On the Cover: GCDD set out across the State to listen to what changes people wanted to see over the next five years in regards to disability services and supports. (See story on page 6.)

Legislative Preview: 2016 Legislative Session

Disability Day: The Disability Vote – Feel the Power!
Employment First: Take Your Legislator to Work Day

On the back cover: Advocacy Days will be expanded in 2016 to train more people with disabilities to advocate for policy changes in Georgia. Join our advocacy team and meet with legislators! (See story on page 12.)

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

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

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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Advocating for a Better Georgia

Once long ago, an advocate yelled at me because the Georgia Council on Developmental Disabilities (GCDD) was calling to get input into our strategic Five-Year Plan. I was told that we already knew the answers and should not waste her time and others when it was apparent what the needs are and what GCDD should do about it.

I shared one of my favorite tales from *Alice in Wonderland*: when Alice comes upon the Cheshire Cat, she asks about which path she should take? The Cheshire Cat replies, “that depends on where you are trying to go.”

GCDD spent most of this past fall gathering information from people with developmental disabilities, family members, advocates and providers about the destination and the path that we want to take over the next five years.
Over 225 people attended 11 public forums representing 63 communities. In addition, over 400 people participated in an online survey. Thank you to all those who took time out of their very busy schedules to either attend a forum or complete a survey.

Council members and staff reviewed those comments and ideas in October and are using them to determine what will be in the next strategic Five-Year Plan. Once the recommendations are ready, you, the readers of Making a Difference and others will have the opportunity to give us your input into whether we are on the right path and working toward the best destination.

This edition of the magazine will focus on the results of the forums and survey. In addition, we present our legislative agenda for the upcoming General Assembly featuring the findings of the recent legislative study committee that discussed inclusive post-secondary
education options and Employment First. I know that many of you with older adult family members with disabilities are concerned that an Employment First policy will result in your loved one not having the option to go to a day center or workshop. However, we believe the focus of Employment First policy will be most beneficial to students transitioning from high school. Once formal schooling has been completed, parents of today’s young adults expect their child to work and they hope they have a job that pays at least minimum wage.

Finally, to support Employment First, GCDD sponsored Take Your Legislator to Work Day. Like the original concept created by the Wisconsin Developmental Disabilities Council, people invited their legislator to spend the day with them on their job. We have heard wonderful stories and connections about legislators and individuals.
I also want to congratulate Sukie Glick, Dorothy Harris, Nandi Isaac, Heidi Moore, Brenda Liz Muñoz and Madeline Petrone, who were all appointed to GCDD by Governor Nathan Deal. We look forward to working with you.

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

Eric E. Jacobson
Executive Director, GCDD
GCDD Hosts Executive Director Leadership Summit

The National Association of Councils on Developmental Disabilities (NACDD) hosted its annual Executive Director Leadership Summit from Nov. 2 - 4, 2015 in Downtown Atlanta. The gathering of executive directors of nationwide and surrounding territory DD Councils brought together leadership and a look at the next big focus of developmental disabilities.

The three-day summit looked into the future of the developmental disability field and what Councils should be focusing on as they develop their five-year state plans. Panels discussed advocacy and community living addressing choice for individuals with developmental disabilities when it comes to housing and what it means for DD Councils and their mission.
Aaron Bishop, commissioner of the Administration on Intellectual and Developmental Disabilities (AIDD), also attended the summit to emphasize the need for diversity in the DD Councils’ state plans.

“The demographics are changing so the question is ‘how do the Councils work together with marginalized communities in their state to bridge those gaps in service and supports?’” said Bishop.

He cited GCDD’s Real Communities as a shining example of working with other marginalized communities and bringing together people with and without disabilities to address issues like food scarcity, poverty, education and more.

NACDD CEO Donna Meltzer added, “It is important that when DD Councils invest in their communities through grant funding or building partnerships with other
organizations, they ensure that those organizations or community stakeholders are also reaching out to people of diverse backgrounds and needs. AIDD’s requirements are in essence forcing us to look deeper and to be more culturally and linguistically competent in all that we do.”

The annual meeting of the DD Council executive directors brings together council leadership for deep and thoughtful discussions on subjects that affect them and their respective Councils. NACDD also uses the opportunity to bring key national leaders in for discussion with the executive directors to assist in designing better tools and supports for their work.

**USDOE Grant to Expand College Access for Georgia Students with Intellectual Disabilities**

The US Department of Education (USDOE) awarded Georgia State University’s School of Public Health a $2.5
million, five-year grant to support a consortium of universities working to improve access to higher education for students with intellectual disabilities.

The Georgia Inclusive Post-secondary Education Consortium, based at the school’s Center for Leadership in Disability (CLD), will provide organization, community education, start-up funding, statewide training and technical assistance for colleges and universities seeking to establish programs for these students.

This is the second round of five-year grants from the USDOE, known as the Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID). The program originated in 2010 in response to changes in the federal Higher Education Act.
Mixed Greens Goes Mobile

GCDD’s Real Communities initiative Forsyth Farmers’ Market is going mobile.

The Forsyth Farmers’ Market Farm Truck 912 will be a mobile market that will bring local fruits and vegetables to Savannah neighborhoods that do not provide healthy food options. Farm Truck 912, named after Savannah’s area code, will both accept and double SNAP/EBT benefits and offer health and nutrition opportunities.

“The goal of our mobile market is to bring nutritious, locally grown produce to neighborhoods with the least access to healthy food. We hope to reach our neighbors who find it difficult to attend our Saturday farmers’ market due to transportation issues or other barriers,” said
Teri Schell, executive director of the Forsyth Farmers’ Market and community builder for GCDD Real Communities.

Farm Truck 912 will be set up at community centers and other locations that have already started to have conversations about health. It is starting with four stops on three days and will expand to at least seven stops by April of 2016.

Some of the initial stops will include:

- **Benjamin Van Clark Neighborhood – WW Law Community Center**
- **Eastside/Hitch Village – Department of Children and Family Services Center**
- **West Savannah – Moses Jackson Community Center**
- **Carver Heights – Carver Village**

The Forsyth Farmers’ Market was created to address food
access issues and to provide all members of Savannah’s community with a welcoming, inclusive place to purchase regional produce. As a GCDD Real Communities initiative, the market in Forsyth Park was created to develop a more welcoming neighborhood, as well as provide opportunities for connection and contribution for people with and without disabilities.

For more information on the Forsyth Farmers’ Market Farm Truck 912, visit farmtruck912.org.

**Governor Deal Appoints New Members**

Governor Nathan Deal appointed 23 people to state boards, including six new members to the Georgia Council on Developmental Disabilities. They include:

- **Sukie Glick** is the youth and social media specialist for disABILITY LINK. She is the co-chair of the
Association of Programs for Rural Independent Living Youth Steering Committee and a youth member of the National Council on Independent Living.

• **Dorothy Harris** is the secretary for People First of Georgia and her local People First chapter. She is a member of the Developmental Disabilities Advisory Council of the Department of Behavioral Health and Developmental Disabilities (DBHDD).

• **Nandi Isaac** is the owner of ScanWithNan, a microenterprise that focuses on helping people save memories. She is a Partner in Policymaking for All About Developmental Disabilities and has completed training in peer-to-peer support. Isaac is a member of the Region 2 Quality Improvement Council and the Developmental Disabilities Advisory Council of DBHDD. She is also a member of the Georgia State
University – Center for Leadership in Disability
Community Advisory Council.

- **Heidi Moore** is an advocate for children’s welfare reform and a member of the State Advisory Panel for Special Education, the Olmstead Planning Committee and various Medicaid healthcare reform committees.

- **Brenda Liz Muñoz** is a family and diversity fellow for the Georgia Leadership in Education on Neurodevelopmental and Related Disabilities at the Center for Leadership in Disability at Georgia State University.

- **Madeline Petrone** is an advocate for community inclusion for people living with disabilities. She has received services in a group home, host home, day center, sheltered workshops and independent living from providers.
FEATURE

Advocating for a Better Georgia

By Devika Rao

The Georgia Council on Developmental Disabilities (GCDD) set out across the State to listen to what changes people with disabilities, their families, caregivers and other advocates wanted to see over the next five years in regards to disability services and supports.

As a part of its mission to bring about social and policy changes that promote opportunities for persons with developmental disabilities and their families, GCDD kicked off its strategic Five-Year Plan by hosting public forums and gathering input through an online community survey.
In accordance with the Developmental Disabilities Assistance and Bill of Rights Act of 2000, GCDD – and all national developmental disability councils – is required to develop and implement a Five-Year State Plan that identifies the most pressing needs of people with developmental disabilities in the State.

The plan, based on extensive community input, focuses on several areas of significance, including employment, education and early intervention services, housing, transportation, self-determination and advocacy, health, recreation, community-based services and supports, and other activities.

**Public Forums and Surveys**

GCDD hosted 11 forums across Georgia during the months of August and September to gather public input.
Over 225 self-advocates with developmental disabilities, family members and friends representing over 63 communities shared their thoughts and concerns regarding the services and supports available to them.

GCDD engaged various local communities on topics of interest by conducting two-hour public forums in the following cities: Dalton, Gainesville, Stockbridge, Macon, Albany, Columbus, Atlanta, Athens, Savannah, Augusta and Atlanta (Spanish).

Attendees were asked three questions, which sparked in-depth conversations of what the next five years should look like for Georgians with developmental disabilities.

1. What are the things in your community that allow people to fully participate in school, in the community and in life? What is working well in your community?
2. What is not working well in your community? Are there things missing that are needed for people to be able to fully participate in school, community and in life? What are the barriers to full participation?

3. What are your ideas or suggestions about how we/your community could have more of what is needed for people to be able to fully participate in school, community and life? How could barriers to services and/or supports be reduced or ideally resolved?

As a part of its community outreach, GCDD also collected input via an online survey that asked 11 questions pertaining to access to childcare, respite care, self-advocacy and integrated activities in the community for people with developmental disabilities.
Over 400 online surveys were received from community members identifying the needs and gaps in services available to people with developmental disabilities. Over 40% of survey participants identified themselves as family members; over 30% as professionals in the developmental disability field; approximately 13% as people with disabilities; and over 10% as advocates.

The questions, both at the public forums and on the survey, revealed commonly held views on certain issues, while some emerged as region-specific barriers with possible solutions.

**What Matters Most**

When addressing barriers, 10 out of the 11 public forums and the online community survey highlighted lack of employment opportunities and accessible and affordable housing as impediments to full participation.
Attendees stressed the need for vocational training, the need to do away with subminimum wages or even helping employers understand the benefit of hiring people with disabilities to make competitive employment a reality.

Overwhelmingly, 57% of those who participated in the survey identified improving transition from school to work or living in integrated communities as the issue most important to enhancing the quality of life for people with developmental disabilities in the next five years.

When it came to housing, people noted the lack of affordable and accessible housing, and they wanted to have a choice of living independently in their own place with or without a roommate. In the online community survey, about 33% of respondents said Georgia needs to work on renting or owning affordable housing, but also having the money to support people who have their own place.
Advocating on behalf of her brother who has a developmental disability, Kelly Parry, a student from Georgia State University, noted the importance of housing.

“Housing is really the issue for me and my family,” said Parry at the Sept. 30th public forum in Atlanta. “My brother is never going to be able to own his own home or have a job, so our options are limited.

There is also a balancing act between caregivers and us as a family who do not have the energy to do what caregivers can.”

A number of forum participants expressed a strong need for self-advocacy and advocacy learning opportunities. Echoing Parry’s sentiments, the community noted a lack
of coaching for self-advocates and the need for parents to know that they had the power to be agents of change.

“My parents would never make it to these [public forums] and it makes me think that there is a pretty hidden part of the population that doesn’t get advocacy or has a hard time having their voices heard,” Parry added.

GCDD Executive Director Eric Jacobson agreed. “That is an excellent point when it comes to advocacy. [Kelly’s] parents not being able to attend a public forum like this one speaks to the population whose voices go unheard and we have to address that as we start building the next Five-Year Plan.”

Additionally, issues such as the lack of funding to support self-advocacy groups resonated at the public forum in Albany, GA.
Other barriers also came up as topics of concern throughout the State.

Residents in Augusta, GA said that lack of transportation limits people with disabilities to work or manage a social life, and that Medicaid doesn’t always pay for transportation. This problem was also an area of concern for people with disabilities and their families, especially when crossing county borders.

Other issues also included a need for doctors to receive more training to work with people with disabilities; respite care for families and more.

GCDD also hosted a Spanish public forum in Atlanta to better understand the needs that affect communities who may have cultural and language barriers when navigating the service system.
Many noted that dual language in schools or webinars and resources where the schools are helping parents with children with disabilities are working in local communities. The lack of adult services or social workers that speak Spanish created barriers towards full inclusion.

The lack of waivers has been an ongoing advocacy issue for GCDD and the UNLOCK (formerly known as “Unlock the Waiting Lists! Campaign”) during Georgia’s legislative session. With a waiting list that barely moves, advocating for more waivers and more pay for caregivers are major concerns for the disability community.

“There are now over 8,000 people on the developmental disability waiting list and over 3,000 people whom the State has determined need services within six months,” Talley Wells, director of the Atlanta Legal Aid Society Disability Integration Project, said at the Atlanta public forum.
Besides the length of the waiting list, community members touched on the process being too complex and the inequity around waiver eligibility. Like many things that affect services and supports, it all comes down to funding.

“We might try and provide grants to local communities to address issues, but often we have to use local issues as a illustration of what is taking place across the State,” said Jacobson.

Solutions

While barriers were noted, GCDD asked both public forum and survey participants what ideas could help improve inclusion in the community.
Many suggestions centered on employment, schooling, transportation and housing options. When addressing transportation, ideas like partnering with car services such as Uber or other ride-sharing programs were discussed.

Advocates also felt that employment could be enhanced with transition coaches and helping students with disabilities get a diploma as opposed to a certificate so they can pursue higher education. Expanding Project Search, which is already in 18 locations in Georgia, will also address the transition from high school to employment issue.

Groups suggested faith-based organizations or other community groups get involved to raise awareness and build more inclusion and advocacy. Community members in Athens, GA also recommended more Partners in Policymaking classes to support the need for advocacy.
and training to improve efforts to affect a strong policy agenda.

Partners in Policymaking is a national program designed to teach people with disabilities and family members the power of advocacy to positively change the way people with disabilities are supported, viewed, taught, live and work.

To address communication and healthcare barriers that many people with disabilities and their families face, there were calls to create resources for healthcare providers, to train medical students to work with people with disabilities and to offer technical support for parents and caregivers.

The Next Steps
The public forums and community surveys were just the beginning of the process to create GCDD’s Five-Year Plan for Georgia’s developmental disability community.

GCDD members and staff reviewed the public forum comments and the survey results and will be discussing goals, objectives and strategies at the January council meeting. Then, a draft plan will be developed and reviewed in April, which will be submitted for public comment.

After additional feedback, the plan will be submitted to the Administration on Intellectual and Developmental Disabilities (AIDD) for approval. The Five-Year Plan (2017-2021) will take effect October 1, 2016.

“The big takeaway from the public forums is that while we have made progress over the last few years, there still remains a huge need for transportation, that people want
to go to work, and that people do not have very many options when it comes to determining who will provide services and supports,” said Jacobson. “GCDD will try and address these issues along with the support of agencies such as Department of Behavioral Health and Developmental Disabilities, Georgia Vocational Rehabilitation Agency, Georgia Department of Education and State Legislators.”

**Charts in Document:**

Source: 2015 GCDD E-Survey, 409 participants, September 2015

**Public Forums in Georgia**

Questions revealed commonly held views on certain issues, while some emerged as region-specific barriers with possible solutions.
Ten out of the 11 forums cited lack of employment opportunities and accessible and affordable housing as barriers to full participation.

- Albany: More access to technology
- Dalton: More medical staff who understand developmental disabilities
- Macon: More training for self-advocates and parents
- Savannah: More inclusion for younger children
- Stockbridge: Help for people who don’t know where to find resources

**What is your gender?**

Male: 17%
Female: 82%
Transgender: 1%

**What category best describes you?**

Family Member: 43%
Professional: 33%
Person with a Disability: 13%
Advocate: 11%

What is your race?
White: 67.5%
Black: 26%
Two or More Races: 3%
Asian: 2%
Hispanic or Latino: 1%
American Indian: .5%
Native American: 0%

What age is your child?
1-22: 51%
23-45: 39%
46-64: 8%
65+: 2%

What issues are most important to improve?
• Improving transition from school to work or meaningful integrated community activities: 56.8%
• Eliminating waiting lists for services: 53.5%
• Increasing paid employment in the community: 52.3%
• Improving family supports including respite care: 45.2%
• Supporting people to participate in meaningful integrated community activities during the day: 40.0%

What is GCDD doing now that is most helpful?
• Providing people with information about what is happening in Georgia and across the country: 57%
• Helping bring people with and without disabilities together in their communities: 55%
• Helping students with disabilities get jobs: 54%
• Hosting Disability Day at the State Capitol: 50%
• Helping self-advocates to be leaders in their lives and communities so they can speak up: 47%
• Including students in post-secondary education: 37%
• Offering scholarships so individuals and families can attend conferences: 29%
• Including children in their schools and clubs: 27%

Creating GCDD’s New Five-Year Plan

Start
• Aug/Sep 2015: Gather Community Input, Public Forums & Online Survey
• Nov 2015: Review Community input
• Jan 2016: Discuss Strategies & Goals
• April 2016: Develop Draft Plan
• May 2016: Public Comment on Plan
• June 2016: Submit Final Plan to AIDD
• Oct 2016: New Plan takes Effect

End

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Looking Forward to the 2016 Legislative Session

By Dawn Alford, GCDD Public Policy Director

As you read this issue, the 2016 Georgia legislative session has already begun. The Georgia Council on Developmental Disabilities (GCDD) is at the Gold Dome on a daily basis working hard alongside policymakers, partners and other allies.

We are committed to being there during the session to uphold our mission of bringing 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. But as with any organization that engages in legislative advocacy, our work to prepare for the 2016 session began even as the last session ended. In particular, we had an especially busy fall ramping up for this legislative
session. Let me tell you about just a few of the things we have been doing leading up to now.

**A Busy Fall Season Leading Up to the Session**

One way in which we prepare for the legislative season is to hear from you, the citizens of Georgia, about what issues people with disabilities and their families are facing. We traveled across the State hosting 11 public forums to hear what you think is working well, what is not working well and what needs to change to improve the lives of people with disabilities. You will hear more about the results of these forums in the coming months as GCDD will be using the information to draft our next strategic Five-Year Plan. Suffice it to say that many of the themes that emerged, such as the need for better employment outcomes for people with disabilities, will be reflected in the current legislative agenda.
We also focused extensively on building up the membership of and making some changes to our cross-disability coalition formerly called “Unlock the Waiting Lists!” For several years, this campaign focused exclusively on reducing Georgia’s Medicaid waiver waiting lists. However, in recent years, this coalition focused more broadly on rebalancing Georgia’s system to shift its long-term supports from institutional to home and community-based services (HCBS). Therefore, this coalition has decided to drop “the waiting lists” from its name and just go by UNLOCK. You will read more about the UNLOCK agenda items later in this article.

Finally, toward the end of the 2015 legislative session, House Resolution 642 was passed with Chairman Katie Dempsey (R – District 13) as the primary sponsor. It initiated a House study committee on “Post-Secondary Education and Employment Options for Individuals with Intellectual and Developmental Disabilities.” Chairman
Dempsey led this study committee and, along with other committee members, held four meetings in the fall.

The committee heard extensive testimony from numerous stakeholders including GCDD and Employment First Georgia. If you haven’t done so, please thank Chairman Dempsey for her leadership and other committee members for all their hard work on this committee: Rep. Amy Carter (R – District 175), Rep. Bubber Epps (R – District 144), Rep. Valencia Stovall (D – District 74) and Rep. Bill Werkheiser (R – District 157). As this issue goes to print, we look forward to reading the report of this committee and the recommendations it contains.

2016 Legislative Agenda

Make Georgia an Employment First State

Employment First means that employment should be the first and preferred option for all people, regardless of their
disability. Under Employment First legislation, employment in the general workforce at or above minimum wage is the first and preferred option for all working-age citizens with disabilities.

Currently, the Georgia system creates many barriers for individuals with disabilities to work. Although the majority of Georgians with developmental disabilities want to work, only 8% of Georgians with developmental disabilities are currently employed in the community.¹ Under an Employment First policy, state agencies will need to re-align their policies and funding to prioritize employment for all working-age Georgians with disabilities.

• Support legislation that will make Georgia an Employment First state.
Support Students to Attend Inclusive Post-Secondary Education Programs in GA

Inclusive post-secondary education (IPSE) provides opportunities for students with intellectual and developmental disabilities to access higher education. This education prepares them to live increasingly independent lives and pursue careers of their choice.

Individuals with intellectual and developmental disabilities who receive post-secondary education are more likely to find paid employment than those who don’t, and their earnings are 73% higher than peers who do not receive post-secondary education.²

Thanks to support from the Georgia General Assembly, the number of inclusive post-secondary programs in Georgia has grown from one to four. Additionally, the Center for Leadership in Disability at Georgia State University recently received a federal Transition
Programs for Students with Intellectual Disabilities grant, which means we can anticipate the addition of more programs within the next few years.

However, students in inclusive post-secondary programs have very few resources available to them to pay for these programs compared to what is available to students of traditional college programs. For example, IPSE students cannot access the HOPE scholarship program. Without financial support, many qualified and eager students simply cannot afford the life-changing opportunity of inclusive post-secondary education.

- Increase student access to inclusive post-secondary educational programs by creating a scholarship to mirror HOPE to assist students who could not otherwise afford these programs.
- Support the sustainability of inclusive post-secondary educational programs in Georgia by doubling the
legislative funding from $200,000 to $400,000. The FY 2017 ASK for new funding: $200,000.

**UNLOCK (formerly “Unlock the Waiting Lists!”)**

GCDD is proud to support UNLOCK, formerly known as “Unlock the Waiting Lists!” The UNLOCK campaign advocates with Georgians with disabilities so they and their families can live full lives and contribute to Georgia communities and its economy. We believe Georgia must rebalance its system of long-term services and supports, so that fewer dollars are spent on institutional care and more dollars are invested into HCBS services.

**We Need More DD Waivers**

Out of the several Medicaid waivers that Georgia offers to those who qualify for this level of care, the New Options Waiver (NOW) and the Comprehensive Supports Waiver Program (COMP) have by far Georgia’s longest waiting list. There are over 8,000 individuals with developmental
disabilities on this waiting list. These individuals and their families are desperately hanging on and need Georgia to throw them a lifeline.

• Fund at least 1,000 NOW/COMP waivers to reduce Georgia’s longest waiting list and allow more individuals to begin to receive services: $16,486,250.

Address the ICWP Rate Disparity
The Independent Care Waiver Program (ICWP) provides vital assistance to people with significant physical disabilities and traumatic brain injury to help them with daily tasks such as toileting, bathing, dressing, meals and housekeeping. The Medicaid reimbursement rate is significantly lower than all the other Georgia Medicaid waivers making it extremely difficult to find qualified caregivers. By the time home health agencies take their cut, caregivers often are paid only $8-9/hour.
• Increase the ICWP’s Personal Support rate to $20/hour to be consistent with other Georgia waivers. We recommend phasing in this amount with an increase for FY 2017 of $3/hour: $7,975,490.

Children’s Freedom Initiative: Bring Georgia’s Children Home

There are a number of school-age children living in nursing facilities or intermediate care facilities. They are in facilities simply because they have a disability and need care despite the fact that it is completely possible to care for them in the community. Georgia needs to shut the front door to these facilities and ensure every child has a permanent loving home.

• Provide funding for all of the young Georgians with disabilities under the age of 22 currently living in facilities to move into permanent loving homes and have the care they need.
The Achieving a Better Life Experience (ABLE) Act
An ABLE account is a tax advantaged savings account that will allow people with disabilities to save money without putting their benefits in jeopardy. It is limited to individuals with significant disabilities who became disabled before age 26 and must be spent on certain qualified expenses. Although the federal legislation that enables these accounts was passed by Congress and signed into law in 2014, states must pass their own bills to establish ABLE programs for their residents. We anticipate multiple ABLE state bills being filed during this session.

- Support legislation that would establish a Georgia ABLE program for Georgia residents.

Support Georgians Who Care for Their Families: The Family Care Act
Many Georgians balance their work lives with caring for their families. The Family Care Act would enable Georgians who have earned sick leave to use up to five days of that leave to care for sick members of their immediate family. The Family Care Act does not add any additional sick days or require employers to provide them; it only allows Georgians to use the sick days they’ve already earned to care for family members.

- Support the Family Care Act.

*Change the Standard to Prove Intellectual Disabilities in Capital Punishment Cases*

In 2002, the US Supreme Court said it is wrong to execute a person with intellectual disabilities because it violates the Eighth Amendment’s ban on cruel and unusual punishment.³ But in Georgia, it is extremely difficult for an individual to prove in court that they have intellectual disabilities. Georgia is the only one of the 50 states that
requires a person to prove “beyond a reasonable doubt” that they have intellectual disabilities in capital punishment cases.

• Change the legal standard of proof for proving intellectual disabilities in the Official Code of Georgia Annotated (OCGA) to “preponderance of the evidence,” which is the standard used in most other states.

The previous items are the focus of our legislative agenda for 2016! In addition, GCDD is also proud to support …

• Changes to Georgia’s high school diploma system that will give more students with disabilities the opportunity to obtain diplomas and access further career and educational opportunities.
• The creation of an Elder and Disabled Abuser Registry in Georgia that would allow employers of direct care workers to have a better way to screen potential employees and may deter abusers.

• The creation of the Phillip Payne Personal Assistance Program, a sliding fee scale program for workers with disabilities to pay a cost share that would allow them to access Personal Assistant Services to maintain their independence.

• The creation of PeachWork, a program allowing workers with disabilities to pay a premium in order to receive medical coverage through Medicaid. Workers on this program could earn a modest income without putting their Medicaid health insurance at risk.

Mark your Calendars and Join Us for 2016 Advocacy at the Capitol!
No matter how robust our legislative agenda, we cannot be successful in our efforts without YOU – the voices of the people with disabilities, their families, and other allies. We will be holding a series of advocacy days along with our annual Disability Day at the Capitol. Each advocacy day will have training, visits with legislators and networking with others in our community.

Register TODAY by going to gcdd.org/advocacy. You don’t want to miss it!

**2016 Advocacy at the Capitol!**

**We Need More DD (NOW/COMP) Waivers Day**

Wednesday, January 20

(sponsored by GCDD and UNLOCK)

**Independent Care Waiver Program (ICWP) Raise the Rate Day**
Wednesday, January 27
(sponsored by GCDD and UNLOCK)

**Inclusive Post-Secondary Education (IPSE) Day**
Tuesday, February 2
(sponsored by GCDD, UNLOCK and the Georgia Inclusive Post-Secondary Education Consortium)

**Intellectual Disability and the Death Penalty**
Tuesday, February 9
(sponsored by GCDD, PAPE Coalition and GFADP)

**Employment First Day**
Thursday, February 11
(sponsored by GCDD, UNLOCK and the Employment First Coalition)

**18th Annual Disability Day at the Capitol***
Thursday, February 18
ABLE (Achieving a Better Life) Act Coalition Day
Wednesday, February 24
(sponsored by GCDD, AADD and the Georgia ABLE Coalition)

Wildcard Day! End-of-Session Advocacy
Tuesday, March 1
(sponsored by GCDD and UNLOCK)
* Disability Day registration information is on pages 16-17.

Receive the latest information throughout the session:
Please go to www.gcdd.org, scroll to the bottom of our homepage and click on “Join our Advocacy Team!” and follow the instructions. You will have the opportunity to select your subscription preferences. Be sure that you sign up to receive our “Advocacy & Policy Alerts” and “Unlock the Waiting Lists! Alerts.” This will also allow
you receive our legislative newsletter, “Public Policy for the People” that comes out every two weeks during session.

References:

   
   http://www.nationalcoreindicators.org/charts/

   
   http://www.thinkcollege.net/publications/fast-facts

The Disability VOTE – Feel the Power!

Register now to participate in GCDD’s 18th Annual Disability Day at the Capitol. More than one million Georgians have some type of disability and approximately 652,000 are voting-age. Exercise your right to vote this election year. Your vote, and your voice, are critical to the political decision-making process. Come to LIBERTY PLAZA and join advocates, meet with state legislators, hear Governor Nathan Deal speak, make your voice heard and your VOTE COUNT.

18th Annual Disability Day at the Capitol
Thursday, February 18, 2016, 9 AM - 2 PM

Join us on LIBERTY PLAZA
Schedule Overview

9 AM – 11 AM
T-Shirt distribution, activities and exhibits at the Georgia Freight Depot before the rally - first come, first served.

11 AM – 12:30 PM
Rally program including Gov. Nathan Deal in Liberty Plaza, Capitol Avenue & MLK, Jr. Dr.

12:30 PM – 2 PM
Box lunch and exhibits at the Georgia Freight Depot - first come, first served.

For more information, visit www.gcdd.org or call 1-888-ASK-GCDD

Participating in Disability Day 2016? Tag your photo with #GCDDannualDisabilityDay on Facebook & Twitter!
Attendee Form:
First Name:
Last Name:
Organization (if applicable):
School (if applicable):
County (required field):
City/State/Zip:
Day Time Phone (required field):
Email Address:
Alternate Contact Name:
Alternate Phone:
Please Confirm Number of Attendees:
Attendees 10 and under: _____ Confirmed number of attendees
Group Size 11 through 50 (ONLY): _____ Confirmed number of attendees
Group Size 51 and over (ONLY) _____ Confirmed number of attendees
Please complete by Feb. 5 and mail or fax with attention to Disability Day 2016.

Georgia Council on Developmental Disabilities
2016 Disability Day Registration
2 Peachtree Street NW, Suite 26-246, Atlanta, GA 30303
Fax: 404.657.2132, Call: 404.657.2121 to learn more.
Groups of 20 or more MUST register online.
If you are unable to register online and need support to register by phone, call 404.657.2121.

**Disability Day Sponsorship Form**

Your sponsorship will support one of the largest statewide events that provide an opportunity for advocates to unite in support of legislation that will promote the independence, inclusion, productivity and self-determination of people with disabilities. Each year, thousands gather at the Capitol to meet with lawmakers,
celebrate growth in community and reignite the bonds of friendship. The success of the event depends on sponsors like you. Please let us know of your commitment no later than February 5, so that you may receive full recognition of your support as described below. (Information received after this date does not guarantee your organization’s placement on any printed materials.)

**Yes! My organization will co-sponsor Disability Day 2016 in the amount of:**

_____ $5,000: Full-page ad in Making a Difference magazine, logo on banner and GCDD website, name on program, exhibit space.

_____ $4,000: Half-page ad in Making a Difference magazine, logo on banner and GCDD website, name on program, exhibit space.

_____ $2,500: Quarter-page ad, logo on banner and GCDD website, name on program, exhibit space.
$1,500: logo on banner and GCDD website, name on program, exhibit space.

$600: logo on banner and GCDD website, name on program.

$200: Name on program and GCDD website.

[___] Yes, my check is enclosed. (Payable to Georgia Council on Developmental Disabilities)

[___] Yes, please invoice me for the amount selected.

[___] Sorry, I am unable to sponsor this year.

Will you or your organization’s staff plan on attending this event? Yes ___ No ___

Please provide an estimated count for lunch ____ and/or number of T-shirts ____

(Sponsors $600 and over may reserve t-shirts for each member of their organization registered to attend Disability Day at the Capitol by emailing kim.person@gcdd.ga.gov with the number of t-shirts and sizes for advance shipment.)
[PLEASE WRITE CLEARLY]

Contact Name:
Title:
Organization Name (Exactly as you want it to appear on event materials):

Address:
City:___________________________ State:
_____ Zip: _________ Phone: ___________________
Email:

Please complete form by Feb. 5 and mail or fax with attention Disability Day 2016
Georgia Council on Developmental Disabilities
2 Peachtree Street NW, Suite 26-246, Atlanta, GA 30303
Fax: 404.657.2132
You may also sign up as a sponsor by contacting: Kim Person at 404.657.2130 or email
kim.person@gcdd.ga.gov
YOUR VOICE... YOUR CHOICE...YOUR VOTE!

Get Ready for Disability Day 2016!

Register ONLINE at http://bit.ly/1OLf9hk by February 5, 2016!

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FEATURE

People with Disabilities Take Georgia Legislators to Work

By Devika Rao

“It was important for me to meet people with disabilities in the employment environment and see what impact they have in the workplace,” said Rep. Scot Turner (R – Holly
Springs), who has a son on the autism spectrum and also is a longtime advocate for people with disabilities.

Rep. Turner participated in Take Your Legislator to Work Day (TYLTWD), hosted by Employment First Georgia (EFG) and supported by the Georgia Council on Developmental Disabilities (GCDD). The initiative, held for the first time in the State, was an exercise to bring together legislators with people with developmental disabilities and employers who are supporting this effort in their districts.

“The idea behind TYLTWD is to allow Georgia state legislators to meet people with disabilities at their place of work and share in their workday experiences,” said D’Arcy Robb, co-coordinator of Employment First Georgia.
Georgia’s TYLTWD kicked off in October 2015 to commemorate National Disability Employment Awareness Month (NDEAM). The objective of this campaign is to raise awareness about the benefits of hiring individuals with disabilities and the belief that employment and successful careers should be the expected and preferred outcomes of all publicly funded services for individuals with disabilities, i.e., Employment First.

“It’s not just someone talking about it, it’s not just statistics on a page. Legislators are actually going to work with someone with a disability to see how it works,” said Robb.

The goal of Take Your Legislator to Work Day is to ask employees with disabilities to invite their legislators to visit their workplace to demonstrate first-hand the power of community-integrated employment for people with
disabilities by showcasing their skills and talents in a work environment.

Rep. Turner went to Canton-based Sweetwater Growers, a hydroponic farm growing live basil and micro-greens throughout the US and Canada. He met with employee Chad Roberts who has become invaluable to the company’s everyday operations.

“Chad plays an important role in the day-to-day functionality of the company. And when you look at Chad and his success, you see the strong family, employer and caregiver support. It’s a team effort to make Employment First a reality for people with disabilities,” he said.

Take Your Legislator to Work Day

The efforts of TYLTWD started with the Employment First Georgia Coalition, a 300-strong group of advocates
including people with disabilities, family members, service providers and advocates who believe that all people with disabilities have the ability to work and that Georgia needs an Employment First policy.

The coalition put out a call to Employment First Georgia members and the general public looking for Georgians with disabilities that work in the communities that they love. Then they were encouraged to sign up for TYLTWD.

“With EFG, we’re going to them with a problem that the State doesn’t do enough to help people with disabilities go to work,” said Robb. “But we’re also coming to them with a solution and saying ‘People with disabilities can work. Here is your constituent working and now we need to make sure that all Georgians are able to do that.’ ”
And the legislative response has been overwhelmingly positive. At the time of this writing, EFG had 11 legislative visits that were completed and five more scheduled while three were pending and 24 more were being arranged. If all these schedules align, over 40 legislators will have visited their constituents with disabilities at work.

Along with Turner, many other connections between legislators, employees and businesses were formed to drive home the message of Employment First and the need for competitive employment for people with disabilities.

Georgia House of Representatives Majority Leader Jon G. Burn (R – Newington) participated in TYLTWD in Effingham County at Edwards Interiors Aerospace, a 200-employee company that makes interiors for Gulf Stream airplanes.
Rep. Burn got to meet Lindsey Kussow, who is helping modernize the company’s purchase orders because the company had rooms full of crates of paper taking up significant real estate to store these records. Kussow helped create a digital record-keeping system, which helped save the company a lot of money and improve organization.

“We want our legislators to see the value and contribution people with disabilities make in the workplace,” said Robb.

Sens. John Wilkinson (R - District 50) and Butch Miller (R - District 49) visited the Project SEARCH site in Hall County where they met a number of employees, including Adrianna Becerra.
Becerra, 19, is a mail room tech at Northeast Georgia Medical Center in Gainesville, GA through Project SEARCH. She organizes and distributes mail for the hospital, which has allowed her to become stronger in skills such as memorization and socialization.

“There is a lot to remember in this job and a lot more to it than most people realize,” she said. “I’m very social so I really like delivering the mail and meeting new people. Working in the mail room has pushed me to get better at memorizing, be at work every day and on time.”

Showing decision-makers the impact of competitive and meaningful employment was the chance of a lifetime.

“I liked the fact that I got to show [the legislators] that people with disabilities can work just like anybody else and shouldn’t be sheltered,” said Becerra. “It’s important
that they know we can do the same things other people can do and we can live independent lives.”

After spending a day at the job site, Wilkinson said his biggest takeaway was that, “you could count on them. The employers were boasting about the attendance record, attention to detail and positive attitude – all things that make a huge difference in the workplace for everyone. These are great things to employers.”

**Why It’s Important Now**

It has been about eight years since advocates began actively seeking an Employment First policy for the State of Georgia. In 2015, the House of Representatives formed the Employment First and Post-Secondary Education Study Committee to look at these issues.
“Our hope is that out of this committee we will get a piece of legislation for the 2016 session that would make Georgia an Employment First state,” said Robb.

What does being an Employment First state mean? Upon becoming law, state agencies would have to reprioritize their policies and funding so employment becomes a priority option for every working age Georgian with a disability, regardless of the significance of their disability. But it also includes a culture change.

“Many of our state systems prioritize segregated services for people with disabilities and there are mindsets that are institutionalized about what people can and can’t do. So it’s a process. I would say I absolutely want [legislators] to support our Employment First legislation but even more so than that, for the long haul I want them to support an Employment First culture,” said Robb.
Currently, 32 out of the 50 states have an Employment First policy.

**How It All Works Together**

At the same time, other federal legislation and mandates like the Workforce Innovation and Opportunity Act (WIOA), the Achieving a Better Life Experience (ABLE) Act and the Home and Community-Based Settings (HCBS) Rule from the Centers for Medicare and Medicaid Services – all which were passed down federally in 2014 – are setting the tone of integrated and inclusive communities, which includes Employment First practices in a state.

WIOA and the HCBS Rule are two really big things on the disability landscape happening right now for people with disabilities. The HCBS rule declared that people with disabilities should receive services in integrated and
inclusive communities not only for employment, but also in transportation, education, housing and other areas.

“The rule says that it is not okay for people with disabilities or people who are aging or people who get any other kind of services to be in an institution and be isolated. When it comes to employment, HCBS as well as WIOA are very supportive of Employment First,” said Robb.

Here in Georgia, it is a priority to want everyone to look at employment as the first option for all working age people with disabilities. All agencies work together but approach it from a different angle. The question behind pushing Employment First is how to get more people with disabilities into the community and how to get them employed just like anybody else.

Advocacy
Like any policy efforts, advocacy remains the strongest way for the community to engage with the legislators and other decision-makers on what issues matter most.

When it comes to Employment First, “there are a myriad of little pieces that could be changed. We need to take things like Project SEARCH, which has been a huge success, to a bigger stage. We need to be able to do customized employment and discovery. And some of these things are in the beginning stages. We really want it to kick start all of that and give it a centerpiece for all of these best employment practices in Georgia. And mostly, the advocates need to keep pushing it forward,” said Robb.

During the legislative session, GCDD and EFG will be hosting Advocacy Day for Employment First on Feb. 11, 2016.
Legislators welcome advocates and suggest that getting involved and building a relationship with them is an important step in advocating. “Tell us what is going on, be specific on what is lacking and come with potential ideas,” said Turner, who will also be sponsoring the Achieving a Better Life Experience (ABLE) Act bill in the 2016 Georgia General Assembly.

What an Employment First Georgia will look like will depend a lot on the legislative session and the voice of the advocates. But through the TYLTWD initiative, legislators who have met employees with disabilities have taken away the most important message of all.

“It is important to realize the potential of all people,” said Wilkinson. “We should not dwell on disabilities, but focus on abilities and their contributions.”
Thanks to all our legislators who took time out of their busy schedules to participate in GCDD’s TYLTWD. For a complete list of the participants, see page 31 or visit our web page for the most up-to-date information:

gcdd.org/public-policy/take-your-legislator-to-work-day-a-success.html

Sidebar Stories

Hall County Project SEARCH intern Hannah Peterson with Sens. Butch Miller (left) and John Wilkinson during their Take Your Legislator to Work Day visit.

Quron Dixon, a graduate of Fulton County Schools Learning Internship for Future Employment (L.I.F.E.) greets Sen. Donzella James at his place of employment, Restaurant Associates. Dixon has been employed for three years and Chef Tom noted he was one of his best employees.
David Stockstill (second from left) started work at Olson Architects as an assistant. Stockstill had worked hard at Southern Regional Technical College mastering the trade of drafting. Rep. Darlene Taylor (center) joined him as a part of Take Your Legislator to Work Day, sponsored by GCDD in collaboration with EFG. Olson Architects has given him the opportunity to try out his skills and learn from the experts.

Rep. Jon Burns visited Lindsey Kussow, who works at Edwards Interiors Aerospace in Springfield. Burns was impressed not only by Kussow’s skills in organizing files, but also by the growth she witnessed in herself after getting her job. She changed from a shy young lady to an outgoing, confident woman ready to take on any task assigned to her.

Rep. Bob Bryant (center) visited BJ Clark (left) and Michael Burris (right) at the office of the Chatham County Clerk of Superior Court to see how they streamline the process of digitizing documents. Chatham County Clerk of Superior Court Dan Massey recognized the opportunity for these two very capable men to gain meaningful employment. Both Rep. Bryant and Massey emphasized the importance of change starting at the local level, creating a working model for others.

State Rep. Mickey Stephens (center) visited Memorial University Medical Center in Savannah, GA and met Jazzmine Smith (left) and Shyeeta Kelly (right), two women who have overcome obstacles to create their own success. Rep. Stephens, who taught special education for
many years prior to becoming a state representative, agreed and voiced his fervent support for supporting employment for people with disabilities.

Memorial is a prime example of how we all benefit as a whole when people are given the opportunity to make a contribution, and the Coastal Center for Developmental Services is proud to have been a part of their success!

Sen. Bruce Broadrick visited Brett Wable at Shaw Industries in Dalton, GA. Wable is a housekeeper for Plant UC and his responsibilities include emptying the recycling containers throughout the plant, bailing cardboard and plastic, running the sweeper and cleaning up damaged goods.

Rep. Bill Hitchens visited Billy Behrens, who has worked at a leading manufacturer in Savannah for over two years. When his job required him to use a computer, he took on
the challenge without hesitation. Though he had no computer skills in the beginning, Behrens closed out over 73,000 work orders for his company and won nine performance awards!


**Take Your Legislator to Work Day Visits**

Thanks to all our participants in this important initiative. Here is the most current list as of press time:

- Chad Roberts visited by Rep. Scot Turner at Sweetwater Growers in Canton.
• Jordan Huffman visited by Rep. Mike Dudgeon and Senator Michael Williams at Roseati’s Pizza in Cumming.


• Brian Mosley, Sarah Parker, and Willie Jones visited by Senator Harold Jones and Rep. Wayne Howard at Walton Options in Augusta.

• Jazzmine Smith and Shyeeta Kelly visited by Rep. Mickey Stephens at Memorial Hospital in Savannah.

• Lindsey Kussow visited by House Majority Leader Jon Burns at Edwards Interiors Aerospace in Springfield.


• Myles Johnson visited by Senator Michael Williams at Chick-Fil-A in Suwanee.

• Mia Nobbie visited by Senator Bill Cowsert at St. Mary’s Hospital in Athens.

• David Stockstill visited by Rep. Darlene Taylor at Olson Architects in Thomasville.

• Christie Entrekin visited by Senator Jeff Mullis at Christie’s Creations in Trion.

• Quron Dixon visited by Senator Donzella James at Café Aquaria in Atlanta.

• Janeanne Napoli visited by Senator Frank Ginn at University of Georgia Law Library in Athens.


• Brett Wable visited by Rep. Bruce Broadrick at Shaw Industries in Dalton.

• James Jordan visited by Rep. Scott Holcomb at Krispy Kreme in Doraville.


• Christopher Varnerin visited by Rep. Pedro Marin at TGI Friday’s in Buford.


• Mike Melton visited by Rep. Beth Beskin at disABILITY LINK in Tucker.

• Bobby Chapman visited by Senator P. K. Martin at Kroger in Lawrenceville.

At press time, the following individuals are scheduling their visits to take their legislators to work:

• Liz Persaud of Georgia Tech in Atlanta.

• Xantha Burghardt of Tow ATL in Buckhead.

• Minna Hong of the Shepherd Center in Atlanta.

• Alicia Hardy of Hardee’s in Dalton.
• Chester Grant & Eric Foster of Thomaston-Upson County Board of Education.

• Christopher Bivins, self-employed, of Moultrie.

• Project SEARCH Bartow County interns at Cartersville Medical Center.

• Viola Wilson of Walton Options in Augusta.

• Jessica Luna of Mulberry Elementary in Auburn.

• Katrina Parsons and Carl Teem of disABILITY LINK in Tucker.

Visit our web page which will be updated as new visits are confirmed or scheduled:
Growing Up with a Sister with Developmental Disabilities

By Sarah Shay

My sister Melissa is three years older than me, but you could never tell. At five-feet-tall and under 100 pounds, I’ve always felt like the older one. That is mostly because Melissa was born with Down syndrome and deafness. I grew up faster than she did in every way possible – potty-training, eating, talking, walking and going to school.
As we both grew into our pre-teens and teens, the different paths our lives were going to take became more apparent. My parents referred me to as their “golden child.” And even at that early age, I knew it had a double meaning. Not only was I “perfect” in their eyes, but I had to act the part as well. I was an honor student, active in band and foreign language, always striving to do my best – never allowing myself to give up or fail.

At the same time, Melissa, the tiny, cabbage-patch-faced baby, had grown up with a wild streak and she simply became more than my parents could handle. This began a long and stressful path of finding her good schools and respite care programs. There was no perfect place or perfect formula.

At special needs schools, they didn’t have a sign language interpreter. At deaf schools, the students would make fun of her for having Down syndrome. Some schools would
lock her in her room at night so she couldn’t wander around and it became apparent that other schools were doing things even worse.

That was a very hard time in my life. On one hand, I wanted to protect her, and every other child with a developmental disability, from the harsh words and deeds of the world. On the other, I was so tired. Melissa was really hard to live with a lot of the time and the stress it put on my family was breaking us apart. I didn’t want her living with us, but I felt guilty having those thoughts. I knew she needed a better place, a place to have some freedom like any young adult would want.

But then weren’t we abandoning her, like so many other kids with developmental disabilities I’d seen dumped at schools and homes over the years?

A divorce and a move would make Melissa’s future clear.
Now alone, my mother had no choice but to put Melissa into a group home. I still try to avoid saying the word group home. It makes me feel like we failed her somehow. But thankfully she thrived there – going to school everyday, taking care of her basic needs, going on outings and interacting with people of different ages.

Would Melissa’s story be different if she was born now? Definitely. For one, the Internet has totally changed how we communicate. A parent who has a child with disabilities now has many resources readily available to them, including the ability to reach out to other parents. Secondly, I think the social mindset has changed so that people with developmental disabilities are seen as part of their community – going to school, working and living with their families or even on their own.

Even though my sister’s story is different, we still have our happy ending, which is all I could ever hope for.
Sarah Shay and her sister Melissa. Shay graduated with honors from the University of Alabama and is now a writer in Atlanta, GA.

Becoming a Sibling Advocate

By Nick Perry

It was Friday, July 13, 1984. That was the day I became a big brother. With the birth of my brother Jarvis, came my expectations of hanging out, playing sports, fighting, goofing off, going to school and growing up alongside my new best friend. Some of these expectations would come to pass, but others would remain fantasy.
My brother was diagnosed with cerebral palsy and an intellectual disability. As the realization that he was not a typically developing child dawned on me, the trajectory of my life changed. My carefree nature was slowly replaced by a feeling of responsibility.

I thought of college and career options at a very early age. I thought that I had to be successful enough to support both my brother and myself for the duration of our lives. Unfortunately, waivers and supports were never explained to me. I was a gifted student and star athlete. I tried not to ever cause trouble or create more of a burden for my family; moreover, I wanted to make them proud. I was chasing perfection. Being captain of an undefeated soccer team, graduating high school with honors, receiving academic scholarships and being gainfully employed since the age of 15, all seemed to go unnoticed.
Thus, all of my struggles were turned inward until the day I suddenly found myself sitting with a gun pressed against my temple. There was no note. I went down my list mentally saying my good-byes when my mind inevitably came to my brother. “What would happen to him after our mother was gone? Who would be there with him? Who would fight for him? What quality of life would he have?” I thought.

These questions gave me pause, and ultimately saved my life. I couldn’t imagine how anyone could face such pain and adversity with a smile the way he does. If he could, so could I.

I began to realize that we would always be able to rely on one another because we’re complementary. I have exceptional physical and mental faculties, and he has uncanny inner strength. It’s ironic how my little brother is the emotional support that I always needed. He is always
there to listen, but never judge. He taught me how to love unconditionally, how to endure life’s challenges and how to be responsible. But most of all, he taught me how to be a man.

As adults, Jarvis and I continue to support one another. Our brotherhood has led me to choose a career path that allows me to be of service to others with developmental disabilities and their loved ones.

Of particular interest are the challenges faced by many siblings of individuals with disabilities. Our voices often go unheard, our struggles unseen. That is what motivated me to get involved with Sibshops, the Georgia Sibling Connection and the Sibling Leadership Network. We siblings face many of the same issues as our parents in addition to those that specifically affect us. Beyond feeling alone, guilty and exhausted from the demands of caregiving, we may also experience embarrassment,
resentment and pressure to achieve. Since the sibling relationship is generally the longest relationship of one’s life, it is important for legislators, agency leaders and most importantly parents to give more consideration to the role that we play.

Often, we become advocates right alongside our siblings. Decisions that affect them affect our lives as well. We have a right to our own lives independent of our siblings with disabilities, and we also have the right to be included in discussions and decision-making processes that impact our families. As the popular slogan goes – Nothing About Us Without Us!

Nick Perry and his brother Jarvis. Perry is the former public policy specialist and sibling coordinator for the Georgia Council on Developmental Disabilities.

For sibling support programs, visit:
Sibling Support Project (Sibshops):
http://www.siblingsupport.org

Georgia Sibling Connection:
tiny.cc/GeorgiaSiblingConnection

Sibling Leadership Network: siblingleadership.org/

EXPERT UPDATE

Sibshops: Celebrations of the Contributions Made by Brothers and Sisters

By Don Meyer

What are Sibshops?
For the adults who run them and for the agencies that sponsor them, Sibshops are evidence of the loving concern for the family member who will have the longest-lasting relationship with a person who has a disability.
However, for the kids who attend them, Sibshops are pedal-to-the-metal events where they meet other siblings, or sibs, (usually for the first time), have fun, laugh, talk about the good and not-so-good parts of having a sib with special needs. They play some great games, learn about the services their brothers and sisters receive and have more fun. More than 400 Sibshops have been established in almost every state and in eight countries.

**Are Sibshops a form of therapy?**

Sibshops may be “therapeutic” for kids to attend, but they are not therapy. Sibshops takes a wellness perspective. They’re a celebration of the many lifelong contributions made by brothers and sisters of people with special health and developmental needs.

**Who attends Sibshops?**
Sibs, of course! Most Sibshops are for siblings of kids with developmental concerns. Increasingly, Sibshops are being offered for brothers and sisters of kids with health concerns and we’re beginning to see Sibshops emerge for sibs of kids with mental health concerns. While Sibshops were developed for sibs 8-to-13-years-old, they are being offered for sibs as young as six and for teens as well.

**Who sponsors Sibshops?**
A wide range of agencies: early intervention centers, school districts, children’s hospitals, local Arc chapters, Easter Seals programs, autism societies, Down syndrome groups, developmental disabilities councils, Jewish community centers, churches, parks and recreation programs, etc. Often, local agencies work with other like-minded agencies to co-sponsor one Sibshop for all the brothers and sisters in a given community.

**What is the impact of Sibshops?**
According to a University of Washington survey of adults who attended Sibshops as kids, over 90% of the respondents said Sibshops had a positive effect on the feelings they had for their siblings. Sibshops taught coping strategies to over two-thirds of respondents; three-fourths reported that Sibshops affected their adult lives; and 94% said they would recommend Sibshops to others. The authors concluded: “The positive effects of the Sibshop program are not only apparent, but enduring.”

**Are there Sibshops in Georgia?**

Yes! Here are two:

Lekotek of Georgia Sibshop, Helene Prokesch
Lekotek of Georgia, Atlanta, GA
404.633.3430, [mailto:info@lekotekga.org](mailto:info@lekotekga.org)

Georgia Sensory Assistance Project
Sibshops, Jennifer Garrett
University of Georgia College of Education
The Georgia Sensory Assistance Project, based out of the University of Georgia, hosts Sibshops for children ages 7-12 and Teen Mentors ages 13-21. These Sibshops are designed for brothers and sisters of individuals with deaf-blindness as well as other disabilities. Sibshops are held three or more times per year in the Atlanta area and other areas of Georgia.

How can I start a Sibshop in my community?  
Visit the Sibling Support Project’s website or call us for more info:

http://www.siblingsupport.org  
mailto:info@siblingsupport.org  
206.297.6368
Another expert resource from Don Meyer:


*Don Meyer is the director of the Sibling Support Project and is best known for creating Sibshops, programs for young brothers and sisters of kids with special needs.*

Supporting Siblings of People with Disabilities

*By Katie Arnold*

The sibling relationship is the longest relationship of most people’s lives and the peer nature of our relationships
make us well-suited to support the self-determination of our brothers and sisters with disabilities.

Siblings play an important role in the lives of those with developmental disabilities, yet our perspective is often overlooked. There has been a growing awareness of the unique perspective and needs of siblings across the lifespan. The Sibling Leadership Network (SLN) has been working to build momentum of the sibling movement across the country.

One of the hallmarks of the SLN is that we are listening to and learning from self-advocates in the movement. People with disabilities are an important part of our SLN Board leadership and Committees ensuring their sibling perspective is included in all our work.

The SLN focuses on three areas:
1. **Support and Information:** Presentations and trainings on siblings have reached audiences across the country to increase awareness of the importance of supporting siblings. Peer support and information sharing happens at the SLN’s national conference as well as state chapter conferences and events. Sibshops are hosted by a number of SLN chapters to provide a fun space for young siblings to gather and get information while playing together. SibNet is the largest online community for adult siblings of people with disabilities from around the world to connect with each other. The Sibling Survival Guide was developed by SLN members and provides detailed information, resources and strategies to navigate the journey as a sibling. The SLN website also has a wealth of information for people to use across the lifespan.
2. **Research:** The SLN is advocating for more and better research on the sibling experience and is working to get it into the hands of siblings and sibling supporters so they can advocate for their needs. A National Sibling Survey was recently conducted to better understand the needs and experiences of siblings from their perspective as well as their siblings with disabilities, parents and professionals. Check out the SLN’s Research Briefs on the SLN website which highlight research related to siblings.

3. **Policy and Advocacy:** The SLN is also working to get the sibling voice at the policy table and is advocating for policies that ensure the definition of family includes siblings. A Sibling Policy Brief has been created by the SLN that highlights key legislation and its relevance to siblings. SLN members have been active at the annual Disability
Policy Seminar. Additionally, the SLN held Sibling Policy Forums and developed an Advocacy Toolkit to help siblings share their stories to effect change.

Founded in 2007, the SLN is a national nonprofit with state chapters dedicated to providing siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.

We invite everyone who is invested in better outcomes for families to join the SLN – it is free and easy to sign up at http://www.siblingleadership.org

Katie Arnold is the executive director of the Sibling Leadership Network (SLN) as well as the director of community education for the Institute on Disability and Human Development. The passion for her work stems
from growing up with her sister with intellectual disabilities.

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MIA’S SPACE

Annie and Christopher’s Space

By Pat Nobbie, PhD, Mia's mom

I assigned this column to Mia’s sister and brother for the sibling issue. I asked them two questions: “What was it like growing up with Mia?” And, “What are you most concerned about for her future and yours with her?”

Annie wrote, “Growing up with Mia was a bunch of silliness. She made everything lighthearted and fun. Mia’s personality brought out the best personality in me. I could be outspoken and real with her. It was interesting to see
how she perceived life and how it compared to my perceptions. And she could be so stubborn. When we were younger, she would have tantrums in public places. I could have looked at it with more of a sense of humor, but at the time it was embarrassing. I wanted her to understand that it embarrassed me, but she was always going to do her own thing in the end.

I’m concerned about her health and well-being. If she needs to come and live with me one day, my concern is that we can co-exist in our living space and that she’ll listen to me when it comes to the serious stuff.”

Christopher added, “We just treated her like a sister, not someone ‘special.’ We always thought she was smarter than people gave her credit for. She really knows people and can manipulate them to get what she wants. When I got older, having lived with her and knowing her friends helped me broaden my outlook on other kids who had
disabilities or who were socially awkward. Knowing her helped me not to judge people and to be more understanding.

I worry about losing her. I’m worried about her health or if something happened to our mom, would she get everything she needs? She needs to be around family. Getting her set up where she lives now was hard. Annie and I would do it somewhere else if we had to but we know it wasn’t easy.”

I’d like to add that Mia was the “big sister,” a position she reveled in. I have many pictures with her arm protectively around her younger brother and sister, getting them to look at the camera, to listen to me, follow. And they expected the same privileges and sanctions for her, as they would have for any other sibling.

Truth be told, I was the softy who caved and let her get
away with things, which Annie and Christopher resented. Guilty as charged. God help me, I was known to have said, “You will both grow up, move away from home and have lives independent of your Dad and me, and Mia will still be here with us. In the larger scheme of things, who gets to sit in the front seat of the car is a small thing.”

She still always claims the front seat when we travel together. But in contrast to my prediction, Mia is setting an example for a life well-lived, in her own home, with lots of friends, and a great job, like any other older sibling might do, and this is as it should be.

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REAL COMMUNITIES

Intellectual Disability and the Death Penalty in Georgia
Leading up to the 2016 legislative session, a new coalition was formed to advocate for a bill that will change Georgia’s current standard of proof for proving intellectual disability from “beyond a reasonable doubt” to “preponderance of the evidence” in death penalty cases involving people with intellectual disabilities.

The Proof to a Preponderance of the Evidence (PAPE) Project is a coalition led by the Georgia Council on Developmental Disabilities (GCDD), Georgians for Alternatives to the Death Penalty (GFADP) and Georgia Catholics Against the Death Penalty. The PAPE Project grew out of GCDD’s partnership with GFADP as a part of the Real Communities Initiative.

Preponderance of the evidence, according to the Legal Information Institute, means that more than 50% of the
evidence points to something. This preponderance is based on the more convincing evidence and its probable truth or accuracy, and not on the amount of evidence.

Of the 31 states that still have the death penalty, 22 states use the standard of “preponderance of the evidence,” five states use “clear and convincing,” three states do not specify a standard, and one – Georgia – has the standard of “beyond a reasonable doubt” for proving an intellectual disability to the courts. This standard is an extremely difficult legal obstacle, and Georgia is the only state with such a high standard placed on people with intellectual disabilities.

Because of the nature of diagnostic processes and necessary documentation needed to adequately prove intellectual disability, a standard of preponderance of the evidence is the only way to ensure that people with intellectual disabilities will not be executed.
In 1986, the State of Georgia executed Jerome Bowden, a man with intellectual disabilities. His execution caused such a backlash that Georgia was the first state to voluntarily ban the execution of people with intellectual disabilities in the state legislature in 1988. Unfortunately, the legislation was largely a symbolic gesture, as this was done by imposing the highest legal standard of proof onto individuals with intellectual disabilities to prove that they do have an intellectual disability “beyond a reasonable doubt.”

Fourteen years later in 2002, the Supreme Court ruled in Atkins v. Virginia that the execution of people with intellectual disabilities was a violation of the Eighth Amendment’s protection against cruel and unusual punishment. The Atkins decision left it up to individual states to decide the standard of proof they would use for determining an intellectual disability.
In 2014, the Supreme Court again revisited the issue of intellectual disability and capital punishment in Hall v. Florida. The decision stated that medical standards must support the state’s enforcement of Atkins protections. The court acknowledged that there is professional medical consensus as it relates to intellectual disabilities and it must guide state law.

Despite the Supreme Court rulings, Georgia continues to be an outlier with “beyond a reasonable doubt,” and as a result, continues to execute people with documented intellectual disabilities, most recently Warren Lee Hill in January of 2015.

GCDD and GFADP will be advocating for this issue in the 2016 General Assembly. Mark your calendars for GFADP’s annual advocacy day on February 9, 2016 at
9:00 am at Central Presbyterian Church across from the Georgia State Capitol.

If you are interested in learning more about this issue, or would like to get involved in advocating for this important piece of legislation, contact Community Builder Dorinda Tatum with GFADP for more information: mailto:info@gfadp.org or 404.749.6889.

Caitlin Childs is the GCDD Real Communities organizing director.

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STRAIGHT TALK

Goals and Aspirations

By Kenneth Gagne

I am 21 years old, and I was diagnosed with cerebral palsy when I was born. A walker gets me around my
house, and a wheelchair gets me around the world outside of it. I rode a different bus to school than most students did since they had no need of a wheelchair lift.

It takes me longer than most people to access certain areas because I have to find a ramp to bypass a set of stairs, find and press a button to open doors (provided the button works), or wait on an elevator to take me to a higher floor in a building. If I happen to be outside when it rains, using an umbrella is actually an inconvenience. Wherever I go, there are people who may stare at me, make comments or assumptions about me, or call me an inspiration just for doing the same things they are.

These people define me by my disability. They have no way of knowing that I took and excelled in several Advanced Placement courses in high school. I studied French and am currently studying Japanese. I can play the ocarina. I am currently pursuing a degree in Computer
Game Design and Development. I voted in the last presidential election, and I recently obtained my learner’s permit.

None of these has anything to do with my having cerebral palsy. Having a disability means living with certain limitations, but it does not affect my goals and aspirations in life. It never has, and it never will. Some people may define me by my disability, and while it is a part of who I am, I live every day knowing that my disability does not define me. I am defined by what I allow to define me.

While I have some issues and concerns some people will never have, I have much in common with many people at and around my age regardless of a disability. I am equally curious and driven just like they are. But, just like my peers without disabilities, I too worry about getting a job once I graduate college.
As we advocate for competitive employment, I must make known my desire to live independently and be gainfully employed in the “real world,” something for which I could not be prepared just by taking a class or reading a textbook (every once in a while, I have to look up how to write a check correctly, for example). I want to apply my degree in game design and development to further advance science and technology – and perhaps even help the mainstream community learn that a disability is not a limit to potential.

I have to learn skills I do not yet have to apply the skills I do have to reach my goals. In any case, I know that even though I have a disability, even though the road upon which I embark may have more potholes than I would like, getting to my destination, whatever it is, is very much possible.
Kenneth Gagne has been a Georgia resident for 17 years and currently resides in Lilburn. He is a 2012 graduate of Parkview High School and a former student at Southern Polytechnic State University, which is now Kennesaw State University. Gagne is an avid bibliophile and can often be found reading horror fiction, historical fiction or someone’s autobiography. He also enjoys writing, which he does most often when practicing Japanese vocabulary and syntax. Most recently, he has taken up swimming and considers nothing else quite as refreshing, liberating or invigorating.

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CALENDAR

March is Developmental Disabilities Awareness Month

January
January 14 - 15
GCDD Quarterly Meeting
Atlanta, GA
www.gcdd.org

January 14
Consortium for Citizens with Disabilities
Annual Conference
Washington, DC
www.c-c-d.org/

January 20
NOW/Comp Waiver GCDD Advocacy Day
Atlanta, GA
www.gcdd.org

January 24 - 27
Georgia Winter Institute
Columbus, GA
www.georgiawinterinstitute.weebly.com/

January 27
Independent Care Waiver GCDD Advocacy Day
Atlanta, GA
www.gcdd.org

February
February 2
Inclusive Post-Secondary Education GCDD Advocacy Day
Atlanta, GA
www.gcdd.org

February 3 - 6
Assistive Technology Industry Association Annual Conference
Orlando, FL
www.atia.org/i4a/pages/index.cfm?pageid=4549
February 5 - 7
Abilities EXPO, Los Angeles, CA
www.abilities.com/losangeles/

February 9
Intellectual Disability and the Death Penalty GFADP / GCDD Advocacy Day
Atlanta, GA
www.gcdd.org

February 11
Employment First GCDD Advocacy Day
Atlanta, GA
www.gcdd.org

February 11 - 12
National Council on Disability
Regional Meeting, Orlando, FL
February 18
GCDD Disability Day at the Capitol
Atlanta, GA,
www.gcdd.org

February 24
ABLE Act GCDD Advocacy Day
Atlanta, GA
www.gcdd.org

March
March 1
Wildcard GCDD Advocacy Day
Atlanta, GA
www.gcdd.org

March 2
Education for All: An Evening with AUCD (Association of University Centers on Disabilities) Washington, DC
www.bit.ly/1MZk62l

March 3 - 5
American Foundation for the Blind Leadership Conference
Washington, DC
www.bit.ly/1MmUXBG

March 7 - 9
National Council for Behavioral Health Annual Conference, Las Vegas, NV
www.bit.ly/1bebKC1

March 9 - 13
Council of Parent Attorneys and Advocates Annual Conference
Philadelphia, PA
www.copaa.org/?Conference

March 14
Junior Blind of America
Workshop for Parents of Children with Multiple Disabilities
Los Angeles, CA
www.bit.ly/1O3ilX9

March 21 - 26
International Technology & Persons with Disabilities 31st Annual Conference
San Diego, CA
www.csun.edu/cod/conference/2016/sessions/

April
April 11 - 13
Disability Policy Seminar
Washington, DC

www.thearc.org/dps

April 21 - 22
GCDD Quarterly Meeting
Atlanta, GA

www.gcdd.org

Planning an upcoming event?
Send your information to GCDD Public Information Associate and Social Media Coordinator Jhai James jhai.james@gcdd.ga.gov; Subject line: “Community Calendar” by Feb. 15 to be included in the calendar. Visit GCDD’s expanded online community calendar to view additional local events at www.gcdd.org/calendar.

Calendar Highlight:
The Disability VOTE – Feel the Power!
Disability Day at the Capitol
February 18, 2016
See pages 16-17 for additional details and registration form.

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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

In The News

National Association of Councils on Developmental Disabilities

www.nacdd.org

US Department of Education

www.ed.gov

Georgia State University
www.gsu.edu

Around GCDD

Forsyth Farmer’s Mobile Market
www.farmtruck912.org

Advocating for a Better Georgia
Georgia Council on Developmental Disabilities
www.gcdd.org

Looking Forward to the 2016 Legislative Session

Achieving a Better Life Experience (ABLE) Act

Children’s Freedom Initiative
www.georgiacfi.org/
Georgia Inclusive Postsecondary Education Consortium (GAIPSEC)

gaipsec.weebly.com/collegesuniversities.html

Georgians for Alternatives to the Death Penalty

www.gfadp.org
mailto:info@gfadp.org, 404.749.6889

GFADP Advocacy Day

www.gcdd.org/advocacy

UNLOCK (formerly Unlock the Waiting Lists!)

www.unlockthewaitinglists.com/

The Disability VOTE – Feel the Power!

Georgia Council on Developmental Disabilities

www.gcdd.org/2016-disability-day
People with Disabilities Take Georgia Legislators to Work

Employment First Georgia
www.employmentfirstgeorgia.org

Georgia Council on Developmental Disabilities
www.gcdd.org

National Disability Employment Awareness Month
www.dol.gov/odep/topics/ndeam/

Becoming a Sibling Advocate

Sibling Support Project (Sibshops):
www.siblingsupport.org
Georgia Sibling Connection
tiny.cc/GeorgiaSiblingConnection

Sibling Leadership Network
www.siblingleadership.org

Sibshops: Celebrations of the Contributions Made by Brothers and Sisters

The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Developmental Disabilities
by Don Meyer and Emily Holl

Sibling Support Project (Sibshops):
www.siblingsupport.org

Support Siblings of People with Disabilities

Sibling Leadership Network
www.siblingleadership.org

Intellectual Disability and the Death Penalty in Georgia

Georgians for Alternatives to the Death Penalty

www.gfadp.org

mailto:info@gfadp.org, 404.749.6889

GFADP Advocacy Day

www.gcdd.org/advocacy

Stay connected!

Like us on Facebook at

www.facebook.com/feorgiaddcouncil

Description: people with and without disabilities push a large ball up a hill to steps leading to the State Capitol.
Written on the ball are all the items in GCDD’s 2016 Legislative Agenda.

Caption: Advocating for a Better Georgia

Sign Up Now at gcdd.org/advocacy for GCDD’s 2016 Advocacy Days!

Wed, January 20 – NOW/COMP Waiver Day
Wed, January 27 – Independent Care Waiver Day
Tues, February 2 – Inclusive Post-Secondary Education Day
Tues, February 9 – Intellectual Disability & the Death Penalty (GFADP) Day
Thurs, February 11 – Employment First Day
Wed, February 24 – ABLE Act Day
Tues, March 1 – Wildcard Day! End-of-Session Advocacy

Meet with Georgia legislators at the State Capitol after advocacy training at any or all of this year’s GCDD Advocacy Days!