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- Looking Ahead to Midterms & the Governor's Race
- Back to School Roadmap to Success
- Socializing in School, Forming Friendships

A quarterly digital magazine from the GCDD

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

PUBLIC POLICY FOR THE PEOPLE

Looking Ahead to Midterms & the Governor's Race in GA

by Hanna Rosenfeld

The political landscape will remain unclear until the general election on November 6. Read about Georgia's candidates for governor, their views on Medicaid and their first priorities if elected.



Back to School -**Roadmap for Success**

by Adrianne Murchison

Anticipation and butterflies around the first day of school are not exclusive to students. Parents can be anxious about how the day will unfold as well, especially those with children with developmental disabilities. Read more about how to prepare for student success.



Socializing in School, Forming Friendships

by Adrianne Murchison

When children with developmental disabilities are separated from children without disabilities in classroom settings, incorrect assumptions are made about their abilities. All children benefit from forming friendships in school, and parents should make sure that students are offered a chance to socialize.

Summer

2018

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On the Cover: Our Back to School issue focuses on navigating the roadmap to success for students with developmental disabilities from pre-school to college.



THE DISABILITY VOTE COUNTS!

I hope you are having a great summer! For some, this time of year reminds you of riding bikes under the streetlights and enjoying family vacations. For me, I remember competing in little league baseball and playing hide-and-seek with other neighborhood kids. Then my family would typically spend some time at the Lake of the Ozarks in Missouri. It was simple, but that was our summer.

For many families, summer camps are an increasingly popular option. In the spring edition of the magazine, GCDD profiled inclusive camps across the state in its article, Camps Rise to the Occasion with Inclusive Summer Programs. We shared links to sites, like the American Camp Association, that allow families to search for local, inclusive camps for kids with and without disabilities.

Perhaps instead of camp, you are opting for afternoons at the pool, evenings at outdoor BBQs or weekends at the lake. Or perhaps your summer is going swimmingly and perfectly harkens back to the lazy days of your childhood.

No matter how your summer is progressing, we are all preparing for the back-to-school season. As we look to the end of the summer and the beginning of another school year, many parents and caregivers find themselves asking questions. Is the school ready? What about when my child is finished with K-12? How will they fare in college?

Many families of children with disabilities may have never considered that last question. But now in Georgia, there are nine universities offering college as an option for students with developmental disabilities. The newest addition to the roster is Project WOLVES (World of Opportunities for Learning, Volunteering, Employment and Socializing) at the University of West Georgia. We are thrilled to welcome them to the community!

GCDD is working hard to expand the number of participating schools, as well as students who have access to colleges and technical schools, because these partnerships lead to employment and a better quality of life. You can expect to see more about this in upcoming editions of the magazine.

Finally, I cannot emphasize enough the importance of knowing your candidates for every elected office at the local, state and national levels. If you don't like the way things are going, vote for someone new. If you like the way things are going, vote to keep the same people in office. The bottom line is – VOTE! MARK YOUR CALENDAR for November 6, 2018 as Election Day!

Until then, educate yourself on voter rights and registration, access to the polls and where the candidates stand on issues. GCDD's The Disability Vote Counts! campaign will



Eric E. Jacobson

continually bring you information on what you need to know about the midterm elections.

For an additional way to discuss key issues, GCDD will host a public forum with candidates for the offices of Secretary of State, Superintendent of Schools and Insurance Commissioner in October in Atlanta. Be sure to stay tuned online to learn how to join us and how these candidates will support people with disabilities.

THE BOTTOM LINE IS – VOTE! MARK YOUR CALENDAR FOR NOVEMBER 6, 2018 AS ELECTION DAY!



Check out GCDD's website at www.gcdd.org and join our advocacy network online to stay informed. We hope you enjoy this magazine. Let us know your thoughts and comments by emailing Managing Editor Hillary Hibben at hillary.hibben@gcdd.ga.gov.

Eric E. Jacobson
Executive Director GCDD



Twenty-eight youngsters from 12 different school districts spent every day for a week learning how to handle a basketball, dribble, strengthen motor skills and play

strengthen motor skills and play the game. Community volunteers, known as "buddies," came from all over Georgia to help and included teachers, high schoolers and parents.



"Mighty Mike" with camper Noah Mote

Led by Mike "Mighty Mike"
Simmel, the camp was launched through a personal experience.
When Simmel was at a basketball camp as a teen, he had an epileptic seizure. The camp insisted Simmel be sent home and not return.
Simmel's parents fought for him to stay, and Simmel vowed to not to let that happen to others.

He began the Bounce Out the Stigma organization in 2005, a grassroots campaign to educate the public, teach healthy lifestyle

Basketball Camp Aims to Bounce Out the Stigma

For the third year, Bounce Out the Stigma Basketball Camp came to Gainesville, GA in June. The camp's mission is to "empower challenged youth to believe they can and erase the stigma from those who believe they can't." The camp is open to boys and girls, ages eight to 18, who are diagnosed with autism, ADD, epilepsy, ADHD and those with slow motor skills development.

choices and empower youth with unique issues – all based on Simmel's personal experiences of growing up with a disability.

One of the camper's parents watching the day's activities remarked, "You treat this as a regular basketball camp!"

Simmel acknowledged and shared that, "It is a regular basketball camp." He admits the camp is rigorous, but also designed so that everyone succeeds, develops better motor skills, effectively dribbles a ball and sees their confidence soar.

The camp allows kids to be kids. Children discover new skills, new friends and an inner confidence on what they can accomplish when given the opportunity. By being with each other, they also get a chance to bond, build camaraderie and learn from each other.

Two campers that stood out, recalls Simmel, were Michael and Savannah. Both with motor skill challenges, Michael saw his developed skills were just what Savannah needed to learn. He followed her everywhere she went, resulting in friendship and peer support that everyone looks for. At the end of

camp, the pair received the brand new "Buddies Award" for working together.

At camp, there is a "Show Me What You Got" time when each participant takes center stage and demonstrates the skills they've learned and achieved.

The goal of the Bounce Out the Stigma project is to motivate and educate young people with disabilities in promoting healthy life choices and becoming aware of disability issues.

Since its launch, the organization has grown the number of programs and camps it offers and is now available in 20 different states.

For details on the programs and camps Bounce Out the Stigma offers, visit www.bounceoutthestigma.org or call 855-997-3900.



A Vision for My Life

by Martha Haythorn

My name is Martha Haythorn and I am 18. I just finished my senior year at Decatur High School.

When I was seven years old, I went with my parents to speak with our senators. And, I have been advocating for people with disabilities ever since.

In April, I went to the Disability Policy Seminar in Washington, DC to advocate for people with disabilities. I went through the support of Stacy Ramirez and The Arc Georgia. It felt exciting and empowering to go to a big gathering to meet other self-advocates who share my mission to raise my voice.



It takes a lot of courage to advocate, but when we raise our voices it feels empowering.

On the trip, I also got to know people from the Georgia Council on Developmental Disabilities. This was really cool. I especially loved meeting Evan Nodvin's sister, Alison, who is an advocate in Washington. I am big fan of Evan's!

While I was in Washington, I met with two disability advocates, Liz Weintraub and Michael Gamel McCormick They have been advocating for people with disabilities for a long time and they were able to help me identify my gifts for advocacy. They are my mentors.

I went to two workshops to learn about Medicaid and voting

rights for people with disabilities. Medicaid helps people with disabilities have the support they need to live and work in our community. It also is important for our healthcare. People like me need Medicaid and need to take a stand.

I will be kicking off a video blog in July with The Arc Georgia called *Advocacy Diva*. I will be interviewing Liz, Michael and other self-advocates. I would also like to interview parents, teachers and elected officials.

I got a chance to vote for the first time this May. I learned at this conference that I have the right to have any person I choose in the voting booth with me. My father, Trace, went with me and helped me understand what I needed to do.

For my Senior Project at Decatur High, I made a video on disability advocacy. I interviewed four people about their experiences of disability. Five other young adults with developmental disabilities and I also spoke before the Decatur City Commission this spring.

At school this fall, I will be the Vice President of Partnerships for Success. This group helps students with and without disabilities get to know each other.



Martha Haythorn attended the Disability Policy Seminar in Washington DC in April. She will be back at Decatur High School in the fall to work on job skills and prepare for inclusive post-secondary education.

It is important for young people to speak up and share their experience. It takes a lot of courage to advocate, but when we raise our voices it feels empowering. Young people have important stories to tell.

I HAVE A VISION FOR MY LIFE:
I WANT TO HAVE A JOB, LIVE IN
AN APARTMENT AND BE MARRIED.
ELECTED OFFICIALS NEED TO KNOW
THESE THINGS TO HAVE A BETTER
UNDERSTANDING OF THE
LIVES OF PEOPLE WITH
DISABILITIES.

I have a vision for my life: I want to have a job, live in an apartment and be married. Elected officials need to know these things to have a better understanding of the lives of people with disabilities.

I hope that our leaders will think about what we are saying. We want to live our lives to the fullest and they are making decisions that affect us.

Looking Ahead to Midterm Elections & the Governor's Race in GA

by Hanna Rosenfeld, GCDD Planning & Policy Development Specialist



As a quick refresher, a primary election is designed to allow a political party to pick one candidate for an open political seat. Primaries help political parties, like the Democrats and the Republicans, unite behind one candidate.

Primary Election Outcomes

There are three potential outcomes of a primary election. It is important you understand which scenario has occurred in your community:

- 1) A candidate wins their primary. There are no rival candidates from outside of their party. Therefore, they are the de-facto winner as they will be running unopposed in the general election.
- 2) Two rival political parties hold primary elections. Each party emerges with one candidate. These two candidates, plus any independent candidates, compete in the general election.
- 3) A political party holds a primary election. No one candidate receives more than 50% of the vote in the primary. The top two candidates then enter a runoff election to determine the party's nominee.

Midterm Elections

Looking ahead, the political landscape will remain unclear until the general election on November 6. You may hear this election referred to as "the midterm election." Midterm elections gain their name because they occur in the middle of a presidential term, meaning that we will not be voting for a new US president in this election. Without high-profile presidential candidates, midterm elections typically have much lower voter turnout than years when a president is being elected. This means that your vote on November 6 is extremely important.

The Governor's Race

In this article, we will focus on the gubernatorial election – a fancy way of referencing the governor's race. Please note our limited focus is a reflection of space constraints, not level of importance. All offices up for re-election, from the governor to your local school board, are equally important. Each elected office in Georgia has a sphere of authority that enables officials to make decisions that impact your life and your community.

Also, it is essential that you research the candidates running in your area. Instead of basing your opinions on TV advertisements or campaign flyers, consider doing your own research. Many candidates have campaign websites full of information on the candidate's platform. Reach out to candidates and ask them about issues important to you. Make sure you are equipped with information you need to make an informed decision come November.

As for the governor's race, the field has narrowed quite a bit. However, there are still five candidates in the running. The Democratic primary saw Stacey Abrams win with 76.5% of the vote. The Libertarian candidate, Ted Metz, and the Independent candidate, Larry Odom, bypass the primary elections entirely. As for the Republican primary, no candidate received more than 50% of the vote. So the two candidates with the greatest proportion of the votes, Casey Cagle at 38.9% and Brian Kemp at 25.6%, must now enter a runoff election. Whichever Republican candidate receives the greatest proportion of the vote will then face off against Stacey Abrams, Ted Metz and Larry Odom in November.

In the following sections, we have highlighted a few facets of the

MEET THE CANDIDATES FOR GOVERNOR OF GEORGIA







Casey Cagle



Brian Kemp



Ted Metz



Larry Odom

candidates' platforms we find relevant, namely their views on Medicaid and their first priorities if elected. It is important to note that GCDD does not endorse any candidate and that the enclosed information encompasses only a small piece of a larger political platform for each candidate. We encourage you reach out to them with questions of your own – and to vote.

Stacey Abrams: Democrat

The former House Minority Leader (2010-2017) and Atlanta resident believes that, "Georgia must pursue expansion of Medicaid as both a stabilization and growth model for delivery of healthcare and for economic growth." 1 Indeed, Abrams went so far as to say that her first priority if elected would be to "[see through the] expansion of Medicaid in the state of Georgia to cover 500,000 Georgians; save our rural hospitals; and make certain that we start to create the thousands of jobs to which Georgia is eligible if we expand Medicaid in the state."

Casey Cagle: Republican

Cagle has served as Lieutenant Governor since 2007. The Gainesville resident's first priority if elected would be to "continue to build the college and career academy network." As Cagle shares, "Really giving kids the opportunity to explore 20 or 30 different career pathways [is key to helping them] find their passion in life. And, what we have seen is a 98% graduation rate, and 100% placement rate. But along with that, we have seen their incomes increase dramatically as well." ²

As for Medicaid, Cagle has asserted, "I philosophically believe in a safety net, but I don't believe in a safety net that becomes a hammock. I believe in a safety net that becomes a trampoline that lifts people up." ³ Cagle has expressed some interest in exploring Medicaid waivers, seen clearly through his Chairmanship of Georgia's Health Care Reform Task Force. He has stated that any Medicaid waiver Georgia pursues should include work requirements, as they, "build good faith with the taxpayers who fund these programs." ⁴

Brian Kemp: Republican

An Athens resident, Kemp has served as Secretary of State of Georgia since 2010. When asked what his first priority would be if elected, Kemp responded, "Well, day one I am going to create a Putting Georgians First Committee that will be made up of business people, not bureaucrats. It is going to start looking at cutting government regulations, cutting red tape, much like we have done in the Secretary of State's office and all of state government. And this is really part of a Conservative Four Point Plan I have to make Georgia number one for small businesses in the country." Regarding Medicaid, Kemp has reportedly said we should be lowering healthcare costs without giving more funding to Medicaid.5

Ted Metz: Libertarian

Chair of the Libertarian Party of Georgia, Ted Metz lives in South Cobb. Asked what he'd do day one as Governor, Metz enthusiastically replied, "I will issue an executive order for law enforcement agencies to stop all arrests for cannabis possession in small amounts, then instruct the courts to stop prosecutions, and then issue pardons to all affected by the Drug War. This will fix many things."

When asked about Medicaid expansion, Metz stated, "With the possible removal of strings attached to Medicaid grants which put 159 agencies in-between people and their doctors, ending certificate of needs for competitive facilities, using innovative approaches to healthcare delivery, expansion would be the right thing to do."

Larry Odom: Independent

At the time this article went to print, Larry Odom did not respond to our request for information. We can share that he is a Senior Project Manager and his campaign slogan is "Making Georgia Work for Everyone."

You will notice that no candidate has supporting people with disabilities as their top priority. Such exclusion reinforces the importance of meeting with candidates to educate them on issues specific to the disability community. As disability advocates, now is the time to get busy!



In the What's Happening in Washington? article in this issue, you can read about what Electronic Visit Verification (EVV) is and how it came to be federally. But what does this really mean for people with disabilities and their families here in Georgia? Moreover, what should individuals do if they are concerned about the potential impact of EVV to the services they receive?

EVV must be implemented by January 1, 2019 for Medicaid-funded personal care services, such as assistance with toileting, bathing, meal preparation, shopping or money management. Specifically, if you or your loved one receive services from any of the following Medicaid programs, regardless of whether it's through the agency or a self-directed model, you should learn as much as you can about EVV:

- Elderly & Disabled Waivers

 (i.e. Service Options Using Resources in a Community Environment [SOURCE] and Community Care Services Program [CCSP])
- Independent Care Waiver Program (ICWP), serving those with significant physical disabilities and traumatic brain injury
- New Options Waiver (NOW)
 & Comprehensive Supports
 Waiver Program (COMP),
 serving individuals with
 developmental disability
- Georgia Pediatric Program (GAPP), serving children who have medically complex needs in their own home

ELECTRONIC VISIT VERIFICATION (EVV): A GEORGIA LOOK

by Dawn Alford, GCDD Public Policy Director

In Georgia, the state agency charged with the administration of Georgia's Medicaid program, and hence the implementation of EVV, is the Georgia Department of Community Health (DCH). States have some discretion on the approach they use to implement EVV. The Georgia DCH has decided to provide an EVV system to existing Georgia providers who can then choose to use that system or select an alternative EVV system. That alternative system must meet DCH requirements, which include:

- Electronic verification of the minimum data points required by the federal law.
- Ability to "talk" with the DCH selected EVV vendor system so that DCH can access the data points collected.
- 3) Mandatory manual entry option.

The Georgia DCH posted an announcement earlier this year on its website about a competitive bidding process to procure an EVV vendor. As of the publication date of this article, no announcements have been made about a vendor selection. Of note, while the mandatory implementation date of an EVV system for personal

support services received through a Medicaid funded waiver is not until January 1, 2019, many providers have already begun to implement EVV systems on their own.

Regardless of the 2019 implementation deadline, the time to get involved and voice your concerns is now. While the Georgia DCH says one of its goals for implementation of EVV is to improve the quality and access to care for Medicaid members, many serious concerns from advocates about potential problems with EVV remain.

If you haven't already, please visit https://dch.georgia.gov/georgiamedicaid-electronic-visit-verification to see the Georgia DCH EVV landing page and to learn more about program details and implementation plans. You can also email Georgia DCH directly with any concerns you have about Georgia's implementation of EVV at evv.medicaid@dch.ga.gov. Finally, check GCDD's website regularly at www.gcdd.org, as the organization plans to release an advocacy resource specifically on EVV and

Georgia

on EVV and designed for families who will be directly impacted.



- 1 https://lwv.thevoterguide.org/v/ajc18/race-detail.do?id=17400777&party=Dem
- $^2\ https://www.ajc.com/news/questions-for-casey-cagle/88Q6OtKcbhKpEXIQFwlaON/$
- ³ https://www.wabe.org/meet-republican-gubernatorial-candidate-casey-cagle/
- ⁴ https://caseycagle.com/cagle-any-medicaid-waiver-should-include-work-requirement/
- ⁵ https://morgancountycitizen.com/2018/04/26/gov-candidate-kemp-comes-to-morgan/

CHECK OUT OUR NEW LEGISLATIVE TRAINING VIDEOS!







Giving Legislative Testimony

Whether you join us at the Gold Dome during the legislative session, visit your elected official's home office, or attend community events such as town halls, advocates need to be confident and ready when presented with the opportunity to speak with your legislators.

The UNLOCK! Coalition and the Georgia Council on Developmental Disabilities hosted three in-depth trainings between May and June to train individuals on the best ways to advocate for issues important to them. For self-advocates, the trainings also supported building capacity in influencing and informing legislators on disability policy.

The two meetings and one webinar ranged in topics that would build strong advocates. Subject matter experts like Kathy Floyd, executive director of the Georgia Council on Aging, also shared her experience in building relationships with policymakers and legislators with attendees.

Those who attended learned skills in:

- Building relationships with their legislators
- Sharing their story in two minutes or less
- Calling for meetings at district offices
- Advocating as a group



The training videos are available on GCDD's website under the videos section at https://gcdd. org/news-a-media/videos.html

GCDD'S PUBLIC POLICY TEAM



DAWN ALFORD, GCDD Public Policy Director



HANNA ROSENFELD, GCDD Planning and Policy Development Specialist



The UNLOCK! Coalition advocates with Georgians with disabilities so everyone can live full lives and contribute to Georgia communities and the Georgia economy. Find out more about UNLOCK and its principles on GCDD's website.

Back to School

by Adrianne Murchison

Anticipation and butterflies around the first day of school are not exclusive to students. Parents can be anxious about how the day will unfold, as well.



Before the first day back, parents of children with developmental disabilities have already been tenacious researchers of resources, discovering the best potential outcomes for their child.

The path to high school graduation and employment for children with developmental disabilities starts as early as three years old. Under the federal act that allows Free Appropriate Public Education (FAPE) for Students With Disabilities, an Individualized Education Program (IEP) is designed for each child. The website, understood.org, will show you how to seek special education services for your child.

An IEP team gathers annually, and sometimes more often, to consider the child's personal needs and strengths, as well as school curriculum and structure. The team assesses how the student will participate in educational milestones, and the most conducive classroom environment, said Zelphine Smith-Dixon, state director for Special Education Services and Supports with the Georgia Dept of Education.

"Although it's called an IEP, it's really about the right services and support for that particular child," Smith-Dixon said. "Federal guidance requires the roles that are represented.

So, the [IEP] team is the parent, a regular education teacher, someone with a grade level curriculum, a special education teacher, and someone who can commit [financial] resources for the district and say, 'Yes, we can do that.'"

With an IEP, students can be in a setting with typical students or solely with classmates who have developmental disabilities.

IEPs are required from age three to 21. At age 22, FAPE is no longer required. However, some school districts can decide if they want to continue to provide FAPE for the balance of the school year after the student reaches 22, Smith-Dixon said.

Parent support can be essential in navigating IEP programs for your child, explains Anne Ladd, a family engagement specialist for the <u>Georgia Parent Mentor Partnership</u>, which helps improve outcomes for students.

"As a family engagement initiative," Ladd said, "we want to empower and educate families to play a role in decision-making in school and in the community. Regardless of how much knowledge you have when you sit at that IEP meeting, everything changes when it's your own child."

Mentors are parents of children with disabilities. They are employed

by the Department of Education and work in participating school districts to bring sensitivity to administrators and educators from the perspective of students and their families. This is particularly helpful during district discussions and stakeholder meetings, Ladd said.

WE WANT TO EMPOWER AND EDUCATE FAMILIES TO PLAY THAT ROLE IN DECISION-MAKING IN SCHOOL AND IN THE COMMUNITY.



"In the beginning of the year, parent mentors can come in to explain to teacher groups why a parent might be angry or under stress," Ladd said. "Sometimes people are overwhelmed and there is a reason they are behaving badly."

Mentors also help parents establish positive, lasting communication with teachers. Family engagement is the key to best outcomes for children, according to the Parent Teacher Association (PTA) and the National Collaborative on Workforce and Disability for Youth. Improved confidence, reading and math skills, graduation rates and more successful

employment occurred when there was a continuous flow of communication between parents and teachers.

Mentors are matched with families through Parent to Parent, an entity of Georgia's Parent Training Information Center. They assist parents setting goals and success towards grade levels and graduation, communicate with teachers, keep track of student progress in class, and provide supportive activities.

A Parent's Journey

Every family has its own set of circumstances that brings complexity to their intended plans, and Jess Goldberg's clan is no different.

Her sons each have disabilities that require careful thought. Goldberg's 12-year-old son is on the autism spectrum and will be a student at a middle school in Gwinnett.

Her 11-year-old has an IEP but has not yet been diagnosed with a disability. He completed elementary school last spring and will attend a private school for children with disabilities in the fall.

Goldberg says her younger son has always been an engaged and happy child, but she had a heightened awareness of his subtle behavior as a result of her older son's diagnosis. A county evaluation of the younger son at age two showed he was not exactly where he needed to be.

"There was this X factor," Goldberg recalled. "He was struggling emotionally and also with focus and executive functioning.

I think they eventually gave him an IEP just on my persistence. The team would consult with his teachers. Every year things got a little more challenging for him."

Goldberg and her husband have college goals for their boys and

are already contemplating what dormitory life would look like. The Gwinnett mom is a fierce protector of her sons, but also a realist with their educational needs.

"The IEP meeting is very formal and a legally binding document," Goldberg said. "It's intense and can be intimidating. I try to go in with an open mind and know I am there for one reason – to make sure my kid is getting everything he needs to be successful. It's a big negotiation. But I have found there are a lot of wonderful resources in Gwinnett."

From Goldberg's perspective, each person on the IEP team, which she meets with a few times a year, has his or her own objective, and some will inevitably conflict. Her greatest concern, beyond grades, is whether her boys understand the tasks that help them manage daily life.

In lower grades, her older son was in an autism level three program that required substantial support. He progressed to level four by sixth grade and has been able to attend classes with students without disabilities. The classes allowed for support staff, if necessary, to escort her son out of the classroom for a brief change of atmosphere.



Project SEARCH interns have real job experiences.

However, the Goldbergs accomplished this by transferring their son to another public school district for the sixth grade only. He returns to his home district this year.

"Our district didn't offer that [service]," Goldberg said. "I've always wanted him in a general education setting as early as he could handle it. He has had some co-classes with general education and special education teachers.

He doesn't want to be known as a kid with autism. He wants to play basketball in middle school and be known as the tall kid who loves basketball. And then, he wants to go to Norcross High School."

Community Resources

Goldberg has accessed many community resources, such as Parent to Parent, to find the right answers for her sons' educational paths.

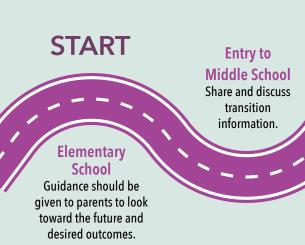
Among them, the Blonder Family Department for Special Needs at the Marcus Jewish Community Center of Atlanta supports families with IEP recommendations, public school resources and parent networking.

"We work with DeKalb County," said director Jennifer Lieb. "But some parents choose private school, and we help them navigate that."

A significant part of Blonder also guides parents seeking an early diagnosis of a disability for their infant or toddler.

"Until you are in a place of needing support, you are not going to look for those services," Lieb said. "Parents might see that their children are not reaching certain milestones, and they get nervous. We help guide them to what steps they can take if they need support."

Such resources include <u>Babies Can't</u> Wait, a program with the Georgia



High School

Discuss whether the student will work during school and the potential impact.

Middle School

Begin transition portfolio with references, descriptions of acquired skills, work/experience and assessments.

High School

Initial transition planning meeting Referral to appropriate agency **High School**

Update transition portfolio with references, descriptions of acquired skills, work/experience and assessments.

Department of Public Health, where professionals assess a child's present level of development from birth to age three. If a child is eligible, Babies Can't Wait will connect families with community resources and develop a service plan that includes desired goals for the child.

Project SEARCH

With supportive resources, from Pre-K through secondary education, children with developmental disabilities can graduate from high school feeling independent and empowered with fulfilling employment.

AS EARLY AS AGE 14, PARENTS
CAN CONTACT THE GVRA TO START
PLANNING FOR THEIR
CHILD'S COLLEGE LIFE OR
PROFESSIONAL CAREER.

Project SEARCH has been especially successful in its high school-to-work transition program for children with developmental disabilities. Students who have finished high school credits but have not completed their IEP, work as interns at Project SEARCH sites, such as hospitals.

Internships can last up to 10 weeks. Part of the goal is to become permanently employed, said Bonnie Seery, the Project SEARCH coordinator for Georgia. "Usually, there are specific jobs that students want or are interested in. With the internships, they can see what their own talents are," she said.

Will Crain of Gainesville, worked three 10-week hospital rotations through Project SEARCH. He worked in the mailroom, helped mud walls, paint and more. "Will is one of those kids who wants to work," his father Scott said. "He is so excited about the possibilities."

After working a Project SEARCH position in the cafeteria at Lanier College and Career Academy, Will secured permanent employment.

"He is a joy," his supervisor Kellie Hoffman said. "I love coming in and knowing he will be there. I just love him. He makes my day better. He is just an awesome person."

Hoffman gives Will a list of duties each day such as sorting, clearing and cleaning that he works through expeditiously, she said. "He would try to beat his time every day. First it took about an hour. Now, it's down to 23 minutes."

Project SEARCH was started in Cincinnati Children's Medical Center in 1996. The goal was to hire and train people with developmental disabilities to fill entry-level positions in the emergency department.

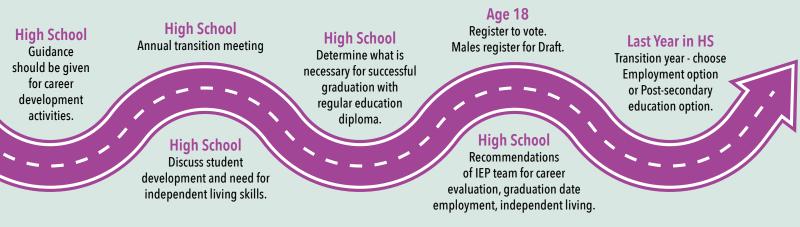
Georgia has been successful in placing interns at each of its nine sites, mostly hospitals including Children's Healthcare of Atlanta and Emory University Hospital Midtown Atlanta. Total Systems Services, a credit card service company in Columbus, GA, also serves as a site.

"Some of what I see – and it still gives me goosebumps – is [interns] come in apprehensive and scared, and by the middle of the year, you just see their confidence change dramatically," Seery said. "Students know their way around the entire hospital [Archbold Medical Center in Thomasville, GA]. They speak to everyone and know them by name. It's such growth."

Interns organize files, order supplies, greet and escort patients to waiting areas, clean spaces and more.



Will Crain has permanent employment in the cafeteria at Lanier College and Career Academy.



BACK TO SCHOOL - ROADMAP TO SUCCESS*

College and Career Goal Planning

As early as age 14, parents can contact the Georgia Vocational Rehabilitation Agency (GVRA) to start planning for their child's college life or professional career.

"We start working with children with disabilities early," said Robin Folsom, GVRA director of communications and marketing. "We work with people of all disabilities and believe everyone who wants to work should have a right to work. It's our job to make that happen."

Counselors guide children in identifying goals for college or careers, then coordinate with schools to establish a plan of support. Every plan is individualized with varying details such as training or devices to assist in hearing or seeing.

Other helpful resources for services and supports are the <u>Georgia</u>

<u>Department of Labor</u> or

<u>Department of Behavioral Health</u>

and Developmental Disabilities.

Higher Learning

Some local colleges and universities offer higher education for students with disabilities, who would not meet typical enrollment requirements, through the <u>Georgia</u>
<u>Inclusive Postsecondary Education</u>

Consortium (GAIPSEC). The consortium is located at the Center for Leadership in Disability (CLD) at Georgia State University (GSU).

In 2015, the CLD within the School of Public Health at GSU received a \$2.5.million, fiveyear grant for the consortium's Inclusive Postsecondary Education (IPSE) Programs for Students with Intellectual Disabilities. The university has been meeting quarterly with state agencies and other stakeholders since 2012, said Susanna Miller-Raines, coordinator of the consortium and grant.

"There is a leadership team," said Miller-Raines. "Members are interested stakeholders who want to be part of this movement. We have trainings for parents, school districts, colleges and universities to help them learn to prepare students for postsecondary education."

The growing list of participants includes Kennesaw State
University's Academy for Inclusive
Learning and Social Growth. In this two-year program, students audit courses and study to earn a Certificate of Social Growth and Development.

Admission requirements for Kennesaw State's non-accredited programs include a third-grade reading level, basic math abilities and skills sets that are cultivated through successful, goal-oriented IEPs.

In East Georgia State College's CHOICE Program for Inclusive Learning, students audit academic classes on a schedule that is tailored for them. They have opportunities for job shadowing and internships.

Like Kennesaw State, students at East Georgia receive a certificate upon completion of the program. "Inclusive college programs prepare [students] for adult life," Miller-Raines said.

Though the journey of a child from birth to adulthood can seem daunting for any parent, there is support for children with disabilities the entire way. Babies Can't Wait, IEPs, vocational rehabilitation and postsecondary education are some of the major guideposts.

"I tell parents, always remember teachers and administrators want the best for your child," Goldberg says. "Also find a network of parents for support. Find your tribe, your village, through your church, synagogue or social media. That's how you learn about options."

*For a more detailed roadmap, download a pdf at https:// www.gcdd.org/roadmap



Socializing in School, Forming Friendships

by Adrianne Murchison

Deborah Hibben had a task at the start of every school year when her daughter Hannah was growing up. She had a conversation with teachers to share what Hannah, who is diagnosed with Down syndrome, responds to, as well as her personality and needs.

I would give teachers a one-page fact sheet on what Down syndrome is," Deborah said. "I would tell them 'These are some of the things she likes,' and try to get a [willingness] from everyone to be inclusive at the beginning of the year. Inclusion benefits all students."

Hannah Hibben (second from left) with co-workers

She also encouraged parents to call her if their child was uncomfortable or had a problem with Hannah.

Hannah, now 23, had many friends and activities growing up, and thrived as a result, her mother said. She went to roller skating birthday parties and even played football in the Faith, Hope and Love Flag Football league for children with disabilities.

"She started as a cheerleader and became a player and is credited with being the first female football player in that league in Henry County," said Deborah, a McDonough resident.

Hannah became so close with two high school girlfriends in a church youth group that she decided to stay in high school until age 19 and graduate with them. This was

despite having completed her

academic requirements a year earlier. As a student with disabilities, Hannah could've stayed in school until age 22.

By the time of her graduation from Ola High School in 2015, Hannah also had a reunion with two friends who were classmates in elementary school that she had lost touch with when her family moved away.

"It was like they had never been apart," her mother recalled.

Deborah and parents like her have said that it's often when children with developmental disabilities are separated from typical classroom settings that incorrect assumptions are made about their abilities.

Aarti Sahgal, of Sandy Springs, found a variety of activities for her son Angad, 18, after transferring him to a private २

Hannah's camaraderie with co-workers is helping to improve her communication skills.

school for children with disabilities. "I had to work extra hard to make sure he could meet kids without disabilities," Aarti said.

Angad, who is diagnosed with Down syndrome, has a black belt in karate, plays soccer and takes weekly swimming lessons, as well as horseback riding lessons at Heaven's Gate Therapeutic Riding.

"He attended regular soccer camp with kids without disabilities," Aarti said. "He was the slowest [on the team], but that's okay. Coaches, teachers and the other kids encouraged him."



outside her

newest place of

employment



Through music therapy at the Georgia Center for Music, Angad has learned to coordinate his hands and legs while playing the drums, a favorite instrument of his.

"The music therapist has helped him to remember the words of songs," Aarti said. "He is starting to believe that he is a singer."

Angad has wanted to be a police officer since he was nine years old and recently joined the Sandy Springs Police Explorers youth program. In learning about local law enforcement, explorers from ages 14-21 develop skills in teamwork, interview witnesses and suspects, learn about officer safety and even Georgia criminal laws.

"They have been so welcoming," Aarti said. "He does all of the activities."

For the July Fourth holiday, Angad was scheduled to help officers direct traffic for the evening fireworks event.

I had to work extra hard to make sure he could meet kids without disabilities.

Aarti enjoys that her son is like every other teenager. "He doesn't want to be seen with me anymore," she laughed. "He will walk in front of me or behind me. I know he is a typical teenager, but like any other parent, I can't say that I have it all figured out."

She has help. Aarti's 24-year-old son lives in New York City, but his hometown friends have watched Angad grow up and treat him as their own little brother by taking him out to dinner, the movies and sporting events.

"They are a huge support for him," Aarti said. "He loves talking. He is fond of people and animals. It all gives Angad so much confidence."

For Hannah, transitioning from high school to adulthood was a challenge, early on. A postsecondary academy was intended to teach her life skills. However, an administrator advised Deborah that Hannah was not employable.

The determined mother set out on her own to find employment for Hannah. A yogurt shop and Great American Cookie Co. hired Hannah immediately, and she recently started a new position with a computer recycling company.

"She loves seeing co-workers everyday," said Deborah. "Her employers are really great about social outings and include Hannah."

Left-hand Photo: Angad Sahgal is proud to be a member of the Sandy Springs Police Explorers youth program. Center Photo: Angad enjoys his support group of friends. Rightpractices with an instructor.

hand Photo: A black belt in karate, Angad

DEBORAH AND PARENTS LIKE HER HAVE SAID THAT IT'S OFTEN WHEN CHILDREN WITH DEVELOPMENTAL **DISABILITIES ARE SEPARATED** FROM TYPICAL CLASSROOM SETTINGS THAT INCORRECT **ASSUMPTIONS ARE MADE ABOUT THEIR ABILITIES.**

Hannah's camaraderie with coworkers is helping to improve her communication skills.

"Every positive experience she has improves it," Hibben said. "From school to church and social activities to relationships at the workplace. One of the ways it shows itself is her behavior is more mature. Most of her co-workers are adults. I can see that she is grasping what it is to be an adult."



I'm excited to be back with another installment of What's Happening in Washington? There's so much going on with federal policy it's hard to keep up! When people hear "federal policy," they usually think about Congress passing laws. But that's not the only way that federal policy is made. A lot of important disability policy is made by federal agencies, like the US Department of Health and Human Services (HHS) or Department of Education (ED). This month, I am going to focus on federal agency activities.

Federal agencies are charged with implementing and enforcing federal laws. One way they do this is by developing federal regulations (also called "rules"). Laws passed by Congress contain broad mandates. Federal rules fill in the details about what the law requires and how agencies will enforce the law. Most federal rules are created through a "notice and comment" process, where the federal agency proposes the rule, the public has an opportunity to give feedback, and then the agency finalizes the rule based on that feedback. Federal agencies also create policies through less formal policy documents (called "sub-regulatory guidance"), technical assistance and even bringing enforcement actions.

Electronic Visit Verification (EVV)

Congress passed a bill called the 21st Century Cures Act in December 2016. The bill requires that states put in place an electronic visit verification (EVV) system for Medicaid-funded "personal care services" and "home health services." EVV systems must electronically record, among other things, the provider and person receiving the service, location the service as provided and the time the service begins and ends. Congress said that EVV would reduce fraud. States must have in place an EVV system for personal care services by January 1, 2019 and for home health services by 2023 or they will get less federal funding for their Medicaid program. Congress directed the federal agency that oversees Medicaid, the Centers for Medicare & Medicaid Services (CMS), to issue guidance about the requirements and options for states' EVV systems.

Many people with disabilities, their families and providers have raised serious concerns about EVV. They are concerned about the government tracking their whereabouts and see it as a privacy invasion. If implemented badly, EVV could limit the independence of people with disabilities and their ability to engage in community activities. For people who selfdirect services, EVV could be particularly problematic.

On May 16 – almost six months later than the deadline set by Congress - CMS issued guidance describing the requirements for states' EVV systems. CMS said that the services covered by EVV are very broad - basically, if you get any Medicaid services provided in any part in your home, it will be covered by EVV. That includes everything from help with getting dressed or cooking, to being picked up at your home to go out into the community or to your job, to in-home respite. EVV applies to in-home services provided by both agencies or self-directed. EVV does not, however, apply to 24-7 residential placements like group homes or assisted living. CMS



ALISON BARKOFF
is the Director of
Advocacy at the
Washington, DC office
of the Center for
Public Representation.
She works on policy
and litigation related
to community
integration and

inclusion of people with disabilities, including Olmstead enforcement, Medicaid policy, employment, housing and education. said that states do not have to track the location of people outside their home as they go throughout the community or use tracking devices like GPS. But it was made clear that states can do so if they choose. CMS also described the limited circumstances under which they will consider giving states more time to implement their EVV systems.

66

Many people with disabilities, their families and providers have raised serious concerns about electronic visit verification (EVV).

> The disability community continues to be extremely concerned about EVV, particularly about the lack of time left for states to implement a system based on meaningful stakeholder input and that minimizes privacy and other concerns. Members of Congress are also concerned, particularly after CMS' guidance. On May 22, bipartisan bills in both the US Senate and House were introduced that would delay EVV implementation by a year. A version of the EVV bill, HR 6042, passed the House on June 19 and then the Senate on July 17. The next step is for the President to sign the bill. If you are concerned about EVV, there are many opportunities for advocacy - with Georgia officials as they design their system, as well as advocacy with Congress and CMS.

Employment of People with Disabilities

Employment of people with disabilities continues to be a top priority for the disability community, including in Georgia.

For too long, people with intellectual and developmental disabilities (I/DD) have had few opportunities for "competitive integrated employment" (or CIE). CIE means jobs where people with disabilities are paid the same wages as people without disabilities, interact with colleagues without disabilities and get the same opportunities for career advancement as their co-workers. Instead, the only option for many people with I/DD is placement in day programs with other people with disabilities or "sheltered workshops" where workers are typically paid well below minimum wage.

In 2014, Congress passed the Workforce Innovation and Opportunity Act or WIOA. WIOA establishes CIE as a national priority and requires states to develop plans to expand CIE. It also significantly limits the use of federal funding of sub-minimum wage sheltered workshops, particularly for students transitioning from school. WIOA required the Department of Education (ED) to issue rules to implement the law.

In August 2016, after notice and comment rulemaking, ED issued rules, and in January 2017, issued further guidance, about CIE. Consistent with previous policies, ED said that for a job to be CIE, and thus a setting in which Vocational Rehabilitation can pay for services, the person must be paid at least minimum wage, interact with co-workers without disabilities in their daily job activities, and that the setting is a mainstream job and not a worksite created only for people with disabilities. For the last

18 months, states have begun implementing these rules. But with the change in Administration, some stakeholders - primarily providers in settings that do not meet the CIE definition - have urged ED to revisit the rules. In May, ED included the WIOA rules on their list for potential rulemaking this year. If the rules are re-opened, it will be critical for the voices of people with disabilities - particularly people who want to work in CIE - to make their voices heard. GCDD will keep you updated about the rules and opportunities for your input.

COMPETITIVE INTEGRATED
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OPPORTUNITIES FOR CAREER
ADVANCEMENT AS THEIR
CO-WORKERS.

Other Issues on the Horizon:

We continue to closely follow many other disability issues happening at federal agencies. Below are a few on our radar:

HCBS Settings Rule
 Guidance: CMS issued
 rules in 2014 that set standards
 for all Medicaid-funded
 home and community based
 services (HCBS). Among

What You Need to Know About . .

Electronic Visit Verification (EVV):

Learn more about EVV and ways you can take action at https://medicaid.publicrep.org/feature/electronic-visit-verification-evv/. GCDD will soon be issuing a paper to help people with disabilities and their families understand EVV and its implementation so far in Georgia.

Employment First in GA:

Advocacy to expand opportunities for competitive integrated employment (CIE) is also happening Georgia. The state legislature just passed HB 831, Georgia's "Employment First" law. This bill declares that CIE be the first and preferred option for publicly-funded services for all people with disabilities. It also creates an "Employment First Council" to develop training, educate stakeholders, and make recommendations to the Governor and General Assembly on needed changes to legislation, policy and funding to advance the Employment First policies. Learn more about the bill here: http://www.legis.ga.gov/legislation/en-US/Display/20172018/HB/831

HCBS Settings Rule:

You can get more information about the home and community based services (HCBS) Settings Rule, the status of Georgia's plan, and how you can get involved at www.hcbsadvocacy.org

Public Charge Rule:

Get more information on the Public Charge Rule at https://medicaid.publicrep.org/feature/public-charge/



Kelsey Gray has a genetic defect called Pallister Killian Mosaic syndrome. Kelsey's parents and teachers help her do everything – eating, moving around in her stroller, using the bathroom and bathing. A lot of her care and medications are covered by her Katie Beckett Medicaid Waiver. Read her story on page 20.

other things, these rules require that any HCBS setting provide people opportunities to access the broader community, make choices in their daily life activities, and have opportunities for employment. States are in the process of implementing these rules by the March 2022 deadline. CMS has said that it plans to issue additional sub-regulatory guidance this summer. We'll update you when that's out. In the meantime, you should continue to work with state officials as they develop the plan for implementing the rules.

• Public Charge Rule

The Administration will soon release a new rule that could limit the ability of people with disabilities and their families to enter the United States or become US citizens. Under this new rule, a person could be denied admission or have their application for lawful permanent residency denied because they or a family member ever used (or even applied for) a wide range of government programs, including Medicaid, on which many people with disabilities rely. When this rule comes out, it will be important for people with disabilities and their families to comment on how this rule could impact them. We'll keep you updated.

As you can see, there's a lot happening in federal policy that impacts people with disabilities and their families in Georgia and across the country!

Clarkston Celebrates Community's Diversity during Annual Culture Festival

With a little over 12,000 citizens, Clarkston, GA is an extremely diverse city active in community engagement. Every year in April, the town celebrates that diversity with the annual Clarkston Culture Fest (CCF), which "highlights the best of what Clarkston has to offer."

Supported by Al-Tamyoz Community Building Group, a Georgia Council on Developmental Disabilities (GCDD) Real Communities Partner, the CCF was held on April 28 and is a day of education, celebration and cultural entertainment. Area musicians and artists portrayed the cultural diversity – including local school groups – and there were plenty of kid-friendly activities.

GCDD's Real Communities

support communities who welcome and utilize the gifts of everyone, including those who have been historically marginalized and work together toward common goals.

CCF also partnered with Refuge Coffee in their annual 5K Walk/ Run, which benefits employment of refugees, job training and social networking in Clarkston.

The City of Clarkston, located in DeKalb County, has been identified as the most diverse city in the nation. The residents come from more than 50 countries and there are over 111 languages spoken in Clarkston.

Festival attendees also participated in the Culture Village, interactive



Bhutanese and Nepalese booth (top photo) and Eritrean booth (bottom photo) at the Clarkston Culture Fest





Madagascar booth at the Clarkston Culture Fest

booths celebrating the community's diversity. A major continued focus of the festival, the Culture Village, highlights different cultures represented in Clarkston. Each booth is staffed by a Clarkston resident who educates festivalgoers about the language, traditions, unique customs and dress of each represented culture.

Cultures of Bhutan, Afghanistan, Pakistan, Wales, the Sudan, Nepal, Nigeria, India, the Philippines and Eritrea were represented this year among others.

Because of its growing popularity, the event was moved this year to the James R. Hallford football stadium, which has a capacity of 15,000. Thousands of attendees, including Clarkston Mayor Ted Terry, Clarkston Police Chief Christine Hudson and numerous city council members, enjoyed the festivities.

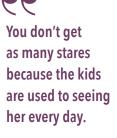
New this year was a classic car show, presented by Positive Growth Inc., a nonprofit organization whose mission is to strengthen the lives of children, youth, adults and families in Atlanta during difficult life transitions.

To view photos and learn more about the Clarkston Culture Fest, visit www.clarkstonculturefest.org.



Kelsey has a genetic defect called Pallister Killian Mosaic syndrome. She cannot walk or operate a wheelchair. She has severe developmental delays and seizures, and she is visually and hearing impaired. Kelsey's parents and teachers help her do everything – eating, moving around in her stroller, using the bathroom

and bathing.



In Missouri, she went to a school entirely for people with disabilities. At Awtrey, while she is in a class with three other students with disabilities,

Kelsey also interacts daily with kids who do not have developmental disabilities. They eat lunch and take extracurricular classes together. This is incredibly significant for Kelsey, and her family appreciates it too.

The Grays aren't in Awtrey's district, and while it's a bit of a hike, it's also worth it. Kids with developmental disabilities learn with kids without disabilities, and they are both enriched by the exposure and resources. Cammie, her mom, and Kelsey's teacher, Terrell, both agree that visibility and inclusion are key.

Inclusive Classrooms Enrich All Students

Kelsey Gray moved from St. Louis, MO to Acworth, GA with her mom, dad and 12-year-old sister in November 2015. Kelsey is a 14-year-old student at Awtrey Middle School, where she is in a class with three other students with significant disabilities. Kelsey is happy at school, where she takes classes on math, social studies, music and art.

"You can tell a difference. You don't get as many stares when you are out because the kids are used to seeing her every day," Cammie effuses happily.

Recently, the school had an awards ceremony to honor students and teachers, and the assembly included kids with and without disabilities alike.

Cammie says, "I searched for months for a school when we moved here. At first, I didn't know where to look because I was used to the 'special needs' schools where we came from, and there wasn't any information on the school district websites. Then, I found out it was because they were integrated with the schools, and it has been fantastic."

When Kelsey's not at school, Cammie does most of the caregiving. Kelsey requires medication, special medical care and supplies and equipment that are costly. Her medication alone costs \$900 a month. This winter, the Grays bought a wheelchairequipped van with a ramp and special safety belts. It cost \$30,000, even though it was the most basic one, but they are relieved to have it.

Kelsey's partially covered under her family's insurance, but that doesn't

even begin to cover what she needs. A lot of her care and medications are covered by her Katie Beckett Medicaid Waiver. Cammie wishes it were easier in Georgia. They had to wait until they moved to reapply, which created an eight-month gap. She wants a more streamlined process for applying for Medicaid Waivers, and she wants more flexibility in deciding how to use the funds, like she did in Missouri.

More than anything, Cammie wants a good life for her family, and to know that Kelsey is cared for. Kelsey moves restlessly, but happily, when she sees her mom. Cammie beams down at her and holds her hand. "If I could say one thing to my legislators, I would say that they need to understand what our life is. Then they would understand why we scream for help."

Kelsey's story is a part of the GCDD Storytelling Project. It was written by Betty Barnard and photographed by Lynsey Weatherspoon. Read Kelsey's extended story on www.gcdd.org



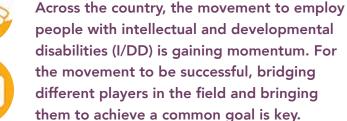


GCDD IMPACT



New Employment Center Opens in Athens







(GCDD), the State's first Employment Technical Assistance (TA) Center has launched to support building an inclusive workforce.

"We are focused on bringing together providers, employers, job seekers and their families to provide best practices and knowledge of what inclusive employment looks like," said Doug Crandell, subject matter expert in Customized Employment with the Employment First State Leadership Mentoring Program at the US Department of Labor, Office of Disability Employment Policy.

By bringing together these three focused areas, IHDD plans to support provider transformation and implementation of best-practice strategies that lead to competitive, integrated employment among individuals with I/DD through individualized, hands-on technical assistance and mentoring; and promoting meaningful employment opportunities for individuals with I/DD through sharing of information, resources and dialogue

through a virtual Community of Practice and Learning Community.

The center hopes to increase opportunities for individuals with I/DD to seek and obtain employment through providers using best-practice approaches such as customized employment, self-employment and individualized placements and supports.

Providers, employers and job seekers will also be able to get resources through webinars, online portals and other successful methods to support the growth of employment for people with I/DD.

Employment providers, specifically, will be able to join a Community of Practice that is a learning and sharing space with the goal to

The center hopes to increase opportunities for people with I/DD to seek and obtain employment through providers using best-practice approaches such as customized employment, self-employment and individualized placements and supports.

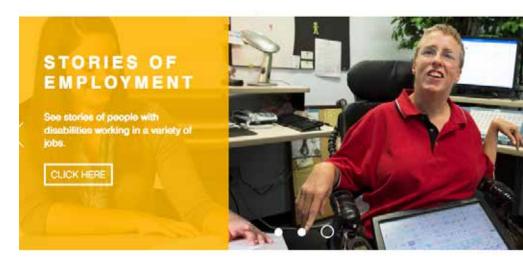
improve employment services and supports for individuals with I/DD. They will also be able to receive free technical assistance from organizations that are well-versed in inclusive employment.

As the TA Center gets off the ground, Crandell wants the ultimate focus to "link communities of practice and share the tools to expand employment opportunities for individuals with I/DD."



Advancing Employment

Building a community for inclusive employment in Georgia



For more information on the TA Center, visit https://www.advancingemployment.com



Consortium Works on Issues Facing Latinos with Disabilities

by Jennifer Bosk

Among the many challenges parents and caregivers of children with disabilities experience is being understood by communities and the public. Add not speaking or limited understanding of the English language and the problem is compounded.

Three years ago, the Center for Leadership in Disability (CLD) of the School of Public Health at Georgia State University (GSU) set out to tackle this very issue. Through their development of the Latino Community of Practice: Supporting Families with Children and Youth with Disabilities (LCP), over 125 Latino-serving family advocates, partners and professionals from the metro Atlanta area and beyond now come together to work on complex issues facing Latinos with disabilities.

Georgia Council on Developmental Disabilities (GCDD) Council member Brenda Munoz co-leads the LCP. Working to provide a great life for her son, whom she describes as "tall, dark, and

LATINO FAMILY NIGHTS ADDRESS A VARIETY OF TOPICS INCLUDING **HOW BEST TO ADVOCATE FOR** CHILDREN, AVAILABLE SERVICES **AND SUPPORTS AND HOW TO NAVIGATE THE** SCHOOL SYSTEM.

handsome as well as profoundly autistic and non-verbal," she found her career following the path to the CLD. She explains her capstone project is the Latino Community of Practice.

Georgia is 10th in the nation with the largest Hispanic population growth. With one in every 58 children on the autism spectrum according to the Centers for Disease Control, it reasons that many Hispanic families are living with a child with a disability. The Latino Community of Practice has decided the best way to help these families is to focus on three key areas:

- 1) professional capacity building and collective impact;
- 2) education and leadership training for parents; and
- 3) formal and informal advocacy in public policy and systems of care.

At the start, this consortium of parents and leaders met quarterly to work on community building and learning about educational and health equity as it relates to intellectual and developmental

disabilities, as well as bilingual community engagement. Some of the consortium's co-founding partners are the City of Atlanta, Immigration Affairs/Welcoming Atlanta, Latin American Association, Marcus Autism Center/Children's Healthcare of Atlanta, Parent to Parent of Georgia, SPECTRUM, Inc., Atlanta Public Schools, Centers for Disease Control and Prevention (CDC) and Learn the Signs Act Early (LTSAE) campaign.

With the success of bringing the supporters and professionals together, Munoz says the group's



Lola Hernández (left) and Brenda Liz Muñoz tape a televised segment on Spanish-speaking families with children, youth and adults with autism spectrum disorders (ASD) at Telemundo Atlanta.





Through the Latino
Community of Practice
(LCP), over 125 Latinoserving family advocates,
partners and professionals
from the metro Atlanta
area and beyond now
come together to work
on complex issues facing
Latinos with disabilities.

focus now is on families. She adds the Latino Community of Practice is currently in a collaboration with SPECTRUM, Inc. Together, they are hosting Latino Family Nights in Duluth to address a variety of topics including how best to advocate for their children, available services and supports and how to navigate the school system. The Latino Family Nights have proven so popular, they will now be held monthly starting in August.

As the Latino Family Nights grow, Munoz is working with the leading Latina researcher and professor of disability and human development at the University of Chicago, Dr. Sandra Magana. Dr. Magana created an English/ Spanish, evidenced-based curriculum titled "Parents Take Action," which Munoz's group will begin using soon at the Latino Family Nights. The curriculum draws from existing knowledge about autism, treatments, services and strategies and makes it accessible to the Spanish-speaking Latino community in a culturally competent and cost-effective way.



The Center for Leadership in Disability, School of Public Health at Georgia State University information table at the Autism Conference & Expo

FOR MORE INFORMATION

on the Latino Community of Practice initiative and its events, please refer to their web page at https://disability.publichealth. gsu.edu/latino-community-practice/ or their Facebook page at https://www.facebook.com/LatinoCommunityofPractice/

—— AUGUST

August 3, 13, 17, 20

DCH Public Forum on EVV and NEMT

Atlanta, GA https://www.eventbrite.com/e/ public-forum-evv-nemt-atlantageorgia-tickets-46297622435

August 5

Chuck E. Cheese's Sensory Sensitive Sundays

Atlanta, Augusta, Buford, Jonesboro & Macon, GA https://gcdd.org/calendar-ofevents/875.html

August 8

Leko-Pals Computer Club

Lekotek on Cliff Valley Way Atlanta, GA *lekotekga.org/calendar.html*

August 24 - 26

People First of Georgia 2018 State Conference

Decatur, GA http://www.peoplefirstofga. com/stateconference

•— SEPTEMBER

September 6

Consumer Health Impact Awards 2018

Georgians for a Healthy Future Atlanta, GA http://healthyfuturega.org/ ghf_event/consumer-healthimpact-awards-2018/ September 8

Potluck Family Fall Picnic

Johns Creek, GA lekotekga.org/calendar.html

September 13

Autism Hope Center Game Night

Columbus, GA www.autismsocietyga.org

September 17

DCH Public Forum on EVV and NEMT

Atlanta, GA https://www.eventbrite.com/e/ public-forum-evv-nemt-atlantageorgia-tickets-46297622435

Walton Foundation Golf Classic (Phil S. Harison)

Augusta, GA www.waltonfoundation.net/ signature-events/phil-s-harisongolf-classic/ September 22 **Sibshop**

Lekotek on Cliff Valley Way Atlanta, GA lekotekga.org/calendar.html

•— OCTOBER

October 11-12

GCDD Quarterly Meeting & Candidates' Forum

Atlanta, GA www.gcdd.org

October 13

Doggie Day

disABILITY Link Atlanta, GA 404.687.8890 ext 108

To find out about more events across the State, visit GCDD's Calendar of Events at https://gcdd.org/calendar-of-events.html



Remember to Vote - Midterm Elections Tuesday, November 6, 2018