

GEORGIA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

Making a Difference

SUMMER 2007

www.gcdd.org

Advocates Celebrate Milestones



Summer Fun:
Activities for Everyone!

Georgians to Leave Institutions

Real Homes. Real Careers. Real Learning. Real Influence. Real Supports.



TABLE OF CONTENTS



pg. 8

18

Advocates Celebrate Milestones at Long Road Home

Marchers happy with new initiatives, but still plan to make sure the state implements them appropriately.

Features

8

Hundreds of Georgians to Leave Institutions

Georgia receives a federal Money Follows the Person (MFP) grant to help people move into the communities of their choice.

12

Georgia Passes Special Needs Scholarship

Parents can now use state education dollars to help fund private school tuition for their children.

21

Summer Fun: Activities for Everyone!

From swimming to horseback riding, recreational opportunities for children and adults in Georgia are explored.

In Each Issue

- 3** Letter from Governor Sonny Perdue
- 27** Editorial Cartoon
- 29** Calendar
- 30** Resources

Departments

4

GCDD Viewpoint

Advocates who "got in the way" helped Georgians with Disabilities lead better lives.

5

Around GCDD

Discovery Tour date set; Organizing Institute drawing to a close; award winners announced.

6

News

Employment a Growing Focus for MHDDAD; Artists, Children with Autism Collaborate on Masterpieces; Perdue Vetoes Therapy Bill; ADAPT Secures Commitments from HUD Secretary

16

Perspectives

Advocates share opinions on the impact of the ADA.

24

Expert Update

Georgia's ADA Coordinator gives advice on how to use ADA to improve lives.

27

Straight Talk

Zen Garcia reveals why he is so committed to the Long Road Home march.

28

Mia's Space

Mia and her family struggle to help her lose weight.

A quarterly magazine of the
Governor's Council on
Developmental Disabilities

The Governor's Council on Developmental Disabilities collaborates with Georgia's citizens, public and private advocacy organizations and policymakers to positively influence public policies that enhance the quality of life for people with disabilities and their families.

GCDD provides this through education and advocacy activities, program implementation, funding and public policy analysis and research.

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FROM THE GOVERNOR

To Georgia's Disability Community,

It is with a great deal of pride that I offer my congratulations to the many advocates for people with disabilities, the Governor's Council on Developmental Disabilities (GCDD) and Gwen Skinner, Director for the State Division of Mental Health, Developmental Disabilities and Addictive Diseases for your leadership and advocacy for people with disabilities. The results of your hard work are remarkable.

Here in Georgia, people with developmental disabilities are benefiting from the largest funding increase in Georgia history – moving Georgia's ranking from 44 – 30 in terms of community-based services according to the 2007 United Cerebral Palsy Report. And, since 2005, close to 4,000 new Medicaid waivers amounting to over \$100 million are being provided to individuals with disabilities including cerebral palsy, Down syndrome and autism. By 2008, the state will be providing services to 3,000 additional people with developmental disabilities.

Together, we have been successful in adding 925 new Medicaid waivers in 2005 for people with developmental disabilities; an unprecedented 1,500 in 2006 and another 1,500 in 2007. Of these waivers, 340 were earmarked just for children. As a result of the new waivers, and consumer-driven services, Georgians with developmental disabilities and their families will have greater control and choice in their daily lives.

These new Medicaid waivers and all of the progress that has occurred is a result of collaboration among advocates, consumers, families and public policy makers. Your achievements and success are shining examples of what can be accomplished by working together to achieve extraordinary results.

Together, we are building a better Georgia for people with disabilities.



Sonny Perdue
Sonny Perdue
Governor



GCDD Urges Advocates to “Get in the Way”

Summer in Georgia means more than sweltering heat, school vacation and outdoor recreation for disability rights advocates. Summer is time for Long Road Home.

For the past four years, on June 22, Long Road Home organizers have commemorated the 1999 landmark U.S. Supreme Court Olmstead Decision that ushered in a new era of civil rights for people with

disabilities who fought to live in the community instead of locked away in institutions. Thanks to the courage of two Georgia women, Lois Curtis and the late Elaine Wilson, the season signals a call to action, marking how far we have come and how far we still have to go toward establishing public policy that affords individuals and families who live with disabilities the freedoms we all deserve.

When Rep. John Lewis speaks of the origin of his civil rights activism, he exhorts, “The action of Rosa Parks, the words of Dr. Martin Luther King, Jr. inspired me to find a way to get in the way. I got in the way; I got in trouble. It was good trouble; it was necessary trouble. You must get in the way, you must get in trouble.”

This year Long Road Home included the recording of stories by today's disability activists; documenting the testimonies of those who continue to advocate, uplift, carry on or just plain get in the way of tired attitudes that hinder them from achieving their goals. We send special thanks to the Atlanta Downtown Central Library where the video recording sessions were held.

While we reflect on the past and move toward the future, we realize we perpetually arrive at new destinations. Each mile traveled is an opportunity, a new challenge, another mountain surmounted, a plateau reached; then respite.

Enjoy the rest of the summer, as you stay informed with this edition of *Making A Difference*. In addition to covering Long Road Home, this issue reports on the \$34 million Money Follows the Person (MFP) grant recently obtained by Georgia; SB10 – legislation which will provide scholarships for school children with disabilities;

ERIC E. JACOBSON



TOM SEEGMUELLER



perspectives on how well the ADA is working; and, options for summer recreation.

Finally, we share with you GCDD's recently adopted core message. The core message offers a general description of how GCDD views the role it plays with its partners in the disability community, how we engage the system, the parties with whom we collaborate and conditions we work to change.

A Message From GCDD...

- Too many Georgians don't live in their own homes, can't get a good education, can't find satisfying work or have a voice in their future – just because they have a developmental disability.
- The Governor's Council on Developmental Disabilities (GCDD) is a resource for leading, supporting, joining and developing welcoming communities across Georgia for people with disabilities, families, friends and neighbors.
- GCDD advocates for Georgians with developmental disabilities so they can live, learn, work, play and worship where and how they choose by engaging community and business leaders, lawmakers and the general public – people like you and me.
- To this end, GCDD funds pilot projects, conducts public policy research and analysis, provides training and distributes public information.

We want to hear from you. Let us know what issues are important in your lives. Contact our editor-in-chief Valerie Meadows Suber at 888-275-4233 or via e-mail at vmsuber@dhr.state.ga.us.

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

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

GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

Discovery Tour to Highlight Best Practices in Employment

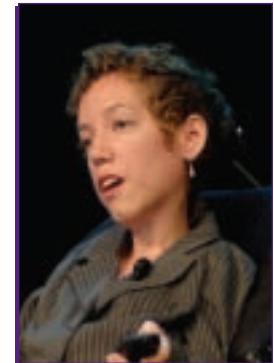
Georgia's top executives, chief diversity officers and human resources officers will learn how people with disabilities can contribute to their companies during the seventh annual Making a Difference Discovery Tour September 27 at The Home Depot headquarters.

Sponsored by the Governor's Council on Developmental Disabilities and The Home Depot, the tour will feature success stories from both employers and people with disabilities.

"Past attendees have been surprised to learn that most people with disabilities often need just a few accommodations to make them productive and reliable staff members," remarked organizer Valerie Meadows Suber, GCDD public information officer and editor-in-chief of *Making a Difference* magazine.

"And many employers discover this vastly untapped labor market to be highly reliable and qualified," she continued.

For more information about the tour, which will be held from 8 AM – 1 PM September 27, contact Suber at 404-657-2122 or vmsuber@dhr.state.ga.us.



First Organizing Institute Close to Completion

Advocates who took part in GCDD's first Organizing Institute have completed the training portion, and most are about half way through their advocacy projects, according to Kate Gainer, GCDD advocacy director.

Though the group is no longer meeting for training sessions, they still check in with each other via conference calls to get input and support from their classmates.

Gainer expects the projects to be completed by the end of September and is planning a graduation in late October to honor the participants.

"This group has worked hard to promote inclusion of people with disabilities in the community," Gainer said. "They should be recognized for that."

A second Organizing Institute, which helps active advocates create lasting change by focusing efforts on the local level to change the hearts and minds of neighbors, friends and family, is in the planning stages.

For information on how to apply to the institute, contact Kate Gainer at 404-657-2125 or nkgainer@dhr.state.ga.us.

GCDD Announces Award Winners

Georgians who played an exceptional role in improving the lives of people with disabilities were honored at GCDD's annual awards banquet July 26 in Atlanta. With so many new initiatives to celebrate, choosing these few winners was difficult, but the following individuals and organizations showed great leadership:

Legislators of the Year

Rep. Tim Bearden (R-Carrollton)
Sen. Renee Unterman (R-Loganville)

Advocate of the Year

Paulette Acevedo

Media Organizations of the Year

Georgia Trend
Waycross Journal Herald
Creative Loafing

Council Person Of The Year –

Carl C. Cunningham Award
Bruce Lindemann

Employment a Growing Focus for MHDDAD

Last year, the Georgia Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) helped more than 8,000 people get jobs – people often isolated from mainstream society. Employment services have become an increasing focus of MHDDAD. MHDDAD funds organizations that help integrate consumers into regular work settings – enabling consumers to earn a living and contribute their skills and talents.

"Helping people get well requires more than talk therapy; they need jobs," said Gwen Skinner, MHDDAD Director. "Therefore, our services include medication management, family counseling and employment."

American Works is one organization that is making a difference. An

MHDDAD funded program, American Works provides employment services for people with disabilities throughout the state. Ken Whiddon, founder and CEO, said, "The only tool that allows people to live life to its fullest is employment. With their earnings, people can get an apartment, a new pair of shoes or go on a date. It also gives them more of a reason to take medicines and see their doctor."

Another example is Project Search, the first program of its kind in Georgia, which supports people with developmental disabilities. Project Search currently works with two Atlanta area hospitals, North Fulton and Crawford Long. Routine work that would otherwise occupy nurses is now handed to people with developmental disabilities including Down syndrome and cerebral palsy.



Gwen Skinner,
MHDDAD Director

The goal of MHDDAD employment support is to assist individuals to acquire meaningful employment that pays competitive wages in an integrated community setting working alongside non-disabled workers. Staff provides specific job development, placement and coaching. Individuals are assessed on a continuous basis for training needs. In addition, staff delivers training while consumers are on the job.

*HUD Secretary
Alphonso Jackson
meets with
ADAPT activists.*



discrimination in housing against persons with disabilities. HUD recently reported that 40 percent of the Fair Housing complaints filed with HUD are based on the "protected class" of disability. This number surpasses, for the first time in history, the percentage of complaints filed on the basis of race (39 percent).

ADAPT Secures Commitments from HUD Secretary

During ADAPT's Spring Action in Washington, D.C. April 28 - May 3, 500 members of ADAPT met with U.S. Department of Housing and Urban Development Secretary Alphonso Jackson and three members of his staff. By the end of the meeting, Jackson had stated, "Fair Housing is a right." And he made a number of commitments to ADAPT, including:

- Informing ADAPT, before the September ADAPT action in Chicago, on how many housing vouchers for persons with disabilities he has recovered from the 58 percent loss in vouchers that the disability community suffered due to a combination of federal budget cuts and misappropriation by local entities that administer the voucher program across the country.
- Vowing to eliminate the "outrageous" level of
- Facilitating a meeting between ADAPT and Reps. Barney Frank (D-Mass.) and Maxine Waters (D-Calif.). Frank is chair of the House Committee on Financial Services, and Waters is chair of the Financial Services Committee's Sub-committee on Housing and Community Opportunity. This Committee and Sub-committee are responsible for legislation affecting changes to the Section 811 program. ADAPT is calling for a restructuring of the Sec. 811 housing program to provide affordable, accessible, integrated housing, as well as increase the number of vouchers available to persons with disabilities, both of which will require action by Congress. Sec. 811 is the segregated housing program for persons with disabilities. The segregated housing program for older persons is Sec. 202.
- Working with ADAPT on implementing its Access Across America Program, which would provide housing vouchers to persons with disabilities in nursing homes and Intermediate Care Facilities-Mental Retardation



(ICF-MR) that, combined with Money Follows the Person and previously existing initiatives in the states, will get people out of nursing homes and into affordable, accessible, integrated housing in their own communities.

- Agreeing to meet with ADAPT three times a year, with the next meeting most likely occurring in Chicago during the ADAPT action, September 8-13.

"ADAPT is pleased that Secretary Jackson came to us, and we are cautiously optimistic at this point," said Cassie James, Philadelphia ADAPT organizer. "His own personal experience with discrimination gives him a window into the unconscionable discrimination in obtaining affordable, accessible, integrated housing that is experienced by people with disabilities all over America. We look forward to the Secretary keeping his commitments and partnering with us to improve the current sad state of affairs."

While in Washington, ADAPT also took over the building that houses the American Hospital Association (AHA), ultimately receiving a commitment from AHA leadership to meet with 15 ADAPT members in the next 30 days.

ADAPT is demanding that the AHA endorse the Community Choice Act (S 799, H.R. 1621); work with ADAPT to develop a hospital discharge protocol that will steer people into community services, not institutional services; put ADAPT on the agenda of the next AHA conference; and finally, write a letter to all AHA member hospitals

encouraging them to make discharge referrals that do not inappropriately segregate and institutionalize people with disabilities, thus complying with the U.S. Supreme Court Olmstead decision.



These pieces were collaborative efforts between artists David Peterson, Brandon Morrison and some children who attend the Marcus Institute.

Artists, Children with Autism Collaborate on Masterpieces

Krause Gallery artists worked with students at The Marcus Institute School and Early Intervention Program to create outstanding works of art. The pieces were incorporated into a show called "All the same...All different...A Convergence of Artists II" and were on display at the Krause Gallery June 8 - July 20.

Perdue Vetoes Therapy Bill

After passing both houses of the Georgia legislature, House Bill 549 was vetoed by Gov. Sonny Perdue May 30.

Georgia legislators wanted to amend Chapter 4 of Title 49 of the Official Code of Georgia Annotated, related to public assistance to ensure children with disabilities receive the medically necessary therapy services to which they are entitled under the Medicaid Early Periodic Screening, Diagnostic and Treatment Program and to simplify the process and paperwork by which occupational, speech and physical therapy services are applied for and received by eligible recipients.

"HB 549 seeks to amend prior authorization requirements for recipients of Medicaid funded services. The proposed changes inadvertently conflict with federal mandates on Medicaid services. Specifically, HB 549 would restrict the State's ability to conduct appropriate prior authorization review as required by federal regulations," Perdue said.

"Federal regulators have also indicated an objection to the establishment of different standards for recipients based on a general categorization of their condition rather than based on an individual's specific medical needs and likely rehabilitation and recovery. For these reasons, federal approval of the changes mandated by HB 549 is not expected. The timeliness of these services, particularly to this constituency is important. I am, therefore, directing the Department of Community Health to continue its efforts to provide for a more streamlined preauthorization process so as not to unduly burden the practitioners and patients this bill seeks to assist," he explained. ●

Hundreds of Georgians to Leave Institutions

More than half of Georgians with developmental disabilities who are living in state-run institutions will soon be able to enjoy life in the community of their choice, thanks to a \$34 million federal Money Follows the Person (MFP) grant recently obtained by Georgia.

The MFP initiative allows Medicaid funding to follow the person to the most appropriate and preferred setting. It also provides special funding for one time or short-term expenses that enable the person to make the transition between the institution and community settings, such as utility deposits or special equipment.

Dr. Joan Krispyn, former director of occupational and physical therapy at East Central Regional Hospital, often advocates for her best friend Kathy Crowder, who has lived at the state institution for 40 years (see sidebar, page 11). "It's not just a matter of the money following the person, the money needs to go ahead, and get things ready – all Kathy wants is a room with a view and lots of friendly neighbors; but her house must also have accessible ramp-access for her wheelchair; an electric lift to move her from bed to chair; a raised tub in the bathroom; a van to take her places."

Applied for jointly by the Departments of Community Health (DCH) and Human Resources (DHR), about \$14 million will go toward moving 600 people with developmental disabilities out of institutions, while the other \$20 million will go to provide community supports for elderly Georgians and people with physical disabilities.

"The first year of the grant is for planning the program," explained Judy Hagebak, DCH

director of Aging and Community Services. "The timeline is to start transitioning people next May."

In the meantime, however, the state will continue its current work. "We're not sitting still on waivers in the interim because the state has been very good to us – we got 1,500 (state-funded) waivers in the last legislative session," said DHR Director of Mental Health, Developmental Disabilities and Addictive Disease Gwen Skinner. "We reserved a portion of those to move people out of hospitals.

"The grant is a continuation of a trend. We've reduced by 50 percent in the last 10 years the number of people with disabilities in our state hospitals, so that tells you how far we've come," she said.

Several work groups on aging, developmental disabilities, physical disabilities and mental health are working simultaneously to determine

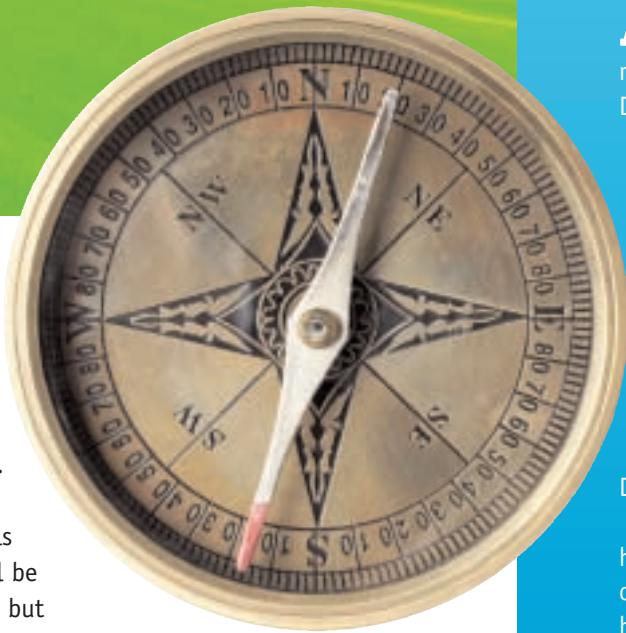
"It's a joint effort to bring all resources together for everybody."

how best to implement the transitions that will be paid for through the grant.

"It's a joint effort to bring all resources together for everybody," Hagebak said. "We want to make sure a waiver slot for a person is available when the person is ready to transition out of the institution, that there's no waiting list."

In addition to planning for the Georgians who will be moving out of the institutions, the planning will also encompass how to transition

“The grant is a continuation of a TREND. We've reduced by 50 percent in the last 10 years the number of people with disabilities in our state hospitals, so that tells you how far we've come.”



workers. "State hospitals will still be needed, but they're not where we want to serve people with developmental disabilities," Skinner said.

John Chandler, director of community-based service provider, Star Choices in Macon, has had some experience transitioning people from segregated settings into more integrated ones.

Chandler worked at a private preschool program for children with disabilities, where the staff went from serving the children in one place to following them into the community. "Eventually we started working toward getting those kids into typical day care and school programs. We realized that's what had to be done, in their best interest, so we made that a priority. Some of the children still required the same level of support – we just delivered support in 10 or 12 different places instead of one. Some needed a lot of support, and many didn't need support, once they adjusted," he said.

While he is concerned Central State Hospital employees might be paid less or lose their jobs as a result of people moving out of institutions, Chandler said the first concern should be about the people who are forced to live there. "The state's responsibility is to the consumer, but often the first questions are about economics. We get that conversation backwards," he said.

Planners are also looking into what services are offered throughout the state. "The number

continued on page 10

Young Woman Finds a Home

After living most of her life in private hospitals and institutions, Sheila Jeffrey moved into a real home with a family in Decatur, Ga. July 13.

"My host family is really sweet. They have a nice house and everything," Jeffrey explained.

She is excited about moving out of Central State Hospital in Macon, Ga., where she currently resides. "I wanted to leave to have more freedom to do more things. I want to do more activities like watching baseball games, going swimming and interacting with people."

Jeffrey received a waiver through the Children's Freedom Initiative, according to her advocate, Jenny Holland, with the Georgia Advocacy Office's Protection and Advocacy for People with Developmental Disabilities division.

"Sheila required services and supports that weren't available to her when she was a child," Holland explained. "So DFCS (Department of Family and Children Services) placed her in Laurel Heights, a private hospital in Atlanta."

When Jeffrey turned 18, she was moved to Central State Hospital in Macon because Laurel Heights only serves children.

Holland met Jeffrey about two and a half years ago and has taken the time to get to know her. "Sheila is an amazing girl. She puts up a tough act for her own protection in the institution, but since I've gotten to know her, I've seen the softer side of her," she said.

Spending time with Jeffrey also helped Holland better advocate for her. When Jeffrey first received word she would be receiving a waiver, her support coordinator initially planned to move her into a group home or apartment run by Central Care, an organization affiliated with the hospital. But Holland knew Jeffrey wanted to move to Atlanta because she had made friends there through her participation in the Georgia Voices That Count advocacy training program.

"We asked Sheila her preference – she said she wanted to live with a roommate who is about the same age or a family because she hasn't lived with a family in so long. She wanted a real home," Holland said.

So Holland called Lutheran Services to help find Jeffrey the living situation she desired and helped coordinate those efforts with the support coordinator in Macon.

Jeffrey had other help, too, from her friends Linda Pogue and Barbaraann Bongiovanni from Georgia Voices That Count, who attended meetings with her to make sure her wishes were considered in the decisions that were being made on her behalf.

Jeffrey plans to work with kids at a daycare center. "I like kids," she said.

But the first thing she did when she moved on July 13 was eat a good meal. With all the new choices she has now, she knew exactly what she wanted that meal to be - pizza.



Sheila Jeffrey looks forward to her freedom.

"I wanted to leave to have more freedom to do more things."



FEATURE

one service provided is personal support services for ambulation, housekeeping, bathing. For a number of people, that's all they need to be able to stay at home," Hagebak said.

"We also have to provide services within the cost of institutional care. We're not allowed to provide services that cost more than they would cost in the institution," she said.

DHR is using "case expediter" to identify and remove roadblocks that may be preventing individuals from leaving the institution.

"People in institutions are under constant review to identify those who are ready to move, supports exist and they want to live in the community. Those will be the first who are transitioned. We're constantly reviewing people in the hospital – should they be somewhere else? If so, why aren't they? Is their paperwork

unfinished? Is there a court issue? Case expediter help resolve these issues," Skinner, who brought the idea from her time working in juvenile corrections, said.

"Sometimes a person needs a certain kind of resource, and sometimes their case gets set aside.

24-7

"When someone says an individual needs an institution, I don't let that go unchallenged. We can provide 24-hour, seven-day-a-week support if someone needs it."

Expediter make sure that doesn't happen. They talk with providers to determine the closest place to their community where they can receive that resource, or would the provider train a person in that community to provide the resource?" Skinner continued.

Chandler feels that all needs can be met in the community. "When someone says an individual needs an institution, I don't let that go unchallenged. We can provide 24-hour, seven-day-a-week support if someone needs it. If they need isolation because of behavioral issues, we can do that. If they need nursing care for medical conditions in addition to having developmental disabilities, there's a way to do that in the community. We don't need institutions," he said.

Skinner said, "We're very pleased the grant helps us continue the work we started on deinstitutionalization. These are going to be very exciting times for people with developmental disabilities and their families. We now have resources in quantities we have not seen before. I give the credit to our legislature and the work of our department and DCH to bring in the grant." ●





Institution Resident Working To Return Home after 40 Years

Kathy Crowder grew up in the country, spending time in the garden and enjoying the feel of rain on her face.

Though her family lived in a very rural area near Warm Springs, Ga., her parents decided to keep Crowder, who has cerebral palsy, at home, without any supports available.

Her sister, Rebecca Crowder, said, "They took Kathy all over the state, all over the Southeast to various doctors, physicians and psychiatrists, who told them to put her in an institution. But our parents are very loving, very forward-minded. They got the best advice from a female psychiatrist – Dr. Gillette – who helped them understand there wasn't a thing wrong with Kathy's brain, and they should treat her like a normal child," she said.

"So they took her to everything that they could. She went to the Columbus Cerebral Palsy Center, a special dentist in Atlanta. Kathy got to go to a lot of places. The whole community knew how Kathy was. She touched many lives," Rebecca Crowder said.

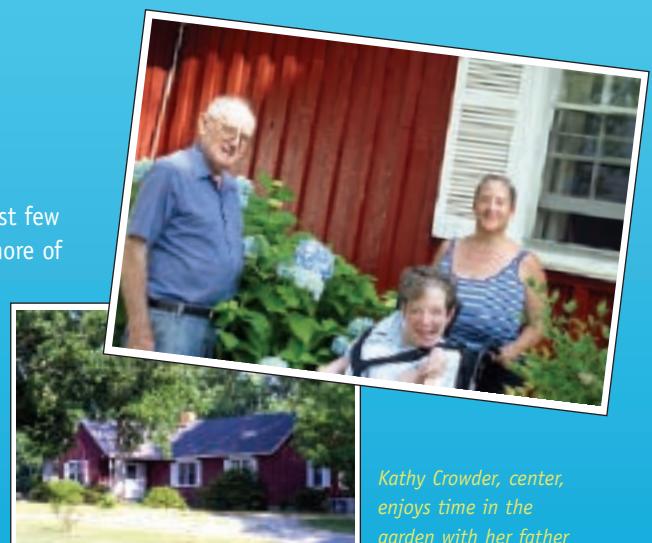
Then when Kathy Crowder was 16, her mother had to have a surgery that rendered her unable to physically take care of her daughter. Soon after, she moved into East Central Regional Hospital, also known as Gracewood.

But over the past few years, as more and more of her friends have moved into the community, and funding for her favorite programs has shrunk, Kathy Crowder has decided she wants to leave.

"Life has become miserable over there, where it wasn't before," Rebecca Crowder said.

"She wants to move as close to home as possible," said Dr. Joan Krispyn, Kathy Crowder's friend and former Gracewood director of occupational and physical therapy.

Unfortunately, things in rural Georgia haven't changed much in the past 40 years, and a lack of services still exists in their area. Plus, the family home would have to be retrofitted to accommodate her extraordinary physical needs. "When someone is as severely involved as Kathy, the money really has to go ahead of them for retrofitting. That's just as important for the people taking care of her, as it is for Kathy," Rebecca Crowder said.



Kathy Crowder, center, enjoys time in the garden with her father and sister. Their family's farm house would need extensive renovations before Crowder could move back.

"Kathy's ready to say goodbye to Gracewood. Her bags are halfway packed."

"Gracewood was the overall best rounded option. It had a good reputation and was considered the flagship institution," Rebecca Crowder said.

And Kathy Crowder enjoyed life at Gracewood, competing in the Special Olympics in swimming, participating in the Gracewood Puppeteers performances around the state and going to chapel services and on outings.

She also participates as an advisory member of the Governor's Council on Developmental Disabilities and in the current class of the Georgia Voices That Count advocacy training program.

"Kathy has been identified to come out of Gracewood; it's just a matter of finding a good place for her," according to her sister. "Kathy's ready to say goodbye to Gracewood. Her bags are halfway packed."

But Rebecca Crowder also said that most of the staff has been very supportive of her sister. "The staff at Gracewood is full of wonderful people like Holley (Hill – a social services provider) and Dr. Joan."

Though she'll miss her friends and staff at Gracewood, Kathy Crowder has plans for what she'll do when she moves. "She wants to go to church every week and wants to have lots of fun," her sister said.

Georgia Passes SPECIAL NEEDS Scholarships

After passionate arguments for and against, Georgia's legislature passed the Special Needs Scholarship bill during the 2007 session, and Gov. Sonny Perdue signed it into law in May.

The new scholarship allows students with disabilities to choose to move to a private school or different public school. The state funding that would have been used at the student's local public school would then shift to the new school.

"There was a lot of support from parents for the bill," said Governor's Council on Developmental Disabilities Deputy Director Patricia Nobbie, PhD.

"I didn't expect it to be so overwhelming. It's an indication of the challenges parents face in the public school system."

Georgia Sen. Eric Johnson (R-Savannah) sponsored the bill. "I continue

to hear frustrations from parents of children with disabilities that they were not getting the services they wanted out of the public school system," he said.

The law, which will go into effect in the upcoming school year has a number of eligibility requirements:

- Parents currently reside in Georgia and have been Georgia residents for at least one calendar year
- The student has one or more of these

disabilities:

- Autism
 - Deaf/blind
 - Deaf/hard of hearing
 - Emotional and behavioral disorder
 - Intellectual disability
 - Orthopedic impairment
 - Other health impairment
 - Specific learning disability
 - Speech-language impairment
 - Traumatic brain injury
 - Visual impairment
- The student spent the prior school year at a Georgia public school, Atlanta Area School for the Deaf, the Georgia Academy for the Blind, OR the Georgia School for the Deaf and was in attendance on both the October and March FTE counts
 - The student has an active Individualized Education Program (IEP) written by the school in accordance with federal and state laws and regulations
 - The parent obtains acceptance for admission of the student to a participating private school
 - The parent submits the scholarship application to the Georgia Department of Education by the annually established deadline

The amount of each scholarship will vary, based on the needed services identified in the student's IEP. The state money that would have gone to fulfilling those needs would be redirected into the scholarship. Federal and local funding for schools would remain unaffected.

GCDD remained neutral on the law, but it did issue a statement of concern.

"There are two primary concerns of the effect of this bill," Nobbie said. "It may unintentionally foster

"I didn't expect it to be so overwhelming. It's an indication of the challenges parents face in the public school system."

Fairness an Issue with Mother, School Board Member

While Holli Cash, a Cobb County School Board member and mother of Chandler, who has Down syndrome, agrees parents should have choices regarding their children's education, she feels the new Special Needs Scholarships will not be fair.

"Unlike Florida (where a similar scholarship program is in place), where private and parochial schools allow most children to attend, most or all of Atlanta's private schools have

"Parents want inclusion, and this will put kids back in self-contained classrooms."

entrance testing requirements. They require a certain level of learning that would not include a child with Down syndrome," she explained.

Cash feels Georgia's private school testing requirements would exclude many children with developmental disabilities from attending the schools because they would be unable to successfully pass their tests.

"Where are the schools that would take Chandler?" she asked. "I tried three private schools, all Christian schools, and none of them would take her."

And if the children could get into a private school, Cash feels there isn't a need for the state to help pay for it. "In a private school setting, there is financial aid based on need. Anybody could have financial aid if their child were to get in," she said.

In addition, parents who use the scholarship forfeit their right to federal funding for their child, as well as their child's right to have an Individualized Education Program (IEP) with goals and regular updates.

"There's no IEP in private school. What if their needs change and they need more or less funding?" she pointed out.

Another problem Cash has is that students who are currently enrolled in private school would not be eligible for the scholarship unless they went back to public school for one year to meet the

requirements. "These children have the hardest time adapting to new settings in some cases. Plus it disrupts the public school to have to write an IEP for all the children coming back to qualify for a scholarship."

The quality of instruction also concerns Cash, as private schools are not held accountable to the same standards as public schools. "Parents want inclusion, and this will put kids back in self-contained classrooms. I'm worried about schools popping up and not meeting the needs of the child," she revealed.

"If the state would have properly funded education and funded my child all along, we wouldn't need such a drastic bill to deal with the issue and make better use of those dollars. This bill does nothing to provide options for my child, nothing." ●





SPECIAL NEEDS SCHOLARSHIP PROGRAM OPTIONS

Eligible students can choose from the following options:

- Attendance at another public school within their home district that has space and provides the services identified in the student's individualized education program
- Attendance at an eligible public school in an adjacent district that has space and provides the services identified in the student's individualized education program
- Attendance at a participating private school in Georgia
- Attendance at one of Georgia's three state schools for students who are deaf, hard of hearing, blind or visually impaired

PLEASE VISIT

public.doe.k12.ga.us/sbl0.aspx to view a list of participating and eligible private schools.

resegregation of children in special schools. When these kids graduate, they won't be connected to their wider community like public school kids.

"The other concern is whether it is a true choice for all children with special needs. Current schools won't accept students with more severe disabilities. All parents can't afford to pay the difference between the cost of tuition and the amount of the scholarship, or pay to transport them to private school. It's not an option for these parents. This bill is using public dollars that are only benefiting some children," she explained.

But the key to the bill, according to Johnson, is parental choice. "Disability advocates have been fighting so long and hard for mainstreaming, and they're concerned this bill will create special schools

or segregation again. Parents may want their deaf child to be with other deaf children for a period of time. That is the parents' choice. This bill is not about segregation, just the unique needs of special needs children," he explained.

Peggy West, president of the Georgia Council of Administrators of Special Education (G-CASE), supports parental choice, but has some problems with the new law.

"We want parents to have choice, but we also want children's rights to be protected," she said.

Students with disabilities' rights are guaranteed under the Individuals with Disabilities Education Act (IDEA), which outlines expected outcomes and procedures, but only public schools are obligated to follow IDEA.

West pointed out that public schools are held accountable for creating, maintaining, updating and meeting the goals laid out in students' IEPs, but private schools are not required to follow or create IEPs for students.

For example, she said, "Some schools for autism are popping up. Not every school for kids with autism is based on research-based methods. Some let the children rock all day or watch a blinking light. What will happen to these children who are going to schools that don't use the research-based methodology?"

"Another concern is that these students won't get the specialized instruction they need, return to public schools and be behind," she said.

The fairness of the law for families who can't afford to make up the difference in tuition also worries the members of G-CASE. "Scholarships aren't going to pay all tuition to private school. Those who can afford the extra money and transportation are upper middle class. It's a matter of equity. It leaves the poorest in the schools that struggle," she explained.

While both sides have passionately supported or opposed the bill, Johnson doesn't think it will make a very big impact on public schools.

"In Florida (where a similar program is in place), less than five percent of special education kids use the voucher. That would be about 15,000 Georgia students," he said.

"Public schools basically do a good job, and the scholarship doesn't include transportation or may not cover the full amount of tuition. For a variety of reasons, we won't see a huge transfer of children from public school to private," he said. ●



Mother Applauds New Choices

Rachael Barron's son Wilson has already been attending private school, and though he wouldn't be eligible for the new Special Needs Scholarship, his mother is an ardent supporter.

"The scholarship provides parents educational choices without having to sue the school system to get them," she explained.

"My son was so mistreated in the public school system that he couldn't function with typical children," she said. "He's been treated better in a private setting. Now he wants to interact with typical children."

Barron decided to move her son into private school after fighting his public school for the supports outlined in his Individualized Education Program (IEP) that he wasn't receiving, such as speech therapy, occupational therapy and visual support therapy.

"The public school recommended a significant and profound classroom, and he had to be bused several miles away from our home district," she explained.

"In private school, the first thing they told me was that my son had taught himself to read over 80 words. The public school said he wouldn't be able to learn to read."

Barron enrolled her son in a

Christian-based school that focuses specifically on children with mild to severe developmental disabilities, but she isn't concerned that he is being segregated from typical children.

"It's misleading to assume in public school, they're included. Most oftentimes in public schools, the children are self-contained. Kids with disabilities have opportunities to be included in

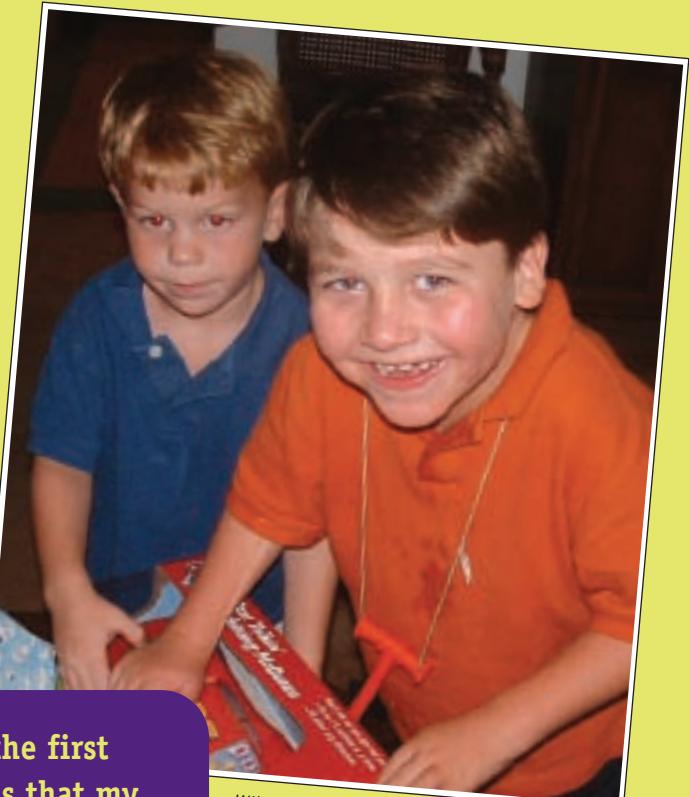
"In private school, the first thing they told me was that my son had taught himself to read over 80 words."

church, girl scouts and boy scouts, as well," she said.

After being in a private school that works with developmental disabilities, Barron feels her son has gained the self confidence he needs to interact with other children, and she is planning to put him back in public school.

But now she feels if the public school doesn't meet his needs, she has a choice.

"This law is an excellent first step to holding school systems accountable without having to sue them," she said. "It affords children the opportunity to go to a special school to address a



Wilson Barron, right, plays with his brother Wyatt.

particular weakness, or transfer to another school if their needs change."

And, she said, it is a good law for the state. "In the long run, this bill will save money for the state. If children are served well now, they will need fewer services later." ●

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The ADA Has Not Met Our Expectations

By Nancy Duncan, Executive Director, Disability Resource Group



Nancy Duncan is the Director of Disability Resource Group and has been its chief executive since its inception in 1994. She has worked for 30 years in the disability field. Her work has included service delivery and administration in substance abuse, seniors with disabilities, people with vision loss and young adults with severe disabilities. She has conducted national workshops in the field of disabilities rights law and was a lead trainer for three years with Project Implement. Duncan has been blind since her teens and is the mother of three children, one of whom has multiple disabilities.

Duncan answers a statewide hotline and is aware of the serious issues faced by Georgians with disabilities. DRG has as its major objective the bringing about of full participation by, and inclusion of, all people with disabilities in all aspects of life throughout Georgia.

I believe that the Americans with Disabilities Act is a powerful, wonderful statement on the civil rights of 58 million Americans with a tremendous variety of disabilities. When it became law in 1990, many of us believed that discrimination would certainly seriously diminish.

Seventeen years later, we know that the unemployment rate for people with disabilities has not changed. Many children with disabilities are still in segregated education programs. Equally effective communication is non-existent in most government services, healthcare facilities, law offices, etc. Thousands of people who have mobility impairments in small towns cannot get into restaurants, banks, pharmacies, etc. We ask ourselves in various disability organizations, "What went wrong?" I believe that the fault is not in the ADA itself but in the response of the nation to it. I have identified three major causes for our failure to realize our dream of full citizenship.

1. Lack of education about the ADA and the nature of civil rights law. Each month the Disability Resource Group receives about 150 calls from all parts of the state and all types of people. Many times, callers know nothing about ADA even though they may have lived with a disability for years. They experienced overt discrimination on the job and quit out of frustration. They did not know their rights, and now it is too late to take action. Thousands of people do not even define themselves as a person with a disability and so they do not believe the law applies to them. Saddest of all, are the disability advocates who know so little about ADA they cannot help the clients/consumers they assist each day.

We speak to high school students with disabilities who have never heard of ADA. The school systems are required to give parents information about the Individuals with Disabilities Education Act, but they do not give out any information about ADA. In 2006, we lost 75% of federal funding that was designated for training and technical assistance on the ADA. We know at DRG that we have barely scratched the surface in terms of educating Georgia about the civil rights of over 1.5 million citizens.

2. Legal services. Last summer a man came to DRG with a blatant job discrimination situation. He had excellent documentation and an excellent work history. He could not find an attorney in Atlanta who would take his ADA case. Most attorneys have little education on ADA. Plus, 80 percent of ADA employment court cases are won by employers. Most people with disabilities do not have the money to pay an attorney up front so the attorney must take only those cases that look very likely to win. Additionally, most ADA attorneys in Georgia are in small firms that can be swamped by the well-funded legal departments of the large employers. The few non-profit legal offices are stretched so thin they can only take a very small number of cases. Unfortunately, justice can be expensive.

3. Fear and lack of solidarity among people with disabilities. Often, when we ask for what is rightfully ours, we ask from a position of weakness rather than strength. So when services or accommodations are provided, they come from a position of charity not entitlement. Too many people with disabilities are not certain that we are equal or entitled to all of the benefits due others. Even within our own families we may not ask for what we need for fear of being a burden. We are isolated from one another and feel so marginalized that we do not join groups of others with our same disability much less other disabilities. We must believe that "we are somebody" before we can believe that we have rights. We must find ways to lift up the lonely and disenfranchised among us before we can speak as one proud voice.

The Civil Rights Act changed the hearts of many Americans and opened doors for minorities. More importantly, over time, it has changed the self-image of the people it protects. Among people with disabilities, this changing of our own sense of worth is our most important mission if the ADA is to truly change our opportunities. ●

Two advocates share their views on the Americans with Disabilities Act

ADA Offers Hope for Those in Institutions

By Susan Walker Goico, Atlanta Legal Aid

Living in the community, we often take for granted the simple freedoms we all enjoy. We get to decide when to wake up in the morning, what to eat for breakfast, lunch and dinner. We get to choose where we want to live and with whom we want to spend our free time. We can go to the corner coffee shop or catch a movie at the multiplex. Simple freedoms, yes, but for so many of our fellow Georgians who live in institutions – nursing homes, mental hospitals and Intermediate Care Facilities-Mental Retardation (ICF-MRs) – these freedoms may seem like elusive dreams. Unfortunately, many people do not know that living in the community is their civil right.

Title II of the Americans with Disabilities Act prohibits discrimination against people with disabilities and includes segregation as a form of discrimination. To remedy this, the ADA's "integration mandate" states that "[a] public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d).

The ADA's integration mandate was at issue in the 1999 United States Supreme Court case *Olmstead v. L.C.* 527 U.S. 581 (1999). *Olmstead* was brought by two brave Atlanta women, Lois Curtis and Elaine Wilson, who were determined to live their lives in the community instead of in the confines of a mental institution. In finding for the two women, the court held that states must provide disability services in the community rather than in an institution if three criteria are met: (1) the state's treatment professionals determine that the person can be served in the community; (2) the person does not oppose living in the community; and (3) the placement can be reasonably accommodated by the state. The court added that a state can show that it is complying with the integration mandate if it has a "comprehensive, effectively working plan" for moving people out of institutions and into the community, as well as a "waiting list that move[s] at a reasonable pace." 527 U.S. at 605-06.

While the decision has many ambiguities, *Olmstead* clearly offers hope and is considered by many to be a roadmap to freedom. What does it mean for Georgians living in institutions or at risk of institutionalization? In my view, the state has an affirmative duty to meaningfully inform people of the available community-based options and to responsibly transition people out of institutions, over time, with the appropriate services. For self-advocates and their families who are navigating the system alone, the principles of *Olmstead* should help guide their quest for services. When you apply for state-funded community-based disability services, like those offered under a Medicaid waiver or the Medicaid Rehab Option, apply in writing and cite to *Olmstead* in the letter. Ask where you are on the waiting list for services. Ask how long you will be on the waiting list. When you get an answer, ask yourself, is the list moving at a "reasonable pace?" Review the state's *Olmstead* plan on Georgia's Department of Human Resources Web site. Is this a "comprehensive,



*Susan Walker Goico is a part-time attorney with Atlanta Legal Aid Society's Mental Health and Disability Rights Project, where she focuses on *Olmstead* issues.*

"...the State has an affirmative duty to meaningfully inform people of the available community-based options and to responsibly transition people out of institutions, over time, with the appropriate services."

effectively working plan" to move the people who want to live in the community out of institutions with the supports they need? If the answers are not satisfactory to you, get involved in this civil rights movement. We need your help.

Even though it has been a long eight years since *Olmstead*, it is critical that the advocacy community remain vigilant in demanding that the state of Georgia fully implement this vitally important decision. After all, civil rights do not fade with the passage of time, and freedoms, no matter how simple, cannot be reserved for those of us who happen not to have a disability. ●

.....Advocates Celebrate Milestones AT LONG ROAD HOME



Adam Funck, left, came from Eatonton to march for his friend, Ben.

Advocates (from top left) Tameria Banks, Lois Curtis, Jessica Long, Bernard Baker, Margo Waters and Cheri Mitchell want people with disabilities to live in their own communities.

Adam Funck's friend, Ben, lives in a nursing home, where he doesn't get to choose what he eats or when he wakes up in the morning. That's why Funck made the journey from Eatonton, Ga., to Atlanta to participate in the Long Road Home March June 22.

"I march in protest for people that live in nursing homes," he said.

Self-advocates from all over the state, from Fitzgerald to Athens joined together to mark the eighth anniversary of the Supreme Court's Olmstead decision that said people with disabilities had the right to receive services and supports in the least restrictive environment. Advocates also welcomed representatives from the U.S. Social Forum, that met in Atlanta in June to provide an open platform to discuss alternatives to economic plans created by



multinational corporations and governments at the World Economic Forum.

Lois Curtis, one of the plaintiffs in the landmark case, was at the march to encourage the other advocates. "Stand up for our rights. Free our brothers and sisters," she said.

While past marches have ended with confrontations at institutions and the state capitol, this march was more about celebrating several key successes achieved this year through active advocacy: Georgia receiving Money Follows the Person (MFP) funding from the federal government; the implementation of a Medicaid buy-in program, and the passing of an advance directive bill.

Kate Gainer, advocacy director for the Governor's Council on Developmental Disabilities, said, "We've done great work for the past four years. We stepped up to the plate and demanded our rights. This year it seems like they finally listened."

And though she emphasized during the rally at the state capitol that the march was more celebratory than confrontational this year, she also encouraged the advocates to make a lot of noise. "A little bit louder, so the governor can hear you in Europe," she said.

GCDD Executive Director Eric Jacobson applauded the advocates for helping MFP become a reality in the state. "Kate Gainer, Mark Johnson, Lois Curtis and Sam Mitchell have inspired us to get in the way and make good and necessary trouble," he said.

**"Free our brothers. Free our sisters.
FREE OUR PEOPLE NOW!"**

But while he celebrated the new MFP grant in the state, he cautioned, "Things in the state are good, but the devil is in the details. Things don't always happen the way they should. Our job is to make sure they do. We need to hold the



"Get us out. Keep us out. Don't put us in!"

state accountable."

Mark Johnson, advocacy director for the Shepherd Center recounted the years since Olmstead was passed, reminding advocates it's been eight years and it still isn't fully implemented.

He also remembered an ugly confrontation at a nursing home, "They're committed to their jobs, but not committed to us living in the community," he said, leading the crowd in a chant, "Free our brothers. Free our sisters. Free our people now!" Self-advocate Samuel Mitchell lived in a nursing home for two years before he began receiving services in the community of his choice and was optimistic about the MFP funding. "It's not a magic formula. It's not a silver bullet, but it's a tool we can use to help people locked away in nursing homes and institutions.

"People don't want to be locked away from our families, places we know and people we love. People live better, healthier and longer lives when they're in their community," he said.

Like Jacobson, he encouraged the advocates to be vigilant about implementation. "We have to keep watch. It's important MFP is implemented the way we want and that it helps people who need it the most. Find out what (the state) is doing, and let them know you're watching and that they'll get bit if they don't do it right."

In addition to the MFP grant, the crowd celebrated the passage of House Bill 24, which simplifies the living will and health care agency process, giving people greater control over their rights to insist on medical treatment, decline it or ask that medical treatment be withdrawn. The bill combines the concept of the living will and health care agency into one, easily understandable document.

The act will allow people to appoint someone who loves and cares about them to act on their behalf, if they are unable to do so, instead of leaving critical health care decisions to the state. "What keeps you safe is people who care about you making decisions," said Josh Norris of the Georgia Advocacy Office. "Sometimes bad decisions

are made out of convenience. No decisions about us without us!"

Many people with disabilities cannot go to work because if they make over a certain amount of money, they will lose their health coverage. But a new Medicaid buy-in program allows people with disabilities, who often have extraordinary medical needs not covered by traditional insurance, to keep their Medicaid benefits by buying into the system, similar to a traditional insurance plan.

Shelley Simmons, a self-advocate, had access to a Medicaid Buy In program in California, but was surprised it didn't exist when she moved to Georgia.

"Today is a great day for Georgia. We've joined 34 other states in offering Medicaid Buy In. The Buy In encourages work. I utilized it in California, and it does work," she said.

One of the Long Road Home organizers, Cheri Mitchell, said the yearly event was important. "It draws attention to the need for services for people with disabilities so they can live in the community. We're people, too; we have the same rights as others, and we're capable of speaking for ourselves."

March attendees Mark Dyer and Jeremy Sloan agreed. Sloan was forced to live in an institution for 10 years, until Dyer, who works for Disability Connections in Macon, noticed him when he was visiting another resident. "I thought to myself, he looks mighty young," Dyer said. "A year later, just by me talking to him, he was a free man."

While Sloan's story has a happy ending, others in Georgia are still waiting to move into communities of their own choice, and the key message of the advocates reflected their concern for these Georgians, "Get us out. Keep us out. Don't put us in," they chanted. ●

Jeremy Sloan, left,
lived in a nursing home
for 10 years before Mark
Dyer, right helped him
move into his own home.



**"A year later,
just by me
TALKING
to him, he was a
free man."**



LONG ROAD HOME

Filmmaker Captures Marchers' Stories

Samuel Mitchell was forced into a nursing home by the state after suffering a stroke. He was there for two long years before his family was able to help him move home.

Mitchell was just one of about 15 advocates who shared their stories with filmmaker Zen Garcia at the central branch of the Atlanta Public Library after the Long Road Home March June 22.

Garcia, who uses a wheelchair, is putting together "Voices of the Long Road Home," a video project that will be part of the Georgia Disability Civil Rights Exhibition, slated to open next year. The project was funded with a grant from the Governor's Council on Developmental Disabilities.

Founder of the non-profit EndeavorFreedom.tv, Garcia plans to show the video on You Tube, at advocacy meetings and wherever people will watch it. He eventually hopes to create a television network featuring programming for people with disabilities produced by people with disabilities.

He started the organization after last year's Long Road Home March, when no traditional media attended the group's post-march press conference, and he knew the disability community's stories had to be told.

He was shocked by some of the stories he recorded. "I interviewed one woman, Mrs. Scoggins, who was put in an institution in the '60s. One nurse burned her with boiling water," he said. "Another nurse terrorized residents with

"It's all people with disabilities coming together to make a statement as a community."



Zen Garcia, above right, interviews members of YOUTH. Barbaraan Bongiovanni left, seated, brought the group to the march.

razor blades, and Mrs. Scoggins tried to report her, but no one listened."

Scoggins finally spoke with the head of the institution who witnessed the behavior first hand and fired the nurse. After six years, Scoggins was released when she was 19.

Cheri Mitchell, who served as one of the interviewers for the project, said telling the stories was important. "A nursing home is not a home. It's like being locked away."

Mitchell, who also uses a wheelchair, participated in the project to make an impact. "All organizations are involved. It's all people with disabilities coming together to make a statement as a community."

Garcia also interviewed first-time participants to get their opinion of the march.

Barbaraann Bongiovanni, a member of the Organizing Institute, which is supported by GCDD, brought some children to the march. She has developed a two-week camp for children called YOUTH – Youth and Others Uniting Together Hand-in-Hand that educates children with and without disabilities, ages 10 – 22, about disability issues such as self-determination and self-advocacy.

The group was interviewed by Garcia. "The Long Road Home March really expanded their horizons. They said they'd never look at their peers with in the same way again. They didn't realize people with disabilities could have such successful lives," he said. ●

Summer Fun; ACTIVITIES FOR Everyone!

Summer has arrived, and everyone is thinking about participating in fun activities. While finding recreational opportunities can be a little challenging for children and adults with disabilities, many organizations offer people with disabilities the chance to have a good time and participate.

Integrated Dance Celebrated

As one of only a handful of integrated dance companies in the United States, Full Radius Dance celebrates the different ways in which each individual moves. This organization offers positive motion classes, a form of modern dance, to everyone with or without a disability, children or adults, and performs at various metro Atlanta venues.

"Studies show that art, and particularly dance, is beneficial in developing both motor and cognitive skills that carry through into all aspects of daily living and learning. This is true for individuals with disabilities as well. Still, many people perceive that for these individuals, dance is not an art form that they can enjoy," said Douglas Scott, co-founder and executive director of Full Radius Dance. "Full Radius Dance, through its Positive Motion dance program,



Laurel Lawson (center) discovers new ways to move with modern dance.

dismisses this notion and brings the artistry of dance to everyone. I do not move the 'right way' just because I do not have a disability. There is no 'right way' to move."

One dancer, Laurel Lawson, started off as a student at Full Radius but when she heard they were having auditions for community performances, she jumped at the chance of doing something new and different.

"Just like every other little girl, I had always been interested in ballet when I was young. In 1985 though, being in a chair didn't make that an option," explains Lawson. "However, I've always been interested in different ways of moving. I've been involved in music, theatre and athletics since the age of five."

The mission of Full Radius Dance is to promote, advance and enhance the modern dance form for persons with disabilities, for dance artists and the general community. Scott, principal dancer at the studio, remembers the day he started to



Photos provided by Ann Lang.

"Just like every other little girl, I had always been interested in ballet when I was young."





FEATURE

With a little exploring, recreational activities can be found for everyone.

explore the idea of integrated dance, "I attended a workshop in the fall of 1992 and met Mary Verdi-Fletcher, born with spina bifida but determined to become a professional dancer, she became the president/founding artistic director and principal dancer of Dancing Wheels in Cleveland, Ohio. She really challenged my thinking about different forms of dance and ultimately inspired me to open up Full Radius."

In addition to dance classes, Full Radius Dance also offers a variety of workshops and lecture demonstrations. For more information, visit www.fullradiusdance.org.

Swimming Toward Success

For individuals who love the water, Swim Atlanta offers year-round indoor swim lessons at pools located in Johns Creek, Roswell, Lawrenceville and coming soon, Hamilton Mill. Swim Atlanta serves ages six months to adults, offering inclusive lessons to groups up to six people. Private lessons are also offered; however, Swim Atlanta promotes inclusive classes. The length of swim lessons vary but generally are from two weeks to six weeks depending on the age and level of the swimmer. For more information on lessons and a referral to the closest pool visit www.saswimschool.com.

Children Gain Independence through Karate

Sidekicks Karate is an adaptive karate program for children five to nine years old with cognitive and physical disabilities. This program is led by physical and occupational therapists who work closely with children, with the goal of mainstreaming them into integrated karate classes.

Sue Soha, a physical therapist and mother herself, started the program three years ago with occupational therapist Belle Wilmer, whom she met through Children's Healthcare of Atlanta.

"Each class is adaptive for each child. Classes are broken up into 15 minutes sessions for children with cognitive disabilities, and for children who need help physically we are there to facilitate their movements," explained Soha.

"The adaptive sessions prepare the kids to be more independent when they enter the integrated classes."

"The adaptive sessions prepare the kids to be more independent when they enter the integrated classes."

The class follows the Japanese karate style of Wadu Ru. Instruction is given on kicks and punches with therapeutic activities incorporated to improve the child's balance, coordination and direction-following skills.

In addition to strengthening the mind and body, there are many benefits to martial arts training. Training teaches socialization skills, and builds confidence and self-esteem as well as self-discipline, respect, concentration and courtesy. The Sidekicks program not only allows the child to develop at his or her own pace but instills mental and physical discipline necessary for a healthy adult life.

The Sidekicks program is open to the public and offers two classes on Tuesdays at Dunwoody United Methodist Church's aerobics room. Each an eight-week session, the sensory integration karate class is at 4:45 to 5:30 pm and the intermediate level class is at 5:30 to 6:15 pm. To enroll in either, parents must first attend an open house/evaluation session September 4, 2007. Some insurance providers may cover the partial or full cost of the program. For more information call Carrie Natoli at 404-329-9730 or visit the Sidekicks' website at www.metooSports.com to see videos of the classes.

Horseback Riding Improves Confidence

Deep into the woods of Blackshear, Ga. is roughly three acres offering serenity and providing strength and self-confidence to children with mental and physical disabilities. Saddle-Up, a therapeutic riding center, provides children ages three to 21 with 10-week sessions of therapeutic, equestrian activities.

Here, children meet once a week for 45 minutes to an hour to do a variety of exercises while on horseback to improve coordination and cognitive skills, eventually building up so students may ride on their own.

"We've seen some tremendous changes in some

RECREATIONAL OPPORTUNITIES

of the students," says Boo Clarke, executive director of Saddle-Up. "One student, whose muscles were so weak, had to lean back against the saddle when he rode, now he is sitting up straight."

Saddle-Up, a local branch of the North American Riding for the Handicapped Association, has one full time NARHA certified instructor at every session. As the Saddle-Up program grows, so will the amount of certified instructors. A new program, started just over a year ago with seven students, is growing with 13 students at the last session and more expected to attend the July session. Clarke, excited about the future of Saddle-Up stated, "We may eventually extend our services to adults and at-risk children, but for now we are concentrating on the students we have."

Another equestrian center offering therapeutic services is Chastain Horse Park. This one, in the heart of bustling Atlanta, is dedicated to serving children and adults of all ages with cognitive, physical or emotional disabilities; however, riders without disabilities and of all ages are welcomed to experience the riding programs as well.

"At Chastain, everyone rides in the same arenas," said Executive Director Mandy Branton, RN. "Whether a rider is riding for the sport or therapeutically, they understand the prevailing feeling horseback riding can provide and respect the presence of the horse."

For the therapeutic lessons, each lesson is individualized – from social skills to motor skills – for that rider's specific needs. Chastain Horse Park and all of its instructors are either certified or members of the NARHA.

"Our organization serves an average of 150 riders per year with special needs," according to Branton. "One of our biggest success stories is a rider, Peter Nagel, who's been with us for over six years."

"Riding has been the great equalizer for Peter – on a horse he can go fast, and he can feel that sensation, something he can't on his own legs."

Diagnosed with cerebral palsy, Nagel has had nine surgeries on his legs and needed three assistants when he first started his therapeutic lessons. Now at age 10, he has progressed so significantly that he competes at horse shows



Peter Nagel enjoys a stroll on his horse.

on his own horse with students without disabilities.

According to Nagel's mom, April Nagel, "Riding has been the great equalizer for Peter – on a horse he can go fast, and he can feel that sensation, something he can't on his own legs."

Paula Drost, another rider at Chastain Horse Park, had her reservations about horseback riding as a therapy, "Riding horses was not at the top of my 'Can Do' list".

Before being diagnosed with multiple sclerosis in 2002, Drost was an avid walker, however all of this changed when MS caused profound weakness in her left side.

"From the moment I transferred from the mounting ramp onto the back of the horse, I knew this was a life changing experience – strength, balance, flexibility, confidence – all soared the first time I went on a trail ride," exclaimed Drost. "Despite life's challenges, I truly feel there are no boundaries to what I can do."

In addition to therapeutic and regular riding lessons, Chastain Horse Park provides opportunities for children from disadvantaged circumstances to develop self-awareness, self-confidence and self-discipline through riding and interaction with the horses.

Each individual instructor has his or her own lesson schedule, fee structure, and billing policy. Lessons are available for beginner through advanced students, started as young as age three. Therapeutic riding lessons are sometimes covered by insurance. A limited number of full or partial scholarships are available. For more information on either of these programs, visit www.chastainhorsepark.org and www.saddleupriding.org ●



Photo by John Spink.

Mia's Weight Control Becomes a Challenge

By Patricia Nobbie, Ph.D., Mia's Mom

In our last column, I described my frustration at how it difficult it was to interrupt Mia's diet, sleep and weight cycle. I've spent a considerable amount of time thinking about the problem and describing it to her primary care physician, her job coach, an eating disorders clinic team and a disease management network nurse, not to mention her grandparents, aunts, uncles, siblings and my husband. Here's the problem:

- She stays up into the wee hours and has terrible sleep apnea. I often find her cross-legged in bed, folded over herself, which I imagine helps keep her breathing passages relaxed and open. Otherwise, she is sucking air and snoring, waking herself up probably a zillion times. Apnea affects energy level during the day, keeping people in a constant state of sleepiness. Therefore she nods off whenever she sits still for any length of time. Another effect is a reduction in her stamina and energy level so she reduces her physical activity, compounding the weight problem.

“...the same confidence and sense of self that enables Mia to view herself as just a person and not a person with a disability also keeps her from seeing herself as an obese person.”

- She loves carbs, not sweets, but bread, crackers, chips. She hoards bread under her bed. We have to hide bread, and we forget to tell other family members where we hid it. When we come across it, in the china cabinet, or on the dining room chairs under the tablecloth, it is moldy or stale as a rock. This would be funny, except other family members can eat bread and wish they could eat it while it was still fresh.
- She doesn't eat enough protein, which would fill her up and keep her satisfied longer, and it would also burn off some of the carbs, but she's tactile defensive to hard-to-chew and crunchy things, so her diet is limited, and she's stubborn

about what she will or will not eat. She eats too much prepared food, and no fruits or vegetables.

Mia was not overweight as a child. I began to lose control of her weight when she started public school at 12. The cafeteria ladies loved her and offered her extra slices of pizza and breadsticks. She discovered the vending machines and bought her own juices. We extracted promises from the cafeteria ladies that they would not load her up with bread, and sent her with vouchers for food items that she chose with our guidance from the school menu. It was hard to keep up, and her weight continued to creep up. When Mia lost her job, she became even more sedentary, and her weight got scary. She is at risk for hip and knee problems, and even heart issues. Despite my seeking help, no one has been able to give me a plan, or offered to support me in a plan that I am willing to attempt. Our family has meetings, and starts out the week with resolve; limit carbs, plan and prepackage meals, disconnect her TV every night, make her walk the dog, etc. There is no end to the plans we have attempted and given up on.

There is a supreme irony to the situation: the same confidence and sense of self that enables Mia to view herself as just a person and not a person with a disability also keeps her from seeing herself as an obese person. Mia doesn't see her weight as a problem (if you say the word "fat" she says, "Don't say the 'F' word!" a reprimand that raises eyes in public!); therefore, she won't cooperate in any solution to the weight problem.

Any interruption in the cycle may help. We have a sleep study planned next month for the apnea. But what I'm thinking will be necessary is a Helen Keller/Annie Sullivan-like intervention, where we go into the woods, I control all the food, the sleep schedule, the TV and provide forced exercise. Conduct an individual boot camp for a month. Then maybe when we get home, we could keep up the routine. But I'd need a month off, which is impossible. Suggestions, anyone? ●



The ADA: A Work in Progress

By Mike Galifianakis, State ADA Coordinator

The Americans with Disabilities Act (ADA) was enacted with great anticipation on July 26, 1990. The ADA, with its ideals of equal opportunity, full participation, independent living and economic self-sufficiency, is the cornerstone of disability civil rights law and policy in the United States.

It has been nearly 17 years since the ADA was passed into law – is it making a difference in the lives of people with disabilities in America? The answer to this question, in large part, depends on one's expectations. Laws alone cannot guarantee equal rights and opportunity. Social change often comes very slowly, and while disability rights law is integral to advancement of these goals, it does not encompass the total solution.

There are important successes to celebrate. Since its enactment, the ADA has begun to make a difference - it has brought the principle of disability civil rights into the mainstream of public policy. The law, coupled with the disability rights movement that made it possible, has started to reshape the way Americans perceive disability.

The ADA has clearly influenced the way we design and build in our nation – and has created increased awareness and understanding of the ways in which the physical and social environment can pose unnecessary barriers to participation for people with disabilities.

And the ADA has made a positive impact in other ways. There is a saying that "necessity is the mother of all invention." The ADA challenges and stimulates thought and creativity about the ways to remove social barriers.

"While the ADA has become a symbol of the promise of human and civil rights, much of that promise remains unfulfilled."

Yet, there is still much more to do. While the ADA has become a symbol of the promise of human and civil rights, much of that promise remains unfulfilled. In many other areas, progress has been far too slow. There continues to be a lack of understanding, confusion,

resistance and opposition to the ADA. Many of us in the public and private sector have not fully implemented the law's requirements. In fairness, it must be acknowledged that the ADA

It has been nearly 17 years since the ADA was passed into law – is it making a difference in the lives of people with disabilities in America?

does create some genuine and unique challenges to full implementation. While many employers, businesses and governments embrace the principles embodied in the law, they continually grapple with some of its key concepts, including reasonable accommodation and the definition of disability itself.

The notion that a business may have to actually recognize someone's difference, in certain contexts, to provide an equal opportunity, is rather different from the notion of traditional equality which stands for the proposition that similarly-situated people are always treated by ignoring a difference of race, gender or national origin, for example. Many entities with responsibilities reasonably ask: When does accommodation turn into preferential treatment? Also, there are often costs associated with full implementation. When is it too expensive? Moreover, some of the ADA's technical



Mike Galifianakis is the Americans with Disabilities Act (ADA) Coordinator for the State of Georgia. The ADA Coordinator's Office works with State agencies to promote full and equal access to state government programs, services and activities for persons with disabilities.

Today, the UNEMPLOYMENT rate among people with disabilities REMAINS HIGH, and a law that requires an equal work OPPORTUNITY raises ADDITIONAL CONSIDERATIONS.

requirements can seem burdensome, especially for entities already regulated in other areas.

Still, these valid concerns do not completely justify the failure to promptly and fully implement the law's requirements. There are not many valid excuses for incomplete strategic plans or other deficient implementation strategies, and those entities with responsibilities should continually seek out technical support and resources to address those difficult challenges and move forward. Implementing the requirements of the ADA is the direct route to creating a customer-oriented culture that includes individuals with disabilities.

Today, the unemployment rate among people with disabilities remains high, and a law that requires an equal work opportunity raises additional considerations. For example, significant numbers of people with disabilities have never worked, and need meaningful training and mentoring opportunities to be successful in the workplace.

For others, even more basic supports, like dependable personal assistance services and reliable public transportation need to be in place before employment is even a viable option.

We still need to bring people with disabilities into the education and employment mainstream, provide affordable healthcare coverage, increase accessible housing options and implement key initiatives to ensure that there are home and community-based alternatives to nursing homes and institutions.

And of course, we must address these issues against the backdrop of a lingering budget crisis at the federal, state and local levels. For the foreseeable future, priority programs of the disability community are very likely to be under severe pressure, and spending may be sharply curtailed.

There have been other setbacks as well, including legal challenges questioning the legitimacy of the law. Individual states have argued that the U.S. Congress did not have the authority to regulate the states in this area. While still very much intact, certain legal remedies the law originally provided have been limited by these court decisions. Other cases have narrowly defined disability to exclude many individuals with significant impairments, thereby denying them protection under the law.

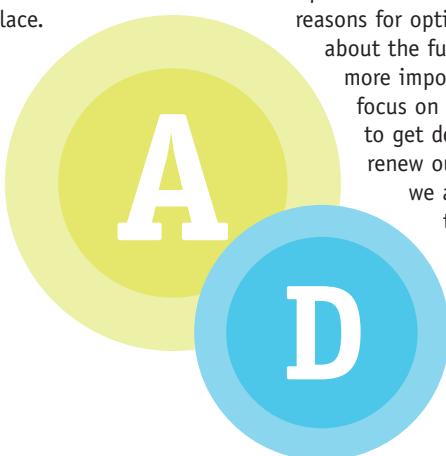
There are still yet other challenges as well. A case in point: electronic and information technology. More and more, information is a principal commodity of government, business and industry, and increasingly, electronic and information technology is the medium for the exchange of information.

Technology offers tremendous potential to connect us all. Web sites that are usable by people with sensory disabilities, accessible hardware and software configurations combined with assistive technology and other tools can create significant opportunities for people with disabilities to more fully participate – if such technology is accessible. Otherwise, many in the disability community will lag further behind.

The ADA is a work in progress. Clearly, there have been significant steps forward.

These past successes offer real reasons for optimism about the future. It is more important to focus on what needs to get done – and renew our energy so we are prepared to fully achieve the ADA's lofty goals. ●

“These past successes offer real reasons for optimism about the future.”



Requesting Reasonable Accommodations from an Employer or Business

Title I of the ADA prohibits discrimination in employment and requires employers to provide reasonable accommodations for employees with disabilities.

A reasonable accommodation is a modification or adjustment to a job, the work environment or the way things usually are done that enables a qualified individual with a disability to enjoy an equal employment opportunity. Examples of reasonable accommodations include making existing facilities accessible; job restructuring; part-time or modified work schedules; acquiring or modifying equipment; changing tests, training materials or policies; providing qualified readers or interpreters; and reassignment to a vacant position.

For additional information about reasonable accommodation under the ADA, visit the Job Accommodation Network website at www.jan.wvu.edu/ or Reasonable Accommodation and Undue Hardship (EEOC Guidance) at www.eeoc.gov/policy/docs/accommodation.html.

Tips For Employees:

- Follow any established procedures your employer has for requesting an accommodation.
- If you are unsure of how to file your request, speak to your Human Resources Coordinator, onsite ADA Coordinator or Supervisor.
- Be specific about the type of accommodation you need. Detailed information will be helpful to your employer.
- If your accommodation request can be fulfilled in several different ways, provide your employer with your suggestions on different options.
- You can make your request orally or in writing; however, a written request will provide you with documentation of your request.
- Make your request as early as possible.
- Be prepared to submit medical documentation from your treating physician identifying the need for an accommodation.
- Depending on established procedures, be prepared to discuss your accommodation request with your Human Resources Coordinator, onsite ADA Coordinator or Supervisor.
- You are not responsible for paying for the accommodation (for example: special computer equipment or materials in large print or Braille). Your employer should provide the accommodation free of charge, unless your employer can demonstrate that the accommodation will cause an undue hardship.

- If your request is approved, allow your employer a reasonable amount of time to provide you with the requested accommodation.
- If your request is denied, follow any established procedures your employer has for appealing the decision. You may also file a complaint with the Equal Employment Opportunity Commission if you feel you have been discriminated against on the basis of your disability. Call 800-669-4000 (voice) or 800-669-6820 (TTY) to reach the field office in your area.

State and local governments, as well as many businesses open to the public also have obligations to ensure equal access to goods, services, programs and activities for people with disabilities.

Tips for Customers or Consumers:

- If you require an accommodation when visiting an agency or business, whenever possible call ahead to give the agency or business advance notice.
- Be specific about the type of accommodation you need. Detailed information will be helpful to the agency or business.
- You are not responsible for paying for the accommodation (for example: interpreting services or closed captioning). The agency or business should provide the accommodation free of charge, unless the agency or business can demonstrate that the accommodation will cause an undue financial or administrative burden or would otherwise fundamentally alter the nature of the program, service or activity.
- Contact the Department of Justice, Civil Rights Division if you feel you have been discriminated against on the basis of your disability at 800-514-0301 (voice) or 800-514-0383 (TTY).

Title I of the ADA prohibits discrimination in employment and requires employers to provide reasonable accommodations for employees with disabilities.

For additional information on access to State of Georgia Government programs, services or activities, please contact the State ADA Coordinator's Office at 404-657-7313.

For all other ADA-related inquiries, please contact the Southeast Disability and Business Technical Assistance Center at 800-949-4232.

LONG ROAD HOME: Why I March

By Zen Garcia



Every three minutes in this country, someone dies warehoused in an institutional or nursing home setting. Often these individuals are forced to suffer preventable deaths due to the neglect incorporated into our country's profit-driven system of long-term care. The nursing home bias in our nation forces families and individuals to suffer unnecessarily while corporations profit. The government fines long-term care establishments for neglect and abuse of their patrons, while at the same time rewarding them for keeping the average cost per hour down.

Individuals inside nursing homes are not granted the authority and responsibility of self-determination. That is why the disability community is focused on

"To get anything done we must come together and embrace our similarities, commonalities which unite us in struggle."

changing the bias and getting money follows the person passed and now are redoubling our efforts to get Community Choice Act of 2007 signed into law.

Because I am on the outside and because the Lord has blessed me with the skills and determination to effect change upon the world, I will do all I can to help set our people free, which is why I am involved in the Long Road Home March. I do believe in the independent living philosophy. I want all people to have choice and the right to live in the most integrated setting as determined by the Supreme Court's Olmstead decision.

I had no idea what kinds of obstacles people with disabilities face. It wasn't until I broke my neck and became a part of the disability community that I understood what kind of prejudices people with

disabilities deal with in everyday circumstances. I consider myself blessed and fortunate as a person with a high level disability, not to be locked away and segregated from the rest of society simply because I must go about life a little differently. My community-based attendants help me bathe, dress and do range of motion exercises. They strap me in the van, then take me where I need to go, like the Long Road Home March.

Because my attendants have families and other jobs, sometimes it's difficult to coordinate events, especially if they run over the various shift changes in my daily schedule. And because I only have 22 hours of coverage, I have to juggle the schedule to make things work.

Because I am lucky to be in the community, with empowerment to make all the decisions of my daily living; I fight for disability, human and civil rights. Each generation is responsible for ensuring a government for the people and by the people. I try to show others that participation in government is every person's civic duty. It is we the people in unity that must come together in one voice of contention, one voice of struggle, one voice of truth. To get anything done we must come together and embrace our similarities, commonalities which unite us in struggle. Issues like health care and long-term care affect us all.

Both the left and the right are compromised and controlled. Corporations cater to politicians through lobbyists who buy political favor with campaign contributions that work against the interests and well-being of the common good. I personally can't sit by knowing what I know and allow it to continue without at least speaking out and making people aware of these kinds of issues. There is no us and them; there is only we. If you can make them understand that the policies and systems we are fighting to correct affect them as well, and that they are part of the problem and the solution, only then will they get serious about getting involved.

I will do all I can to help our brothers and sisters without voice, without choice, lost in the rule world of institutional bias to hold onto hope and the knowledge that there are others who care about what they're forced to endure. As long as I have voice and breath I will do all I can to change the nursing home bias of this country and right the wrongs preventing people with disabilities from full inclusion and equal citizenship. ●

JULY

July 26

Anniversary of ADA and Brain & Spinal Injury Trust Fund Annual Meeting
Columbus, GA
patunder@aol.com

September 27

Discovery Day
The Home Depot
Atlanta, GA • 1-800-ASK-GCDD
www.gcdd.org

OCTOBER

October 24-27

National Association for the Dually Diagnosed Annual Conference
Atlanta Renaissance Hotel
Atlanta, GA
845-331-4336
www.thenadd.org

DHR Board Meetings

August 15 - Atlanta
September 19 - Atlanta
October 17 - TBA
November 14 - Atlanta
December 12 - Atlanta

AUGUST

August 2

Here I Come!
Transition from High School to College
Summer Workshop 2007

The University System of Georgia & the Alternative Media Access Center (AMAC)
The University of Georgia, Tate and Student Learning Centers, Athens, GA • 706-542-1299
www.amac.uga.edu/sw2007.php

August 24-26

People First Conference
Jekyll Island, GA
404-552-9101

SEPTEMBER

September 8-13

ADAPT Fall Action
Chicago, IL
www.adapt.org

September 16-19

Southeastern Association of Area Agencies on Aging and Georgia Gerontology Society: Aging Takes Center Stage
Savannah, GA
www.georgiagerontologysociety.org



Good thing John had supports in place BEFORE moving out of the institution!

RESOURCES



Below, please find further resources of information related to the articles in this edition of *Making a Difference* magazine.

Governor's Council on Developmental Disabilities (GCDD)
www.gcdd.org
404-657-2126 or
888-275-4233 (ASK-GCDD)

State Government
Department of Community Affairs
Georgia Housing Search
www.georgiahousingsearch.org
877-428-8844

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

General Information
www.georgia.gov

Georgia General Assembly
www.legis.state.ga.us/

Georgia House of Representatives
www.legis.state.ga.us/legis/2003_04/house/index.htm

Georgia Senate
www.legis.state.ga.us/legis/2003_04/senate/index.htm

Georgia Governor's Office
www.gov.state.ga.us/
404-656-1776

Georgia Lieutenant Governor's Office
www.ltgov.georgia.gov/02/ltgov/home/0,2214,2199618,00.html
404-656-5030

Money Follows the People

Department of Community Health
www.dch.state.ga.us
404-656-4507

Department of Human Resources
www.dhr.georgia.gov
404-656-4937

Statewide Independent Living Council
www.silga.org
770-270-6860
Toll Free: 888-288-9780

Special Needs Scholarships

Georgia Department of Education
public.doe.k12.ga.us/sb10.aspx

Georgia Council of Administrators of Special Education
www.gcase.org/committee_pages/legislative.htm

Long Road Home

Olmstead Decision
www.cms.hhs.gov/apps/media/press/release.asp?Counter=369

Endeavor Freedom
www.endeavorfreedom.org
www.myspace.com/endeavorfreedomtv

Recreation Options

Full Radius Dance
www.fullradiusdance.org
404-724-9663

Swim Atlanta
www.saswimschool.com
678-442-7946

Sidekicks Karate
www.metooSports.com
404-329-9730
cnatoli@comcast.net

Saddle-Up Therapeutic Riding Center, Inc.
www.saddleupriding.com
912-449-0634
booann38@bellsouth.net

Chastain Horse Park
www.chastainhorsepark.org
404-252-4244
mbranton@chastainhorsepark.org

Parent to Parent of Georgia
www.parenttoparentofga.org/roadmap

Americans with Disabilities Act

Georgia's ADA Coordinator's Office
www.state.ga.us/gsfc/ada/
404-657-7313

ADA Information and Technical Assistance
www.ada.gov
800-514-0301
800-514-0383 (TTY)

Job Accommodations Network
www.jan.wvu.edu/

U.S. Equal Employment Opportunity Commission ADA Guidance
www.eeoc.gov/policy/docs/accommodation.html





United Cerebral Palsy of Georgia

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www.ucpga.org

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- Day Program - Creative alternative to supported employment
- Transition Program - Life Skills Development

**For information call 770.677.9379 or email
DisabilitiesServices@jfcs-atlanta.org
www.YourToolsForLiving.org**

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Making a Difference

The quarterly magazine of the Georgia Governor's Council on Developmental Disabilities

Volume 8, Issue 1 • Summer 2007

Dozens of advocates marched from the STATE CAPITOL to the main branch of the ATLANTA PUBLIC LIBRARY June 22. The fourth annual **Long Road Home March** participants hoped to DRAW ATTENTION to the hundreds of **Georgians** with disabilities who are FORCED to live in nursing homes and INSTITUTIONS, instead of in their own communities. Attendees also celebrated some advocacy MILESTONES this year in Georgia: receiving federal Money Follows the Person (MFP) funding; the passage of ADVANCE DIRECTIVE LEGISLATION; and the establishment of a Medicaid buy-in program for people with disabilities who want to go to WORK.



long road home march • long road home march • long road home march

SEE FULL STORY, PAGE 18.



Governor's Council on Developmental Disabilities
2 Peachtree Street, NW, Suite 26-246
Atlanta, GA 30303-3142
404-657-2126, www.gcdd.org

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