# Making a Difference







Fall 2019

## A TRIBUTE TO

Dawn Alford



## **Making** Difference

A quarterly digital magazine from GCDD

#### VOLUME 20, ISSUE 2

#### FALL 2019

EPARTMENTS

The Georgia Council on Developmental Disabilities (GCDD) is driven by its Five Year Plan (2017-2021) goals of education; employment; self-advocacy; Real Communities; and formal and informal supports. The Council, charged with creating systems change for individuals with developmental disabilities and family members, will work through various advocacy and capacity building activities to build a more interdependent, self-sufficient, and integrated and included disability community across Georgia.





#### PUBLIC POLICY FOR THE PEOPLE A Tribute to Dawn Alford

In July, the Georgia Council on Developmental Disabilities unexpectedly said goodbye to an amazing, hard-working advocate for people with developmental disabilities. GCDD honors Dawn and her impact in photos and memories from across the state.

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## Tap Into Your **Do IT YOURSELF** Self-Advocacy Power!

Take Your Legislator to Work Day returns, and this year, we are putting the power in your hands! The annual employment advocacy event provides an opportunity for employees with disabilities to invite their legislator(s) to visit them at work and form valuable relationships. In 2019, find out how to DIY (Do It Yourself)!

### In the Workplace

by Adrianne Murchison

The Americans with Disabilities Act (ADA) was signed into law in 1990. Almost 30 years later, many disability advocates will state that the employment numbers are still dismal for people with disabilities. Competitive, integrated employment, customized employment and supported employment are working to provide an inclusive and fulfilling environment for employees with disabilities.

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On the cover: GCDD says goodbye to Public Policy Director Dawn Alford, who left a legacy on disability rights and established strong long-lasting relationships with legislators and community members across the state.



## GCDD

## VIEWPOINT

## THE RIGHT TALENT, RIGHT NOW

October is <u>National Disability Employment Awareness Month</u>, and this year's theme is *The Right Talent*, *Right Now*. In Georgia, we are working with advocacy organizations, businesses and the government to connect people with intellectual and developmental disabilities (I/DD) who want to work with employers looking to fill jobs. According to recent studies by the <u>Institute for Community</u> <u>Inclusion</u>, 42.8% of people with disabilities in Georgia want to work, yet only 12% have obtaining a job as a goal in their support plans.

I believe there is a three-legged stool that illustrates how Georgia can begin to climb from the bottom in many rankings to a top-tier state for employment for people with disabilities. Each component is critical for us to reach a compelling goal set by the Department of Behavioral Health and Developmental Disabilities (DBHDD): to increase the number of people with I/DD in <u>competitive</u>, integrated <u>employment</u> by three times by the year 2025. GCDD is an enthusiastic supporter and collaborator in this goal.

The first leg focuses on advocates. People with I/DD, families and others must be at the table in helping to design and implement new employment initiatives. They must continue to tell legislators and other policymakers that they want to go to work and get paid the same as others.

Second, many businesses are already recognizing the value of people with disabilities as part of the workforce. Members of **Disability:IN** understand that a diverse workforce including people with disabilities is more productive and effective. According to a recent study by the organization, employees with disabilities offer tangible benefits including increased innovation, improved productivity and a better work environment. In addition, Disability:IN found that businesses that employ people with disabilities outperform their competitors by two times.

Finally, the government must use its resources and policymaking authority. This includes raising the rates of providers who offer competitive, integrated employment, eliminating sub-minimum wage and making sure individuals with disabilities are paid the same market rate as others. Efforts like Georgia's Employment First Council, DBHDD's employment initiative and the Advancing Employment TA Center provide us with the mechanism and enthusiasm to get this accomplished. However, it will take all three legs of the stool to change where we are and make Georgia a leader in competitive, integrated employment for people with disabilities.

Throughout this edition of *Making a Difference*, you will learn how you can get involved in the effort to increase employment opportunities for people with disabilities. Part of that education includes a new way to experience Take Your Legislator to Work Day, an initiative we've been championing for years at GCDD. This year, we're encouraging you to take the reins with a <u>DIY tutorial</u> on planning your own Take Your Legislator to Work Day this month.

We also have a tribute to Dawn Alford, who as the GCDD Public Policy Director, was instrumental in educating lawmakers about such important issues as the need for an Employment First initiative and the value of inclusive post-secondary education.



Dawn passed away in July, but her legacy will live on for generations.

You will also read about <u>efforts</u> <u>to increase the disability vote</u> for upcoming elections and about <u>a</u> <u>summit that spotlights communities</u> <u>that welcome all people</u>.

HOW GEORGIA CAN BEGIN TO CLIMB FROM THE BOTTOM IN MANY RANKINGS TO A TOP-TIER STATE FOR EMPLOYMENT FOR PEOPLE WITH DISABILITIES.



Check out <u>GCDD's website</u> 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 Managing Editor, Hillary Hibben, at <u>hillary.bibben@gcdd.ga.gov</u>.

Eric E. Jacobson Executive Director, GCDD

Tell us your thoughts about the magazine or what topics you would like to see addressed by emailing us at *hillary.hibben@gcdd.ga.gov*, subject line: Letter to the Managing Editor



Every year, the exhibition features four to five photographers and one commissioned work along the themes of social justice and around ALA's work.

A lot of progress has been made, but we have a long way to go.

This year, *Picturing Justice* commissioned a special exhibition documenting and exploring the lives of ALA clients who have been impacted by the US Supreme Court's famous 1999 *Olmstead v. L.C. and E.W.* decision.

*Olmstead*, celebrating its 20th anniversary this year, has its roots in Atlanta. The case was filed by ALA was on behalf of Lois Curtis and Elaine Wilson, two women with intellectual disabilities who had been isolated in psychiatric hospitals for many years.

The legal agency argued that these women had the right to live in the community with appropriate supports. The US Supreme Court found that under the Americans with Disabilities Act, it would be unlawful for the state to discriminate against a person based on his or her disability and that services must be provided in

## Olmstead Exhibit Opens in Atlanta

<u>Picturing Justice</u>, an annual photography exhibition hosted by <u>Atlanta Legal Aid</u> (ALA), opened this month and aims to use photography to illuminate and create empathy for stories of lives improved by the work of social justice advocates.

the community for people with disabilities. This ruling became known as the *Olmstead* decision.

Angie Tacker, director of annual giving and communications at ALA, shared that the exhibit is meant to be honest and authentic. "We wanted to share the whole story about *Olmstead* – not just success stories of those individuals living in the community, but also those clients who we couldn't help or are still in the process of helping."

ALA commissioned Robin Rayne, an Atlanta-based photojournalist and documentary producer for the Institute on Human Development and Disability at the University of Georgia.

The special exhibit is called "*Olmstead* at 20: Promises Kept, Promises Unfulfilled," and features a photo essay created by Rayne and Atlanta author Robin McDonald. The photo essay explores how



PICTURING JUSTICE | OCT 16 - NOV 30 2019

the decision has and is impacting clients of Atlanta Legal Aid.

"Olmstead changed the landscape legally for people with disabilities. A lot of progress has been made, but we have a long way to go," said Rayne. "I want people to be able to see the personal side of what those lives are like."

The 2019 *Picturing Justice* exhibit opened on October 16 at Atlanta Legal Aid at 54 Ellis Street and will run until the end of November. It is free and open to the public.

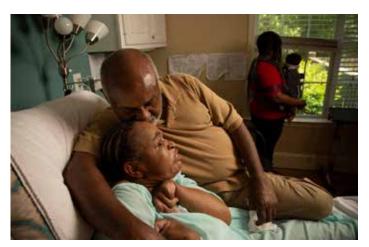
#### **Commemorating** *Olmstead's* 20th Anniversary

On August 8 – 9, the Georgia State University College of Law hosted *Olmstead* at Twenty: The Past and Future of Community Integration, a conference focused on the state of compliance and the path forward. <u>Read more about the event in our September GCDD e-news.</u>

#### Atlanta Legal Aid Society presents

## picturing Justice

curated by Atlanta Celebrates Photography



**Nafeesah Shaheed** was a vibrant social worker with advanced degrees from Columbia University and Hunter College in New York. After a medical accident catastrophically starved her brain of oxygen, leaving her bedridden and non-verbal, she required around-the-clock care. At growing odds with nursing home personnel who parked the formerly vibrant woman in a wheelchair and left her unattended for hours, her husband and her eight children resolved to bring her home. They succeeded with the help of lawyers at the Atlanta Legal Aid Society and a landmark U.S. Supreme Court ruling that Legal Aid originated. *Olmstead vs. L.C. and E.W.* marks its 20th anniversary this year.



Charles Anderson, 65, confronted a medical crisis that stripped him of independence and confined him to a nursing home. Then he met Legal Aid lawyer Toni Pastore, manager of Legal Aid's Disability Integration Project. Pastore helped Anderson qualify for community support services, kept his spirits up while he remained on the waiting list, and alternately prodded and encouraged him to believe that he could make it on his own. "I always knew in my heart I would leave," said Anderson, who now lives in a Christian City duplex. But without Pastore's help, he didn't know how. "A new me has emerged," he said. I wasn't going to be seen for the wheelchair. I would be seen for me. And I was going to be okay."



Mikaiah Epps, 21, holds his mother's hands during their visit time in a sparsely-furnished crisis home. After an altercation with his stepfather, Epps had been confined to a DeKalb County jail. With no one willing or able to post bail, he was in custody for nearly a year.

The state's developmental disability staff denied his Medicaid waiver, insisting that mental illness, not an intellectual disability, was Epps' primary problem. "In Georgia, we have a hard time serving people who have both mental illness and developmental disabilities," said Susan Walker Goico, director of Atlanta Legal Aid's Disability Integration Project. "The two systems point to each other and say, 'He's not mine, he's yours.' That's what is happening here." Epps was forced to live in the crisis home with little supports or activities, while waiting for a more permanent home.

Captions and their enclosed language are not those of GCDD, but of the exhibit author.



Tykeem Valentine, 22, has autism that has left him unable to speak and, as a teenager, made him prone to extreme behaviors that cycled him in and out of hospital emergency rooms. Tykeem's mother, Deborah Valentine, has multiple sclerosis and faces her own physical challenges. But with help from the Comprehensive Supports Medicaid waiver, Tykeem now lives in a group home with around-the-clock support and is able to visit regularly with his mom.

"If you have a child with a disability, you are constantly thinking, 'How is this child going to manage after I'm gone?,'" said Susan Goico, managing attorney of Atlanta Legal Aid's Disability Integration Project. "We as a society need to help these families so it is not such a weight. We need to make sure these adult children are taken care of. It makes such a difference for families so they are not terrified about what's going to happen to their child."

## A TRIBUTE TO

## Dawn Alford





In July, the Georgia Council on Developmental Disabilities (GCDD) unexpectedly said goodbye to an amazing, hard-working advocate for people with developmental disabilities.

Elizabeth Dawn Alford (known to her friends, family and colleagues as "Dawn"), GCDD's Public Policy Director, left a legacy on disability rights and established strong long-lasting relationships with legislators and people across the state.

We heard from a lot of you – all over Georgia – who shared their memories and thoughts with us. GCDD wanted to honor Dawn and the impact that she made on agency leaders, legislators and families.

### 99

When Dawn was born and diagnosed with muscular dystrophy, her life expectancy was about 10 years. She was the MD poster child in 1984, met President Reagan and graduated as valedictorian from Temple High School and magna cum laude from Georgia Tech in chemical engineering. The Tech fight song was played at the end of her services as her heartbroken parents left their pews. She was a star everywhere she went, admired by all and fiercely determined to succeed on behalf of others.

[Advocates at the Capitol] do not always enjoy a positive image from the public, but Dawn made us all better people by her presence and advocacy ... It is impossible to state how much she will be missed, and we all feel the painful gap from her absence in the work world of politics. May you rest in peace, Dawn, and thank you for your service.

- Representative Mary Margaret Oliver, Georgia District 82







We were saddened to hear this news! She was a great advocate and one of the first folks I met when I moved here who literally helped me understand "the ropes." Our condolences to GCDD and her family.

- David T. Wilber, Executive Director, Diversified Enterprises











Dawn was not only a subscriber of Georgia Lobby, but she was a friend that both Brooke Oakley and I enjoyed interacting with daily during session. Dawn worked hard with a heart for GCDD. Always a smile on her face and ready for the business of championing the cry of those with disabilities. Both Brooke and I will sorely miss her this coming session and we already do miss her now.

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- Pamela Adams and the Georgia Lobby Team





She will be missed but will be remembered as a champion for all those experiencing disability and for her dedication to her advocacy work.

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- Beate Sass, photographer



## Tap Into *Your* Self-Advocacy Power!

October celebrates National Disability Employment Awareness Month (NDEAM), and this year, the theme is *The Right Talent, Right Now.* 

And what better way to bring that message home than to announce the return of GCDD's Take Your Legislator to Work Day! And this year, we are putting the power in your hands!

The annual employment advocacy event provides an opportunity for employees with disabilities to invite their legislator(s) to visit them at work. It allows legislators and decision makers to see the far-reaching benefits to employers, employees and communities alike of hiring people with disabilities.

It's also a great way to create opportunities for Georgians with disabilities to form and nurture relationships with their elected officials.



Sen. Kay Kirkpatrick visits Angad Sahgal (center) at the Sandy Springs Police Headquarters during last year's TYLTWD.



Host Rose Scott (second from right) interviewed (I to r) Hanna Rosenfeld, Rep. Dale Rutledge, Arianna White with her employer Jonathan Kendrick of Work4Eli at Digital Technology Partners (far right) during last year's TYLTWD at WABE.

### Here's How You Can Take Your Legislator to Work!

#### Schedule Your DIY (Do It Yourself) Visit

- Employer Permission: Your employer must give written permission for your legislator to visit you at work. <u>Use this form for your employer to sign</u> and email to <u>info@gcdd.org</u>
- Identify your senator and representative for your particular district on <u>Open</u> <u>States by filling in your address.</u>
- Click on their name or find their contact information on the <u>Georgia State</u> <u>Senate</u> or <u>Georgia House of Representatives</u> page.
- **Contact Legislator:** Use their contact information to send an email to set up a meeting with the senator and/or representative you'd like to connect with. <u>Use this sample copy.</u>
- Set up a date and time that works for you, your employer and your legislator. <u>Complete this form before your visit.</u>

#### **Plan Your Itinerary**

- Plan for a tour that should be approximately 30-45 minutes. Be sure to highlight where you work and what your job responsibilities are, and introduce the legislator to your co-workers.
- If you work with a job coach, or receive another form of support, try to include that person in the conversation with the legislator.
- Be sure to include your employer and available co-workers in the conversation, as their perspectives will be very important to the legislator.
- Although it is important to include the co-workers, the job coach and the employer in the discussion, the visit should primarily focus on your experience as the employee.

#### On the Day of the Visit

- Be on time to welcome your legislator.
- Share with your legislator why they should support competitive, integrated employment, funding for waivers, Medicaid home and community-based services, Employment First and inclusive post-secondary education.

#### Share Your Story with GCDD!

- You made the connection. You had the meeting. And now we want to know!
- Take a few minutes to <u>complete this form and upload your pictures</u>. GCDD may contact you for further information about your visit for our next issue!

# GCDD THE DISABILITY VOTE ON NOVEMBER 5TH!

## Even though the nation's focus is on the 2020 general election, there are elections happening this year too on November 5, 2019!

Across the state, local elections are happening from Gwinnett to DeKalb to Sumter counties and all across Georgia. These are as important as federal elections. Here, you vote for city council persons, school board members, and other officials that govern your local community. These local lawmakers are key to making sure that the town you call home is also working on behalf of people with developmental disabilities and their families.

Check your local newspapers to see if there are elections being held in your area or connect with <u>your county liaison</u> to find out more information.





#### The Disability Vote Counts! series is a finalist in Content Marketing Awards!

The 2018 *Disability Vote Counts!* series published in *Making A Difference* was a finalist in the <u>2019 Content Marketing Awards</u>. The four-part series informed and educated people with disabilities about the midterm elections and candidates and also featured a guide to getting out the disability vote!

GCDD Celebrates October 2019 National Disability Employment Awareness Month!

**#NDEAM** 



National Disability Employment Awareness Month #NDEAM | dol.gov/odep



Digital Technology Partners employees: (front, I to r) Hannah Hibben, Mandie Potts and Arianna White. (back, I to r) Jonathan Kendrick (owner) and direct supervisor Shawn Adkins

> Hibben, 24, has Down syndrome and was very shy when she started working at the Conyers office last year. She now shows pride in her work productivity and will boast, "I did 100 hard drives this week," according to her supervisor Shawn Adkins.

"It's amazing to see the confidence that Hannah has now in presenting," said Adkins, a Digital Technology Partners director.

Hibben, White and Potts were hired into the <u>Work 4Eli E-Waste</u> <u>Employment Program</u>, which Digital Technology Partners created to empower people with developmental disabilities in the workplace.

#### In the past, we have not thought about job seekers' strengths.

The company provides new computers, software, printers and scanners to dentist offices and disposes of old previously used equipment.

"Jonathan Kendrick, [Digital Technology Partners, chief executive officer], didn't know what to do with this stuff and said, 'Why don't we tear it down?'

## In the Workplace

#### By Adrianne Murchison & Devika Rao

Every Friday, Digital Technology Partners holds a lunch-staff meeting where each department shares positive activities that took place throughout the week and benefit the company. Among the employees who give a brief report is Hannah Hibben on how many computers her department dismantled in recent days. Her two co-workers, Arianna White and Mandie Potts, join her. Their duties are a key company task.

[Hannah, Arianna and Mandie] break the items down for us. They gut the whole computer into a shell and separate parts. I have found buyers who purchase used equipment from us, and we put 100% of the proceeds into the program."

Kendrick's young son, Eli, has autism.

"He didn't know what his son would do [later in life] and he wanted to create a work environment to help," Adkins added. "Hannah was our first employee that we hired in the program."

She separates computer RAM processors, heat sinks and batteries; and destroys hard drives by running them through a gouging machine to tear out the motherboard. She also assists Adkins with any salvageable parts that can be sold on eBay. The two decide which photographs and descriptions to post.

"She is an incredible employee," Adkins added.

#### **Customized Employment**

Digital Technology Partners' approach to providing a fulfilling environment for employees with disabilities is aligned with best practices described by Doug Crandell, project director for <u>Advancing Employment</u>, a program managed by the Institute on Human Development and Disability (IHDD) at the University of Georgia. Its Technical Assistance Center and Community of Practice help organization's strengthen their employment services for people with disabilities.

"Most of my work is training and helping staff at provider agencies [that provide supports for people with developmental disabilities] on how to offer job development that suits someone's strength, and how to customize employment on behalf of the job seeker," said Crandell. "In the past, we have not thought about job seekers' strengths. We just said, 'These are the jobs that are open.' Customized jobs, it's the most empowering thing that I can think of."



Hibben separates computer RAM processors, heat sinks and batteries; and destroys hard drives by running them through a gouging machine to tear out the motherboard.

The Office of Disability Employment Policy at the Department of Labor (ODEP) defines customized employment as: a process that personalizes the relationship between the job seeker and the employer. In addition, there is an established goal to match the job candidate's interests, strengths and conditions with the business needs of the employer.

In 2015, Crandell co-moderated focus group discussions with employers who had already customized jobs for people with disabilities. Conducted by the <u>ODEP-funded LEAD Center</u>, a collaborative of disability, workforce and economic empowerment organizations, the focus groups aimed to garner the perspective of employers of various sizes, sectors and locations who had hired individuals with disabilities into customized jobs.

Employers emphasized the importance of a reciprocal relationship with supporting provider agencies. They wanted providers to understand that their company goals and objectives are as essential as the job seeker's employment.

Below are additional points for providers to consider when seeking quality employment for job seekers, according to The LEAD Center's Information Brief of Perspective Employers on Customized Employment:

- Knowing the business, including its products, services and customers. Doing research beforehand and coming to the initial meeting with this information.
- Understanding and addressing the needs of the business (versus the need of the provider to place an individual on the job).

- Listening to the employer more than talking/selling to the employer.
- Knowing the capacity of the job seeker and his/her potential value to the employer.
- Being creative and flexible in how to meet the needs of the employer while effectively utilizing the skills and interests of employee.
- Being passionate about the work of finding employment for individuals with disabilities.
- Being responsive and available to the employer when needs/ issues arise.

The focus group members underscored that company inclusivity improved morale, camaraderie and support among staff, as well as employees understanding of the organization's mission.

#### **Employment Comes First**

Additionally, there are many policies and practices under development, which will further the availability of competitive, integrated employment for people with disabilities and employers.

Georgia Department of Behavioral Health and Disabilities (DBHDD) Commissioner Judy Fitzgerald recently talked about the work the agency is doing to further the supported employment model. Specifically, Fitzgerald announced the formation of a state-level, interagency leadership team and six regional grassroots leadership teams called Gardens of Change.

Its goal: to triple the number of individuals with intellectual and developmental disabilities (I/DD) who are engaged in competitive, integrated employment.

Currently, 16.3% of people with I/DD are engaged in competitive

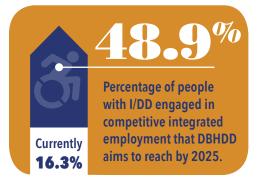
EMPLOYERS ... WANTED PROVIDERS TO UNDERSTAND THAT THEIR COMPANY GOALS AND OBJECTIVES ARE AS ESSENTIAL AS THE JOB SEEKER'S EMPLOYMENT.

integrated employment, and Gardens of Change aims to reach 48.9% by 2025.

Supported employment will be its primary vehicle to help people with significant disabilities obtain real jobs and the chance to build financial independence and security.

Scaffolding this group is the national movement Employment First. According to the ODEP website, Employment First is the approach to, "an overall systems change effort that results in increased communitybased, integrated employment opportunities for individuals with significant disabilities."

A legislative victory for employment for people with disabilities, Georgia created an <u>Employment</u> <u>First Council</u> (EFC) through House Bill 831 in 2018. This represents the state's first step towards full transformation of the publicly funded system. Georgia's EFC brings together 14 individuals with ties to the community or roles in state agencies serving people with disabilities with the charge of making recommendations to the legislature.



**IN RECENT YEARS, PARENTS HAVE BEEN INCREASINGLY FIRM IN** ENSURING THE CONFIDENCE AND SELF-ESTEEM OF THEIR **CHILDREN WITH I/DD** IN THE WORKPLACE.



Chaired by Georgia Vocational Rehabilitation Agency's (GVRA) Executive Director, currently Shawn Ryan, "the mandate of the Employment First Council is to bring together information and make recommendations to the legislators that will streamline and coordinate efforts towards employment," said John B. Wells, EFC vice chair and parent advocate.

Mandates for the EFC as outlined in HB 831 are:

- **Developing an Employment First** training plan for providers;
- **Coordinating and conducting** educational activities with other agencies to increase awareness of Employment First;
- **Evaluating the funding** mechanism for inclusive postsecondary education (IPSE) programs in the state; and
- **Reviewing and making** recommendations in a biannual report to the Governor and the General Assembly

Currently, the EFC is formalizing and submitting a report to legislators as a "path of implementation" for Employment First. Being a fairly new council, the work is underway, and the goals are setting a direction for clear, concise communication between agencies and the community.

"Our goal is to bring agencies together into one space and have better communication, so the

option of employment is easier for parents or the individual with a disability," said Wells. "There is a tremendous hurdle, and we want to improve this on the client side."

The bigger goal is to accumulate all the data of various agencies. Currently, on the EFC, there is a representative from the Technical College System of Georgia, Department of Education and similar stakeholder agencies. By bringing together all of this data, the EFC will be able to create a central clearinghouse that will provide information to parents, individuals, employers and other community stakeholders.

Additionally, it will allow the EFC to provide clear recommendations for rural parts of Georgia or smaller cities, where the needs and resources differ from metropolitan areas.

#### **Changing the System**

One of the key changes seen in states that successfully adopt an Employment First approach is the shift of resources from sheltered workshop environments to competitive, integrated employment services. Sheltered workshops are a relic of an old system. They require people with developmental disabilities to provide labor for mere pennies on the dollar, and individuals who attend can often find this unfulfilling and unfair.

However, it's important to note that neither the EFC or GCDD are suggesting that sheltered workshops all immediately shutter, leaving people out in the proverbial cold. These settings often provide people with developmental disabilities and their families peace of mind and engagement with others that they might not find anywhere else in the system.

What Employment First is looking to do is change this system.

"As we learn and grow, our understanding about people with I/DD also evolves. This means that things that were once considered out of reach, like employment, are now becoming achievable. Employment First aims to make competitive, integrated employment the first option for people with developmental disabilities," said Eric Jacobson, executive director of GCDD and member of the EFC.



What this means is that true employment is becoming the first thing they consider after high school and/or college. By expanding the options and adding a pathway to employment, Employment First means that agencies, leader and community stakeholders are working towards creating a system that considers employment for people with I/DD as a realistic goal.

It is important to note that, "The goal is lofty, and the timeline is long. Systems change doesn't happen overnight," added Jacobson. "As we work toward adding employment as an option for people with I/DD, we continue to learn from the individuals themselves and the communities that surround them and remain committed to removing the barriers to them living the lives they want."

#### DEFINING EMPLOYMENT TERMINOLOGY

#### **Supported Employment:**

DBHDD provides supported employment services as ongoing supports to assist individuals with disabilities in locating and maintaining meaningful employment in their communities. Supports are designed to capture the individual's strengths, needs and interests. *Source: DBHDD* 

#### **Customized Employment:**

Customized employment is defined by WIOA as, "competitive integrated employment, for an individual with a significant disability, that is based on an individualized determination of the strengths, needs, and interests of the individual with a significant disability, designed to meet the specific abilities of the individual with a significant disability and the business needs of the employer, and carried out through flexible strategies."

Source: Workforce Innovation and Opportunity Act

#### The Power of Advocacy

In recent years, parents have been increasingly firm in ensuring the confidence and self-esteem of their children with intellectual and developmental disabilities in the workplace, according to Crandell.

"Younger folks with I/DD leaving school are more accustomed to being heard," he said, adding that this translates to the workplace. "Some of this has to do with younger parents who pushed to make sure they were heard in the classroom. I think that's a generational change as we try to improve transitional services to make sure people have real relationships and can be heard, not only for their opinions but for feedback."

Brandt White, a self-advocate from Augusta, GA, understands the importance of advocating all too well. Diagnosed with Asperger's syndrome at 13, White and his parents advocated on his behalf until he was 25.

He graduated from Augusta Technical College with a diploma in business administration with a concentration in medical office administration, securing a job he



loved. Through his advocacy and work in the community, he was then appointed to Georgia's EFC and is on the communications subcommittee for the EFC.

"As a self-advocate, it is important to never give up," said White, now 35. "There are a lot of resources and I always encourage people to ask questions. Everyone's situation is different and what works for someone may not be for someone else." Formerly a nurse's aide, White is currently interviewing for a new job with Camp Winshape.

#### What Change Looks Like

The Americans with Disabilities Act (ADA) was signed into law in 1990. Almost 30 years later, many disability advocates will state that the employment numbers are still dismal for people with disabilities.

According to the <u>US Bureau of</u> <u>Labor Statistics 2018 report</u>, 79.2% of people who identified with having a disability are currently unemployed.

With the passage of <u>Workforce</u> <u>Innovation and Opportunity</u> <u>Act (WIOA)</u> and the <u>Achieving</u> <u>A Better Life Experience Act</u> (<u>ABLE</u>), there are small headways being made to clear the barriers for employment.

And, Kathie Snow, a parent advocate and founder of <u>Disability</u> <u>Is Natural!</u>, is focused on outcomes.

Kathie Snow, a parent advocate and founder of Disability Is Natural! with her son Benjamin who is diagnosed with cerebral palsy, is focused on outcomes for people with disabilities.

#### Competitive, Integrated Employment:

Competitive, integrated employment means full or part-time work at minimum wage or higher, with wages and benefits similar to those without disabilities performing the same work, and fully integrated with coworkers without disabilities. *Source: <u>National Association of State Directors</u> <u>of Developmental Disabilities Services</u>* 

"There is a natural assumption that people without disabilities will go to college or work after high school, and they are taught skills that can help them get there," said Snow. "But the same isn't true for people with disabilities. An outcome to me, for example, is teaching someone with disabilities **bow** to get a job on their own."

Snow is also the keynote speaker at this year's <u>Georgia's Association</u> of People Supporting Employment First Conference being held at the University of Georgia from October 28-30, 2019. Her keynote, "It's Not Rocket Science," will focus on inclusion for people with disabilities, what will it take to make it happen and what adjustments are needed in attitude, determination and dedication.

The right attitude does make all of the difference, and one that Digital Technology Partners is embracing because it is making a positive difference for the entire team.

Adkins noticed, early on in Hibben's employment that the more he treated her in the same manner that he would an adult without a disability, the more she would come out of her shyness.

"When we are out and about getting lunch, Hannah talks to everyone and gives them high fives," said Adkins. "She has just blossomed."

## What's Happening in Washington? Federal Disability Policy Updates

by Alison Barkoff, Director of Advocacy, Center for Public Representation

Summer is winding down in DC, and Congress is returning from their recess. This summer was unusually active, with a number of significant federal rules coming out that impact people with disabilities. This issue will focus on these rules, as well as our top priorities with Congress this fall.

#### Updates on Federal Regulations and Guidance

#### The "Public Charge" Rule:

On August 14, 2019, the Department of Homeland Security (DHS) finalized the "public charge" rule that applies to people seeking to enter the US (get a visa) or become a permanent resident (get a green card). DHS says this rule is meant to prevent people who are not "self-sufficient" from entering the country. Last fall when DHS proposed the changes to the public charge rule, disability groups strongly opposed the rule, commenting that it would harm and discriminate against people with disabilities. Over 250,000 comments were submitted opposing the proposed rule. Unfortunately, the final rule is virtually the same as the proposed rule.

The most significant changes in the final public charge rule for people with disabilities include:

 Previously only "substantial reliance" on cash benefits or Medicaid funded long-term institutional care counted against an individual. The new rule adds consideration of adults who use, or even one day might use, any Medicaid services, including home and community-based services (HCBS). Medicaid HCBS (usually provided to people with intellectual and developmental disabilities through "waivers") is typically the only source of the critical services that help people live and participate in their communities since private insurance does not cover HCBS. (Note that the rule does not include the use of Medicaid by children under 21 or pregnant women.) The new rule also adds federal nutrition (called SNAP) and housing assistance to the benefits considered.

- The new rule greatly expands the impact of having a disability or chronic health condition. It weighs against an individual having a medical condition that is "likely to require extensive treatment, institutionalization or interfere with the ability to care for self, attend school or work." Most people with I/DD will fall under this definition. The absence of a medical condition is considered a positive factor.
- For people with any medical condition, the new rule also looks at whether they have private insurance that can cover all expected future

#### The new public charge rule is creating a lot of fear and confusion.

medical costs. Because private insurance does not cover HCBS, most people with I/DD will be unable to meet this factor.

The new public charge rule is creating a lot of fear and confusion. It is important to remember that it only applies to limited immigration statuses and only to certain benefits. You should consult an immigration lawyer about your specific situation before deciding not to take advantage of needed healthcare programs or other related benefits.

#### Affordable Care Act (ACA) Anti-discrimination Rules:

This summer, the Department of Health and Human Services (HHS) sought comment on proposed changes to rules implementing antidiscrimination requirements of the ACA, called <u>Section 1557</u>. Section 1557 prohibits discrimination by health programs or facilities that receive federal funds from discriminating based on race, color, national origin, age, disability or sex.

HHS proposes to:

• Limit the health programs and facilities subject to Section 1557, including exempting private health insurance;

- Remove protections against discrimination for LGBTQ people, including based on gender identity and sexual orientation;
- Weaken requirements that ensure meaningful access to people with limited English proficiency;
- Make it more difficult for people to access reproductive services;
- Remove requirements to provide notices and information about nondiscrimination protections and the availability of language assistance services; and
- Limit the right of individuals to enforce their rights under Section 1557 in court.

The proposed rule also sought comment on whether HHS should make changes to Section 1557's accessibility requirements for people with disabilities. Disability organizations submitted <u>comments</u> opposing changes that would harm people with disabilities. We expect HHS to issue final Section 1557 rules in the coming months.

#### Forthcoming Federal Regulations:

As we've noted before, the Department of Education previously announced that it intends to revisit the definition of "competitive, integrated employment" (CIE) in the Workforce Innovation and Opportunity Act (WIOA) rules by the end of the calendar year. If and when these rules come out, it will be critical for people with disabilities, families, employment providers and other stakeholders to submit comments about the importance of CIE. Also, the Department of Justice announced that it will soon be issuing proposed rules about deporting individuals who are a "public charge," aligning with DHS rules relating to immigration. We'll keep you updated on opportunities for comment.

#### **Electronic Visit Verification**

Electronic Visit Verification (EVV) – the requirement for states to electronically verify Medicaid-funded HCBS provided in an individual's home by January 1, 2020 - continues to be an ongoing concern in the disability community. On August 8, 2019, the Centers for Medicare & Medicaid Services (CMS) issued new guidance, stating that EVV does not apply when the provider and consumer live together; that EVV need not track the consumer's specific locations in the community; and that electronic timesheets alone are insufficient to meet the EVV requirements. CMS also notified states that it is accepting "good faith exemption requests" for states who need an additional year for implementation of EVV requirements.

#### **On the Horizon in Congress**

As the congressional session progresses, top priorities for the coming months include:

#### **Money Follows the Person:**

Disability groups continue to push for long-term funding of the Money Follows the Person (MFP) program to help people with disabilities and older adults move out of institutions and into the community. Late this summer, Congress passed a third short-term extension of MFP, extending funding through December 31, 2019. However, many states slowed or even stopped transitions until the program has longterm funding. We are working with bi-partisan members in the Senate and House on passing the EMPOWER Care Act, which would fund MFP for four years, this fall.

#### **Disability Employment:**

In late July, the House passed the <u>Raise</u> <u>the Wage Act</u>. This bill to raise the federal minimum wage also eliminates the payment of subminimum wages to people with disabilities under Section 14(c) of the Fair Labor Standards Act. Although we do not expect the Senate to take up this legislation, it is noteworthy that this was the first time a chamber of Congress voted to phase out Section 14(c). The disability community continues to work to advance the <u>Transformation</u> to Competitive Employment Act, a bipartisan bill introduced in the House and Senate that would provide funding to states and providers to expand opportunities for CIE while phasing out over six years the use of subminimum wages under Section 14(c). The House will conduct a hearing this spring, and we hope the bill will move forward to a "mark-up" later this year.

#### **Get More Information About:**

- The Public Charge Rule, its impact on people with disabilities and updates on litigation challenging the rule.
- Additional resources on the Public
  Charge Rule from the Protecting
  Immigrant Families Campaign including
  individuals who may be impacted
- The Proposed Section 1557 Rules
- Updates on <u>Competitive</u>, Integrated Employment (CIE)
- Updates on Electronic Visit Verification (EVV) from the <u>Center for Public</u> <u>Representation</u> and <u>GCDD's EVV page</u>
- Updates on <u>Money Follows</u> the Person (MFP)
- Updates on <u>Disability Employment Policy</u>

We'll keep you updated on other relevant federal legislation as this term of Congress moves forward.

Alison Barkoff works on policy and litigation related to community integration and inclusion of people with disabilities, including Olmstead enforcement, Medicaid policy, employment, housing and education.

Please note: information in this article is current as of October 15, 2019.

FALL 2019 15



The community groups will gather October 24, from 10 a.m. to 5 p.m. for the first <u>Welcoming Community</u> <u>Dialogue Summit</u> at Clarkston Community Center, 3701 College Ave, Clarkston, GA with a goal of learning, sharing and adopting ideas from each other. People and organizations interested should register for the summit to talk, listen, and learn with others who are actively involved in changing their world through conversations and collaborative action.

#### This is ... an important conversation to have together to make positive changes.

The format of the summit will begin with groups sharing about their community issues. Facilitators will then guide the groups' discussion around the seven elements of the Welcoming Community Dialogues:

- 1. Changing Narratives
- 2. Radical Hospitality
- 3. Human Rights
- 4. Listening, Connecting & Building Relationships
- 5. Respect & Empathy
- 6. Active Contributors
- 7. Shared Power & Decision Making

## Welcoming Community Dialogues Hosts Inaugural Summit

Earlier this summer, when Welcoming Community Dialogues (WCD) implemented its community meetings, the key question was, "Who's missing from the table?" This month, the WCD team will bring together communities throughout Georgia for an extensive dialogue on issues, lessons and next steps for communities.

"During the Summit, current Welcoming Community Dialogue groups will come together to build relationships, dream, share strategies, learn from and work with one another and others to plan collaborative actions for creating welcoming communities," says Malaika Geuka Wells, community organizing coordinator for Global Ubuntu.

Groups gathering for the summit will also share about race, class, poverty and the impact these have on their communities. As the summit winds down, a list of action items specific to each community will be created.

"The Welcoming Community movement means all are welcome, all have a sense of belonging and all are contributing to society," says Sumaya Karimi, the project organizing director for Real Communities Partnership and founder and director of Global Ubuntu.

"This is a collaborative effort. It is an important conversation to have together to make positive changes," explains Wells.

GCDD and Global Ubuntu will continue to offer financial support, technical assistance, training and other resources to each community group as they work towards Welcoming Community Dialogue Summit October 24 • 10 a.m. - 5 p.m.

Clarkston Community Center 3701 College Avenue Clarkston, GA

eliminating childhood poverty, empowering women, securing affordable housing and mitigating the impact of the prison system for people with and without disabilities, among other issues.

For information on this initiative or about the upcoming Welcoming Community Dialogue Summit, check out <u>Global Ubuntu's website</u> or <u>GCDD's Real Communities</u> <u>website page</u>. Space is limited and <u>registration is now open</u> for this FREE event. Please register by October 20.

THE WELCOMING COMMUNITY MOVEMENT MEANS ALL ARE WELCOME, ALL HAVE A SENSE OF BELONGING AND ALL ARE CONTRIBUTING TO SOCIETY.



#### EXPERT UPDATE

## **Change Takes Time**

by John B. Wells

Fourteen years ago, my son, Joshua, used to work in a sheltered workshop. He was frustrated and wasn't thriving. So, with the help of an employee at the workshop, my wife and I decided to take "Employment First" into our own hands. We advocated for him, deciding together that we would find opportunities for him to work in the community.

Through coordinated efforts, Joshua has been working at Red Robin and Dunc's BBQ Kitchen in Newnan, where we live, and thriving.

When I was appointed to the <u>Employment First Council</u> (EFC), I knew it was an honor and came with a responsibility to influence legislation so that other parents could navigate a system that was easier, involves less hurdles and solves problems.

I learned a whole new language who does what, how they operate and how they interact. And what I learned was that while Georgia has a great apparatus in place to deliver services to families and individuals with disabilities, we need better communication.

Our goal is to bring agencies together, so we can make this

better for all parents. We hope to develop a clearinghouse - a one-stop-shop - where individuals with disabilities, parents and other community stakeholders can get all of the information they need.

> And what I learned was that while Georgia has a great apparatus in place to deliver services to families and individuals with disabilities, we need better communication.

What I also learned is that the people at these various agencies are some of the most passionate and dedicated people who are



determined to make a difference. And change takes time.

But as a parent, I know navigating this can be a minefield. I have been involved and advocating on my son's behalf, and it has been a lifelong journey. But many parents don't have the advantage that I do.

As the EFC advocates towards developing a more streamlined effort, I cannot recommend enough to encourage parents to develop relationships with a job coach because the breakdown happens after your student will leave high school.

As parents, we must push, we must get involved, because only then good things can happen.

John B. Wells is a parent advocate and the vice chair of the Employment First Council.



Joshua Wells outside Dunc's BBQ Kitchen, one of his two places of employment



Cheering on UGA - Joshua Wells (left), a Georgia fan and Joshua's father, John

Joshua Wells (center) with Georgia Senator Matt Brass and former Lt. Governor Casey Cagle at the Capitol advocating for Employment First



High school graduate Zariah Wheeler (left) from Columbus interned with credit card service company, TSYS through Project SEARCH. Here she works with with her mentor. employee Barbara Smith.

"People told us about the need for work; they told us about the need for school systems that are more responsive," he said. "This population of kids coming out of school today is not the same population that came out in previous years. The expectations are higher."

Based on that information, GCDD has education and employment as priorities in their strategic plan. But it can't happen in a vacuum. It requires the determination, talent and energy of partners who can provide the educational and occupational skills that will give young adults the chance to live independent and productive lives.

One of the partners working toward that end is Project

**BEYOND THE** 

PEACH STATE,

**MORE THAN** 

AND

SEARCH, a statewide initiative that launched in the early 2000s. The **PROJECT SEARCH** idea HAS GROWN TO **PROGRAMS STATES** COUNTRIES

## **Project SEARCH Provides Path** to Employment by H. M. Cauley

While the issues facing people with developmental disabilities are many, a few key areas have the most impact on the quality of life. Five of those specific areas – education, employment, formal and informal supports, real communities and self-advocacy – comprise the cornerstone of the Georgia Council on Developmental Disabilities' current five-year plan, as laid out by Executive Director Eric Jacobson.

came from a similar program created in the 1990s in Ohio, where Erin Riehle, an emergency room director of a children's hospital, had a difficult time finding people to work in entry-level positions. She worked with the county's board of developmental disability services and local career campuses to fill the jobs and to create a model that could be replicated in other work environments.

Riehle has since become an authority in developing job opportunities for people with disabilities, and her model program became Project SEARCH.

Working closely with Riehle was Susie Rutkowski, now the codirector and education specialist for Project SEARCH and an active supporter of the organization's work in Georgia, where the program operates from 25 sites, including the three newest at Middle Georgia State University in Bibb County, Woodbridge Industries in DeKalb County and the Wimberly Center in Barrow County. Beyond the Peach State, Project SEARCH has grown to more than 600 programs in 48 states and nine countries.

"Project SEARCH has been an outstanding means of skill training for work with great success," said Bonnie Seery, Ph.D., who coordinates the Georgia program.

"Interns are taught and experience work skills in the work setting five days a week for the school year."

With the goal of combining classroom education with on-thejob training, Project SEARCH has paired with Georgia companies such as Fifth Third Bank, Embassy Suites and Emory Midtown Hospital, to name a few.

The program emphasizes skills related to job placement and can be as varied as unloading trucks, stocking shelves, filing, assembling furniture, leading activities and exercises and serving food. Student interns usually transition to permanent employment: Project SEARCH in Georgia has hiring rates hovering around 75% in positions that average 25 hours a week and pay approximately \$9.61 an hour.

But the curriculum goes well beyond that focus.

"I'm also teaching soft skills, how to write resumes and how to handle job interviews," said Shanna Overstreet, the Project SEARCH instructor in Coffee County who is based at the county's regional medical center in Douglas. "There's also a finance portion as well."

The Coffee County project is now in its 11th year and can work with eight 18- to



Zaebrion Herron, a Project SEARCH intern, practices the work skills needed in materials management in his job at a participating medical center.

22-year-olds. This year, Overstreet is working with four students – a number she'd like to increase.

In Effingham County, Project SEARCH was started in the fall of 2012 and based at the Effingham Health System in Springfield. Instructor Jennifer Spitko usually has between seven and 10 students, including some from nearby Screven County that does not have a Project SEARCH program in place. Students work in various hospital settings, from the operating and physical therapy rooms to the human resources and business offices.

And every month, the students participate in an employment planning meeting that involves Project SEARCH, Vocational Rehabilitation and EmployAbility, a supported employment agency based in Savannah. They all work together to develop a customized employment plan factoring the student's interests, strengths and personal goals.

As a result, Effingham County's Project SEARCH graduates are now working in the community at local companies, restaurants, government agencies and more. Two of the graduates were also hired back into the hospital's information

technology department.

Overstreet, at Coffee County, believes that one of the successful parts of this program is its focus on self-advocacy. "We teach them how to advocate for themselves, specifically in an employment setting," she shared. "They learn how to communicate and advocate for what they need to be successful at their job."

In her experience, Overstreet has seen employers enjoy working with the interns and treat them like they are a part of the team. In turn, her students' confidence, social skills and capabilities rise - making the case for the push towards competitive, integrated employment nationally.

"Competitive employment is the goal and the rule," said Seery. "Project SEARCH changes expectations, changes communities, changes families and, most of all, changes lives." At the 2019 Project SEARCH Annual Conference in Anaheim, CA, 192 program sites from 37 states and 4 countries were recognized for achieving 70% to 100% employment for their 2018 program graduates.

Six locations achieved 100% employment for their graduates in Georgia.

### Project | SEARCH LOCATIONS IN GEORGIA

- Archbold Medical Center
- Candler Hospital
- Cartersville Medical Center
- CHI Memorial Hospital
- Coffee County Regional Medical Center
- Colquitt Regional Medical Center
- Effingham Health Systems
- Emory Midtown Hospital/Emory Healthcare
- Grady General Hospital in Cairo
- Hamilton Medical Center
- Memorial Satilla Health
- Middle Georgia State University & Bibb County
- Navicent Health
- North Fulton Hospital
- Northeast Georgia Health System
- Phoebe Putney Memorial Hospital
- Piedmont Fayette Hospital
- Redmond Regional Medical Center
- Shaw Industries
- St. Joseph's Hospital
- Georgia Southern University-Armstrong Campus
- TSYS
- University of West Georgia
- Wimberly Center & Barrow County
- Woodbridge Industries & DeKalb County

#### Locations in yellow achieved 100% Employment in 2018

For more about this initiative, visit projectsearch.us or the Georgia Council on Developmental Disabilities.

## FOCUS ON OUTCOMES

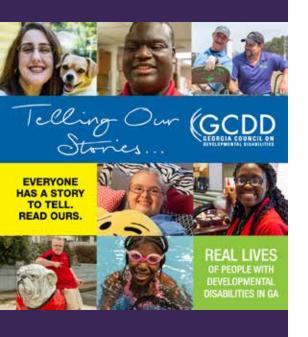
Project SEARCH outcome measures are based on a rigorous definition of competitive employment that includes the following criteria:

- **Competitive employment in an integrated setting** (*i.e. among co-workers with and without disabilities*)
- Year-round, non-seasonal employment
- 16 hours/week or more
- Prevailing wage

#### NATIONAL PROJECT SEARCH OUTCOMES

PS Interns	2014-15	2015-16	2016-17	2017-18
#Enrolled	2370	2876	3232	3733
#Completed	2205	2643	3026	3511
% Completed	92.7%	<b>92</b> %	93.6%	94%
#Employed	1697	2016	2420	2357
% Employed*	75.5%	75.5%	70.2%	67.1%

\* Jobs meet Project SEARCH Criteria



## **Telling Our Stories**

Through its <u>Storytelling Project</u>, GCDD paints a picture of the complex systems of support that enable people with developmental disabilities to live their best lives. Often mountains of paperwork, appointments, school IEP meetings, and/or job coaches and supervisors demand time and energy.

Within this superstructure that supports citizens at our local, state and national levels, many laws are made, often without insight from the people most impacted. This is especially true for people with developmental disabilities. As a result, we create a system rife with barriers that can prevent a person from living the life they want.

In addition to laws, the interrelated intricacies such as health professional shortages, transportation, housing, education and the like can become stop signs in the full utilization of available services. The following two stories highlight racial disparities, socioeconomic inequities and how a situation can play out in two different circumstances, where people with and without resources are or are not supported by the system.

## **Callie's Path**

#### by Shannon Turner, Photographer Lynsey Weatherspoon

Callie Moore, a 22-year-old woman with seizure disorder and cerebral palsy is on a new journey toward independent living. She's learning how to be independent of her mother, Pam, and is looking at getting an apartment in nearby Athens. It's only a recent development through her newly completed PATH. PATH stands for "Planning Alternative Tomorrows with Hope," a process designed by three leaders in the inclusive community movement Jack Pearpoint, John O'Brien and Marsha Forest. It helps people of all ages and abilities realistically plan to successfully reach their goals.

Callie's mom, Pam works for Georgia Options, which is an Athens-based nonprofit which supports people with disabilities to live in their own homes and to have typical life experiences. Previously a high school English teacher, after Callie was born, Pam found that she was unable to support her daughter's medical needs, if nothing else, on a logistical level: "Callie was my unintended entrance into the disability world."

Callie has a trailblazing and pioneering spirit. Callie's biggest groundbreaking act is the lawsuit she won in 2008, Anna Moore vs. Georgia Medicaid. Within six months after she started nursing services at the age of three, Medicaid balked and said she didn't need that much nursing care.

From the time Callie was three to age 12, every six months or



This waiver system can make a huge difference in the quality of someone's life. It can make life worth living.



so, they would get a letter saying that she needed less nursing care. They would have mediations and hearings in the state courts. Every time, she won, but Medicaid continued to threaten to lessen her services. They started meeting with the Georgia Advocacy Office and learning about state laws.

When Callie was 12, they got yet another notice they were going to cut her hours. The Georgia Advocacy Office advised it was time to let Callie's case provide some precedence and stop the state courts from trying to intervene in her care.

In the final ruling, the federal district court found that states participating in the Medicaid program do not have the discretion to deny funding for treatments

#### GCDD STORYTELLING

PLEASE KNOW THAT THE SYSTEM IS BROKEN. CALLIE'S SUPPORT IS A WIN, BUT THERE ARE PEOPLE WHO NEED SERVICES AND AREN'T GETTING THEM.

> and services when prescribed by a treating physician for a Medicaideligible child. The case had implications for more than 700,000 children in Georgia who were eligible for Medicaid. It earned her name recognition throughout the disability community.

> Callie now receives the COMP Medicaid Waiver, which started when she turned 21, and pays for all of her nursing supports. The application process was long, but they feel like maybe that's necessary to know what individuals really need. She and her mother encountered hurdles when setting up services. Like many people, Callie was approved for waiver funding but faced a shortage of providers in their area. Pam says,

"There needs to be energy put into making sure waiver services don't just look good on paper but are being provided as approved."

Callie typically has two practitioners with her when mom's at work. She has a nurse and a certified nursing assistant (CNA) for community access support. For the CNA, they typically try to get someone around Callie's age who enjoys doing the same things as Callie. Callie also has a nurse overnight. These are all supports paid for by her Medicaid waiver.

We asked Callie what she would like to tell an elected official, if we brought them into the conversation. She replied, "This waiver system can make a huge difference in the quality of someone's life. It can make life worth living." Pam follows up: "Please know that the system is broken. Callie's support is a win, but there are people who need services and aren't getting them. Waiver recipients and their families are able and willing to help state leaders find solutions."







THE APPLICATION PROCESS WAS LONG, BUT THEY FEEL LIKE MAYBE THAT'S NECESSARY TO KNOW WHAT INDIVIDUALS REALLY NEED.



She says that she knows her son could hear before his illness because, before he went into the hospital, he would make lots of babbles and had begun forming pre-language "mama" type sounds. Afterward, he stopped responding.

ONE OF THE MOST ISOLATING ASPECTS OF MICHAEL'S LIFE IS THAT HE HAS NO ACCESS TO INDEPENDENT TRANSPORTATION BECAUSE HE AND MARY LIVE IN A VERY RURAL PART OF JONESBORO.

> Mary has an undiagnosed learning disability herself. She is unable to read or write and ended her formal education after her eight grade year. Being able to take care of Michael has been very challenging at times. Mary has to work hard to stay on top of his paperwork and medications. Some things are made possible by the fact that he has SSI and a COMP Medicaid Waiver. So much more could be made possible if he had in-home assistance and

## **Believing in What is Possible**

by Shannon Turner, Photographer Lynsey Weatherspoon

Michael Griggs is a 34-year-old man living in Jonesboro, Georgia. When Michael was three months old, he came down with a very bad cold. It led to meningitis. After three months in the hospital, Michael came home, seemingly healthy again. However, by the end of his first year, his mother Mary and others who spent time with him began to notice that he was not hearing.

the other supports that those services should bring to bear if Mary knew how to ask for them.

One of the most isolating aspects of Michael's life is that he has no access to independent transportation because he and Mary live in a very rural part of Jonesboro. Due to this lack of mobility Mary and Michael are unable to easily visit the recreation center, the grocery store and other businesses that provide goods and services.

Their rural location does not stop Mary and Michael from staying active and serving their community on foot. Where others in their position might struggle with diabetes or other health-related issues, Mary makes a point to make sure they walk for their health. They volunteer for their church, World OverComers Community Church, by walking many blocks every week, distributing flyers and pamphlets as part of its ministry.

For a long time, the lack of knowledge of and access to supports and services meant that Michael's days weren't spent preparing for his future. He would spend long hours in his room with his building blocks, puzzles and cars. Michael had been out of school for five years, yet no one was helping him get a waiver or live an engaged life. Things started to change when he got his Medicaid waiver after nearly six years of waiting.

Beate Sass is an Atlanta-area photographer who connected with Mary a few years back while making the Real Stories, Real People photojournalism project. As Beate is also a mother of a young woman with a developmental disability, she became a friend and ally to Mary. Beate says, "It's amazing how she's managed. No one ever understood how much they were going through. She's a fighter. She perseveres. She loves her child and has done all she can to help him along."

If Mary had a chance to sit down and speak with a legislator, she would want him or her to know



#### GCDD STORYTELLING

some things about their lives, starting with the fact that she's not going to be around forever. "I just want Michael to learn how to communicate for himself. If something were to happen to me, how is he gonna survive? How's he gonna do things?" She goes on to talk about the fact that she still

One wonders how Michael might have fared in a different situation,with more access to resources, more people joining with his mother and helping her to advocate for him. dresses Michael every day. "I want him to learn how to fix his own food. Maybe not on the stove, but still, learn how to do some things." She speaks about her dream of Michael being able to make a sandwich for himself when he feels hungry, not just knowing how to do it, but also living in a place where he feels welcome to do that.

One wonders how Michael might have fared in a different situation, with more access to resources, more people joining with his mother and helping her to advocate for him. For them both, really.

In expressing her dreams for her son, Mary says, "I want him to keep learning. I do what I can at home." Her belief in Michael's capacity to keep learning is important. It's a place from which to build a dream.





HIS MOM DREAMS OF ... MICHAEL BEING ABLE TO MAKE A SANDWICH FOR HIMSELF WHEN HE FEELS HUNGRY, NOT JUST KNOWING HOW TO DO IT, BUT ALSO LIVING IN A PLACE WHERE HE FEELS WELCOME TO DO THAT.





Read more stories about the experiences of individuals living with developmental disabilities in Georgia at <u>Telling Our</u> <u>Stories</u>, the Georgia Council on Developmental Disabilities (GCDD) Storytelling Project. The goal is to collect over 75 stories accompanied by 6-12 photographs, that will be instrumental in the efforts of GCDD to advocate for Georgians living with disabilities.

GCDD Storytelling Project

## 

## OCTOBER

October 24, 10 AM - 5 PM **Real Communities Welcoming Community Dialogue Summit** -Clarkston, GA <u>RSVP required by October 20</u>

October 26, 2 – 4 PM Lekotek of Georgia's Halloween Party – Tucker, GA <u>Register online</u>

October 28 – 30 Georgia APSE 2019 Training Conference – UGA Center for Continuing Ed, Athens, GA Registration information online

October 29, 11 AM – 12 Noon **A Morning with Judy Heumann,** International Disability Rights Activist – Decatur, GA Registration required – <u>Register FREE online</u>

October 30, 9:30 AM – 3 PM **5th Annual Disability History Symposium** – Athens, GA UGA's Institute on Human Development and Disability *Find more information online* 



November 15, 9:30 - 11:30 AM **Special Education for Parents and Families Training** -Waycross, GA <u>Find more information online</u> A Morning with Judy Heumann

International Disability Rights Activist

FREE event <u>Registration required</u>

November 17, 12 – 5 PM Sensory-Friendly Program: Rudolph the Red-Nosed Reindeer – Center for Puppetry Arts – Atlanta, GA Purchase tickets online

November 19, 2:30 – 4 PM Advancing Equal Employment Opportunities Webinar Sign up for webinar

November 21, 6 – 8 PM **Bike Meet Up** Recycle Macon – Macon, GA <u>Find more information online</u>

November 26, 2 – 5 PM **Sensory Friendly Afternoon** Southern Museum of Civil War and Locomotive History – Kennesaw, GA *Find activity information online* 

## DECEMBER

December 3 International Day of Persons with Disabilities Find more information online Tuesday, October 29, 2019 11 AM - 12 Noon at the Atlanta Friends Meeting Decatur, GA

> December 4 – 5 Georgia APBS 2019 Conference – Atlanta, GA <u>Get tickets online</u>

December 16 – 17 Disability Awareness Training – Kingston, GA Registration information online

December 31, 2 – 5 PM **Sensory Friendly Afternoon** Southern Museum of Civil War and Locomotive History – Kennesaw, GA *Find activity information online* 

## JANUARY

January 7 – 9, 2020 GCDD Quarterly Meeting Atlanta, GA Find more information online

January 14, 7:30 – 11:30 AM Health Care Unscrambled 2020 – Atlanta, GA <u>RSVP online</u>

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