

# ***Making a Difference Magazine***

A Quarterly Magazine of the Georgia Council on  
Developmental Disabilities

Real Homes. Real Careers. Real Learning.  
Real Influence. Real Support.

**Spring 2017**

Volume 17, Issue 4

**On the Cover:** Rep. Tony Coelho (D - California)  
speaking about employment for people with disabilities in  
the Georgia Senate with (l to r) Hannah Hibben, Debbie  
Hibben, Elizabeth Appley and Eric Jacobson. (*See story  
on page 10.*)

**On the back cover:** Changes are coming to GCDD's  
*Making a Difference Magazine (Read all the details.)*

*The Georgia Council on Developmental Disabilities, a federally funded state agency, works to bring about social and policy changes that promote opportunities for persons with developmental disabilities and their families to live, learn, work, play and worship in Georgia communities.*

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Tell us your thoughts about the magazine or what topics you would like to see addressed by emailing us at [valerie.suber@gcdd.ga.gov](mailto:valerie.suber@gcdd.ga.gov), subject line: **Letters to the Editor.**

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Letters should include the writer's full name, address, phone number, and may be edited for the purpose of clarity and space.

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## GCDD VIEWPOINT

### **Change Is in the Air**

Welcome to the new *Making a Difference* format! After much discussion, Georgia Council on Developmental Disabilities (GCDD) has made the commitment to go paperless while finding new and better ways to get information to you in a timely manner.

This means that *Making a Difference* will now be distributed online. We hope that you find this format easier and more reliable as GCDD aims to provide you with the timeliest information that impacts people with disabilities and their families. Don't worry, if you prefer a paper copy, you can download and print the magazine from the online version.

The primary focus of GCDD and our advocacy for the last three months has been on the state and federal legislatures. In Georgia, members of the General Assembly met for 40 days to determine policy and budgets. GCDD changed its advocacy efforts to focus on getting you to talk with your legislators, and during the five advocacy days, over 300 people attended and met with their state senator or representative. They advocated for more waivers; inclusive post-secondary education (IPSE); changing the wording in Georgia code from mental retardation to intellectual disability; promoting employment for people with disabilities; changing the bar for determining intellectual disability in death penalty cases; and supporting families who need to take off from work to care for loved ones.

I believe that while we did not get new money for waivers, we had a successful legislative session.

While all of this depends on Governor Nathan Deal's signature – he has 40 days to sign legislation – there will be a change in wording around the “R” word, thanks to the great advocacy of The Arc Georgia. Families will now be able to take time off from work to care for loved ones, thanks to persistence by many advocates for families and children. We received new money for IPSE programs and a strong partnership with Georgia Vocational Rehabilitation Agency to expand this program and better support students.

On the federal level, Congress began discussions about repealing and replacing the Affordable Care Act. As part of this discussion, there were recommended changes to the Medicaid program. Many people in the disability community were concerned that recommended changes might impact federal funds available for waiver programs, how insurance and Medicaid would support pre-existing

conditions, and what happens to states such as Georgia that have traditionally underfunded Medicaid.

As of this writing, repeal and replace was not voted on by the House of Representatives and there are reports they will renew discussion after the Easter recess.

Advocacy helped push the issues, on both the state and federal level. Locally, groups such as the Georgia Advocacy Office, The Arc, People First of Georgia, People First of Fitzgerald, People First of Atlanta and others were at the Georgia Capitol working to create change. Nationally, over 900 people attended the Disability Policy Seminar and met with federal legislators to tell them about concerns especially with the proposed American Health Care Act. Without your voices, the work of GCDD and others is not credible. It is very important that you, as constituents and citizens of Georgia, let your elected officials know what issues are important. Keep up the advocacy!

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Remember that GCDD is here to assist you. Check out our website and join our advocacy network so that you can stay informed. We hope you enjoy reading this magazine and we want to hear from you. Let us know your thoughts and comments about the magazine by writing to the Editor at [valerie.suber@gcdd.ga.gov](mailto:valerie.suber@gcdd.ga.gov)

Eric E. Jacobson

Executive Director, GCDD

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[\*\*AROUND GCDD\*\*](#)

## **GCDD Welcomes New Deputy Director**

Kate Brady joins the Georgia Council on Developmental Disabilities (GCDD) as Deputy Director to continue her work in the field of disability policy, service and systems

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advocacy. She has worked in multiple systems including the Georgia Vocational Rehabilitation Agency (GVRA) and Department of Behavioral Health and Developmental Disabilities (DBHDD), the state developmental disability agency.

She brings over 14 years of experience to GCDD in leading organizational, team and individual change through the development and implementation of elaborate program design, implementation and evaluation efforts. As the deputy director, Brady will primarily focus on employment programs and policy for people with disabilities.

“We have kicked off the Employment First State Leadership Mentoring Project (EFSLMP) at GCDD, and this allows us to work with agencies across the State towards furthering the alignment of policies and practices that enable strategies like customized employment to be

available for the entire disability community,” said Brady. She brought the project to GCDD from her work at GVRA.

Through the work of the EFSLMP Group, conversations with DBHDD, Department of Education, Medicaid, GVRA and Workforce Development are hosted to support the coordination of agency efforts to support people with disabilities in getting to work.

Recognizing the strengths of GCDD, Brady is also excited to bring her experience in cross collaboration and evaluation to the organization. “We have a strong community development team, a strong public policy team, and tremendous external partnerships,” she added. “Through collaboration, we will not only be able to continue this great work, but also better evaluate and capitalize on the impact our programs have in the community.”

Brady's passion derives from her early experiences working as the customized employment coordinator at the Cobb Community Services Board. In this role, she coordinated Project Exceed, a US Department of Labor Office of Disability Employment Policy Customized Employment initiative intended to support people with high impact of disability in reaching customized employment goals such as resource ownership and self-employment.

She earned a bachelor's degree in communications and performing arts from St. Andrews Presbyterian College in North Carolina and did her Masters in industrial/organizational psychology at Clemson University in South Carolina. Kate is ABD (All But Dissertation) status in completing a Doctorate of Psychology at the University of West Georgia. She also consulted for University of Georgia's Institute for Human

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Development and Disability and the National Center on Workforce and Disability at the University of Massachusetts on best practices in the support of employment for people with disabilities. She also worked at the federal level for the National Organization on Disability.

## **GCDD's Making a Difference Launching Digital Look and Outreach**

This year GCDD will be moving towards publishing and distributing Making a Difference magazine and a new e-newsletter in digital formats to reduce printing and mailing costs. Our goal is to improve statewide communications efforts by expanding reporting of disability-related events across Georgia, using more video and photography, and sharing our message and stories with more people via social media, the website and traditional media.

Not only will this help the environment, but the money saved will be used to reach even more people with disabilities and provide them with more information and access to services and supports.

As always, accessibility is our most important goal. The magazine will continue to be available in large print, audio and accessible PDF. A Spanish translation is created after the magazine is published. All videos will be captioned and all photography will be provided with alternate text.

We hope you are excited about our new direction!

Please Note: The new e-newsletter will only be in digital format so you must provide your email to receive.

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## Creating Sustainable Change

In *Making a Difference* Winter 2017, we previously covered Real Communities Partnerships which create welcoming and inclusive communities where people of all abilities are valued equally and are active participants in making life better for everyone. Through a circle and collaborative approach, we can influence change to value and honor everyone in the process.

To achieve this, Real Communities uses two methodologies, Popular Education and Asset-based Community Development (ABCD), to create welcoming communities.

Popular Education, which was developed by Paulo Freire, offers several established practices to deepen the collaborative approach. Anne Hope and Sally Timmel

simplified the Popular Education philosophical language into theory and practice in the book, *Training for Transformation*.

Popular Education is critical of our current education system, because the system is not relevant to most of society. For example, the curriculum in school is conducive only to students that function in a standardized system; however, students that learn differently such as visual or hands-on learners are labeled with learning disabilities. The aim of popular education is a radical transformation of culture where all of us are called upon to change our personal life, community, environment and ultimately the society.

The four basic principles of popular education are:

- People/Learner centered
- Self-discovery
- Problem posing

- Action producing

**People/learner centered** focuses on generative theme and dialogue. Generative theme is a common and strong feeling such as a vision the community has for itself or any aspect of each participant's life. This principle allows the community to decide what is relevant to the group, rather than an expert imposing their opinion. A fundamental component is identifying a generative theme through dialogue. It is important to hear from everyone in the community when conversations are being held and decisions are being made about needed changes. Experience shows that an expert's solution for a community does not bring about sustainable change. This methodology believes that the way to sustainable change is through listening to everyone because their input is just as important as the experts.

**Self-discovery** is part of the Popular Education process that allows community participants to learn about themselves through reflection and action. In the broader process of community transformation, people learn about their value, strengths, weaknesses, biases, motivation, personality ... etc. The following quote from Witcher-Cottrell & Hilton describes it best:

“The learning process is one of self-discovery.

Information is not fed or handed out to participants. In this process, people come to their own awareness and understanding as they analyze the reality of their situation through codes, case studies, discussions, etc. People learn best what they discover for themselves.”

**Problem posing** allows us to raise awareness and consciousness around social issues and interconnections. We analyze the issues by asking why? Here is a great

example from David Werner the author of Where There is No Doctor, who calls this method the “But-Why Method.”

“ The child has septic foot.” – “But why?”

“ Because she stepped on a thorn.” – “But why?”

“ Because she has no shoes.” – “But why?”

“ Because her father cannot afford to buy shoes.” – “But why?”

“ Because he is paid very little as a farm laborer.” – “But why?”

“ Because the farm laborers have no trade union.”

Problem posing is not focusing on the problem – rather it encourages the community to act together to find solutions.

**Action producing** is reached when you use feelings to motivate and break through apathy. This inclusive process

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allows each community member to feel as though they are responsible. With each member feeling equally responsible, an effective and more powerful community is created.

Once the community is mobilized and empowered they are tasked with taking on their own challenges on a continuing basis which is the essence of a sustainable process.

*Sumaya Karimi is the GCDD Real Communities organizing director.*

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## **FEATURE**

### **A Review of the 2017 Georgia Legislative Session**

*By Dawn Alford, GCDD Public Policy Director*

Another year has come and gone and the Georgia Council on Developmental Disabilities (GCDD) spent every day of the 40-day legislative session advocating under the Gold Dome so we can fulfill our mission to promote public policy that enables integrated community life for people with disabilities, their families, friends, neighbors and all who support them. This article will give you an overview of the work that took place and will highlight some of the outcomes as it relates to Georgians with disabilities and their families.

The first day of session was on Monday, January 9 and the last day of session, referred to as Sine Die, occurred on Thursday, March 30. Crossover day, the deadline by which a bill must “crossover” to the other chamber in order to stay alive for that particular session, was March 3 this year. A grand total of 950 bills were introduced this session, and of those 336 were passed by the House of Representatives; 378 were passed by the Senate; and only

284<sup>1</sup> were sent to the Governor Nathan Deal's desk and therefore eligible to become law. The total budget amount for the Fiscal Year (FY) 2018 state budget that was passed was a record breaking \$25 billion. Major funding priorities included a 19% salary increase for child welfare workers; a 2% raise for teachers; and included over \$2 billion for new schools, college buildings, roads and bridges, as well as repairing existing structures. As this article goes to print, the budget bill now sits on the Governor's desk awaiting his signature. In Georgia, the governor has the power to line item veto specific parts of the budget if he so desires. He has 40 days from the last day of session, or May 9, to decide how he will act on this and other bills that were passed during the 2017 General Assembly.

## **GCDD Priorities – led by GCDD**

### **DD Waivers**

Out of the several Medicaid waivers that Georgia offers to those who qualify for this level of care, the New Options Waiver (NOW) and the Comprehensive Supports Waiver Program (COMP) have by far the longest waiting list.

There are 8,821 individuals with developmental disabilities on this waiting list as of March 31, 2017, according to the Department of Community Health (DCH). GCDD, together with the UNLOCK! Coalition and many advocates like you, asked the Georgia General Assembly to fund additional DD waiver slots to address the long waiting list. We also advocated for budget language to direct the Department of Behavioral Health and Developmental Disabilities (DBHDD) to come up with a multi-year plan on how they will reduce and eliminate the waiting list.

Across the Amended FY 2017 budgets and the new FY 2018 budget, a total of 500 new DD waiver slots were added to fulfill the requirements of the Extension

Settlement Agreement. These additional slots will address those leaving the state hospitals but for the most part will not address the long waiting list of those in the community who are desperately hanging on. Although no waiver slots were added specifically to address those individuals on the DD waiver waiting list, we were successful in our advocacy to get budget language added that directs DBHDD to come up with a plan to eliminate the waiting list. The language is as follows:

*“The department (DBHDD) shall develop and report to the Georgia General Assembly on a multi-year plan to reduce and eliminate the waiting list for NOW and COMP waivers with yearly outcome measures by December 31, 2017.” (CC: YES) <sup>2</sup>*

### **Inclusive Post-Secondary Education (IPSE)**

Inclusive post-secondary education (IPSE) programs provide opportunities for study beyond high school to

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students who historically have not been presented with these possibilities. These programs change lives by making college accessible for students with intellectual and developmental disabilities. Further, this education prepares them to live increasingly independent lives, pursue careers of their choice and provides the potential for increased earnings long-term.

GCDD is the legislative lead for the Georgia Inclusive Postsecondary Education Consortium (GAIPSEC). The GAIPSEC (<http://www.gaipsec.org/>) legislative ask for the 2017 session was \$300,000 in new funding for the IPSE programs for program sustainability and to provide scholarship opportunities for these young adults who wish to attend but are unable to afford the tuition and fees. Our advocacy was hugely successful in that we received more than we asked for. The IPSE programs received a total of \$325,000 in new state funds “for scholarships and operations” within the Georgia Vocational Rehabilitation

Agency (GVRA) budget. Also, \$175,000<sup>3</sup> of the IPSE funding already established in previous years within the GCDD budget was shifted to GVRA.

There are huge benefits to shifting this funding to GVRA in that for every state dollar in the GVRA budget for IPSE, there is a potential to draw down up to four federal dollars. There is also budget language within the GVRA IPSE budget item to “recognize Memorandum of Understanding with GCDD to maintain council’s active participation in the IPSE partnership.”<sup>4</sup> Although it is unlikely that every single state dollar can be matched 4:1, if it could, then for a total of \$500,000 in state funds an additional \$2,000,000 in federal funds could be drawn down for the IPSE programs. GCDD looks forward to our continued partnership with GVRA on the IPSE programs.

### **GCDD Priorities – supported by GCDD but led by other entities**

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## **Family Care Act (SB201) –**

### **PASSED/Waiting on Governor’s signature**

*Primary Sponsor: Sen. Butch Miller (R - Gainesville)*

Many Georgians balance their work lives with caring for their families. The Family Care Act allows employees who are working 30 or more hours per week for an employer with at least 25 employees without a stock ownership plan to use up to five days of earned sick leave in a calendar year to care for an immediate family member. SB201 does NOT add any additional sick days or require employers to provide them; it only allows Georgians to use the sick days they’ve already earned to care for family members. It sunsets, meaning the authorization of the Family Care Act expires on July 1, 2020.

## **Changes MR to ID (HB 343) – PASSED/ Waiting on Governor’s signature**

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*Primary sponsor: Rep. Scott Hilton (R – Peachtree Corners)*

Words that were once used as clinical terms are now used as insults for people with intellectual disabilities. This bill does a “find and replace” by replacing the very offensive words “mental retardation” (MR) with the words “intellectual disability” (ID) within the Georgia criminal code.

**Change the Standard to Prove Intellectual Disabilities in Capital Punishment Cases (SB185) – DID NOT PASS BUT STILL ALIVE FOR 2018 SESSION**

*Primary sponsor: Sen. Elena Parent (D - Atlanta)*

In 2002, the US Supreme Court declared it wrong to execute a person with intellectual disabilities because it violates the Eighth Amendment’s ban on cruel and unusual punishment.<sup>5</sup> However, right now in Georgia, it is

extremely difficult for an individual to prove in court that they have intellectual disabilities. Georgia is the only one of the 50 states that requires a person to prove “beyond a reasonable doubt” that they have intellectual disabilities in capital punishment cases. This bill seeks to change the current standard of proof from “beyond a reasonable doubt,” to the standard used in most other states – “preponderance of the evidence.” This bill got introduced and a hearing was held in the Senate Judiciary Subcommittee B where strong testimony was given by a diverse group of advocates and stakeholders. Although it did not make the crossover deadline, this bill is still alive for next year. To get involved in the PAPE Coalition leading this important work, please contact Caitlin Childs at *childs.caitlin@gmail.com*.

## **In Other Legislative News**

### **BUDGET**

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- Additional funds were added to the budget for autism including:
  - 1) Funds to cover behavioral health services for children under 21 who have autism,<sup>6</sup>
  - 2) Funds to reflect enrollment growth to match Medicaid age requirements for the treatment of autism spectrum disorders effective January 1, 2018,<sup>7</sup> and
  - 3) An increase in funds to establish an Adolescent to Adult Transition model to improve outcomes for adults with Autism Spectrum Disorder.<sup>8</sup>
  
- The Statewide Independent Living Council of Georgia (SILC) received \$100,000 for “special housing home modifications and provide annual reports by December 31 on the number of clients assisted.”<sup>9</sup>

- Funds for the Citizen Advocacy Program that is administered by the Georgia Advocacy Office were fully restored in the amount of \$224,902 in the FY 2018 budget from where they had been cut in the FY 2017 budget. Citizen advocates provide protection and advocacy to individuals with developmental disabilities by initiating and supporting one-on-one citizen advocacy relationships.
- Service Options Using Resources in a Community Environment (SOURCE) and Community Care Services Program (CCSP) Medicaid waivers received an “increase [in] funds to increase reimbursement rates for personal support and extended personal support services” 10 in the amount of \$500,000 in state funds.

## **BILLS**

### **Medical Cannabis (SB 16) –**

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## **PASSED/ Waiting on Governor's signature**

*Primary sponsor: Sen. Ben Watson (R - Savannah)*

Expands those who can use low THC oil to include Alzheimer's disease, AIDS, autism, epidermolysis bullosa, peripheral neuropathy, Tourette's syndrome and those in hospice care. It also allows people from out of state, with a registration card issued by another state allowing the same possession of low THC oil as Georgia, to use the card when in GA for less than 45 days.

## **Proxy Caregiver (HB 486) –**

### **PASSED/ Waiting on Governor's signature**

*Primary sponsor: Rep. Tommy Benton (R - Jefferson)*

An amendment to the Nurse Practice Act that allows for DBHDD and DCH to select and approve a training curriculum for instructing Proxy Caregivers in medicine administration. Previously only medical professionals

could provide the training, but now providers may train with the curriculum and not have to find a medical professional. To learn more about what a proxy caregiver is see GCDD's guide at

<http://gcdd.org/images/Reports/proxy%20care%20guide%20-%20gcdd.pdf>.

## **Updates since the 2016 Legislative Session**

### **Independent Care Program (ICWP) Rate Increase – Received in 2016 Session**

GCDD and UNLOCK! advocated for a personal support service rate increase for ICWP during the 2016 session since it was the lowest reimbursed waiver in Georgia.

While the increase was scheduled to go into effect on July 1, 2016, it was postponed while the DCH worked to get the federal Centers for Medicare & Medicaid Services (CMS) approval that was necessary for the rate increase. Finally, as of January 19, 2017, CMS gave its approval. Those on ICWP waivers should speak with their case

manager to fully understand what levels of care you receive and therefore how much of an increase you received. Then, speak with your provider agency to ask how much of this rate increase they plan to pass on to your direct care workers. Individuals on both the agency model and those using self-direction benefit from this rate increase.

### **ABLE Act (HB 768) – PASSED in the 2016 Legislative Session**

An ABLE account is a savings account that will allow people with disabilities to save money for qualified disability expenses without violating the \$2,000 asset limits that apply to eligibility for Medicaid and Supplemental Security Income (SSI). It is limited to individuals with significant disabilities who became disabled before age 26. Georgia passed HB 768 during the 2017 legislative session but is still working on implementing the startup of these accounts in Georgia.

The plan is for Georgia to join the Ohio STABLE program. In the meantime, the best source of information about the range of available programs can be found at the ABLE National Resource Center:

<http://www.ablenrc.org/>. For a State of Georgia contact for the ABLE program, contact the Office of the State Treasurer: Kim Asher at 404.656.2168.

<sup>1</sup> The Atlanta Journal Constitution Legislative Navigator (as of April 19, 2017)

<sup>2</sup> Line 57.15 of HB 44 (FY2018)

<sup>3</sup> Line 67.1 of HB 44 (FY2018)

<sup>4</sup> Line 200.5 of HB 44 (FY2018)

<sup>5</sup> See *Atkins v. Virginia*, 536 U.S. 304 (2002)

<sup>6</sup> Line 90.8 HB 44 (FY2018)

<sup>7</sup> Line 92.9 HB 44 (FY2018)

<sup>8</sup> Line 238.6 HB 44 (FY 2018)

<sup>9</sup> Line 77.3 HB44 (FY2018)

<sup>10</sup> Line 89.18 HB44 (FY2018)

## **Get Involved! Join Our Advocacy Team**

*Stay Connected with GCDD to get the latest Advocacy and Policy News and Get Involved!! Be sure to go to [www.gcdd.org](http://www.gcdd.org) and click on “Public Policy” to see the final outcome of the budget and other highlights.*

## **GCDD CALL TO ACTION**

Advocates: Thank you for all you have done this year to better the lives of people with disabilities.

It is not too early to begin your advocacy for the 2018 legislative session.

Get to know your legislator now.

Go to [www.openstates.org](http://www.openstates.org) and find out who is your state senator and representative and make an appointment with them.

Talk to them about what is important to you!

ALSO . . .

The DD Waiver waiting list IS still way too long! Please tell your elected officials that Georgia needs to provide more funding to reduce and eliminate the waiting list!

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## **FEATURE**

### **Talking Disability Advocacy at the Georgia State Capitol** *By Ruksana Hussain*

The Georgia Council on Developmental Disabilities (GCDD) held the 2017 Advocacy Days in February and March this year at the Georgia State Capitol – five different days of advocacy dedicated to issues that are

integral to the success of the developmental disability community in the State. While a lot has been achieved, continued efforts help make Georgia a place where everyone, regardless of ability, can live, learn, work, play and worship in the community. No matter how robust the legislative agenda, success cannot be achieved without the voices of people with disabilities, their families and other allies included in the conversation.

The 2017 Advocacy Days offered a slightly different approach from the big event that GCDD hosted previously as Disability Day at the Capitol – a one-day rally featuring speakers and attended by thousands. GCDD wanted to have a bigger impact. Through Advocacy Days, GCDD was able to afford opportunities for participants to speak to their legislators face to face about issues that are important to them. This is the second year that GCDD hosted Advocacy Days.

The days covered many different issues that affect all Georgians with disabilities. DD Waivers Day advocated for more funding toward medical waivers for people with developmental disabilities. It was held on two dates because, particularly in GA, there is a very long waiting list of 8,821 people as of March 31, 2017, according to GCDD. Inclusive Post-Secondary Education (IPSE) Day focused on increased funding for programs for college students with developmental disabilities who would not generally qualify for the general admissions process, and witnessed lots of youth participating that day.

Enable Work and Families Day focused on Family Care Act, PeachWork and Phillip Payne Personal Assistance Program. Home and Community Day (Elder and Disabled Abuse Registry, Offensive Language, Transportation, Residential Housing Study Committee) targeted the Georgia Code to replace the term mental retardation with intellectual disabilities.

## **A Big Day for Employment**

Employment Advocacy Day was a highlight this year as it welcomed Rep. Tony Coelho (D - California) as its keynote speaker at a press conference prior to heading to the Gold Dome. Coelho is the primary sponsor of the Americans with Disabilities Act (ADA), and has opened many doors for the disability community, especially in the workforce. Given his lifelong commitment to the developmental disabilities community, he spoke to people with disabilities, family members and people in the community who care about employment.

Coelho addressed media, legislators and attendees about why having a job is important for the disability community. “It is an opportunity to participate in society just like everybody else, an opportunity to fail like everybody else. Georgia is way behind the rest of the states in providing opportunities for employment. It is

important to recognize that we, as a community, want this assistance. If you want to see if we can do a job, give us a job,” he shared, while encouraging everyone to get engaged and involved during Advocacy Days and afterwards.

Josh Wells and Kurt Vogel, individuals with developmental disabilities, spoke about their personal experiences and the importance of employment in their lives.

Senator Nan Orrock (D - Atlanta) and Representative Valencia Stovall (D - Forest Park) also spoke to the crowd about advocating for issues that matter for people with disabilities. Stovall, who has a son with an intellectual disability, shared the importance of pushing legislators to understand the need for competitive, meaningful employment.

Employment Advocacy Day had the highest attendance.

“Employment resonates with so many people as it is tangible,” says Dawn Alford, GCDD’s public policy director. “Not everyone understands what it means to have a waiver and be on the waiting list, but generally everyone can relate in some way to employment, and that’s one reason it is well attended.”

Additionally, Eric Jacobson, executive director of GCDD, also reminded everyone that advocacy is strength in numbers.

“While it’s 20% of the population that has disabilities, when you count everyone who knows someone or cares about someone with a disability, it’s a much bigger group. Think about how powerful we can be,” said Jacobson.

He encouraged attendees to share their story with at least five people in their local communities, and have them call legislators to show support for employment.

“The thing about disability is that it doesn’t care what gender, religion, or color you are – it affects everyone,” he added.

### **Partnering for Advocacy Success**

“Some of the issues like waivers, IPSE and employment were like previous years. Those are perennial issues, so we need to continue advocating to make more progress on them. Other issues were partner-led and we worked with other agencies and coalitions to bring advocates to the Capitol and speak on the other issues that we feel strongly impact people with developmental disabilities,” says Hanna Rosenfeld, planning and policy development specialist at GCDD.

These include partnerships with the Georgia Inclusive Postsecondary Education Consortium for IPSE Day; the Statewide Independent Living Council and the Proof to a

Preponderance of the Evidence Coalition for Enable Work and Families Day; and The Arc Georgia, the American Wheelchair Society and the Georgia Job/Family Collaborative for Home and Community Day.

The Arc Georgia promotes and protects the human rights of people with intellectual and developmental disabilities (I/DD) and actively supports their full inclusion and participation in the community over the arc of their lifetime. The focus is to develop programs and advocate for public policy giving people with I/DD the opportunity to learn, live and work inclusively in their communities. GCDD partnered with The Arc Georgia's Stacy Ramirez, the state director, who has been facilitating the UNLOCK! campaign. The campaign advocates for Georgians with disabilities so they and their families can live full lives and contribute to communities and the economy. UNLOCK! is working to rebalance the state's system of long-term services and supports so that fewer

dollars are spent on institutional care and more dollars are invested into home and community-based services and supports.

Ramirez also assisted with much of the preparation involved in hosting Advocacy Days.

Additionally, GCDD partnered with self-advocacy group, People First of Georgia, to bring at least 30 of their members from across the State to participate in Advocacy Days.

People First not only met these goals but exceeded it, bringing at least 50 members, some repeatedly.

“As these attendees got comfortable with the legislative process, they were able to become team leaders themselves, and this is what we want for our advocates – to learn about the legislative process, realize they have a

voice and feel comfortable using it effectively for the issues they care about,” shares Rosenfeld.

## **Experience of Advocating**

Advocacy Days heralded a diverse group of people from different cities, with different disabilities, and even varied experiences of advocacy. Some had been to the Capitol before and for others, it was their first time advocating at this scale.

Each day included a welcome orientation so participants understood the issue for the day, and what they were asking of legislators. This was followed by demonstrations and role-playing, where attendees were divided into teams to practice their legislative visit.

A parent advocate at GCDD and executive board member this year, Christine Clark attended two Advocacy Days, driving in from Woodstock to participate. “It was my first time going down to the Capitol so that was exciting,” she

says. “I was able to talk to both my senator and representative. I found the whole day very liberating and fascinating.”

Currently a student of Georgia State University working on a masters in social work, Clark lists legislative change, employment, healthcare and waivers as her interests in disability issues. She plans to participate in Advocacy Days next year, and hopes to attend as many as her schedule will allow.

Chattanooga-based Scott Kramer, program director and founder of GCA Centre for Adult Autism (a program of the Chattanooga Autism Center) is a seasoned advocate who drives two and a half hours each time from Tennessee to Downtown Atlanta to meet with legislators. “The first time I attended, I had a lot of anxiety about speaking with politicians but now that I have been to the

Georgia State Capitol a few times, I don't have any qualms speaking with senators," he said.

Kramer also offered experienced advice on meeting with legislators for the first time. "See them as human beings who have emotions too. To understand their constituents, they have to understand what's going on, and the only way legislators can know what is important is when advocates speak up about issues that directly affect them and their community."

Along with Clark and Kramer, several other members and supporters of the local disability community attended this year's Advocacy Days, averaging 90 people for each day. The highest attendance clocked in with 130 advocates! Alford reflected on 2017 Advocacy Days and said, "We had a great many more self-advocates, which has a lot to do with the People First chapters, and that was a huge positive. We are grateful to all the self-advocates who participated because that is important to us at GCDD, that

we not only lift up the voices of family members, but those of self-advocates as well.”

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## **FEATURE**

### **The Future of Georgia’s Medicaid Program**

*By Jennifer Bosk*

With sweeping changes occurring in Washington, DC under the new administration, one of the biggest proposals to come out of the White House was the American Health Care Act (AHCA) – a replacement for the Affordable Care Act (ACA) that became law on March 23, 2010.

Many of those changes would directly affect Medicaid services and supports on which people with disabilities

rely. Georgia Council on Developmental Disabilities (GCDD), with Alison Barkoff, director of advocacy for the Center for Public Representation, hosted a webinar to discuss the changes and how it could affect the disability community.

## **Healthcare Acts**

The Affordable Care Act (ACA) has several pluses for people with disabilities. The biggest advantage to the ACA was insurance companies could no longer deny coverage to people with preexisting conditions or charge them higher rates. As we experience high unemployment among people with disabilities, the ACA further helped with lower insurance premiums and lower out-of-pocket expenses such as deductibles and copays.

In the past, people with disabilities were often denied Medicaid benefits or disability benefits because they were not seeing a doctor for treatment or didn't have test results

to corroborate their disability. With the ACA, healthcare became more accessible and more people who applied for disability assistance have been seeing doctors regularly, receiving proper diagnoses and records to support findings of disabilities.

Currently, Medicaid serves as the primary health insurance for 10 million non-elderly people with disabilities across the United States. People with disabilities make up 21% of the national Medicaid population but account for 48% of Medicaid costs, often due to long-term services and support needs.

The Medicaid program is jointly funded by the federal and state governments. The share the federal government pays is based on the income and poverty level of the state. Currently in Georgia, 68.5% of every Medicaid dollar is funded by the federal government, while Georgia's state

funds cover the remaining 31.5% of Medicaid costs. In 2016, Georgia ranked 48th in Medicaid spending.

## **AHCA and Medicaid**

The biggest threat is to Medicaid, which could result in significant changes for Georgians who currently rely on the program if the ACA is repealed.

The AHCA is required to go through federal budget reconciliation, meaning the plan must reduce the federal deficit. Therefore, not only must the AHCA be a cost-neutral bill, it also must save money over a 10-year period. Congress plans to use the money saved from Medicaid cuts to cover the new AHCA.

The Medicaid cuts will come from per capita caps, or federal funding per enrollee. Enrollee spending during the year would be tracked and that amount would increase over time based on a pre-set amount (i.e., inflation or

inflation plus a percentage). This means that the federal government will now pay a set amount per Medicaid enrollee rather than paying for Georgia's actual Medicaid service costs.

The per capita caps differ from block grants, where states receive a pre-set funding amount for Medicaid (not based on number of enrollees) that could be increased each year, again based on inflation or inflation plus some percentage. The per capita caps do account for changes in Medicaid enrollment, but do not account for new health technologies, aging population, changing health needs, etc. The goal of both per capita caps and block grants are to massively reduce federal spending.

The federal government, under the AHCA, will now use a formula for giving money to the states on a set amount per person enrolled in Medicaid based on their 2016 spending. For example, this funding will not consider an

aging population who may begin to need more services. States like Georgia that spend less per capita on Medicaid (seventh lowest spending in the United States) will be negatively impacted.

Under the AHCA, funding will begin with setting a base year spending level, possibly as soon as 2018. A growth index, such as the Consumer Price Index, will be used to set the yearly growth rate for the base spending level. The issue is that growth indexes increase much more slowly than Medicaid spending. This will make the federal funding gap grow every year and Georgia's state budget Medicaid program shortfalls will increase each year.

As Georgia considers raising provider rates to make sure people who have more complex behavioral or medical needs receive services, the State won't be able to cover those rates under this formula. Georgia, which has almost 9,000 people on the Medicaid waiting lists for various

needs and supports, won't have funding available to help them.

While the per capita cap does provide more money if more people enter the Medicaid program, it will not provide more money for growing healthcare needs and changing technology assistance, among other things.

The entire AHCA bill's savings is \$327 billion, however the Congressional Budget Office is estimating an \$880 billion cut in federal Medicaid spending over the next 10 years. That is over a 25% cut to Medicaid. As state Medicaid budget shortfalls grow, chances are people will see reduced services or total elimination of optional services such as waivers. Waiting lists, which are already lengthy, would increase. And provider rates, already low in Georgia, would more than likely decrease.

Funding caps will likely cripple state flexibility in program design. Creation of innovative and new programs

often requires up-front investments to help in changing systems.

“It’s up to all of us to educate our [government] representatives and to tell our stories about what Medicaid means to people with disabilities,” urged Barkoff on the webinar.

Shortly after the webinar, the House Republicans withdrew the AHCA from voting – meaning the ACA is still the law of the land. However, healthcare remains a hot topic and people with disabilities should continue to educate themselves while informing their legislators to continue working towards a strong Medicaid program.

## **Ways to Get Involved**

**Educate your representatives in Congress.** For so many people with disabilities and their families, Medicaid can

make the difference in living independently, providing in-home supports so parents can work outside the home, etc. Help Congress understand how important Medicaid is, how cost-effective it is, and what the cuts will mean for people with disabilities.

- Educate your governor and state representatives. Georgia's governor and representatives will have to deal with Medicaid budget shortfalls. Help explain how per capita caps will hurt the budget because it shifts costs to our state.
- **Tell your story.** There is nothing better than explaining how you and your family will be personally impacted by the AHCA and the per capita caps. Be honest and up front about what this will mean for you. Share how great this negative impact would be.
- **Build state-level advocacy coalitions.** Because these Medicaid cuts will impact so many, connect with

others in your community and circle of influence. Remember, in addition to people with all types of disabilities, these changes will affect seniors and those who are low-income. Partner and work together to advocate together.

- **Connect with national efforts already in place.** The Consortium for Citizens with Disabilities ([www.c-c-d.org](http://www.c-c-d.org)) and The ARC of the United States ([www.thearc.org/](http://www.thearc.org/)) already have efforts underway to fight against these Medicaid cuts. These organizations and groups have information and updates going out to those who connect with them so everyone can have the latest news and developments.
- **Engage the media.** Write a letter-to-the-editor, post on social media, make your voice public and share your knowledge. The hashtag for the movement is *#savemedicaid*.

## Contact Your Legislators:

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Find your Georgia federal legislators at

<https://www.govtrack.us/congress/members>

Georgia's state legislators are listed at

<https://openstates.org>

Governor Nathan Deal (R) can be reached at  
404.656.1776.

Keep Informed: <https://medicaid.publicrep.org/>

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**FEATURE**

## **Georgia Options Leads The Way**

*By Ruksana Hussain*

Since 1992, a little known nonprofit organization in Athens, GA has been steadily making strides in caring for individuals with intellectual and developmental disabilities (I/DD). By working on a case by case basis, Georgia Options has dedicated itself to ensure people with disabilities thrive in mainstream society by supporting them to live in their own homes and enjoy typical life experiences.

Founded by a small group of family members, people with disabilities and other citizens concerned about the well-being of adults with disabilities, Georgia Options began with offering support to five people and has gradually grown not only in number of persons served, total 76, but also in their understanding of quality of support provided.

“We don’t look at people as a number. We look at each person, figure out what they need, what support they want from us and how we can provide it to help them meet their goals,” said Rena Harris, executive director at Georgia Options. “We are intentional about people joining our organization, and that the ability to provide excellent, evidence-based services is always there.”

### **Focusing on Choice**

This clear focus has contributed to Georgia Options being one of the most progressive residential providers for the disability community. All people they serve live in their own homes, choose where and with whom they want to live. Direct Support Professionals (DSP) assist people and provide person-centered support at varying levels in all areas of a person’s life – enabling everyone to pursue their hopes and dreams; to be active in the community; and to live the best life possible.

“Success here isn’t measured by the services we provide – that is a vehicle,” said Harris. “The measure of success for us is what impact does our support have on a person’s life, not considering the people that are paid to support them. We don’t look at our service provision as a measure of success; we look at what a person is able to accomplish and have in their life that they wouldn’t ordinarily have without our services.”

Georgia Options values the people they serve as persons with dignity and capacity, who not only have the right to live in a home of their choosing, but who also have untapped potential to contribute to the community in immeasurable ways. What truly pushes this organization to a higher level is that they support people in their own homes. Individuals have their own support staff during the day and all activities are based on their interests and preferences. Georgia Options provides support throughout

the life span of an individual, treating their family as partners in this journey.

## **Promoting Community Living**

While individuals with severe disabilities are usually assigned to community living in a home with a large group where individual needs are not necessarily met, at Georgia Options, there is a minimum of two DSPs for every person they assist, meaning every person has individualized support during a typical day. DSPs are specifically recruited for each individual. The person served and family actively participate in interviewing and hiring the direct support staff.

Harris cannot stress enough the importance of this under-appreciated segment of the disability community. The challenging job scope and difficult training period paired with below average pay doesn't provide much incentive for DSPs to continue in the field when they could be

earning double that anywhere else, but the need for their services is enormous.

“For the people we have accepted into our service right now, we are at an over 20% vacancy rate for DSPs,” explained Harris. “Statewide, the shortage is only going to grow – it is going to become more challenging. Turnover in general is high, but our turnover rate is lower.”

They are extremely dedicated to the people that they support and not paid nearly enough for what they do. This is not a job for everybody for what our funding permits us to pay, but if they excel at this job then we will do everything in our power to make sure that they are satisfied and continue with us,” she added.

The organization currently employs about 80 DSPs, with many having worked with the organization for 18-20 years – unheard of in this field.

## **Successes of Independent Living**

In providing such customized, best practice support services, Georgia Options regularly witnesses candidates enjoying independent lives and contributing to their community. While families' adult children are refused services by other providers because of the level of their disability, Georgia Options has excelled in providing support leading to excellent outcomes.

A recent example is a gentleman with autism who was institutionalized. His family's search for a provider eventually led them to Georgia Options where he now receives support, has social connections and a job.

“We pride ourselves on being accepting to people with a significant level of need, recognizing that they are just as entitled to quality, person-centered services and level of choice as people with less severe challenges,” said Harris.

The quality of services Harris refers to is outlined in a 2015 National Council on Disability study which concluded that individuals receiving home and community-based services and supports in smaller, more dispersed and individualized community settings demonstrated signs of greater community integration and positive life outcomes. Many studies conducted in the US found that outcomes such as greater individual choice, satisfaction, stability and community participation are positively related to people living in smaller, more “typical” home settings.

Another example Harris cites is of a young lady who was turned down by three other organizations because of her level of personal care needs, but is now supported by Georgia Options.

Not everyone provided services through this organization necessarily continues, and there have been instances where individuals have chosen to go a different route.

“If an individual decides we are not the right service provider for them, then we respect that and will make sure we do everything we can for them to get to the right service provider,” says Harris. “Their needs might change over time and people might want to try something different. People should have that choice and an informed and experienced alternative should be possible.”

### **Cause for Concern**

An integral issue is the availability of Medicaid waivers. The NOW/COMP waiver has the longest waiver list in Georgia of 8,821 individuals (as of 3/31/17). The current fiscal year’s ask is to fund at least 2,470 new waivers for a state impact of \$33,058,273.

It is unclear how the recent revision of the Medicaid waiver will affect Georgia Options.

“We relied on 98% Medicaid and 2% other income,” discloses Harris, “which is worrisome in terms of funding. My priorities, in addition to making sure that our services are top-notch and our employees are experiencing job satisfaction, are to figure out different ways to enhance our revenue, become less reliant on Medicaid and diversify our income sources.”

Additional funding outside of Medicaid will help the organization continue to provide best practice services for every individual accepted.

## **Full Steam Ahead**

Funding crises and supporting DSPs has not limited Harris’ plans for the immediate future and the long-term goals for Georgia Options. The goal for next year is to

improve sustainability. She plans to develop the board, search for grants that support best practices, seek connections to foundations that support the cause, cultivate corporate donors and establish partnerships, develop collaboration within the community and bolster outreach and awareness.

Despite 25 years in operation, Georgia Options is a well-kept secret in the Athens community and within the larger disability community that it serves.

While disability of any nature might have been a less discussed topic in 1992, today it is a conversation in the general community. There is a growing force of not just self-advocates and their families, but also members from the communities who are recognizing that people with disabilities bring an intrinsic value, irrespective of the extent or nature of their abilities, to mainstream society.

Harris is optimistic for what lies ahead. “I do believe that the community will partner with us, people will want to collaborate with us because we do best practices and that is really important. We have a cause and a model worth fighting for.”

**Gabby:** Gabby requires complete assistance with personal care and has severe medical needs. She is new to Georgia Options and was turned down by at least three other providers. At some time, her mother had been advised that a nursing home was the best option.

**Matt:** Matt spent time at Gracewood Hospital and with a traditional provider. He has severe behavioral challenges and requires the company of two direct support professionals when he leaves home. He has close relationships with his neighbors and works at the YMCA. Matt’s dad, Phil, is also the Board President.

**John:** John came from Central State Hospital in 2011. His parents were extremely worried about whether he would be safe outside of the hospital. He has 24-hour support, lives in his own apartment and is doing very well.

**Martin:** Martin (right) requires complete assistance with personal care. Martin and his mom had some challenges with Georgia Options prior to current administration, so they left to try services with another provider. They returned a few months ago. Martin is pictured above with staff member, Jim.

For more information on Georgia Options, visit

<http://www.georgiaoptions.org/>

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**MIA'S SPACE**

## **Alternative Math**

*By Pat Nobbie, PhD*

People with disabilities and their families are forever in a defensive posture for defending the legitimacy of their need for Medicaid to provide healthcare and home and community-based services (HCBS) so they can live in the same communities as everyone else. Believe me, those of us fortunate enough to have an HCBS waiver appreciate what a blessing it is, because with that support, we can live our lives.

But families who have services are always on guard to protect them and families on waiting lists are continually advocating to get them. Quite often we can be made to feel guilty for using “government” resources that could be spent somewhere else.

We must be particularly vigilant now with an administration that is considering how to reconfigure Medicaid. The narrative, on a very basic level, is that somehow people receiving Medicaid are undeserving – too dependent, for too long, without justification. And some important distinctions are missing – Medicaid beneficiaries run the gamut between low-income women and children, infants and toddlers with developmental disabilities, children to age 21 with special healthcare needs, children and youth in foster care, people with presumptive disabilities, people with acquired disabilities and older adults. Among this diverse population, is it helpful to characterize people as either “givers” or “takers” because of their need for public assistance?

What I want to share here is the economic contribution that someone like Mia, who has a Medicaid waiver and receives Social Security Disability Insurance (SSDI), makes to the economy.

Mia's waiver pays two direct support people; one pays \$225 in taxes on the income she makes from Mia every two weeks, and the other pays about \$100 in taxes every two weeks; about \$8,125 annually.

Mia's waiver includes supported employment; she has a job for 25 hours a week at St. Mary's Hospital. She pays about \$105 in state, federal, FICA and Medicare every two weeks, \$2,500 average per year on her income. Her waiver pays Briggs and Associates, the company that provides her job coach, \$10,670 per year. Mia's job coach pays taxes on her income.

A support coordination agency also gets paid \$900 per year from her waiver.

Mia's SSDI helps with her living expenses – utilities and groceries – approximately \$7,500 a year. With her

paycheck, she spends about \$2,500 a year on clothes, restaurants, movies, bowling and swimming, on all of which she pays sales tax.

Her social connections and busy schedule keep her healthy, so Medicaid rarely gets billed for healthcare.

Because her waiver keeps Mia well supported in the community, I can work at a good paying job. Last year, I paid \$23,000 in state and federal taxes.

So let's do the math. Mia returns about \$32,000 to the economy, roughly 50% of the funding that she receives for her support. And this doesn't include what her siblings or I can contribute from full time work, knowing she is well supported.

The benefit of her presence in the community is a bonus. Not a bad equation, wouldn't you say?

## **PERSPECTIVES**

### **Teaching Advocacy**

*By Sandra Mason*

As a special education teacher, my students and I always attended the Disability Day at the Capitol rallies because I wanted to make sure that our kids learn that it's important for them to speak up for themselves. This year, due to a change in the program, I now teach a 12th grade class of students who are being prepared for transition.

The program, Unique Learning, prepares the kids for transition as they leave high school. A part of our curriculum is to teach them advocacy. With Advocacy Days, we figured we would use the opportunity this year to show them what advocacy is in real action.

We came for Employment Advocacy Day because all my students are aiming at and doing vocation skills training. They work at the Darnell Center three days a week and they're learning about real employment. We chose employment because they have learned through our advocacy lessons, that employment for people with disabilities is difficult to get. They sat in the workshops and learned what to say, how to speak to the legislators during advocacy day. Through that training, they weren't afraid to speak with legislators at the Capitol.

When I saw my students interact with legislators, they were polite; they were professional; and they were passionate when they spoke about issues that mattered to them.

Having already previously met Senator Vincent Fort through different volunteer opportunities, it was

wonderful when he stopped and listened to them. They told him how important it is that they have real jobs and opportunities for summer employment, which is something that is completely cut out for our kids now.

Advocacy Days helped support our curriculum because the idea is for them to make adult decisions and to realize that, once you are over 18, having a disability doesn't stop you from being an adult. So they learn about things like registering to vote, and making good choices when they do. They learn about what their legal rights are as a person with a disability, and all the rights that a person with disabilities should have.

I'm hoping that as our students transition and grow older, they will know that just because they have a disability, it doesn't stop them from having a real life, a full life. They have the same opportunities as everyone else. They can

learn from what they have experienced in school and other experiences.

As an educator, I was excited to show learning in action. You hope that what you teach sinks in and that students can generalize what you've taught them and apply it to their lives. We need them to recognize that just because they have a disability shouldn't stop them. Disability is just a stepping stone. It's just something that they can keep going and keep going forward.

*Sandra Mason is a special education teacher at Benjamin Banneker High School in College Park, GA.*

## **Facilitating Changes in Policy**

*By Senator Nan Orrock and Representative Valencia Stovall*

Senator Nan Orrock and Representative Valencia Stovall spoke at the Employment Advocacy Days reminding attendees that sharing their story is the way to facilitate change in policy that affects people with disabilities. Below are excerpts of their brief addresses to the advocates.

**Senator Nan Orrock (D - Atlanta)**

I am the Senator from District 36 which is right here in Downtown Atlanta, all of Southeast Atlanta, Northeast Atlanta and a bit of Southwest Atlanta. The Georgia Council on Developmental Disabilities has been a long-time partner for a lot of battles fighting for disability issues. Your voices, your life experience and your passion on your issues is critically important and that is why people who see you and meet you, need to know your story. The strongest thing that you can do is share your story.

We're the real experts on talking about our own lives, aren't we? There's nobody who knows more about your life than you do. So, sharing your story, sharing how you've taken and put other things to the side and made this your priority to come and be here today shows that you care about the issues.

The challenge to Georgia is to step up to the plate and address employment issues. We don't have the best track record on that. That is why bringing your voices and your life experience here to the Capitol, and talking to your legislators is one of the strongest things that you can do to help move the needle. That helps get us in a position where we are fully engaging with the exciting possibilities of people with disabilities having many more entry paths to meaningful employment.

People have come down here, with their stories, and helped change policy. I have seen it. It can happen. That's

why we're here today. Thank you for being involved. A lot of people cannot be here. You're here for them. A lot of people don't understand the importance of being here. I just want to applaud all of you for getting it and bringing your story here and engaging with us to set good policy for Georgia.

### **Representative Valencia Stovall (D - Forest Park)**

I have a son who is has an intellectual developmental disability. He's 25 and he still has some problems getting gainful employment. They want to give him something that is mediocre and don't believe that he can work in a high paying job. I want to advocate here at the State and do whatever I can do to help push employment for the disability community.

I think that we're missing a big jewel when it comes to employment when we are leaving out our individuals with developmental disabilities. It's very important that you all

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come out to advocate, and share your stories for Employment First here in Georgia.

Stovall also serves with Chairwoman Katie Dempsey on the House Study Committee on Post-Secondary Options for Individuals with Developmental Disabilities.

*Senator Nan Orrock (D - Atlanta) spoke at GCDD's Employment Advocacy Day.*

*Representative Valencia Stovall (D - Forest Park) addressed the crowd of advocates in support of employment for people with disabilities.*

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**EXPERT UPDATE**

## **Representative Tony Coelho Speaks at GCDD Employment Advocacy Day**

*The following is a transcript of remarks given by  
Rep. Tony Coelho at Employment Advocacy Day.*

I take the view that if you give me the right to fail then I have the opportunity to succeed. What happens in our country today is so many people ask the question “can you do this if you have a disability?” And I’m saying [employers], how do you know unless you give us the opportunity? You give everybody else the opportunity to fail, why not give us the opportunity to fail?

I always go back to Jerry Lewis. He had telethons (and he was a comedian) and what he’d do is raise money off the back of those of us with disabilities. He’d have somebody come up to the podium – and he’d pat them on the head and say how sorry he was about their disability. Then, he’d send them back into the corner and he would do

everything. I don't want to go to the corner. I want to be part of you. I've had epilepsy and seizures for 50 years. I'm 75. That gives you an idea. I just had one last week.

But I have an opportunity. I've had the opportunity to work even though I was discriminated against. I was discriminated against by my parents who thought I was possessed by the devil – that's a cultural thing with a lot of different groups. I always say my Republican friends know I'm possessed, but to have your family think you're possessed is a bit different. I couldn't get a job. I was kicked out of the seminary – I wanted to be a priest – all because of epilepsy. And that goes on across the board.

Seventy-five percent of people with disabilities don't have a job. Why is a job so important? A job is important because we get the opportunity to provide for ourselves and our loved ones. We get an opportunity to have a home

and potentially buy a car. We get an opportunity to participate in society just like everybody else.

I've said to the last five Presidents of the United States that I don't know of any group other than ours who wants to pay taxes. We are willing to pay taxes because that means we have a job. We want the opportunity to fail just like everybody else. And if you want to see if we can do the job, give us a job. And if we can't do it, fire us.

There's nothing that says they can't if we don't do the job. And so when people say that they're afraid to give us a job because they can't get rid of us, I say "you're wrong, if we can't do it you have the right to dismiss us." But you've got to give us the opportunity to fail like you do for everybody else in society. Give us that same opportunity.

I love the fact that you're pursuing people in the state assembly and state legislature to help them understand

Georgia is way behind. Georgia is way behind the rest of the states in providing opportunities for employment. And it's so important that they recognize that we as a community want this assistance.

We'll never get the opportunity to fail if you don't press people to give us that. And, we as a community, have to get aggressively involved politically so that people know that we have votes – that people know that we have influence. And if you aren't willing to be involved then don't complain about government not taking care or insisting that you get an opportunity to work.

If you take the fact that 10% of our population are people with disabilities and then you take our loved ones and you take those who care for us – that's about 20% – that is an amazing part of the population. There is no other group larger than us, except for women. And so everybody else gets an opportunity to participate except for us. Why not?

We don't participate because we're not engaged, we're not involved. So one of my efforts besides advocating for disabilities is to make sure that those of us with disabilities get engaged, be involved. When you go across the street, tell those legislators that you want the opportunity to fail – that's what counts.

Keep it up. Go for it. Fight. Make a difference.

*Tony Coelho has worked to advance the lives of people with disabilities. Diagnosed with epilepsy at 22, Coelho's work is marked by significant milestones. Among them, he is the primary author and sponsor of the Americans with Disabilities Act. He is a former six term US Congressman from California who specialized in disability rights. He worked with then-President Bill Clinton to establish the Department of Labor's Office of Disability Employment Policy and he fathered the United States Business*

*Leadership Network, which partners with corporations to increase the employment of people with disabilities.*

To see a video of Tony Coelho's speech on Advocacy Day, go to: <http://gcdd.org/news-a-media/videos/96-rep-tony-coelho-speaks-at-gcdd-employment-advocacy-day.html>

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## **STRAIGHT TALK**

### **My Life. My Advocacy.**

*By Kurt Vogel*

My name is Kurt Vogel, I'm a student at Georgia Tech's Expanding Career, Education and Leadership Opportunities (Excel) Program, a program for students with intellectual and developmental disabilities (I/DD).

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Through Excel, I am a research assistant at Georgia Tech's Center for Assistive Technology and Environmental Access (CATEA), which has helped me realize that I want to combine computer technology with helping people. I am also a trainee in the Georgia Leadership and Education in Neurodevelopmental Disabilities (GaLEND) Program.

This spring, I was invited to testify before the Georgia Legislature on two policy issues.

First, I testified at the Judiciary Committee for House Bill 343, advocating that the word "retarded" be removed from all legislation because it is not a very respectful word to describe people with I/DD. I explained that hearing the word "retarded" used about me, or someone with a disability, is personally insulting. Using the words "intellectual disability" or "developmental disability" is descriptive and connotes respect. I greatly encouraged the

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legislators to discontinue the use of the word and to bring Georgia in line with the language used by the federal government.

I then presented to advocates at GCDD's Employment Advocacy Day on the importance of hiring people with disabilities. I shared my belief that people with disabilities want the same opportunities to have a job as people who do not. A study from the Job Accommodation Network showed that the benefits to employers who hire people with disabilities far outweigh the cost of accommodations.

Specifically, I stated, "I want you to see me as a gifted and capable employee. I have a passion for using computers and other technology to help me, and others with disabilities, get the kind of opportunities we deserve. I understand what it means to be labeled with a disability. It often means that people expect less of me. I want to encourage everyone who hears me today to have high

expectations of me, and others with disabilities, because helping us achieve the self-determined life we want begins with all of us having high expectations of each other. I want to work together with people without disabilities because sometimes the best is brought out in people when they work together toward a common goal.”

I had never given much thought before to being a disability advocate. But having a disability myself has helped me realize the strength of my voice and that sometimes the most long-lasting progress is not made by taking quick, huge steps, but by taking gradual steps over time.

Having a disability wasn't a choice and I will have it for the rest of my life and I want to be thankful for the opportunities it has opened for me.

So I want to leave you with one question:

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Instead of seeing a disability as something that someone has or doesn't have, can't we start seeing disability as an ability that not many people have the opportunity to experience?

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**Back Cover:**

**Changes Coming to GCDD's *Making a Difference* Magazine**

This year GCDD will be moving towards publishing and distributing *Making a Difference* magazine and a new e-newsletter in digital formats to reduce printing and mailing costs. Our goal is to improve statewide communications efforts by expanding reporting of disability-related events across Georgia, using more video and photography, and sharing our message and stories with more people via social media, the website and traditional media.

You may have received our surveys asking you to give us your opinions on whether you prefer digital or print.

Responses indicated a willingness to convert to digital to allow us to reach even more people with disabilities and provide them with more information and access to services and supports. It will also allow us to provide more timely news by publishing a newsletter between magazines.

As always, accessibility is our most important goal. The magazine will continue to be available in large print, audio and accessible PDF. A Spanish translation is created after the magazine is published. All videos will be captioned and all photography will be provided with alternate text.

Let us know your thoughts and comments about the new direction by writing to the Editor at

[Valerie.suber@gcdd.ga.gov](mailto:Valerie.suber@gcdd.ga.gov).

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