. You have to raise your hand to ask for help. You can't have lunch at any time of the day. It's important to help kids think



about the things they'll have to do in the classroom that they didn't have to do at home and to help them understand there are certain times when there's recess or work."

THEY KNOW THERE NEEDS TO BE A RENEWED FOCUS ON THE KIDS WHO HAVEN'T BEEN IN THE BUILDING AND HAVEN'T HAD THAT SOCIALIZATION.

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Logistically, it may be difficult to meet the needs of students with I/DD as schools work to get everyone up to speed, Roach said. “There’s a possibility that things like re-evaluations and IEP (Individualized Education Program) meetings might be harder to schedule. There will be more kids needing more evaluations; meetings that didn’t happen last year need to be scheduled this year. Families may potentially see schools working really hard to manage all these things, and I’d encourage parents to be good advocates for their children but also recognize that in most cases educators will be doing the best they can with the resources they have, and they’ll have more on their plates than usual.”

Meeting the Challenges

The good news for parents is that schools are aware of the challenges and are working to meet them, said Roach.

“A lot of schools are putting plans in place, like potentially having counselors and psychologists to provide support systems,” he said. “Many special educators will think about how to do that as students

come back. I know within many school districts there are screening procedures to help kids having social, emotional or learning issues.”

Roach also expects that parents will have their own anxieties around sending their children back to school – a situation that calls for some intensive TLC.

“It’s really important for everyone – families, educators and children – to be gentle with themselves and recognize everyone will be adapting to a new reality that is somewhat like the old reality,” said Roach. “I’m a big believer in self compassion and compassion for others.”

Getting Help for Students

At the same time, Leslie Lipson, an attorney whose work often centers on children with I/DD, says parents need to be firm about getting the help their students need.

“There will be a lot of different scenarios for students coming back,” she said. “Some kids have been out of school and doing some type of distance learning; others may have been offered great instruction. But others, because of their I/DD, may have found material wasn’t very accessible. Kids with disabilities have a legal right to receive special education services as part of a free and appropriate public education, and kids who should have had that during the pandemic and didn’t might be eligible for compensatory service – makeup services that weren’t offered or weren’t able to be offered.”

As an example, Lipson considers the case of a child who was supposed to receive social skills work once a week. During COVID, that work didn’t happen, even though it was in the student’s

educational plan. “The school can come up with a plan to offer those services in another way,” said Lipson. “Maybe they put them off until the summer or offer them in greater frequency in fall.”

In another example, Lipson describes a student who was receiving group reading instruction but couldn’t access it online.

“Especially for younger kids with learning disabilities, learning across the internet is really hard,” she said. “A school could offer something in the summer or fall as a compensatory service. So, parents should be asking about the services that weren’t offered during the global pandemic.”

Lipson expects smart schools will be staffing and matching kids with smaller groups led by well-trained teachers. “That could be much more successful than coming back to a large classroom with kids who don’t know each other or the teacher,” she said.

“Administrations are going to have to allow teachers to get to know their students and their needs, and really work on orientating kids. I also hope it’s not all back on parents when many have been doing all these roles for the past 15 to 18 months.”

Practicing Different Approaches

Special needs teachers in Fulton County’s public schools have specific ideas of how to handle the transition back to the classroom. They’ve been practicing different approaches since September, when students with autism, intellectual disabilities and other developmental delays began returning to their classrooms. The shift from virtual to face-to-face happened after a



summer of planning, said Blake McGaha, executive director of Services for Exceptional Children.

"We worked diligently to produce deliverables for families at home and teachers supporting them, especially for lower-functioning students who needed visual support," he said. "As summer progressed, we developed more strategies to bring those kids back."

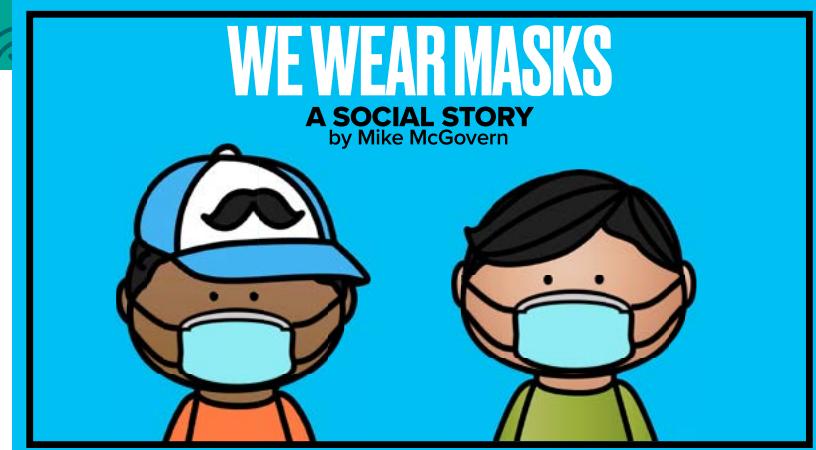
The cornerstone of the plan was a series of social stories designed to help students understand and implement rules around in-person learning, such as wearing a face mask, riding the bus and sneezing. Other stories revolved around hybrid learning and addressed kids' fears about schools shutting down on a moment's notice. And some spoke to bigger concerns: how learning at school is different from being at home, how to meet old friends in a new way, how to handle anxieties and perceptions around people who aren't wearing masks.

Take three deep breaths. Then remember this is an unusual situation, but there are people ready to support you.

“

"The idea was to create a social narrative of how things are different, but we're still doing school, and this is what it looks like now," said McGaha.

Last fall ended with about 63% of the special needs population in classrooms and the remaining students opting for virtual learning. Those returning were greeted with music and celebrations that reinforced going back was a good experience and that school was a welcoming place with safe adults.



Click the image at left to download the social story.

"It was all about smiles and making a positive environment," said McGaha. "But we still need to focus on that 37% that has not stepped into a school for 15 months."

That focus includes giving schools the autonomy to build their own social narratives for students in their communities.

"We can provide some social stories and lesson plans to build that support, but each school can add on their own plans to make things more robust," said McGaha. "But they know there needs to be a renewed focus on the kids who haven't been in the building and haven't had that socialization. We're looking at ways for families to meet the administration and support staff, and integrating social games to create interaction so teachers can measure who needs extra, hands-on help."

McGaha has shared these approaches during monthly brainstorming sessions with about 17 other service directors in the Atlanta metro area. In addition, Rachel Greene, Fulton's coordinator of autism, is part of the Georgia Department of Education's autism and support initiative with five sites across the state. "We have a group email chain that started in March of last year, and we share the cool resources or ideas we find," said Greene.

No One-Size-Fits-All Strategy

Sharing information and insights is key since each school is different. Zelphine Smith-Dixon, the state director of the Division for Special Education, acknowledges that "there isn't a one-size-fits-all strategy to address the needs of students with disabilities."

"These decisions are determined on a case-by-case basis by the Individualized Education Program," she wrote in an email. "It is the responsibility of the team to review updated data and current levels of performance, and ultimately decide what supports and services are appropriate and necessary."

Gwinnett County's White believes the schools in her district are up to the challenge.

"It may initially be a new experience, but our teachers and paraprofs will help students get back into the routine very quickly and reacclimate them to the school experience," she said.

As for parents and students, Roach offers a key bit of advice: "Take three deep breaths. Then remember this is an unusual situation, but there are people ready to support you."



What's Happening in Washington?

Federal Disability Policy Updates

By Serena Lowe, consultant
at the Center for Public
Representation

If 2020 felt like a long crawl across the Sahara Desert, 2021 feels a lot more like being in a race at the Indy 500 here in Washington! Check out the whirlwind of activity occurring both on Capitol Hill and with the new Biden administration with respect to hot topics like COVID-19, Community Living & HCBS, Disability Employment, Inclusive Education and Criminal Justice Reform.

COVID-19: CDC and ACL provide nearly \$100 million in grants to help older adults and people with disabilities get vaccines

In late March, President Joe Biden announced several actions to expand access to COVID-19 vaccines, including an exciting partnership between Administration for Community Living (ACL) and the Centers for Disease Control and Prevention (CDC) to increase vaccine access for people with disabilities and older adults. Throughout the pandemic, ACL has advocated alongside the aging and disability networks and advocates, and with partners across US Department of Health and Human Services

(HHS) and the federal government, to ensure equal access to care for older adults and people with disabilities. These grants will provide assistance with scheduling vaccine appointments, transportation to vaccine sites, direct support services needed to attend vaccine appointments, connection to in-home vaccination options, and education about the importance of receiving the vaccine. In addition, these grants will enable the aging and disability networks to identify people who are unable to independently travel to vaccination sites and to provide technical assistance to local health departments on improving access to vaccines.

Approximately \$5 million will fund national hotlines to connect older adults and people with disabilities with local disability and aging agencies that can assist with vaccine registration and provide services and supports necessary to get the vaccine. An additional \$93 million

For more on the HCBS Settings Rule, check out the [HCBS Advocacy Coalition](#).

will be distributed as follows: State Units on Aging and Area Agencies on Aging (\$50 million); Aging and Disability Resource Centers (\$26 million); Centers for Independent Living that receive federal funding directly from ACL (\$5 million); University Centers of Excellence in Developmental Disabilities (\$4 million); Protection and Advocacy systems (\$4 million); State Councils on Developmental Disabilities (\$4 million).

This partnership was established to further the National Strategy for the COVID-19 Response and Pandemic Preparedness, which includes protecting those most at risk and advancing equity as goals.

Community Living: Administrative Priorities: CMS releases guidance to states on enhanced FMAP funding as part of the American Rescue Plan Act (ARPA)

On May 13, the Centers for Medicare & Medicaid Services (CMS) issued guidance on how states can receive enhanced

More on the disability community's priorities for vaccine allocation, as well as federal resources and state plans can be found here.

funding, provided through the ARPA, to increase access to home- and community-based services (HCBS) for Medicaid beneficiaries.

The additional federal funding made available under the ARPA allows states to tailor HCBS enhancements based on the needs and priorities of residents, while protecting and strengthening the HCBS workforce, safeguarding financial stability for HCBS providers, and accelerating long-term services and supports reform and innovation. Section 9817 of the ARPA provides states with a temporary 10 percentage point increase to the federal medical assistance percentage (FMAP) for certain Medicaid HCBS from April 1, 2021 through March 31, 2022 to improve HCBS under the Medicaid program. States must also comply with a number of Maintenance of Effort (MOE) requirements and can spend the funds through March 2024. Georgia's spending plan was due to CMS by July 12, and we will continue to monitor and report on any updates.

Congressional Priorities: Bicameral Democratic leaders introduce Better Care Better Jobs Act

As the country begins to resurrect itself after the most devastating global public health pandemic in recent history, the Biden administration and Congress are working towards moving a massive \$4 trillion infrastructure development and jobs package that reflects the most significant investment in the nation's economic recovery since Roosevelt's New Deal and Johnson's Great

American Society programs. And among this massive recovery plan is the introduction of the Better Care Better Jobs Act, which would allocate \$400 billion toward reducing waiting lists of over 820,000 Americans who wish to receive support in their homes instead of in institutional settings, as well as to improve the quality of life of the 3.5 million older adults and people with disabilities already receiving HCBS.

On June 24, Sens. Bob Casey Jr. (D-PA), Ron Wyden (D-OR), Chuck Schumer (D-NY), Patty Murray (D-WA), Tammy Duckworth (D-IL), Maggie Hassan (D-NH), and Sherrod Brown (D-OH) introduced the Better Care Better Jobs Act. This legislation – along with its House companion introduced by Reps. Debbie Dingell (D-MI), Frank Pallone (D-NJ), Jan Schakowsky (D-IL), and Doris Matsui (D-CA) – would invest in and expand access to home- and community-based services for seniors and people with disabilities while boosting the wages, benefits and unionizing opportunities for home care workers.

The Better Care Better Jobs Act seeks to strengthen the country's HCBS landscape by giving states more money to expand their Medicaid HCBS while also making certain popular policies permanent. Specifically, the bill would –

- **Enhance Medicaid funding for HCBS** by making states eligible for a permanent 10 percentage point increase in the federal Medicaid match for delivering HCBS as well as enhanced funding

for administrative activities associated with improvement efforts. To receive these dollars, states must:

- strengthen and expand access to HCBS by expanding financial eligibility criteria for HCBS to federal limits; require coverage for personal care services; expand supports for family caregivers; adopt programs that help people navigate enrollment and eligibility; expand access to behavioral health care; improve coordination with housing, transportation and employment supports; and develop or improve programs to allow working people with disabilities to access HCBS.
- expand access to Medicaid HCBS and strengthen the HCBS workforce (which is largely made up of low-wage workers, the majority of whom are women and people of color) by addressing HCBS payment rates to promote recruitment and retention of direct care workers; regularly updating HCBS payment rates with public input; passing rate increases through to direct care workers to increase wages; and updating and developing training opportunities for this workforce as well as family caregivers.

● Provide an initial \$100 million to encourage innovative models

that benefit direct care workers and care recipients and offers additional incentives to help states build HCBS workforce programs that register direct

care workers; help connect them to seniors and people with disabilities seeking care; facilitate coordination between the state and direct care workers; support care safety and quality; and help workers organize, among other functions.

States would have to show improvement in quality over time by demonstrating improved availability of services; reduced disparities in accessing and using HCBS; evidence of competitive wages and benefits for workers; and increases in HCBS spending. If passed, the Better Care Better Jobs Act would also provide more funding to CMS to conduct oversight and monitoring activities.

In addition to the previously outlined provisions, the Better Care Better Jobs Act would make permanent both the spousal-impoverishment protections in Medicaid and the Money Follows the Person program, the latter of which is meant to help people transition out of long-term care facilities back into their homes.

In all likelihood, the Better Care Better Jobs Act will not make it into a bipartisan infrastructure package. This means that the HCBS bill will have to pass as a standalone bill that goes through the traditional legislation process. That route is similarly doubtful, however, with Democrats and Republicans effectively lodged in a stalemate for sway in the Senate. Another avenue could be reconciliation, with Democrats actively working on a plan to unilaterally push through important chunks of an immediate infrastructure package that got scrapped. Working in the bill's

[More information on the Better Care Better Jobs Act can be found here.](#)

favor is the constant attention that HCBS has been receiving since the COVID-19 pandemic began, plus the clear and growing demand for more integrated services at home and in the community.

Disability Employment:

Administrative Priorities: Executive Order requires federal contractors to pay the \$15 minimum wage to workers both with and without disabilities

On April 27, President Biden signed an [executive order](#) (EO) requiring federal contractors to pay a \$15 minimum wage to hundreds of thousands of workers who are working on federal contracts. The EO builds on the Obama-Biden Executive Order 13658, issued in February 2014, requiring federal contractors to pay employees working on federal contracts \$10.10 per hour, subsequently indexed to inflation. The minimum wage for workers performing work on covered federal contracts is currently \$10.95 per hour and tipped minimum wage is \$7.65 per hour. Specifically, the EO:

- Increases the hourly minimum wage for federal contractors to \$15. Starting January 30, 2022 all agencies will need to incorporate a \$15 minimum wage in new contract solicitations, and by March 30, 2022, all agencies will need to implement the minimum wage into new contracts.

Agencies must also implement the higher wage into existing contracts when the parties exercise their option to extend such contracts, which often occurs annually.

- Continues to index the minimum wage to an inflation measure so that every year after 2022 it will be automatically adjusted to reflect changes in the cost of living.
- Ensures a \$15 minimum wage for federal contract workers with disabilities. To ensure equity, [similar to](#) the Obama-Biden minimum wage executive order for federal contractors, this executive order extends the required \$15 minimum wage to federal contract workers with disabilities.
- Eliminates the tipped minimum wage for federal contractors by 2024.

Congressional Priorities: House reintroduces the Transition to Competitive Integrated Employment Act (TCIEA)

On April 6, Representative Bobby Scott (VA-03), chairman of the Committee on Education and Labor, and Representative Cathy McMorris Rodgers (WA-05), ranking member of the Committee on Energy and Commerce, introduced the

[More on the Transformation to Competitive Integrated Employment Act can be found here.](#)

[Transformation to Competitive Integrated Employment Act](#) (H.R. 2373) to provide states and employers with the resources to transition workers with disabilities into fully integrated and competitive jobs while phasing out the subminimum wage for individuals with disabilities.

A Senate companion bill is expected to be introduced by Senator Bob Casey (D-PA) in the near future. [Read the full legislative text here.](#)

Healthcare:

Organ transplant discrimination prevention legislation introduced in the US House of Representatives:

Charlotte Woodward Organ Transplant Discrimination Prevention Act (HR 1235). Despite federal protections, such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973, people with disabilities still face discrimination determining eligibility to receive organ transplants. There are currently laws against organ transplant discrimination in the states of California, Delaware, Florida, Georgia, Indiana, Iowa, Kansas, Louisiana, Maryland, Massachusetts, Missouri, New Jersey, Ohio, Oregon, Pennsylvania, Virginia and Washington. As of yet, there is no companion bill being prepared in the Senate.

Inclusive Education:

Keeping All Students Safe Act (KASSA) reintroduced

Senators Chris Murphy (D-CT) and Patty Murray (D-WA),

What You Should Know

- As the country reopens, lots of money is coming down the pike to get Americans back to work and to rebuild the country, including Home- and Community-Based Services (HCBS).
- In the meantime, states do have enhanced temporary funding through the American Rescue Plan Act of 2021, and advocates are urged to push Georgia to use this funding to expand and enhance HCBS.
- In addition, federal policymakers are focusing heavily on COVID-19 vaccine mobilization targeting people with disabilities and direct support professionals, HCBS modernization efforts, and improving access to competitive integrated employment for young adults with disabilities.

chair of the Senate Committee on Health, Education, Labor and Pensions (HELP), and US Representatives Don Beyer (D-VA), Robert C. “Bobby” Scott (D-VA) and A. Donald McEachin (D-VA) reintroduced the [Keeping All Students Safe Act](#), legislation to protect students from dangerous seclusion and restraint discipline practices in school. The most current data reveals that 101,990 students were subjected to seclusion or restraint in the United States during the 2017-18 school year, 78% of whom were students with disabilities and disproportionately Black youth.

In Other News:

President Biden nominates Taryn Williams as assistant secretary for the Office of Disability Employment Policy (ODEP)

Williams is currently the Managing Director for the Poverty to Prosperity Program at the Center

for American Progress, which works on progressive policies focused on a broad range of anti-poverty strategies. Before joining American Progress, Williams served as ODEP’s chief of staff during the Obama administration, and later as the director of the Youth Policy Team. Throughout her career, Taryn has worked on a variety of issues related to education, workforce policy, Social Security, Medicaid and civil rights. The Senate Health, Education, Labor and Pensions (HELP) Committee [advanced](#) Williams’ nomination to serve as assistant secretary of labor for Disability Employment Policy by a vote of 18 to 4 on June 16, and a final vote on her nomination is expected by early July.

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

Note: information current as of 6/25/2021

Going Back to School

Featuring Attorney Leslie Lipson, Founder, Lipson Advocacy

For students with intellectual/developmental disabilities (I/DD), I don't think we'll be able to find many students that haven't typically had some negative impact around their education for the past two years during the COVID-19 disruptions.

For many students, especially if they're immunocompromised, not yet vaccinated, or they're not going to be vaccinated for whatever reason, they have not been in school at all for almost a year and a half. That means kids that started first grade in March 2020 will be going back to school this fall in third grade, and those are really different grades.

So, we have a lot of students who number one, missed academic instruction; and number two, missed social and learning opportunities through being a student in our schools. Number three, kids have been home with their parents a lot, and they're probably very strongly attached to being at home. And that's also going to be an interesting transition.

Let's talk about what the school year holds for families, and what they can do to help kids be more successful as they're coming back to school. 

So, as we go into Fall 2021, kids with I/DD are probably going to fall into three different groups – the first would be kids that have not had in-person and face-to-face learning since March 2020. The second would be kids who went back in some fashion, probably early fall or mid-winter. And they probably had a lesser level of services, but they have been to school face-to-face. They would be returning this fall to a typical school day and a typical week.

Then the third group is kids that are likely still immunocompromised. They are not yet vaccinated, have had heart surgery in the past year, or live with extra vulnerabilities. And COVID-19 has had a disproportional health impact on them. So, some children will not be returning face-to-face in the fall, and they will probably still be seeking a virtual program.

Let's talk about what the school year holds for families, and what they can do to help kids be more successful as they're coming back to school.

All schools are going to have pre-planning for teachers for a week or more even before school starts. So arrange for your child to go meet their teacher. Go see the space, especially if your kid is transitioning from elementary to middle, or middle to high school, or you've moved and they're in a totally different school.

Get them physically into the space and feeling a little more comfortable. Get them back on a schedule. Get them used to getting up in the morning. Do some small academic tasks at home. If you have the means, put your child in a day camp, or do some summer activities to get them used how the day moves from one activity to the next. Those are good opportunities.

Communicate clearly with the school what your child may have been missing and set up a meeting right before school starts. The teachers need to know where your student is, and where they should be if there had not been a global pandemic.



One of the major questions in the field of education is what is Fall 2021 going to look like? Is it going to be different in light of the COVID-19 disruptions? I want to tell you that one of my biggest fears is that it's not. And I think we have to remember that students and educators and parents have been through a collective trauma – and everybody is going to come back to school different than they left.

There's a lot of conversation about loss of academics. We also have to remember that people have had a really hard time beyond even the pandemic. There have been major issues in America around economics; 600,000 people have lost their lives; and there have been major racial disruptions, tensions and protests.

Most of us will look back on this year as a pivotal year, and we will bring all of that with us to school. So, we must remind ourselves to be patient. If you're an adult who just took a year and a half off working remotely, and now you are going back in person – think about the things you are worrying about.

Students and teachers will have these same fears. For kids that have been in school that are now returning, it may be weird to be in school without a mask or dividers. Another piece that's going to be different is that both state and federal guidance is not very clear around if masks are required for kids who are unvaccinated, or if there are partitions, or if classes are going to be smaller. We really just don't know. You should familiarize yourself with your local

school board, so you can communicate with them about your kids.

One of the situations that is going to be challenging is kids who've been home for the past year and a half. For parents, we're used to knowing exactly what our kid ate and how they slept last night. What happens during their school day? Will we be having a lot of separation from our kids?

You might not always know what's happening in the school day. Even though we didn't always know before, we were used to it. And now we're not. We're expecting to see a fair amount of separation anxiety for lots of kids – and probably lots of parents. We're really all used to being together. It's going to require a lot of courage for kids to get on that bus, even though they're excited to go back to school.

The anxiety of living through a pandemic hasn't left us, even if we're entering a new post-quarantine stage, because we are not post-COVID. That is going to be really challenging. There will be a lot of new teachers. Many teachers did not enjoy the experience of distance teaching and some said, I'm not willing to go back in the classroom.

It's going to take students some time to learn their way around the building, to figure out how to really re-interact with peers and teachers again. How do you work a locker? What does it look like to change for PE? Ride the school bus?

First, focus on being in the role of a student, making sure that they feel safe physically and emotionally in school. That is the prerequisite for academic instruction. Making sure kids understand behavioral expectations, health and safety expectations, the school day, the physical layout and then academic expectations.

Coming into the school year, if your student currently has an Individualized Education Program (IEP) and is eligible for special education-related services, use that to help you understand where your student is academically, where they should be, and what you can plan and hope for this year.

I encourage you to request an IEP meeting during a time like pre-planning, because it gives the school information about your student. If your kid has been in school, there's information from the year before. If your kid's been home, the parent has the information about the kid's educational progress. So, pre-planning can set the stage for success. Wait two or three weeks after school starts and the teacher knows your kid. That means the teacher will say, "I've seen your kid struggling with this, and really strong at that. I think we should focus on this for your kid," and they'll have a lot of that information.

So, definitely make sure you have something on the books. Teachers are going to be understandably busy, and every kid is going to need an IEP meeting. The teacher may say, "We did one at the end of last year." Well maybe, but summer regression's always an issue for students with I/DD.

You really need to push for this if you want to understand academically where your student is in reading, in math, in writing. Take a look at those scores for the first month of the school year. Then take a look at the scores the last time your kid was in school. If they had really good virtual schooling and got good benchmarks, see what type of progress your student is making. If they haven't made academic progress in the past year, ask for something called compensatory services for the services your student has missed.

You can also ask for physical therapy, occupational therapy and speech therapy. If your student has missed

There may be many people out there who think that kids with I/DD are just happy-go-lucky, and not experiencing the same grief that other people experience. But we know in the advocacy world that is untrue.



therapy during the past year and a half, whether in-person or virtual, it does not matter. Ask for compensatory education. It's good for your student. It's actually really good for the teachers for students to have more individual attention so they can bring their class to where it needs to be. That is the way the law is supposed to work. It doesn't mean that the school did anything wrong. But it does mean students have a legal right to services, and schools have the opportunity provide them.

A lot of kids have experienced trauma and major disruptions in their lives. Pay attention to your kid's psychological and emotional needs. Request services from the school to support social and emotional growth.

There may be many people out there who think that kids with I/DD are just happy-go-lucky, and not experiencing the same grief that other people experience. But we know in the advocacy world that is untrue. People have all of the same emotional breadth and deserve the same supports, if not more during this time.

So, I also encourage all of us to look at what's happened, not just within the school or academically, but also holistically for kids during this year.

**VIDEO
INTERVIEW:**
[Watch the
captioned
presentation
by Attorney
Leslie Lipson](#)



Progress on GCDD's Five Year Strategic Plan

The federal government requires all Developmental Disabilities Councils to create new strategic plans every five years.

The Five Year Strategic Plan determines how each Council will allocate funding to create systems change for individuals with intellectual/developmental disabilities (I/DD) and family members through advocacy and capacity-building activities.

In Georgia, the plan is the foundation of how the Georgia Council on Developmental Disabilities (GCDD) will do its work across the state. By hearing from individuals with I/DD, family members, caregivers, siblings and the community-at-large, it sets the course of what the Council has to work on for the next five years, or 2022-2026.

All GCDD efforts aim to ensure that people with I/DD are independent and interdependent, have greater economic self-

sufficiency, are integrated and included in their respective communities and self-determined in their lives.

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

The new plan is nearly complete and will be presented for adoption to the Council members on July 15, and then submitted to the federal government in August.

The first part of the planning process engaged over 500 Georgians through a survey, focus groups, interviews and townhalls. People told GCDD that the things they cared about most are improving services and supports, employment and housing.

The government requires that each Council have a Self-Advocacy goal and a Targeted Disparity goal. Along with those goals, the GCDD strategic planning committee, with input and feedback from GCDD Council members, developed one additional goal.

The goals read as follows:

Systems Change: With support from allies, advocates, stakeholders and communities, people with intellectual/developmental

THE FIRST PART OF THE PLANNING PROCESS ENGAGED OVER 500 GEORGIANS THROUGH A SURVEY, FOCUS GROUPS, INTERVIEWS AND TOWN HALLS.



disabilities and their families, will have increased access to and benefit from equitable quality supports and services that increase self-determination and meet their needs and preferences.

The goals and objectives went out to the public for feedback through surveys and townhalls. Feedback was overall positive.

Self-Advocacy: GCDD will provide more opportunities for the voices of individuals with intellectual/developmental disabilities to be heard by strengthening capacity among Georgia self-advocacy organizations and initiatives, supporting cross-disability coalitions and leadership development programs for and by people with intellectual/developmental disabilities.

Targeted Disparity and Diversity: The Council's activities and those done in collaboration will be conducted with a focus on equity that increases the access of marginalized communities with particular emphasis on

racial and ethnic minorities and those in rural areas.

Each goal has two to four objectives with activities which will inform the work for the next five years. While GCDD has the required Targeted Disparity goal, GCDD is committed to embedding equity into its practices at all levels and not just through the specific targeted

disparity. GCDD accomplishes its work through advocacy, public information and capacity building.

The goals and objectives went out to the public for feedback through surveys and townhalls. Feedback was overall positive and there were no significant changes made to the goals and objectives.

The planning team has been hard at work creating, prioritizing

and budgeting the activities; creating an evaluation plan; and finalizing outputs, outcomes and performance measures.

Following successful adoption at the July Council meeting, the plan will be uploaded and officially submitted and an infographic to show the simplified plan will be created for distribution to the public.

GCDD's 2022-26 Five Year Strategic Plan Goals

GOAL 1 Systems Change

To increase access to and benefit from equitable quality supports and services that increase self-determination and meet needs and preferences.



GOAL 2 Self-Advocacy

To strengthen capacity among Georgia self-advocacy organizations, supporting cross-disability coalitions and leadership development programs.



GOAL 3 Targeted Disparity & Diversity

To focus on equity that increases the access of marginalized communities with particular emphasis on racial and ethnic minorities and those in rural areas.



Welcoming Community Movement Adds Think Tank Partner to Coaching Group

by Jennifer Bosk

TeMaya Eatmon has been chosen as the Think Tank Partner for the Georgia Council on Developmental Disabilities (GCDD) initiative the Welcoming Community Movement (WCM), overseen by Global Ubuntu. Eatmon joins other leaders who are coaching those participating in the WCM in the additional areas of inclusion, sustainability and restorative healing.

Currently nine counties in Georgia are home to WCM initiatives working in their communities to hold Welcoming Community Dialogues. These are formal and informal conversations with community members, local government, businesses and everyone willing to actively participate in creating a welcoming community for all who reside and/or work there, no matter their abilities, ethnicities and beliefs. WCM is working to build a movement where the community culture shifts from one of hate, unfairness and dehumanization to one of love and belonging, where the principle of morality is practiced as the norm.

Eatmon holds a health law degree from Emory University and has also done advocacy work in Washington, DC. In her role of Think Tank Partner, Eatmon will work to meld the advocacy efforts of the grassroots Welcoming Communities with the advocacy work being done by GCDD. “I believe you meet people where they are, so I did one-on-ones with the initiative organizations,” Eatmon explained. She is working to narrow down the issues the nine Welcoming Communities are currently tackling, finding common ground among them.

In listening to the goals of three Welcoming Community groups, Eatmon has helped them whittle down their issues to a single one that impacts all three of them. Peacebuilders Camp in Americus, Mixed Greens in Savannah, and Inspire Positivity in LaGrange are focusing on inclusion, race issues, poverty and empowerment. But Eatmon was able to help them dig down to a base issue of the need



for healthy food and overcoming the food deserts within these communities.

As the three Welcoming Communities begin to research this basic human need for food and its impact on other issues the residents are facing, they can now join forces to work and advocate together. “My hope is they will galvanize, get with other clients and communities, and share this focus. That would be ideal,” Eatmon said. This food issue is also currently being discussed in a Georgia House of Representatives committee providing WCM groups with another avenue to advocate.

Eatmon added, “The thing about advocacy and policy work is that is the way you make change. We don’t look at Republicans or Democrats. It’s about the issues. That’s our main focus. I want to have an impact on the groups I serve. I want to help others think it through. Advocacy is telling your story, it’s not lobbying. Talking about yourself and those you love are what changes policy.”

Eatmon will also collaborate with GCDD’s public policy staff. GCDD promotes public policy that creates an integrated community life for persons with intellectual/developmental disabilities (I/DD), their families, friends, neighbors

TeMaya Eatmon, New Think Tank Partner for WCM

ADVOCACY IS TELLING YOUR STORY, IT'S NOT LOBBYING. TALKING ABOUT YOURSELF AND THOSE YOU LOVE ARE WHAT CHANGES POLICY.



GCDD'S CURRENT WELCOMING COMMUNITY MOVEMENT PARTNERS



Abilities Discovered



Compassionate Atlanta



ConnectAbility



Filling in the GAPS



GREEN



Inspire Positivity



Mixed Greens



New Neighbors Network



Peacebuilders Camp

and all who support them. As GCDD sets its legislative agenda for 2022, ways for the Welcoming Community members to connect will include GCDD's Advocacy Days at the Capitol; individual outreach advocacy efforts to local, county and state legislators; as well as utilizing [GCDD's toolkit for grassroots advocacy efforts](#).

As the coaches work one-on-one with the Welcoming Communities, the entire nine organizations plan to gather September 15-19 for their

annual WCM Retreat and Summit. "This is a place for the members of the Welcoming Communities to connect and bond, to reflect on how we are working, discuss the challenges we face, look at what to change for next year," explained Sumaya Karimi, founder and co-director of Global Ubuntu.

"One of our goals will be to increase the involvement and leadership among people with I/DD and people of color within their community initiatives," Karimi added.

You can [read more about GCDD's WCM here](#), [GCDD's public policy efforts here](#), and [Global Ubuntu's work with WCM here](#).



Model of Hope

by Moira Buccarelli, Photographer: Virginie Kippelen



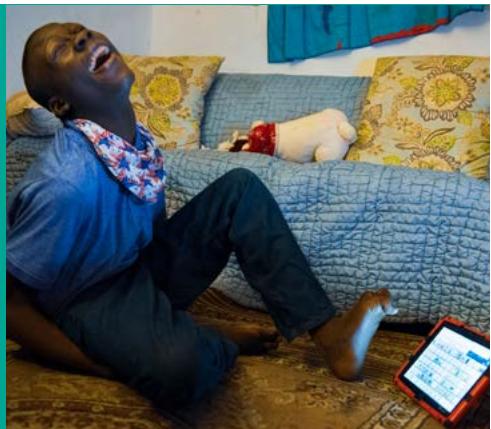
"I'm ready to tell my story! Have you seen any of my movies?"

This is how Eric Naindouba, a soon-to-be 14-year-old with cerebral palsy greets us as we meet for the first time in a local McDonald's. Eric is with his friend Kathi Frankel, who has known him since he was five. This is where Eric wants to start his story – how he and Kathi met. "Me and Carol and Mama were at the hospital ..."



Clearly an extrovert, Eric is all about communication. He wants to be known and to contribute to the conversation and to the world. But speech does not come easily for Eric. Each word he says is hard-won. Cerebral palsy affects his ability to control his muscles, including his mouth and vocal cords. His voice expressively ranges in tone from highs to lows, and he repeats words or phrases urgently to be understood. It takes time and effort to understand him, and sometimes Kathi acts as a translator. Her skills as a physical therapist and her awareness of his history and personality give her a quick grasp of Eric's speech.

Eric has had to face people who doubted his capacity to communicate or think. Throughout our conversation, Eric speaks of his love of learning and being engaged.



Eric's Number One goal is to do his work on his iPad.

"When I return to my old school, I go to summer school. I love that! It gives me more to do on my goals."

When asked what his goals are he states: "Number One, to do my work on my iPad. Number Two, reading and math, and science and social studies." Kathi adds with a smile, "He's a stickler for details. He's very methodical." In the busy and distracting environment of a McDonald's birthday party, with friends and family coming and going, stopping to give Eric a hug and a smile, it is Eric who brings us back to the conversation, remembering exactly where we left off and what he wants to say next.

Eric was born while his mother was fleeing a war in the Central African Republic, their home, en route to a refugee camp in Cameroon. The trip was difficult, and Eric suffered brain damage as a result. He lived his first five years in a refugee camp. The camp provided medical care, but life was difficult living on flour and water, enduring long lines, and not having schools.

In 2010, with assistance from the International Refugee Commission (IRC) Eric and his mother, Nestorine, landed in Atlanta, GA. His father remained in Cameroon. Which brings us back to the story of how Eric and Kathi met.

Kathi Frankel is a pediatric physical therapist who works at a children's hospital. She went down to get a cup of coffee one day and noticed a mother and a young child in a small stroller. The mother looked lost. Kathi noticed the IRC emblem on a bag. Having worked with refugees, Kathi knew they may be feeling overwhelmed at the hospital. She went over and asked if they needed any help.

Eric Naindouba with Kathi Frankel, who has become an advocate and friend

ERIC HAS MANY DREAMS FOR HIS FAMILY AND HIS LIFE. HE WOULD LIKE TO INVENT THINGS FOR PEOPLE LIKE HIMSELF AND GO TO GEORGIA TECH.

”

Eric was five years old at the time, and was there for a swallow study. Because of the muscle control issues, aspiration, or choking on food, is a common safety threat for children with cerebral palsy. Eric was there to be evaluated for his risk.

He had been eating fine and not had any issues. Kathi says, "He ate well by mouth. His body would lean to the side. It wasn't traditional – so the doctors were

afraid ..." Some of the doctors insisted that he was going to need a g-tube (gastrointestinal tube). At the recollection of this, Eric becomes agitated, his voice ranging up and down, and he says: "What? No! I eat WELL!"

Kathi checks in with Eric to see if he is OK and asks him, "Should I tell them who they called?"

Eric has had to face people who doubted his capacity to communicate or think. Throughout our conversation, Eric speaks of his love of learning and being engaged.

Eric nods yes. "We had a run-in with the department of child and family services," says Kathi. "I felt that this family did not need to have intervention from a social service agency, and that he was not aspirating for the test and that calling the agency was crossing a line." But after the phone call was made, Kathi became involved and was present at home visits from the DeKalb County Division of Family and Children Services (DFCS).

This built into a crisis where Eric was at risk of being separated from his family. Kathi advocated strongly for the Naindoubas to stay together. She knew that the mother and child bond was strong and that Nestorine was capable of caring for her son. They needed time and support, not punishment. The county's concern was that Eric was medically fragile, at risk for aspirating, and that his mother was not capable of providing for all his needs. That is when Kathi

realized that helping this family was going to entail more struggles than she anticipated. It wasn't going to be just about offering to help them find wheelchairs. Kathi was taking on more legal responsibility in her role as a volunteer and family friend. She worried: if he did ever aspirate his food, would she be responsible?

After that experience, Kathi was determined to help the Naindoubas get more support that would prevent them from falling through the cracks. Kathi successfully applied for the comprehensive Medicaid or COMP waiver, which now pays for caregiving support for Eric.

After hearing this story again, Kathi seems worn out by the memory and asks Eric, "What's something fun we've done?" "Derona!" says Eric.

Derona King, the head of Citizen Advocacy of Atlanta/DeKalb, is helping Eric learn how to be an advocate for others who have intellectual/developmental disabilities (I/DD), like him. He has been speaking at a yearly history of disability symposium.

Eric and Kathi are helping another refugee mother from Congo, who also has a child with developmental needs. Eric speaks proudly of the letter he wrote to the then-mayor of Clarkston, Ted Terry, asking for better schools for refugee kids. He invited the mayor over to visit, and Mayor Ted accepted.

"Even the mayor knows Eric," smiles Kathi.

Eric has many dreams for his family and his life. He would like to spend more time in the community, hold meetings at the local coffee shop to listen to others and hear



Eric sees himself as an advocate, and he welcomes others to see his vision and help advocate for him.

the voices of refugees. He would like to invent things for people like himself and go to Georgia Tech. Eric sees himself as an advocate, and he welcomes others to see his vision and help advocate for him.

Kathi shares what she has learned from her friendship with Eric: "He has led me down a path of love and understanding that no one can teach in school. He is a model of hope, but he is also a real, intelligent person in that struggling body. He wants what we all want – to be a regular person, and be treated as such."

Telling Our Stories

paints a picture of the complex systems of support that enable people with I/DD 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 I/DD.



COMMUNITY CALENDAR

JULY

July 19-23, 9:30 AM - 2:30 PM
Virtual Annual Conference on Independent Living: Liberty, Independence, Freedom, and Equity (LIFE)
[Register here.](#)

July 25-30
Camp Krazy Legs
Children's Healthcare of Atlanta camp for youth with spina bifida
[Find details here.](#)

July 27, 2 - 5 PM
The Southern Museum Sensory Friendly Afternoon
[For more information, click here.](#)

AUGUST

August 2-5
National ADA Symposium: Virtual
[More information and registration here.](#)

August 2-5, 2 - 5:30 PM
NACDD 2021 Online Annual Conference
[More information and registration here.](#)

August 4, 1 - 2 PM
Electronic Visit Verification (EVV) Townhall
[Register FREE online.](#)

August 5, 6 - 7 PM
Electronic Visit Verification (EVV) Townhall
[Register FREE online.](#)

August 12, 7 - 8 PM
Lekotek's Virtual Parent Support Group
[For more information, click here.](#)

August 18, 3 - 4:30 PM
Planning for All Ages and Abilities Through Walk Audits
[Find details and register here.](#)

August 19, 11 AM - 2 PM
DiversityX Diversity Virtual Hiring event
[Register FREE online.](#)

August 30 - September 3
Developmental Disabilities Ministries: Camp Twin Lakes Rutledge
[More information here.](#)

SEPTEMBER

September 18, 9 AM - 3 PM
Special Needs Kids Day At The Lake - Glade Marina on Lake Allatoona
[Find the details here.](#)

September 21
Course on Supervision of Special Education in Schools in Secondary Classes
[Course info and details here.](#)

September 24, 3 - 7 PM
2nd Annual Disability Fall Resource Fair
[More information here.](#)

September 25, 10:30 - 11:30 AM
Lekotek Sibshops
[For more information, click here.](#)

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



2ND ANNUAL DISABILITY FALL RESOURCE FAIR

September 24, 3 - 7 PM
A FREE disability resource fair for Georgia families with children with I/DD
[More information or register here.](#)

OCTOBER

October 3
Childrens Museum of Atlanta Sensory Session
[More information here.](#)

October 9, 10 AM - 12 Noon
Lekotek Pumpkin Patch
[Open calendar here and go to October 9 for info.](#)

October 14-15
GCDD Quarterly Council Meeting - Atlanta, GA
[Find more information online.](#)