

# Making a Difference



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Spring  
2018



- Looking Back at the 2018 Legislative Session
- It's Election Season! The Disability Vote Counts
- Camps Rise to the Occasion with Inclusive Programs

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

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*Inclusive summer programs are proving how children with disabilities can thrive when they are accepted in the same way as every other child. Learn about the variety of inclusive camps that parents have to choose from in Georgia.*

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On the Cover: Students head to the State Capitol to advocate for Inclusive Post-Secondary Education during GCDD's 2018 Advocacy Days.



## THE NEED FOR UNITY

A recent article by *Respectability* announced that last year 343,483 people with disabilities got jobs. This was four times the number of people who got jobs from the previous year. What makes this even more exciting was that Georgia had the second largest growth at 28,000 people with disabilities getting jobs. This is great news but it still means we have a long way to go because Georgia is still ranked 36th in the nation when it comes to employment for people with disabilities.

The Georgia Council on Developmental Disabilities (GCDD) believes that the legislature took a big step towards improving these numbers this session by passing House Bill 831 – Georgia’s Employment First Act. This legislation will create an Employment First Council that will examine policies and funding with the goal of promoting employment as the first and preferred option for people with disabilities. This is now part of Georgia code.

I want to reiterate what I wrote late last year that even with this legislation, it will be difficult and we must make sure that we provide support and assistance to those who are now being asked to provide a new kind of service. GCDD recently awarded a grant to develop a technical assistance center to assist providers who are interested in moving to a more integrated form of employment.

We understand that some may oppose this legislation. That is okay if we are civil in our opposition. We can have open debates about our disagreements, but if we get caught up in the kind of rhetoric seen on the news, it will

only lead to further splits in our community when what we really need is unity. If we want to address issues such as the waiting list and more systemic issues, then we must work together.

Now that the legislative session is over, we must begin to focus on the upcoming elections and getting our messages out. GCDD hopes to work with groups around the State to sponsor candidate forums and develop questions that you can ask candidates about issues important to people with disabilities.

When we recently met with a legislator to discuss the waiting list, we were told to make sure that it becomes a priority for the candidates for governor. Only you can make that happen!

Finally, it’s not hard to notice that *Making a Difference* might look a little different. We heard that you wanted more information on community events, personal stories and public policy. We have added new sections and said farewell to some too. Alison Barkoff will be providing an in-depth look at federal policy; Public Policy for the People is now a standing department;



Eric E. Jacobson

Around the State will feature statewide stories so we can reach all 159 counties in the State; and so much more.

**GEORGIA IS STILL RANKED 36TH IN THE NATION WHEN IT COMES TO EMPLOYMENT FOR PEOPLE WITH DISABILITIES.**



This issue will also feature the final Mia’s Space and I want to thank Pat and Mia Nobbie for their years of contributing to *Making a Difference*! Thank you, Pat and Mia!

We hope you enjoy reading the new *Making a Difference* magazine and we want to hear from you. Let us know your thoughts and comments about the magazine by writing to [maria.pinkelton@gcdd.ga.gov](mailto:maria.pinkelton@gcdd.ga.gov)

*Eric E. Jacobson*

Eric E. Jacobson  
Executive Director, GCDD

DALTON

COLUMBUS

## Columbus Town Hall Addresses Issues for People with Disabilities

The City of Columbus held a town hall meeting with the Mayor's Commission for Persons with Disabilities (MCPD) to resolve the issues facing individuals with disabilities in Muscogee County.

"Our mayor has Town Hall meetings on a regular basis, so we thought it would be good for us to do the same for the disability community," said Joy Norman, chair of MCPD, and director, Center for Accommodation and Access at Columbus State Univ.

Over 25 people attended the town hall, and the group informed and presented its concerns to the department or manager. MCPD acts as a liaison between the Columbus government and the 50,000 people with disabilities in our community. The main purposes of the meeting were to:

- Make sure people with disabilities knew that they were heard
- Take notes on any issues that needed to be addressed either by the city or some other agency.

The three main issues were:

1. Public transportation (Metra and Dial-a-Ride) concerns:
  - No bus route to the Dept of Motor Vehicles (DMV), where people must go for State IDs. People trying to move out of nursing homes need to be able to get IDs via public transit.
  - Some routes have been eliminated or the # of trips reduced.
2. Need for curb cuts at bus stops
3. Need for accessible housing

At the meeting directors from Metra and Dial-a-Ride addressed the issues while acknowledging the challenge – a decrease in ridership

in those areas. They also took note of the need for curb cuts at bus stops. Possible solutions were for the DMV to have a satellite office on a bus route or Metra provide a trip once a month to the DMV.

As to accessible housing, "I am looking into who and what agency to talk to. Some concerns about sub-standard housing have been ignored and MCPD plans to follow up on how to resolve this long-standing issue," added Norman.

To continue the momentum, MCPD plans to host more Town Hall meetings in the coming year.



The winning photo of Lucas, submitted by his mom, Cortney Warren, to the Gerber Spokesbaby contest.

## New Gerber Baby from Dalton

One of Dalton, Georgia's youngest residents, Lucas Warren, was announced as Gerber's newest spokesbaby earlier this year. And the announcement from the baby food company has catapulted Lucas and his family into a brand new life.

State Senator Chuck Payne (R-Dalton) presented a Georgia Senate resolution honoring Lucas as the first Gerber spokesbaby with special needs on March 19, 2018.

The senator's goal was to bring attention to the disability community and shine a light of

awareness on individuals with disabilities. The resolution also states that with Lucas' newest role, there is an increased sense of "acceptance, awareness and inclusion" for children with disabilities and their families around the world.



# What's New with Making a Difference?

## You asked; we listened!

To serve our community better, the magazine was realigned to include more public policy information, feature more local and statewide stories, and offer more sections that will highlight advocacy and community events around the State to help get you more involved!

Here is what's new in *Making a Difference*:

### ▶ Around the State

This new section will feature more statewide stories to highlight and feature what is going on within our disability community across the State. If you have a story you'd like us to feature or explore, write to us at [info@gcdd.org](mailto:info@gcdd.org)

### ▶ Public Policy for the People

Georgia Council on Developmental Disabilities (GCDD) Public Policy Director Dawn Alford and Planning and Policy Development Specialist Hanna Rosenfeld will provide an overview of statewide policies and legislation that will impact people with disabilities and their families across the State of Georgia.

### ▶ What's Happening in Washington?

To add to the great information from GCDD's public policy team, Alison Barkoff, director of Advocacy at the Washington, DC office of the Center for Public Representation, will also provide an in-depth view of national legislation and conversations that affect people with disabilities. This column will be featured in every magazine.

### ▶ Community Calendar

Many of you told us that you wanted to know more about events happening in your local neighborhoods, cities and towns. The magazine will now feature the community calendar to highlight events in various parts of Georgia. Share your events with GCDD at [info@gcdd.org](mailto:info@gcdd.org)

### ▶ GCDD Impact

GCDD advocates and works for people with developmental disabilities across the entire State. Through our great initiatives and partners, we will be sharing stories of self-advocates, families, employers and many other individuals and organizations that are working to make Georgia more integrated and inclusive for people with disabilities.

# Looking Back at the 2018 Georgia Legislative Session

by Hanna Rosenfeld, GCDD Planning & Policy Development Specialist



**The first day of the 2018 legislative session was on Monday, January 8th. The last day, known as Sine Die, occurred on Thursday, March 29th. Indeed, they did not drop the gavel for the last time until a few minutes past midnight (technically very early on March 30).**

2018 marks the end of the two-year legislative cycle in Georgia. While the bills from this past year's legislative session (2017) remained active in the 2018 legislative session, the slate will be wiped clean going forward into next year. That means that any bill that either did not pass or is vetoed by Governor Nathan Deal must be re-introduced in next year's legislative session (2019).

The Georgia General Assembly fulfilled its one constitutionally required task when it passed the Amended Fiscal Year 2018 Budget (AFY18), the current fiscal year, and the Fiscal Year 2019 Budget (FY19), which begins July 1 and goes through June 30, 2019. The FY19 budget is comprised of \$26.2 billion.

One pleasant surprise came in the last week of the legislative session when Governor Deal increased his revenue projections for the State of Georgia and recommended to the General Assembly that an additional \$166.7 million be included to fully fund the Quality Basic Education (QBE) formula for K-12 education in GA for the first time since 2002.

Other key priorities seen in the FY19 budget include: \$100 million in transit bond funding; over \$19.7 million for children's mental health programs; and over \$7.5 million to address the opioid and other addiction epidemic that seems to be plaguing much of the United States. The FY19 Budget currently sits on Governor Deal's desk, and he has up to 40 calendar days after Sine Die, or May 8, to act on any bill passed in GA. His options are to sign, to veto, or only in the case of the budget, do a line item veto.

## We Love Medicaid:

This legislative session, the Georgia Council on Developmental Disabilities (GCDD) focused on educating legislators about the importance of Medicaid in the lives of Georgians with disabilities. GCDD launched the "I Love Medicaid" campaign to remind legislators to protect Medicaid funding, especially for home and community-based services. We know that there are changes coming in the healthcare systems of Georgia and we want to be sure legislators fully understand how

Georgians with disabilities rely on Medicaid when they make decisions.

One big healthcare decision came in the form of HB 769, sponsored by Rep. Rick Jasperse (R-Jasper), which creates the Rural Health System Innovation Center. The Center is tasked with researching, identifying and evaluating best practices for potential improvements for affordable healthcare in rural GA.

**THIS LEGISLATIVE SESSION, GCDD FOCUSED ON EDUCATING LEGISLATORS ABOUT THE IMPORTANCE OF MEDICAID IN THE LIVES OF GEORGIANS WITH DISABILITIES.**



Another big change comes from SB 357, sponsored by Sen. Dean Burke (R-Bainbridge), which creates the Health Coordination and Innovation Council. This Council is tasked with identifying and promoting solutions to improve GA's healthcare system. While neither of these directly impact Medicaid, they both have the potential to create healthcare solutions in the future that might impact Medicaid.

There are 7,515 Georgians with developmental disabilities waiting for NOW/COMP waivers.

### Supported Employment:

GCDD advocated for an additional \$4.8 million in dedicated long-term employment supports for Georgians with developmental disabilities who do not have a New Option Waiver (NOW) or Comprehensive Supports Waiver Program (COMP).

Although this ask was not funded, GCDD remains committed to highlighting the importance of supported employment for individuals with disabilities.

GCDD is also excited about moving one step closer towards the State recognizing that competitive integrated employment should be the first and preferred option in the provision of publicly funded services for all working-age citizens with disabilities, regardless of the level of disability.

Spearheaded by the GA Vocational Rehabilitation Agency (GVRA) and sponsored by Rep. Terry Rogers (R-Clarksville), HB 831 would create a 14-member Employment First Council comprised of state agencies, providers, individuals with disabilities, a family member and someone from the business community. The primary duty will be to study employment barriers for Georgians with disabilities and make policy recommendations to the Governor and GA General Assembly. Of importance, this bill does not create policy. It only creates the Council to make policy recommendations.

### DD Waivers Waiting List:

The NOW and COMP Waivers continue to have the longest waiting list of all Medicaid Home and Community-Based waivers in

GA. The waivers offer those who require an institutional level of care the option to receive those services in the community. As of March 9, 2018, there are 7,515 Georgians with developmental disabilities waiting for a NOW or COMP waiver. GCDD knows that for many of these Georgians, the need is urgent and they cannot wait any longer.

With the help of advocates, GCDD asked the GA General Assembly to fund 600 additional NOW and COMP waivers to make a small dent in the waiting list. This ask was based on Department of Behavioral Health and Developmental Disabilities' (DBHDD) multi-year plan to address the waiting list in GA. While we were unsuccessful in our goal of 600, our advocacy retained Governor Deal's recommendation that 125 new NOW and COMP waivers be added to the budget at a cost of \$3,138,073.

### Inclusive Post-Secondary Education (IPSE):

IPSE programs provide opportunities for study beyond high school to students with intellectual and developmental disabilities. Currently, there are eight IPSE programs in GA and two are slated to open in the next year. IPSE programs prepare students to live increasingly independent lives, pursue careers of their choice, and provide the potential for increased earnings long term.

GCDD is the legislative lead for the GA Inclusive Postsecondary Education Consortium (GAIPSEC). Last year, the GA General Assembly brought the funding level of IPSE programs to \$500,000 and transferred the funding, which was previously housed at GCDD, to the GVRA. The FY19 Budget maintained level funding and transferred the \$500,000 in state funding back to GCDD.

## 2018 ADVOCACY DAYS



GCDD held its third Advocacy Days at the Capitol to empower advocates, families and the community to educate legislators about issues that affect people with disabilities across Georgia. There were six Advocacy Days covering DD Waivers, Employment, Inclusive Post-Secondary Education, UNLOCK! Coalition and Medicaid.



GCDD also kicked off its "I Love Medicaid" Campaign on February 14th (Medicaid Advocacy Day) to collect and share stories of why Medicaid is important for people with developmental disabilities.



For more photos of Advocacy Days, visit <https://gcdd.org/news-a-media/photos.html>

GCDD thanks all the Georgia legislators who met with advocates during the legislative session. Here are just a few:

## OTHER FY19 BUDGET HIGHLIGHTS:

### Department of Behavioral Health & Developmental Disabilities (DBHDD)

- **\$220,000** increase to the Albany Advocacy Resource Center to fund their pre-school program for children with disabilities
- **\$6,000,000** increase for Behavioral Health Crisis Centers
- **\$250,000** increase for the Matthew Reardon Center for Autism
- **\$5,922,917** increase for crisis services for children under 21 with autism
- Utilize **\$266,119** in existing funds for telehealth services and three positions for behavioral health services for children under 21 with autism

### GA Council on Developmental Disabilities (GCDD)

- **\$14,000** increase to fund an agricultural summer camp for youth with disabilities

### Department of Community Health (DCH)

- **\$894,519** increase for the electronic visit verification system for Home and Community-Based Services (HCBS)
- **\$847,962** increase to develop capacity for behavioral health services for children under 21 with autism
- Utilize **\$962,022** in existing funds for increased background checks for owners and employees of long-term care facilities
- Utilize **\$50,700** in existing funds for one program coordinator position for children under 21 with autism
- **\$16,894,882** nursing home rate increase
- **\$1,204,573** to increase personal needs allowance for nursing home residents by \$15 per month
- **\$399,670** to increase Adult Day Health Centers reimbursement rates
- **\$1,000,000** to increase reimbursement rates for Licensed Practical Nurses and Registered Nurses in the Georgia Pediatric Program



### Department of Public Health (DPH)

- **\$100,000** to develop capacity for children under 21 with autism
- Utilize **\$50,700** in existing funds for one program support coordinator position for children under 21 with autism
- **\$399,005** increase to Emory Autism Contract
- **\$1,103,716** increase for occupational, speech and physical therapy rates in the Babies Can't Wait Program
- **\$119,922** increase to the Brain & Spinal Injury Trust Fund to reflect 2017 collections

### GA Vocational Rehabilitation Agency (GVRA)

*- within the Department of Human Services budget*

- **\$200,000** increase for a state hub geographically located to provide outreach and services to support independent living for Georgians with disabilities living in Southwest Georgia
- **\$20,000** increase for Friends of Disabled Adults and Children equipment

### Department of Community Affairs (DCA)

- **\$100,000** to the Statewide Independent Living Council for home modifications



Senator John Albers (R-Roswell)



Representative Wayne Howard (D-Augusta)



Senator Nan Orrock (D-Atlanta)



Senator Horacena Tate (D-Atlanta)



## BILLS THAT PASSED:

**HB 65:** Creates a Joint Study Commission on Low THC Medical Oil Access to study in-state access to medical cannabis and THC oil, as well as adds PTSD and intractable pain as conditions that qualify for low THC oil usage. (Rep. Allen Peake, R-Macon)

**HB 635: The Disabled Adults and Elder Person's Protection Act** – This bill allows for the creation of “Adult Abuse, Neglect and Exploitation Multidisciplinary Teams to coordinate the investigation of and responses to suspected instances of abuse, neglect or exploitation of disabled adults or elder persons.” (Rep. Sharon Cooper, R-Marietta)

**HB 740:** Before a school can expel or suspend a student in PK-3 for more than five consecutive or cumulative days during a school year, the student must first receive a multi-tiered system of supports. If the student has an IEP or plan under Section 504 of the federal Rehabilitation Act of 1973, a meeting must be convened first before suspension/expulsion. (Rep. Randy Nix, R-LaGrange)

**HB 803:** This bill defines the human trafficking of an adult with a disability or the elderly as a felony if the accused through “deception, coercion, exploitation or isolation, knowingly recruits, harbors, transports, provides or obtains by any means” an adult with a disability or elderly person “for the purpose of appropriating” their “resources” for their own benefit. (Rep. Wendell Willard, R-Sandy Springs)

**HR 1257:** House Study Committee on the Workforce Shortage and Crisis in Home and Community Based Settings (Rep. Jesse Petrea, R-Savannah)

**SB 118:** Raises the age limit for coverage of autism services under private insurance policies to age 20. (Sen. Renee Unterman, R-Buford)

**SB 370:** Instructs the GA DCH to submit an amendment to the federal Centers for Medicare and Medicaid Services that waives any claim by Medicaid Estate Recovery on the first \$25,000 in an individual's assets. (Rep. John Wilkinson, R-Toccoa)

**SB 406: Georgia's Long-Term Care Background Check Program** – This bill requires background checks of employees with direct access to patients in long-term care settings such as nursing, personal care homes, and home healthcare. It also creates the Central Caregiver Registry to allow employers to search for caregiver background checks. It allows family members who are employing caregivers for their loved one (age 65 or over) to obtain an employment eligibility determination from DCH for the applicant caregiver. This was a GA Council on Aging priority for 2018. (Sen. Brian Strickland, R-McDonough).

**SR 467:** “Senate Study Committee on Service Animals for Physically or Mentally Impaired Persons” (Sen. Renee Unterman, R-Buford)

**SR 506:** “Senate Study Committee on the Excessive and Duplicative Regulatory Oversight of Community-Based Intellectual and Developmental Disability (IDD) Services” (Sen. Mike Dugan, R-Carrollton)

## BILLS THAT DID NOT PASS:

**HB 668:** This bill would allow guardianship proceedings when an individual is 17 years old. (Rep. Betty Price, R-Roswell)

**HB 768: Proof to a Preponderance of the Evidence** – This bill sought to address the issue of Georgians with intellectual disabilities being executed for capital crimes by introducing a pre-trial proceeding to determine intellectual disability with a clear and convincing standard, as well as a system to raise intellectual disability claims prior to the sentencing phase with a preponderance of the evidence standard. (Rep. Scott Hilton, R-Peachtree Corners)

**HB 891:** This bill looks at discrimination that parents who are visually impaired or blind face in regard to child custody, adoption and visitation. (Rep. Carl Gilliard, D-Garden City)

**The GA Special Needs Scholarship** (the SB10 waiver) was the topic of two bills this legislative session, HB 759 and HB 801. While neither passed, GCDD understands that a group of legislators will be working on this issue over the summer in a non-official study committee. We will keep you updated as we learn more!

### GCDD'S PUBLIC POLICY TEAM



DAWN ALFORD, GCDD  
Public Policy Director



HANNA ROSENFELD,  
GCDD Planning and  
Policy Development  
Specialist

**NOTE:** Governor Deal has until May 8th to sign or veto these bills. If Governor Deal chooses not to veto or not to sign, the bill will become law. This is not a comprehensive list of all bills that passed during the GA General Assembly.

**IT'S ELECTION SEASON!**

**THE DISABILITY**

# VOTE COUNTS

**It's election season again! In November, millions of Americans will head to the polls to vote in the 2018 Midterm Elections taking place on November 6, 2018.**

Midterm elections are held between presidential elections, and this year, all 435 seats in the United States House of Representatives, and the full terms for 33 out of the 100 seats in the United States Senate are up for election.

## GEORGIA GENERAL ASSEMBLY

**House: All 180 Seats  
Senate: All 56 Seats**

In addition to the federal election, there are 39 gubernatorial (governor) races, state elections and hundreds of local elections taking place across the country.

While most attention leans towards federal elections, it is important to pay attention to state and local elections as well. Like all elections, this year it is important for people with disabilities to head to the polls to make their voices heard.

## CIVICS 101

When educating yourself on who is running for office, it is helpful to know what responsibilities each office holds. Once this is clear you will most certainly want to stay informed on every level.

## FEDERAL - US HOUSE

Also referred to as a congressman or congresswoman, each representative belongs to the legislative branch, the part of the government that makes laws. Each is elected to a two-year term serving the people of a specific congressional district – there are 435 in the country.

A congressional district is an electoral constituency that elects a single member of Congress. It is based on population, taken by the US census every 10 years. The US House represents the people directly.

## FEDERAL - US SENATE

Senators also belong to the legislative branch, the part of the government that makes laws. The Senate ratifies treaties and confirms appointments to judicial and executive branches, including cabinet secretaries and Supreme Court justices.

A senator's job is to represent the people living in his or her state. Senators serve staggered six-year terms, meaning that not all individuals are up for election at the same time. Rather, elections are held every two years for one-third of Senate seats.

## STATE OF GA ELECTIONS

Voters in Georgia will also be selecting a new governor, state senators and representatives, and city council men and women.

The Georgia General Assembly is the state legislature. It is bicameral, meaning it consists of the Senate and the House of Representatives. Each of the General Assembly's 236 members serve two-year terms and are directly elected by constituents of their district. While both houses have similar powers, each also has unique duties. (e.g. the origination of appropriations bills only occurs in the House, while the Senate is tasked with confirming Governor's appointments.)

## GEORGIA - STATE SENATE

A state senator represents constituents in their respective districts. Their votes are based on feedback from constituents in order to represent the people in legislative sessions. In addition to their role as negotiators within the state legislature, many participate in committees and oversee committee members as well as contractors responsible for projects in their district.

Composed of 56 members elected every two years, the GA Senate meets over a non-consecutive 40-day period beginning in mid-January to set the state's operating budget and create and amend

## US CONGRESS

**Senate: 35 of 100 Seats  
House: All 435 Seats**

a variety of laws on topics ranging from healthcare (like Medicaid and DD Waivers) to public safety.

## GEORGIA - STATE HOUSE

With its 180 members from districts across the State, the GA House of Representatives is the larger of the two chambers of the General Assembly. Its members serve two-year terms and each January convene to set the state's operating budget and priorities ranging from agricultural development to tax policy.

## LOCAL ELECTIONS

Local elections are equally as important as state and federal elections. This level of government is more directly responsible for serving your community. Local government – like city councils, mayors, school boards and more – impact almost every aspect of an individual's daily life.

The powers and duties of the Mayor and City Council are contained in state law and City ordinances, resolutions and regulations. The Council works to adopt regulations for the health, safety and welfare of the current and future inhabitants.

Local government works on:

- Local school quality
- Policing / public safety
- Rent costs / affordable housing
- Public transit
- Alcohol / marijuana ordinances
- City colleges / job training

The individuals you choose to represent you on a local level play an important part in how communities serve everyone, including people with disabilities.

*(See Calendar on page 24 for more important Georgia Election Dates.)*

## 2018 MIDTERM ELECTIONS

### FOCUS ON GEORGIA

#### WHO WILL GEORGIANS BE VOTING FOR?

- All 56 State Senators
- All 180 State Representatives
- The 14 US Representatives from the State of GA
- Governor of GA
- Lt. Governor of GA
- GA Executive Branch *(see sidebar to right)*
- Local Officials

To find out who is seeking election or re-election in your district in Georgia, visit <https://ballotpedia.org/Elections>



Save the Date!  
Nov 6, 2018  
2018 MIDTERM ELECTIONS

## RESPONSIBILITIES OF THE EXECUTIVE BRANCH IN GA

**Governor** - heads the state's executive branch and has considerable control over budgeting, appointment of many officials (including judges), and a considerable role in legislation.

**Lieutenant Governor** – second highest elected official in state, influences state policy and spending priorities. As President of the Senate, presides over debate and oversees legislation. Serves the unexpired term if the Governor dies or exercises those powers if the Governor is incapacitated.

**Secretary of State** - responsible for the administration of secure, accessible and fair elections; registration of corporations; regulation of charities and securities; and oversight of professional licenses.

**Attorney General** – acts as chief legal advisor to the state and state's chief law enforcement officer.

**Commissioner of Agriculture** – heads the GA Dept. of Agriculture, responsible for regulating and promoting GA agriculture industry.

**Commissioner of Insurance** - administrative head of the Office of Insurance and Safety Fire Commissioner, which regulate the state's insurance industry and oversees state fire safety initiatives.

**State School Superintendent** – responsible for overseeing and coordinating the state's elementary and secondary schools.

**Commissioner of Labor** - responsible for implementing the state's labor regulations, operating unemployment insurance and rehabilitation programs and producing GA labor statistics.



Camper with and without disabilities work together at the Marcus Jewish Community Center of Atlanta summer camps.

# Camps Rise to the Occasion with Inclusive Summer Programs

by Adrienne Murchison

Lifelong memories are created at summer camp. The mix of self-discovery and recreational experiences bring the kind of joy to children’s faces that every parent wants to see. For Leanne and Anthony Abraham, it was delight in seeing their son Amiri ride a horse at the Marcus Jewish Community Center of Atlanta (JCC) summer camp in 2014.

Just before then eight-year-old Amiri started camp, the couple was asked by the director, what was the one thing they wanted him to be exposed to? They wanted him to be comfortable atop a horse.

Amiri, now 12, is diagnosed with Down syndrome and riding horses is among the many things he has enjoyed during the summer getaway where campers with and without disabilities participate together in activities such as swimming, boating, sports and arts and crafts.

“He loves it,” Leanne said. “It’s a very warm feeling as a parent. He’s made friends that he plays with outside of camp. We thought that because he has inclusion at school, summer camp should be too.”

Inclusive summer programs are proving how children with disabilities can thrive when they are included. Registration at most camps close soon, however they do provide waiting lists to fill inevitable cancellations. While all camps are not equipped to accommodate children with disabilities, parents have a variety of inclusive

camp administrators and staff are deliberate in facilitating safe, as well as adventurous daily experiences accessible to all children.

With the Abrahams, Jennifer Lieb, director of the Blonder Family Department for Special Needs at JCC, visited Amiri in his school setting to see if he would be a good fit for their summer camp and what specific assistance he would need.

The JCC has about 100 different types of summer programs with nearly 600 attendees per week. Camp runs from Memorial Day to the first week of August. JCC camps are not faith-based and children of all faiths are welcomed.

“Traditional is the most popular for campers with disabilities,” said Lieb, referring to Pre-K through middle school programs. “It’s an overnight camp experience in a day camp setting. We have an inclusive team to support the child and can make basic modifications.”

JCC’s summer program boasts a nearly 100% retention rate. Lieb

said lines blur between campers as they are eager to partner on teams and celebrate each other’s birthdays.

“The exposure is amazing,” she said. “It’s truly inclusive.”

The JCC and other programs such as Peacebuilders Camp in South Georgia allow for facilitators to be with children throughout the day for one-on-one support.

Located on a 250-acre farm, Peacebuilders overnight summer camp teaches middle-schoolers about the importance of human rights and how to have a positive, meaningful impact on the world. Through games they learn about past and present activists, including teenage trailblazers. Camp counselors blend in service projects and discuss thought-provoking topics related to the Universal Declaration of Human Rights.

To explore the right of everyone to have access to adequate food, Peacebuilders brought in staff from Carver Neighborhood Market in South Atlanta last year to introduce the concept of food deserts. They set up a game for campers to learn how a person’s circumstances can hinder their ability to shop at markets



We want them to have shared experiences and to have a wonderful summer experience.

located a significant distance away from their neighborhood.

For many people, including those with disabilities, this is a reality. The point of the game was for all of the campers to develop empathy for others and know that everyone has a right to have access to food.

Peacebuilders hosts three one-week camp sessions in July. Each session has only 20 campers. "Within that, we know them really well," said McDonald. "We work to make sure no one is turned away and approach them on a case-by-case basis."

While the camp may not be able to accommodate everyone currently, it is working on increasing its reach and capability.

## INCLUSION IS IMPORTANT IN GENERAL BECAUSE IT GIVES EVERYONE AN OPPORTUNITY TO LEARN FROM EACH OTHER.



The camp organization is funded in part through the Real Communities Partnerships initiative of the Georgia Council on Developmental Disabilities (GCCD). A main objective is to inspire campers with and without disabilities to be social justice advocates and realize goals that they set for themselves.

"We follow up with campers to record stories of what they have accomplished," McDonald said.

In the past, Peacebuilders' counselors have designed curriculum and activities to meet the individual physical needs and learning abilities of campers who would benefit.

Last summer, a camp counselor stayed alongside a camper with muscular dystrophy to provide specific physical movements designed to keep him engaged in activities, McDonald said.

In preparation for its 2018 summer camp, Peacebuilders has collaborated with the Atlanta Area School for the Deaf (AASD) on ideas to create the best possible experience for students attending camp for the first time this year. Campers will have sign language interpreters.

"Often, our students here are home for two months during the summer and feel isolated [as they] don't have a lot of people to communicate with," said Adam Garfinkel, high school transition coordinator. "And we want them to have shared experiences and to have a wonderful summer experience."

The existence of inclusive summer camps helps build awareness of basic needs that self-advocates and families have to fight for, that others move through easily, said John Serrano, AASD school superintendent. "Unfortunately, it's not a given," he added.

Peacebuilders seeks to counter the notion of a child feeling like an outsider. "It's about creating programs that are fully inclusive and having campers feel included," McDonald said. "That's the bottom line that we are trying to achieve."

Susanna Miller-Raines' works with the Center for Leadership in Disability at Georgia State University helping to inform the larger community by translating research on the best practices in developmental disabilities into programs that ultimately support and benefit people with disabilities.



Campers with and without disabilities mix ingredients in a cooking class at SciKidz summer camp.

That includes children with disabilities and their families.

"Inclusion is important in general because it gives everyone an opportunity to learn from each other," Miller-Raines said.

There are varying dynamics for children with disabilities and their families. "There are situations where you have a camper with a disability who might not be as included in the rest of their life," she said. "And camp gives them an opportunity to learn skills through observations of other peers. Also, students in school are more and more included all of the time, so it's been more natural to be included, which is beautiful."

## PARENTAL INVOLVEMENT

Parents have an essential role in how their child's summer unfolds into a successful camp experience. It benefits them to make inquiries on applications and ask how equipped counselors are to meet children's individual needs as they arise.

For example, Athens-Clarke County programs provide a range of support for children with disabilities, with the exception of personal care needs. Its camps include sports, arts, a nature center and more.

"We have children with various disabilities in our programs and will work to see what's needed for additional support" said Leslie Trier, a certified therapeutic education specialist. "But we do sometimes get



SciKidz campers find a sense of belonging, camaraderie and friendship.



Adult volunteers and campers work together on a project for a hospitality house at Peacebuilders Camp.



Campers with and without disabilities work on projects at the Marcus Jewish Community Center of Atlanta summer camps.

requests for things I cannot change. For example, if a gym echoes and a child cannot handle a lot of noise, camp may not be the best place.”

The ratio of counselors to campers is good to know as well. Athens-Clarke County’s inclusive programs have about one counselor per 10 kids.

Camp directors also stress the importance of families providing complete information on children including medical, medicinal and dietary needs. Bob Hagan, co-owner of Club SciKidz, said there have been occasions when parents omitted crucial information on forms and camp counselors were at a disadvantage as a result.

“We’ve had kids [who are diagnosed with autism or] have emotional issues and there is nothing on the forms,” Hagan explained. “And we are scratching our heads and wondering what is wrong.”

SciKidz offers science-based summer day camps to students from Pre-K to ninth grade at churches and schools around the Atlanta metro area in June and July. Campers’ interests are piqued by topics such as crime scene investigations, 3D printing, advanced robotics and space engineering.

During Veterinary Science Camp students learn first aid techniques

for pets, such as how to clean a dog’s ears. During microscopy, they analyze bacteria and blood samples provided by local veterinarians.

SciKidz site directors must hold current classroom teaching positions in Georgia. Counselors are trained in education and inclusivity.

The camp has had many participants with various needs. “Some have had a feeding tube, sometimes kids have a disability with just one arm or hand and might need some assistance,” said Hagan.

Some parents hire private facilitators who are beside a camper all day.

Additionally, at SciKidz, a counselor of the same gender can assist somewhat physically independent children that adapt well without aid, but perhaps need help standing or toileting, Hagan added.

Counselors and directors are a great help, said Fionnuala Burdett, the mother of 11-year-old twin boys who are on the autism spectrum and attend the JCC summer camp.

“This will be their fifth year,” said Burdett. “They would not be able to attend this camp if they did not have help during the day. Counselors ask for my advice and Jennifer has been my lifeline. Brendan is nonverbal and Aidan socially finds it hard to interact.”

The facilitators are adept at keeping children focused, she said. “Aidan knows every type of tsunami, hurricane and storm. The facilitator will say, ‘Let’s not talk about the weather right now. Let’s talk about what you did on your vacation.’”

To ensure parents and children are equally excited and comfortable with attending camp, SciKidz and JCC allow families to tour and learn about the experience and surroundings before opening day.

The JCC will hold an open house for families interested in their day camp on May 24 at the Zaban Park location in Dunwoody. Parents and children can walk the grounds and sample activities that will take place when camp begins.

“I highly encourage a camp tour,” Lieb said. “Parents are our best allies. We try to work closely with them to know the child. We encourage them to share things with us so we can frame their child’s experience positively.”

### GAINING INDEPENDENCE

Last year, an excited Amiri brought home flyers on Camp Barney every week and pleaded with his parents to let him go. So, the Abrahams are considering their son attending a week away for the first time ever.

# INCLUSIVE SUMMER CAMP PROGRAMS

## **Athens-Clarke County Leisure Services**

706.613.3800

<https://www.accgov.com/148/Leisure-Services>

## **Atlanta Area School for the Deaf**

404-296-7110, [aasdweb.com](http://aasdweb.com)

## **Camp Best Friends**

City of Atlanta Office of Recreation

Email: [CampBestFriends@atlantaga.gov](mailto:CampBestFriends@atlantaga.gov)

Website: <http://bit.ly/2InvESG>

## **Club SciKidz**

678.493.5651, [clubscikidz.com](http://clubscikidz.com)

Summer Camp starts on June 4, 2018!

## **Marcus Jewish Community Center of Atlanta**

678.812.4000, [atlantajcc.org](http://atlantajcc.org)

OPEN HOUSE - May 24, 2018

## **Peacebuilders Camp - Koinonia Farm**

404.373.8036, [peacebuilderscamp.org](http://peacebuilderscamp.org)

## **Spruill Arts Summer Art Camps**

770.394.3447

<http://www.spruillarts.org/>

[youthclassesandcamps](http://youthclassesandcamps)

## **RESOURCES FOR SUMMER CAMPS**

### **Atlanta Parent Magazine**

<https://www.atlantaparent.com/summer-day-camps-listings-atlanta-georgia/>

### **American Camp Association**

<http://find.acacamps.org/>



Children at the Peacebuilders Camp wait for fireworks to begin on July 4, 2017.

Anthony Abraham finally agreed, but Leanne contemplates Amiri's dietary restrictions and wellbeing.

Leanne said, "Every year, he becomes more self-sufficient. He had a facilitator when he first started camp and last year he shared one. I guess we are over-protective."

Understandably, all parents are protective when their son or daughter is attending camp for the first time, but their children's excitement is always reassuring.

Burdett recalls her unexpected tears of joy after Brendan and Aidan's first day of summer camp.

"They were sweaty and had dirty hair," she said. "It was just like what you would consider a typical summer camp to be for kids." The Burdett boys have become more independent and are eager to go back to school as a result of camp.

"Brendan has more eye contact now," Burdett added. "Aidan, getting him out of his shell is very much a big deal."

For parents who have children with disabilities, the separation is naturally easier to bear with day camps than sleep-away programs. Those can prove especially difficult as some have strict rules that limit communication with family to establish a sense of independence.

"I do think campers need to have that separated experience, but staff could be more willing to communicate with families," Miller-Raines said.

In 2010, she was camp director at Talisman Summer Camp in North Carolina, which served young people on the autism spectrum or diagnosed with Asperger's syndrome and attention deficit hyperactivity disorder (ADHD).



Twins Brendan and Aidan Burdett have flourished at JCC's summer program, which they have attended for five years.

"The camp I worked at, there were weekly phone calls," she said. "A lot of camps don't do that." Instead, most camp administrators update families on children's progress.

Amiri's increased independence is likely linked to the amount of time he spends at camp, which has extended each year, his mother said. In 2017, he went for six weeks.

**THEY WERE SWEATY AND HAD DIRTY HAIR. IT WAS JUST LIKE WHAT YOU WOULD CONSIDER A TYPICAL SUMMER CAMP TO BE FOR KIDS.**



Leib said campers benefit greatly by attending for at least a month. "We recommend at least three consecutive weeks," she said. "Week one they're figuring it out. Week two they're getting comfortable, and by three, they've got it."

Indeed, by that third week, campers have a found a sense of independence, belonging and camaraderie.

Inclusive summer camps demonstrate children with and without disabilities not only want to feel included in every type of activity, but they thrive in the experiences resulting in new-found confidence and security within themselves.



# What's Happening in Washington?

## Federal Disability Policy Updates

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

I am excited to be starting a new column for *Making a Difference* titled *What's Happening in Washington?* to provide insight on the many federal policies that impact the lives of people with disabilities. This includes bills in Congress and actions by federal agencies. As the sister of a self-advocate Evan Nodvin, who serves on the Georgia Council on Developmental Disabilities (GCDD), I always want to support Evan and my family in finding ways to impact the important policies that effect our lives. I hope that this column will be a way for me to share this same type of information with Georgia's statewide disability community.

### Federal Budget

Budgets may sound boring. But they're how the President and Congress lay out their priorities for federal programs and agencies. Congress translates these budget priorities into "appropriations bills" that make spending decisions about individual programs. Disability advocates spend a lot of time educating members of Congress about the importance of, and need to fund, federal programs that impact people with disabilities – from Medicaid, to employment and education programs, to the Councils on Developmental Disabilities (DD Councils).

Right now, budget activities are happening for two different fiscal years – the rest of this fiscal year (FY '18, through September 30, 2019) and for Fiscal Year '19 (which starts on October 1, 2019). As I am writing this article, the

President literally just signed an appropriations bill (passed by both houses of Congress) to fund federal programs and agencies for the rest of FY '18. Because Congress reached a deal last month to raise the amount of money that can be allocated to all types of federal programs, we were hopeful that the bill would not make significant cuts to programs that help people with disabilities in this bill. In fact, we are pleased to see that many disability programs actually received increased funding, including the DD Councils, state protection and advocacy organizations, University Centers for Excellence in Developmental Disabilities, as well as other programs that benefit people with disabilities like affordable housing. The omnibus did not address a number of healthcare related issues, such as funding for healthcare subsidies or re-authorization of the

Money Follows the Person program (*see page 18*). These issues may be addressed in separate bills later.

In contrast, disability advocates are very concerned about what might end up in the appropriations bills for the next fiscal year. The FY '19 process began in mid-February when President Trump sent his budget request to Congress. It contains many proposals that, if adopted by Congress, could harm people with disabilities and their families, including:

### Cuts to Medicaid:


The President's budget request proposes to cut over \$675 billion in spending from Medicaid, along with additional reductions in federal subsidies for health insurance. Medicaid is the primary funding source for long-term services and supports for people with disabilities, including home community-based services



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

inclusion of people with disabilities, including *Olmstead* enforcement, Medicaid policy, employment, housing and education.





The budget also proposes huge cuts to programs that help people meet their basic needs.

(HCBS). Medicaid is what funds, for example, Georgia's HCBS Waivers like NOW, COMP, ICWP and CCSP. Significant cuts to Medicaid could lead to services being reduced or eliminated and waiting lists for community services growing. The budget also proposes additional healthcare policy changes, including weakening some of the Affordable Care Act's protections for people with pre-existing conditions and adding work requirements to Medicaid (*see discussion later on*).

### Cuts to Disability

**Programs:** The President's budget also proposes deep cuts to programs that provide employment, support and advocacy to people with disabilities. Three of the four programs created under the Developmental Disabilities Act would receive significantly reduced funding: the Councils on Developmental Disabilities, the University Centers for Excellence in Disabilities and the Projects of National Significance. In addition, grants to help people with disabilities get jobs and train medical professionals on treating people with developmental disabilities would be completely eliminated.

### Cuts to Programs that Support Basic Needs:

The budget also proposes huge cuts to programs that help people meet their basic needs, including many people with disabilities and their families. The budget proposes approximately \$70 billion in cuts to Social Security programs, including Supplemental Security Income

(SSI) and Social Security Disability Insurance (SSDI); \$6.8 billion from housing assistance programs; and \$213 billion from nutrition assistance programs.

Fortunately, the President's budget is just a request; Congress must develop and pass appropriations bills. And cuts to programs like Medicaid, Medicare and Social Security that are considered "mandatory" cannot be made through appropriations bills. Congress would have to pass a set of specific instructions to relevant committees. While Congress did this last year, we are hearing they are not likely to do so this year. Regardless, disability advocates should continue to educate their members of Congress about the importance of "discretionary" programs that we care about – like disability employment, education and DD Councils.

### Medicaid Policies

Disability advocates from across the country spent most of 2017 working to prevent Congress from significantly cutting or restructuring Medicaid. While Congress is not currently considering any similar legislation, the President's budget request does encourage Congress to do so again. We will continue to educate Congress about the importance of Medicaid to the lives of people with disabilities and about how cuts would hurt us and our families.


Instead, significant changes to Medicaid have been occurring through federal agency policies. Most recently, the federal agency that administers Medicaid (the Centers for Medicare & Medicaid Services, or CMS) issued a policy that for the first time allows states to impose work requirements as a

## WHAT'S HAPPENING IN WASHINGTON?

condition of receiving healthcare services through Medicaid. Disability advocates are very concerned that imposing work requirements could lead to people with disabilities and their families losing access to Medicaid because:

- Most people on Medicaid already work or face barriers to working, including having an illness, disability or caring for a loved one.

**DISABILITY ADVOCATES SHOULD CONTINUE TO EDUCATE THEIR MEMBERS OF CONGRESS ABOUT THE IMPORTANCE OF "DISCRETIONARY" PROGRAMS THAT WE CARE ABOUT.**



- Even though this policy exempts some people with disabilities (those who meet the strict criteria for "disabled" for purposes of SSDI or SSI), many others with disabilities or chronic conditions who do not meet these standards will be subject to these policies.
- Work requirements do not include job training or services or supports to help people find a job. Nor do they address barriers to employment, like transportation or childcare. In fact, the policy prohibits states from using Medicaid funds for these activities.
- In other programs (such as nutrition assistance), work requirements have not been shown to increase participants' employment and the burdens imposed (such as requirements

# Keep Updated and Take Action:

I VOTE!



- ★ Keep updated and take action on the budget process at <https://medicaid.publicrep.org/feature/the-federal-budget/>
- ★ Learn more about MFP and take action to help pass the EMPOWER Care Act at <https://medicaid.publicrep.org/feature/money-follows-the-person/>. And you can learn more about Georgia's MFP program at <https://dch.georgia.gov/georgia-money-follows-person-ga-mfp>
- ★ For more information about the concerns of the disability community about work requirements, see <https://medicaid.publicrep.org/feature/medicaid-work-requirements/>
- ★ Learn more about and keep updated on ADA Reform Act bills at <http://www.c-c-d.org/rubriques.php?rubpage=43>

to regularly document work) have led to eligible people losing access to benefits.

CMS has already approved requests for work requirements in several states, including Kentucky, Indiana and Arkansas. We are closely watching other proposals that states have said they would like CMS to consider. This includes lifetime caps on benefits, which would be harmful to people with disabilities who have long-term care needs.

## Money Follows the Person (MFP)

MFP gives states additional federal Medicaid funds to help transition people from nursing homes and other institutions to the community. MFP has helped 75,000 people with disabilities and seniors move to the community. It has resulted in improved outcomes for participants and cost savings for states. Georgia's MFP program will help 2,600 individuals move to the community.

Unfortunately, the MFP program expired on September 30, 2016. All states' MFP funding, including Georgia, will run out by the end of 2018. As a result of advocacy by disability and aging advocates, the Senate and House have both

recently introduced the EMPOWER Care Act to re-authorize the MFP program. We are asking disability advocates to educate their members of Congress about the MFP program, ask them to co-sponsor the EMPOWER Care Act, and encourage them to pass this bill as soon as possible.

## Americans with Disabilities Act

The Americans with Disabilities Act (ADA) was passed in 1990 to prohibit discrimination against people with disabilities in all aspects of life. One critical part of the ADA is its requirement that "places of public accommodation" – things like stores, restaurants and doctors' offices – be accessible. Even though businesses have had 27 years to come into compliance with these rules, some members of Congress believe that the ADA should be amended to set up additional requirements before people with disabilities can access the courts to enforce their rights. On February 15, 2018, the House of Representatives passed the "ADA Education and Reform Act," also known as HR 620. The disability community across the board opposed this bill for the following:

- It would remove all incentives for places of public accommodation to proactively comply with the ADA. The bill requires notice to the business and gives them months merely to show "substantial progress" in removing the barrier.
- The bill adds a "notice and cure" requirement. A person with a disability must notify the business of the access problem and give them 60 days to respond and another 60 days to make "substantial progress" in addressing the barrier. That means people with disabilities would wait months to gain access to inaccessible public places.
- It would create hurdles for enforcement of rights by people with disabilities that don't exist under other civil rights laws.

So far, this bill has only passed the House. A number of Senators have already expressed concern about any similar bill introduced in the Senate.

There is a lot happening in Washington that impacts the lives of people with disabilities and their families – both in Georgia and across the country! I look forward to sharing information about these policies, and how you can impact them in this column.

## Achievable Goals

by Christine Clark

**My son, Jack Clark, had a big transition this year as he started middle school. My husband and I saw it as the perfect opportunity to teach him how to advocate for himself. We started this summer by fighting against Medicaid cuts proposed by the US Congress. Jack will proudly tell you “No Caps, No Cuts!” He also participated in his annual IEP meeting last fall, and successfully advocated to spend more time with his friends.**

I started a transition myself last year. I started graduate school at Georgia State University. I also began my first year as a parent advocate on the Georgia Council on Developmental Disabilities (GCDD). Both new adventures got me involved in advocating during the legislative session. I still have a lot to learn, but I quickly picked up on how important it is to do your homework and use all of your resources before heading to the ropes.

**I STILL HAVE A LOT TO LEARN, BUT I QUICKLY PICKED UP ON HOW IMPORTANT IT IS TO DO YOUR HOMEWORK AND USE ALL OF YOUR RESOURCES BEFORE HEADING TO THE ROPES.** ”

First, research your representatives online. Find common ground with them. The House of Representatives have other careers, see if there is a commonality. Look up what bills they are sponsoring and get a feel for what they support. Find past or current

legislation that you agree with or find an initiative that they are supporting in the community.

Every representative is required to be on a committee and so research which ones yours supports. Think about the issue that you are advocating for and try and understand it from their point of view. If they are a Republican on the budget committee, think about how the issue may save money or reduces government oversight. If they are a Democrat on a health and human services committee, identify how the issue will positively affect the people in their district.

Plan on what you want to say after you introduce yourself as their constituent. Show support for a previous piece of legislation or initiative in your community to put both of you at ease and to get their attention. Or share a joint interest group or profession that you have with them. Then introduce why you are there today. Explain how the issue affects you and your family. Highlight a benefit to them for supporting your point of view.

The legislative session is an opportune time to get in front of your representatives, but it isn't the only time. Initiatives pop up all year, and they may have more

Advocates at 2018 Advocacy Days head to the State Capitol to meet with legislators during the session.



Christine Clark (r) is a parent advocate and a member of the Georgia Council on Developmental Disabilities. She is pictured here with her husband and son Jack.

time to sit down with you after the legislative session is over. Also, the ropes during session can be sensory overload for anyone and not the best environment for you to have a conversation. Reach out to your representative via email or by calling to schedule a time in the afternoon when session breaks or find time during other times of the year.

Last but not least, one final bit of advice, everyone is nervous the first few times they do it, especially if the issue is crucial to you or your family's future. Don't let that stop you!



## 14 Years of Lessons

by Pat Nobbie, PhD

*Making a Difference* is taking a new direction, so this is our last Mia's Space. Two thousand words a year, for 14 years, have managed to capture our experience as a family living, learning, laughing and occasionally crying with Mia pretty well. So many positive changes in disability policy and practice have happened in her lifetime. But, we are in danger of losing this progress – from forgetfulness, from lack of vision, from resource scarcity. Here are some things I want people to remember about Mia's story.



MIA'S SPACE

First, despite what people may think, I don't have all the answers. There were lots of times I had heart-dropping moments, no clue what to do next, doubted my decisions, went totally on faith and if nobody got hurt, took a deep breath and went on.

Second, I fully appreciate that Mia seems "easy" and other families have a much harder struggle to keep their lives on track – the fact that I was sometimes challenged with someone easy to support is indicative of how much work we need to do to support families better.

Third, Mia's great life is the result of all of us looking outward – expanding her experiences and inviting others in. She has her own space that is easy for her to manage. She has a job that she loves with a hospital staff that looks after her, enjoys her, and invites her to social events, to which she also contributes.

She is a Sunday School teacher, and a few weeks ago, I attended a teacher appreciation breakfast with

her. I heard from staff and children alike how valued she is. She has friends that check in with each other regularly, attend each other's milestone events, have sleepovers, dances, karaoke, go to swimming and bowling. She is in so many spaces in her community that if she doesn't show up somewhere she is expected, within 15 minutes I am getting a text, "Where is Mia? Is she late? Sick? Away?" These relationships are what keep her safe, and me confident in that safety.

Fourth, her consistent support – from the Whitakers whom she lives with, Fabersha who has been a companion since high school, Celandra, her support coordinator to Briggs and Associates employment support. Knowing how well these folks know her, have their own relationships with her, is invaluable.

Fifth, I have a community. Too numerous to name here, but I have other moms, friends, colleagues and professionals from all walks, and sometimes total strangers that make me think, encourage and challenge me. Eric [Jacobson]

always supported me to have a family life and to bring the challenges into work so we could make things better. I've often said that I've watched Mia out there in the world, saw what needed to happen and worked on it, but that she never got to benefit from anything I did at the Council. She was always ahead. But, I couldn't have done Mia's Life without MY people.

**WE HAVE TO MAKE A WORLD THAT WORKS FOR EVERYONE. EVERYONE MEANS EVERYONE. AND EVERYONE NEEDS EVERYONE TO MAKE IT POSSIBLE.**

”

It is so hard to sum up 14 years of accumulated experience, but I think Beth Mount said it best: "We have to make a world that works for everyone. Everyone means everyone. And everyone NEEDS everyone to make it possible."

Bye for now! Thanks for reading!

*Pat and Mia*

## Youth Camp Encourages Peacebuilding

About two and a half hours south of Atlanta, the Peacebuilders Camp at Koinonia Farm (Peacebuilders) is nestled in Americus, GA.

A unique overnight summer camp, Peacebuilders invites youth ages 11-14 to spend a week together learning how to work towards peace and justice. Campers enjoy farm life, games, sports, field trips and crafts as they learn about human rights, make new friends and explore the stories of peacemakers past and present.

With support from the Georgia Council on Developmental Disabilities' Real Communities Partnership, Peacebuilders is able to include more youth with disabilities and offer more programming that educates and inspires all campers by highlighting the work and heroes of the disability rights movement.

Peacebuilders' curriculum is based on the United Nations' Universal Declaration of Human Rights (UDHR). Campers of different races, religions, ethnic backgrounds and socioeconomic levels; from rural, suburban and urban neighborhoods; and those with and without disabilities live



and work together as a community for a week at Koinonia Farm, an intentional community with a rich history in social justice activism.

Each day of camp, discussion and activities are focused on one human right from the UDHR. Campers are encouraged to consider the importance of that right; which communities may be left out of that right; and what can be done to expand it with and for at-risk communities and individuals.

Field trips, service projects and opportunities to meet peacemakers and activists offer further inspiration. Each day at camp also includes recreation and free time, during which campers form strong bonds across lines of diversity and begin to understand others' points of view.

At the end of each session, campers commit to one action that will promote justice and encourage peace in their home communities. Peacebuilders Camp is an empowering week for youth seeking to make a difference in their world.

**CAMPERS COMMIT TO ONE ACTION THAT WILL PROMOTE JUSTICE AND ENCOURAGE PEACE IN THEIR HOME COMMUNITIES.**

### 2018 CAMP DATES

- Session One (ages 11-12)  
July 2-7, 2018
- Session Two (ages 13-14)  
July 9-14, 2018 (waiting list only)
- Session Three (ages 13-15)  
July 16-21, 2018

*Registration: <http://www.peacebuilderscamp.org/registration/registration-1/>*

*For more information, visit <https://gcd.org/real-communities/current-partners/>*

Peacebuilders invites youth ages 11-14 to spend a week together learning how to work towards peace and justice.



Robin Wilson (middle) with her grandmother Sandy (left) and mom Jody (right) has found independence after receiving the COMP Waiver when she was 20 years old.

## Am I Gonna Be Stuck With You?

Fridays are Robin Wilson's favorite days. She gets to work at FurKids, the largest cage-free, no-kill shelter in the Southeast for rescued cats and dogs. Robin walks dogs, does laundry used in the care of the rescued animals, and prepares kits that are sent home with every new adoption.

Her work at FurKids is supported by her job coach, Beverly Anderson, who Robin's mom says "is more like a life coach."

Robin is a 32-year-old woman diagnosed with Williams syndrome, a developmental disorder characterized by mild to moderate intellectual disability or learning problems, unique personality characteristics, distinctive facial features and cardiovascular problems. However, Robin has no cardiac issues, and her

family is thankful every day for her healthy heart. Robin also has some OCD and a severe peanut allergy, which has limited her ability to participate in some public events, such as sporting events, as she'd like to. Her mom, Jody, explains

that people tend to throw peanut shells on the ground. Robin picks anything up she sees, and a peanut shell could throw her into anaphylactic shock quickly.

When asked what Robin likes about FurKids, she enthusiastically says, "They [the staff and volunteers] are nice, sweet and work very hard." She calls preparing the adoption kits "doing the baggies" and shares that she does a good job. Each bag contains shampoo, conditioner, snacks, a brush, and instructions – items donated by a pet supply line by Paul Mitchell.

Julia Galotti, FurKids staff member who runs the front desk, says Robin is

a big help to the team. "It just makes so much sense and it's so helpful," she says. "We'd probably be running to the back ourselves to throw those kits together in the middle of the lobby being full on a crazy Saturday morning when everyone comes in to adopt."

FurKids has other volunteers with developmental disabilities besides Robin, including a whole class of youth with disabilities from Eaton Academy who help walk the dogs.

Robin has been on the COMP Medicaid waiver since she was 20 years old. She'd been on the waiting list for two years at that point. Her mom, Jody, says that being on the waiting list was one of the hardest periods of their lives.

She called their administrator every day to keep them at the top of his list. Most of the time, he didn't answer, but she left messages for him. He would tell her that he had to make notes every time she called. When Robin got ill and needed surgery, it bumped them to top of the list immediately.

Jody says, "It's sad that sometimes people have to wait until they are 75. It's really unfortunate that's what it took."

Robin lives half-time with her mom and the other with her grandmother, Sandy, affectionately called "Nanny," and Nanny's dog, Gilbert. This situation is working out very well for them since her grandfather passed away about a year ago.

"Robin is very helpful in a lot of ways," her mom says. As if right on cue, Robin begins by demonstrating

how to make coffee or hot chocolate on the Keurig. She also makes sure to put ice in her own cup "because I don't want to burn myself."

The Medicaid waiver has supported Robin and, by extension, them as a family. "The whole reason Robin has continued to grow and learn is because of the waiver."

Jody speaks about how Beverly in particular has made such a difference in Robin's life. Her skills do not change overnight, but every six months or so she notices Robin is learning new things.

"I never thought Robin would be able to sort her laundry, put it in the wash. She has three grown brothers, and if I tell her Michael put a red shirt in with his white towels and everything's pink, she'll get hysterical laughing. 'You're not supposed to do that! You do not put anything in with the whites!'"



She had started asking a lot of questions about what was next for her life.



Robin packs the adoption kits that are given with each animal adopted from FurKids.

Jody says that there are a few things about the waiver she'd like people to know. She has goals for her daughter, and she and Beverly meet about those goals. But, as she says, "Imagine being 32, and your mother's still telling you what to do. She doesn't want to hear it from me."

There was a time in Robin's late teens and early twenties when that struggle became really painful for the both of them. One day, as they were disagreeing with each other, Robin wanted a Diet Coke, something which is actually hard on her digestive system, and she opened the car door to leave. They had stopped at an intersection but Jody had just

waiver, which is working out very well. With 35 hours a week of support, and 20 nights per year of respite care, they frequently convert respite care into day shifts. Medicaid is supposed to pay Robin's medical bills, but none of her doctors actually take it. For instance, she had to battle with Medicaid to pay for the life-saving EpiPen she has to keep on her at all times for her peanut allergy.

Robin attends a day program four days a week. Jody's not terribly happy with it and says Robin is "stagnating there." She'd like to find a better situation, but she feels stuck because of the limited funds through the waiver. It's currently the only viable option with their allotment. Fridays at FurKids, then hanging out with Beverly is a first step toward more fulfillment.

She is also a wonderful painter, and has won awards and given presentations about them. She's also a great bowler, though she has to use a ball with no holes in it because her fingers are not strong enough. Every night, she gets up at dinner and gives a little speech about all the people whom she's thankful for in her life.

And her desire to communicate sometimes gets her in trouble. She recently figured out how to use her grandmother's Amazon Echo Dot and called her brother while he was on a date, even though she'd been told not to bother him. Mom says, "None of us knew that was it was possible to make a phone call that way. She had never seen us make a call using the Dot, and we couldn't figure out who she was talking to in her room." Since the call came up as "Nanny," he thought something was wrong. They had a good laugh, and of course he didn't mind talking to his sister for a few minutes.

One of the great things about the timing of Robin's waiver is that it came right when her younger brother, Michael, was leaving for college. His transition got Robin thinking about her future. She had started asking a lot of questions about what was next for her



Robin Wilson sits with Beverly Anderson, her job coach, who supports Robin in her work and tasks at FurKids.

## THE WHOLE REASON ROBIN HAS CONTINUED TO GROW AND LEARN IS BECAUSE OF THE WAIVER.



started to accelerate. It scared Jody a lot. She called the administrator again that day and added the incident to the file. It wasn't long after that her surgery came into play, and things changed. When we ask Robin if she remembers that time, she says, "Yes," very quietly, and how she feels about that time, she says, "Sad."

Beverly has been Robin's job coach and assistant caregiver for five years. "How does it feel to have Beverly in your life to help you do things?" we ask Robin. "Good!" She tells us enthusiastically about their plans to go to the grocery store and get ingredients to make taco salad. "We're gonna start about five," she tells us.

Both Jody and Robin had to go through an adjustment when the Medicaid waiver helped them start to separate a little. "I had to turn her over to another person. And, there's a big difference. She was done with me. I kind of got that."

They recently decided to transition to the Self-Direct version of the COMP

life. Sometimes she would ask her mom, "Am I gonna be stuck with you now?"

That's a question that has come to mean many things over the course of her life. At first it meant, "Do I have to sit through my brother's baseball practice because there's nothing else for me to do?" to more recently "Do I have anyone working with me this weekend or am I stuck with you?" and even more broadly, "What will happen to me as we both get much older?"

What will happen to Robin when they both get much older is still a question. For now, she seems to have settled into a happy rhythm of sharing time between mom, grandma, work and fixing taco salads for all her company.

## GCDD Storytelling Project

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



# COMMUNITY CALENDAR

## APRIL

April 17  
**Self-Advocacy Network Planning Meeting**  
 Athens, GA  
[www.sanghaunitynetwork.org/current-projects.html](http://www.sanghaunitynetwork.org/current-projects.html)

April 21, 2018  
**2018 Southside Art Day and Musical Saturday**  
 Peachtree City, GA  
<https://conta.cc/2pO8LB8>

April 26  
**Self-Advocacy Network Planning Meeting**  
 Cartersville, GA  
[www.sanghaunitynetwork.org](http://www.sanghaunitynetwork.org)

Until April 27  
**GA Artists with Disabilities Juried Art Show**  
 HealthSouth Walton Rehabilitation Hospital  
 August, GA  
<http://georgiaartistswd.org/contact-us.php>

April 28  
**Let's Create ... at the Park**  
 Engage in an arts & crafts  
 Richmond Hill, GA 31324  
<https://gcdd.org/calendar-of-events/791.html>

## MAY

May 8  
**Self-Advocacy Network Planning Meeting**  
 Tifton, GA  
[www.sanghaunitynetwork.org/current-projects.html](http://www.sanghaunitynetwork.org/current-projects.html)

May 22  
**Self-Advocacy Network Planning Meeting**  
 Statesboro, GA  
[www.sanghaunitynetwork.org/current-projects.html](http://www.sanghaunitynetwork.org/current-projects.html)

May 19  
**Scavenger Hunt at The Park**  
 Lake Mayer Park  
 Savannah, GA  
<https://gcdd.org/calendar-of-events/792.html>

May 20  
**Bowling Night - LekoPals**  
 BowlMor Atlanta  
 Atlanta, GA, 404.633.3430

## JUNE

June 6  
**Day at the Museum**  
 Ink's Children Museum  
 Gainesville, GA  
 404.633.3430

June 23  
**Movie Screening (Two Locations)**  
 Studio Movie Grill  
 Alpharetta, GA & Duluth GA  
<https://gcdd.org/calendar-of-events/794.html>

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



2018 MIDTERM ELECTIONS

## Georgia's Election Dates to Remember

General Primary, Nonpartisan General Election and Special Election Date	May 22, 2018
General Primary, Nonpartisan General Election and Special Election Runoff Date	July 24, 2018
General Primary Runoff Date for Federal Races	July 24, 2018
<u>General Election/Special Election Date</u>	<u>November 6, 2018</u>
General Election/Special Election Runoff Date	December 4, 2018
General Election Runoff Date for Federal Races	January 8, 2019