MAKING a DIFFERENCE

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



NEWS FOR YOU:

CFI 10TH ANNIVERSARY: The Fight for 41 Children

ADA25: Georgia Celebrates the ADA 25th Anniversary

DEPARTMENT OF JUSTICE VS GEORGIA: Where Are We Now?



SUMMER 2015

The ADA25 Georgia Legacy Parade in Downtown Atlanta led by (I to r) disability advocates Eleanor Smith, Eric Jacobson. Leslie Irby-Peoples, Mark Johnson and Claudia Gordon. (See story on page 12).

On the Cover:

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.



Eric E. Jacobson Executive Director eric.jacobson@gcdd.ga.gov

Valerie Meadows Suber Editor-in-Chief & Public Information Director valerie.suber@gcdd.ga.gov

2 Peachtree Street NW Suite 26-246 Atlanta, GA 30303-3142 Voice 404.657.2126 Fax 404.657.2132 Toll Free 1.888.275.4233 TDD 404.657.2133 www.gcdd.org

O'Neill Communications

Devika Rao devika@oneillcommunications.com

> Nancy O'Neill Design & Layout

On the Back Cover:

More pictures of Atlanta's
celebration of the ADA 25th
anniversary – the ADA25
Georgia Legacy Parade
and the ADA Legacy Tour Bus.

MAKING@DIFFERENCE

A quarterly magazine of the Georgia Council on Developmental Disabilities

VOLUME 16, ISSUE 1

The Fight for 41 Children	page 8
Advocates ask why it has been so hard to move the	
remaining 41 children with disabilities living in institutions	
into integrated and inclusive communities	

Georgia Celebrates the

ADA 25th Anniversarypage 12

People with disabilities, their families, caregivers and advocates gathered in Downtown Atlanta to participate in the ADA25 Georgia Legacy Parade commemorating the landmark legislation.

Department of Justice vs Georgia:

Where Are We Now?page 18

How will the State move forward to accomplish the ADA goals after failing to meet the June 30, 2015 deadline?

FEATURES DEPARTMENTS

A Time for Solidarity3
In The News Society for Disability Studies Conference
Around GCDD Jacobson Appointed to MARTA Board, Munoz Selected for Leadership Academy5
Eric's Excellent ADA Adventure6
Expert Update Change is a Movement by Claudia Gordon16
Guest Articles The Empowerment of the Americans with Disabilities Act

by Mark Johnson.....24

GCDD Viewpoint

Perspectives

Children Need Communities by Beth English	.22
Let's Advocate for the Kids by Pamela Walley	23

Mia's Space

Seeing With Your Own Eyes....26

Real Communities

Real Communities'
Connections Help Launch
Clarkston School27

Let People with Disabilities

Straight Talk

Make an Impact by Tia Nelis	28
Calendar	29
Resources	30

Cartoon and Ads 31

GCDD VIEWPOINT



A Time for Solidarity

Happy Anniversary, ADA. On July 26, we will celebrate the 25th anniversary of passage of the Americans with Disabilities Act, the most important piece of legislation for people with disabilities. It is *your* civil rights legislation and *your* movement for equality.

While the fight must continue, the ADA has brought about better access and visibility for people with disabilities. It has become the template for countries around the world for creating physical and societal accessibility, such as the UN Convention on the Rights of People With Disabilities. Without the ADA, the United States Supreme Court could not have ruled that institutions were a form of segregation and we would not have the *Olmstead* decision.

This edition of *Making a Difference* celebrates this historic event. It reports on the many events that happened in Atlanta during this anniversary year tying together the ADA and the National Center for Civil and Human Rights (*see previous edition*). It seems like the ADA Legacy Tour Bus was in and out of Atlanta every week. You can read about my experiences with Tom Olin on the bus with our stops in Johnson City and Knoxville, TN.

There were national conferences and local celebrations in Augusta and Gainesville, and the ADA25 Georgia Legacy Parade was held in Atlanta in June. We had ample opportunities to show our solidarity. So why am I feeling that last month's ADA25 parade was a big missed opportunity for Atlanta's disability community?

The strength of our numbers and activism simply wasn't on display that day. We could have marshaled a bigger crowd for a city of four million people that was the center of the Civil Rights movements in the 1960s and played a role in successful passage of the ADA. Maybe a thousand marchers parading to the booming percussion of the Shiloh High School Drum Corps would have forced someone from CNN to walk across the street and ask what was happening.

With a thousand or so in attendance, we just might have made the news and the public would have learned that Claudia Gordon of the US Department of Labor and former White House advisor came to deliver a rousing keynote. They would have discovered author, disability activist and filmmaker Simi Linton's most provocative reading from her book, *Claiming Disability: Knowledge and Identity.*

Larger attendance would have brought well-deserved attention to the ADA Legacy Tour Bus and Disability Rights Museum on Wheels that were staged at the parade site and remained for two days. For the marchers and onlookers along the parade route to Centennial Park, joined by those who were attending the Society for Disability Studies Conference here, it was a truly incredible occasion.

This edition is dedicated to all individuals who have fought for the rights of people with and without disabilities. Let us remember that people with disabilities are also people of color, men and women, straight and gay, lesbian or transgender, Jewish, Christian, Islam or whichever faith they choose or not choose to believe in. Each has had to fight for equality and to be recognized for what they are – human beings.

I hope you enjoy reading this edition of *Making a Difference*. We want to hear from you. Let us know by writing our Editor-in-Chief Valerie Meadows Suber at valerie.suber@gcdd.ga.gov.

Eric E. Jacobson
Executive Director, GCDD

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

Letters To The Editor.

GCDD **VIEWPOINT**

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

Audio or Large Print Versions:

For an audio version of *Making a Difference*, please contact GCDD. A large font version is available for download at www.gcdd.org.

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.

NEWS

It gives a genuine sense of empowerment

TO WORK TOGETHER

and find

SOLIDARITY

across various perspectives.

Society for Disability Studies Conference Brings Together Disability Community

IN THE **NEWS**



Every June, the Society for Disability Studies (SDS) brings together a vibrant mix of academics, activists, artists, students and community members to share and learn ideas on building places and spaces that gives access to everyone – with or without disabilities.

"It is a conference that covers everything from academia to grassroots movements," said Tammy Berberi, past SDS president and 2015 site chair.

Downtown Atlanta was host to this year's SDS annual meeting where dozens of academic panels, discussions, workshops, presentations and social gatherings were held at the Hyatt Regency Hotel from June 10 - 13. Members and other conference attendees shared ideas, met local disability justice activists and formed valuable professional relationships.

society for disability studies

in scholarship, activism, and the arts

Kicking off the annual conference was the Summit on Disability and Social Justice hosted by the Georgia Council on Developmental Disabilities (GCDD) and SDS.

This day-long summit gathered academics, grassroots organizers and activists to examine the way disability justice is connected to other social justice struggles. Led by GCDD's Real

Communities Director Caitlin Childs, the summit used engaging participatory panels and breakout sessions to understand how disability rights fits into social justice work.

The four workshops discussed topics such as incarceration and institutionalization; youth organizing; food justice; and sexuality as a human right and reproductive justice.

"The Real Communities model fits in extremely well with SDS' mission of showing how communities can be strengthened by learning from each other," said Berberi. "It gives a genuine sense of empowerment to work together and find solidarity across various perspectives."

The Social Justice Summit was honored with a proclamation by Sen. Gail Davenport (D-District 44) and City of Atlanta Councilman Clarence Terrell "CT" Martin who proudly declared June 10 as Disability Justice Day.

With over 500 attendees, the 2015 conference also commemorated the 25th anniversary of the Americans with Disabilities Act (ADA) through various events including the ADA25 Georgia Legacy Parade held on June 13 (*Read more about the parade on page 12*). In its work, SDS thrives to find ways to afford full participation and access for all people.

The 2016 Society for Disability Studies Conference will be held from June 8 -11 in Phoenix, AZ.



AROUND GCDD



Eric Jacobson Appointed to MARTA Board

Eric Jacobson, executive director of the Georgia Council on Developmental Disabilities (GCDD), has been recently appointed to the Board of Directors of the Metro Atlanta Rapid Transit Authority, or MARTA. The city's mass transportation system also provides MARTA Mobility, the paratransit service for people with disabilities and senior citizens.

In his role, Jacobson will provide guidance and insight on decisions about the regional transit system and how it will affect people with disabilities who use or consider using mass transit.

The MARTA Board of Directors is a panel that votes on important decisions affecting the direction of the company made up of representatives from the City of Atlanta, Fulton County, DeKalb County, the Georgia Regional Transportation Authority and the Georgia Department of Transportation.



GCDD Executive Director Eric Jacobson participated in a recent panel for the Children's Freedom Initiative's 10th Anniversary.



Council Member Selected for Leadership Academy

Brenda Munoz, GCDD Council Member and parent advocate, was selected as one of thirty out of a hundred applicants to receive a full scholarship to attend the Leadership Academy in Santa Fe, New Mexico on June 22-25, 2015.

Hosted by The Georgetown University National Center for Cultural Competence, the Leadership Academy aims to advance and sustain cultural diversity and cultural and linguistic competence in networks supporting individuals with intellectual and developmental disabilities.

Through this opportunity, Munoz believes that, "I have a charge to co-create with the GCDD leadership a diversity and inclusion blueprint for Georgia, and will gain access to a year-long professional national expert/mentor in order to provide guidance and technical assistance."

The Academy is part of the Leadership Institute for Cultural Diversity and Cultural and Linguistic Competence funded by Administration on Intellectual and Developmental Disabilities, Administration on Community Living, and US Department of Health and Human Services.





GCDD's Executive Director Eric Jacobson copiloted the ADA Legacy Tour Bus for five days. The following is a first hand look at his journey.





Copilots Tom Olin (I) and Eric Jacobson celebrate the end of their five-day ADA adventure.

Eric's Excellent ADA Adventure

By Eric Jacobson

It began on May 11 with a double rainbow casting over the Tennessee mountains and ending with a triumphant return to Atlanta on a Friday afternoon, May 15th. Little did I know six months ago when Mark Johnson, the chair of The ADA Legacy Project, asked me if I would be interested in going on the ADA Legacy Tour Bus, that it would have such a profound impact on me. First, it's important to clarify that this is not just a bus. It is a recreational vehicle (RV) that has made a journey quite like no other.

The RV is covered in photos taken by Tom Olin, photographer of the disability movement, storyteller, owner and driver of the RV. He was also my copilot for these five days, and it was just the two of us on an adventure to help tell the story of the Americans with Disabilities Act (ADA). Tom has been driving around the country with other copilots since July 2014 and has already visited 34 states. The Tour will complete its journey on July 26 in Washington, DC to celebrate the 25th anniversary of the passage of the law. Tom's photographs will be displayed at the John F. Kennedy Center for the Performing Arts as part of the formal celebration.

Throughout this trip, I was reminded of the many people who came before us, laying the foundation for much of the struggle of which we are all a part.

Our first stop after leaving the National Center for Civil and Human Rights was the first exit off I-85 in South Carolina where Tom gave me my own set of keys and told me to drive the RV. I have never driven one before, let alone one on the curvy interstate headed toward the mountains. Tom promptly took a nap.

Our first real stop was Johnson City, TN, home of the northeast office of the disABILITY Resource Center. Director Tyler Venable arranged for a resource fair with the ADA bus as the main attraction. We set up banners with information about the ADA and of course, a display of Tom's photos. Each photo includes a story and it was my privilege to hang around and listen to Tom relay each one. People arrived to see the bus, get information and tell their own stories. Some drove from nearby Virginia and others took day outings to see history on wheels.

We listened to stories about how the ADA had changed lives by allowing people who were once ignored to now live a meaningful life. We also heard how the expectations of the ADA may not have been met for all people because some still struggle to have a "real life."

We also heard how the expectations of the ADA may not have been met for all people.

Not everything was as enlightening as those meaningful stories. In the middle of the day, Tom went to get in the RV only to discover we were completely locked out – the keys were not working. For two hours we banged, pushed, pulled and struggled to open a door.

Finally, a latch was jimmied and we were able to get in, but the lock needed to be replaced. After a detour to Elizabethton and a short drive, we found ourselves at an RV park halfway between Johnson City and Knoxville – our day three stop.

Were individuals aware of the struggles or was the segregation of people with disabilities new to them?

We would spend two full days in Knoxville. The staff and board members from the disABILITY Resource Center, Katherine Moore, Basil Farris, Nicole Craig and Dennis Clark did a great job creating two events. The first one took place at the Turkey Creek Regal Pinnacle movie theaters where we displayed over 30 of Tom's photos. People on their way into and out of a movie took the time to pause to see the photos of young and old, some of whom had been handcuffed by the police utilizing the ideas of Mahatma Ghandi and Dr. Martin Luther King, Jr. demanding justice and equal access. Not many asked questions, but I had to wonder about their impressions and thoughts as they walked away.

Were individuals aware of the struggles or was the segregation of people with disabilities new to them?

The next day was a celebration in Downtown Market Square where hundreds of people wandered throughout the day. Mayor Madeline Rogero, State Senator Becky Duncan Massey and City ADA Coordinator Stephanie Brewer Cook helped the Center celebrate the 25th anniversary and the arrival of the ADA Legacy Tour Bus. People who had attended the signing of the ADA came by to see the bus and reminisce about being there and what has happened in the 25 years since. One guy who writes a blog about disability and the media thought progress had been made as more people with disabilities were being featured on television and in advertisements. At the very least, this shows that society has recognized people with disabilities' economic potential.

Our final day began with a trip to the Highlander Research and Education Center, the place where Civil Rights activist Rosa Parks came before her historic decision to remain in her seat on a Montgomery City bus. It is where men like US Congressman John Lewis came to organize the Student Nonviolent Coordinating Council. It is where a group of people, including Tom Olin, came 25 years ago to discuss equal rights for people with disabilities.

I could feel the spirits of those who came before us and have let us ride on their shoulders in that room. The next stop on our Road to Freedom journey would take us full circle, back to the Center for Civil and Human Rights in Atlanta.

We arrived back in Atlanta to much excitement. GCDD Council members and advocates wanted to know how the trip went and I detailed as much as I could muster before exhaustion began to set in. Tom needed to prepare for the next leg of his journey. Throughout the trip, I wished that we had someone who was documenting these stories both in words and through pictures as the experience could reach so many more people that way. While I had no idea what to expect, the trip turned out to be one of the most enjoyable and worthwhile times I have ever had.

SPIRITS of those who came before us and have let us RIDE ON THEIR

RIDE ON THEIR SHOULDERS in that room.



Tom Olin and Eric Jacobson get ready for adventure in the cockpit of the ADA Legacy Tour Bus.



This is a

MERITORIOUS EFFORT

that we can and should be working on,

AND WE ARE.



The Fight for 41 Children

By Devika Rao

In April, disability community leaders, people with disabilities, parents, caregivers and citizens gathered together to seek answers to a very important question – why has it been so hard to move the remaining 41 children with disabilities living in skilled nursing facilities and private institutions into integrated and inclusive communities?

They came together at the Atlanta Community Food Bank for the Children's Freedom Initiative: A 10-Year Celebration and Call to Action event honoring the coalition's work over 10 years, but also to remind everyone that there is still more work to be done – specifically for those 41 children who are in these facilities.

Since 2005, the Children's Freedom Initiative (CFI), disability rights advocates and state agencies have worked hard to move all 144 children living in private facilities back into communities where they are able to thrive.

Sharon Lewis, principal deputy administrator of the Administration for Community Living and senior advisor to the Health and Human Services Secretary on Disability Policy, addressed the fundamental concept of community living in her keynote speech.

"Social isolation is twice as deadly as obesity, and the most vulnerable are children," said Lewis. "And we know Georgia has every opportunity to become a zero state with no children living in institutional facilities."

To address this possibility, a number of state agency leaders served on an expert panel to discuss moving these children into the community through legislative means. They included Georgia Department of Community Health Commissioner Clyde Reese, Georgia Division of Family and Children Services Director Bobby Cagle, Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) Commissioner Frank Berry and Kim Grier, adult guardianship

specialist at the Division of Aging in the Department of Human Services.

Across the board, there was sound agreement from the community to the state agencies that children should not be in skilled nursing facilities or private institutions.

"Georgia has every opportunity to become a zero state with no children living in institutional facilities."

"I can say unequivocally that every time the subject of children in nursing homes has been broached with me, I have been clear and I absolutely agree there should not be children in nursing homes," Reese said. "I believe this is a worthwhile objective. This is a meritorious effort that we can and should be working on, and we are."

The Challenge

In 2010, Georgia was sued by the Department of Justice, and at the time, the State signed the most comprehensive settlement agreement in the country. The requirement was to transition all individuals who were in state institutions into a community-based setting by the end of June 2015. (Read more about the Department of Justice Settlement on page 18.)

The settlement agreement was a five year plan that stipulated that the State will move 150 people each year for the first four years, and "all remaining" by the fifth year into integrated and inclusive communities.

The agreement was to bring the State in compliance with the 1999 US Supreme Court ruling of *Olmstead vs L.C.*, which mandated that states eliminate unnecessary segregation of persons with disabilities and to ensure that they receive services in the most integrated setting appropriate to their needs.

However, during the transitions, independent reviewers brought photos of unlivable conditions such as rat poison or antifreeze underneath the stoves and broken glass on porches. As a result, "I stopped transitions," said Berry.

Berry's purpose was to ensure that, "when we move someone back home, into the community, we can look family members in the eye and say that it will be a place that people *want* to call their home."

The transitions have met with two distinct challenges keeping the State from accomplishing this goal.

"One, it's the quality of care that individuals get in the community. And the second one is the oversight that our department provides for that quality of care," he added.

Family Support

National Core Indicator data shows the quality of life for an individual who is living in a relationship-based circumstance – whether it's with family, roommate or someone of their choosing – is healthier and happier in the long run.

Families cannot do this alone.

While the evidence on living in nurturing, inclusive communities points to positive impacts, "families cannot do this alone," Lewis said. "We know that if families are not adequately supported, that's a problem."

As a result, a lot of children are being put at risk of institutionalization and other bad outcomes because they are not getting the proper support they need.



Deputy Administrator Sharon Lewis, keynote speaker, stands with members of one of the expert panels (I to r): Adult Guardianship Specialist Kim Grier, Commissioner Frank Berry, Commissioner Clyde Reese and Director Bobby Cagle.

There is \$450 billion of unpaid caregiving provided by families across this country. Although Medicaid is the big funder for waivers for people with disabilities, long-term supports and services have not been addressed and it's a critical issue, according to Lewis.

"Huge benefits have come for people such as Medicaid covering diapers and other things like nursing support," Pam Walley, a parent advocate, said while applauding the changes that have come through Medicaid. "But, what is really missing is the supports to keep the kids out of the facilities. It comes back to long-term care support because as the kids get older, so do the parents and it becomes harder to keep up."

Walley and her daughter, Callie Moore, have been advocates for moving children out of skilled nursing facilities or private institutions since 2005 and were recognized for their advocacy work at the event. (Please see sidebar on page 10 for the complete list of recognized advocates.)

The demand for waivers will also increase in the coming years due to the aging population – including parents of children with disabilities.

In addition, there is a dire need for professional in-home care or nursing supports. Metropolitan cities like Atlanta provide access and availability to care, but the trouble has been in rural Georgia where DBHDD has had a difficult time recruiting and retaining high quality staff or caregivers.



CHILDREN'S FREEDOM INITIATIVE'S RECOGNIZED ADVOCATES:

Seated (I to r): Mathew Harp and Callie Moore. Standing (I to r)
Brenda Parker, Zenobia Willis, Pam Walley, Karl Lehman, Sally Carter, Jim Schnupp, Greg Schnupp,
Bobbie Davidson, Former Rep.
Judy Manning, Katie Chandler,
Dottie Adams. Not present: Beth
English, Pat Nobbie, Joe Shapiro and Gwen Skinner.

The following advocates were recognized at the CFI 10th anniversary event for their work in moving children out of facilities and into inclusive communities.

- Sally Carter and
 Bobbie Davidson
- Beth English, executive director of Easter Seals Southern Georgia
- Mathew Harp and Zenobia Willis
- Karl Lehman, president and CEO of Childkind, Inc.
- Former State Rep. Judy
 Manning (R District 32)
- Pat Nobbie, PhD, program specialist at the Administration for Community Living
- Brenda Parker
- Greg, Jeaunette and Jim Schnupp
- Joe Shapiro, investigation correspondent for National Public Radio
- Gwen Skinner
- Pam Walley and Callie Moore



Alternative Solutions

A challenge in Georgia has also been in finding people who are interested in opening up their homes to kids as foster models.

Nancy Rosenau, executive director of EveryChild, Inc. located in Austin, TX noted the similarities between Georgia and Texas' attempts to remove children from these settings.

"The majority of the children who we have helped move from facilities have NOT returned to their own homes," said Rosenau. "They have moved in with families in the community who have opened their homes to them and we have found that has been a necessity in order to create family life."

EveryChild started similar work like CFI in 2002. Since then, leaders and advocates throughout Texas worked to bring 955 children out of nursing homes and currently have 318 left to move into the community.

"People are very surprised that we have a need for foster homes in general. I think we've not done a good job, as government, in relating the need to the community because what we're finding is when we relate the need, people step forward," Cagle remarked about the need for foster homes in Georgia.

But, depending on the service system isn't enough.

Zolinda Stoneman, director of the Institute on Human Development and Disability at the University of Georgia noted that it is important to engage the communities. "We really need to figure out ways of engaging all those people who are shocked to learn that there are kids living in nursing homes," said Stoneman. "There are families who right now would be more than willing to talk about potentially supporting a child and their family. But they don't have any notion that there are kids out there who really could use and need them."

But, depending on the service system isn't enough.

The State of Texas passed permanency legislation that provided alternative solutions such as adoption or foster care rather than congregate care. For Georgia, CFI and its band of collaborative organizations would have to explore how to take congregate care off the table.

"If we know that what it really takes to keep kids – keep anybody, not just kids, not just people with disabilities, but anybody – safe, is to have neighbors, friends and loved ones around you, then it is about going into a community and saying 'how do we bring people together?' "said Eric Jacobson, Georgia Council on Developmental Disabilities (GCDD) executive director.

But to provide quality care in the community means that the State must plan to improve the quality of support, including workforce development, ensuring that support workers are paid a living wage, reducing staff turnover and addressing those concerns in the State. It also means that the State needs to start building regularly scheduled respite care into the treatment planning process so families don't burn out.

"How do we support families, through the community, to support their kids and not necessarily through the Medicaid program or [Early and Periodic Screening, Diagnostic and Treatment]?" added Jacobson. "We know that there will never be enough financial resources — even in a State where the economy is growing — that will be available to take care of everybody, and if we don't figure out the community aspect of it I think we're going to be lost."

The Commitment

Although there was a lot of discussion in terms of getting those 41 children out of skilled nursing facilities or private institutions – both in political commitment and acknowledgement of barriers – state agency leaders provided stark realities of when they will be out of these settings.

"I was asked to come and talk about whether or not I could commit on the behalf of the State to say that there never would be another child admitted to a nursing facility. I was clear then, and I have to say now that I don't believe I could commit to that. Not because I don't agree with it, but I don't think I'm in a position to say that there will never be a circumstance where it would not happen," said Reese.

Berry also added that the State recognizes the urgency. "Lieutenant Governor [Casey Cagle] states that this is a top priority," he said. "We're in agreement. But I am not going to set a deadline from our department's standpoint."

Even though the commissioners couldn't provide specific details on moving the children, advocates spoke about what they can do to hopefully move the process along.

"We don't want to wait around if the Commissioners, for example, want to have a moment of admiring the problem and not quite jumping into the urgency and action we are hoping for," said Ruby Moore, executive director of the Georgia Advocacy Office. "I don't want to put all of our eggs in one basket and say 'unless we can get them to do that we can't move forward' because there is always something that we can do."

"I think that there is a commitment to get them out."

Along with legislative support, community engagement is becoming the central key to continuing advocacy for removing the 41 children out of these facilities.

"I think that there is a commitment to get them out. It may not be by the end of the year, it might not be – as one legislator wanted – by the time school begins in the fall, but I think that there is support both on the legislative, bureaucratic as well as the advocacy side, to figure this thing out and get those kids moved out," Jacobson added.

I think the greater question is how do we shut that front door, lock it, and make sure it never opens again? And that's the tough part."

Advocate Mathew Harp attended the Children's Freedom Initiative's anniversary celebration in Atlanta this past spring.

During CFI's celebration and call to action event, Brittany Curry covered the back wall with graphic depictions of the comments and opinions expressed by the attendees and speakers.



We've made some progress but there's

MORE WORK TO DO.

We're not there yet, but today it's time to

CELEBRATE.

Georgia Celebrates the ADA 25th Anniversary

By Richard M. McKay



"Rosa [Parks] wanted to ride in the front of the bus. We wanted to get on the bus."



The ADA Legacy Project Chair Mark Johnson and GCDD Executive Director Eric Jacobson address an enthusiastic crowd at the ADA25 Georgia Legacy

Disability advocates assemble on a hot summer day in Downtown Atlanta's Hardy Ivy Park, at the start of the ADA25 Georgia Legacy Parade. Perched in a tree's shade from Atlanta's summer sun, Mark Johnson, director of advocacy at the Shepherd Center, called those words into a microphone evoking the Civil Rights icon that helped end racial segregation.

On June 13 at Downtown Atlanta's Hardy Ivy Park, people with disabilities, their families, caregivers and advocates gathered to celebrate the 25th anniversary of the Americans with Disabilities Act (ADA) and participate in the ADA25 Georgia Legacy Parade, a commemorative event for the landmark legislation declaring people with disabilities have a right to equal opportunities.

He's one of dozens who brought together this celebration. It included a cross-country ADA Legacy Bus Tour, hosted by The ADA Legacy Project which Johnson chairs, that will culminate on July 26 at The White House to

The parade was only five blocks, but they've already traveled far across decades of prejudice, legal and social hurdles.

mark the exact date the act was signed into law in 1990.

On parade day, Johnson was flanked by Eric Jacobson, the executive director of the Georgia Council on Developmental Disabilities (GCDD), who's made it his career to fight for better laws and programs for people with disabilities.

"It's been 25 years," Jacobson said. "We've made some progress but there's more work to do. We're not there yet, but today it's time to celebrate."





Led by the beats of the Shiloh High School Drum Corps, Claudia Gordon, chief of staff at the US Department of Labor's Office of Contract Compliance; Eleanor Smith, founder of Concrete Change; and Leslie Irby-Peoples, Ms. Wheelchair USA 2015 joined Johnson and Jacobson on the parade front line.

The parade was only five blocks, but they've already traveled far across decades of prejudice, legal and social hurdles.

Preserve, Celebrate, Educate

"Nobody is going to know our story unless we preserve it," Johnson told the crowd as he encouraged people to text, take photos, record videos and post on social media the day's events.

That's the mission of The ADA Legacy Project – preserve disability history; celebrate its historic milestones; and educate the public and future generations.

And, Atlanta is steeped in ADA history.

"How many of you are familiar with *Olmstead*?" Johnson asked, invoking the 1999 US Supreme Court case that ended most institutionalization of people with disabilities, deciding that it was unjustified segregation violating the ADA.

He spoke about the 75 Spring Street Sitin in Downtown Atlanta where dozens of protesters with disabilities occupied 75 Spring Street, now the Richard B. Russell Federal Building, drawing national attention to one call – put chairlifts on all public buses. "They were dragging us out of that building until someone called the president. We negotiated the final language of the ADA from that," said Johnson.

That's what the celebration is about. It honors the law that in 1990 brought order to a patchwork of rules and well-meaning ordinances, as well as casting out cold indifference across the country.

Advocacy

Parade attendee Autumn Baskin said that this is a community that is strong and proud.

"I'm here to show my daughter [Ayah] that she's part of a community that has a sense of pride," Baskin said. "I'm here to show her she has something to celebrate. People ask, 'what's wrong with her?' And I say 'Nothing.'" Baskin's daughter was diagnosed with cerebral palsy and is on the autism spectrum.

"What the ADA did for me? ... It gave me accessibility to any building you can get into."

William C. Harris of Atlanta, a wheelchair user, remembers the years before the ADA and what it has done since its passage.

"What the ADA did for me?" he said. "It gave me accessibility to any building you can get into. It gave me some semblance of Leading the parade (I to r) Eleanor Smith, founder of Concrete Change; Leslie Irby-Peoples, Ms. Wheelchair USA 2015; Claudia Gordon, chief of staff at the US Department of Labor's Office of Contract Compliance; Mark Johnson, The ADA Legacy Project chair; and GCDD Executive Director Eric Jacobson.



Georgia ADAPT marches to the slogan "Free Our People" in support of equal rights for people with disabilities.



University of Georgia's Institute on Human Development and Disability proudly participates in the parade.

While we have challenges,

WE ARE

We are differently abled.

Disability rights photographer and Road to Freedom bus driver Tom Olin (I), stands before the ADA Legacy Bus with Mark Johnson (c) and Eric Jacobson.





Actor on the TV show *NCIS: New Orleans* (r) and active wheelchair user Daryl "Chill" Mitchell was a guest speaker at the expo.



Attendees at the 2015 Mobility Expoviewing the latest technologies, products and services for people with disabilities.



opportunity. At jobs they had to give me a real look and not just say they couldn't hire me because I'm in a chair."

But more importantly, he said it helped change the mindset of the people around him.

"While we have challenges, we are able," he said. "We are differently abled."

The Legacy Rolls On

Approximately 100 parade attendees were edged along by the tailing ADA Legacy Bus, wrapped in pictures of ADA history and the words "The Road to Freedom." On the sides were blended images of protests, people demanding rights to get on buses and the right to access into buildings, stretching back 35 years.

Tom Olin, the self-declared disability historian has been photographing the fight for rights for people with disabilities for decades. "I guess I've been floating around the country following this for more years than I can count," he said.

He pilots the ADA Legacy Bus, a 50-foot, 2001 Fourwinds RV that has traveled 15,000 miles to 27 states and 50 cities since last September spreading the word and reminding America of the anniversary.

On a recent five-day leg of the trip, Jacobson joined Olin as his copilot and they went on a loop from Atlanta to Johnson City, TN ending on May 15 at the North Atlanta Trade Center in Norcross, GA. It was also the weekend of the 2015 Mobility Expo.

Upon arrival, an energized Jacobson called it a great week where people really connected with the history of the ADA. But Jacobson said that the most moving part was arriving at the Highlander Research and Education Center in New Market, TN – the same school where Rosa Parks received her civil rights training before the bus boycott.

"It was impressive to feel all that history there, and know that we're connected as a part of an ongoing story," Jacobson said.

Inspiring the Future

Twenty-five years later, the ADA is being celebrated nationwide to commemorate the past, but to also inspire the future for ongoing advocacy.

At the ADA25 Georgia Legacy Parade, parade attendees convened at Centennial Olympic Park, where the Office of City of Atlanta Councilman Kwanzaa Hall declared the day Disability Pride Day in the City of Atlanta.

The event also featured speeches from two leaders in disability rights: Simi Linton and Claudia Gordon.

"This is deeply moving and I am very thankful and grateful for this opportunity to be here in Atlanta with all of you at a very meaningful time in our history," said Linton, who read an excerpt from her book *Claiming Disability: Knowledge and Identity.* Most recently, she and Christian von Tippelskirch produced *Invitation to Dance*, a documentary about the disability rights movement portrayed through dance.



Claudia Gordon, chief of staff at the US Department of Labor's Office of Contract Compliance, gave the keynote speech.

Gordon, who also worked in the White House as the Public Engagement Advisor to the Disability Community, gave the keynote speech. "We are all gathered together to celebrate a law that has truly transformed how our society views, treats and accommodates citizens with disabilities," she said. (Read an excerpt from her speech in Expert Update on page 16.)

A performance by Full Radius Dance, a professional physically integrated dance



Full Radius Dance, a professional physically integrated dance company, closed the festivities of the ADA25 Georgia Legacy Parade.

company, closed the festivities of the ADA25 Georgia Legacy Parade.

"I just thought an anniversary sounds like a parade," said Gillian Grable, citizen-advocate and organizer of the parade. "We need to celebrate our advances, but focus on what needs to be done. We can't just celebrate. We have to also renew our commitment to making this world better for everyone."



Disability advocates with People First Mike and Mary Ann Curry took part in the parade promoting "Disable the Label" for people with disabilities.



About the ADA25 Georgia Legacy Parade

The Georgia ADA25 Legacy Coalition is made up of the following like-minded partner organizations: Atlanta Legal Aid Society, Concrete Change, disABILITY Link, Georgia Council on Developmental Disabilities, Georgia Disability History Alliance, Georgia State University Center for Leadership in Disability, One Billion Rising, the Shepherd Center, Statewide Independent Living Council of Georgia and University of Georgia Institute on Human Development and Disability. We would like to gratefully acknowledge the support of the Center for Civil and Human Rights, Georgia State Financing & Investment Commission. State ADA Coordinator's Office and the Society for Disability Studies. The Coalition also gratefully acknowledges the following additional sponsors: Diversified Enterprises, Easter Seals of Southern Georgia, Georgia Advocacy Office and Georgia Municipal Association.



An Excerpt from Claiming Disability: Knowledge and Identity by Simi Linton

Disabled people, and I will immediately identify myself as one, are a group only recently entering everyday civic life. A host of factors have typically screened us from public view. We have been hidden, whether in the institutions that have confined us, the attics and basements that sheltered

our family shame, the special schools and classrooms designed to solve the problems we are thought to represent. Or riding in segregated transportation, those "invalid coaches" that shuttled disabled people from one of these venues to another.

The public has gotten so used to these screens, that as we are now emerging, upping the ante on demands for a truly inclusive society, we disrupt the social order. We further confound expectations when we have the temerity to emerge as forthright and resourceful people, nothing like the self-loathing, docile, bitter or insentient fictional versions of ourselves the public is more used to.

We have come out not with brown woolen lap robes over our withered legs or dark glasses over our pale eyes but in shorts and sandals, in overalls and business suits, dressed for play and work – straightforward, unmasked and unapologetic. We are, as Crosby, Stills and Nash told their Woodstock audience, letting our "freak flag fly." And we are not only the high-toned wheelchair athletes seen in recent television ads but the gangly, pudgy, lumpy and bumpy of us, declaring that shame will no longer structure our wardrobe or our discourse.

For more about *Invitation to Dance*, a documentary film by Christian von Tippelskirch and Simi Linton, visit *www.invitationtodancemovie.com*

CHANGES DO NOT HAPPEN

in a moment; they happen in a

MOVEMENT.



CLAUDIA L. GORDON currently works as chief of staff at the US Department of Labor's Office of Federal Contract Compliance Programs. Previously, she held a position in the White House Office of Public Engagement as the public engagement advisor to the disability community.

Change is A Movement

This is an excerpt from Claudia Gordon's keynote address given at the ADA25 Georgia Legacy Parade held on June 13, 2015 in Downtown Atlanta.

Friends, we gather together to celebrate a law that truly transformed how our society views, treats and accommodates citizens with disabilities. That law, the landmark disability civil rights known to us and the world as the Americans with Disabilities Act (ADA) has positively impacted the lives of thousands of Americans living with disabilities, including mine, for the past 25 years.

Let me echo something that my friend and fellow disability rights advocate Mark Johnson said: "the Americans with Disabilities Act is an integral part of our nation's civil rights journey."

So true. Disability rights are civil rights.

For far too long, our needs, our issues and our concerns were viewed as matters of charity. For too long, society's primary preoccupation was on fixing us – through medical interventions, therapy and so forth – versus accommodating us; teaching us dependency versus providing us with the tools with which we can become independent and self-sufficient; forcing us into isolation versus integration and inclusion; controlling our freedom of choice versus empowering us make to informed decisions and fostering self-determination.

The signing of the ADA was a moment of incredible hope and optimism for people with disabilities and their families. The ADA symbolized the hope of a more inclusive society where all individuals could have the chance to live up to their full potential. It placed our country and the economy on the path to benefit from the talents and contributions of all Americans.

Helen Keller, who was deaf and blind, is one of the most beloved historic figures of all time because she embodied the American spirit of limitless possibilities. From the time she discovered the art of language at the water pump outside her home in Tuscumbia, AL, she never stopped breaking down barriers.

"People think that a revolution begins with injustice. They don't. A revolution begins with hope."

Ms. Keller taught the world that everyone has something positive to contribute when they are given an opportunity. She showed the world that with the right tools and attitude, anything is possible.

After all, we are to be defined not by our limits – but by our potential.

An advisor to Dr. King said: "people think that a revolution begins with injustice. They don't. A revolution begins with hope." I stand on the shoulders of countless disability rights advocates/activists and allies including parents of children with disabilities, who like

The ADA symbolized the hope of a more inclusive society where all individuals could have the chance to live up to their full potential.

Helen Keller taught us, believe everyone has something positive to contribute when they are given an opportunity.

They hope for a future wherein people with disabilities would enjoy equal access and full participation in all aspects of mainstream society; wherein we would lead independent lives, make informed choices and enjoy self-determination; wherein disability rights would be recognized as a civil right and not a matter of charity.

Their hopes laid the foundation for the ADA. Then, their action and sacrifices led to its drafting and passage.

Things didn't just get better for the disability community. People had to act to make it better. We may not have defining moments that are etched in our nation's consciousness like the Seneca Falls Convention – a milestone of women's civil rights movement/ women's suffrage, or Selma or the Stonewall riots of the LGBT community.

But our people sacrificed enormously to make things better for us.

I understand now what I didn't understand in 1990 – the ADA didn't come about overnight. Change does not happen in a moment; it happens in a movement. Just like the other civil rights movements before it: like the African-Americans who sat at the segregated lunch counters and refused to move to the back of the bus; people with disabilities obstructed the movement of inaccessible buses and marched through the streets to protest injustice – injustice such as being forced to live in institutions rather than in their communities with the necessary services and support.

They worked for years in cities and towns throughout the US attending protests, licking envelopes, sending alerts, drafting legislation, filing lawsuits and lobbying Congress.

Some of them are with us today – thank you.

This past March, our nation commemorated the 50th Anniversary of the Selma to Montgomery March. I paused to truly reflect on what it means to stand on the shoulders of giants – I am here because they marched! I am here because so many sacrificed for me – Dr. Martin Luther King, Jr., Congressman John Lewis and countless others who braved the violence of Bloody Sunday.

President [Barack] Obama said during his speech commemorating the anniversary, "Because of what they did, the doors of opportunity swung open not just for black folks, but for every American ..."

The passage of the ADA swung the door open for me.

I was a junior going into senior year of high school at the time the ADA was signed into law. It wasn't until the summer of 1991 that I truly gained an understanding of what the law symbolizes. I took a summer job with a nonprofit organization in New York City called Hospital Audience, Inc. Their mission is to provide cultural access to music, dance, theatre and the visual arts for individuals with disabilities and the elderly who live in nursing homes and other institutional settings as well as to children at health and social service facilities.

I was part of a cross-disability accessibility team. Together, we navigated our way around the Manhattan theater district visiting and surveying selected facilities for their accessibility features in anticipation of the ADA implementing regulations. We also measured curb cuts, counted wheelchair accessible parking spots, etc.

I learned so much and gained a new sense of awareness about the needs of individuals with disabilities other than deafness. I left NYC for college at Howard University with a new sense of empowerment and knowledge about my rights.



GCDD Executive Director Eric Jacobson (I) with Claudia Gordon, chief of staff at the US Department of Labor's Office of Contract Compliance at the start of the ADA25 Georgia Legacy Parade in June.

POSITIVE TO CONTRIBUTE when they are given an OPPORTUNITY.



Read Claudia Gordon's full speech on www.gcdd.org or scan the QR code to watch the video. People with significant disabilities

HAVE THE RIGHT to get institutional services in the COMMUNITY.



Department of Justice vs Georgia: Where Are We Now?

By H.M. Cauley

It all started with a mom who just wanted to go home.

That legal case centered around a Pennsylvania woman who sued under the Americans with Disabilities Act (ADA) to get the support she needed to move out of a nursing home and back into her community. Under *Helen L. vs DiDario* (1995), it was contested that such a facility was a segregated setting, and living in the community with support services was a more integrated environment.

The woman won her case, which blazed a path for two patients at the Georgia Regional Hospital Atlanta, a facility for those with mental health issues and developmental disabilities, to demand similar consideration.

"They argued that doctors said they could live in the community and that it wouldn't cost very much," said Talley Wells, director of the Disability Integration Project for the Atlanta Legal Aid Society.



Olmstead plaintiff, Lois Curtis, speaks to the crowd at GCDD's 2014 Disability Day while RespectAbility USA CEO Jennifer Laszlo Mizrahi looks on.

The two women were Lois Curtis and Elaine Wilson, who have become synonymous with the landmark US Supreme Court case, *Olmstead vs L.C.*

"They believed they had a right to get those services in the community. The US Supreme Court took their case and ruled in their favor and now, it is the law of the land," said Wells. "People with significant disabilities have the right to get institutional services in the community."

1999: The Ruling

That ruling, handed down on June 22, 1999, became known as the *Olmstead* decision. Though it confirmed the rights of adults with disabilities to live in communities of their choice, the State of Georgia did little to make that happen for its patient population.

"There just wasn't a lot of progress," said Wells, who notes that the transitional program applies only to adults. "The rest of the people at Georgia Regional did not get the same support and services as the plaintiffs in that case. In fact, *Olmstead* was not actually implemented, and hospitals became worse places of abuse, neglect and death."

When a 2007 investigation by the *Atlanta Journal-Constitution* uncovered more than 100 deaths at state-run facilities, the Department of Justice (DOJ) and the State met with experts and advocates from the mental health community to address the problem.

2010: The Settlement

After more than a year of deliberations, the DOJ and the State agreed to a new settlement that included moving patients from institutions to community-centered environments. The deadline to implement those changes expired at the end of June 2015, and Georgia was not able to meet the settlement.

While much work remains to be done, some substantial positive gains have been made.

"At the heart of the recovery movement is the importance of having employment along with medication, treatment and peer support," Wells said. "But the crown jewel is housing. It has been a game changer and made us a model for other states. For people with long-term and persistent mental illness, who have been in and out of jails and homeless, housing is the key to recovery. Until you've got a stable place to live, it's hard to go forward with other parts of recovery and treatment."

Under the settlement, the State issued 2,000 housing vouchers that allowed many people to establish stability and move forward. In addition, hundreds of peer-support workers have been trained. "Talk to anyone in the mental health community, and they'll say both these things have transformed people's lives by having housing and intense levels of service," said Wells. "People who otherwise would be in institutions can now live in the community."

While considerable strides have been made for those with mental health issues, patients with developmental disabilities have not seen similar results. "For people with developmental disabilities, there was no specific action around the number of housing units or vouchers that the State must make available," said Georgia Council on Developmental Disabilities Executive Director Eric Jacobson. "Most of the settlement language was around making sure that people with developmental disabilities get to make 'informed choices' about where they live i.e., their own home or with a family member, a host home or other congregate setting. The truth is that the settlement did not have many specific actions required of the State other than getting people out of

institutions, funding a robust family support network and creating better crisis response efforts and support coordination."

2013: The Moratorium

At a May forum held at The Carter Center, Frank Berry, Georgia's commissioner of Behavioral Health and Developmental Disabilities, stated that 268 people still remain in state facilities. A news report aired on WABE-FM 90.1 quoted Berry, saying, "Almost two years ago I had to stop transitions because we were concerned about the quality of those transitions to the community."

Berry's key concern, the report noted, was the deaths of several people who moved into community environments, and until improved systems could be put in place, the process of relocating patients was halted.

"The State decided that to do it right, it needed to stop the process, fix the problems, then start up again," said Wells. "It's worked on fixes, but it has not started the transitions back up, and there are still a lot of issues with the provider network and system of care."

Along with calling a moratorium on transitions, "Georgia has lagged in complying with other areas of the settlement," said Lewis Bossing, a senior staff attorney at the Bazelon



THE DEADLINE TO IMPLEMENT THOSE CHANGES EXPIRED AT THE END OF JUNE 2015, AND GEORGIA WAS NOT ABLE TO MEET THE SETTLEMENT.



Center for Mental Health Law in Washington, DC. The nonprofit represents various stakeholders in the system.

The faces of people with disabilities who have benefitted from the *Olmstead* decision that confirmed the rights of adults with disabilities to live in the communities of their choice.

There have been
MANY
STUMBLING
BLOCKS along the
way and WE ARE
BEHIND.



"It's ironic that *Olmstead*took place in the State
of Georgia, but we still
don't have a plan in
place to implement it."

There is widespread

agreement that it has to be

done and be done right.

"The State was supposed to assemble persons who could provide support to people with developmental disabilities, develop individualized service plans, help people in transition gain access to medical care, education, transportation, housing and other services," Bossing explained. "And it was to monitor individual service plans to make sure people who did transition had support coordination services provided in an effective manner."

As late as spring of 2015, an independent reviewer of the settlement's progress found the State noncompliant with many of those obligations.

"The State has characterized this as an issue about the capacity of the community to serve people effectively and safely," Bossing

said. "It wants to ensure that all the services are in place, so wherever a person chooses to live, they will have access to all the services they need. But it hasn't happened on the timetable the parties agreed to."

Bossing notes that after five years, the number of people affected by these changes is relatively small. "There are about 300 to 400 people currently served in the state hospitals and facilities," he said. "And virtually all of them could be served in the community if the State and its providers can make available the services needed."

Other states charged with meeting the same goals have done so, though it has taken time, Bossing notes. "Some states have even closed their institutions. Sometimes it took years; sometimes there was political opposition. But I think the DOJ and State [of Georgia] thought it could be accomplished in five years. Now the question is how much longer will it take?"

2015: The Deadline

As of the end of June, Georgia and the DOJ were still working toward a plan to complete the state's obligations under the 2010 settlement.

Officials from the Department of Behavioral Health and Developmental Disabilities wouldn't give particulars on what form that plan might take due to the complexity of the issue, but provided this statement:

"We continue to work cooperatively with the individuals we serve and their family members, providers, advocates and the United

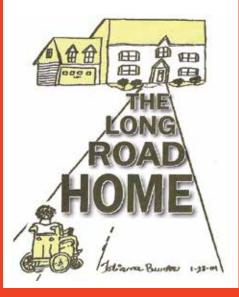
States Department of
Justice to implement
the agreed-upon
requirements of the
2010 Settlement
Agreement. As a
department, we
remain focused on our

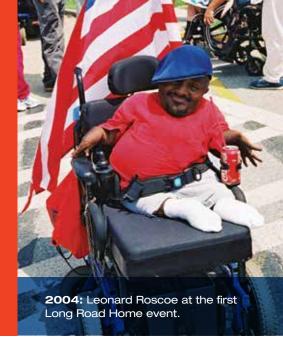
vision of easy access to high quality care that leads to a life of independence and recovery for the people we serve."

Just how the State will move forward to accomplish the ADA goals remains to be seen.

"The Department of Justice settlement was a major statement that people with developmental disabilities must be moved out of state operated institutions," said Jacobson. "When the settlement was negotiated it would have been better if the same level of detail around services, the number of people served and dollars allocated that were provided for mental health had been included for developmental disabilities. There have been many stumbling blocks along the way and we are behind. Hopefully, in a renegotiated settlement we can make sure that issues such as housing, employment and quality of life can be addressed."







Remembering Olmstead: The Long Road Home

Eleven years ago, a band of local activists came together to educate others in Georgia about the promises and accomplishments of the *Olmstead vs L.C.* decision. The US Supreme Court ruling, handed down on June 22, 1999, declared that segregating persons with disabilities was a form of discrimination that violated the Americans with Disabilities Act.

The group's original concept was to stage a march from Milledgeville to the Georgia State Capitol as a way for those with developmental disabilities and their families and supporters to demonstrate the importance of the decision. The Long Road Home, as the event was dubbed, became an annual June event celebrating the connectivity of community.

Over the years, the event has shifted its focus to the challenges and the unmet promises the decision created.

"It's ironic that *Olmstead* took place in the State of Georgia, but we still don't have a plan in place to implement it," said Cheri Mitchell, who chairs the campaign and nationwide celebrations. "So now we are more about bringing attention to the issues." This year, seven states hosted events to commemorate and raise awareness of the landmark legislation.

In Georgia, gatherings took place in Atlanta, Bainbridge, Fitzgerald, Gainesville, Savannah, Tifton, Thomasville and Toccoa. There were walks, rallies and information sessions and in Atlanta, supporters staged a rally and mounted a display of works by artists with disabilities at the State Capitol on June 22.

No matter what form the event takes, Mitchell said there is always a key component: "We want to tell stories of how people with disabilities have gotten out of institutional settings and are living successfully in the community."

The Long Road Home celebration was sponsored by People First of Atlanta,

People First of Georgia, Georgia
Advocacy Office, Georgia Council on
Developmental Disabilities, Center for
Leadership in Disability at Georgia State
University, Atlanta Chapter of the Autistic
Self Advocacy Network, Statewide
Independent Living Council of Georgia,
Georgia Mental Health Consumer
Network, disABILITY LINK and the
National Federation of Blind of Georgia.

For more details on the Long Road Home, visit *peoplefirstofga.com*.



2015: Chair Cheri Mitchell and Lois Curtis at this year's Long Road Home event.



CHILDREN should grow up in HOMES NOT HOSPITALS.

PERSPECTIVES



BETH ENGLISH is the executive director of Easter Seals Southern Georgia.



To learn more about

Easter Seals Southern

Georgia, visit

www.easterseals.com/

southerngeorgia

Children Need Communities

By Beth English

One of the most difficult times in my career was watching a young child named Lori move to a nursing home and later to a state institution where she spent her childhood. There were very few community-based residential services for individuals with significant disabilities in 1979 and certainly none in rural Georgia.

Forever ingrained in my memory is my first visit to Central State Hospital in Milledgeville. It was 1973 and I was a psychology major at Abraham Baldwin College. Our class toured the hospital, but one memory that is poignant is the day I was in the Boone Building. The room was lined with metal cribs and in each bed was a child with a disability. It was overwhelming to me – the sterile environment, the smell of pine cleaner and those dreary pale green walls. The visit made an impact on every student in the class – several changed majors and some dropped the class. For me, the visit lit a flame that continues to burn even now.

In 2001, history repeated itself when I received a phone call from a local agency. A one-year-old baby with congenital birth issues, including shaken baby syndrome, was hospitalized and needed placement. Meeting after meeting took place and to my dismay, this precious little girl was placed at Central State Hospital. For almost a year, Easter Seals Southern Georgia worked to develop a safe and happy home and in January of 2002, Natalie* moved out of the hospital. Over the years that followed, I am really not certain who received the most benefit from this relationship – Natalie or her new mom. Natalie changed the face of disability in our community and bridged so many barriers simply by her presence.

Easter Seals has been entrusted with the care of a number of children with significant

disabilities. Some have come to us from state institutions, others from their families – all medically fragile with very complex needs. Getting it right the first time is not a choice; it is the only acceptable outcome. Caring for these children is risky. It is time consuming but is by far the most important work that we do.

Getting it right the first time is not a choice; it is the only acceptable outcome.

I have watched children develop new skills and express themselves in new ways. I have watched the bonding take place between family members, caregivers and friends. I have seen community members engage with children who would have never crossed their paths if not for our services, and the results are immeasurable.

The world is a very different place from the 1970s. But the lesson from that first visit to the hospital has stayed with me all these years.

Children should grow up in homes not hospitals. Whatever our State has to do to make that happen is the right thing to do. The results are life changing, not just for the individual with the disability, but for all of us who live, work, play and worship with them.

*name has been changed

Let's Advocate for the Kids

By Pamela Walley

We have all the luck.

I pause to write this, between Callie's respiratory treatment and another position change. Still mindful of last night's seizure, I wonder whether to call the neurologist or just pray that we're back to our "normal" type of seizure today.

I'm still watching for signs, performing all the other ongoing assessments, no matter what else I'm doing. In the back of my mind are the next medications, the equipment repairs and supply orders that are way past due. The fact that no matter how overwhelmed I feel, at least I can use words to express my frustration. Callie is still patiently waiting for the right communication device that will allow her to fully translate 20 years of thought into sounds the rest of the world can hear...

So how is it we are the lucky ones?

In just a few minutes, Callie's nurse will arrive and she will head off to her second week of summer camp. She will be greeted by friends, some she's known for the last 10 years. She'll also meet new people, some at the campsite and some when she goes out to explore Athens, GA. Callie's afternoon may include an hour in a karaoke bar or a leisurely walk through the Botanical Gardens or whatever "20-somethings" in this college town are doing. All the while, Callie's medical needs are being met by her qualified nurse who has been trained to monitor and intervene for Callie (the patient) when needed. Equally important, this nurse has been trained to blend into the background and afford Callie (the young woman) the maximum amount of independence possible in her ever-widening world.

Unfortunately, there are those who aren't so "lucky," though just as medically-needy. They aren't getting necessary nursing support.

These individuals are at high risk for the acute complications of chronic conditions and slow deterioration that results when families aren't able to meet all their child's needs.

Even the most dedicated families find themselves facing a terrible choice: do I keep my child at home where I know I can't meet his medical needs or do I access medical care in an institutional setting?

This is a choice no family should ever have to make, and the fact that we've not faced it is another reason we count ourselves lucky.

We are able to advocate not only for Callie, but for everyone who needs medical support. Because we know that community-based services work, we are passionate about advancing the mission of the Children's Freedom Initiative, which recently observed a 10-year anniversary. The Georgia Advocacy Office, Georgia Council on Developmental Disabilities and other partners have invited us to help pave a path in Medicaid Early and Periodic Screening, Diagnostic and Treatment reform and to work with policymakers to improve services over the years.

We consider this our responsibility. Our job isn't done until all Georgians with disabilities have the opportunity to live in real homes, not in a facility.

So as one of the lucky ones, Callie will continue to live her life as an example of what's possible when adequate community supports are in place and continue to pave a path for community access.

OUR JOB ISN'T DONE

until *all* Georgians with disabilities have the opportunity to live in

REAL HOMES.

not in a facility.

PERSPECTIVES



PAMELA WALLEY is a parent mentor in Madison County with the Georgia Parent Mentor Partnership. The partnership is established in 90 school districts around Georgia to improve outcomes for children and youth with disabilities and their families. She is pictured above with her daughter Callie.



To learn more about the Children's Freedom Initiative, visit www.georgiacfi.org

COUNTLESS ADVOCATES,

for over 25 years,

have made a

DIFFERENCE

for the lives of people with disabilities.



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 national 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 fourth installment.



The Empowerment of the Americans with Disabilities Act

By Mark Johnson

By the time you read this article, we will be coming up on the 25th Anniversary of Americans with Disabilities Act (ADA) on July 26, 2015.

We have been celebrating, commemorating and bringing attention to the ADA over the past year, and it is important to recognize what the ADA has accomplished.

The answer lies with each individual who chose to participate. When Eric Jacobson copiloted the ADA Legacy Tour Bus with Tom Olin, this part of his journey made me smile.

"Gosh, did we have a great time with Tom (Olin) on our ADA25 tour! We got a lot of media coverage of the events and the ADA. I can tell you that best of all was spending so much time with Tom and hearing about history and his experiences. I truly count it as one of the highlights of my life as far as memories I will hold. While I have been an advocate for years, this time something new has stirred in me."

On February 14th, 2009, I had emergency surgery. Six years later, I published my memoir, *I Love Today: A Story of Transformation*. As I reflect on the ADA 25th anniversary and all it took to get people with disabilities to have equal opportunities, it reminded me of this moment when I saw the world as one, cohesive community – the vision behind the ADA.

I shut my eyes and relaxed again. This time I began to see a slideshow of images and faces. I saw Susan, Lindsey and other people I loved. There were friends from various times in my life and people I had worked with in the past, including Wade and Justin. I saw scenes from my advocacy work, a collage of images from ADAPT actions, speeches I'd given, the Shepherd Center, and groups I'd worked with. Eventually the scenes began to change. Now I watched as dozens of pictures of people started flashing across my mind, only this time I didn't recognize any of them. They were from all races and ethnicities, every country around the world, representing all religions and with all levels of ability. All were equal. All had value, and all were coming together to celebrate. Faster and faster, the pictures started coming at me, forming a human kaleidoscope, until they started to come together to form one cohesive community. Watching them, I had this image of myself looking up, back arched, with this stream of positive energy flowing into my body. It was beautiful.

For more information on *I Love Today: A Story of Transformation* by Mark Johnson, visit http://amzn.to/1FLnHND

ADA25 reminded me of this vision, and it was beautiful.

Justin and Yoshiko Dart were advocates that changed the face of the disability rights. Activists and advocates for people with disabilities, they worked tirelessly to pass the Americans with Disabilities Act of 1990 and co-founded the American Association of People with Disabilities (AAPD).

The Darts embarked on two Road to Freedom Tours, nationwide trips that brought attention to the importance of equal rights for the disability community. As the ADA Legacy Tour went around the country this past year, I was reminded of the advocacy and the fight that got us to where we are today.



Yoshiko and Justin Dart advocate for people with disabilities.

So where do we go from here? From the achievement of the ADA, Dart believed in a culture of individualized empowerment. It formed the idea that people are allowed to make their own choices and create their own successful lives based on the development of their best personal abilities fulfilling their self-evident responsibilities to the interdependent quality of democracy.

Countless advocates, for over 25 years, have made a difference for the lives of people with disabilities. And as we celebrate, we must continue the work of our pioneers for the next 25 years so we, as a community, can live in inclusive and independent communities with self-determination.



HAPPY 25 ADA!

Beloved Colleagues in Justice:

I love you! Justin loved you and continues to love you!

It has been our distinct honor, privilege and profound happiness to be soldiers in the struggle for justice, especially for the ADA alongside with you. Thanks to you, we have made a lot of progress in many areas. Yet we are keenly aware we must keep moving forward and upward vigorously toward a realization of the Dream.

Justin was writing his manifesto, vision for the next step, FROM ADA TO RIE – Revolution of Individualized Empowerment to inspire a culture where people make their own choices.

I hope and pray you will be able to feel/hear his love and cry. Thank you all from the bottom of my heart for your leadership, dedication to the cause of justice, and friendship and love! It will be my privilege to continue our struggle together until my last days. I love you!

POWER OF LOVE AND TRUTH!

POWER OF UNITED ADVOCACY!

POWER OF GLOBAL SOLIDARITY FOR JUSTICE FOR ALL!
RIE! REVOLUTION OF INDIVIDUALIZED EMPOWERMENT!

Yoshiko (and Justin) Dart

FROM ADA TO RIE – Revolution of Individualized Empowerment. www.mouthmag.com/justin/empower.html

CHOICE IS MEANINGLESS WITHOUT OPTIONS.

Let's make those options **REAL.**



PAT NOBBIE, PhD, Mia's mom

MIA'S SPACE



Seeing With Your Own Eyes

By Pat Nobbie, PhD

Recently, a column by Frank Bruni in *The New York Times* described the Anderson Monarchs, the little league team out of South Philadelphia with the ace pitcher, Mo'Ne Davis, who pitched a shut-out in the Little League World Series last summer, focusing national attention on her, her team and their coach, Steve Bandura.

The coach devised a tour to ground his team in baseball and civil rights history. This summer, as they play little league teams around the country, they'll visit the site of the 16th Street Baptist Church bombing in Birmingham and the bridge in Selma, AL; Little Rock Central High School in Little Rock, AR; and Medgar Evers' home in Jackson, MS.

They'll read historical accounts, view documentaries and discuss them. In the process they gain perspective on their role as ambassadors of the game and as youth, an obligation to represent opportunity for their futures and the futures of people they will meet along this journey.

Of the story of the four little girls in Birmingham, Davis says, "You never know what they could have done." And, Bruni goes on to write, "That's not just true of children who don't get to grow up. It applies to millions more ... who are denied a real chance, maybe because there's no one to guide them, maybe because no one ever spots and heralds their gifts." Sound familiar?

This summer marks the 25th anniversary of the Americans with Disabilities Act and the 16th anniversary of the *Olmstead* decision. Across the country individuals with disabilities and their communities organized road trips not unlike that of the Anderson Monarchs.

One such event occurs in Georgia each year, the Long Road Home, organized by People First and supported by a coalition of advocates in the State. Both road trips looked back into the struggles and accomplishments of the movements that got us to this point in time and both sought to raise awareness of the work still to be done.

Something Davis was quoted as saying came down to an individual level for me. She said, "You've got the see the world. You have to see it with your own eyes."

Against the struggles described by providers and the angst expressed by families on the challenge of making home and community-based settings more integrated, this statement is clear and simple. People need to see their options in order to make choices.

In each transition Mia has experienced, I, or others in her circle, took her to see her options. She visited middle schools, high schools, job sites, homes and even churches. In some cases, she was very adamant in her opinion. In others, I wasn't sure, but her behavior was a good indication. In reaction to one job site rotation in high school she had stomachaches every Tuesday and Thursday and managed to miss the bus — this from a teen who loved school and never missed a day.

Let's not skew the choice conversation. The Civil Rights movement and the disabilities movement really come down to this.

People need to see the world with their own eyes, even if that world is the few blocks beyond where they live and work now. Choice is meaningless without options. Let's make those options real.

Source: Frank Bruni, "Baseball and Black History." *The New York Times*, June 14, 2015.

Real Communities' Connections Help Launch Clarkston School

It started with a personal purpose for Maha Al-Masoodi. The mother of four wanted to build a community that would help her assimilate to the Clarkston neighborhood and also help her son, Mohammed, who has disabilities, find the proper resources that would make him thrive.

She met Basmat Ahmed, a GCDD Real Communities community builder, who connected Al-Masoodi with a range of family support services for her son. It resulted in a friendship that inspired local action to better the community the women already live in.

First, it began with an accessible playground to make sure it's safe for not only her children, but also all the children in the community. Then, it became about Al-Masoodi's goals.

"She wanted to find a job, she wanted an opportunity for her son to socialize and make friends, and she also wanted to make friends," said Ahmed.

With Ahmed, Al-Masoodi started attending Clarkston Early Network meetings hosted by CDF Action: A Collective Action Initiative. The initiative connects and engages the residents of Clarkston, GA by helping them recognize and develop their assets to create activities and services that benefit the community.

The meeting brought together the community to discuss early learning projects, and after a few gatherings, "she (Al-Masoodi) asked 'where's the action?' " said Roberta Malavenda, director of education at CDF Action. "To me, that was a real parent advocate."

The simple question became a catalyst for change in the Clarkston community, which

has a large contingency of families from Sudan and Iraq, all of whom speak Arabic.

Through various connections from Councilman Dean Moore's office to the property management team of the apartment complex where Al-Masoodi lives, CDF Action received space on the apartment grounds to build a school for the families in the community to learn English and prepare the children for pre-kindergarten.

In May, the Clarkston READY School opened its doors to help children, with and without disabilities, learn English and continue practicing Arabic, their native language. Al-Masoodi now teaches at the school that currently has a class of 12 children where the curriculum is taught in Arabic and English.

"I wanted to find a place that would help children get familiar with the English language before they went to school," said Al-Masoodi. "It was a place where they could gain confidence, learn a new language and culture and also keep practicing Arabic."

The Clarkston READY School is a true representation of the Real Communities mission of designing intentionally inclusive activities throughout the State to create opportunities for all people – with and without disabilities – to work together as full partners in the social life and civic development of their communities.

To learn more about the **Clarkston READY School**, visit *cdfaction.org*To learn more about **Real Communities**, visit *gcdd.org*



Yahyia Tammer, a student at the Clarkston READY School stands before bright posters of the alphabet in English and Arabic.

I wanted to find a place that would help children get familiar with the English language

BEFORE they went TO SCHOOL.



Maha Al-Masoodi helped launch the Clarkston READY School in Clarkston, GA with CDF Action through connections made with GCDD Real Communities Builder Basmat Ahmed. I don't think a lot of people with disabilities understand the things that they

CAN DO TO PLAY A PART

in the matters that affect them.

STRAIGHT **TALK**



TIA NELIS is the president of Self Advocates Becoming Empowered, Illinois. SABE works for the full inclusion of people with developmental disabilities in the community throughout the United States.



Let People with Disabilities Make an Impact

By Tia Nelis

When I attended the Children's Freedom Initiative celebration event in Atlanta this spring, I was in a room surrounded with Georgia's state agency leaders, advocates and people with disabilities who are determined to get the remaining 41 children out of institutions into inclusive communities.

It was an inspiring room with leaders who discussed what is being done to make Georgia a zero state – having no children in institutions.

But one of the things that I saw up there when the questions, "what could people with disabilities do?," "what could People First [of Georgia] do to support this?" or how could they be involved were asked, *nobody* answered the questions.

And I think it's really important that it's presented in a way that people can understand what they can contribute to make it happen.

I don't think a lot of people with disabilities understand the things that they can do to play a part in the matters that affect them. And if you don't have a strong advocacy group or support group backing some of those things and someone to explain what is going on, then they're not going to be involved.

It's important to say, "here, this is how you can help make this happen," or "here are some things that we can do to bring attention to that issue to your state legislative leaders." And, allowing action and advocacy to help make things happen for other places that are going through the same struggles for the disability community.

I live in Illinois, and we still have a lot of institutions open. We still have legislators that

have family members in those institutions and strong unions and Voice of the Retarded (VOR) in our backyard headquarters in Chicago.

It's important to say, "here, this is how you can help make this happen."

In Illinois, people are always talking about how people with disabilities should live in the community with the supports they need and not be dumped. There should be a plan to help support people. People get involved in rallies and work groups that involve people being in the community with supports they need not in institutions or a gated community. There are people moving out and getting supports.

Georgia should – yes – celebrate its accomplishments because that is going to keep it going and inspired to make strides for the disability community.

But, as the leaders in the disability community start to work on, "what do we do next?" they must engage the community and let people with disabilities make an impact in the decisions that will affect them, their families and caregivers.

July

July 16 - 17

GCDD Quarterly Meeting Atlanta, GA www.gcdd.org

July 18 - 24

National Jr. Disability Championships Union County, NJ http://bit.ly/1CsR47f

July 21 - 23

National Association of Councils on Developmental Disabilities Annual Conference, Reno, NV www.nacdd.org

July 27

National Disability Leadership Alliance ADA 25th Anniversary Washington, DC bit.ly/1xvHbsn

July 27 - 29

Global Summit on Innovations in Health & Intellectual and Developmental Disabilities Los Angeles, CA aadmd.org/conference

July 27 - 30

National Council on Independent Living 2015 Annual Conference Washington, DC www.ncil.org/

July 31 - August 2

Abilities Expo Houston, TX www.abilities.com/bouston/

August

August 4 - 7

National Association of Qualified Developmental Disability Professionals 20th Annual Conference New Orleans, LA http://bit.ly/1KcPM8v

August 14 - 16

People First of Georgia Annual Conference, St. Simons Island, GA www.peoplefirstofga.com/

August 17 - 20

World Congress on Special Needs Education, Philadelphia, PA www.wcsne.org

September 24 - 26

National Association of the Deaf Leadership Training Conference Birmingham, AL nad.org/2015nltc

September 25 - 26

Autism National Committee 25th Anniversary Conference Manchester, NH www.autcom.org/conf2015/

September 28 - October 2

Tamarack Institute for Community Engagement Collective Impact Summit, Vancouver, BC, Canada tamarackcommunity.calevents

October

October 3 - 5

The ARC's National Convention Indianapolis, IN convention.thearc.org/

October 6

Diversity, Inc. Webinar Cultural Competence for National Disability Employment Awareness Month nod.org/news_events/events

October 16 - 17

GCDD Council Meeting Pine Mountain, GA 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 Sept. 15 to be included in the calendar. Visit GCDD's expanded online community calendar to view additional local events at www.gcdd.org/calendar.



HIGHLIGHT:

People First of Georgia Annual Conference

August 14 - 16

St. Simons Island, GA
For more information visit:

www.peoplefirstofga.com/

RESOURCES

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

Georgia Council on
Developmental Disabilities (GCDD)

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

State Government

Georgia Senate & House of Representatives

www.legis.state.ga.us

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

404.656.1776

Department of Community Affairs

www.dca.ga.gov

Georgia Housing Search

www.georgiahousingsearch.org 877.428.8844

Department of Labor

www.dol.state.ga.us

General Information

www.georgia.gov

Georgia Lieutenant Governor's Office

www.ltgov.georgia.gov 404.656.5030

In The News

Society of Disability Studies www.disstudies.org

Around GCDD

The Georgetown University National Center for Cultural Competence

www.nccc.georgetown.edu

Metro Atlanta Rapid Transit Authority www.marta.com

The ADA Legacy Tour

www.adalegacy.com

The Fight for 41 Children

Children's Freedom Initiative www.georgiacfi.org/

Administration on Community Living www.acl.gov

Department of Community Health www.dch.georgia.gov

Division of Family and Children Services www.dfcs.dhs.georgia.gov

Department of Behavioral Health and Developmental Disabilities www.dbhdd.georgia.gov

Department of Human Services www.dhs.georgia.gov

EveryChild, Inc.

www.everychildtexas.org

Georgia Celebrates the ADA 25th Anniversary

Georgia Council on Developmental Disabilities www.gcdd.org

ADA25 Georgia Legacy Parade www.gcdd.org/ada25parade

ADA Legacy Project

www.adalegacy.com

The Mobility Expo

www.themobilityexpo.com

Simi Linton

www.similinton.com

Invitation to Dance: a documentary film by Christian von Tippelskirch and Simi Linton www.invitationtodancemovie.com

Department of Justice vs Georgia: Where Are We Now?

Department of Behavioral Health and Developmental Disabilities www.dbhdd.georgia.gov Atlanta Legal Aid Society

www.atlantalegalaid.org

The Bazelon Center for Mental Health Law www.bazelon.org

The Long Road Home

www.employmentfirstgeorgia.org

Perspectives: Children Need Communities

Children's Freedom Initiative

www.georgiacfi.org/

Easter Seals Southern Georgia www.easterseals.com/

southerngeorgia

The Empowerment of the Americans with Disabilities Act

ADA Legacy Tour

www.adalegacy.com

Americans with Disabilities Act Pledge

www.adaanniversary.org/pledgeon

From ADA to RIE: Revolution of Individualized Empowerment

www.mouthmag.com/justin/empower.html

Real Communities

Clarkston READY School www.cdfaction.org

Straight Talk

Self Advocates Becoming Empowered www.sabeusa.org

Stay Connected!



Like us on Facebook @

facebook.com/georgiaddcouncil



Follow us on Twitter @

twitter.com/georgiacouncil





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.

Special Thanks to the SPONSORS of the ADA25 Georgia Legacy Parade!

























society for disability studies







Georgia Council on Developmental Disabilities 2 Peachtree Street, NW, Suite 26-246 Atlanta, GA 30303-3142 404.657.2126, www.gcdd.org

Address Service Requested

MAKING DIFFERENCE

A quarterly magazine of the Georgia Council on Developmental Disabilities

VOLUME 16, ISSUE 1

SUMMER 2015



Missed the ADA Parade? What about the ADA Legacy Tour Bus? See page 12 for photos & details:

Georgia Celebrates the ADA 25th Anniversary

