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MAKING a DIFFERENCE

A quarterly magazine of the Georgia Council on Developmental Disabilities **VOLUME 14, ISSUE 1**

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



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Summer in Full Swing at GCDD

It's summer time and I am always reminded of the Martha & The Vandellas song, "Dancing in the Street" – "Callin' out around the world, are you ready for a brand new beat? Summer's here and the time is right for dancin' in the street." It's the time of year when kids are out of school, people go on vacation and everyone takes a breath before the fall and the hustle and bustle begins again.

Well, that's how it used to feel anyway. Nowadays it seems there is little time to slow down and that is true for us at the Georgia Council on Developmental Disabilities (GCDD). This edition provides a hint to what is going on in preparation for the fall and even winter for the legislative session. However, we didn't want to miss out on the summer fun, and we offer some ideas and tips for thinking about how to access some of the many activities available such as going to camp or participating in sports activities. More and more, organizers of these activities are finding ways to welcome kids with disabilities into their programs to participate with their typical peers. It is the way things should be – kids playing with kids.

For others it's also the time of year for preparing for college, maybe for the first time. In Georgia, 19 students with disabilities at Kennesaw State University have had the opportunity to participate in the college experience. Now, thanks to the legislature and the work of advocates, more students will get the opportunity for Inclusive Post-Secondary Education, as additional colleges and universities will begin developing the supports necessary for students with disabilities to be a part of campus life.

For GCDD, the summer means we are organizing a summit for students with and without disabilities to come together and learn about how they can create change in their communities. We hope that a group of kids can show us what it means to join together and make places that are better for everyone. Additionally, GCDD's Real Communities Initiative will be expanding this fall. Over 100 people attended three workshops to learn how they can join this Initiative, and GCDD staff will be meeting with groups over the summer to determine if they are the right fit.

Finally, there's been much controversy about "Ava's Law," a bill that would require insurance companies to cover autism therapies for children with disabilities, and we provide an overview on the different stances. Therapies can be quite expensive and many parents are looking for alternative ways to pay for them. However, many are concerned about some of the therapies that are currently being used. This is legislation that will be debated in next year's legislative session, so let your representatives know what you think.

There is a lot happening so stay tuned to *Making a Difference* and through GCDD's website and Facebook page. We hope you enjoy reading this magazine and we want to hear from you. Let us know what you like or don't like by writing to vmsuber@dhr.state.ga.us.

Eric E. Jacobson
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 vmsuber@dhr.state.ga.us, subject line:

Letters To The Editor.

GCDD VIEWPOINT

How to Reach Us

Letters to the Editor

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

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State of Georgia ADA Settlement Agreement Update

By Dr. Charles Li

GUEST ARTICLE



DR. CHARLES LI is the Assistant Commissioner at DBHDD – Division of Developmental Disabilities

Since 2010, the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) has committed extensive time, energy and resources to compliance with a settlement agreement between the agency and the United States Department of Justice (DOJ).

The agreement requires DBHDD to transition all individuals with developmental disabilities (DD) from state institutions into community-based settings with the goal of allowing people with DD to live in their own homes and communities. This provides individuals with care plans custom-fit to their needs, as well as supports and services that afford them the opportunity to live the life of independence they deserve.

Now in year three of the settlement’s implementation, changes to the model of healthcare delivery have significantly impacted both the individuals who receive services and the service delivery system.

Since the inception of the settlement agreement, 437 individuals have transitioned from state institutions into community-based settings. Seventy-nine of these transitions occurred in FY 2013. For the first time since the Civil War, there are now fewer than 300 individuals with DD in state institutions. Further, DBHDD plans to close the Craig Skilled Nursing facility at Central State Hospital in Milledgeville and the Rose Haven DD facility at Southwestern State Hospital in Thomasville by December 31, 2013.

As clients are transitioned out of institutionalized care, community-based service options are rapidly expanding. In FY 2013, 1,380 individuals received DD services, including 895 who were granted DD Medicaid waivers and 485 who obtained state-funded services.

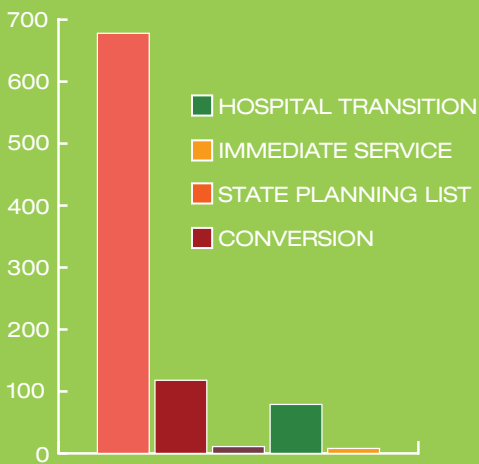
The quality of community-based DD placements and services has become a key focus of the settlement agreement. DBHDD is working closely with providers, advocates, the DOJ and other

stakeholders to ensure a safe and high quality placement and living experience for each consumer.

Recently, DBHDD deployed six special quality review teams to assess the 79 transitions made in FY 2013. A comprehensive audit tool, the Monitoring Questionnaire, has been employed for the review. The results of the evaluation will be used to identify deficiencies in the service delivery system and to develop an action plan for improving quality. The current improvement projects include provider education and training, developing an enhanced transition plan, improving support coordination and providing training to regional quality review team members. Metrics for quality implementation will consider environmental safety, health and medical services, individual rights and choice, behavior support and community integration.

Service settings and programs are shifting toward community integration. New congregate housing projects are no longer being developed, and community-based placements are increasingly interspersed within residential settings. More individualized day programs and supportive employment opportunities are being created to replace the sheltered workshop model. Some innovative programs, such as individual career path and customized employment, have already been introduced into the system.

There are still many challenges as DBHDD works to meet the goals and mandates of the settlement agreement. The agency is confident that with the partnership and support of all stakeholders, the goals set forth will be achieved, bringing a new future to all consumers who utilize and benefit from DBHDD services.



Federal Court Denies Warren Hill's Appeal to Halt Execution

IN THE NEWS

The Georgia Council on Developmental Disabilities (GCDD) has been closely advocating for and following the national controversy surrounding the Warren Hill case, a man with an undisputed intellectual disability who is in a legal fight to have his death penalty sentence overturned. Despite being officially diagnosed with mental retardation*, Georgia law places an even higher burden of proof on defendants in death penalty cases, requiring them to prove "beyond a reasonable doubt" that they have intellectual disabilities.

After two previous execution halts in July 2012 and February 2013, on April 23, 2013 in a 2-1 vote, the 11th Circuit US Court of Appeals denied Warren Hill's petition for the court to consider new evidence that proves he has an intellectual disability and would halt his execution.

"People with intellectual disabilities deserve to live as full citizens of this country and State, protected by laws designed to recognize our diversity and uphold our basic rights, despite our differences," said GCDD Executive Director Eric Jacobson, who has been active with other disability organizations in advocating for Warren Hill's rights as a person with intellectual disabilities.

Representative Plans to Study Georgia's Death Penalty Requirements

Due to the unconstitutional call for the execution of Warren Hill, Representative Rich Golick (R-Smyrna) pledged to take a closer look at Georgia's death penalty law during the off season of the legislative session.

Georgia is the only state in the nation that requires those on death row must prove "beyond a reasonable doubt" that they have an intellectual disability. Advocates across the board are calling for Georgia's legislature to re-examine its current law on death penalty requirements for persons with intellectual disabilities.

Golick, chair of the House Judiciary Non-Civil Committee, says his committee will commission a study to take a closer look at the current law.

"It may result in a change, it may not," Golick says. "But I think when you're alone in a particular approach on a very serious issue, and there's no more serious issue than the death penalty, a serious study of that issue is warranted."

"IT MAY RESULT IN A CHANGE, IT MAY NOT..."

* In this case, the term "mental retardation" is the official legal term for intellectual disabilities.

“People with intellectual disabilities **DESERVE** to live as full citizens of this country and State, protected by laws designed to recognize our diversity and uphold our basic rights, despite our differences.

SAVE THE DATE
JAN. 26-29, 2014

Save the Date for the 2014 Georgia Winter Institute!

The 2014 Georgia Winter Institute will be held on January 26-29, 2014 in Columbus, GA. The theme will be Community-Builders Person-Centered Planning and will show how the benefits of using community-building and person-centered planning to create stronger neighborhoods and more active and involved populations of people with disabilities. These relationships empower and create opportunities for community members who are often marginalized or forgotten. The 2014 Georgia Winter Institute will focus on the topics of inclusive employment, homes, education, supports, leadership and communities. Don't forget to save the date on your calendar! For more information, contact Stacey Ramirez at 678.313.3177



Top photo: GCDD staff, Council members and Ryan Johnson at the Disability Policy Seminar in DC

Bottom photo: Rep. Tom Price and Ryan Johnson

Photos provided by Ryan Johnson

There were incredible learning opportunities at the seminar, both formally in the presentation sessions and informally while connecting with other the other conference participants.



GCDD Attends the 2013 Disability Policy Seminar

Several members from the Georgia Council on Developmental Disabilities (GCDD) attended this year’s annual Disability Policy Seminar in Washington, DC on April 15-17, 2013, to learn about and discuss the most pressing topics in disability public policy. The two-day seminar is an opportunity for advocates from across the nation to gather and advance the grassroots movement for people with intellectual and developmental disabilities, followed by a final day to speak directly to elected officials on Capitol Hill.

GCDD Executive Director Eric Jacobson, GCDD Public Policy Director D’Arcy Robb, along with three GCDD Council members, Teresa Ann Heard, Teresa Johnson and Lisa Newbern, and Ryan Johnson from, the Center for Leadership and Disability (CLD), were among the more than 650 attendees.

This year’s seminar focused on presidential election-year issues and how to make a difference with grassroots advocacy. The first two days of the seminar offered opportunities to network with peers, as well as 15 informative and educational in-depth sessions with disability policy experts on topics including Medicaid and community living, federal funding, social security, employment and education, healthcare and asset development.

“There were incredible learning opportunities at the seminar, both formally in the presentation sessions and informally while connecting with the other conference

participants,” said GCDD Council member Lisa Newbern who attended the seminar.

According to Robb, the presentations dedicated to Social Security/SSDI/SSI made the most impact on her. “There were excellent breakdowns and details on how those funds work, which can become quite complicated, and good discussions on their solvency for the future,” she said.

In addition to the informative topics explored during the sessions, the group representing GCDD valued the opportunity to network with other disability advocates and the chance to take their concerns and issues directly to Capitol Hill in meetings with nationally elected representatives.

They were able to meet with several representatives including Rep. Tom Price (R-Dist 6) and Sen. Johnny Isakson (R-Dist 10). They also met with staff for Sen. Saxby Chambliss (R-Dist 8), Rep. Phil Gingrey (R-Dist 11), Rep. Jack Kingston (R-Dist 1) and Rep. Tom Graves (R-Dist 14).

The visits with the senators focused on the Convention on the Rights of Persons with Disabilities (CRPD) treaty. CRPD is an international human rights instrument of the United Nations that is intended to protect the rights of individuals with disabilities. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made to effectively promote, protect and ensure their full rights. In addition to speaking with senators, they had the opportunity to speak with Rhonda Neuhaus, policy analyst for government affairs of the Disability Rights Education and Defense Fund (DREDF), a leading national civil rights law and policy center directed by individuals with disabilities who have children with disabilities, about promotion for the treaty. GCDD fully supports this advocacy effort and encourages Georgia citizens to contact Sen. Isakson and Sen. Chambliss urging them to support the convention as well.

For more information about the CRPD, visit: www.gcdd.org/blogs/gcdd-blog/2497-a-brief-look-into-the-convention-on-the-rights-of-persons-with-disabilities.html.

While meeting with various representatives, the GCDD members explained their advocacy work and highlighted successful programs such as Project SEARCH, a business-led school-to-work transition program designed for students with disabilities whose main goal is employment and had 70% of this year's participants employed by the program's conclusion.

"Our main goal was to educate the elected officials about the work we do at GCDD and our role as innovators for advancing the rights of people with disabilities and Georgia communities as a whole," shared Robb.

Council member Newbern agrees that education is a key factor in gaining support

GCDD Elects New Leadership

The Georgia Council on Developmental Disabilities (GCDD) is pleased to announce the recent election of new officers and executive committee members to the organization to help drive its legislative advocacy and community-building activities. The 26-member body of GCDD elected two executive officers and three members at-large:

Chair: Mitzi R. Proffitt, Parent Advocate; Brooklet, GA (Statesboro area)

Vice Chair: Tom Connelly, Self-Advocate; Albany, GA

At-large: Josette Akhras, Parent Advocate; Eatonton, GA

At-large: Geneice McCoy, Parent Advocate; Augusta, GA

At-large Advisory: Lisa Newbern, Parent Advocate; Atlanta, GA

"It's an honor to chair this organization which is at the forefront of social and policy change for people with disabilities in Georgia and beyond," Proffitt, the new council chair said. "Because at least 60% of our members either have a developmental disability or a family member who does, this is a knowledgeable, caring and passionate group."

For a complete list of current GCDD Council members, visit www.gcdd.org/about/the-council.html.



Mitzi R. Proffitt



Tom Connelly



Josette Akhras



Geneice McCoy



Lisa Newbern

Welcome!

for the rights of people with disabilities. "We must work with providers to truly see each person they serve. It's about people, not just numbers," she said. "GCDD must continue being visible. With each new legislative session, there are many new people who need to be educated. Being at the conference reaffirms how many people are working on behalf of individuals with disabilities and GCDD is in a unique position to lead this educational outreach back in Georgia."

All in all, the group made good connections with national officials on advocating for the passage of CRPD, gained good perspectives and initiated thought-provoking conversations on the future of crucial

entitlement programs such as Medicaid and Social Security. "There is no easy way forward, but we are committed to being a part of forging that path in a way that works for individuals with disabilities and their families," Robb declared.

The 2013 Disability Policy Seminar was hosted by the American Association of Intellectual Disabilities (AAID), the Arc, the Association of University Centers on Disabilities (AUCD), the National Association of Councils on Developmental Disabilities (NACDD), Self Advocates Becoming Empowered (SABE) and United Cerebral Palsy (UPC). For more information on the 2013 Disability Policy Seminar, visit www.thearc.org/page.aspx?pid=2171.



Step Up to the Plate and Challenge Recreation Programs to be Welcoming to All

By Alison Heinz Stephens

Thirteen-year-old Angad Sahgal has his eye on the prize. The teen will test for his brown belt at the Tommy Cho Martial Arts studio in Marietta in just a few days. To keep himself motivated, Angad focuses on a photograph Master Cho keeps in the studio. It is an image of Angad performing a beautiful and difficult kick. It reminds him that he can do it.

Angad has Down syndrome and he trains, practices and tests alongside his peers without disabilities at the karate studio each week. There is no special treatment for him, a policy both his mother, Aarti Sahgal, and Master Cho feel strongly about.

Programs that do not separate kids with disabilities from kids without disabilities can be beneficial to everyone involved once the right activity is found for each individual and parents and program leaders work together.

“When you segregate, you take away choices. We believe and understand that people with disabilities are part of the community. They BELONG there.”

Reaching out and approaching an organization that doesn't make a point to advertise programs specifically geared for disabilities can be daunting. But what many parents and advocates are discovering is that a

warm reception is more likely to be the norm rather than the exception.

George Martin, president of the Arcadia Institute in Kalamazoo, MI, has much first-hand experience approaching organizations about inclusive programs through the Institute's Community Participation Initiative.

“We have worked with 300 plus individuals on a personal basis and about 80 different community organizations and agencies,” said Martin. “Only a few have resisted.”

The Arcadia Institute's mission is to make it possible for people with disabilities to be welcomed and supported in their community. They created the Community Participation Initiative to provide agencies and individuals with any assistance they might need in order to offer activities that are open to all citizens.

“When you segregate, you take away choices,” explains Martin. “We believe and understand that people with disabilities are part of the community. They belong there. They make great teachers and role models, but segregated programs send the message that setting them apart is the way it should be.”



The Kalamazoo Nature Center camp



Angad Sahgal performing a kick at Master Cho's karate studio.

Programs that do not separate kids with disabilities from kids without disabilities can be beneficial to everyone involved once the right activity is found for each individual and parents and program leaders work together.

The Arcadia Institute has successfully partnered with the Kalamazoo Nature Center (KNC) camp in their efforts to include children with disabilities. Jennifer Metz, camp director, said her program is not run any differently than other camps.

"It really just requires flexibility," she said. "Most everybody, once they get used to the fact that they're not in the little compartmentalized world, can really thrive."

The KNC campers are learning life lessons from both each other and the staff.

"A kid who comes to us is exposed to the idea that everyone is welcomed and valued. If you can follow the general rules and everyone is safe, then everyone can be here."

Metz notes the campers come from a wide variety of ethnic, financial and cultural backgrounds, which means every participant, with or without a disability, has moments of feeling different from his or her peers.

"None of that matters here and our staff members are excellent role models by demonstrating appropriate ways to deal with other people."

Although Georgia does not have a standout program comparable to the Arcadia Institute, there are still organizations that welcome people with disabilities and support their participation in their programs.

In Atlanta, Rob Sayer, founder of The Music Class musical education program that

promotes early childhood introduction to music through 45-minute classes involving singing, dancing and instrument play, actively seeks students with disabilities to join.

"We have offered inclusive classes for over 15 years," said Sayer. After a colleague at the Marcus Institute introduced him to the value of welcoming all children and how to work with children with disabilities, "We never looked back," he explains. Including children with disabilities turned out to be such a positive experience that The Music Class now works with family service coordinators to offer scholarships to approximately 50 children with disabilities each year. They work with each family individually to determine if The Music Class is a good match. "Our goal is to communicate openly and often with parents to make sure their child's individual needs are being met," he says.

The program offers mixed age classes and there are no specific expectations, which lends itself to a very comfortable and supportive environment for all children. The physical, language and social aspects of music can often be a great motivator for children with disabilities. One parent, whose child participated in the program and has Down syndrome says, "Music helped her feel more normal as she saw she could do what others were doing, and the interaction with other children is so good for her."



Top photo: A camper at the Kalamazoo Nature Center camp; Bottom photo: Kids learning music at The Music Class.



A kid who comes to us is exposed to the idea that everyone is welcomed and valued. If you can follow the general rules and everyone is safe, then everyone can be here.



Top photo: At the Kalamazoo Nature Center camp; bottom photo: Introduction to music at The Music Class; photo on the right: At the Kalamazoo Nature Center camp.

“All are welcome and interact and progress at their own level, so there’s not a significant divide between the children with disabilities and those without” says Sayer. “As long as they’re safe and happy, a policy that applies to every child, then we want them here.”

But, how can parents find programs and activities that are welcoming to their child? Just ask.

“Parents should not be afraid to call us up and ask, ‘What can we do to get my child involved and make this a successful experience?’” says Bobby Harris, camp director of the Union for Reform Judaism (URJ) Camp Coleman, an overnight camp in Cleveland, GA that welcomes children of all abilities and offers an inclusive program and coordinator to help make a match for a successful partnership for everyone.

“There is no point in holding back information about your child because the more we know, the more we can prepare for challenging situations and make accommodations to create a positive camp experience,” he says.

The URJ Camp Coleman has been using an all-welcoming approach to get children of all abilities involved in the Coleman community since about 2004. They do a lot of planning and preparing ahead of time with individuals with disabilities and their families to figure out their needs and the best practices to employ that allow the individual to participate in all of the camp activities.

“A person should feel welcomed regardless of where they come from or what they can or can’t do,” explains Harris. “Sometimes we need to make adjustments, such as have a kid come up and visit camp early to gain a first-hand experience of what a typical camp day would look like, or partner another camper to go around with an individual. We understand that each individual has their own unique needs and we try to make a successful partnership as much as possible.”

It’s always important for parents to form relationships with the leaders and instructors who work with their children, but it is

especially important for families of children with disabilities. Approach the organization with the assumption that your child will be welcomed. Chances are they will be.

Angad’s mom Aarti has seen many doors open for her son just as soon as she was willing to walk through them.



“Sometimes we need to make adjustments, such as have a kid come up and visit camp early to gain a first-hand experience of what a typical camp day would look like, or partner another camper to go around with an individual.”

“I had heard negative things from another parent about the YMCA’s programs not being inclusive. But finally I went there myself and was pleasantly surprised,” she said. “I told them, ‘This is my son, Angad. Can you find him a team that is not super competitive with a good coach who can work with Angad?’ That is all I had to say.”

Angad’s coach, Steve Hartman, said he wanted to prepare the other players for welcoming and playing alongside a teammate with a disability. “That first season at practice, we had a quick discussion about being respectful and letting Angad participate fully,” he said.

It was a speech Hartman only made once. “I learned it wasn’t necessary. The kids didn’t

need to hear it. He's a part of the team, he's running laps and doing drills and that is that."

Angad's team thrived, even winning three championships.

Hartman has not had any special training. "I felt like if there was a problem I could have reached out to other people at the Y, but it has not been an issue so far."

There was a special needs soccer program, which Angad enjoyed, but he wasn't being particularly challenged. Playing on coach Hartman's team, Angad has fun but also knows what it feels like to experience a disappointing loss after a hard-fought match. "These are the same life lessons every other kid is learning," said Hartman.

"There is not going to be a community created just for them when they are older, so why put them in a special needs program now? It leads to isolation," says Aarti. "Although parents have good intentions, they can take away their child's chance to take risks," she said. "I think there can be too much structure for children with disabilities."

She said she does worry that Angad will struggle sometimes among his peers without disabilities, but that is okay.

"Hartman encourages parents to keep an open dialogue with the coach. Also, know when to hand things over to the person in charge. "Hang out for the first part or first couple of practices but then leave. You need to transition your presence and leave just like all the other parents. Be supportive but not stifling."

Another piece of advice for parents – know when to move on and walk away. Although a welcoming attitude and willingness to work together is common, there is always a chance of resistance.

The first time Aarti enrolled Angad in a karate class, she was told they would charge her more due to his disability. Her older son was already enrolled at that particular studio and she quickly decided to pull him out.

"It's not worth it," she said. "Focus on the good things. There are a lot of welcoming people out there, so let's focus on them."

Cheri Pace, mother of a son with autism, said that in order to have him embraced by non-segregated organizations, she had to change her way of thinking.

"I've struggled. I used to have a tendency to put the disability first. I had to hang that up and really critically look at what I was doing because I was creating more isolation in his life."

"I've struggled," she said. "I used to have a tendency to put the disability first. I had to hang that up and really critically look at what I was doing because I was creating more isolation in his life."

Pace said her own experience has taught her that training and experience specific to working with children with disabilities is not always necessary. Her son, his coaches and teammates are capable of working together and figuring things out as they go along.

"Don't let fears get in the way and prevent you from signing up," she said. "People are a lot more creative and resourceful than we give them credit for."

And, don't turn away from places and organizations that do not advertise inclusive

policies. As she explains, "In my experience, once a program uses the word 'inclusive,' it becomes non-inclusive. It's going to make it hard to attract parents of children without disabilities."

Parents need to be aware that it's often necessary to blaze a trail all on their own. Pace admits changing minds can be tough, especially since so many professionals have been brought up in a culture of segregation.

"Maybe people will come along and maybe they won't," she said. "The goal is to use what we already have in the community instead of creating new programs. I believe the right people will come."

Even some disability advocates are slow to warm to the concept of recreation that brings everyone together. Martin advises that parents need to be prepared to provide information, encouragement, and sometimes, a push. He suggests organizing with other parents if need be.

The fight is worth it, stresses Martin. "We see a spin-off effect," he said. "One good experience leads to other good experiences and we can guide these kids to another level of involvement."

In some cases, people with disabilities turn into their own advocates.

No matter what activity or sport is pursued, it's important to remember that all parents want the same things for their kids – to build a sense of community.





START WITH YOUR CHILD'S INTERESTS AND LET THEM GUIDE YOU...

What Should You Do to Get Your Child Involved?

While many organizations and programs are receptive to including children from all types of backgrounds and abilities, parents are often unsure how to begin the process. Below are some great starting tips to keep in mind when approaching a program for your child with a disability.

- Start with your child's interests and let them guide you to the camp/sport/lesson/activity of his or her choice. It needs to be their decision.
- Be open-minded. Approach the group with the assumption that your child will be welcomed and treated respectfully and equally. Remember that just because they don't advertise a policy of inclusiveness, doesn't mean they are not willing to work with your child and make accommodations.
- Understand that there may be issues but that you can work through them. Communication is key.
- Be prepared. Issues will be much easier to resolve when the staff/coaches are prepped ahead of time. If your child has known triggers, sensitivities, strong preferences or dislikes, then you need the instructors to be aware of them. It's likely the program will have paperwork for parents to complete ahead of time, but it may be necessary

for you to supplement that with a few lists of your own. Some things to consider could include:

- Food allergies and sensitivities
 - Medications
 - Issues with transition, loud noises or personal space
 - Physical limitations
 - Any prior recreational experiences that impacted your child – positive or negative
 - Suggestions for how to calm or comfort your child if he or she becomes agitated or upset
- Be aware that the people working with your child may not necessarily have extensive training or experience dealing with disabilities, but that does not mean they are not up to the task. Be a resource for them, but be prepared to step aside and let them figure things out too. Remember, the goal is to have your child be included – not to highlight the disability.
 - Be mindful of the fact that your child may struggle. Feeling anxious or discouraged at times is something ALL children are likely to experience when trying a new activity.
 - Know when to move on. In some cases the program or activity is not going to turn out to be the right fit. But keep searching. The goal is to find and encourage your child's special

gifts and talents while fostering a sense of community.

- Focus on the positives. Dwelling on a negative experience can lead your child toward feelings of isolation.
- Enlist the help of a support network. Partnering with other parents can produce powerful results.

“If you want your child to be treated like the other children, then you must BEHAVE like the other parents.”

- If you want your child to be treated like the other children, then you must behave like the other parents. For example, once you get to know the coach, leave if other parents leave. Don't hang around at practice if most of the other parents drop off and pick up their kids.
- Be flexible. The coach/leader/instructor may do things differently than you would. Give it a chance and see if your child is able to adapt and follow along like his or her peers.
- Remember that tomorrow is another day. If today's soccer practice was a disaster, take a deep breath and try again. A bad day doesn't spell the end of your child's soccer career.
- Have fun!

Accessibility is Not Just for Recreation Programs

While kids are out of school and many programs are in the off-season, there are many activities accessible to all in Georgia to keep busy including:

Atlanta Botanical Gardens –

The garden's winding paths and exhibits are nearly all wheelchair accessible. Wheelchairs are available on a first-come basis and electric mobility scooters are available for rent.

Chestatee Wildlife Preserve –

The exotic animal rescue and wildlife preserve in north Georgia is home to white Siberian tigers, African lions, grizzly bears and other exotic and endangered species. The zoo's pathways are "natural" but the staff will happily assist wheelchair users, if necessary, although most people have no problems. Contact the staff ahead of time for any accommodations.

Georgia Aquarium – The aquarium is wheelchair accessible with wheelchair emblems on the floor at designated exhibits for unblocked access to the windows. Several of the touch pools have special wheelchair access and staff members can provide wheelchair guests with a personal experience touching the animals. A visual script of the cell phone and iPod tours is available for guests with hearing impairments. For guests with visual impairments, tactile elements are included at the education stations in each gallery and staff are located throughout the galleries to give detailed descriptions of the exhibits and help with hands on experiences at the touch pool. Additionally, the aquarium offers a downloadable picture book aimed at helping children with autism prepare for their aquarium experience.

Georgia Sports Hall of Fame and Museum –

The museum houses more than 3,000 artifacts. The state-of-the-art facility is ADA compliant and accessible to everyone. Kids will enjoy the hands on action at the replica football field, basketball courts and racecar.

High Museum - All buildings, galleries and restrooms at the High Museum of Art are wheelchair accessible. Additionally, the High Museum of Art offers guided tours to groups with sight, hearing or physical disabilities.

Imagine It! The Children's Museum of Atlanta – Filled with interactive exhibits aimed at children ages eight and younger, the museum is all on one level and is wheelchair accessible.

Inside CNN Studio Tour – Elevator-assisted tours are available but advance reservations are recommended. Contact CNN ahead of time for assistance for guests with visual or hearing impairments. Sign-language interpreters are also available.

LEGOLAND Discovery Center – Located inside Phipps Plaza mall, the newly-opened LEGOLAND was designed to accommodate full wheelchair access.

Tellus Science Museum – The huge, interactive museum takes at least three hours to tour. Visitors will enjoy four permanent galleries (the fossil gallery is especially captivating with a life-sized Tyrannosaurus rex), a digital planetarium, café and solar house. Save time at the end to dig for fossils and pan for gems. The museum and exhibits are wheelchair accessible.

Turner Field – The Braves baseball venue offers accessible parking, elevators, courtesy rides, wheelchair seating, restrooms, lowered concession counters and drinking fountains and specific ticket purchasing assistance.

World of Coca Cola – World of Coca Cola Ambassadors are available throughout the attraction to assist guests with special needs. In addition, the building and the parking garage are fully ADA compliant and accessible. Handheld text and audio devices are also available.

Zoo Atlanta – The zoo entrance is curb accessible and wheelchairs are available for rent for anyone needing walking assistance.




“A visual script of the cell phone and iPod tours is available for guests with hearing impairments. For guests with visual impairments, tactile elements are included at the education stations in each gallery and staff are located throughout the galleries to give detailed descriptions of the exhibits and help with hands on experiences at the touch pool.

- GEORGIA AQUARIUM



Ava's Law – How Will it Affect Individuals With Autism?

By D'Arcy Robb



During the 2013 Georgia General Assembly, a bill known as Ava's Law (HB 309/SB 191/HB 559), was introduced that would require insurance plans to provide coverage for a range of autism therapies. Ava's Law is named after eight-year-old Ava Bullard from Lyons, GA, who has autism and whose mother Anna, started publically leading the effort for change after her insurance company would not cover the costly treatments. The original House Bill 309 is sponsored by Representative Ben Harbin; Senate Bill 191 is sponsored by Senator John Albers and House Bill 559 is sponsored by Representative Chuck Sims.

REFERENCES:

* ULCA/Lovaas is a type of ABA therapy. ESDM blends ABA with a relationship-focused developmental model.

Warren, Z., et al. (April 2011). "Therapies for Children With Autism Spectrum Disorders." Comparative Effectiveness Review No. 26. (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2007-10065-I.) AHRQ Publication No. 11-ECH029-EF. Rockville, MD: Agency for Healthcare Research and Quality. Available at: www.effectivehealthcare.ahrq.gov/reports/final.cfm

FOR MORE INFORMATION VISIT:

www.effectivehealthcare.ahrq.gov/ehc/products/106/656/CER26_Autism_Report_04-14-2011.pdf

Ava's Law did not pass out of the House or Senate chamber this session, but it is currently being reviewed by the non-legislative health insurance mandates committee, which will make a recommendation on Ava's Law before the 2014 legislative session starts. In Georgia, many disability advocates are passionate supporters of Ava's Law, but there are also some advocates who object to the bill. Below is a breakdown of Ava's Law and what it is proposing.

What Would Ava's Law Do?

Broadly speaking, Ava's Law would require insurance plans in Georgia to cover a range of behavioral health therapies for autism spectrum disorders for up to \$50,000/year to be adjusted each year for inflation.

Ava's Law would not apply to those covered by Medicaid, and not all of Ava's Law will necessarily apply to those who will be covered by "qualified health plans" offered under the health benefits exchange as per the federal

Affordable Care Act. The qualified health plans are required to provide essential health benefits, as defined broadly by the federal government and more specifically by each state. The federal essential health benefits include "behavioral health treatment" but do not make any specific mention of Applied Behavioral Analysis (ABA).

What Are Considered Autism Therapies?

Specific bill details of autism therapies include:

- "Treatment for an autism spectrum disorder, prescribed by a licensed physician or licensed psychologist as medically necessary and appropriate for the type of care, shall be a covered benefit under an accident and sickness contract, policy or benefit plan...." (HB 309, lines 70-72)
- "Treatment for an autism spectrum disorder means medically necessary services for the evaluation, assessment, testing, screening, diagnosing and treatment of autism spectrum disorders using evidence-

based practices and include behavioral health treatment, pharmacy care, psychiatric care, psychological care and therapeutic care.” (HB 309, lines 47-50)

- Therapeutic care is defined as services from a licensed speech therapist, occupational therapist or physical therapist.
- “Behavioral health treatment’ means counseling services and treatment programs that develop, maintain or restore to the maximum extent possible, the functioning of an individual, including Applied Behavior Analysis and other structured behavioral or developmental programs, that use evidence-based practices, provided by or under the direction of a licensed psychiatrist, licensed psychologist, board certified behavior analyst or other qualified professional.” (HB 309, lines 29-34)
- “Applied Behavior Analysis’ means the design, implementation and evaluation of environmental modifications using behavioral stimuli and consequences to produce socially significant improvement in human behavior, including the use of direct observation, measurement and functional analysis of the relationship between environment and behavior.” (HB 309, lines 20-24)

Advocates are generally in agreement that individuals with autism need access to and can benefit from therapy. The disagreement is over whether behavioral therapies, particularly ABA, are helpful or harmful to people with autism – and therefore, whether they should be covered by a measure like Ava’s Law or not.

Advocates Supporting Ava’s Law Argue:

- Georgia currently does not require insurance companies to cover therapies for autism, which can be very expensive. Many families struggle to cover these costs or cannot afford them, which also creates a gap between those who can and cannot afford therapies.
- Therapies *can be* highly beneficial, especially if received at a young age. (Some advocates would say therapies *ARE* highly beneficial).

Advocates Against Ava’s Law Argue:

- ABA therapies, which are included under the current Ava’s Law, *can be* harmful. (Some advocates would say ABA *IS* harmful).
- Behavioral programs that focus on teaching normative behaviors are asking someone to change their identity, which is wrong – therapy should be about learning useful skills.

- Behavioral interventions – 78 unique behavioral studies were identified. Early intensive behavioral and developmental intervention may improve core areas of deficit for individuals with autism spectrum disorders; however, few randomized controlled trials (RCTs) of sufficient quality have been conducted, no studies directly compare effects of different treatment approaches and little evidence of practical effectiveness or feasibility exists.
- Within this category, studies of UCLA/ Lovaas-based* interventions report greater improvements in cognitive performance, language skills and adaptive behavior skills than broadly defined eclectic treatments available in the community. However, strength of evidence is currently low. Further, not all children receiving intensive intervention demonstrate rapid gains, and many children continue to display substantial impairment. Although positive results are reported for the effects of intensive interventions that use a developmental framework such as the Early Start Denver Model (ESDM), evidence for this type of intervention is currently insufficient because few studies have been published to date. (p. ES-7; our emphasis added)

What is GCDD’s Stance?

Ava’s Law, in various forms, is an issue that has been under discussion in Georgia for several years now. GCDD has worked to bring advocates who support and oppose the provisions together to work on a common vision that the full disability advocacy community can support. But our efforts at finding a common ground have not been successful.

GCDD has not taken a formal position on Ava’s Law. In accordance with our beliefs on the importance of providing information to all advocates and the expressed wishes of our members, GCDD will continue to provide information and updates on Ava’s Law. In that spirit, we invite you to consider the two different advocate perspectives on the next two pages.

Ava’s Law would not apply to those covered by Medicaid, and not all of Ava’s Law will necessarily apply to those who will be covered by “qualified health plans” offered under the health benefits exchange as per the federal Affordable Care Act.

Disagreement Among Georgia Advocates

There are many disability advocates in Georgia who are supporters of Ava’s Law and the therapies it would cover, but there are others who object to the bill, particularly its inclusion of ABA therapy. The following reflects the Georgia Council on Developmental Disabilities’ (GCDD) understanding of the advocates’ arguments for and against the current version of Ava’s Law:

A Brief Look at ABA & Behavioral Therapy

In 2011, the Vanderbilt Evidence-Based Practice Center did a review of 159 studies on treatments for children with autism spectrum disorder. The review was done on behalf of the Agency for Healthcare Research and Quality, which is a division of the federal Department of Health & Human Services. Excerpts from their findings include:

Georgia Can Do Better than Ava's Law

By R. Larkin Taylor-Parker

PERSPECTIVES



R. LARKIN TAYLOR-PARKER is a student at Agnes Scott College and an occasional blogger who writes on topics related to autism. To read her blog, visit <http://iamthethunder.tumblr.com/>.

“Making insurers cover ABA would most likely incentivize it, increase demand for it and cause more cases to spring up quickly. Nothing is at its best when rushed.”

I look like a typical 20-something in Atlanta. I attend college, work and volunteer. Unlike most of my peers, I am autistic. My wonderfully ordinary life comes with a twinge of something like survivor guilt. Most people with labels like mine lack the independence, agency and physical and psychological security that I almost take for granted.

In my opinion, the proposed insurance legislation named Ava's Law, would not improve matters in Georgia. My main concern is that it incentivizes the use of Applied Behavior Analysis (ABA), which is a controversial practice. There is research suggesting it “helps” a number of autistic children, but the extent varies. I wonder what “helping” means. Are the “improved” children better at skills that will free them to pursue dreams and goals of their own, or are they reaching arbitrary benchmarks like making eye contact? Training children to make a constant effort to look normal may distract, exhaust and further impair them. Done in this spirit, “help” accomplishes more harm than good. To an extent, that is true of all therapies that insurance companies would cover if the bill passed. More widely implemented, these autism therapies would be a complex patchwork of good and bad.

However, ABA is a special problem. It is notorious. I never had this therapy, but those who did tell me I am lucky. In the autistic community, childhood memories of ABA go hand-in-hand with Post-Traumatic Stress Disorder. Breaking down children, rebuilding them in the image of what some of us wish they were tends to damage them. There are people in the autistic community who believe that ABA is always wrong. They have never fully convinced me. I agree that using ABA and aversive, pain infliction to change behavior is immoral. Acts difficult to distinguish from torture usually are. That being said, someone, somewhere

is probably using ABA well and for the right reasons. Unfortunately, its best iterations are not its most common. Making insurers cover ABA would most likely incentivize it, increase demand for it and cause more cases to spring up quickly. Nothing is at its best when rushed.

“Training children to make a constant effort to look normal may distract, exhaust and further impair them.”

The passage of this bill would create an environment conducive to the expansion of a risky practice's least thoughtful forms. The autism world is nuanced, contentious and brimming with wrong-headed good intentions, lousy with quacks. We need to be cautious. Georgia could do more to help autistic people, but Ava's Law is not the answer. We will only find a real solution through discussion that includes autistic voices, uses empirical evidence and prioritizes need within the State over organizations' national policy agendas. Autism Speaks, almost universally opposed by autistic adults, is entangled with this to some not-fully-knowable degree. Autism Speaks moves under a cloud of perpetual controversy and its own hyperbolic rhetoric. Its presence is bad for clear-headed, rational discourse. I believe Georgia can do better than Ava's Law.

Ava's Law – Creating Options Where None Have Existed

By Teri R. Williams and Anna Bullard

At two-years-old my granddaughter, Ava, had never said mama or daddy. We told ourselves Einstein was a late talker too. But other behaviors couldn't be so easily dismissed. Ava cried when we sang to her. She never played with toys. She rarely gave eye contact and never responded to her name. By the time she was two and a half, we knew she was quickly slipping away from us into a world of her own. On November 6, 2006, a specialist diagnosed Ava with autism.

Ava was covered under her father's state insurance for schoolteachers. The insurance company immediately dropped Ava's coverage of speech therapy after the diagnosis. We were told that no therapy for autism was covered. If a person is diagnosed with cancer and there is the prospect of recovery with medical treatment, isn't treatment covered by insurance? There are documented studies that proved evidence-based therapy could produce significant improvement for at least 50% of children with autism who received it. And, almost all showed some measure of improvement.

Anna, Ava's mother, contacted a Board Certified Behavior Analyst (BCBA). The BCBA provided an individualized program for Ava and for two years she received intense Applied Behavior Analysis (ABA) therapy for 30 to 40 hours per week. The cost alone would have ruined most young families' finances, but Ava had the advantage of help from family that many simply do not have.

“Some say autism is an issue for the educational system, but the educational system cannot treat a medical condition.”

At the age of four, Ava entered pre-k in a regular classroom. Her improvement was mind blowing.

This year Ava tested into the program for advanced students. She also received an award for the highest score on the math section of the CRCT in her grade.

In 2009 Anna was asked to share Ava's story before a state insurance committee. A bill had been proposed that would require insurance to cover evidence-based therapy for autism. Georgia was one of only 18 states that had not already passed a similar bill. After hearing Ava's story, proponents decided to name the bill Ava's Law.

Some say autism is an issue for the educational system, but the educational system cannot treat a medical condition. More importantly, by the time a child is old enough for school, the most critical time for early intervention has passed.

If Ava's Law is passed, children with autism will be able to receive insurance coverage for evidence-based medical care according to individual needs. The state insurance committee has been presented with documentation that proves Ava's Law will save the State millions of dollars that will otherwise have to be paid for services for those who will become dependent on the State, rather than independent contributors to society. Although insurance companies cite concerns that the mandate would cause premiums to increase, evidence from other states proves the increase is only a few cents a month.

Ava's Law provides options for individuals on the autism spectrum where none have existed before.

“We were told that no therapy for autism was covered. If a person is diagnosed with cancer and there is the prospect of recovery with medical treatment, isn't treatment covered by insurance?”

PERSPECTIVES



ANNA BULLARD is the mother of Ava, for whom Ava's Law is named and Teri R. Williams is the grandmother.

“Although insurance companies cite concerns that the mandate would cause premiums to increase, evidence from other states proves the increase is only a few cents a month.”



A Matter of Pride - High School Diplomas Are More Than Just a Piece of Paper

By Alia Hoyt

One test was all that stood between Russell Padgett and his high school diploma. Although it was just a couple of thin sheets of paper, it might as well have been a concrete wall.

Diagnosed with autism at age four, Russell spent all but one year of his education in the Georgia public school system (his mother home schooled him in the 4th grade). “I tried to become an involved, educated parent because I didn’t know what his true abilities were, just that he was really struggling,” says Russell’s mother, Teresa Johnson, a Walton County schools parent mentor and advisory member of the Georgia Council on Developmental Disabilities (GCDD). “We started working in elementary school to master the skills to get him all the way through high school.”

Johnson, like many parents of children with developmental disabilities, has been Russell’s staunch advocate since his education began. Parental involvement is always recommended for any student and is often an important

factor in success, but it is also critical for each student to be their own biggest advocate and take initiative to ask specifically for what they want to accomplish and believe in themselves.

However, there are still barriers for many students with disabilities to confront in meeting Georgia’s high school graduation requirements each

year. According to the Georgia Inclusive Post-Secondary Education Consortium and the Georgia State University Center for Leadership in Disability, more than 1,400 students receiving special education services in Georgia are leaving high school each year without receiving a high school diploma. This is a number that needs to change.

Navigating the System

The high school diploma system for students with disabilities is often tricky. There are two assessment tracks available for Georgia students – the state required, standardized End of Course Tests (EOCT) or the Georgia Alternate Assessment (GAA). Although both can lead to a high school diploma, each has its different challenges.

The GAA meets state requirements to provide academic opportunities to children with significant cognitive disabilities, but it requires a lot of extra work from teachers and only one to two percent of students are placed on the GAA track.

For students to be eligible for a GAA diploma, they have to complete the state standard 23 course units, which includes instructions in English Language Arts, Mathematics, Science and Social Studies through access courses taught by teachers trained to instruct students with disabilities.

“We started working in elementary school to master the skills to get him all the way through high school.”



Top photo: Russell Padgett and his family.



Bottom photo: Russell Padgett at sports camp.

Additionally, they have to take electives, pass the alternative assessments, earn a score of Established Progress or Extending Progress on all sections of the high school GAA and reach either their 22nd birthday or transition to employment/training in which the supports needed are provided by an entity other than the local school system.

“If students complete the GAA they get a diploma,” explains D’Arcy Robb, public policy director at GCDD. “But one of the problems with this type of diploma is that it doesn’t open the doors that a real diploma does. The student essentially just receives a diploma in name, but that diploma will not be recognized if the student wants to pursue opportunities such as college, the military or technical schools after high school.”

Russell, like many other students with disabilities, did not meet the criteria for the GAA, and was placed on the general track. When he was attending high school, in order to receive a high school diploma, students had to pass the Graduation High School Test, which was one big test junior year students had to pass to graduate.

Although Russell completed the same material as students without disabilities and was regarded as a friendly, capable student who steadily worked his way through math, science and history curriculums, his disability made it difficult to express himself in language arts.

“The student essentially just receives a diploma in name, but that diploma will not be recognized if the student wants to pursue opportunities such as college, the military or technical schools after high school.”

“He could read and understand, but not regurgitate the information,” explains Johnson. So, when it came time for the opinion-based graduation writing test, “He couldn’t even get a sentence on paper.” The

realization that her child would come so far to fall short in one area was crushing. “Here, my child has gone to school all this time and he can’t pass the writing test, so he’s not going to be able to walk at graduation because of this one test,” says Johnson.

Russell could have opted to receive a Certificate of Attendance, but Teresa resisted. “He passed all of his classes, did everything he was supposed to do, but has one test hanging over his head,” she says. “Sorry, you didn’t meet the requirement, so you don’t get to walk and just get a certificate.”

Johnson felt her son deserved a full-fledged diploma and all of the advantages that come with it, so they looked at other options. Because private schools do not receive government funding, they are not subject to the same state tests. Russell enrolled in Faith Academy, where he was able to complete the requirements to graduate.

“When I saw him come out with the gold sash on, that was a pretty moving moment for us,” Johnson recalls. “But, how many people have access to that kind of opportunity for their kids that have enough intelligence to do well, but don’t have the skill set to pass a graduation test? The message is ‘thanks for showing up for 14 years, but you’re not good enough.’”

A Changing System

However, some policy changes have been made since Russell’s experience. The end all be all Graduation High School Test is being phased out and students now take EOCT to be eligible for a diploma. This became Georgia’s official high school accountability assessment starting in 2011-2012. Through this system, all students must complete the 23 course units in English Language Arts, Mathematics, Science and Social Studies, and then take and the EOCT in each subject. For students enrolled in grade nine for the first time before July 1, 2011, the EOCT counts as 15% of the student’s overall grade. For students enrolled in grade nine for the first time on July 1, 2011 or after, the EOCT counts as 20% of the their final grade.

“HOW MANY PEOPLE have access to that kind of opportunity for their kids that have enough intelligence to do well, but don’t have the skill set to pass a graduation test? The message is ‘thanks for showing up for 14 years, but you’re not good enough.’”



Teresa Johnson and her son Russell Padgett.

“The realization that her child would come so far to fall short in one area was crushing.”

SHARE YOUR THOUGHTS:

This article brings up several questions on how the high school diploma system works in Georgia. Let us know what your thoughts are by reaching out on our Facebook page at www.facebook.com/georgiaddcouncil or by emailing a letter to the *Making a Difference* editor at vmsuber@chr.state.ga.us with the subject line "Letter to the Editor."

This new system can be helpful for students with disabilities who can stay on track with the regular coursework, but it does add pressure for students who may struggle in certain areas or need more support to keep up and not fall behind. Because teachers are required to get through the entire coursework in the allotted timeframe, it makes it difficult for them to spend any additional time or offer extra support to students who might need accommodations to complete the work. Although this puts extra challenges on both the students and teachers, this system means that the student does not have to rely solely on a pass/fail test to graduate. While each student must obtain a passing score on each EOCT, this grade is only a small factor in determining a student's overall grade to earn a diploma.

Though EOCT is a step in the right direction to improving Georgia's graduation requirements, there are still too many kids, both with and without disabilities, slipping through the cracks and leaving high school without a diploma that could open doors for their futures.

barrier that makes it much harder for them to get a job or even qualify for a promotion if they are employed," says Robb. "Regardless of what opportunities you wish to explore, obtaining a high school diploma can create a world of professional and personal possibilities."

For Russell, graduation was the beginning of a new era of possibility. Although he is still seeking steady employment, Russell (now 21), has volunteered extensively in the community. "While that (writing test) was a very negative part of his life, it wasn't the end of his life," Johnson declares. Like Russell, some kids are fortunate enough to navigate the system successfully toward graduation, but there are still many who don't have access to the private school route when Georgia's system creates roadblocks for students with disabilities. The disparity between students who can afford private school tuition and those who can't is disturbing.

"Money should not be a factor in whether a student, regardless of having or not having a disability, graduates," says Robb. "We have



"These kids with real capabilities, real dreams, want to go out to work, but we've created this barrier that makes it much harder for them to get a job or even qualify for a promotion if they are employed."

An Issue of Economics

A high school diploma is not just a matter of pride and achievement. It's also a direct line to future opportunity. Students without a diploma or with a GAA diploma are cut off from many options, including scores of employment opportunities, admission to two or four-year colleges, technical schools and military service. For a group that often has fewer than average options to choose from, this reality can be daunting.

created a group of people who are therefore more likely to be more dependent on the system," said Robb. "Without a high school diploma, it's much harder to find a job, pursue additional learning opportunities or even just be an active participant of your community. Georgia has made improvements, but students with disabilities should have the same expectations as their peers, and we need to continue advocating for those opportunities."

"These kids with real capabilities, real dreams, want to go out to work, but we've created this

Creating Post-Secondary Education Opportunities for All

By Becca Bauer



With the close of the 2013 General Assembly, Georgia's disability advocates pushing for Inclusive Post-Secondary Education (IPSE) opportunities celebrated a victory as a portion of their requested funding to expand IPSE programs in the State was approved by the Senate. Due in large part to the support from Senator Butch Miller (R-Dist 49) and Senator Jack Hill (R-Dist 4), the Senate added \$100,000 out of the \$350,000 requested funds to the FY2014 budget for IPSE in Georgia.

Half of the funds will be given to the Academy for Inclusive Learning and Social Growth (AILSG) at Kennesaw State University (KSU), which is a two-year program that provides students with intellectual disabilities a college experience and was launched in 2009 with support from the Georgia Council on Developmental Disabilities (GCDD). Currently, this is the only IPSE program in the State, and the additional funds will be used to make enhancements to the program. The other half of the funds will be put toward the development of a similar IPSE program at a university in South Georgia.

Sen. Miller became interested in this legislation after a visitation day at KSU. Although impressed with the program, the limited funding and spots available were obvious. "This became important to me not just as a parent but as a legislator too, because I am in support of making all state schools and programs inclusive to address the needs of our total population," he said.

To get this conversation started among his colleagues, Miller reached out to Sen. Hill, along with several other legislators to address the need for more IPSE opportunities across Georgia.

"This became important to me not just as a parent but as a legislator too, because I am in support of making all state schools and programs inclusive to address the needs of our total population."

"I've heard from several of my constituents that I've known for years who have children with disabilities about the lack of post high school options," said Sen. Hill. "So, the fact that I was starting to hear about this situation from both my district and a fellow senator made this a top priority for me."

Together they reached out to the Cobb County Delegation under Sen. Judson Hill (R-Dist 32) for help, and every member on

"Currently, this is *THE ONLY* IPSE program in the State, and the additional funds will be used to make enhancements to the program."

I think realistically we can expect to have five to 10 universities begin offering opportunities for students with developmental disabilities over the next few years.



Students in the AILSG program at KSU.



the Delegation was very supportive and signed a letter to the appropriations committee to move this issue forward.

Ultimately, getting this funding passed took a combination of efforts from many elected officials and advocacy organizations. All About Developmental Disabilities (AADD) adopted the creation of post-secondary education options as one of their legislative priorities. GCDD and the Center for Leadership in Disability (CLD) at Georgia State University (GSU) will both play instrumental roles in determining how the new IPSE programs will roll out.

Although advocates were hoping to get the requested funding fully approved, they still consider this a great success, especially during these tough financial circumstances. The push for more IPSE has been going on for several years by the Georgia Inclusive Post-Secondary Education Consortium (GAIPSEC) housed in the CLD at GSU, which was created through a mini grant from Think College!, a national organization dedicated to developing, expanding and improving research and practice in inclusive higher education for people with intellectual disabilities.

GAIPSEC is a gathering of Georgia educators, college/universities, families, self-advocates, providers and advocacy organizations dedicated to ensuring that every Georgia student has access to learning after high school, regardless of an intellectual or developmental disability, and it will play an instrumental role in developing the new IPSE programs.

“It’s lonely having one program, and there is a great demand for more post-secondary education options,” said Dr. Daniel Crimmins, director of the CLD at GSU. “KSU has done a great job, but just as you would never think one college could be the right one for every student, we want and expect new programs to develop their own personalities to meet the interests of all students who want to attend.”

Currently, there are six schools from around the State that have expressed interest in starting their own IPSE program. The

details on how to determine the location and structure are still being worked out, but it will be an open competition through a state required request for proposal process. The legislative funding specified that one new program should be in South Georgia, but Crimmins believes that there may be enough money available to provide start up funding for two or three programs statewide. The new program will be similar to KSU’s AILSG and should be inclusive in that students with disabilities have access to the same classes and events as others, it offers academics focusing on real content and it provides a pathway to employment among other things.

“KSU has done a great job, but just as you would never think one college could be the right one for every student, we want and expect new programs to develop their own personalities to meet the interests of all students who want to attend.”

“There are still several details to work out, but we are hopeful that the chosen university will begin developing its program by the fall and be ready to operate by the 2014 academic year,” said GCDD Executive Director Eric Jacobson.

And as for the future, “We want as many IPSE programs as there are universities in Georgia,” says Jacobson. “I think realistically we can expect to have five to 10 universities begin offering opportunities for students with developmental disabilities over the next few years.”

With only one IPSE program in Georgia out of more than 100 colleges and universities, the time is now to make expansions in IPSE programs. In the surrounding southeastern states, Alabama and Tennessee each have two programs, South Carolina has six programs, North Carolina has eight and Florida has nine.

“We are just beginning to do the things our neighboring states have been doing for years,” Miller says. “I think this legislation is an appropriate response for not only making

Georgia competitive in terms of the economy, but also helping our students become independent, plan for their futures and become contributors to their community.”

Since launching with only three students, the KSU AILSG has grown to 19 students at the start of the 2013-14 academic year. With this new funding, KSU plans to build upon the efforts for those already in their program to be successful and transition into employment opportunities. Additionally, KSU would like to continue to grow its program in order to accommodate first-year and second-year students each year. By the 2017-18 academic year, they are hoping to have openings for a total of 48 students, more than double what they currently have for the upcoming year.

Experiencing college is often seen as a milestone of growing up, and AILSG focuses on giving students the opportunity to experience a typical college experience with all of the social activities and freedom to have a say in their future.

“What makes AILSG stand out from others across the country is the extent of inclusivity,” says Executive Director Dr. Ibrahim Elsayy. “The students have access to the same campus activities and supports as typical students. They spend approximately 75% of their time participating in inclusive activities including KSU courses, workshops, student life events, work training and internships,” Elsayy adds.

“The majority of academy students live in the KSU dorms alongside typical students.”

And if there are questions to whether Inclusive Post-Secondary Education opportunities are beneficial, the answer is clear: “Six students graduated in 2012, and today they are all employed,” said Kari Cain, employment counselor. “The 2013 cohort graduated just a few weeks ago and already 50% of them are working and one is continuing his training on campus.”

“This is about giving students an opportunity to experience what life has to offer and helping them look for sustainability over the long-term, and these types of programs could be very beneficial in the long run,” says Sen. Hill.

“The funding received to make enhancements to KSU and create another program is a great step in the right direction, but we will need to continue pushing for more,” declares Jacobson. “The Governor has been a great advocate so far, and we would like to continue working with him to gain more support for Inclusive Post-Secondary Education opportunities and make expansions into his budget recommendations.”

It could be a long and tough road ahead, but every person with developmental disabilities should be able to have the option to experience what it means to be a college student and develop their passion and skills.

“This is about giving students an opportunity to experience what life has to offer and helping them look for sustainability over the long-term, and these types of programs could be very beneficial in the long run.”



Benjamin B. Lewis

What Do AILSG Graduates Think?

“My parents attended college, so I felt like I should do the same,” said Benjamin B. Lewis, a 2013 graduate from the AILSG program. “College is a privilege, and it’s something that one shouldn’t take for granted.”

Like many other students, Lewis, who enjoyed exploring his interests with classes in fitness, health and sports, says some of his favorite memories from KSU were making new friends. “It was about being able to feel like a regular college kid,” he adds.

After graduating in May, Lewis plans on continuing his education and getting certified as a massage therapist at the KSU College of Continuing and Professional Education, as well as pursuing his dream job and becoming certified to be a Crossfit coach one day.

“I think going to college helped connect me with places and people who might want to employ me. I am excited about my future and the opportunities I have.”



UNDERSTANDING THEIR GIFTS, ABILITIES AND INTERESTS IS OFTEN MORE VALUABLE THAN KNOWING ABOUT THEIR DISABILITIES.

EXPERT UPDATE

Inclusion Means Building Relationships Around Children's Gifts

For several years, the Arcadia Institute has worked closely with organizations in Kalamazoo, MI to help them welcome, support and respect people with disabilities who want to participate in their activities. More specifically, we provide training and coaching about how to support youth with disabilities be successful in programs with children who don't have disabilities. Some of the many programs we have partnered with include the Southern Shores Council of Boy Scouts, the Boys and Girls Club of Greater Kalamazoo, the YMCA of Greater Kalamazoo, the Kalamazoo Nature Center, the Portage District Library and the Media Arts Academy.

Throughout the training sessions, we consistently talk about the importance of getting to know the youth with disabilities, as well as their families. Building relationships with all children is important, but it is even more important when working with participants who have disabilities.

During one of our sessions, an issue was brought to our attention by some program staff. Parents either do not share what needs their children may have or they only share their children's problems. This creates limitations for program staff to know what a child's gifts and interests are, which is the very information that staff need in order to support participants in their programs.

Having this information is vital if a child is struggling with his or her behavior or ability to participate. When staff members build relationships based on a child's gifts, they can support the child by redirecting that behavior. They are better prepared to assist the individual because they understand what works.

A few years ago, a program director requested us to develop guidelines about what information organizations need from parents about their children, specifically children with disabilities. We created a handout for parents called, *Helping All Children to Have a Great Experience*.

This handout encourages parents to share as much information as necessary. Good program staff will want and need to know as much as

possible. The most important information they need is the child or youth's strengths, gifts and interests. The handout asks that parents don't dwell on their child's problems, but rather suggests they list the areas in which they may have talents. These areas might include:

- Art
- Science
- Athletics
- Outdoors/Nature
- Social and good at making friends
- Communication – reading and writing
- Numbers

Program staff have found this handout to be valuable when working with parents who want to get their children involved. When staff have adequate information, they are able to include children with disabilities who attend their activities.

Do challenging situations still arise? Yes, but any child or youth may struggle at times. Nevertheless, having a strong relationship built on knowing gifts diminishes these challenges. Program staff and parents can work together to successfully navigate rough situations.

So, from the Arcadia Institute, our primary tip for programs and organizations to be successful in including youth with disabilities is to build relationships with them. Understanding their gifts, abilities and interests is often more valuable than knowing about their disabilities.



ALLISON HAMMOND

is the program director for The Arcadia Institute. She has worked with people

with disabilities for over 20 years. Along with Dr. Billye A. Cheatum, Hammond co-authored the book, *Physical Activities for Improving Learning and Behavior: A Guide to Sensory Motor Development*. She received her Doctor of Education degree from Western Michigan University.

Visit, gcdd.org/resources/real-learning-resources.html, to access the *Helping All Children Have a Great Experience* handout.

When staff members build relationships based on a CHILD'S GIFTS, they can support the child by redirecting that behavior.



The Children of the One Percent

By Pat Nobbie, PhD, Mia's Mom

A couple of weeks ago, my friends, colleagues and I got riled up at a report aired on CNN about the “one percent” in New York City, who were hiring people with disabilities to accompany them at Disney World in Orlando as “tour concierges” so their children wouldn't have to wait in the lines. There appeared to be an underground network of knowledge and contacts that this elite group of parents passed among each other.

The company that provided the service, Dream Vacations, is in the business of organizing vacations FOR people with disabilities and was fairly well regarded. Dream Vacations charged \$130 an hour, or \$1,040 for an eight-hour day, for someone who used a wheelchair to accompany these families as members of their party. Disney World offers a VIP guide and fast passes for \$310 to \$380 per hour, so the disabled tour concierge is quite a bargain.

Who is offended by this practice? Families who really do have a member with a disability? The families who pay Disney's higher fee to avoid the lines? People with disabilities who can't afford to go to Disney World themselves? People with disabilities who are unemployed? The thousands of people who do wait in lines and are fine with a person who has a disability going to the front of the line if their challenges make waiting difficult, but I imagine would resent this type of cheating? Everyone who was raised to believe in fairness and waiting your turn?

Disney, to its credit, issued this statement, “It is unacceptable to abuse accommodations that were designed for guests with disabilities. We are thoroughly reviewing the situation and will take appropriate steps to deter this type of activity.”

When we were living in the Virgin Islands (VI), Mia and I took four other families who had children with Down syndrome to the International Down Syndrome Conference held at Disney World. The VI Human Services agency gave us a small grant that paid for registration, airfare, hotel, food, babysitting and ‘camp’ for the kids so the parents could attend the conference.

On the last day, we went to the park. Mia walked two blocks into Magic Kingdom, sat down on a curb and refused to budge. It was just too much walking. My mom was also with us and suggested we get a wheelchair. I didn't even realize Disney had that service. I protested. She could walk. Some other kids couldn't. I felt guilty. But my mom insisted I just get it so Mia could see the park and I could get a break. So I pushed, Mia rode and we got around and had the most amazing time.

There are more questions than answers in this little story – questions about fairness, cheating, entitlements and transactions. In the end, I'm thinking about the children of the one percent, whose parents took care of their waiting problem by using people with disabilities to help them cheat. They probably didn't give them a second thought when the day was done.

Exactly.

“In the end, I'm thinking about the children of the one percent, whose parents took care of their waiting problem by using people with disabilities to help them cheat.”

MIA'S SPACE



REAL COMMUNITIES INITIATIVE

GCDD's Real Communities Initiative is Expanding!

The Georgia Council on Developmental Disabilities' (GCDD) cutting edge Real Communities Initiative is bringing new communities on board. Since launching in 2010, GCDD has supported seven communities as part of the Real Communities Initiative and now it will add three to five additional communities in 2013.

GCDD actively supports its Real Communities in a number of ways including technical assistance, training, popular education and at times financial support. Each project is determined by the individual community and varies according to its local needs and goals. They range from community-based transportation and cooperatives to community gardens. By handing the reins to individual communities and leading by stepping back, GCDD supports Real Communities as they flourish and achieve real and lasting community-based change.

possibilities of partnering together to start a new GCDD Real Communities Initiative.

By handing the reins to individual communities and leading by stepping back, GCDD supports Real Communities as they flourish and achieve real and lasting community-based change.

The Expansion

In June, GCDD hosted three training sessions in Macon, Albany and Atlanta for those interested in joining the Real Communities Initiative. These workshops were attended by approximately 100 Georgians who are interested in participating as a Real Communities Initiative. During the training, attendees received an overview on Asset-Based Community Development (ABCD) principles which make use of already-existing resources in the community in a different and newly successful manner, as well as an overview of Real Communities, focusing on the core purpose, vision and values of the Initiative.

GCDD accepted applications from interested communities until July 1, and will be spending the rest of the summer reviewing all applications, making in-person visits with select communities and exploring conversations about the

What Does it Mean to Join Real Communities?

A Real Communities Initiative means taking a thoughtful and active learning approach that equips community members, people – involving both those with and without disabilities, at the local level to work together toward common goals to improve their own community using person-centered supports, community-centered connections and consistent reflective learning.

When joining, a Real Communities Initiative accepts four commitments and responsibilities:

1. **Action focuses on making the community better for everyone:** This means learning to listen carefully to fellow citizens outside the circle of those primarily concerned with

We are very energized about making connections throughout the community, and we look forward to building more relationships in the community for our upcoming program.

disability to discover what local issues people care enough about to take action together.

- 2. People with developmental disabilities are active members who influence the group's direction and participate in doing its work:** This means learning to keep asking, "Whose gifts are missing?" and discovering how to reach out, invite and actively involve people who need personalized support in order to contribute to their community.
- 3. Over time, the initiative builds up local capacity for collective action by creating and strengthening continuing relationships with a variety of associations and groups:** This means learning to build and strengthen local alliances and networks.
- 4. Participants take responsibility for sharing what they are learning:** This means learning to reflect together on the work and identify and communicate its lessons.

Macon Building Upon the First Youth Roving Listening Project

In early July 2012, GCDD's Real Communities project with the Centenary United Methodist Church in Macon, GA debuted its first youth Roving Listening program. The youth successfully connected with members in the community to initiate meaningful conversations to build relationships and understand the gifts and interests of the people who live in the Beall's Hill neighborhood. Originally the group started with about 30 listeners, but continued to grow throughout the month-long project as brothers, sisters and friends took interest and asked if they could join too.

Overall, Stacey Harwell, minister of community-building at Centenary, said the first-time project was successful and the community responded well. Since the end of the summer program, they have been in the process of cataloging all of the responses they heard from the community members. Some of the most common themes the Roving Listeners discovered the community members most liked about Macon included its rich history and the people. On the flipside, the prevalence of crime and violence and the desire for more activities for youth and activities that promote community interaction for everyone to get to know each other were high on the list for improvements they would like to see in their community.

In order to initiate change and make connections between the community members who have shared interests and gifts, a resident of the Beall's

Hill neighborhood will serve as the Roving Connector to facilitate the process. The person will work five hours each week with the information gathered and ensure people's gifts and ideas are being utilized and mobilized.

"The main reason we wanted to hire a Roving Connector was so we could make sure we are honoring those we spoke and listened to, and we followed up with their interests," said Harwell.

Centenary has also been having monthly community dinners since the launch of their project to stay in touch. They even conducted a scaled down version of the Roving Listening project with eight people going out into the community one day a month for eight months throughout the rest of the year to keep the momentum going.

Several community organizations such as the College Hill Alliance/Commission and the Community Foundation of Central Georgia have also become involved and worked with the group on creating publicity outside of the Roving Listening project.

Harwell is excited about the progress that has been made since the launch, and the group is currently concentrating on making final preparations for this summer's program.

"We are very energized about making connections throughout the community, and we look forward to building more relationships in the community for our upcoming program," said Harwell.

The Korean Coalition Initiative Hosts a Picnic

GCDD's Real Communities Korean Coalition Initiative hosted their first annual spring picnic at Jones Bridge Park in Norcross on April 6 as a way to unite Coalition members and their circles of supports to meet and share ideas in a fun and interactive way. The first event was a great success with more than 150 people coming together to attend.



The Korean Coalition Initiative's 1st annual picnic.



Middle photo: Roving Listeners out in Macon; Bottom photo: The Clarkston International Community Garden ribbon cutting ceremony

.....
Participants take responsibility for sharing what they are learning: This means learning to reflect TOGETHER on the work and identify and communicate its lessons.

Clarkston International Garden Holds a Ribbon Cutting Ceremony

GCDD's Real Communities Clarkston International Garden Initiative hosted a ribbon cutting ceremony on June 29 to celebrate its many accomplishments. Attendees were treated to garden tours, a dance performance, a vegetable costume contest, speaker presentations and more.

I'm Ready and Excited for College

By Charlie Miller

STRAIGHT TALK



CHARLIE MILLER is a 2012 graduate of Flowery Branch High School and will be attending Kennesaw State University's Academy for Inclusive Learning and Social Growth program.

My name is Charlie Miller. I am a 2012 graduate of Flowery Branch High School. I graduated with a standard diploma as a result of a lot of time and hard work from myself and others. There were many key people involved in my high school success. Ms. English and our football coach, Lee Shaw, were especially helpful and encouraging. Ms. English, along with my mom, kept me focused on my school work and Coach Shaw, his staff and the football team never gave up on me.

I am excited about attending Kennesaw State University's (KSU) Academy for Inclusive Learning and Social Growth (AISLG) for many reasons. Mostly because I will have a chance to meet new people and have social opportunities that will help me become more independent as I get older. I am looking forward to college, joining clubs and getting involved in organizations. There are a lot of things I will need to learn to take care of on my own: laundry, cooking, transportation and many others. In preparation I have been doing my own laundry at home. I have always cooked a lot of my meals but I'm going to have to do my own grocery shopping as well. My laundry hasn't been too bad this summer, and my mom has even been able to get the faded red out of my white shirts!

the Braves game my mom made my dad secretly follow me to the stadium. They were worried I would get lost, I guess?

"There are a lot of things I will need to learn to take care of on my own: laundry, cooking, transportation and many others."

I would like to study psychology, military support or public safety. I would also like to be a manager for one of the sports teams and join a flying club.

Your friend,
Charlie Miller

I am looking forward to college, joining clubs and getting involved in organizations.

I am looking forward to living in the dorm at KSU, too. My car has hand controls and I plan to drive it to school. I have driven as far as Gray, GA to visit my friend, Jay Phillips, and I have driven to Athens and Atlanta to sports events. I found out recently that when I was 17 and drove to

COLLEGE BOUND!

July

July 18-19

GCDD Quarterly Meeting
Atlanta, GA
404.657.2126

July 24-27

2013 Annual Conference
on Independent Living
Re: GENERATION
Washington, DC
www.ncil.org/

July 26-27

Autism Speaks National Conference
for Families and Professionals
Columbus, OH
www.autismspeaks.org/

July 29-31

National Center on Inclusive
Education Summer Institute:
When Behavior Gets in the Way
Manchester, NH
603.228.2084
events.iod@unh.edu

July 29 – August 3

National Federation of the Blind
NFB STEM-X
Baltimore, MD
www.nfb.org

August

August 2-4

Abilities Expo
Houston, TX
www.abilitiesexpo.com

August 2-5

The Arc's 2013 National Convention
Bellevue, WA
www.thearc.org

September

September 20-22
Abilities Expo
Boston, MA
www.abilitiesexpo.com

October

October 3-5

2013 NAD Leadership Training Conference
National Association of the Deaf
Omaha, NE
www.NAD.org

October 4-6

10th Anniversary Cerebral Palsy
Group Conference
Crystal City, VA
www.thecpgroup.org

October 18-19

GCDD Quarterly Meeting
Atlanta, GA
404.657.2126

October 23-25

NADD 30th Annual Conference
and Exhibit Show
Baltimore, MD
800.331.5362
www.nadd.org

2013 CALENDAR

Planning an upcoming event?

Send your information to Dee Spearman, GCDD Public Information Assistant at dyspearman@dhr.state.ga.us; Subject line: "Community Calendar" by September 1 to be included in the fall calendar. Visit the GCDD website at gcdd.org/events-calendar to view our expanded online community calendar with additional local and national events.

HIGHLIGHT:

GCDD values your input and encourages you to share your thoughts on the magazine, the topics addressed or what topics you would like to see addressed in the future. Please send letters to the editor, Valerie Meadows Suber at vmsuber@dhr.state.ga.us with the subject line "Letter to the Editor" to let us know what you think.

RESOURCES

For additional information about the articles and issues in this edition of *Making a Difference* magazine, consult the following resources.

Georgia Council on Developmental Disabilities (GCDD)
www.gcdd.org
404.657.2126 or
888.275.4233 (ASK.GCDD)

State Government

Georgia Senate & House of Representatives
www.legis.state.ga.us

Georgia Governor's Office
www.gov.state.ga.us
404.656.1776

Department of Community Affairs
www.dca.ga.gov

Georgia Housing Search
www.georgiahousingsearch.org
877.428.8844

Department of Labor
www.dol.state.ga.us

General Information
www.georgia.gov

Georgia Lieutenant Governor's Office
www.ltgov.georgia.gov
404.656.5030

Around GCDD:

Disability Policy Seminar
www.thearc.org/page.aspx?pid=2171

Convention on the Rights of Persons with Disabilities
<http://gcdd.org/blogs/gcdd-blog/2497-a-brief-look-into-the-convention-on-the-rights-of-persons-with-disabilities.html>

News:

The Georgia Winter Institute 2014
Columbus, GA
<http://georgiawinterinstitute.weebly.com/gwi-2014.html>
For more information, contact Stacey Ramirez at 678.313.3177

Recreation Programs:

The Arcadia Institute
www.thearcadiainstitute.org/

Kalamazoo Nature Center
www.naturecenter.org/

The Music Class
www.themusicclass.com/index.aspx

Tommy Cho Martial Arts studio
<http://tommychomartialarts.com/>

Atlanta Botanical Gardens
www.atlantabotanicalgarden.org/

Chestatee Wildlife Preserve
www.chestateewildlife.com/

Georgia Aquarium
www.georgiaaquarium.org/

Georgia Sports Hall of Fame and Museum
www.gshf.org/

High Museum
www.high.org/

Imagine It! The Children's Museum of Atlanta
www.childrensmuseumatlanta.org/

Inside CNN Studio Tour
www.cnn.com/tour/

LEGOLAND Discovery Center
www.legolanddiscoverycenter.com/atlanta/

Tellus Science Museum
<http://tellusmuseum.org/>

Turner Field
<http://atlanta.braves.mlb.com/atl/ballpark/index.jsp>

URJ Camp Coleman
www.coleman.urjcamps.org/

World of Coca Cola
www.worldofcoca-cola.com/

Zoo Atlanta
www.zooatlanta.org/

Ava's Law:

Effective Health Care Program
www.effectivehealthcare.ahrq.gov/index.cfm

Perspectives:

R. Larkin Taylor-Parker
<http://iamthethunder.tumblr.com/>

Post-Secondary Education:

Center for Leadership in Disability
<http://publichealth.gsu.edu/678.html>

Georgia Inclusive Post-Secondary Education Consortium
<http://gaipsec.weebly.com/index.html>

Kennesaw State University Academy for Inclusive Learning and Social Growth
www.kennesaw.edu/chhs/academy/

Think College!
www.thinkcollege.net/

Expert Update:

Helping All Children Have a Great Experience
<http://gcdd.org/resources/real-learning-resources.html>

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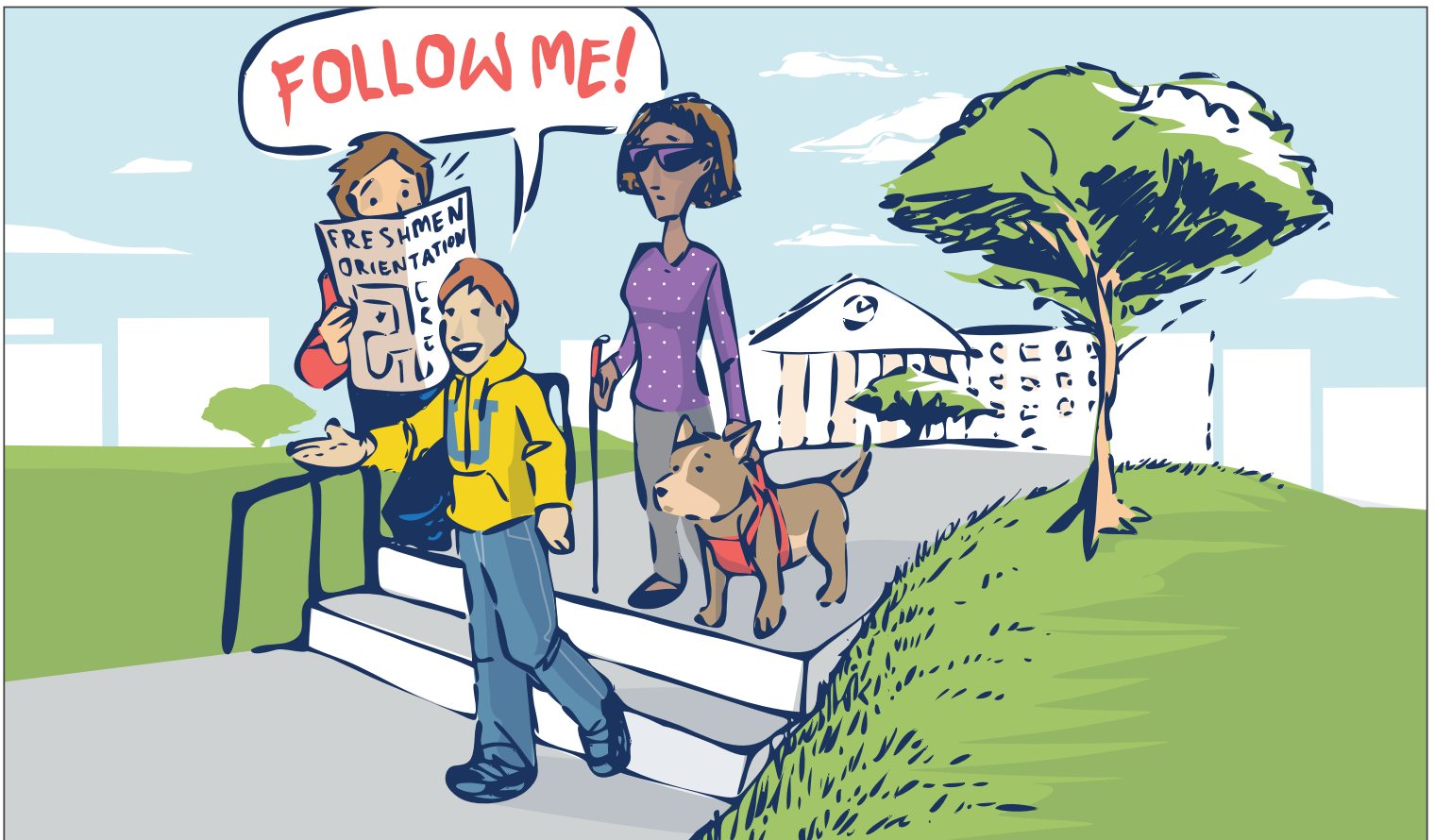


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MAKING **a** DIFFERENCE

A quarterly magazine of the Georgia Council on Developmental Disabilities

VOLUME 14, ISSUE 1

SUMMER 2013

THE CLARKSTON INTERNATIONAL
COMMUNITY GARDEN
RIBBON CUTTING CEREMONY
CHILDREN'S VEGETABLE
COSTUME CONTEST

