## VOLUME 22, ISSUE 4 O Difference SPRING 2022

# Moving Forward in Advocacy

Tips for Finding Inclusive Summer Camps

President Biden Appoints GCDD Chairman to Serve on Committee

**COVID-19 Updates** 



## Making a Difference

6

### PUBLIC POLICY FOR THE PEOPLE

### Official Recap of Georgia's 2022 Legislative Session

By Isabel Knofczynski

This year, GCDD's policy and advocacy experts, along with self-advocates, family members, community members, and disability professionals and advocates, have pushed for funding and support for the developmental disability community. Now that the 2022 legislative session has come to a close, GCDD is excited by the success of the advocacy efforts of the community that led to increased funding and legislation in support of people with developmental disabilities.

### **COVID-19 UPDATE**

### **18** GCDD's COVID-19 Initiatives & Updates

By Naomi D. Williams & Hilary Vece

The COVID-19 pandemic has disrupted the lives of people with developmental disabilities for over two years, but GCDD has been working collectively with advocacy and health-focused organizations throughout the state to ensure people with developmental disabilities aren't forgotten. From dissemination of resources to COVID-19 vaccine clinics and assistance, GCDD is active throughout Georgia.

### SUMMER RESOURCES

### 22 Tips for Finding the Right Summer Camp for your Child with Developmental Disabilities

By Kimberly Hudson

With the excitement of the end of the school year comes the opportunity for children with developmental disabilities to attend summer camps. Parents or campers may have concerns about what to expect, but there are many ways to find the right camp to fit children with developmental disabilities' needs. Inclusive summer camps are present and ready across the state.

SHARE YOUR FEEDBACK

### CONTENTS

#### VIEWPOINT

Farewell	
By Eric E. Jacobson <b>3</b>	

### SELF-ADVOCATE SPOTLIGHT

Self-Advocate Gives Powerful
Speech at State Capitol
Featuring Michael Housel4

#### SPECIAL ANNOUNCEMENT

GCDD Chairman Nick Perry Appointed by President Biden to Serve on Committee By Tianna Faulkner ......11

### **EXPERT UPDATE**

Advocate by Creating Change Where You Are Featuring Shelley Spivey......12

#### GCDD STORYTELLING

#### **Holding Hands and Jumping**

By Shannon Turner Photography by Lynsey Weatherspoon......**14** 

### **GCDD IMPACT**

Understanding How Data Can
Empower Us to Move Forward in
Advocacy
By Kimberly Hudson16

### **INCLUDE COLLEGE**

### WITH GRATITUDE

Peers Reflect on Executive Director Eric Jacobson's Leadership Over the Years

#### 2 MAKING A DIFFERENCE MAGAZINE

### FAREWELL

### Dear Readers,

For the past 30 years, I have written this column introducing *Making a Difference*. This is my final column as I retire from GCDD on May 31, 2022.

It has been difficult writing this column as I end my current work with you and the council. We have seen many victories, and a few defeats along the way. I am very proud of the work that we have done together over the years. We have created a strong advocacy voice both on the legislative level and amongst self-advocates. And while we still have a long way to go, we can look back favorably over these past thirty years and reflect on successes like Project WINS, Uniting for Change, Real Communities and Welcoming Dialogues, Advancing Employment, Customized Employment, visitable housing, inclusive post secondary education, Unlock the Waiting List, Disability Day at the Capitol, and many more. Together we have built one of the strongest advocacy networks in Georgia and across the country.

I know that many of you will read this and say "yes, but we are still not where we should be." I could not agree more. We still have over 7,000 people on a waiting list. People still do not have accessible, affordable housing, people are paid subminimum wages and have difficulties finding a job, and we still have students housed in GNETs. We are not there, but these are issues that advocates across the state are working on, and GCDD will continue to be there to support these efforts. Over the next year, GCDD will be discussing the issues of health care, employment, housing, and transportation. These conversations will lead to new and innovative efforts. These efforts will require your input and support.

One of my favorite authors, Margaret Wheatley, wrote that "there is no power greater than a community discovering what it cares about." The future can be a brighter day for people with developmental disabilities and their families. It starts with a strong coalition of individuals, families, and allies that develop a shared agenda for moving forward. I want to emphasize that the

Enic E. (Lacobson Eric E. Jacobson

GCDD Executive Director

### GCDD VIEWPOINT



role of GCDD is not to lead these efforts but to provide the backbone support to ensure success. YOU are the people who must drive these efforts. You are the people that must discover what you care most about. It is up to you to meet with your legislator and those running for public office and ask the questions about how they will support disability rights.

I want to thank the many people who served on GCDD over the years, the staff that have made this organization so successful, and our readers and supporters. This group allowed GCDD to be successful in our efforts and allow me to leave knowing the future is bright. It has been my honor and privilege to be a part of the disability rights movement—it has made me a better person than when I started. On February 28, 2022, Michael Housel, a selfadvocate from Tifton, Georgia, gave a powerful and passionate speech at the State Capitol in Atlanta, Georgia, in support of Senate Bill 208.

Mr. Housel is a founding member of Uniting for Change and is active in the Leadership Collective. His speech was part of a press conference organized by Sen. Sally Harrell where he stated:

SB 208 would compel Georgia's Department of Behavioral Health and Developmental Disabilities to fully fund the NOW/ COMP waiver waitlist within five years, but is subject to available funding.



Self-Advocate Michael Housel (right) with Pastor Don Mclauglin

Good afternoon, ladies and gentlemen, it is my honor to be here at our State Capitol to speak to you today. Thank you, Sen. Harrell, for your hard work and dedication to all our friends and family to have the supports needed to live a life worth living... *IN THE COMMUNITY.* 

> My name is Michael Housel, and I represent the Leadership Collective of Uniting for Change, a statewide, grassroots movement of self-advocates living all over our beautiful state of Georgia. We have hundreds of members from Atlanta to Valdosta, Athens to Columbus, and many other small towns like Tifton where I live.

> Senate Bill 208 is the lifeline that so many people I know need to live a life they love in the community with the people they choose in the places they want and with their wants and needs being the focus in their own homes.

> Right now, there are over 7,000 people like me that live waiting... on a list... the Medicaid waiver planning list. Some are in family homes that struggle to meet their needs, some are in hospitals, some are in nursing homes, some are in jails, some are in institutions. *THIS IS NOT LIVING, THIS IS WAITING!*

SB 208 would end that waiting in five years. I would not be able to live in my apartment without supporters paid by the Medicaid waiver. I'm an independent person, but I need help, just like all of you need help.

There are other problems that need to be fixed in that same time. Supporters of people with disabilities live in poverty. The average worker that supports people, DSPs (Direct Support Professionals), make less than \$11 per hour to make sure people have their needs met, make sure we have a safe home, take us where we want and need to go, help us with our finances, medical treatments, write everything down, meet all the state and federal requirements, and make sure we are living the life *WE LOVE*. Until the workers can earn a decent living, there will be constant turnover.

I've had more DSPs than I can remember. Some are the best, but they can't survive on the low wages. We must address the way our state, not just our state, *OUR NATION*, pays for supports. Any person here could need supports at any time, having a disability label is one accident, one medical treatment, or one medical problem away from being a reality for all Americans.

Like my friend Sheila Jeffrey said about SB 208, *"LET THE MONEY GO, FREE OUR PEOPLE!"* 

Thank you, and God bless us all!



Uniting for Change is a statewide, grassroots network of self-advocates, allies, and supporters in Georgia that was founded in 2019 through a grant from the Georgia Council on Developmental Disabilities. This network is committed to advocating, organizing, showing up, and being heard. Uniting for Change members seek to share information, create opportunities, and influence change. Advocates pose with Senator Sally Harrell at the Georgia State Capitol at February 28 rally in support of legislation to fund NOW/COMP Medicaid waivers



# Official Recap of Georgia's 2022 Legislative Session

By Isabel Knofczynski

### Georgia's 2022 legislative session was defined by the effects of a lingering pandemic and looming elections.

Most of our advocacy efforts and each of our three Advocacy Days were virtual. Although "the ropes" at the Capitol were not open to the public, we built on our knowledge gained from nearly two years' experience advocating during the pandemic and made our priorities known to our legislators. Advocates offered both virtual and in-person testimony at committee meetings, heard from legislators at advocacy days, and sent many, many emails using our new Phone to Action campaigns.

Every seat in the Georgia legislature is up for election in November. We saw an influx of "campaign promise" bills that focused on hot-button issues, from voter fraud to vaccine mandates. This reality informed our advocacy efforts as we worked to determine which bills were introduced primarily to excite voters and which were actually likely to move forward.

As always, we remained focused on bringing about policy change that promotes opportunities for Georgians with developmental disabilities to live, learn, work, play, and worship in their communities.

### Home and Community-Based Services

NOW and COMP waivers provide funds for people with disabilities to receive services in their homes and communities, helping them to lead self-directed lives and avoid having to live in a nursing home or other institution. The Georgia Council on Developmental Disabilities (GCDD) has advocated for waiver funding for many years, and 2022 was no different. Over 7,000 people are waiting for waivers, but Georgia has been slow to add funding, so this issue remains central to our advocacy efforts.

At our February 26 Advocacy Day, hundreds of advocates emailed their legislators about how important NOW/ COMP waivers are to our community. We also heard from legislators and community members.

Many advocates attended and spoke in a <u>press conference</u> hosted by Sen. Sally Harrell about her bill, SB 208. SB 208 would compel Georgia's Department of Behavioral Health and Developmental Disabilities (DBHDD) to fully fund the NOW/COMP waiver waitlist within five years, but is subject to available funding. Although it did not pass this session, it served as a talking point and drew attention to this important issue.

Sen. Sally Harrell also introduced SR 770, which creates a Senate study committee to analyze access to NOW/ COMP waivers and waiver services. SR 770 passed on the second-to-last day of



session. The study committee includes eight members, including five political appointees, the DBHDD

commissioner, the DCH commissioner, and GCDD's executive director. We hope that this study committee offers an opportunity to continue to address the NOW/COMP issue in substantive ways.

We are excited that our advocacy efforts led to increases in funding for additional NOW/COMP waiver slots in the fiscal year 2023 budget. The House Appropriations Committee included funds for 325 new NOW/COMP waiver slots, and the Senate added additional waivers slots, bringing the total to 513 slots funded by over \$10 million.

Although this still leaves thousands of Georgians without necessary services, this is by far the largest number of waiver slots added in a decade—a true testament to the hard work of our advocates!

### Pay for Direct Support Professionals

As people move off the waitlist, it is important for them to actually receive the services they are entitled to. Right now, people with waivers struggle to find direct support professionals (DSPs) to provide their services. DSPs receive low pay and few benefits, resulting in high turnover.

Our first Advocacy Day focused on addressing this problem: again, advocates emailed their legislators about this issue and asked them to fund a 5% provider rate increase. Many also offered testimony in Appropriations subcommittee meetings.

In the 2023 budget, the House included \$2.4 million to fund a 1% rate increase for providers. This rate increase was removed by the Senate but re-added and doubled by the budget conference committee. Additionally, the final budget bill includes a provision to use \$500,000 in funds from the American Rescue Plan to fund a rate study of developmental disabilities providers.

Additionally, <u>SB 610</u> passed the Senate. It requires the Department of Community Health to conduct a comprehensive rate study for all waiver providers every three years. In addition to NOW and COMP providers, this also includes providers who offer services under several other waiver programs. Rate studies can offer valuable information about how much money direct support professionals should make and offer other workforce insights. We hope that continued study and increased awareness of the workforce issues that exist within home and community-based services will provide a foundation for future advocacy efforts to raise wages.

An additional provision was added to this bill relating to Medicaid reimbursement for mental health and substance use disorder treatment. Advocates are not unified in their views of this addition, but we are glad to report that the original waiver rate study language did not change.

### **Employment**

Our final Advocacy Day focused on promoting competitive, integrated employment opportunities for people with disabilities. Following changes in workforce participation rates brought about by the pandemic, many businesses are having problems recruiting and retaining staff. At the same time, only 13% of individuals with disabilities are currently in competitive, integrated employment. Because of this, we believe now is a critical time to explore the systemic barriers that prevent people with developmental disabilities from getting the support they need to successfully contribute to Georgia's economy by working in competitive jobs. Hundreds of advocates contacted their legislators to request that they address the issue of competitive, integrated employment.

### **Education**

We tracked several bills relating to K-12 education to ensure students with disabilities receive safe, inclusive, and supportive education. We supported Gwinnett SToPP's efforts to end the school-to-prison pipeline as a part of our new five-year strategic plan. Students with disabilities are disproportionately affected by the school-to-prison pipeline: they are twice as likely to receive out-of-school suspensions as general education students. Several bills in the legislature were introduced and passed relating to this issue. HB 272 passed the House and changed the jurisdiction of the juvenile court system to include all children under 18. Currently, some 17-year-olds have their cases heard in adult courts,



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



ALYSSA MILLER, PsyD GCDD Public Policy Research & Development Director



CHARLIE MILLER, GCDD Legislative Advocacy Directo



ISABEL KNOFCZYNSKI GCDD Public Policy & Advocacy Fellow

### **POLICY WINS**

### GCDD Advocacy Days

Three Advocacy Days resulted in over 1,500 emails sent to legislators across Georgia on the issues of necessary funding for NOW/COMP waivers, the DSP shortage, and the importance of competitive, integrated employment.

### Fiscal Year 2023 Budget

- 513 Medicaid waiver slots funded by over \$10 million—the largest number of waiver slots added in a decade.
- 2% provider rate increase, totaling nearly \$5 million in funds In support of DSPs.
- A provision to use \$500,000 in funds from the American Rescue Plan to fund a rate study of developmental disabilities providers

### SR 770:

Creates a Senate study committee to analyze access to NOW/COMP waivers and waiver services

### SB 610:

Requires the Department of Community Health to conduct a comprehensive rate study for all waiver providers every three years

### HB 1013:

Increases access to mental health care in Georgia by requiring insurance coverage and strengthening the provider workforce

### HB 1008:

Moved STABLE accounts under the authority of the same board that oversees Georgia's Path2College 529 Savings Plans. This can increase awareness and use of these accounts by Georgians with developmental disabilities and their families which can lead to harsher sentencing. SB 106 passed the Senate. It requires that students in preschool through third grade are offered wraparound support before they are suspended. Finally, we supported the passage of HR 917 which would create a study committee to research "Too Young to Suspend"-a concept that young students, such as those in pre-k or kindergarten, should not be suspended. None of these bills were able to pass both chambers before the end of session. We hope they still serve as conversation points to encourage movement away from overly punitive school discipline and toward support that helps all students be successful.

We tracked several bills, including SB 587, SB 589, SB 601, HB 60, and HB 999 that would have expanded school choice in Georgia by allowing students to receive state dollars to attend private schools. We were concerned that these bills did not include adequate protection for students with disabilities who choose to use these scholarships. In public schools, federal and state laws prohibit discrimination and mandate that all students receive an education that is appropriate to their needs and abilities. Private schools are not subject to the same laws, so students do not have the same protection. None of these bills passed this session, although education and school choice could come up again in future sessions.

Our education advocacy also extended to post secondary programs. We advocated for continued funding to Georgia's eight (soon to be nine) Inclusive Post Secondary Education (IPSE) programs and used our Phone to Action campaign platform to let legislators know about how important these programs are.

### **Disability in All Policy**

Outside of our policy priorities that we continue to advocate for year after year, we also tracked legislation related to a wide range of issues to ensure that the needs and desires of people with disabilities are included in all types of policy issues. This session, many of these issues were determined by the "campaign promise" bills and other priorities of legislators.

### Mental Health

House Speaker David Ralston prioritized mental health legislation this year. Along with Reps. Todd Jones and Mary Margaret Oliver, he introduced HB 1013, the Mental Health Parity Act. This bill aims to increase access to mental health care in Georgia by requiring insurance coverage and strengthening the provider workforce. GCDD submitted suggested language to make sure that people with disabilities are included in these efforts. In addition, our partner organization, the Georgia Advocacy Office, worked to modify concerns about mandated treatment and patient registries. Additional protections were added to the mandated treatment provision and registry language was removed in the final version. HB 1013 passed the House and Senate unanimously and has been signed into law by Governor Kemp.

### Voting Accessibility

Last year, voting was a focus of the legislative session that culminated in



the passage of omnibus voting bill <u>SB</u> 202. Although Republican leaders in the General Assembly stated that they were not interested in revisiting the issue of voting this year, several voting bills were introduced. We tracked several bills that would have reduced voting access by banning dropboxes, which are especially helpful for voters with disabilities. The legislature did pass a controversial last-minute voting bill <u>SB 89</u> on day 40, but it does not include any provisions relating to dropboxes.

### COVID-19

Last year, HB 290 was introduced. It would prohibit hospitals, nursing homes, and similar institutions from enacting policies that limit patients' ability to receive visitors during a public health emergency like COVID-19. It makes this a necessary condition to obtain or maintain the permit necessary to operate a hospital or nursing home. During the committee process, language was added that would have changed laws about guardianship. GCDD and other groups advocated against this last year and continued to track HB 290 this year. The guardianship language was removed, but afterward, the bill did not pass.

We tracked <u>SB 345</u>, which was introduced this session by Sen. Jeff Mullis. Originally, this bill would have banned public institutions from requiring any type of vaccine. This created concerns that schools would no longer be able to require many vaccines that have long been proven effective at preventing disease. In response to these concerns, SB 345 was modified to focus only on COVID-19 vaccines.

### **Other Important Legislation**

We tracked several bills that were not part of our original policy priorities but addressed issues that are important to people with disabilities.

HB 1008 made some administrative changes to STABLE accounts, which allow people with disabilities and their families to save and invest money without affecting social security eligibility. We tracked this bill's progression through the legislature to make sure that it did not include any provisions that would affect the availability and accessibility of STABLE accounts. Under the bill, these accounts will be under the authority of the same board that oversees Georgia's Path2College 529 Savings Plans. Legislators and advocates are hopeful that this change increases awareness and use of these accounts among Georgians with disabilities and their families. HB 1008 passed with strong majorities on day 40.

<u>SB 360</u>, also known as Colton's Law, amended an existing law to require harsher punishment for people convicted of cruelty against a minor who has a disability. It passed the Senate unanimously but lacked momentum in the House and never passed out of committee.

SB 108 creates the Commission for the Blind and Visually Impaired. It also transfers supervision of the Georgia Industries for the Blind from the Georgia Vocational Rehabilitation Agency to the commission. Despite having only Democratic sponsors, SB 108 passed the Senate with a strong majority.

SR 613 was introduced by Sen. Donzella James and passed the Senate with strong support on Crossover Day. It urges the Georgia Building Authority to develop a plan to make Georgia's Capitol Building more accessible for people with disabilities in alignment with the Americans with Disabilities Act. As a historic building, the Capitol was not designed for accessibility. We are excited about the possibility of this resolution to make the processes of democracy more accessible to both legislators and constituents.

### **Next Steps**

We are proud of the successes we were able to achieve this year with the invaluable help of our partners and advocates. We had hundreds of advocates send over 1,500 emails to their state legislators over the course of our three Advocacy Days. Our efforts contributed to the addition of tens of millions of dollars to the state budget that will support the needs of many Georgians with disabilities. However, our work is not done—advocacy is an ongoing process. We look forward to building on our progress over the coming days, months, and years. There are many advocacy steps that can be taken during the legislative off-season.

1) Continue to build relationships with your legislators by reaching out about important issues and finding opportunities to invite them to community events. Legislators have more time when they are not in session, so it is an ideal time to start educating them about the issues that will be important later and thank them for their work this session.

**2)** Attend state agency board meetings, including the Department of Behavioral Health and Developmental Disabilities (DBHDD), the Georgia Vocational Rehabilitation Agency (GVRA), and others. These meetings are a good chance to learn about agency work year-round.

3) Reach out to the governor's office to share your thoughts on what should

be included in next year's budget. The budget process takes place year-round. Work on the fiscal year 2024 budget begins almost as soon as the fiscal year 2023 process is over.

4) Stay connected to GCDD for additional "off season" advocacy opportunities. Off-season events might include community gatherings to build relationships, opportunities to share thoughts at public comment sessions, and trainings to become better equipped to advocate year-round.

 $\star$   $\star$   $\star$ 

### The Continuum of Inclusion



Exclusion occurs when people with developmental disabilities are directly or indirectly prevented from or denied access to activities, education, and programs in any form.

Exclusion can be overt or can be hidden within restrictive policies, often citing legal or insurance reasons as rational for excluding people with developmental disabilities.

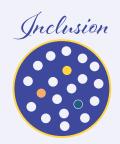


Segregation occurs when the participation of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from people without disabilities.



Integration is a process of placing people with disabilities in existing mainstream settings (such as educational institutions), as long as the people with disabilities can adjust to the standardized requirements of these institutions.

Integration does not automatically guarantee the transition from segregation to inclusion.



Real inclusion provides all people with developmental disabilities of the relevant age range with an equitable and participatory experience and an environment that best corresponds to their requirements and preferences.

Inclusion involves a process of systemic reform that requires changes and modifications in content, teaching methods, approaches, structure and strategies to overcome barriers.

Placing people with developmental disabilities within mainstream environments such as camps and classes without making structural changes like policies, logistics and teaching and learning strategies does not constitute inclusion.

Although significant advances have been made, and the word inclusion is often used, real inclusion for people with developmental disabilities has not yet been universally achieved.

To learn more take the Georgia Coalition of Family Advocates online training course or join the coalition.

### GCDD'S CHAIRMAN NICK PERRY HAS BEEN APPOINTED BY PRESIDENT BIDEN TO SERVE ON THE PRESIDENT'S COMMITTEE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

By Tianna Faulkner

### President Biden announced in March his intent to

appoint 21 individuals to serve as members on the President's Committee for People with Intellectual Disabilities (PCPID). Nick Perry, Georgia Council on Developmental Disabilities (GCDD) Chairman, has been selected to serve on this committee.

Perry is a sibling of a young man with intellectual and developmental disabilities (I/DD), and he's also been a foster father to children with disabilities. Perry has over 25 years of cumulative



experience in the disability field, ranging from disability policy and implementation to corporate disability inclusion strategy. Currently, he is the Disability Inclusion Subject Matter Expert for the Boeing company. Additionally, Perry was appointed by Governor Kemp and leads the Georgia Sibling Connection, a support and social group for siblings of individuals with disabilities.

The President's Committee on People with Intellectual Disabilities serves as a federal advisor to the President and the Secretary of Health and Human Services on matters relating to persons with intellectual disabilities.

The PCPID has 2I citizens members who serve two-year terms. Individuals appointed to this committee reflect the diversity of America and include people with intellectual disabilities and their family members, researchers, service providers and other professionals, community and business representatives, and systems advocates. Perry has served as GCDD Chairman just over a year.

• • •

It is such a great honor to be appointed to the PCPID by President Biden. I am committed to continued advocacy with, and on behalf of, the disability community.

-Nick Perry

### Advocating Beyond Legislative Session: Building Avenues for Change

Featuring Shelley Spivey

eing an active advocate isn't just about protesting, working on legislation, or contacting your representative. It starts small in moments and opportunities that reveal themselves to you daily. It's about having meaningful, connected conversations with the people you interact with in your daily life and making change where you can. This is where family advocate Shelley Spivey shines.

When Spivey's son was diagnosed with autism in 2018, she quickly knew she needed to connect with other parents and students with autism but couldn't find a solution that worked for her family. This vacuum inspired Spivey to create Waves Autism Center in Warner Robins, Georgia, and to become

"I just wanted to bring people together to be able to connect with and create relationships with others that have experienced similar concerns and challenges.



involved in a number of advocacy efforts.

Shelley continually looks for and participates in several formal and informal community groups relating to developmental disability advocacy. She is a founding member of the Leadership Circle on the Georgia Coalition of Family Advocates on Developmental Disabilities. When joining the coalition, Spivey said, "I hope to help facilitate conversations that will improve the lives of our children, young adults, and students in our state. I hope to connect with others in our community and around Georgia to create bridges of communication, leading to wellbeing and an increase of support and resources."

Spivey continues to be an active member of the coalition and shared her experience as a family advocate during a 2021 Virtual Lunch and Learn session with the Coalition of Family Advocates.

Her participation has assisted in growing her advocacy network. "We



want to be able to create bridges so that we can start opening up more opportunities," said Spivey. "The more organizations and people we connect with the more opportunities we unlock for our students."

Spivey also serves on the Project AWARE of Houston County and the Middle Georgia Regional Transition Council.

Shelley Spivey knows that the path forward to more opportunities for children with autism and other intellectual or developmental disabilities in Georgia is a challenging path. But it's one that starts with partnerships with parents, advocates, schools, and organizations.

"I just wanted to bring people together," said Spivey, "to be able to connect with and create relationships with others that have experienced similar concerns and challenges."

Spivey, a therapist by training,

previously worked with women and children who were emotionally abused or women exiting the prison system but she decided it was best for her family to refocus her efforts on autism support for her son and eventually, for others.

Shelley isn't alone, the whole Spivey family is involved with Waves: sons Schuyler and Cameron Spivey serve as peer mentors to other students with autism. When he's not working as a peer mentor, Schuyler Spivey is an active self-advocate and has worked with partners across Georgia to advocate for opportunities for students with autism. Schuyler is a member of the Gen Z Georgia Community Mentorship Program. The success of programs at Waves helped to push Schuyler to become active in advocacy. "Schuyler is a totally different person than he was four years ago," said Shelley. Growing a new generation of advocates is a positive but unintended outcome of Spivey's efforts.



Shelley Spivey (center) and sons Cameron (left) and Schuyler (right)

My son has hopes and dreams of earning his business degree and opening a cafe or bakery one day. I've had conversations with businesses in our community about employment opportunities. My son and many students are afraid to even mention they have autism in fear it will cost them an opportunity to find employment. I hope to see changes made in the coming year so that my son and others in Georgia can have hope and a future for a wonderful life.

The road to making meaningful change is often not a straight line or a clear path. Challenges and inequities can be daunting, and self-care is an important part of being a long-term advocate. Spivey shared that self-care has always been an important part of her professional career as a therapist. This holds true today as a parent of a child with a developmental disability and an advocate. She uses music to help her feel centered and to relax.

Sometimes advocacy is looking at the issues that we can move forward most easily. It's in finding common ground and having meaningful discussions with people who have opposing viewpoints. And it's about finding or building the resources or paths our students need that are missing. "My goal is to provide hope and a clear path forward," said Spivey.

Shelley Spivey 478-733-2597 wavesautismcenter@gmail.com

### Holding Hands and Jumping By Shannon Turner Photography by Lynsey Weatherspoon

Columbus, Georgia (Senate District 29)

### It's Friday afternoon at Chattahoochee Scuba in Columbus, Georgia.

Kaylee and Micah Asante are getting suited up, not for scuba lessons, but rather for swimming instruction and therapy. Kaylee, 10, and Micah, 16, both have autism. Jo Durst, who was recommended to them by Family Support at New Horizons Behavioral Health, slips into the pool and starts distributing toys to use during the session. "Are you ready? Are we going? Ready! Set! Swim!"

Dorothy Asante adopted Kaylee and Micah after fostering them from different families. They have two other siblings as well. One is 25, and the other is Micah's twin sister. Their autism is suspected to be a result, at least in part, from fetal alcohol syndrome. In Micah's case, testing at the Marcus Autism Center revealed a deletion of the short arm of chromosome 16. Dorothy says that both Kaylee and Micah need speech therapy, but obtaining timely and needed services has been one of her greatest struggles with the school system.

Micah and his twin sister, Michelle, first came to live with Dorothy when they were just a few months old. That first time, she had them until they were three. Then, the courts decided to move them to another state to live with distant family members. Because they suffered some trauma in that situation, the family returned them to the child protective services system and Dorothy took Micah and Michelle back in. Dorothy adopted them soon thereafter. A few years later, Kaylee came to live with them when she was a baby and was

adopted into family early on.

The Asantes have been on the waiting list for Medicaid waivers since 2012. Dorothy is very grateful that a case worker at New Horizons walked her through the process of making the application, so it was less complicated than many others have experienced. Kaylee was moved to the short-term waiting list in 2017; Micah moved in 2018. Dorothy was diagnosed with a blood clot in her leg not long before the family was in a car accident in September this year. She's been told that this change in their circumstance may help to move the children up the waitlist, but no change has been communicated so far.

In the meantime, although there is a low cap on it, the family support program at New Horizons offers funding for

**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.





୭୦୦ Kaylee & Micah Asante ରର୍ଦ

similar services to what they might receive from a Medicaid waiver. It makes today's swim lesson possible. Dorothy says that it's helpful, but she still has to pay out-of-pocket on a lot of things that would promote their independence because the cap on eligible expenses is \$3,000 per child. Dorothy speaks passionately about what the waiver could do with them in terms of further supports and stability. "I know what they need," she says, "I just can't do it by myself."

Micah and Kaylee receive Medicaid, and they also have Adoption Assistance available to them for things that Medicaid may not cover. They go through those funds swiftly every year. Micah has braces now, for which Dorothy had to pay the first four months of payments before they were covered. The kids are also being seen by a therapist who does not take Medicaid. Dorothy says the kids are familiar with that therapist. She's successful with them. So, as their mom, she wants to keep them there.

If given the opportunity to speak to a legislator, Dorothy says she would say, "Our lives are not easy. It really is hard when you're dealing with kids that have developmental disabilities, and it's important to really get them the help they need at the beginning, instead of the middle. In the middle it helps, but they need so much more." She goes on to speak about the importance of a good foundation and the parallels between investing early in support for a person with a disability and the education system more broadly. Dorothy also states how strongly she feels about having her

children participate in a general classroom because then they will be held accountable for their behavior by the same standards, rather than being coddled or excused because they've been deemed to have exceptional needs.

As the swim lesson wraps up, Kaylee goes through a routine Dorothy says has become standard. She gets everyone to cheer her on so she'll jump in. "Are you gonna do it?" Dorothy encourages, "Who's my big girl? You're doing great!" Eventually, everyone rallying as if it is for an Olympic gold medal, Kaylee jumps into Jo's waiting arms. Hopefully, with an even more robust network of supports, Kaylee and Micah will be able to continue to grow and thrive, jumping into more opportunity that awaits them.



### Understanding How Data Can Empower Us to Move Forward in Advocacy

By Kimberly Hudson

Every activity and initiative that the Georgia Council on Developmental Disabilities (GCDD) engages in starts with data. Understanding how it's collected and used can be a powerful tool to help us move forward in advocating for people with developmental disabilities in Georgia.

GCDD is authorized under Public Law 106-402, the Developmental **Disabilities Assistance and Bill of** Rights Act Amendments of 2000, also known as the Developmental Disabilities Act or the DD Act. The organization is funded and protected by this federal law. All states and territories have a council on developmental disabilities similar to GCDD. When funding is sent from the federal government to a state government, both the federal government and the state government are required to track how the money is being used and the impact that those funds are making in your community.

Data is important. It's data that decides how much funding is allocated to specific states, for example GCDD's funding is decided by the population of people with developmental disabilities in the state. Other states may receive more or less funding based on their state's population. It's data that helps support our advocacy efforts by persuading the legislature to hear our concerns. It's data that helps us make our voices heard when we say people with developmental disabilities are being disproportionately impacted by COVID-19.

Additionally, any company or organization that receives money from the state, such as vendors and grant partners with GCDD, are required to report on how the money is spent and the impact of those funds on the developmental disability community in Georgia.

If you've engaged in activities and events with GCDD, you have likely been asked to participate in a survey or to share your story. These surveys collect important information about who is being served through these federal/state dollars. Surveys often include information about your relationship to a person with developmental disabilities, where you live, your race, your gender, if you have gained knowledge or resources, or have increased your advocacy or decision-making abilities based on the activities you have engaged in. Surveys also typically include how satisfied you are with a particular program activity. These surveys can seem formulaic, but the metrics are purposeful. They reveal the deliberate intention by the federal government, the state of Georgia, and GCDD to serve people across all racial groups, geographic areas, and genders. They also underscore the importance of developing programs and initiatives that truly make a difference in communities.

Additional information that is collected through GCDD staff and grant partners includes the number and outcomes of advocacy efforts, systems change measures, and public and media awareness around developmental disability experiences and systemic barriers.

It may seem dry or boring, and sharing data likely doesn't elicit the same feeling you get when you're directly connecting with a person, but participating in data collection is a very impactful way for you to make your voice heard. This is because

You're an important part of a much bigger movement than you may realize.

FEDERAL GOVERMENT

Funding and reporting flows from the federal government, to state governments and state developmental disability councils. Information is then gathered from DD councils in all states and reported back to show positive use of funds.

INFORMATION FROM ALL STATES

ADVOCACY WORK IN COMMUNITIES IN GEORGIA & ACROSS THE COUNTRY

the same way that funds flow down from the federal government, your voice—in the form of data—flows up to GCDD, the state, and the federal government.

GCDD applies an important ethical standard to data collection. It is "no data without stories, and no stories without data." One is never sufficient without the other. This ethic helps to ensure that data in the form of numbers and metrics (also called quantitative data) isn't misrepresenting reality. Stories (a form of qualitative data) ensure that the proper context is given to what we know from the data available in the form of numbers and metrics.

Data is used continuously to evaluate what efforts are being funded, how they will last, what needs are present in the community that aren't being met, and what new efforts need to be funded to advance GCDD's work on behalf of people with developmental disabilities. Every year, GCDD submits an annual report, called a performance progress report, to the Administration on Community Living (ACL), a federal agency that directs initiatives aimed at supporting people with developmental disabilities. During this process the ACL is also reviewing and analyzing reports from the other 55 state and territory developmental disability councils. In doing this, the ACL can see challenges that are unique to Georgia, affect specific regions, or are universal across most or all states.

Data may not seem very exciting, but know that by participating in activities and advocacy, working individually or together in coalitions, you are creating measurable change every day. Those activities and that change is being measured and reported on. Because of that, you are part of a much bigger movement than you may realize. When you participate in work that supports people with developmental disabilities in Georgia, you are a moving, living, breathing embodiment of the Developmental Disabilities Act in action.

STATE OF GEORGIA

The Developmental Disabilities Act is protected by law, and this means the work that we're doing is also protected. But it's always important to keep moving forward, to take nothing for granted, and to keep making positive change for people with developmental disabilities. The information that GCDD, grant partners, the state, and the federal government collect recognizes the important work you are doing on the ground. So, keep up your great work, and keep sharing your experiences through data.



### GCDD's COVID-19 Initiatives & Updates

By Naomi D. Williams & Hilary Vece

Two years into the COVID-19 pandemic, the Georgia Council on Developmental Disabilities (GCDD) is still actively collaborating with community partners and funding initiatives to support the developmental disability community throughout the state.

Through education, outreach, and opportunity, GCDD is working to keep people with developmental disabilities and their family members informed on important pandemic developments and increase access to COVID-19 vaccines for people with developmental disabilities, their family members, and care network.

### State-Wide Collaboration & the Creation of Georgia Developmental Disability COVID-19 Network

At the start of the COVID-19 pandemic, Georgia public health and developmental disability advocacy organizations recognized that the quickly spreading coronavirus was going to significantly disrupt the lives of people with developmental disabilities. By April 2020, GCDD began to take action and connected with influential organizations focused on developmental disabilities throughout the state to form the Georgia Developmental Disability COVID-19 Network.

"We understood early in the pandemic that COVID-19 was disproportionately impacting people with intellectual and developmental disabilities. It was especially impacting people in group homes and other congregant care facilities," recounts Mark Crenshaw, Assistant Director of the Center for Leadership in Disability (CLD) in the School of Public Health at Georgia State University (GSU), and GCDD council member.

The Georgia Developmental Disability COVID-19 Network held weekly calls to stay connected, understand community concerns, create and share resources, and disseminate important information to organization constituents. The network started with a collaboration including GCDD, the Georgia Advocacy Office (GAO), Center for Leadership in Disability (CLD) at Georgia State University (GSU), Institute on Human Development and Disability (IHDD) at the University of Georgia (UGA). As the pandemic continued,

the network grew to include organizations such as Parent to Parent of Georgia, FOCUS, Arc of Georgia, Pineland BHDD, Spectrum Autism Support, and the Georgia Department of Public Health with support from many local and national expert physicians, public health practitioners, and scientists.

Creating the network made sense because the organizations involved already knew and/or saw the gaps and needs within the developmental disability community; had access to official information and could clarify misinformation; understood the potential of their collective impact; and fit the mission of each organization.

Crenshaw elaborated, "We wanted to do everything we could to stop the rate of people with I/DD and their family members who were getting sick and dying from COVID. We also had a focus on trying to get folks connected to resources to support them in getting through lockdown. The meetings were very topical based on what was going on in people's lives and what was going on with COVID-19."

Dana Llyod, Program Director at GAO, and Susanna Miller-Raines, then Operations Coordinator and Community Support Specialist at the Center for Leadership in Disability (CLD) at Georgia State University (GSU)—now Program Manager with Think College at the Institute for Community Inclusion at the University of Massachusetts Boston—were critical leaders in the development of the Georgia Developmental Disability COVID-19 Network.

The calls became a source of resources for network members and community members and resulted in successful collaboration and initiatives.

"Our goal was to create a clear path of easy-to-understand facts and resources from reputable organizations and experts. We did this through general question gathering sessions and subject specific calls to address the most pressing questions and topics," said Maria Pinkelton, GCDD Public Relations Director.

An email account dedicated for COVID-19 information was created for two-way communication, as well as a COVID-19 resource bank and website. To provide information—and receive feedback from the community—the network offered webinars with experts that provided real-time information and updates regarding COVID-19 and the vaccines.

"Our participants needed understandable facts, experts to talk to, transparency, and safe spaces for conversations and questions," said Pinkelton.

The pooled efforts and outcomes led to a total of 1686 individuals participating in 30 calls that were organized by 15 disability-focused agencies.

In addition to sharing resources, the network advocated with state agencies and the governor's office for support for people with developmental disabilities and assisted with communication and logistics for vaccination clinics.

The Georgia Developmental Disability COVID-19 Network is still active and continues to meet twice a month to stay connected, provide organization initiative updates, and strategize for the continued access to pertinent information and outcomes for the developmental disability community. Naomi Williams, GCDD's COVID-19 Vaccination Project Coordinator, leads the on-going efforts of the network as well as other GCDD COVID-19 vaccination initiatives, including managing grants distributed to support COVID-19 prevention efforts in Georgia for people with developmental disabilities.

### Vaccine Access for People with Developmental Disabilities Funding & Grant Initiatives

In late March 2021, President loe Biden announced national initiatives to increase access to COVID-19 vaccines, including nearly \$100 million in grants through the Administration for Community Living (ACL) and the Centers for Disease Control and Prevention (CDC) specifically for people with disabilities and older adults. GCDD had the opportunity to award some of this funding to three organizations to increase vaccinations for people with developmental disabilities and their family members.

While nationally 76% of the population has received at least one dose of the COVID-19 vaccine and 65% are fully vaccinated, Georgia's vaccination rates are significantly lower with only 65% received at least one dose and 54% fully vaccinated.

Two supported organizations, Benjamin Academy and Just People Inc., worked directly in the community to host vaccine clinics and aid in coordinating vaccine appointments. These were widely successful initiatives and distributed or coordinated a combined 270 doses of the COVID-19 vaccine.

Benjamin Academy, a private school in McDonough, Georgia, that serves students with developmental disabilities, conducted outreach to people with developmental disabilities and their family members and provided education and information on the COVID-19 vaccines and how to access them. Benjamin Academy directly reached out to families at the school, local churches, and rural areas. They also found that word of mouth is an effective tool within their community and network.

In addition to outreach, Benjamin Academy helped people with developmental disabilities who needed assistance finding a location or making an appointment to receive a vaccine and assisted with finding transportation or providing information on locations of drive-in vaccination clinics. "Life is to be celebrated—we're in the COVID-19 pandemic—but that still stays true. You can't stay home until this is over—that's not realistic. We know that there is additional stress on families who have family members with I/DD. Things in your life shouldn't stop, but we need to provide the appropriate protection—and education is key," said Dawn

# Don't Measure

*Everyone is unique. The health and safety measures we choose in response to COVID-19 are unique too.* 

"you don't need to wear a mask in here"

> "Please don't measure the measures I follow to keep myself and my community healthy"

### Health & Safety Measures:

- COVID-19 vaccine & boosters
- Face masks indoors & in large crowds
- Physical distancing
- COVID-19 testing
- Quaranting with illness or exposure

Degal, administrator of Benjamin Academy.

Degal continued, "Now that things are loosening, people are less desperate than they were in December. We are still reminding people 'Don't let your guard down, don't get too comfortable.' We have to stay mindful about our risks and do what we can to stay safe."

Just People Inc., a nonprofit in Norcross, Georgia, that provides support services to adults with developmental disabilities, hosted a vaccine clinic that distributed 143 doses of the COVID-19 vaccine, including 88 doses to people with developmental disabilities and 41 doses to family members of people with developmental disabilities. This is the second vaccine clinic that Just People has hosted during the pandemic, and they used lessons learned from their first clinic to ensure people in the waiting and observation rooms were comfortable.

Kelli Ivey, Vice President of Just People, emphasized that despite the difficulties that Just People and the community they serve have faced during the last two years, "We have found the positive in COVID." Recognizing that there are many things that they learned their members and employees are now able to do. "People who haven't left the house can use FaceTime and Zoom; we never would have thought it would be possible to provide services this way before COVID."

Claritas Creative, the third organization supported through

grant funding, is developing and sharing bilingual resources on COVID-19 vaccines, filling the gaps in information, and combating misinformation about the COVID-19 vaccines. They are connecting with community-based organizations throughout the state to boost the number vaccinations for people with developmental disabilities and their family members.

### Moving Forward Safely with COVID-19 Here to Stay

Despite relaxed restrictions and an increased sense of prepandemic normalcy, the COVID-19 pandemic is not over. New waves and variants are expected hit the US again soon. As people become more comfortable going out in their community and socializing in larger groups, it is vital they are aware of the ongoing risks and how to protect themselves from contracting or spreading COVID-19.

Understanding that COVID-19 is here to stay, everyone, especially the developmental disability community, must continue to use prevention as they resume regular daily activities: get the COVID-19 vaccine; wear a mask when around others, especially indoors or in crowded spaces; physically distance whenever possible; and most importantly, stay informed with up-to-date COVID-19 news from reliable sources, like GCDD, the CDC, the Georgia Department of Public Health, and other public health officials.



# Calendar of Events

### -APRIL-

			SPRING 2022 21	
18-	-22	National Association of Councils on Developmental Disabilties (NACDD) Annual Conference	Info	
14	-15	Georgia Council on Developmental Disabilties (GCDD) Quarterly Council Meeting	<u>Info</u>	
1	1 4pm	Uniting for Change Community Strong Virtual Gatherings (held every monday)	<u>Register</u>	
	5 4pm	Uniting for Change Community Strong Virtual Gatherings (held every monday) $\bigcup LY$	<u>Register</u>	
		JUNE		
2	6 1pm & 6pm	COVID-19 Vaccine & Autism Community Listening Sessions Hosted by Claritas Creative	Register	
17.	-20	Family Advocacy Small Group In-Person Meetings & Community Listening Tour Hosted by Georgia Coalition of Family Advocates	Info	
3.	-5	Virtual ADA Conference for State and Local Governments Hosted by Georgia ADA Coordinator's Office	<u>Register</u>	
	2 4pm	Uniting for Change Community Strong Virtual Gatherings (held every monday)	Register	
		MAY		
2	8 12-12:45pm	Coalition of Family Advocates Virtual Lunch & Learn Hosted by Georgia Coalition of Family Advocates	Register	
2	6 2-3pm	Business Development Conversation with Mo Bunnell Hosted by Advancing Employment Spring Webinar Series	Register	
1	9 2-3pm	Twenty-Two Cents an Hour: Disability Rights and the Fight to End Subminimum Wages <i>Hosted by Advancing Employment Spring Webinar Series</i>	<u>Register</u>	
1	8 4pm	Uniting for Change Community Strong Virtual Gatherings (held every monday)	Register	
1	4 1pm	Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) Virtual Board Meeting	Info	



(🗟) Submit an Event to GCDD's Event Calendar



### Tips for Finding the Right Summer Camp for your Child with Developmental Disabilities

By Kimberly Hudson

Summer is a time when children get a break from rigorous school schedules and academics. They usually have more time for self-directed, play-based activities that fit their strengths and interests. For parents of children with developmental disabilities, it can be challenging finding the right camp for your child. Camps can be costly, and they often book up early. Scheduling around vacations, work, and other activities can be challenging. The good news is that the number of inclusive camps is growing. If your child hasn't attended camp before, you've moved, or they are ready for a new experience, ask around. Teachers, therapists and service providers, and other parents may have some great recommendations for local camps. Here are some tips that may help you find the right summer camp for your child with a developmental disability.

### 1) Find Your Focus

Think about if there is there a particular skill or area that you want your child to focus on. Camps are offered on a variety of topics and interest areas. Children are often more open to meeting new people, exploring new spaces, and engaging in activities that align with their interests and strengths. The number and diversity of camp programs are ever-expanding. Putting together a wish list of the type of activities and experiences you want your child to get out of camp is a great starting point.

### 2) Consider the Setting

While the number of inclusive camps is growing, parents may choose a non-inclusive camp or a more specialized camp. When you're looking for a camp, consider the topic, but also how your child will experience the setting. Camps are offered as full-day and half-day sessions and overnight stays in a variety of settings (in the woods, at a pool, in a community center, or at a school). While it's good to push boundaries and challenge assumptions about what your child is capable of, it's also good to build upon positive experiences that your child has had. If this is

the first time your child is going to camp, you may want to stick to a day program rather than choosing an overnight option.

### 3) Filling the Gaps

Depending on your child's experience with school during the pandemic, you may want to focus on critical areas of education for your child. This might be academic-focused or more associated with social, emotional, or therapeutic activities. Take a moment to think through what your child likes to do and what might be the best use of their time this summer.



### 4) Finding the Right Balance

Summer is a time that your child can have a break from more rigorous school routine, while you'll want to keep them busyand if you're a working parent, need to keep them busy-it might be helpful to put together a schedule for your child. Doing so may help you balance the structured educational and recreational experiences so your child can have an educational, but fun and rewarding summer, mixing both structured activity with free time and exploratory play.

### 5) Prepare Your Camper

If your child had reduced social interactions due to the COVID-19 pandemic, you'll want to consider that this may be the first time in a while that your child is introduced to a new group of people. Prepare your camper by talking to them about their experience. You may want to talk about the location of the camp, what activities they will do, what they might eat for lunch or snack, what they might wear, and who they may meet (new friends or current friends who are attending). If it's their first time in a new group setting in a while, or if they are prone to separation anxiety, be sure to make the camp staff aware. Giving your camper a short goodbye, telling them when you will return, and being on time for the pickup can help your camper cope with separation anxiety and help your child learn the drop-off and pick-up routine.

### 6) Transportation

Don't forget to consider transportation. Some camps offer bussed transportation, while others require parents and guardians to drop off and pick up. If you find a camp that is a perfect fit for your child, but you need transportation, first contact the camp: Staff can sometimes facilitate carpools or connect you with other campers who have similar issues. Consider setting up a carpool with another parent. If you are a working parent and are working remotely, research if there is an area where you can safely work remotely close to the camp. Local libraries, cafes, and some parks have Wi-Fi available for public use. Finally, search out other support organizations near you that might be able to help with transportation.

### 7) COVID-19 Precautions & Procedures

Unfortunately, it looks like COVID-19 is here to stay. Medical experts are predicting a new wave of COVID-19 infections. You may want to ask your camp about their COVID-19 safety measures and procedures. This might include asking if masks and COVID-19 vaccinations are required, how many children your camper will be in contact with, what the process is for notification if someone at the camp or in your child's group has COVID-19, and what happens if camp is cancelled due to COVID-19 infections. It's a good idea, regardless of COVID-19 case counts, to remind your camper to wash their hands.

30

### **Overcoming Barriers to Inclusive Camps**

If you're looking for an inclusive camp experience for your child—meaning that your child is fully included with campers without disabilities—you'll want to make sure the camp can accommodate inclusion that is specific to your child. It's a good idea to review the camp policies in detail and have conversations with the camp administration during the registration process to ensure that your child's needs can be met. Some common barriers to inclusive camp participation are potty training, medical requirements, food restrictions, and accommodations that require additional staff. Understand that when policies are written, they are usually written without people with developmental disabilities in mind. If a particular policy would exclude your child from participating (like a potty training requirement), reach out to the camp administration to see if there is any flexibility in this requirement.

When approaching conversations about accommodations for your camper, it's most productive to go into these conversations with a positive spirit. It's also helpful to let the camp administration know what your goals are for your child's camp experience. This can be as simple as "I want Kevin to make new friends," or "I want Jane to get more comfortable in the water, so pool time is important." Be clear with the camp about what the required accommodations are for your child to participate. Be sure to let the camp know if there are things you are willing to do to support them with accommodations. For instance, you can offer to talk to the counselors who will be working with your child before the start of camp to provide information about your child's specific needs and abilities. You can offer to help with a camp activity if they need volunteers or stay in the area for the first day to help address any behavioral challenges. It's always good to show that you're committed to your child having a good camp experience and willing to assist the camp in understanding how to support you and your child.

Understand that not every camp can or will support full inclusion. Although it isn't right, there are many reasons camps may not be prepared to support full inclusion. Some of these reasons are logistical, some are perceived challenges, and some are based on attitudes about people with developmental disabilities.



### Inclusive Summer Camps in Georgia

### **Camp Barney Medintz**

*Overnight* • *School age* Cleveland, GA 30528 706-865-2715 www.campbarney.org

### Camp Hollywood

Day Camp • Ages 5-29 Lawrenceville, GA 30043 770-234-9111 www.veryspecialcamps.com/ summer-camps

### **Camp Southern Ground**

Overnight • Ages 7-17 Fayetteville, GA 30215 678-561-9600 www.campsouthernground.org

### **Faces Camp**

Overnight • School age Cloudland, GA 30731 423-266-1632 www.faces-cranio.org/camp-registration

### **Girl Scouts of Atlanta**

Day Camp, Overnight • Girls K-12 Grades Cobb, Meriwether, and Floyd Counties 770-454-7599

www.girlscoutsummer.com

### Hoof Hand and Heart: Camp One For All

Day Camp • Ages 5-15 Acworth, GA 30102 404-983-5355 www.handhoofheart.org/summercamps

### Lekotek of Georgia

Day Camp • Ages 4-11 Tucker GA 30084 404-633-3430 www.lekotekga.org/camp.html

#### Squirrel Hollow Summer Camp Day Camp • Ages 6-14

Fairburn, GA 30213 770-774-8001 www.thebedfordschool.org/programs

The listing above is not an exhaustive list and is not endorsed by GCDD or GCDD vendors. Be sure to contact the camp prior to enrollment to make sure it's the right fit for your camper. Know that having conversations with camp administration about inclusion is critical in starting or continuing conversations about the importance of inclusion. If you need support advocating for inclusion for children with developmental disabilities at a camp in your area, reach out to Parent to Parent of Georgia for guidance and assistance.

If you need assistance with inclusion supports contact:

Parent to Parent of Georgia

www.p2pga.org

800.229.2038

If you've had a positive experience with an inclusive camp in Georgia share it here.

SPRING 2022 25

#### **INCLUDE COLLEGE**



### Students with Intellectual Disabilities Find Success Through Digital Expression in Art and Media Fields at Georgia State University

By Hilary Vece

Inclusive college, called inclusive post secondary education (IPSE), is not new to Georgia, and there is a positive trend of more and more universities developing IPSE. There are <u>311 IPSE programs</u> at universities across the country, with <u>eight in Georgia</u> (and a ninth on its way). The expansion of IPSE is demonstrating how university administrations and faculty are beginning to understand the importance, and the value, of inclusive college for people with intellectual disabilities.



Georgia State University IDEAL student uses VR

There is no one design for IPSE, and existing programs vary in length and activities. Generally, **IPSE** includes a combination of academic coursework. career development, independent living, and socialization components. Georgia State University's (GSU) **IPSE IDEAL** 

(Inclusive Digital Expression and Literacy) is a novel Georgia IPSE which, unlike others in Georgia, has a special focus on the arts.

IDEAL is a two-year program that includes academic coursework, career development, job skills training, mental health counseling, career counseling, and psychosocial groups. IDEAL offers four areas of focus: film, art, music, and theater. IDEAL graduates earn a Certificate of Career Readiness.

IDEAL is currently in its fifth year, after they began accepting students in January 2017. Starting small, GSU IDEAL nearly doubles in size every year. Starting in Fall 2022, IDEAL will be welcoming 5-7 new students, totaling to 20-22 students active in the program.

Students in IDEAL audit curriculum courses with a focus on technology use, digital and media literacy, communication skills, success in the college environment, self-determination, and career development. Students also audit elective courses in their area of focus. These classes are offered to general undergraduate students, and IDEAL students

# **GEORGIA STATE**

participate in these classes alongside their peers without intellectual disabilities. They have access to all the same student organizations and resources as the general student population, another way that students interact with their peers without intellectual disabilities. Many IDEAL students are involved in activities at the student recreation center or work at the campus movie theater.

Many of the graduates of IDEAL are employed in art-adjacent spaces, like customer service at museums and art spaces. "Eighty percent of our graduates are working or continuing their education with an average pay rate of \$12/hour," said Spenser Norris, IDEAL Project Manager.

Housed in the university's Center for Leadership in Disability, IDEAL staff always reach out to make connections across the university to provide opportunities for students who express a special interest. IDEAL has made partnerships with the GSU football and soccer programs to support students interested in sports management and marketing—a popular interest in the program—that has led to employment in the field. "Several of our graduates work at Mercedes Benz Stadium," said Norris.

IDEAL works with its students to reach their goals while in college

and after they graduate.

"We have a student exiting ... this year who has a goal of getting a college degree," said Norris, speaking about IDEAL secondyear student Kyle Brooks. Norris continued, "Because he graduated from high school with a special education diploma, we have been supporting him to get his GED so that he can apply to a university."

Speaking on what IPSE means to him, Brooks said...

I used to have an invisible shield to protect myself and was vulnerable when I first started the program. Now I feel comfortable, I'm getting straight A's and walking around campus by myself. IDEAL has helped me grow to understand what the world really means.



2021 IDEAL graduate Deriq Graves now attends Georgia Film Academy

Image: state biological state

IDEAL graduate Deriq Graves has continued his studies at the Georgia Film Academy, a goal he set for himself while in IDEAL.

Across the state, IPSE has seen program funding decrease at both the federal and state level through changes in grant funding and policy changes to how funds are distributed.

Norris acknowledged the importance of funding IPSE saying, "We are always taking donations or looking for financial sponsorships to support students." Funding is needed not only to support sustainability of IPSE but also for the expansion of IDEAL, as it sees lots of potential for expansion. "We can see a space for supported transition for students," said Norris, "with offerings for an optional third or fourth year."

This piece is another in our series of articles <u>highlighting Georgia's</u> <u>IPSE programs.</u>

Applications for Fall 2023 admissions will open in October or November of this year.

For more information on the GSU IDEAL program, visit <u>CLD.GSU.edu/IDEAL</u>.



Georgia State University IDEAL graduates pose on graduation day

### Peers Reflect on Executive Director Eric Jacobson's Leadership Over the Years

Eric Jacobson, Executive Director for the Georgia Council on Developmental Disabilities (GCDD), announced his retirement last October, saying he wants a new person to lead the DD Council work. Jacobson began working for what was then called the Governor's Council on Developmental Disabilities in 1992.



### By Tianna Faulkner

In 1997 he was appointed the Executive Director and has overseen the organization ever since. Jacobson has led GCDD on its mission to collaborate with Georgia citizens, public and private advocacy organizations, and policymakers to positively influence public policies that enhance the quality of life for people with developmental disabilities and their families. A few of his peers reflect on Jacobson's leadership and work over the years.

Donna Meltzer, Executive Director of the National Association of Councils on Developmental Disabilities (NACDD), describes Jacobson as a passionate leader who is multi-dimensional, helping others to see the light that he sees. Jacobson and Meltzer met in 2012, when she was new to her job at NACDD only a few weeks in her role. Jacobson served on the national board and called Meltzer one afternoon and introduced himself.

"He shared wisdom and insight of the role of the organization, welcoming me. We were at a leadership summit for learning and sharing with other leaders to connect with one another. Eric was planning an additional day program, as he had gone through the Asset Based Community Development and wanted my support," said Meltzer. "I understand him as a leader in the national council and in our field nationwide. He gave the opportunity for our peers to learn, grow, and move forward in a new concept of how we build our communities for people with developmental disabilities and get support for them. I have spent a lot of time with Eric over the last 10 years. He gave me many opportunities to come down to Georgia and spend time with the Georgia Council."

A special memory Meltzer has of Jacobson is when he offered to host a meeting in Atlanta. She told him that she wanted to get the leaders at the meeting out of the hotel rooms to see the city. Meltzer explained that Jacobson has passion for civil rights and social justice. Together they hired an Atlantan to coordinate the day for the leaders. The group ended up seeing the AIDS quilts, the Martin Luther King Jr. Museum, Ebenezer Baptist Church, and the Center for Civil and Human Rights Museum.

"Others look to him as a strong

leader and visionary. His attitude is how can I get the best out of everyone and how can I get the best for everyone," said Meltzer. "That's how he thrives. He is a deep thinker who thinks through the issues. He says what are we going to do next and makes it happen."

Ruby Moore, Executive Director of the Georgia Advocacy Office (GAO), said Jacobson brought other leaders in the state of Georgia together to learn about the developmental disability community, not being set back by policies, but by focusing on actual community support. That Moore said, is Jacobson's strength.

"When we started The Children's Freedom Initiative, GAO, Jacobson, and IHDD, these were defining moments of my relationship and leadership relationship with Eric," said Moore. "It was so clear what we had to do, which was to work together. We all had to lead."

Moore said Jacobson has done great work at GCDD and in the developmental disability community and said that he is passionate and has a great sense of humor, which helps him to navigate some of the things incredibly hard to do in a role like his. "We're pretty close. I wish him the best, and what I want for him is that he can see a clear path to the next cool thing that he will be doing. I'm looking forward to seeing what he does next," said Moore.

Zolinda Stoneman, Ph.D., Director and Anne Montgomery Haltiwanger Distinguished University Professor at the Institute on Human Development & Disability at the University of Georgia, said she has known Jacobson since he started to work for GCDD.

"When Eric took the role as Executive Director, there were a number of challenges. It was a difficult period, but he took it from that point to one of the strongest councils in the nation. I believe today that GCDD is one of the strongest councils in the country, and that happens because of leadership," said Stoneman.

She says part of Jacobson's success is that he respects people, and he has a great capacity to connect with people of diverse backgrounds. Stoneman went on to say that he has a wonderful background when it comes to decision making and planning. A memory that she has working with Jacobson is when they worked together in 2005, when three DD programs were charged at the national meeting to come up with a topic. Jacobson, Stoneman, and a third person were at a hotel on a sofa and were having a brainstorming conversation. They were excited about this idea where no child is in a facility or other bad situation where they may not be getting the best care. Out of the conversation, they came up with the idea for the Children's Freedom

### Initiative.

"Eric has been involved in and has shown leadership in this over the past two decades. His passion has persistence about trying to make the world better with significant change in the state of Georgia. There is no doubt in my mind that he's going to keep working to make people's lives better on a new journey to improve the lives of people in a new role just like he has done at GCDD," said Stoneman.

Colleen Wieck, Executive Director for the Minnesota Governor's Council on Developmental Disabilities, and former director, Ann Trudgeon, both met Jacobson 30 years ago at a national conference. They both shared that he has always served as a leader in interacting with federal officials and is able to fly to Washington D.C. to be their Ambassador General, no matter how big or how small the issue. According to both Wieck and Trudgeon, Jacobson knows the DD Act extremely well and can work out details in a fair manner. He has excellent diplomacy skills by synthesizing the widest ranges of opinions into a coherent position they added.

### Others look to him as a strong leader & visionary

"Eric was able to creatively use grant funding to apply John McKnight asset-based community organizing approaches in his state. People with developmental disabilities always come first in Eric's values and leadership. He listens, learns, and acts in ways that are inclusive," said Wieck. "He has served as a mentor to many."

A special memory Wieck and Trudgeon is when Eric and his children, along with Council directors and members, attended an Atlanta Braves baseball game. Prior to the game, Wieck and Trudgeon purchased two baseballs from the gift shop. During the game when a long fly ball headed to the upper deck where they were all sitting, timing and sleight of hand were critical. A souvenir ball would be tossed up and Jacobson would catch it without a glove. He would then present it to one of his kids. What a dad! Then another fly ball headed in their direction and again, miraculously Jacobson reached up and caught the ball without hesitation and presented it to his other child. Everyone cheered Jacobson's athletic prowess to catch two balls in one game, according to Wieck and Trudgeon.

"We want Eric to have the best send-off possible. We only want the very brightest future for Eric and his family. We wish Eric will bring all of his knowledge, skills, and abilities to the federal level. His level of creativity is needed to help all states," said Wieck and Trudgeon.

Steve Wiseman, Executive Director of the West Virginia Developmental Disabilities Council, said that as a fellow director of a DD Council, he has had the privilege over the past 22 years of knowing and learning from Jacobson. Wiseman said he





has always admired Jacobson for leading the way on civil rights issues and community building and that Jacobson has always addressed the big and small discussions at their national meetings with thoughtfulness and wisdom, often mixed with a bit of humor.

"I remember a retreat attended by a few of our fellow executive directors that followed a leadership development weekend several years ago. We met at the family vacation home of one of the directors. It was an opportunity to share our thoughts on the issues of the day for our councils or to simply relax with no agenda. None of the attendees ran out of ideas and opinions to share," said Wiseman. "Everyone felt it was a great thought provoking and restorative open-ended time together."

Wiseman said he was honored that Jacobson brought his family to West Virginia for a vacation when his children were II years old. The family enjoyed white water rafting, swimming, hiking, and other outdoor activities that

the south-central part of the state affords. Wiseman said Jacobson's family seemed to have a great time and that he was particularly proud to be able to take them to a gourmet Italian restaurant that is tucked away in the mountains and is owned and operated by his friends.

I wish Eric the best in his retirement and whatever he 'gets into.' He will be sorely missed by his many friends in the national network of DD councils.

Steve Wiseman, Executive Director West Virginia Developmental Disabilities Council

Former GCDD Chair Mitzi Proffitt

"No one ever asks what you want to change, but Eric did ask. He has led a force as a great leader, and he is well-educated in this topic. He does not have children with disabilities, but over the years I noticed at meetings how he was always the first to greet individuals who had disabilities. He never shies away from people with disabilities," said Proffitt.

Proffitt says Jacobson has the respect of his peers and all DD leaders. Whenever she shared with Jacobson that she needed help in an area, he would teach her. Additionally, she said he is supportive, and he handles controversy well because he has a great ability to get people to understand complex issues when he spoke.

"I have a child with a disability. Eric never makes you feel below him. He looks at everybody who has a disability. Eric has a sense of humor. He always made sure everyone understood what we were talking about when it came to policies. I'm happy he's retiring," said Proffitt.

who works at Parent to Parent of Georgia has known Jacobson for 13 years and says he is a meticulous trainer and a great leader who knows the history of the DD Act in Georgia and how to advocate for people with disabilities.

Georgia Council on Developmental Disabilites (GCDD) 2 Peachtree Street NW, Suite 26-246, Atlanta, GA 30303-3142 Voice 404.657.2126, Fax 404.657.2132, Toll Free 1.888.275.4233 TDD 404.657.2133, info@gcdd.org, www.gcdd.org

Managing Editor, Tianna Faulkner Tianna.Faulkner@gcdd.ga.gov

Claritas Creative LLC, Publication Design & Production Visualize@ClaritasCreative.com

audio, and large print. https://magazine.gcdd.org





WITE CO

The Georgia Council on Developmental Disabilities (GCDD) is driven by its Five Year Strategic Plan (2022-2026) goals of systems change; self-advocacy; and targeting disparity and diversity. The mission of the Georgia Council on Developmental Disabilities is to bring about social and policy changes that promote opportunities for the wide spectrum of diverse people/persons with developmental disabilities and their families to live, learn, work, play, and worship in their communities.