Making a Difference

ADVOCACY DAYS 2019

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SPRING 2019

Legislative Session A Success for People with Disabilities!
PUBLIC POLICY FOR THE PEOPLE

2019 Legislative Session a Success for People with Disabilities!
by Hanna Rosenfeld

The 2019 Georgia General Assembly has come to an end. In total, 1,020 bills were introduced during this legislative session. Overall, it was a successful year for the disability community. Find out what bills passed and what progress was made on GCDD Legislative Priorities.

2019 Advocacy Days

Close to 300 advocates attended GCDD’s Third Annual Advocacy Days in February and March during the Georgia General Assembly legislative session. Important topics covered were the DD Waiver waiting list, employment, inclusive post-secondary education, direct support professionals and home and community-based services.

Roads Less Traveled
by Adrienne Murchison

People with disabilities are looking for new options for transportation and getting help in innovative ways. Find out how several are using Lyft ride-sharing to get to work and how a small town in south Georgia created a transit system to better provide for their citizens’ needs.

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On the Cover: Disability advocates head to the State Capitol to meet with Georgia legislators during this year’s GCDD Advocacy Days. Advocates had the option to attend five different training sessions in February and March on topics important to the disability community.

Making a Difference magazine is available online at gcdd.org in: English, Spanish, Audio and Large Print. Previous Issues are archived on the website as well.
Welcome to springtime in Georgia! This time of year means great weather and the end of the 2019 session of the Georgia General Assembly. It is a time for us to look back on what happened during the legislative session and how it impacts the lives of people with disabilities.

Some of the highlights during session include several days during which advocates gathered at the Capitol. I want to thank those who attended our GCDD Advocacy Days, The Arc Georgia Day or the Statewide Independent Living Council Day. Because of their work, legislators heard from people with disabilities, family members and other stakeholders. In this edition of Making a Difference, Dawn Alford and Hanna Rosenfeld discuss details, as well as other victories and barriers during session.

One such barrier, transportation for people with disabilities, has long perplexed me. However, these issues are not unique to people with disabilities. Across our state, people who don’t own cars cannot get to the store, work or the doctor without begging someone for a ride or waiting for an unreliable van service that must be reserved weeks in advance. As a step to address transportation issues this year, the legislature appropriated funds for transportation. However, Gwinnett County voters rejected the opportunity to expand MARTA into their neighborhoods.

Insufficient access to transportation is a roadblock to having a meaningful day and a meaningful life. So what are the alternatives? Public transit? Ride-sharing services like Lyft and Uber? What if there were enough buses, vans and trains to take you any place you wanted? Who would pay and how would you access this? In this issue, we take a look at these questions and more.

Finally, I want to report on progress being made to create work opportunities for people with intellectual/developmental disabilities (I/DD). In March, a group of individuals with I/DD, parents, providers, support coordinators and state agency representatives met to discuss how to increase the number of people in competitive, integrated employment (CIE). For the first time, three things happened that I believe will move Georgia forward in its quest to help people get real jobs.

First, both the Department of Behavioral Health and Developmental Disabilities and the Georgia Vocational Rehabilitation Agency came together with a common focus and plan. Second, a goal was set to increase the number of people with I/DD who are in competitive, integrated employment by three times the current amount by 2025. This means the state is setting CIE as a priority, and its resources should be focused on this. Third, there is an effort to provide technical assistance to communities and providers who want to make CIE a priority. Overall, these three things suggest we might be on the right path. Check out GCDD’s website and join our advocacy network to stay informed.

We hope you enjoy reading this magazine, and we want to hear from you. Let us know your thoughts by writing to Managing Editor, Hillary Hibben, at hillary.hibben@gcdd.ga.gov.

Tell us your thoughts about the magazine or what topics you would like to see addressed by emailing us at hillary.hibben@gcdd.ga.gov, subject line: Letter to the Managing Editor.
“The purpose of the group is for people on the autism spectrum to build their own communities and social circles. What we find is that a lot of children on the autism spectrum seem to lack friends or the opportunity to make friends.” Kramer is also an adult on the autism spectrum and a self-advocate.

The group appeals to people of all ages so children and adults can build a sense of community as they get older. Most importantly, it’s important for them to build a community “between meetings.”

“We established early on that it’s important for these individuals to connect outside of the meetings,” added Kramer. “Connect with each other socially – go to the movies, hang out and really build long-lasting friendships.”

The groups of northwest Georgia meet at Dalton State College or the Anna Shaw Institute. The Metro Atlanta North Social Support Group meets in east Roswell; and the Metro Atlanta Intown Group meets at Kirkwood Public Library.

There are approximately 17,000 - 19,000 people on the autism spectrum in Atlanta alone. And, the plan is to increase the presence of these groups in the city and across Georgia.

“We want to see groups that are close to where people live and can meet their needs,” said Kramer.

For information on going to a Social Support Group or starting one in your neighborhood, email Scott Kramer.

Learn more about the GCA Centre for Adult Autism.
The Power of the Pedal
by Jennifer Bosk

Getting around Macon just became a lot more accessible to those who have no car, live far from bus stops or can’t walk long distances. Re-Cycle Macon, a program through Centenary Community Ministries, provides free bicycles to adults who need transportation.

Started in June of 2017, Re-Cycle Macon has sought bicycle donations and utilized their partner, Bike Tech to refurbish them. “We provide stop-gap transportation for adults, so they have a way to go out to look for jobs, to access social services, to attend community and church events,” explains Eric Mayle, executive director of Centenary Community Ministries (CCM), a part of Centenary United Methodist Church that focuses on developing sustainable communities.

In exchange for five hours of volunteer time at CCM, adults receive a refurbished bike, helmet and bike lock. Now, thanks to funding from the Georgia Council on Developmental Disabilities (GCDD), CCM has expanded their services to provide the typical wear-and-tear repairs for people who have received a bike from the program.

One of last year’s bicycle recipients is Jeffrey, an individual with a developmental disability. He enjoys the exercise he gets riding his bicycle. Additionally, he has found the bike helpful in his daily routines. “A bike helps me get back and forth from the doctor and get prescriptions filled,” Jeffrey says.

In exchange for five hours of volunteer time at CCM, adults receive a refurbished bike, helmet and bike lock. (Photo courtesy of Eric Mayle)

One of last year’s bicycle recipients is Jeffrey, who enjoys the exercise he gets riding his bicycle. (Photo courtesy of Eric Mayle)

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In exchange for five hours of volunteer time at CCM, adults receive a refurbished bike, helmet and bike lock. (Photo courtesy of Eric Mayle)

Nearly 70 people attended including several residents from Wesley Glen, an adult home for people with disabilities in Macon. It was one resident’s lucky night as he, a huge cycling enthusiast, won the raffle for a $200 gift card to use at Bike Tech.

Mayle says that transportation is number two or three on Macon’s list of needs. The infrastructure to support bicycling in Macon is getting better thanks to the advocacy work of organizations like Bike Walk Macon, Georgia’s first grassroots bicycle and pedestrian advocacy group working to enhance mobility in the Macon-Bibb area, according to Mayle. “There are a few miles of bike lanes in the urban core of Macon right now,” he adds.

Mayle also points to there being excitement and energy around biking in Macon as the city’s five-year action plan has goals for its pedestrians and cyclists. “Macon has forward thinking leaders taking us in the right direction,” said Mayle.

To date, 50 bikes have been given to adults with and without developmental disabilities. At their first bike meetup in January, nearly 70 people attended including several residents from Wesley Glen, an adult home for people with disabilities in Macon. It was one resident’s lucky night as he, a huge cycling enthusiast, won the raffle for a $200 gift card to use at Bike Tech.

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In exchange for five hours of volunteer time at CCM, adults receive a refurbished bike, helmet and bike lock. (Photo courtesy of Eric Mayle)
The bills that did pass both the House and the Senate now sit on Governor Brian Kemp’s desk. Governor Kemp will have the option to sign the bill into law, do nothing and the bill becomes law or reject the bill through a veto. Governor Kemp also has the power to line-item veto the budget bill, which means he can simply reject certain parts of the bill without rejecting the entire thing. In theory, the House and Senate may override the Governor’s veto with a two-thirds vote in each chamber. With a deadline of May 12, it may still be some time before we know which bills Governor Kemp will veto and which he will sign.

**GCDD LEGISLATIVE PRIORITIES:**
Overall, 2019 was a successful year for the disability community. In particular, the Georgia Council on Developmental Disabilities (GCDD) made significant progress on a number of our Legislative Priorities. While we educated legislators around Medicaid, supported decision-making, caregiver registry expansion and the shortage of direct support professionals, we made concrete progress on three of our Legislative Priorities.

**DD Waivers**
Governor Kemp included 125 new NOW and COMP waivers for Georgians with intellectual and developmental disabilities. This allocation was included in the final version of the budget, coming in at approximately $4.2 million. In some respects, any increase in funding for NOW and COMP waivers is a win for advocates. Still, we know that with almost 6,000 Georgians waiting for a NOW and COMP waiver, our work is far from over. We must continue to advocate for all Georgians to have the home and community-based services they need to live full and meaningful lives in their communities.

**Inclusive Post-Secondary Education (IPSE)**
The Senate added $106,500 in state funds to the final version of the Georgia Vocational Rehabilitation Agency’s (GVRA) budget for academic transition teachers to work in Georgia’s nine inclusive post-secondary education programs. The Senate believes GVRA will be able to draw down additional federal funds, for a total of $500,000 in funding for academic transition teachers. Time will tell if this draw down occurs.

**Children’s Freedom Initiative**
Through his sponsorship of HR 723, Representative David Dreyer (D – Atlanta) raised awareness of children with disabilities stuck in institutional settings and in foster care here in Georgia. Indeed, the resolution went so far as to declare June 22, 2019 as Children’s Freedom Initiative Day at the Capitol. We thank him for his leadership in this excellent first step towards ensuring all children have permanent, loving homes.
BUDGET HIGHLIGHTS

The House and Senate worked out their differences in Conference Committee on April 28. Remember though, Governor Kemp may line-item veto any part of the budget he does not like. Until he signs the budget bill, we will not know for sure what will be funded.

Department of Behavioral Health & Developmental Disabilities (DBHDD)
- $3.7 million to annualize 125 NOW and COMP waivers added in Fiscal Year 2019
- $4.2 million to fund 125 new NOW and COMP waivers
- $120,417 to fund a provider rate increase of 10% for supported employment for individuals with developmental disabilities
- $50,000 in one-time funding for permanent supported housing for individuals with developmental disabilities in Forsyth County and to create a model plan for statewide utilization
- $100,000 in existing funds to provide the final installment of the three-year plan for Georgia Options
- $7 million to offset a reduction in Medicaid patient revenues to maintain ongoing state hospital system operations

Department of Community Health (DCH)
- $737,639 to fund four additional positions, training and associated operations for increased background checks for owners and employees of long-term care facilities pursuant to SB 406 (2018 session)
- $513,000 to serve medically fragile children through the Champions for Children program
- $401,524 in funds for the second installment of a two-year plan to increase the personal needs allowance for nursing home residents by $5 to meet the $20 per month requirement pursuant to the passage of HB 206 (2017 session)
- $330,000 in funds for nursing homes to support enhanced background checks

Department of Human Services (DHS)
- $143,991 in funds for the second installment of a two-year plan to increase the personal needs allowance for nursing home residents by $5 to meet the $20 per month requirement pursuant to the passage of HB 206 (2017 session)
- $1.3 million to fund 17 new adult protective services caseworkers
- $366,752 to fund five new public guardianship caseworkers
- $338,802 to sustain options counseling, program outreach and quality assurance for the Aging and Disability Resource Connection (ADRC)
- $157,000 for assistive technology to assist older Georgians, to be dispersed to the nine Centers for Independent Living and 12 area agencies on aging at approximately $7,500 per location
- $849,951 to fund 50 new Medicaid-aged, blind and disabled eligibility caseworkers

GA Vocational Rehabilitation Agency (GVRA)
- $149,733 to expand outreach of independent living for individuals with disabilities in underserved areas
- $106,500 to increase funds to provide a state match to deploy academic transition teachers in inclusive post-secondary education (IPSE) programs; and, in collaboration with the Center for Leadership in Disability and GCDD, develop job descriptions and memorandums of understanding that are in compliance with federal statutes, regulations and the terms and conditions of the federal grant fund to be implemented on July 1, 2019

The bills that did pass both the House and the Senate now sit on Governor Brian Kemp’s desk. Governor Kemp will have the option to sign the bill into law, do nothing and the bill becomes law or reject the bill through a veto.
SB 106: Partial Medicaid Expansion
Sen. Blake Tillery (R – Vidalia)
Georgia’s partial Medicaid Expansion Bill, SB 106, has already been signed into law by Governor Kemp. SB 106 allows Governor Kemp to submit two waivers to the Centers for Medicare and Medicaid Services (CMS). The first waiver is a Section 1115 Waiver, which would allow Georgia to cover people living up to 100% of the federal poverty level with Medicaid. The second waiver is a Section 1332 Waiver which looks at the private health insurance markets and might seek to reduce costs for consumers through innovative strategies. At this time, no official waiver proposal has been shared. Of note, Section 1115 and 1332 Waivers are different from the HCBS Waivers (NOW, COMP, SOURCE, CCSP, & ICWP) we often speak about in the disability community. Additionally, SB 106 includes a time limit on waiver submission which means that should a future Governor wish to submit an additional waiver, new legislation would be needed.

HB 324: Low THC Oil Access in Georgia
Rep. Micah Gravley (R – Douglasville)
As you may recall, the legislature has previously allowed Georgians with specific medical conditions to use low THC oil, a form of medical cannabis. However, there was previously no legal method by which qualifying people could obtain the low THC oil. HB 324 creates a system for in-state cultivation and distribution of low THC oil to those eligible. The University of Georgia and Fort Valley State University are charged with creating medical marijuana programs. Additionally, up to six licenses will be granted to private companies interested in production and distribution. It is important to note that HB 324 only applies to a very specific population using low THC oil. For the vast majority of Georgians, marijuana remains illegal.

HB 316: Voting System Update
Rep. Barry Fleming (R – Harlem)
One of the more spirited issues debated this legislative session, HB 316 updates Georgia’s voting system. Specifically, it states that elections in Georgia will use, “scanning ballots marked by electronic ballot markers” and counted “using ballot scanners.” Additionally, the “electronic ballot markers” will provide voters with, “paper ballots which are marked with the elector’s choices in a format readable by the elector” – essentially a receipt. Further, the bill refines the process by which voters are removed from the voting rolls, as well as regulating voting location closures in advance of an election.

HB 79: Parental Rights for Parents who are Blind
Rep. Carl Wayne Gilliard (D – Garden City)
Spearheaded by the National Federation of the Blind, Georgia Affiliate, HB 79 seeks to diminish the discrimination parents who are blind face when raising children, specifically as it relates to, “the courts, the Department of Human Services, or a child-placing agency in matters relating to child custody, guardianship, foster care, visitation, placement or adoption.” Additionally, provisions are included for supportive parenting services meant to, “assist a blind parent or prospective blind parent in the effective use of nonvisual techniques and other alternative methods to enable the parent or prospective blind parent to successfully discharge parental responsibilities.”

SB 15: School Safety
Sen. John Albers (R – Roswell)
SB 15 looks at improving safety in Georgia’s schools through updated safety plans and drills, as well as routine threat assessments. Additionally, the Georgia Information Sharing and Analysis Center is charged with creating a smartphone app for reporting suspicious activity in schools. As schools in Georgia are largely controlled at the local level, it is important that parents of children

Key Terms:
HB: House Bill
HR: House Resolution
SB: Senate Bill
SR: Senate Resolution

Public Policy for the People

There may come a time in the future though when we need your help to make sure any waiver proposal takes the needs of Georgians with disabilities into account.
with disabilities show up to local forums and meetings to ensure the needs of students with disabilities are considered as schools seek to improve safety.

**SB 2 / SB 17: Internet Access in Rural GA**
Sen. Steve Gooch (R – Dahlonega)
SB 2 and SB 17 allow electric membership corporations and telephone cooperatives to provide internet to their customers. As these companies already operate in rural Georgia, the legislature hopes this change will allow for broadband services to finally blanket Georgia’s rural communities. It is believed that broadband access will improve these communities’ desirability as business locations, as well as improve local healthcare services and educational opportunities.

**SB 48: Mandatory Dyslexia Screening in Schools**
Sen. P. K. Martin IV (R – Lawrenceville)
SB 48 requires that all public schools screen their students for dyslexia starting in kindergarten. Implementation is not required until the fall of 2024. In addition to screening, the bill also makes provisions for increased teacher training. Of note, the screening mandate will not go into effect unless the Georgia General Assembly approves funding for the program.

Want to read the whole law? Visit the website www.legis.ga.gov and use the bill search feature in the upper left corner on the page.

Several Georgia legislators met with disability advocates in the halls of the State Capitol during the 2019 legislative session. Advocates were participating in this year’s GCDD Advocacy Days training sessions.

Looking Ahead ...

With the legislative session behind us, you may be thinking all the hard work is done. You would be wrong though! The work of an advocate is never over.

1. First, as this was year one of a two-year legislative cycle, any bill that did not pass into law still has a chance to become law next year. For example, SR 193 and SR 194 look at moving the oversight of NOW and COMP waivers to the DCH, while HB 426 looks at increasing punishment for hate crimes (crimes based on bias or prejudice). That means if you have strong feelings about a bill, good or bad, now is the time to make sure your Senator and Representative know how you feel. With the summer and fall ahead of you, you have no excuse not to take a few minutes and call your legislators or write them a letter.

2. Second, if you have not met your Senator or Representative yet, try to arrange a meeting with them this summer. It is never too early to start building a relationship with your elected officials. If your legislator gets to know you in the quiet months of summer, they will be more likely to answer your email or call during the hectic months of the legislative session. Invite them to coffee or to an event your organization is holding. The sky is the limit!

To find your legislator, simply visit www.openstates.org.
Over 280 disability advocates came to the Georgia State Capitol in February and March to meet with their legislators and discuss the issues that were of importance to the disability community in Georgia. The Georgia Council on Developmental Disabilities (GCDD) hosted its Third Annual Advocacy Days during the Georgia General Assembly legislative session.

Five different Advocacy Days focused on policies affecting people with disabilities and brought together advocates from across the state to speak with their elected officials. Topics included the DD Waiver waiting list, employment, inclusive post-secondary education, direct support professionals and home and community-based services.

“All of our advocates – whether a self-advocate, a family member or a caregiver – were empowered to connect with their legislators and inform and educate them about issues that matter to them,” said Eric Jacobson, executive director of GCDD. “It was motivating to see advocacy in action and be at the forefront of positive change for people with developmental disabilities across Georgia.”

GCDD would like to thank all of the legislators who took the time to meet with advocates and listen to their concerns during the 2019 Advocacy Days.
David Bryan, like many folks, rises early in the morning, gets dressed and goes to work. Getting there, however, with ease and peace of mind is a relatively new luxury for David, who has an intellectual disability. On work days, a driver with Lyft comes by to take him to his place of employment at The Epstein School, located five miles away from home, and brings him back later in the afternoon.

“I like it a lot,” said David. “It saves a lot of time.”

He has taken these pre-scheduled Lyft rides through a Medicaid waiver since January. It’s part of a Medicaid pilot program inspired and initiated by Carol Pryor, a local mother, who was in search of an avenue that would pay for her daughter Jenny’s travel to work.

“I have been an advocate for my daughter here in Georgia for over 25 years, so I know the infrastructure,” said Pryor. “Looking at the infrastructure on anything is how you roll it out, and that’s what I love to do.”

David and Jenny receive Lyft services through Medicaid in two different ways, yet the mode of transportation has been impactful for them both.

David, 46, had previously relied on MARTA Mobility for travel to work. “Lyft has made a big difference for him in a short period of time; it’s giving him an opportunity to have a really nice lifestyle,” said Allan Bryan, David’s father.

Since utilizing Lyft, David can sleep an extra hour on work mornings, and he’s back home within 15 to 45 minutes after the end of his work shift. Whereas the MARTA van would at times arrive at the school up to an hour and a half after David got off work, Bryan said.

A Mother on a Mission

For years, there has been a need for increased transportation services for adults with intellectual and developmental disabilities. Some people, such as Carol Pryor, have addressed the need with a passion. She returned to the Atlanta area in 2017 after living in Florida, North Carolina and south Georgia for several years while still being her daughter’s advocate for services.

“She was taking Lyft to work every day and paying out of her own money, which is a limited amount,” said Pryor. “The maximum amount allocated to funding for transportation in her PA budget is $2,797 per year. There was no way

Pryor, with the help of others, found the answer within four months. “Every Medicaid waiver recipient has a PA budget, and there is a line item for transportation,” she said. “It shows the different services that are provided to that individual. Transportation is among the services that is offered through Medicaid waivers.”

Pryor discovered that Jenny’s transportation funds had not been used in six years. A task at hand was to connect Jenny’s need for Lyft transportation to the corresponding line item in her PA budget.

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to take that transportation funding for a vendor such as Lyft ride-sharing services, and have it paid through the Medicaid waiver.”

Pryor credits her vast work experience with state and federal government, as well as the corporate world, in providing her with the ingenuity to bring Lyft and Medicaid together.

As an advocate for Jenny, she had been in ongoing communication with someone in participant-directed services at the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) for about a year before returning to Atlanta.

“I found the executives in top leadership at Lyft and I said that I was a part of creating a [transportation initiative for adults with disabilities] in Georgia and we would like to talk to Lyft about being a part of it,” recalled Pryor.

The ask was simple: the ride-share service would provide individuals with disabilities transportation to work in supported employment. Lyft was on board with the idea. A company statement for this article noted data by the American Hospital Association that says a lack of transportation prevents 3.6 million people per year from getting the care they need.

“The key was to see if Lyft met criteria under DBHDD guidelines for common or commercial carriers, as well as criteria under regulations for participant-directed services, which would allow Medicaid to pay for the transportation. The answer was yes to both. Before contacting Lyft to make her request for a transportation program to benefit adults with disabilities, Pryor then brainstormed a name for the program in the making: Georgia Medicaid Waiver Lyft Transportation Initiative.

“Every time Jenny takes a ride the amount is deducted,” said Pryor. “Every month, I submit a Lyft ride history report to the participant-directed manager at DBHDD.”

From Jenny’s perspective, Lyft is a smooth ride. She simply calls them when she needs transportation to work or elsewhere.

“Before Lyft, I was asking people to take me to work,” Jenny said. “It was a bit of a challenge. Now I feel more independent. I can take myself places and leave when I want. I’ve met drivers from around the world: Iran, Iraq, Vietnam, Korea, China and Colombia. I even rode in a Tesla. It was great.”

Another Road to Transportation

While Jenny receives Lyft services through Medicaid’s participant-directed services, David’s transportation funds are allocated under provider services. Pryor accomplished this for him with Jean Millkey of Jewish Family and Career Services (JFCS), which is a concierge partner with Lyft.

David, whose wife also has a developmental disability, has been a part of the JFCS independent living program for nearly 30 years.

“I have private clients that come to me, and I advocate for them for Social Security benefits, or whatever is needed,” said Pryor. “During an ISP (Individualized Service Plan)
meeting, I realized David did not have a dedicated line item for transportation in his PA budget.” Pryor worked with the support coordinator responsible for overseeing David’s care, services and Medicaid waivers to add an addendum for transportation and a line item for funding.

Through STAR (Service Change/Technical Assistance Requests), the support coordinator responsible for David’s services facilitated the addition of transportation funding in his PA budget.

JFCS provides Alterman/JETS Transportation to adults with developmental disabilities and senior citizens offering rides to work and other destinations on weekdays.

“We have a fleet in house and a small staff of paid drivers,” said Millkey, JFCS office and transportation manager.

“It is a big help, but when you consider the time constraints [of JETS], we wanted to expand,” said Millkey. “Lyft was a logical way to expand when we don’t have drivers.

“David goes through JFCS as a concierge partner with Lyft. We have access to their ride scheduling system and can schedule unlimited rides up to one week in advance.”

The Lyft concierge portal offers additional benefits for David, as well as other Lyft riders, who are not in the pilot transportation program.

“We can monitor where the Lyft driver is by looking at a screen and call them, if necessary, and say, ‘Not that building, this one,’” said Millkey. “So, it gives some security to seniors and those with developmental disabilities, who are intimidated by the thought of arranging their own ride.

“Lyft then bills us by the month and we in turn get payment from the client or the program. So that means David does not have to set up his own account with a credit card.”

For now, David and Jenny are the only two participants representing the pilot models for the Georgia Medicaid Waiver Lyft Transportation Initiative, and it appears unlikely that there will be others in the near future.

“It’s on our radar and is something we want to pursue,” said Amy Riedesel, DBHDD Director of Community Services.

“This is a pilot project of the [Centers for Medicare and Medicaid Services]. The department stands behind it and recognizes the [value to recipients]. There are waiver amendments that are being considered and this is not one of them at the moment.”

If you support the waiver amendment to expand the Lyft pilot program, you can email Amy Riedesel at amy.riedesel@dbhdd.ga.gov or call her at 404-657-7858 to let DBHDD know.

Georgia Town Creates Transit System

Reliable transportation can be more than life-changing; it can be life-saving. About 185 miles outside of Atlanta in Fitzgerald, GA, Jill Alexander helped to bring a transportation van service to citizens with disabilities, senior citizens and others in need.

Before the existence of Ben Hill Transit, many people who use wheelchairs would find their way to appointments or shopping destinations by navigating along sidewalks and streets.

“Two people were killed,” said Alexander. “One person would take the back alleyways and she would get herself flipped over.”

Alexander now resides in Gainesville, GA, however, Fitzgerald was her home for 35 years. Before moving away in 2012, she generated a groundswell of support for transportation for people with disabilities.

“I was a community builder for the Georgia Council on Developmental Disabilities (GCDD),” she said. “My [son] has developmental disabilities. I had a navigator team through Parent to Parent. I had taken Partners in Policymaking training and sat on the Council as an advisor. I started to gain interest in the issue by talking about the problem and got the ball rolling.

[GCDD] started to support me, and they got people to rally around the idea of a] transportation system.”

The first city official that Alexander approached directly laughed at the idea of the town creating a transit system, but she was not deterred. She held community talks with the elderly; visited apartment residents; and sought to understand how easy or difficult it was for people with mental health problems to visit the mental health center in Tifton for medication and appointments.
“We put together a survey – a kind of needs assessment,” said Alexander. “I started connecting groups and spurring interest and organized a town hall meeting. We had a phenomenal turnout.”

By that time, Alexander had decided to turn to people running for public office, such as Philip Jay, who would become a Ben Hill County Commissioner and is former executive director of The Jessamine Place, which advocates for people with disabilities and provides support services.

“I saw a very legitimate need for it,” said Jay. “We had folks who were walking everywhere. Walmart is a couple of miles out of town for most folks, and the streets aren’t safe for pedestrians or wheelchairs.”

People First of Georgia, an advocacy group for people with disabilities became interested, and GCDD’s Real Communities had an active role in helping Fitzgerald figure out a path to bringing a new transit system to town.

“Real Communities brings people with and without disabilities together to address local problems,” said Eric Jacobson, GCDD executive director. A team met with citizens and local political leaders to determine what assets already existed there that could assist in the need for a transit system.

“Our job was to publicize,” Jacobson said. “This was a community-based effort. The community decided on a local special option sales tax as a way of building their own transit system.

“We funded Jill to be a community organizer during that time period, and get local folks talking about transportation.”

Ben Hill Transit System started in Fitzgerald on July 1, 2015 with three vans. There are now six vehicles.

The Federal Transit Administration pays up to 45% of the cost for the transit system, according to Michael Erwin of Resource Management Systems, which operates the service. “The rest is made up by the purchase of service contracts that we as operators of the system procure … to provide trips at a minimal cost to riders.”

Van rides are scheduled 24 hours in advance. A regular one-way ride is $3. There can be half-priced rates for senior citizens, veterans and others in need, he added.

Last November, members of Fitzgerald, including Alexander and Shirley Brooks, current executive director of The Jessamine Place, made a presentation at the University of Georgia’s Institute on Human Development and Disability, on how they created Ben Hill Transit.

“The transit system is for everyone in the community,” said Brooks.

“Before Ben Hill transit, many people who use wheelchairs would find their way by navigating along sidewalks and streets.”

“I saw a very legitimate need for it,” said Jay. “We had folks who were walking everywhere. Walmart is a couple of miles out of town for most folks, and the streets aren’t safe for pedestrians or wheelchairs.”

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Super Fest is an inclusive football and cheerleading clinic and gameday experience held the day before the Super Bowl in the host city. Its purpose is to showcase inclusion and provide an opportunity for youth with developmental disabilities to participate together with their peers, be genuinely welcomed and made to feel a part of the football weekend. The skills-based clinic culminates in a gameday experience with the national anthem, football players running through a cheerleading tunnel, football scrimmages and cheer performances.

And for the first time, the organizers introduced the opportunity for participants to sign up to be a sideline reporter for those who are not medically cleared to participate in the football or cheer clinic.

Participants were welcomed by Thomas Dimitroff, general manager, Atlanta Falcons and learned football and cheer skills from NFL alumni, Georgia Tech football players and Los Angeles Rams and New England Patriots cheerleaders. Miss Georgia Annie Jorgensen kicked off the gameday experience with pre-game festivities, a cheer performance by participants and a football scrimmage. To top it off, ESPN and 11Alive’s Kaitlyn Ross were filming the event.

“The Georgia Council on Developmental Disabilities (GCDD) was so excited and proud to be a part of Super Fest,” said Eric Jacobson, executive director. “Playing outside with friends, making memories and having fun is what childhood is about – regardless of disabilities. And, participating in everyday experiences is truly what inclusion is all about.”

In addition to GCDD and the Atlanta Falcons, Super Fest was supported by Emory University, Down Syndrome Association of Atlanta, Center for Leadership in Disabilities and more.

The Matthew Foundation was formed to improve the quality of life for persons with Down syndrome and developmental disabilities over their entire life span. It launched the first and only endowment fund for Down syndrome research; supports inclusion through sports; and works to encourage employers to hire adults with developmental disabilities and help them receive access to training.
Through a grant from Georgia Council on Developmental Disabilities’ (GCDD) Learning Opportunity Support Fund, the Ninnesses were able to attend this conference. The fund helps individuals with disabilities and their families attend advocacy, learning events and conferences.

“The chance to meet 15 families who were walking in our shoes was something we couldn’t pass up. We want Thomas to know other friends who have challenges and strengths like he does. When I began researching grant opportunities, I came across GCDD and immediately made contact. Between this grant and frequent flier miles, something that didn’t seem possible, became so,” added Keri.

Ross, who works for Home Depot, and Keri, a part-time childcare consultant for Cultural Care Au Pair found what they needed at the symposium. “We received a crash course in genetics from leading scientists, and it provided so much new information and understanding of our rare disease. It helped us connect the dots between the science and the symptoms,” she said.

Beyond the medical information were additional nuggets of support. They met families with older children and got a peek into a possible trajectory for their younger children. “We learned from the other families’ experiences about treatments and interventions,” explained the Ninnesses.

Macon-based Mark and Jill Vanderhoek utilized the fund to travel to the Eighth Annual Summit of Lives in the Balance Conference where Dr. Ross Greene, an expert they avidly follow, was speaking. It was held in Portland, ME last November.

“Our youngest child, who is two-and-a-half, has been diagnosed with Autism Spectrum Disorder,” explained Mark. “We have read much of Dr. Greene’s work, and the annual conference had a number of interesting topics and speakers we thought would benefit our family.”

Mark is a farmer and founder of Cud Crew, a vegetation management company in central Georgia, and Jill is the executive director of Macon’s Community Partnership. Their biggest takeaway from the conference was from one of the speakers, Dr. Julie Causton, a full-time professor at Syracuse University where she directs the Inclusive Education Program.

“Her presentation helped us to understand what inclusion can look like and what it means – not only for the children who are included, but the students who might otherwise miss out on being part of a learning environment that values all children. The lesson in empathy, compassion and joy that it provides in the lives of all children involved sticks with us,” said Mark.

Already the Vanderhoeks are using what they have learned. “We have become stronger advocates for our children within the school system, and it helped us to reframe our own thinking about how to work through challenging behaviors with our children. This has translated into new skills for our children and a new way of helping them to grow,” explained Mark.

Okur-chung neurodevelopmental syndrome was discovered three years ago, and only eight children were diagnosed with it then. Keri and Ross Ninness’ son, Thomas, was number six of those eight. Last August, when the Ninnesses of Georgia saw an Okur-chung Neurodevelopmental Syndrome Symposium in Newark, NJ, “We couldn’t miss a chance to meet with scientists and doctors and other families to pool our information,” said Keri.
On March 23, students and parents gathered in the break room for a Project SEARCH open house and information session. The yearlong transitional work program combines education and career training to help students secure competitive employment in jobs where they may not otherwise be considered. The event served as the program’s launch in DeKalb County and the first step toward building a cohort of interns.

“We have students with multiple needs,” said Brenda Ann Rice, the lead teacher for special education at Warren Technical School in DeKalb. “One size does not fit all, and programs like this add an extra layer of support.”

The open house began with an introduction to the program and process. By collaborating with local businesses and government agencies, Project SEARCH is able to provide young people with disabilities unique opportunities for employment. Representatives from Woodbridge, the DeKalb Community Service Board (CSB), the Georgia Vocational Rehabilitation Agency and the DeKalb County School District were present, and they will all work together to make successful outcomes possible.

“The benefit of this program is two-fold,” said Nick Perry, the director for developmental disability services for east DeKalb CSB. “One is to build confidence and soft skills such as self-advocacy and workplace appropriateness. The second prong to that is building a network and establishing relationships, which we all use for seeking employment.”

Jack Robinson, an employment specialist at the DeKalb CSB, is excited to see the program implemented in the community.

“When you’re in it, and you see it, and you listen to the terminology, a job becomes second nature,” said Robinson. “I go out and develop jobs, but this here is a one-stop shop: education, training and innovation.”

Two students recommended by their schools were in attendance. Following the presentation, they were guided through the application process. The next steps include a skills assessment and an interview at Woodbridge. By July, the new cohort will begin attending company workshops and getting experience in various roles within the plant.

Andre Atkins, one of the students at the open house, previously worked with children for a nonprofit, and an accessible training environment goes a long way to easing his worries about starting a new position.

“We don’t want anyone to be limited,” said Rice. “We want to open doors. When you take students with challenges and develop them, they can contribute and be a good fit. All students can learn and achieve with the right opportunities.”
What’s Happening in Washington?  
Federal Disability Policy Updates

by Alison Barkoff and Molly Burgdorf, Center for Public Representation

The 116th Congress is off to a busy start! Congress has already introduced a number of bills impacting people with disabilities. Federal agencies also continue to take action on disability issues. Below are some of the most significant developments since the beginning of the year:

Money Follows the Person
The disability community spent last Congress advocating for re-authorization (asking for ongoing funding) of the Money Follows the Person (MFP) program. MFP has helped more than 88,000 people with disabilities and older adults – including more than 2,200 Georgians – who want to move out of nursing homes or other institutions transition back to their communities. Congress introduced two bills in January that would advance employment opportunities for people with disabilities.

In late January, Congress passed (and the President signed) a bill providing short-term funding for the MFP program. States have until September 30, 2019 to spend this money, although many states will run out of money well before September. We are continuing to advocate for long-term funding of the MFP program. In late February, Congress introduced the EMPOWER Care Act (H.R. 1342 and S. 548), a bi-partisan bill that would fund MFP for five years and improve the program by reducing the amount of time a person has to stay in an institution to be eligible for MFP from 90 to 60 days. Reauthorizing MFP before states run out of money is a top priority for the disability community.

Employment
In the winter issue, we talked about the importance to people with disabilities of competitive integrated employment (CIE) – jobs where people with disabilities are paid the same wages; have the same opportunities for advancement; and work alongside co-workers without disabilities. Disability employment is already a hot topic this year.

We continue to be concerned about potential action by the Department of Education to weaken the definition of CIE in regulations implementing the Workforce Innovation and Opportunity Act (WIOA), a law prioritizing CIE for people with disabilities. This fall, the Department gave public notice that it plans to revisit these regulations, and we expect they could be out for public comment in the coming months. It will be

- The Disability Employment Incentive Act of 2018
  Transformation to Competitive Employment Act (H.R. 873 and S. 260) would provide funding through a grant program to states and providers to expand the capacity of CIE by helping providers change their business models. The bill would also phase out over six years Section 14(c) of the Fair Labor Standards Act, which allows employers to pay certain employees with disabilities less than minimum wage.

- Raise the Wage Act of 2019
  (H.R. 582 and S. 150) would raise the federal minimum wage and also would phase out over six years Section 14(c)’s allowance of subminimum wages for people with disabilities.
important for stakeholders to share their employment stories and why CIE is important to them.

Right to Community Living
Despite having a right to community living under the Americans with Disabilities Act and the Supreme Court’s Olmstead decision, too many people remain in institutions or are placed at risk of entering one due to a lack of access to home and community-based services (HCBS). This is in part because of Medicaid’s “institutional bias” – states must provide institutional services but can place people who want HCBS on long waitlists. The Disability Integration Act (DIA) (H.R. 555 and S. 117) was re-introduced in January to provide people with disabilities a civil right to community living by guaranteeing HCBS and ending Medicaid’s institutional bias.

HEALTHCARE CONTINUES TO BE A HOT TOPIC IN THIS NEW CONGRESS. SEVERAL HEALTHCARE REFORM PROPOSALS HAVE NOW BEEN INTRODUCED OR ARE EXPECTED TO BE SOON.

Healthcare
Healthcare continues to be a hot topic in this new Congress. Several healthcare reform proposals have now been introduced or are expected to be soon. The Medicare for All Act of 2019 (H.R. 1384) was introduced in the House in late February. The bill would create a national health insurance program with drastically expanded eligibility and healthcare benefits than those currently covered by Medicare. Long-term services and supports (LTSS) for people with disabilities would be fully covered by the proposed Medicare for All program, and recipients of all ages and disabilities who need LTSS would receive them through HCBS unless the individual chooses otherwise. We expect the Senate to introduce a companion Medicare for All bill soon and for the House to re-introduce the Medicare for America bill, which would create an expanded public healthcare option (including LTSS) alongside employer-sponsored insurance that meets certain requirements. We also expect to see several other bills to expand access to healthcare through Medicaid buy-ins or lowering the age eligibility for Medicare.

We’ve also discussed a number of attacks and changes that weaken the Affordable Care Act (ACA), including its protections for people with pre-existing conditions that are important to people with disabilities. The 116th Congress has started oversight hearings on the ACA and has introduced several bills to address areas where the ACA has been weakened.

Seclusion & Restraint
The seclusion and restraint of students with disabilities has long been a concern of the disability community. The use of seclusion and restraint in schools has caused trauma, injury and even death, with no evidence of effectiveness in improving behavior or academic performance. While some states, including Georgia, have passed laws governing seclusion and restraint, Congress has yet to pass a bill setting strong national standards. In February, the House held a hearing on the inappropriate use of seclusion and restraint on students with disabilities. We expect the Keeping All Students Safe Act (KASSA) prohibiting seclusion and limiting physical restraint to emergencies and focusing on prevention and training (introduced in the last Congress as H.R. 7124 and S. 3626) will be re-introduced in the coming months. KASSA will be a priority for advocates of students with disabilities.

Home and Community-Based Services (HCBS) Settings Rule
We have reported several times about the HCBS Settings Rule, a federal rule to ensure that everyone receiving Medicaid-funded HCBS has the full benefits of community living. Georgia is in the process of developing its final statewide transition plan for fully implementing the rule by March 2022, which will have to go out for public comment. We also are expecting new guidance from the Centers for Medicare and Medicaid Services (CMS), likely as soon as this month. You can keep updated about the rule at www.hcbsadvocacy.org.

Please note: information in this article is current as of April 15, 2019.
As a result, Alan had many of the challenges that so often accompany premature birth. He was given a 0% chance to live, and his chances didn’t improve for a very long time. For the first 15 years of his life, he was in and out of hospitals with seizures, pneumonia and asthma attacks. He was in the hospital more than he was at home.

Annette attributes the change in Alan’s health to the fact that his lungs had finally matured and strengthened enough to where his asthma no longer sent him into crisis mode. That and some advancements in medicine. One contributing factor to Alan’s surprisingly good outcomes was that his father was in the Air Force, so he was receiving top-notch, free treatment through military hospitals all over the country, especially when they lived in California.

Then, one day, many of the health problems that had been plaguing Alan seemed to vanish. Annette says that the family didn’t understand or appreciate the transition that had occurred. “After all those years of not being able to travel very far from doctors and always having emergency plans, it felt like we remained on high alert for about 10 years after his last hospital stay.”

Now 56 and living independently since 1993, Alan is a happy and relatively healthy man with autism, cerebral palsy and some visual impairment from retinopathy of prematurity. He recently had a surgery to replace his retinal implant and came through it with little pain. Alan has regular visits with his family doctor, eye doctor and psychologist. Alan owns his own small home through an income-dependent mortgage from the USDA. If his income changes, then his mortgage payments have some flexibility.

Of all the things Alan is proud of in his life – and there are many things for which he can and should feel accomplished – working at Walmart for more than 30 years now is high on the list.

Alan’s income is supplemented with social security disability payments and a COMP Medicaid Waiver. The waiver pays for his supported employment.

A job coach, Cody, comes to work with Alan once a week to check on his behaviors, schedules and reporting. Finally, and most significantly for both Alan and Annette, it pays for an aide, Bridget, to come to his home three times a week.

Weighing 1.9 pounds at birth in 1962, Alan Bittaker was the smallest male in America to survive when he was born during the sixth month of his mother’s pregnancy. His mom, Annette, has no idea what caused her to go into premature labor. But as it was her second pregnancy, she could tell the difference right away. “It had been a troubled pregnancy from the beginning,” she recalled.

Alan has worked for Walmart for over 30 years.

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**From 0% to 110%**

by Shannon Turner

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hours a day to assist him with daily activities like creating and implementing his to-do list, meal planning and grocery shopping. All of Alan’s services are run through Unison Behavioral Health Agency.

Unison led Alan and Annette through the application process. It took a while, but the difficulty and stress was less because Unison did all the footwork. He was a client receiving supported employment and a caseworker through Unison for about 15 years when they helped lead the process.

What prompted the need for an application was a major change in developmental disability services. That’s when it became evident that they were going to need a waiver in order to receive the services he needed. As he’s gotten older, Alan’s needed more support in certain areas, especially the aide who helps with daily tasks and his complex medical situation.

Alan has already participated in some advocacy, even going to Washington, DC. If given the chance to speak to a legislator now, he would talk about the importance of supported employment and increasing funding – rather than cutting it – for people with disabilities.

Annette agrees that working is really important to Alan. Annette goes on to discuss the fact that the most apparent need in rural counties is transportation, particularly for people like Alan who are working.

They pay for a cab in the morning because there is zero public transportation. His caseworker picks him up in the afternoon and takes him home for their work together. If his caseworker happens not to be available, paying $5 a day, one-way, is doable, but $10 per day changes the picture substantially.

**The Most Apparent Need in Rural Counties is Transportation, Particularly for People Like Alan Who Are Working.**

As science has continued to improve across the course of Alan’s life, many things have come to light. “Everyone in so many thousand pregnancies work out this way. As statistics happen, sometimes, you’re the statistic,” Annette reflects.

Alan likes to put it this way, “I went from 0% to 110%.”

**OF ALL THE THINGS ALAN IS PROUD OF IN HIS LIFE – WORKING AT WALMART FOR MORE THAN 30 YEARS NOW IS HIGH ON THE LIST.**

This feature is a part of Georgia Council on Developmental Disabilities (GCDD) Storytelling Project. The goal is to collect 75 stories representing the experience of individuals living with a developmental disability in Georgia. These stories, accompanied by 6-12 representative photographs, will be instrumental in the efforts of GCDD to advocate for Georgians living with disabilities.

Writer: Shannon Turner, Photographer: Lynsey Witherspoon
### April

- **April 22, 9 AM**
  **Summer Camp Registration**
  Adaptive Inclusive Recreation of Rockdale – Conyers, GA
  [Find more information online](#)

- **April 24, 10 AM – Noon**
  **Positive Behavior Support Parent Academy in SPANISH**
  Parent to Parent – Atlanta, GA
  [Find more information online](#)

- **April 25-28, 9 AM**
  **Wheelchair Tennis Tournament** – McDonough, GA
  [Find more information online](#)

- **April 27, 6 – 11 PM**
  **Gala 2019 - An InCommunity Benefit Night**
  InCommunity – Atlanta, GA
  [Register online](#)

- **April 29-30, 9 AM**
  **SPADD’s 16th Annual Conference: Celebrating Connections** – Augusta, GA
  [Find more information online](#)

### May

- **May 2, 11 AM – 2:30 PM**
  **Top Golf Cinco De Mayo Event for Easter Seals**
  [Find more information online](#)

- **May 3-5 (2 Day Retreat)**
  **Sangha Unity Network, Inc. Uniting for Change: Growing the Self-Advocacy Movement**
  Callaway Gardens, GA
  [Find more information online](#)

- **May 7, 10 – 11:30 AM**
  **Locating Employment Avenues with Peer Support**
  disABILITY LINK – Tucker, GA
  [Find more information online](#)

- **May 8, 10 AM – Noon**
  **Positive Behavior Support Parent Academy in SPANISH**
  Parent to Parent – Atlanta, GA
  [Find more information online](#)

- **May 14-16**
  **United States Disabled Open Golf Championship**
  Richmond, VA – [Register online](#)

- **May 15, 8 AM – 5 PM**
  **Sangha Unity Network, Inc. Power of People Workshop**
  Martinez, GA
  [Register FREE online](#)

- **May 15-16**
  **2019 Autism Conference & Expo of Georgia**
  Georgia State University
  Student Center – Atlanta, GA
  [Find more information online](#)

- **May 16, 8 AM – 5 PM**
  **Sangha Unity Network, Inc. Power of People Workshop**
  Savannah, GA
  [Register FREE online](#)

- **May 18, 9:30 AM – 5 PM**
  **RespectAbility Webinar Training for Latinas with Disabilities and Their Allies**
  [Register FREE online](#)

### June

- **June 4, 8 AM – 5 PM**
  **Sangha Unity Network, Inc. Power of People Workshop**
  Columbus, GA
  [Register FREE online](#)

- **June 12, 2 PM**
  **Think College Webinar: Successful Inclusive Campus Housing Partnerships**
  [Register FREE online](#)

### July

- **July 18-19**
  **GCDD Quarterly Meeting**
  Atlanta, GA
  [Find more information online](#)

To find out about more events across the state, visit GCDD’s Calendar of Events.

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### Support GCDD’s Partner and sign up for SUN’s Advocacy Workshops!

Power of People Workshops
Sangha Unity Network, Inc.
May 15 – Martinez, GA
May 16 – Savannah, GA
June 4 – Columbus, GA
June 5 & August 12 – SOLD OUT!
[Register FREE online](#)