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REAL HOMES. REAL CAREERS. REAL LEARNING. REAL INFLUENCE. REAL SUPPORTS.

NEWS FOR YOU: HCBS SETTINGS: The New Rules LEGISLATIVE ADVOCACY: What's Ahead for 2015 ADA CELEBRATION: Kicking Off 2015



On the Cover: Ray Saltamacchio (left) instructs Riad Akhras on traditional karate lessons as a part of his private classes in Eatonton, GA.

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



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On the Back Cover:

The 17th annual Disability Day at the Capitol will be held on March 5, 2015 at the new Liberty Plaza, across the street from the Gold Dome.

Making a Difference A quarterly magazine of the Georgia Council on Developmental Disabilities VOLUME 15, ISSUE 3

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HCBS Settings Rule page 14 The new mandate from the Centers for Medicare

New Year Brings ADA25 Celebration

to Atlantapage 22 The ADA Legacy Tour kicks off its celebration for the landmark legislation and Project Chair Mark Johnson shares the tour's goals leading up to July 26, 2015.

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2 MAKING a DIFFERENCE

GCDD VIEWPOINT



The New Year of Change and Celebration

From the GCDD family to yours, we wish you a very happy new year! We hope that 2015 will be a great year for all of us in the disability community. This year could be the time when Georgia finally takes its place as a leader in meeting the needs of individuals with disabilities and their families.

I know what you are thinking. We already have had enough change and still things have not gotten better. It seems like every year we are bombarded with changes in waivers, staff and direction. Will the services we currently have be here next year or will we have to search for what we need?

This edition of Making a Difference will examine several of those changes coming. We start with the inauguration of Governor Nathan Deal's second term and the 2015 legislative session. We hope to share with you legislative support around the waiting list; ensuring that employment becomes a first option, especially for children leaving high school; the ability of students who are enrolling in inclusive post-secondary education programs to access the HOPE scholarship; and discussions about ensuring that when those students graduate, they receive a diploma allowing them to access their next step in life. We also hope to see in the next year the closure of state institutions and ending the practice of sending children to live in nursing homes.

Much of the change happening is driven by policies and rules established in Washington, DC through the United States Department of Health and Human Services. Many of you attended town hall meetings convened by the Georgia Department of Community Health to discuss changes in all Medicaid Waivers. The Centers for Medicare and Medicaid Services have established new rules that define home and community-based services. For some, this has been happily anticipated for many years, but for others there is concern about whether services such as day supports will be considered a home and community-based service. Much of the preliminary work on changes to the NOW, COMP, ICWP and CCSP will happen this year, but implementation will probably not happen until next year.

Finally, this is the 25th anniversary of passage of the Americans with Disabilities Act. We will be reporting on this right up until the national celebration in July. It will be part of the theme for the 17th annual Disability Day at the Capitol, which will be held on March 5 at the new Liberty Plaza across the street from the Gold Dome. I hope that all of you attend.

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

Eric E. Jacobson Executive Director, GCDD

Tell us your thoughts about the magazine or like to see addressed

Letters To The Editor.

GCDD VIEWPOINT

How to **Reach Us**

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

Contact Our Editor and Public Information Director: Valerie Meadows Suber valerie.suber@gcdd.ga.gov P: 404.657.2122 F: 404.657.2132

or: 2 Peachtree Street, NW Suite 26-246 Atlanta, GA 30303-3142

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Subscriptions / Back Issues: Visit us at our website: www.gcdd.org or call us: 404.657.2126.

It is our policy to publish readers' comments. Contents do not necessarily reflect the opinions of GCDD, the editors or state government.

Magazine Sponsorship:

For sponsorship opportunities contact: Devika Rao at 678.384.7836 or devika@oneillcommunications.com.

AROUND GCDD



AROUND GCDD

GCDD Welcomes Six New Advisory Council Members



Marcia Singson Parent Advocate Singson is the founding president of the Georgia Aspergers Organization and an employment specialist with Project SEARCH.



Eren Kyle Denberg Self-Advocate

Denberg is an ambassador for All About Developmental Disabilities as an advocacy speaker about autism.



Brenda Munoz Parent Advocate Munoz is a 2014-2015 GaLEND Family Fellow at the Center for Leadership in Disability at Georgia State University.



Pam Hunter Dempsey Parent Advocate Dempsey sits on the Georgia State Department of Education Advisory Panel for Special Education.

Correction



Making a Difference's Fall 2014 issue covered a story in the Real Communities Initiative section (page 27) about Basmat Ahmed, the community

builder who helped found the Clarkston Relationship Builders Group.

Ms. Ahmed's picture was misidentified and her correct photo is printed above. The young woman was not Ms. Ahmed, and the magazine apologizes for the error. The picture has been also been replaced on the website edition with the correct photo of Ms. Ahmed.



Rickie Jodie Wren Parent Advocate Wren has worked with children and adults with developmental disabilities for eight years and is an active volunteer within her community.



Trace Haythorn Parent Advocate

Haythorn serves on the Atlanta Rotary's Education and Youth Foundations, which provide support to literacy and youth employment initiatives. He also served as an advisory member of the Real Communities Initiative.



GCDD Welcomes New Grants Manager, Lisa Eaves

Eaves joined GCDD as Grants Manager in Fall 2014 to coordinate all aspects of contracts and grants procedures between staff and GCDD partners, under the direction of Chief Financial Officer Gary Childers. Those interested in applying for GCDD Partnership Funds or Conference Sponsorships can contact Eaves at lisa.eaves@gcdd.ga.gov or visit www.gcdd.org and select the Funding Opportunities tab for details.

SAVE THE DATE!

June 13, 2015 for Atlanta's ADA Parade

ELECTIONS

On November 4, 2014,

people headed to the

midterm elections. The

Georgia governor and

Senate races had the

following results:

voting booth for the

UPDATE

IN THE NEWS

ADA25 Georgia Plans Atlanta Parade



Georgia disability groups plan to celebrate the 25th anniversary of the Americans with Disabilities Act this year with a parade in Downtown Atlanta on **June 13**, coinciding with the Society of Disability Studies national conference scheduled for June 10-13. The parade, which is being organized to educate the public about the significance of the ADA for people with and without disabilities, includes a program and forum for discussion.

"We want participants to go away not just with a captivating visual experience and brochure, but also the opportunity for deeper dialogue," said parade co-organizer Eleanor Smith, who is founder of Concrete Change.

Those interested in participating in the parade are encouraged to send an email to adaparade@gmail.com and include their contact information to receive details on how to get involved.

Pat Puckett Receives Visionary Award

The Georgia Budget and Policy Institute (GBPI) awarded Pat Puckett, executive director of the Statewide Independent Living Centers, the Visionary Award for her work to improve the lives of people with disabilities.

The Possibility Gala, held on Oct. 2, 2014 in Atlanta, celebrated the founding of the Georgia Budget and Policy Institute, of which Puckett was also a founding board member.

"[Pat] is an active member of many state and national organizations working to accomplish inclusive disability policy and services," said GBPI Executive Director Alan Essig. "Her lifetime of work advocating for the rights of people with disabilities represented the best of what GBPI stands for."

Founded in 2004, GBPI seeks to build a prosperous Georgia in which economic opportunity and well-being are widely shared among all.



GBPI Visionary Award Honoree Pat Puckett (right) with David Blanchard at the Possibility Gala. Photo Courtesy of GBPI.



Governor: Nathan Deal - R

US Senate: David Perdue - R





D'ARCY ROBB is the co-coordinator of Employment First Georgia.

I was fortunate enough to attend the annual Marc Gold & Associates Discovery retreat last fall in Ocean Springs, MS, and owe a tremendous thanks to Norciva Shumpert, Michael Callahan and my fellow participants for so generously sharing of their knowledge. I highly recommend the MG&A materials to anyone interested in learning more about Discovery: **www.marcgold.com**

Employment First: Focusing on Strengths

By D'Arcy Robb

"She needs to work on appropriate workplace social skills." "He needs substantial training before paid employment can be considered." "It is highly unlikely that she will ever hold a job." "He is unemployable."

All too often, individuals with disabilities find attention focused on their perceived deficits instead of their strengths. Particularly when it comes to the world of work, that approach is self-defeating and backwards. How many people do you know start their job search by making a list of tasks they struggle with and activities that they hate to do? Yet for many individuals with disabilities, a traditional job evaluation can feel like exactly that.

In such an environment, it's no wonder that some employers, parents and people with disabilities struggle to envision each individual with a disability as a fulfilled, valuable member of the workforce.

Job discovery is a way out of that tired old loop of "can't, can't, can't" by providing a fresh and exciting way to see people build their careers. Job discovery starts with a relationship between a job developer and a job seeker. The team gets to know one another as the job developer spends time with the individual and the people who are most important in his or her life by having both casual conversations and targeted interviews. They both interact in a variety of environments, and participate in activities that are both familiar and unfamiliar to the job seeker. The last thing a job developer does is to review files or paperwork about the job seeker.

Why is that the last step? Because the job developer doesn't want to be influenced by the perceptions (and misperceptions and negative outlook) of others about the individual. If the job developer wants to check on any possible issues, he or she can

MAKING a DIFFERENCE

call the job seeker's referral source and simply say, "Is there anything I should know?"

The idea behind job discovery is to get to know and appreciate a person - to see them in their most beautiful light. Once the job developer truly sees the job seeker, it's time to write the profile.

> Self-employment and resource ownership are two hugely promising avenues of employment for people with disabilities.

A profile accurately and positively describes the job seeker, and translates the essence of who that person is into the ways he or she could contribute to the world of employment. "Accurately and positively" means that everything in the profile is true, absent of judgment and written to focus on possibilities. A profile will not say, "He slowly made his way across the room, hugging every person he saw. He does not have workplace social skills and can't appropriately interact with co-workers." A profile will say, "He crossed the thirty-foot room in two minutes and twelve seconds, hugging ten people as he went. Adam hugs people the first time he sees them each day. He will benefit from an environment where he interacts with a limited number of co-workers."



A profile focuses on a job seeker's interests, contributions and conditions. Interests, of course, are the topics and pursuits that naturally attract a person, often indicated by the things they do with no prompting. Contributions are the ways in which a job seeker can contribute to a work environment, including tasks that the job developer reasonably expects the job seeker could be taught to do. And conditions are the circumstances that must be met in order for the job seeker to succeed. A condition could refer to a physical accommodation, the need for a particular type of schedule or just about anything a person needs in order to make a job work for them. And of course, we all have interests, contributions and conditions - these elements are not unique to the discovery process, although they provide an excellent way of fleshing them out.

The best way for a job developer to know if he or she "got it right" in the profile is to have the job seeker review it. Asking the job seeker to be the profile reviewer shows that the relationship between the job developer and the job seeker should not be hierarchical, or characterized by one person trying to "help" another. Discovery works best when it is done between equals – a job seeker and a job developer going on an exciting journey together.

Once the profile is ready, it's time to find and negotiate the job. That is the goal of discovery – to lead to employment after the writing of the profile. The job developer reviews a list of potential employers, asking to meet with them to discuss possibilities for this particular job seeker. When a job developer meets with employers, he or she is looking to build a relationship while identifying unmet needs.

Every business and every community has needs that are unmet. As a job developer, they identify those unmet needs, figure out a match between the need and a job seeker and negotiate a job based upon that. A customized job should be a winwin situation that benefits both the job seeker and the employer. The amount of job coaching and subsequent support will depend on the needs of each individual.

Every business and every community has needs that are unmet.

Not every discovery process leads to a traditional employer. Self-employment and resource ownership are two hugely promising avenues of employment for people with disabilities that I will be covering in future columns. Nor is discovery only for people with disabilities. Anyone who needs a non-traditional entrance to the workforce can benefit from discovery, including persons with mental illness or individuals transitioning off welfare benefits.

As a friend of mine who is struggling in her job recently said, "Anyone could benefit from this!" Discovery works best when it is done

BETWEEN EQUALS

- a job seeker and a job developer going on an

EXCITING JOURNEY together.



For information on Employment First Georgia, visit *www.employmentfirstgeorgia.org*



UNLOCK THE WAITING LISTS!

Unlock the Waiting Lists! advocates are

investing in Georgians with disabilities so they and their families can live full lives and contribute to Georgia communities and the Georgia economy. Unlock the Waiting Lists! and GCDD believe Georgia must rebalance its system of long-term supports, so that fewer dollars are spent on institutional care and more dollars are invested into long-term supports in the community. Visit www.unlockthewaitinglists.com **TODAY** for more information!

Legislative Preview: It's Advocacy Season in Georgia!

By Dawn Alford, GCDD Acting Public Policy Director

By the time you receive this issue, the 2015 Georgia legislative session will be underway. As many of you know, legislative advocacy is one of the primary tools that the Georgia Council on Developmental Disabilities (GCDD) uses to further its mission.

The mission of GCDD is to bring about social and policy changes that promote opportunities for persons with developmental disabilities and their families to live, learn, work, play and worship in Georgia communities. We know that Georgians with disabilities want to live full lives in our communities, and they are fully capable of doing so. When all our citizens are able to use their gifts and talents and pursue their dreams, it creates a better Georgia for us all.

And working to create a better Georgia for us all, including its citizens with disabilities, is just what this year's GCDD legislative agenda seeks to do.

2015 Legislative Agenda Support an Employment First Policy for Georgia

In an Employment First policy, employment in the general workforce at or above minimum wage is the priority service outcome for individuals with disabilities in the publicly funded service system. Right now, that is not the case in Georgia. Service providers receive more money for supporting an individual in a non-work option than they do for supporting an individual to work in the community. Georgians with disabilities want to work, and the reality is that virtually everyone with a disability is able to work with supports in the right situation. GCDD member Evan Nodvin of Dunwoody is one example of an individual who is thriving with the right supports to work in the community. He has worked full-time with senior citizens for the past 14 years and recently received a promotion.

For every dollar put into employment support for Georgians with intellectual disabilities, Georgia taxpayers reap \$1.61 in benefits.¹

Furthermore, when Georgians with disabilities work, it benefits all Georgia taxpayers. For every dollar put into employment support for Georgians with intellectual disabilities, Georgia taxpayers reap \$1.61 in benefits.¹

But despite all this, only 14% of Georgians with developmental disabilities are currently employed in the community.² To change this situation, Georgia needs an Employment First policy – a clear-cut policy that works across agency lines to establish integrated employment as the priority outcome for individuals with disabilities in the publicly funded service system. Therefore, we will work diligently to educate the governor, legislators and other policymakers about the need for an Employment First policy in Georgia.

Support Unlock the Waiting Lists!

The GCDD is proud to support Unlock the Waiting Lists! These advocates are investing in Georgians with disabilities so they and their families can live full lives and contribute to Georgia communities and the Georgia economy. Unlock the Waiting Lists! and GCDD believe Georgia must rebalance its system of long-term supports, so that fewer dollars are spent on institutional care and more dollars are invested in long-term supports in the community.

- Increase funding for 1,000 NOW/COMP waivers to address the community waiting list of over 7,000 Georgians. \$16,493,000
- Fund housing vouchers to support 100 Georgians with developmental disabilities who wish to live in their own home or apartment. <u>\$600,000</u>
- Increase the Independent Care Waiver Program's Personal Support rate to \$20/ hour to be consistent with other Georgia waivers. We recommend phasing in this amount starting with increasing the Personal Support rate by \$3/hour for FY 2015. \$7,975,490
- Fund 26 COMP waivers so that young Georgians with disabilities under the age of 22 who are currently living in nursing facilities or intermediate care facilities can move out of these facilities into permanent loving homes. \$799,316

HOPE for Students: Inclusive Post-Secondary Education

Inclusive post-secondary education provides opportunities for students with intellectual disabilities to access higher education. *This education prepares them to live increasingly independent lives and pursue careers of their choice.* Individuals with intellectual disabilities who receive post-secondary education are *more likely to find paid employment than those who don't, and their earnings are 73% higher than peers who do not receive post-secondary education.*³

Charlie Miller, a second-year student at the Academy for Inclusive Learning at Kennesaw State University (KSU), says, "The best way I can explain inclusive learning is it's a chance to fully express yourself out from under your mom and dad's wing, into being a productive person in society."

Thanks to legislative support, the number of inclusive post-secondary programs in Georgia has grown from one to four. However, students in inclusive post-secondary programs are not currently eligible for the HOPE scholarship program. And these inclusive post-secondary programs are so new and innovative that parents did not realize that they needed to save for a post-secondary education because for so long it was out of reach for so many students with intellectual or developmental disabilities. Without HOPE or some type of scholarship program, many qualified and eager students simply cannot afford the life-changing opportunity of inclusive post-secondary education.

• Allow students in Georgia's inclusive postsecondary education programs to access either HOPE or other scholarship funds.

Support Georgians Who Care for Their Families: **The Family Care Act**

Many Georgians balance their work lives with caring for their families. The Family Care Act would allow Georgians who have earned sick leave to use up to five days of that leave to care for sick or injured members of their immediate family. *The Family Care Act does NOT add any additional sick days or require employers to provide them; it only allows Georgians to use the sick days they've already earned to care for family members.*

• Support The Family Care Act

The previous items are the main focus of our legislative agenda for 2015! In addition, GCDD is also proud to support ...

The mission of GCDD is to BRING ABOUT SOCIAL AND POLICY CHANGES that promote

opportunities for persons with developmental disabilities and their families to live, learn, work, play and worship in Georgia communities.



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- 1. Cimera, R. (2010). National Cost Efficiency of Supported Employees With Intellectual Disabilities: 2002 to 2007. American Journal on Intellectual and Developmental Disabilities: January 2010, Vol. 115, No. 1, pp. 19-29.
- 2. National Core Indicators 2011-2012. National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. www. nationalcoreindicatorsorg/charts/
- 3. Migliore, A., Butterworth, J., & Hart, D. (2009). Postsecondary Education and Employment Outcomes for Youth with Intellectual Disabilities. Think College Fast Facts. No 1. www. thinkcollege.net/publications/fast-facts



Advocates gathered at the Georgia State Capitol for the 2014 Disability Day at the Capitol.

Want to be involved in advocacy?

Get Involved!

Join Our Advocacy Team

Become part of our advocacy team! Go to www.gcdd.org and click on "Public Policy" in the navigation bar. Then click on the green "Get Involved" button. Be sure to choose "advocacy" as one of your interests!

- Changes to Georgia's high school diploma system that will give more students with disabilities the opportunity to obtain diplomas and access further career and educational opportunities
- Annualization of the 2% cost-of-living adjustment added in 2014 for providers of services and supports to persons with disabilities
- A 3% adjustment for providers to be utilized for wage increases for direct support professionals
- Changing the legal standard of proof for proving intellectual disabilities in capital punishment cases to "preponderance of the evidence," which is the standard used in most other states.

So as you can see, we have many important issues that we will be working on during this session. Moreover, given the nature of how the legislative session operates, there could also be unexpected surprises that pop up that could be of significance to Georgians with disabilities. Given this and our robust legislative agenda, we will definitely need to call on our network of grassroots advocates to help us.

In fact, we cannot be successful unless we all join together to let our voices be heard!

Get Involved: Join Our

Advocacy Team!

So you may be saying to yourself, "I would love to help make some positive changes in Georgia for people with disabilities but what do I know about being an advocate? This all seems so very intimidating to me!" Well, do I have some good news for you!! If you are a person with a disability, love someone with a disability, or simply are concerned about issues facing Georgians with disabilities, we need **YOU** to be a part of our advocacy team – and we will teach you all you need to know about speaking to your legislators.

Leading up to the 17th annual Disability Day at the Capitol, there will be a series of Advocacy Days. We will start the day with fun, interactive advocacy training across the street from the Capitol at Central Presbyterian Church. All are welcome but due to limited space, you must register in advance. Then, we'll go over to the Capitol together to educate our legislators about what they can do to support individuals with disabilities and their families. Firsttimers and seasoned advocates alike are welcome! Take a moment now to look at the schedule and decide which advocacy days you want to attend (and why not come to all of them!), mark your calendar, and then go to www.gcdd.org for details on how to sign up. Further details will be emailed to all registrants. (Please see page 11 for complete information on Advocacy Days at the Capitol.)

And when you sign up for the Advocacy Days, sign up for GCDD's 17th annual Disability Day at the Capitol, Georgia's largest advocacy rally, to be held at its new location of Liberty Plaza on Thursday, March 5, 2015.

We will definitely need to call on our network of grassroots advocates to help us.

We hope that you can make it to some or all of these events. But even if you can't attend any of them, there are still other ways you can get involved. Here are just a few:

• Make appointments with your State Representative and State Senator and share this article with them. (You can also go to www.gcdd.org to print out separate copies of our 2015 legislative agenda to share with them. If you're not sure who your State Representative and Senator are, you can find out by going to www.votesmart.org or www.legis.ga.gov.)

- While you're at www.gcdd.org, scroll to the bottom of our homepage and click on "Join our Advocacy Team!" and follow the instructions. You will have the opportunity to select your subscription preferences. If you are specifically interested in receiving calls-to-action, legislative updates and other notifications that require action from our advocates, be sure that you sign up to receive our "Advocacy & Policy Alerts" and "Unlock the Waiting Lists! Alerts."
- Visit the Unlock the Waiting Lists! website at www.unlockthewaitinglists.com for regular legislative updates during the session.

- Join our weekly legislative teleconference calls for advocates to hear the latest highlights of what is going on at the Capitol and what you can do to help. Go to www.unlockthewaitinglists.com for details on how to join the call.
- Email your advocacy question to gcdd.publicpolicy@gmail.com and it may be answered in an upcoming issue of the GCDD public policy newsletter. Use the subject line, "Advocacy Question for Newsletter."

We look forward to seeing you at the Capitol and advocating for more "opportunities for persons with developmental disabilities and their families to live, learn, work, play and worship in Georgia communities."

2015 Advocacy Days at the Capitol!

Location: Central Presbyterian Church, 201 Washington Street SW, Atlanta, 30303

We Need Waivers Day Wed., Jan. 21, 9 AM-12 PM

Did you know over 7,000 Georgians are on the waiting list for a NOW or COMP waiver? Join us as we advocate to get more waivers!

ICWP Raise the Rate Day Thurs., Jan. 29, 9 AM-12 PM

Georgia families are in crisis because they cannot find caregivers who will work for as little as \$8 an hour. Join us as we advocate to raise this impossibly low rate!

Kids Need Real Homes, Not Nursing Homes Day Wed., Feb. 4, 9 AM-12 PM

Right now, 39 school-aged children in Georgia live in nursing homes or facilities for people with disabilities. Join us as we advocate for 39 COMP waivers to bring these children home!

Employment First Day Wed., Feb. 11, 9 AM-12 PM

Working age Georgians with disabilities want real jobs in their communities. Join us as we advocate for real jobs with Employment First!

Youth Day Thurs., Feb. 19, 9 AM-12 PM

Calling all youth with disabilities! Come advocate for yourself and your friends and enjoy the excitement of the legislature in action!

We will start the day with a fun, interactive advocacy training to teach you all you need to know about speaking to your legislators. Then, we'll go over to the Capitol together to educate our legislators about what they can do to support individuals with disabilities and their families.

17th annual Disability Day at the Capitol* Thurs., March 5, 9 AM-2 PM

Be a part of Georgia's largest, disability advocacy event by gathering to promote access, opportunity and meaningful community living for all Georgians.

All are welcome but due to limited space, you must register in advance. (See pages 12-13.)

Register for the 2015 Advocacy Days at the Capitol and the 17th annual Disability Day at the Capitol at www.gcdd.org/2015DisabilityDay

*Disability Day will be held at Liberty Plaza, across from the Capitol.

We cannot be successful unless WE ALL JOIN TOGETHER

to let our voices be heard!

Find

your State Representative and Senator at www.legis.ga.gov or www.votesmart.org or 1-800-VOTESMART



Fulfilling the Promise of the ADA

VOTING RIGHTS. SOCIAL JUSTICE. EMPLOYMENT.

This year's theme celebrates the 25th anniversary of the Americans with Disabilities Act! Be a part of Georgia's largest, disability advocacy event by gathering to promote access, opportunity and meaningful community living for all Georgians in a new location! The event will be in Liberty Plaza, the Capitol's new "front door." It's an outdoor area adjacent to the State Capitol that provides a safe space for crowds to gather for rallies and events including the 17th Annual Disability Day at the Capitol.

17TH ANNUAL DISABILITY DAY AT THE CAPITOL **THURSDAY, MARCH 5, 2015**

NEW LOCATION: LIBERTY PLAZA

SCHEDULE OVERVIEW

9 AM – 11 AM

T-Shirt Distribution, Activities & Exhibits before the Rally at the Georgia Freight Depot

9:30 AM Advocacy 101 \

at the Georgia Freight Depot

11 AM – 12:10 PM Rally program in new location: LIBERTY PLAZA

12:30 PM – 2 PM Lunch & Exhibits at the Georgia Freight Depot

* T-shirts and lunch are distributed on a first come, first served basis.

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







ATTENDEE FORM:

First Name:	Last Name:
Organization (if applicable):	
School (if applicable):	
County (required field):	
City/State/Zip:	
Day Time Phone (required field):	
Email Address:	
Alternate Contact Name:	
Alternate Phone:	
Please Confirm Number of Attende	ees:

Attendees 10 and under: (Confirmed number of attendees
Group Size 11 thru 50 (ONLY): _	Confirmed number of attendees
Group Size 51 and over (ONLY)	Confirmed number of attendees

Please complete by Feb. 27 and mail or fax with attention to Disability Day 2015

Georgia Council on Developmental Disabilities 2014 Disability Day Registration 2 Peachtree Street, NW • Atlanta, GA 30303 Fax: 404.657.2132 Call: 404.657.2126 to learn more.

You can also register online at: http://bit.ly/1vAbrdP

12 MAKING a DIFFERENCE

Disability Day Sponsorship Form

Your sponsorship will support one of the largest statewide events that provide an opportunity for advocates to unite in support of legislation that will promote the independence, inclusion, productivity and self-determination of people with disabilities. Each year, thousands gather at the Capitol to meet with lawmakers, celebrate growth in community and reignite the bonds of friendship. The success of the event depends on sponsors like you. Please let us know of your commitment no later than February 11, so that you may receive full recognition of your support as described below. *(Information received after this date does not guarantee your organization's placement on any printed materials.)*

Yes! My organization will co-sponsor Disability Day 2015 in the amount of:

- _____ \$5,000: Full-page ad in *Making a Difference* magazine, logo on banner and GCDD website, name on program, exhibit space.
- _____ \$4,000: Half-page ad in *Making a Difference* magazine, logo on banner and GCDD website, name on program, exhibit space.
- _____ \$2,500: Quarter-page ad, logo on banner and GCDD website, name on program, exhibit space.
- _____ \$1,500: logo on banner and GCDD website, name on program, exhibit space.
- _____ \$600: logo on banner and GCDD website, name on program.
- _____ \$200: Name on program and GCDD website.
 - [___] Yes, my check is enclosed. (Payable to Georgia Council on Developmental Disabilities)
 - [___] Yes, please invoice me for the amount selected.
 - [___] Sorry, I am unable to sponsor this year.

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

Please provide an estimated count for lunch _____ and/or number of T-shirts _____ (Sponsors \$600 and over may reserve t-shirts for each member of their organization registered to attend Disability Day at the Capitol by emailing jhai.james@gcdd.ga.gov with the number of t-shirts and sizes for advance shipment.)

[PLEASE WRITE CLEARLY]

Contact Name: _	
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_____ Title: _____

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

Address: ___

City:_____ Phone: _____ State: ____ Zip: _____ Phone: _____

Email: _____

Please complete form by Feb. 27 and mail or fax with attention Disability Day 2015 Georgia Council on Developmental Disabilities

2 Peachtree Street, NW, Suite 26-246, Atlanta, GA, 30303

Fax: 404.657.2132 • Call: 404.657.2126 or email jhai.james@gcdd.ga.gov.

You can also register online to become a sponsor at: http://bit.ly/1wnPdzw



NEW PLACE, NEW DATE **SAME** ADVOCACY

ADVOCACY 101

You can also sign up for "Advocacy 101" workshops when you register for the 2015 Disability Day! The workshops will be held at 9:30 AM and include a visit to our legislators prior to the 11 AM rally at Liberty Plaza across from the Georgia State Capitol. First-time and seasoned advocates alike are welcome!

Register for Disability Day and the Advocacy 101 Workshop at www.gcdd.org/2015DisabilityDay

COME CELEBRATE COMMUNITY, ADVOCACY & FRIENDSHIP!



Rita Young helped facilitate the HCBS community meetings held in November 2014.

New HCBS Rule*

requires that a setting:

- Is fully included in the community, is part of the community and provides full access to the greater community.
- Is selected by the individual from more than one setting option.
- Supports individual choice of services and supports.
- Ensures privacy, dignity and respect.
- Never forces an individual to do something they don't want to do or keeps them from doing something they do want to do.
- * In Georgia, the new rule only applies to day programs, assisted living, group homes or provider-owned or operated settings.

New Home and Community-Based Services Settings Rule Brings Focus on People with Disabilities

By Lindsay Gladu and Devika Rao

John-Mark Gaines, 24, of Lizella, GA, had the time of his life when he went whitewater rafting down the Ocoee River in North Carolina last summer.

"Cross that off his bucket list!" his mother Sheila Gaines said, explaining that it was possible because of the individualized service plan that his day program has in place for him, "They asked him about the things he likes to do and planned it accordingly," she said. "It's very individualized."

John-Mark had waited five years to be on the COMP, or Comprehensive Supports, waiver plan, which now allows him to participate in his day program. He's receiving individualized benefits and has a schedule brimming with activities like visits to the library, dining out and hopefully going on a ride-along with a canine police officer and his human partner.

With daily activities centered on John-Mark's personal interests and unique needs, his is an example of the new Centers for Medicare and Medicaid Services (CMS) Home and Community-Based Services (HCBS) Settings Rule that went into effect in March 2014.

The Final Rule

On March 17, 2014, CMS declared that programs receiving Medicaid funding under this rule are expected to maximize the opportunities for people to access the full benefits of community living and to receive services in the most integrated setting possible, consistent with the Americans with Disabilities Act (ADA) and the Supreme Court's decision in *Olmstead v. L.C.* The HCBS rule provides the definition and qualifications of a home and communitybased setting under Medicaid, defines personcentered planning and conflict of interest for case management and requires transition planning to ensure states adopt and follow the new requirements. *(Please see sidebar for definition of an HCBS setting.)*

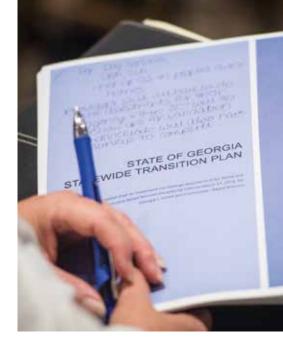
It brings attention to how HCBS should be delivered or helps the elderly or people with disabilities stay in the community by adding person-centered planning (PCP) and selfdirection (SD). The person-centered planning will support individual choice in how, where and when people receive services as well as what services they receive. Self-direction would apply to certain waivers giving individuals more decision-making power about how their service dollars are spent and who is hired to provide services to them.

The HCBS rule is aligned with Section 2402(a) of The Patient Protection and Affordable Care Act (ACA), which was enacted in 2010. It requires that all states that receive federal funds for service systems respond to the needs and choices of those receiving services. States are to also ensure that those individuals are achieving maximized independence and self-direction; are provided with coordination for a community-supported life; and are able to enjoy a more consistent and coordinated approach to their support program.

¹⁴ MAKING a DIFFERENCE

"The rule gives states more direction on how to deliver and meet those personcentered planning objectives," said Patricia Nobbie, PhD, program specialist for the Office of Policy Analysis and Development under the Administration for Community Living. "The rule focuses on the principles of integrated community living and brings a high level of consumer engagement."

John-Mark's experiences are an example of how Georgia's new transition plan spearheaded by the Georgia Department of Community Health (DCH) is supposed to look in the future. and all other states, to propose how it will develop tools and implement evaluations of the settings where the waivers are currently available. The transition plan will affect the Independent Care Waiver Program (ICWP), New Options Waiver (NOW), Comprehensive Supports Waiver Program (COMP), Elderly and Disabled Waivers, Services Options Using Resources in a Community Environment (SOURCE), Community Care Service Program (CCSP) and Georgia Pediatric Program (GAPP). The plan will also address methodologies to include public input and provider compliance checks.



Cross that off his bucket list!



The new rule is centered around the idea that individuals "should have the full experience that life has to offer as if you did not have a disability or you did not rely on services," said Marcey Alter, Deputy Medicaid Director, Aging and Special Populations, at DCH.

To comply, the State will have to submit a transition plan for all HCBS services to ensure they meet the new specifications. "This is the most substantial change to waivers in over 30 years," said Nobbie.

In Georgia, the new rule only applies to day programs, assisted living, group homes or provider-owned or operated settings.

The Transition Plan

The federal rule requires the State of Georgia,

DCH held four community meetings in Marietta, Macon, Athens and Fayetteville and three virtual meetings in November 2014 to receive stakeholder input for the direction Georgia will take in its services. The meetings allowed consumers and family members to learn about important changes to the HCBS rule from Medicaid leaders, participate in a focused discussion with other advocates and also review the draft of the plan.

"We wanted the community to understand that the federal regulation will have an impact on the people, from state to individual," said Alter. "But, this is also an outlet to create the general understanding that this mandate is raising the bar on the quality of life and we are moving away from John-Mark Gaines went whitewater rafting last summer on the Ocoee River. The outing was a part of his individualized plan.

The new rule is centered around the idea that individuals "should **HAVE THE FULL EXPERIENCE**

that life has to offer as if you did not have a disability or you did not rely on services."



In November 2014, self-advocates, caregivers, guardians and providers attended the HCBS community meetings held by the Georgia Department of Community Health to learn about the new CMS mandate affecting Medicaid waivers.

It is really good to give consumers a voice and bring more focus to the person-centered planning that has

POSITIVE LONG-TERM EFFECTS.

a 'menu of services' and towards a personcentered and self-directed focus."

In fact, the transition planning process will be broken into five stages:

- 1. Identification of all settings that need to be brought into compliance.
- 2. Assessment of the settings.
- 3. Remediation or how to get them into compliance.
- 4. Outreach and engagement with the stakeholders.
- 5. Monitoring and evaluation once the new rules are put in place.



People took part in discussions about the new mandate and how it will affect their services once the State submits the transition plan in March 2015. For the State of Georgia, settings are defined as provider-owned or operated facilities such as group homes, day programs, assisted living centers, etc. The rule will affect almost 3,000 settings across the entire State.

"It's our intent to keep this engagement going," Alter said. "Just because the public forums end doesn't mean the dialogue ends. This is a five year process and we're going to have touch points all along the way."

The Assessment

One of the most integral parts of the new settings rule and statewide transition plan will be the assessment component administered and reviewed by DCH.

The assessment will have three different kinds of input: a provider's self-assessment, a random sampling administered by a caseworker to review the provider's assessments and a consumer's survey documenting their experiences with the provider.

Providers will have to address the following questions:

- 1. Does the provider support the individual receiving services to be fully included in the full community and have access to the full, greater community?
- 2. Was the individual given a choice of provider and services?
- 3. Does the provider ensure individual privacy, dignity and respect?
- 4. Does the provider honor and respect individual's daily choice?

The same questions are written in first-person format for consumer input.

During the community meetings around the State, self-advocates and caregivers questioned the validity of provider selfassessments. Meeting participants weren't sure the assessment tool would provide an accurate litmus test on compliance.

"How would we know that the providers would be honest?" they asked.

It is important that the providers actually support individuals to make choices and let them do what they want to do as opposed to saying 'yes or no' to plans that were already laid out.

All three forms of assessments will be submitted to DCH for review and compliance check under the new mandate. The response from the surveys will allow DCH to determine the compliance level and remediation for alignment between the provider's selfassessment, case manager validation and the consumer survey. The assessments will also provide a baseline for future training to ensure that the person-centered planning requirements are being met.

This process is how Georgia, specifically, is choosing to evaluate compliance with the HCBS settings rule.

It is also giving a voice to consumers and pushing active engagement in the planning and service deliveries. This is not the first time the question about consumer's input has been asked – but now, "it went from a nice-to-do, to a must-do," said Kathy Floyd, executive director of the Georgia Council of Aging. "It is really good to give consumers a voice and bring more focus to the person-centered planning that has positive long-term effects."

Yet person-centered planning isn't without its challenges. Joe Sarra, an advocate with

the Georgia Advocacy Office who has two cousins with disabilities, said that people who have never made individual choices before have a harder time deciding what they want because it's scary.

The help of a support person and individualized service plan should allow for an easier transition into the community. And where people with disabilities don't use words to communicate, a support person, parent or guardian would help draft a plan with the individual's wants and needs in mind.

Giving an individual the ability to make personal choices such as what food they would like to eat for lunch or what movie they want to watch is something most people take for granted. More compliance will support people with disabilities to have the freedom of choice to live more meaningful lives.

"They are trying to close loopholes and make things more specific for a provider, but it is about trust," said Josette Akhras, GCDD Council member and parent advocate. "It is important that the providers actually support individuals to make choices and let them do what they want to do as opposed to saying 'yes or no' to plans that were already laid out."

Her son, Riad, who happens to be a purple belt in karate, says an ideal day for him would involve, "grocery shopping and picking out the things I want to buy instead of having someone do it for me," he said.

However, many self-advocates expressed concern about the new policy's effect on parents, guardians and independent living.

At the community meetings, Alter specified that if an individual lives in their own home or their family's home, or are under guardianship, the new settings rules and assessments do **not** apply to them. If they receive a day service outside the home, the rules do apply.

And, it's with hope that these rule changes also allow for innovation in areas such as housing and employment. "What are some other options and avenues we haven't taken yet?" asked Nobbie. "For instance, it opens up ideas to collaborate with the private

Provider Survey Questions:

- Does the provider support the individual receiving services to be fully included in the full community and have access to the full, greater community?
- 2. Was the individual given a choice of provider and services?
- Does the provider ensure individual privacy, dignity and respect?
- 4. Does the provider honor and respect individual's daily choice?



Riad Akhras (left) takes private karate classes with instructor Ray Saltamacchio.

It's with hope that these rule changes also allow for **INNOVATION IN AREAS** such as **HOUSING AND EMPLOYMENT.**

What the rule does say is that those who are receiving services are to get the best services centered on their **INDIVIDUAL NEEDS.**

business sector to develop and advocate for Employment First.

"We are going to learn a lot in the next five years, and it brings a real opportunity to change things for the better."

The Waivers and The Waiting Lists

Waivers allow states to test new or existing ways to deliver and pay for healthcare services in Medicaid and the Children's Health Insurance Program (CHIP). Each state has about six to seven waivers, and most fall under Section 1915(c) of the Medicaid program. The vision is a smoother transition and a system that will, "also make more sense to someone coming into the program," said Floyd, citing the increase in the Baby Boomer generation (those born between 1946-1964) that will begin to seek services in the upcoming years. "Someone who is entering the system would get the resources they need right away to get their necessary supports. This is what they expect."

The Providers

As the HCBS settings rule is moving toward a person-centered focus and allowing states to



HCBS meeting attendees take part in discussions about the new settings rule that will focus on the quality of life of people with disabilities.

For additional questions to the Centers for Medicare and Medicaid Services, email hcbs@cms.hhs.gov For more information on the

Home and Community-Based Settings Rule, visit www.dch.georgia.gov/waivers or www.hcbsadvocacy.org But even with the implementation of the new rule, one of the places a change won't occur is the waiting lists. According to DCH, currently, almost 40,000 people receive services through waivers, but the problem is that there are too many still waiting. Over 7,000 people are waiting for the NOW and COMP waivers, while the CCSP waiver list has over 1,600 people. SOURCE currently has none, and ICWP has about 106 people.

Among those receiving services, 3,000 are under self-directed care. "This is stepping away from the 'menu of services' and allowing individuals to be the employer of record and create an individualized plan that adds to their quality of life," said Alter.

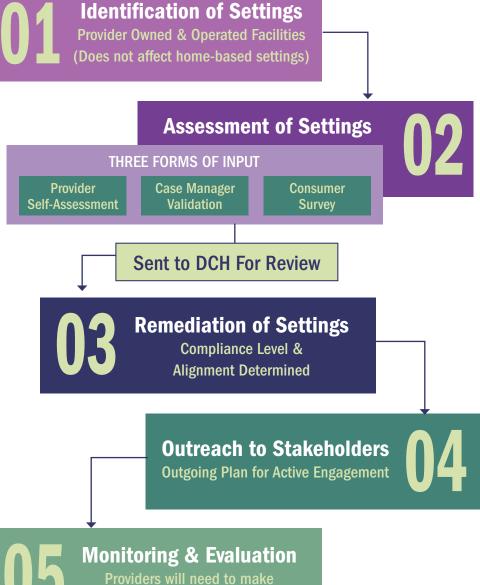
The new settings rule establishes compliance measures for each waiver, but it does not provide quicker access, shorten the list or put more money in budget. What the rule does say is that those who are receiving services are to get the best services centered on their individual needs. make their services more consumer-focused, the providers will bear the weight of the new mandate.

> We are going to learn a lot in the next five years, and it brings a real opportunity to change things for the better.

Providers will need to make changes to comply with the new definitions. According to DCH, that could mean allowing residents/consumers more flexibility in their scheduling, access to food, visitation hours and privacy; training and evaluating staff on person-centered service delivery; and creating more opportunities for consumers to be active in the community.

State of GA Transition Plan* GA Department of Community Health (DCH)

*Affects ICWP · NOW · COMP · Elderly & Disabled Waivers · SOURCE · CCSP · GAPP



changes to comply.

"I'm very concerned about what is going to happen to day programs since they haven't said what is acceptable," said Allen Freeman of All Care in Macon, GA. "One of the things I asked for was that [the Department for Community Health] come up with a best practices plan. It's very easy to put policies out there and say 'Make this work in your company' and that's left to interpretation. What I want them to say is 'Here is a model that works really well and we want you to incorporate that into your company.""

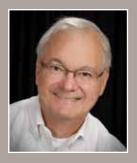
The new HCBS rule aims to provide more opportunities for people like John-Mark or Riad to enjoy the life that is the most meaningful to them. As the new rule gets underway in Georgia and is fully implemented in 2019, the future looks like a more inclusive and person-centered community for people with disabilities.

Georgia Medicaid Waivers:

- New Options Waiver

 (NOW) and COMP
 (Comprehensive Supports
 Waiver Program) provide
 supports to people who want
 to live with their family or in
 other kinds of community living
 arrangements. The services
 offered through these waivers
 can make it possible to have
 supports during the day, at
 night or on the weekends.
- Services Options Using Resources in a Community Environment (SOURCE) is an enhanced primary care case management program that serves frail elderly and disabled beneficiaries.
- The Independent Care Waiver Program (ICWP) offers services that help a limited number of adult Medicaid members with physical disabilities to live in their own homes or in the community instead of a hospital or nursing home.
- Community Care Service Program (CCSP) provides community-based social, health and support services to eligible consumers as an alternative to institutional placement in a nursing facility.
- Elderly and Disabled
 Waivers provide home and community-based services to individuals 21-years-old and older who would require the level of care provided in a nursing facility.
- Georgia Pediatric Program (GAPP) serves children who are medically fragile and in need of skilled nursing care.

Individuals with disabilities want to live and have the SAME RIGHTS AS THOSE WITHOUT A DISABILITY.



DAVE ZILLES is a parent advocate and a public policy consultant for Unlock the Waiting Lists!

EXPERT UPDATE

The New Rules and The Waiting Lists

By Dave Zilles

Individuals with disabilities want to live and have the same rights as those without a disability. The Americans with Disabilities Act defines an individual with a disability as "a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such impairment."

In reality, all of us might eventually have a disability. Everyone wants to be safe and healthy, have a place to live and have family and friends as well as a meaningful day, which could include employment or activities in the community.

In Georgia, according to the recently released 2014 Annual Disability Statistics Compendium, the total population of Georgia is 9,800,887 with 12.4% (1,211,831) having a disability. They define a disability as having a difficulty with; hearing, cognitive, ambulatory, self-care and/or independent living.

Many of these individuals are living by themselves and receiving daily care (if needed) by a family member or friends. Many older adults are taking care of their children with disabilities as they themselves age and are not able to provide the support.

-			-
Age	Total	Disability	Percent
Under 5	657,016	4,046	0.6
5-17	1,830,063	93,305	5.1
18-64	6,151890	673,255	10.9
65-Over	1,161,918	441,225	38.0

GEORGIA POPULATION BY AGE GROUP

What is the answer if you are no longer able to get the services and supports you need to live a normal and healthy life? One alternative that is available is to enter institutions like a nursing home for your 24-hour care. The preferred choice of many is to continue to live in their own home and receive the necessary services and supports they need based on their individual person-centered care plans in the home.

In order to receive these services in your own home, you need to pay for them from your financial resources or be on Medicaid and request to receive a Home and Community-Based Waiver. These waivers provide a variety of services that include case management, personal care support for activities of daily living, residential settings, day services and supported employment.

Georgia currently offers five waivers for the Elderly and Disabled, people with developmental disabilities and the significant physical disabilities, which include those with Traumatic Brain Injury (TBI). There are currently 39,660 individuals being served by these waivers with 9,145 on a waiting list.

Home and

Community-Based Services

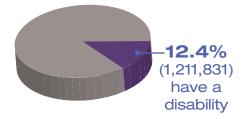
The Centers for Medicare and Medicaid Services (CMS) released their final rule on Home and Community-Based Service (HCBS) Settings on January 10, 2014, which was passed down as an official mandate in March.

GEORGIA MEDICAID WAIVERS

Waiver Name	Population Served	Active as of 9/30/14	Wait List as of 9/30/14
Community Care Service Program	Elderly and Disabled	10,798	1661
SOURCE	Elderly and Disabled	15,697	0
Independent Care Waiver Program	Significant Physically Disabled and TBI	1,351	106
New Options Waiver	Developmental Disabilities	4,793	7378
Comprehensive Supports Waiver	Developmental Disabilities	7,021	

This rule strengthens the requirements for personal autonomy, community integration and choice in home and community-based services funded through Medicaid. It makes clear that the requirements apply to both residential and non-residential settings and sets specific and more stringent rules for provider-owned or controlled residential settings. It requires an independent assessment of individual needs and strengths and a person-centered planning process to ensure that individuals receive the services they need in a manner they prefer.

Total population of Georgia is 9,800,887



The final rule creates a single definition of a home and community-based setting for Medicaid waivers. The rule describes home and community-based settings by being more integrated in the greater community and focused on the individual's choosing.

To continue advocating for a more integrated community and ensure the best quality of life for people with disabilities, the new rule also determined what a setting is not.

For provider-owned or controlled residential settings, the rule states the following additional requirements (that can only be modified using a process described below):

• Units or rooms must be a specific physical place, the kind that could be owned or rented in a typical landlord-tenant agreement

- Individuals have privacy in their living or sleeping units, meaning that
 - Units have lockable doors and entrances, with only appropriate staff having keys to doors
 - Individuals who share rooms have a choice of roommate in that setting
 - Individuals can furnish and decorate their own units within the limits of the lease or agreement
- Individuals control their own schedules, including access to food at any time
- Individuals can have visitors at any time
- The setting is physically accessible to the individual

The rule states that the following are **never** home and community-based settings:

- Nursing facilities
- Institutions for mental diseases
- Intermediate care facilities for people with intellectual disabilities
- Hospitals

Why Is This Important? Why Should We Care?

As parents or self-advocates we need to understand what these new rules mean for our loved ones. This new rule is all about *choice* with a focus on what the individual needs and how they want to live their lives in the most integrated community setting.

For the first time, Georgia is seriously looking at all the current HCBS services and making an assessment of the current providers to see if they meet the objectives of the new rule. We want to see the best for our children – as parents, not just as caregivers or advocates. By moving the settings to be more people-centered, we can see our children succeed by contributing their talents in a more integrated community.

What can I do?

By moving the settings to be more people-

CHILDREN

SUCCEED by

in a more integrated

community.

contributing their talents

centered, we can see our

Our voices need to be heard. We represent almost 40,000 individuals receiving services as well as the 9,000 on the Medicaid Waiver Waiting Lists.

Get involved: tell your story to your legislator. If you think your loved one is experiencing a service or support that does not meet these rules, let us know at unlockthewaitinglists@ gmail.com.

There will be more updates in the future and you should look to GCDD (*www.GCDD.org*) and Unlock the Waiting Lists! (*www.UnlockTheWaitingLists.com*) to keep you informed.



In 1988, Justin and Yoshiko Dart embarked on a historic 50-state journey to garner grassroots support for the yet-to-be-passed ADA. Photo credit: Tom Olin



MARK JOHNSON is the director of advocacy for the Shepherd Center, the top spinal cord & brain injury rehabilitation hospital in the nation. Johnson also serves as the council chair for The ADA Legacy Project.

Making a Difference will feature five guest columns by Johnson on the legacy of the ADA and how national and state groups are commemorating the anniversary. This is the second installment.



New Year Brings ADA25 Celebration to Atlanta

By Mark Johnson

Since the last edition of *Making a Difference*, Phase One of the ADA Legacy Tour was completed. In 2014, the Tour made stops in 18 states and traveled almost 12,000 miles.

Wrapped in disability rights photos, the ADA Bus and Legacy Tour pays tribute to the crossdisability efforts that led to the passage of the Americans with Disabilities Act (ADA) in 1990. The bus was originally procured for the 2006-2007 Road to Freedom Tour, which sought to engage the nation in the story of the ADA and the need for amendments to further the law's impact.

Both the Road to Freedom and the ADA Legacy Tours were inspired by the historic 50-state journey taken by the husband-and-wife team of Justin and Yoshiko Dart in 1988 to garner grassroots support for the yet-to-be-passed ADA.

The Tour includes not only the bus, but also a mobile museum that has a four-panel display on the history of self-advocacy, courtesy of the Museum of disABILITY History; disability history quilts; an archive of disability history milestones, locally and nationally; displays on the history of the Road to Freedom Tour; and information about The ADA Legacy Project and the ADA.

Local disability groups plan most of the programming around the stops. Youth Organizing! Disabled & Proud, based in CA, participated in San Jose in November 2014. Staff encouraged attendees to fill out cards on what the ADA means to them. One response: "Because of the ADA, I'm no longer someone who can be put in the back and ignored. I'm no longer shunned. I'm not invisible anymore."

The Tour is homage to the grassroots movements that started it all. Local ADA25 groups will be planning and implementing 25th Anniversary activities. As many as 250 celebrations are expected to commemorate this landmark legislation. In March, the ADA Legacy Tour will officially start Phase Two in Austin, TX. And in Georgia, the project is partnering with GCDD for its Disability Day on the Capitol on March 5 at Liberty Plaza, across from the Gold Dome. GCDD's Disability Day theme, *Fulfilling the Promise of the ADA*, will salute the ADA and also join a commemoration that will preserve, educate and celebrate the spirit of the law. (*Please see pages* 12-13 for information about Disability Day.)

Because of the ADA, I'm no longer someone who can be put in the back and ignored. I'm no longer shunned. I'm not invisible anymore.

In keeping with the project's theme of "educate," The ADA Legacy Project will also be partnering with the Six by '15 Campaign to promote its goals. Six by '15 is honoring the 25th anniversary of the ADA and 40 years of The Individuals with Disabilities Education Act.

The campaign is working to achieve six national goals by the end of 2015 in the following areas:

Employment

In March of 2014, almost five million people with disabilities participated in the labor force. That means less than 20% of people with disabilities are working or looking for work, compared to 68% of people without disabilities. By the end of 2015, the campaign would like to see that number reach six million.

Community Living

The Patient Protection and Affordable Care Act (ACA) included a new Medicaid option for states called Community First Choice (CFC). States that take up the option can provide home and community-based services without a waiver or waiting list and receive increased federal financial support for the services. By the end of 2015, the campaign would like to see four more states implement the CFC and address the institutional bias in their Medicaid programs.

Education

In the 2010-2011 school year, 22 states graduated over 60% of their students with disabilities with a regular diploma. Some graduated as low as 23%. The campaign would like to see at least six more states reach the goal of graduating 60% or more of their students with disabilities with regular diplomas by the end of 2015.

Transition

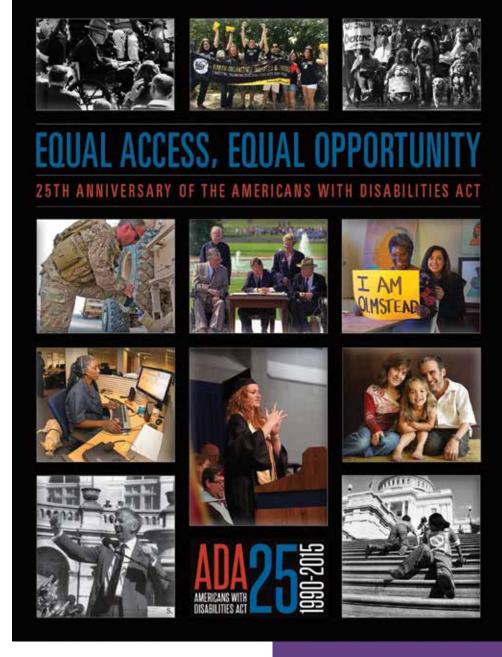
From 2004 to 2006, an average of 8% of youth with disabilities applied for vocational rehabilitation services. Of those who applied, only 56% actually received services. The goal is for at least six states to commit to supporting internships, scholarships and other evidencebased services to help youth with disabilities transition from high school to higher education and employment.

Healthy Living

In 2009, the New York State Department of Health Center for Community Health adopted a policy that all public health programs must explicitly include children and adults with disabilities and their families as a target population in health promotion efforts. All programs must discuss the importance of people with disabilities in the project and all applicants for grant funding must describe how they will include people with disabilities in their programs. New York is the first state to take on such a policy of deliberate inclusion of people with disabilities. The campaign hopes that by the end of 2015, six more states will take this step to build a more inclusive public health system.

Early Childhood

An estimated 17% of children in the US have a developmental or behavioral disability like intellectual disability or autism, but less than half of these children are identified before starting school. Early identification connects children with disabilities to services so they can start school ready to learn. The campaign hopes that by the end of 2015, six states will have increased their current rate of developmental screening for



children from birth to three by 15% and at least six states will commit to improving the crosssystem information exchange that supports access to services for children identified by screening.

The celebration is not just about honoring what has been done; it's about inspiring the community to get more done. As we start counting down to July 26, 2015, share your stories, come to Disability Day, or tell us how the ADA changed your life. The ADA, like Disability Day and other grassroots movements, started with a voice wanting to make a difference. As we kick off 2015 to honor the legacy of the past, we must remember to create a platform for the future.

For information about local activities, visit www.adalegacy.com/get-involved The ADA Legacy Project published a commemorative magazine highlighting the history of the landmark legislation and its progress since 1990.

Find the ADA Legacy Tour information, including stops in Georgia, at *www.adalegacy.com*

The ADA means that I can be WHATEVER I WANT TO BE

and live up to my full potential.

PERSPECTIVES



CHARLIE MILLER, 21, is a sophomore at Kennesaw State University's Academy for Inclusive Learning and Social Growth. He is also a former GCDD public policy intern.

Want to see your ADA story in *Making a Difference?*

Visit **www.gcdd.org** and tell us how the ADA's passage has impacted your life today. We look forward to reading your story! #ADAlegacy

The ADA Generation Speaks Up

By Charlie Miller

Recently, I was asked what the Americans with Disabilities Act (ADA) means to my generation. For me, the ADA means that I get to live my life. If the ADA wasn't here, then no one with a disability would be either. Things like bathrooms, kitchens or even public buildings wouldn't be accessible, and that would keep a whole group of people from living their best life.

People with disabilities have given a lot to society in, for example, research, art and movies. The ADA means that I can be whatever I want to be and live up to my full potential. This generation of people with disabilities is going places that other generations haven't been before. We are now traveling across the globe to learn new things so that we can all grow together. Before the ADA, you couldn't travel with a disability.

People saw that there needed to be a change, and they took action to help one another. The older generation had to fight to get the law put in place, but my generation has never had to live in a world without the ADA. However, my generation needs to work to make the ADA better.

When the ADA was enacted, it worked for that generation, but now it is time for the younger generation to pick up where the older generation left off.

I want to share a story: I recently went to an event downtown. It was a huge event, and I was very excited to be there and be a part of it. However, when we went to the restaurant for dinner, there were only stairs to get into the restaurant. My brother went upstairs and asked the hostess to help us. The manager, then, had to go to a different building and unlock an elevator to get us into the restaurant, and I ended up having to go into dinner through the kitchen. Yes, this building was technically accessible, however, the way I had to go about getting in made me feel like there is room for improvement.

As the future, we need to make sure that we don't get left behind waiting for someone else to make the world accessible.

My generation needs to work to make the ADA better.

There is still some disconnect between people with disabilities and people without disabilities. A person without a disability doesn't understand the preparations that I have to make every day. For example, I have to do more research before I go on a vacation. I have to make sure that where I'm going is accessible. If I'm going to the beach, I have to make sure that there is a ramp to the beach, and that there is a beach wheelchair available for me to use.

It is time to start moving forward so that current and future generations don't have to be anxious about the world being more accessible. Thanks to the ADA, I'm going to a university, living on my own, and working to make the world more accessible. The ADA has brought us hope in everyday challenges, but there are still some improvements that could be made.

Now it is time to gather together to make the future brighter for the next generation.

ADA's Impact in Our Readers' Words



Chad Roberts, 22 Cherokee County

Hi, I'm Chad. I am 22 and live with Autism. My entire life my mom and others have helped support me. I sometimes have trouble understanding things. I like being with other people who believe in me and know that I am smart. I don't talk a lot but I have a DynaVox, a communication speech device, which I love. It helps me to communicate what I want and need, helps me make friends. I am happy to have a way to communicate with others. I hope I

am helping to teach others that even people who don't talk a lot still have a lot to say. I hope I am teaching people that people who don't talk a lot can still work and have a good life. There were people who tried to tell my mom and me that I would never work. Those people were wrong. I am happy they were. I have four jobs. I like each job and do something different at all of them. I want to work more and hope I can soon. I also volunteer at our church and YMCA. I have my own ministry and help out the animal shelter. I have a lot of friends. I am happy living in my own home. It would be sad if I ever had to leave. It's not easy for me to make new friends in new places. My life would have been different if my mom would have believed the people who never thought I would or should work – or even if the ADA wasn't a law allowing me to have an opportunity to work. I am glad she knew better and always told me I was smart. And I am glad that with the ADA, I can work, volunteer and be a part of the community.



Jonathan Waters, 24 Atlanta

Because of the ADA, I have grown up with the same rights as everyone else even though I was diagnosed with Down syndrome. I have a great life. I've been able to live with my family and have a job in the community. I am able to spend some of my days at the Frazer Center where I have many friends. I also have many friends at my job in the community where I get paid a fair wage and I am able to save my money. I get to go to Chick-Fil-A and other

places in the community without anyone telling me to leave, and people are always nice to me. I am so glad I get to work at Innotrac too. My friends and I get to sweep the floors of their big building every Thursday. The work is not too hard and I enjoy doing it. I like getting a paycheck. At Creative Enterprises, where I get to go during the week, I sometimes get to pack boxes full of trash bags. I definitely like this. Sometimes I put packs of coffee creamers in boxes too. I like my packing jobs at Creative. I also get to use computers at Creative Enterprises. Most of the time it is fun and I enjoy looking up things. I am definitely glad the ADA has allowed me to go to Creative Enterprises, the Frazer Center and to work some too. I really like being able to hang out with my friends and the staff too. I am very thankful for the ADA.

The ADA GENERATION

is comprised of individuals that grew up after the landmark legislation was passed in 1990.

PERSPECTIVES

GCDD asked millennials, "What has been the law's greatest impact on your quality of life such as your expectations for access to opportunity, education, technology and employment?"

Read their stories, and see how you can submit your own story to GCDD on page 31. When people get to make

REAL CHOICES,

and others see the result,

they begin to picture

SOMETHING DIFFERENT, and

begin to ask for it themselves.



PAT NOBBIE, PhD, Mia's mom

MIA'S **Space**



MIA'S SPACE

Building a Currency of Choice

By Pat Nobbie, PhD

Andrew Solomon, author of *Far from the Tree: Parents, Children and the Search for Identity,* writes, "I believe choice is the only true luxury, that the striving inherent in decisionmaking gives decisions value. In modern America, choice is the aspirational currency ... I'd like to imagine a future in which we would be able to choose everything."

If choice is the currency, or a true luxury as Solomon says, who is holding the bank on choice? Where is choice stocked up? Is choice something you lose if you don't use it? Do you have to earn the right to make choices? Who has the power to grant us choice or take it from us?

There could be great debate about this, but let's think about who gets the luxury of that debate. The service system we have constructed for people with disabilities is holding the bank on choice. We created the terms by which people needing support get to choose – or not. We are concerned for their health and safety. They may not choose wisely. They may be influenced or taken advantage of.

So we say they can choose from this list of things we have decided are "safe." Or we authorize someone else to choose for them. We have a hard time supporting someone who has challenges in communicating to choose anything – where they want to live or work, what they eat, who their friends are or if they even get to have friends. We aren't very skilled at this, so we've created a system for deciding very important things for people.

It's hard to make choices when you can't picture the outcome. How often do the rest of us pick where to live from a list? How many of us would move in with people we had never met? We want to see the places and meet the people because not doing that is risky. We feel more vulnerable when we are less certain of the options. Yet this is standard practice for other people whom we consider to be more vulnerable than we are. We have a hard time supporting someone who has challenges in communicating to choose anything – where they want to live or work, what they eat, who their friends are or if they even get to have friends.

A couple of weeks ago, I spoke to a group of advocates about how this is the furthest I have lived away from Mia and it was scary to cede the risk to her for taking more control. But there she is with her great life, and here I am trying to figure out how that works for other people like her. I keep thinking about the power of person-to-person movements.

When people get to make real choices, and others see the result, they begin to picture something different, and begin to ask for it themselves. Later that day, one of the advocates in the group thanked me saying she can now picture possibilities for her daughter's choices that she hadn't pictured before – just like another mom had shown me something different for Mia's life long ago. Just like Mia's life shows possibilities to her group of friends.

Person-to-person movements show that we can bank a currency of choice so more people living in the community get to draw on it.

REAL COMMUNITIES INITIATIVE

New Work, New Culture: What is it?

By Caitlin Childs

In October 2014, Real Communities Community Builder Teri Schell and I traveled to Detroit, MI, for the New Work, New Culture Conference. This was our second learning journey to Detroit.

Because the realities of a rapidly changing economy and impacts of globalization hit Detroit long before the rest of the country, organizers have had many years to envision and put into practice truly sustainable economic development approaches. Instead of waiting for corporations or politicians to solve these problems for them, grassroots organizers and activists dedicate their energies to what is called "Visionary Organizing." Visionary Organizing requires us to imagine the world we want to live in and work to develop the capacity necessary for ordinary people and community organizations to make these visions a reality now, even if it is on a small scale.

In Detroit, viewing the economic crisis as both a danger and an opportunity, folks are reimagining how we think about work and creating the cultural changes necessary to make it reality.

Real Communities is focused on communitybased solutions to the social issues that impact people with disabilities. I was curious to learn how reimagining work and economy fits in with our increased efforts around employment for people with disabilities in Georgia through the lens of Real Communities.

What I learned is that new work is about moving away from the idea that "work" and "job" are different words for the same thing. It is about supporting folks to figure out what they are truly passionate about and what gives them energy and power. It is about finding ways to reduce the number of hours people need to participate in the traditional job economy through the use of tools like Community-Based Production (CBP). Then people can dedicate more time to activities they are passionate about and that drive them – or activities that make their neighborhoods and their communities stronger, safer, more connected and self-sustaining for the long haul.

Sounds idealistic, right? But what I observed over and over again is that people in Detroit are putting this into action and developing real strategies to provide for folks' basic needs through CBP models. Creation of products and skills can be exchanged or bartered through Time Banks – a resource that allows people to exchange time for projects and services – and other non-monetary exchange processes. Community-based production in Detroit includes large-scale community agriculture and the development of cooperatives of all kinds – everything from cafes and bakeries to housing co-ops and energy cooperatives.

Teri and I were able to visit Incite Focus, a "fab lab" guided by Visionary Organizing philosophies, which uses new technologies, digital fabrication tools and permaculture to put the tools of production directly in the hands of people in Detroit to create sustainable housing, transportation and other avenues toward economic development.

How can we learn from organizers in Detroit? Can we find opportunities to put some of these philosophies in action here in Georgia?

I hope that in the coming years, Real Communities can find partners who want to do just that. We have to acknowledge that in a rapidly changing economy and decreasing services to support non-traditional workers, new approaches are not just a good idea ... they are a necessity.



REAL COMMUNITIES INITIATIVE



CAITLIN CHILDS is the GCDD Real Communities organizing director.

We have to acknowledge that in a rapidly changing economy and decreasing services to support nontraditional workers,

NEW APPROACHES are not just A GOOD IDEA ... they are a NECESSITY. I AM CAPABLE of doing things.





RIAD AKHRAS, from Eatonton, GA, is studying to be a black belt in karate.

MAKING REAL CHOICES for people with disabilities shouldn't be a choice itself.

STRAIGHT TALK

Making Real Choices

By Riad Akhras

I want to talk about real choices for people with developmental disabilities. Making my own choices about what I want to do or buy is important to me. My brother does not have a developmental disability, and he gets to decide what he wants to do. So, why can't I do that too?

I want to tell you something about me. First, I like to talk about the weather; and second, I like to buy shoes. I have my own checking account, and I get shoe catalogs like Eastbay in the mail. There are lots of shoes in that catalog. Nobody tells me which ones I should buy. I get to choose.

In January 2014, I moved to a group home. I lived there for 10 months. I was stuck in a day program, and had to do what they wanted me to do each day. You want to know what I did each day at the day program? I just sat most of the time. They gave me worksheets each day just like school. Other times, I was given coloring sheets or watched movies. One day a week, they would dance to loud music, but I don't like loud music. Sometimes they would take us on field trips, but I had no choice about where I would go.

Someone else decided that for me. If I said "no," the staff would say I was choosing not to participate. Sometimes they would try to convince me to go on the field trip, and that would make me uncomfortable. I don't like crowded places like festivals or fairs – they are too noisy and there are too many people there. They didn't like it if I said "no." It made me very sad. Nowhere was my choice taken into consideration.

I live at home again now, and I am planning on getting a job. My mom and I talk about the things I want to do. I have friends in Athens, GA. I meet them at the mall and we hang out. I go bowling on Thursdays, and sometimes we go out to eat after. I go to karate twice a week with Mr. Ray where I am working to earn my black belt. I talk to my friends every day. I go with my mom to meetings about disability rights advocacy, and see what work is being done to make lives for people with disabilities better. I want to see if they are getting to choose what they want to do or decide what services are best for them.

My mom and I talk about the things I want to do. I have friends in Athens, GA. I meet them at the mall and we hang out.

Making real choices for people with disabilities shouldn't be a choice itself. Making decisions for myself not only lets others know that I am capable of doing things, but, it makes me feel good also.

January January 15-16

GCDD Quarterly Meeting Atlanta, GA 404.657.2126 www.gcdd.org

January 19

Martin Luther King, Jr. March & Rally Disability Rights Component Atlanta, GA greenpogue@disabilitylink.org

January 21

Advocacy Day at the Capitol We Need Waivers Day Atlanta, GA www.gcdd.org/2015DisabilityDay

January 25 - 28

Georgia Winter Institute Columbus, GA *georgiawinterinstitute.weebly.com*

January 28-31

Assistive Technology Industry Association 2015 Annual Conference Orlando, FL *www.atia.org*

January 29

Advocacy Day at the Capitol ICWP Raise The Rate Day Atlanta, GA www.gcdd.org/2015DisabilityDay

February 4

Advocacy Day at the Capitol Kids Need Real Homes, Not Nursing Homes Day Atlanta, GA www.gcdd.org/2015DisabilityDay

February 11

Advocacy Day at the Capitol Employment First Day Atlanta, GA www.gcdd.org/2015DisabilityDay

February 19

Advocacy Day at the Capitol Youth Day Atlanta, GA www.gcdd.org/2015DisabilityDay

February 21-24

2015 Midyear Meeting American Council of the Blind Arlington, VA www.acb.org

March March 5

17th Annual Disability Day at the Capitol Atlanta, GA *www.gcdd.org/2015DisabilityDay*

March 5-8

Council of Parent Attorneys and Advocates 2015 Annual Conference San Diego, CA www.copaa.org

March 6-8

Abilities Expo Los Angeles, CA www.abilitiesexpo.com/losangeles

March 12

Think Differently & Get More Jobs Georgia APSE www.gapsenetwork.com

March 22

National Association of Disability Representatives Annual Conference Austin, TX www.nadr.org

April

April 8-11 Council for Exceptional Children

2015 Annual Conference San Diego, CA www.cec.sped.org

April 13-15

2015 Disability Policy Seminar Washington, DC www.thearc.org

April 16-17

GCDD Quarterly Meeting Atlanta, GA 404.657.2126 www.gcdd.org

2015 CALENDAR

Planning an upcoming event?

Send your information to GCDD Public Information Associate and Social Media Coordinator Jhai James at jhai.james@gcdd.ga.gov; Subject line: "Community Calendar" by March 15 to be included in the calendar. Visit GCDD's expanded online community calendar to view additional local events at www.gcdd.org/calendar.



The new Liberty Plaza

HIGHLIGHT:

Fulfilling the Promise of the ADA

Disability Day at the Capitol, March 5, 2015 at Liberty Plaza, across from the Gold Dome See pages 12-13 for additional details and registration form.

Photo courtesy of Georgia Building Authority

RESOURCES

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

Georgia Council on

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

State Government

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

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

Department of Community Affairs www.dca.ga.gov

Georgia Housing Search www.georgiahousingsearch.org 877.428.8844

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

General Information www.georgia.gov

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

Around GCDD

GCDD Welcomes Six New Council Members www.gcdd.org

In The News

ADA25 Georgia Plans Atlanta Parade adaparade@gmail.com

Georgia Budget and Policy Institute www.gbpi.org

Employment First: Focus on Strengths

Marc Gold and Associates www.marcgold.com

Employment First Georgia www.employmentfirstgeorgia.org

Legislative Preview: It's Advocacy Season in Georgia

Unlock the Waiting Lists! www.unlockthewaitinglists.com

GCDD: Public Policy www.gcdd.org/public-policy

Georgia State Legislature www.legis.ga.gov

Project Vote Smart www.votesmart.org 1-800-VOTESMART

2015 Advocacy Days at The Capitol www.gcdd.org/2015DisabilityDay

2015 Disability Day at the Capitol www.gcdd.org/2015DisabilityDay

Attendee Online Registration http://bit.ly/1vAbrdP

Sponsor Online Registration http://bit.ly/1wnPdzw

New Home and Community-Based Services Settings Rule Brings Focus on People with Disabilities

Centers for Medicare and Medicaid Services www.cms.gov hcbs@cms.hhs.gov

Georgia Department of Community Health www.dch.georgia.gov

Unlock The Waiting Lists! www.unlockthewaitinglists.com

Administration on Community Living www.acl.gov

Georgia Council on Aging www.gcoa.org

Georgia Advocacy Office www.thegao.org HCBS Advocacy www.hcbsadvocacy.org Home and Community-Based Settings Rule www.dch.georgia.gov/waivers

Expert Update

Unlock The Waiting Lists! www.unlockthewaitinglists.com

New Year Brings ADA25 Celebration to Atlanta

ADA Legacy Project www.adalegacy.com

Perspectives www.gcdd.org/ ADAcallforsubmissions

Real Communities

New Work, New Culture www.reimaginingwork.org

Time Banks www.timebanks.org

Correction

Making a Difference's Fall 2014 issue printed an editorial by Bob Kafka, Expert Update, in which the photo in the sidebar on page 25 was misidentified. The man was not Mr. Kafka, but Mike Auberger, a fellow ADAPT activist of Kafka's, and the magazine apologizes for the error. The cutline has been corrected on the website edition.



Thanks to OUR SPONSORS for their Support!

If you are interested in being a sponsor for *Making a Difference* magazine, please call Devika Rao at 678.384.7836.

MILLENNIALS, SHARE YOUR STORY!

The ADA Generation is comprised of individuals that grew up after the landmark legislation was passed in 1990.

Millennials with disabilities (30 or younger), what has been the law's greatest impact on your quality of life such as your expectations for access to opportunity, education, technology and employment? In 250 words or less, tell us your thoughts and you could be included in an upcoming edition of *Making a Difference* magazine.

Submit your ADA Generation Story to GCDD's *Making a Difference* Editor-In-Chief, Valerie Meadows Suber at *gcdd.org/ADAcallforsubmissions*.

#millennials #adalegacy

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We want to hear from you!



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MAKING DIFFERENCE VOLUME 15, ISSUE 3 A quarterly magazine of the Georgia Council on Developmental Disabilities

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Parent Parent

WE WANT ON



Fulfilling the **Promise of** the ADA

Fill out the form inside on page 12 or register online at www.gcdd.org before February 27, 2015.

Ve All Have A Story ... al's Yours?