

WINTER 2008

# Making a Difference

## Advocacy Graduates Spur Change

STRENGTH!

GET US OUT!  
KEEP US OUT!  
DON'T PUT  
US IN!

WE VOTE!

GCDD Sets  
Legislative Agenda

Women with Disabilities:  
Desirable and Desiring

[www.gcdd.org](http://www.gcdd.org)



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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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### To Georgia's Disability Community,

The shifting of seasons from summer to fall is a reminder that change is ever eminent. My vision for Georgia is that of change and the drive for continuous improvement. To this effort, I am proud to announce that many promising strides have been made within Georgia's disability community.

One of the most pressing issues facing the disability community is that of jobs and new job opportunities. We, as a community and as a state, recognize that having a meaningful, rewarding job is the very basis of America's free

Sonny  
Perdue  
Governor



*Sonny Perdue*



## GCDD Helps Advocates See the “Big Picture”

Almost every day the Governor’s Council on Developmental Disabilities receives telephone calls or e-mails from individuals with disabilities and family members seeking resources and looking for assistance to access services and supports. Occasionally we receive a phone call from someone who is very interested in getting more information and more involved. For example, we received a call from a mom with a young son who was having difficulty getting the services he needed from his school. They wanted to place him in a segregated program but would not let her visit that program with an advocate. They also told her she could not bring anyone with her to the Individualized Education Plan meeting.



ERIC E. JACOBSON

After several conversations about her rights and the rights of her child, she said, “I am part of a support group, and many of us are in the same position and don’t know our rights.” We could tell that once she took care of her son’s issues with the school, with the proper support, this mom might be ready to help other parents or even get involved in other issues. Our question to her was, “Are you or your friends interested in participating in training to learn about your rights and how to be better advocates?” She responded with cautious curiosity. We then suggested advocacy and leadership development programs, such as Partners in Policymaking, could assist her and her friends, and we could provide them with contact and application materials.



TOM SEEGMUELLER

We don’t know if this mom will take us up on our offer or will find another program, but this kind of conversation takes place quite often. GCDD-funded and supported advocacy programs such as Partners in Policymaking, Georgia Voices that Count and the Organizing Institute are among our most popular and most visible programs. We are fortunate to have great partners such as the Atlanta Alliance on Developmental Disability, disABILITY LINK and Project South that have the passion to make these initiatives successful.

Not everyone needs to go through these programs, but for many people, it can be the first time they think beyond their own issues and begin to see the “big picture” known as disability advocacy, and they recognize they are part of a larger movement. Many will use their training and get involved in committees and campaigns across the state and nation. Others will complete their course work, and we will never hear from them again.

This issue of *Making a Difference* magazine will focus on these advocacy efforts, and you will hear from some of the graduates. If you have not already participated in one of these programs, we encourage you to do so. For those who have participated, we need to hear from you – make sure that you are not one of those whom we never hear from again! And tell your friends and encourage them to sign up, too.

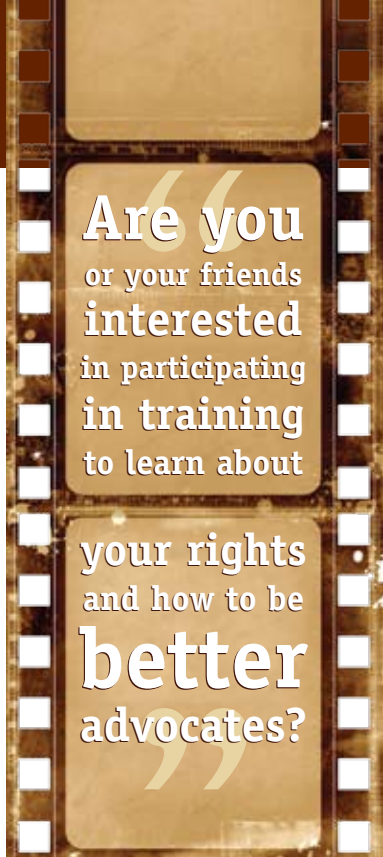
I want to take this time to thank some old friends of GCDD and welcome some new ones. During this last quarter, we had some changes to the Council. We thank Vallorie Butler, David Cowen and Lee Tian for their commitment to GCDD and to the disability community. We welcome Kim Chester, Carl Flair and Ken Whiddon. In addition, we welcome new advisory members: Jill Alexander, Riley Buckmaster, Glen Friedman, David Glass, Nick Harris and Madeline Ponder.

Finally, please join GCDD on February 21, 2008 as we celebrate the 10th anniversary of Disability Day at the Capitol. This year’s event promises to be our biggest and best yet.

We want to hear from you. Contact our editor-in-chief Valerie Meadows Suber at 1-888-275-4233 or [vmsuber@dhr.state.ga.us](mailto:vmsuber@dhr.state.ga.us).

*Eric E. Jacobson*  
Eric E. Jacobson  
Executive Director, GCDD

*Tom Seegmueller*  
Tom Seegmueller  
Chairperson, GCDD





## Letters to the Editor

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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### Audio or Large Print Versions:

For an audio version of *Making a Difference*, please contact GCDD. A large font version is available for download at [www.gcdd.org](http://www.gcdd.org).

### Sponsorship:

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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

## My Vote is for REAL

REAL HOMES • REAL CAREERS • REAL LEARNING • REAL INFLUENCE • REAL SUPPORTS

**10th Annual Disability Day at the Capitol**  
**Thursday, February 21, 2008**

Join the Governor's Council on Developmental Disabilities and more than 1,800 Georgians with disabilities, their families and supporters from across the state for the 10th annual Disability Day at the Capitol to:

- Rally on the Capitol steps
- Meet your legislator and explain what issues are important to you
- Celebrate community, advocacy and friendship
- Register to vote with the Georgia Disability Vote! Project
- Let legislators know YOUR VOTE MAKES A DIFFERENCE!



**FOR MORE INFORMATION, VISIT**  
**WWW.GCDD.ORG OR CALL 888-ASK-GCDD.**

## LEGISLATORS

Please join more than 1,800 disability advocates from across the state for the **"My Vote is for REAL" Rally** on the Capitol steps **February 21 at 11 AM.**

- Discover the issues facing the disability community
- Meet constituents from your district
- Speak to hundreds of voters with disabilities
- Be recognized as a supporter of the disability community in *Making a Difference* magazine

Sponsored by the Governor's Council on Developmental Disabilities, the day will also feature opportunities for you to visit with your constituents over breakfast (beginning at 9:30 AM) or lunch (beginning at 12:30 PM).

Please check in at the legislative/media table to receive your information packet and to have your photo taken for *Making a Difference* magazine!

**For more information, visit [www.gcdd.org](http://www.gcdd.org) or call 404-657-2126 or 888-ASK-GCDD.**



## ATTENDEE RSVP FORM

**Disability Day at the Capitol • February 21, 2008**

Please register to attend the breakfast OR luncheon.

**RSVP: 404-657-2126, Toll Free 888-ASK-GCDD, FAX 404-657-2132,  
TTY 404-657-2133, or [www.gcdd.org](http://www.gcdd.org)**

Name: \_\_\_\_\_

Organization: \_\_\_\_\_

Total # attending: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

E-mail: \_\_\_\_\_

Telephone: \_\_\_\_\_

I plan to attend (please check one) \_\_\_\_\_ Breakfast \_\_\_\_\_ Lunch

Optional \$10.00 donation per person to support breakfast or luncheon is appreciated, but not required.

Total payment amount: \_\_\_\_\_ Total amount enclosed: \_\_\_\_\_

**Please make check payable and return to:**

Governor's Council on Developmental Disabilities • Disability Day Registration  
2 Peachtree St. NW, Suite 26-246, Atlanta, GA 30303.

Please note special accommodations we should be aware of:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# Disability Day SCHEDULE

**9:30 AM**

**Breakfast at the Georgia  
Freight Depot**

**11:00 AM**

**My Vote is for REAL Rally  
on the Capitol Steps**

**12:30 PM**

**Lunch at the Depot**



.....  
**FEBRUARY 21  
2008**



## Jacobson's Influence Recognized for Second Year



Governor's Council on Developmental Disabilities Executive Director Eric Jacobson has been recognized for the second year in a row as one of the 100 most influential Georgians by *Georgia Trend* magazine.

"I hope this wonderful distinction will highlight how the disability community continues to come together to speak with one voice on the issues that affect all of us," Jacobson said. "I am deeply honored by the recognition."

Former GCDD council member Annette Bowling, of the Albany Advocacy Resource Center was also named to the prestigious list, and Mark Johnson, advocacy director for Shepherd Center was recognized as a Notable Georgian in the piece. The distinctions will be announced in the January edition of *Georgia Trend*.

## GCDD Reaches out to Gainesville

During its quarterly meeting, in October, GCDD interacted with the Gainesville community by partnering with the Greater Hall Chamber of Commerce to host a media roundtable briefing and luncheon for news organizations and disability advocates. GCDD also held a forum to hear public comments from the north Georgia community. WDUN News Radio and its Martha Zoller talk show, as well as *Georgia Trend* magazine and WNEG-TV 32 covered portions of the three-day session.



## Montford Named Fiscal Officer

The Governor's Council on Developmental Disabilities' new Fiscal Officer Lisa Montford brings more than just number crunching skills to GCDD. She brings a commitment to improving the lives of people with disabilities, including her son, who has Down syndrome.

**"...I have seen the issues that persons with disabilities face."**

"Being Gregory's advocate, I have seen the issues that persons with disabilities face. I'm always grateful

I can serve as a second voice for him in this world," she said.

As the fiscal officer, Montford will coordinate and manage GCDD's budget, inventory, contracts and procurement, as well as reimbursement systems. She formerly managed multi-million dollar budgets for the state of Georgia's Insurance Commissioner, Department of Technical and Adult Education and Department of Community Affairs.

In addition to smoothly managing GCDD's financial assets, Montford hopes to improve her advocacy skills.

"I was very excited to come to work for GCDD because my experience here will enable me not only to better advocate for my son, but also for other persons, with or without disabilities, who come into my life," she said.

Montford, a native of Atlanta, has an accounting degree from Clark Atlanta University and lives with her husband, Greg, and two sons, Gregory and Brandon.

## GCDD Releases PSA

GCDD has just released Public Service Announcements for TV, featuring former CNN Anchor Bobbie Battista and Atlanta Falcons Quarterback D.J. Shockley. The 60-second PSA portrays Battista and Shockley describing their personal connection to developmental disabilities and why Georgians should learn more about how to make a difference by visiting GCDD's Web site. The spots are being distributed to air during the legislative session on TV stations throughout Georgia. View the PSA at [gcdd.org/press%20room/index2007.htm](http://gcdd.org/press%20room/index2007.htm).



*continued on page 8*



*continued from page 7*

## Endeavor Freedom Receives Nomination, GCDD Grant

www.EndeavorFreedom.tv was recently nominated for the National Spinal Cord Injury Association's (NSCIA) Spinal Cord Injury (SCI) Hall of Fame. Endeavor Freedom Founder Zen Garcia and his colleague, Santina Muhai, were nominated for the production of six episodes of a show called SCI News and Views.

www.EndeavorFreedom.tv is a new Web site, made possible through an Innovative Grant from GCDD, dedicated to expanding the power and presence of people with disabilities by generating news, information and video content that is also written and produced by people with disabilities.

In just four months as an active media organization, more than 112,000 people have viewed Endeavor Freedom videos on YouTube. Endeavor Freedom videos have been picked up and shared over hundreds of different Web sites in 27 countries.

The award-nominated program series included interviews of well known leaders and advocates, such

as Marcie Roth, executive director of NSCIA; Jesse Billauer, founder of Life Rolls On; Professor X, a rapper and film maker who uses a wheelchair; Briana Walker, author and dancer; and Eric Robinson, founder of the Extremity Games, and president of College Park Industries. Endeavor Freedom board members Mark Johnson, Charles Lamb Jr., Greg Smith and Richard Gaskin are also NSCIA Hall of Fame nominees. Visit [www.EndeavorFreedom.tv](http://www.EndeavorFreedom.tv) for more information.

Drafts of the report have been circulated, and the three organizations expect positive reviews of their efforts to ensure Georgians with disabilities are fully included in community life.

## New Conference Slated for June

The Against All Odds Conference will be held June 1 - 3 at the University of Georgia's Continuing Education Building.

The conference is for providers, families and self-advocates. Seminar tracks include transforming the service delivery system and employment, as well as sessions for direct support professionals and a self-advocacy summit. Connie Lyle O'Brien is the conference coordinator and is asking nationally known speakers to share their experiences in operating person-centered agencies with individualized budgets who have maintained their financial stability.

## New Members Join GCDD

GCDD welcomes three new members including Kim Chester, a parent advocate from Cartersville whose young daughter has cerebral palsy; Carl Flair, another parent advocate from Macon whose adult daughter has physical and mental disabilities; and Ken Whiddon, a parent advocate from Saint Simons Island, who has a son with learning disabilities.

## Disability Organizations Evaluated By ADD

Georgia's three federally-funded disability organizations, the Governor's Council on Developmental Disabilities, the Georgia Advocacy Office and the Institute on Human Development and Disability were recently evaluated by the U.S. Administration on Developmental Disabilities (ADD) Monitoring & Technical Assistance Review System (MTARS).

## Gainer Earns Award

GCDD Advocacy Director Kate Gainer received the KES DAY Pioneer Service Award, December 9, 2007, "in recognition and honor of her service to help build resources, build support and promote the inclusion of the physically and developmentally challenged in our community."

KES, Inc. provides residential and community support services for children and adults. KES DAY offers adult day services, adult and children supported employment, respite, case management as well as life skills and personal development through daily inclusion and community integration. ●





## Social Security Holds Hearing on Compassionate Allowances

The Social Security Administration held a two-day public hearing December 4 - 5 in Washington, D.C., with some of the nation's leading experts on rare diseases. The experts presented testimony and shared their views about Social Security's efforts to identify and implement "compassionate allowances" for children and adults with rare diseases.

"We need to identify and fast-track disability cases that are certain or near-certain to be allowed," said Michael J. Astrue, Commissioner of Social Security.

"The compassionate allowances initiative will allow the Social Security Administration to



**"We need to identify and fast-track disability cases that are certain or near-certain to be allowed."**

make decisions on cases involving certain categories of conditions in days or weeks instead of months or years."

Compassionate allowances are a way of quickly identifying diseases and medical conditions that invariably qualify under Social Security's Listing of Impairments based on minimal objective medical information. Compassionate allowances will let Social Security quickly target individuals for allowances based on quickly-obtained objective medical information. Many of these claims

can be allowed based on confirmation of the diagnosis.

The hearing is the first of four public hearings that Social Security plans to hold over the next year.

### Supreme Court to Hear ADA Case

The Supreme Court of the United States announced December 7 it would hear arguments in *Pam Huber v. Wal-Mart*.

Huber was injured while working as a grocery order filler at Wal-Mart. The injury left her with a permanent disability that made her unable to perform her job duties.

Huber then asked to be reassigned to a vacant router position that paid about the same as her original job, but was not hired. She was qualified for the position, but not the most qualified candidate. Wal-Mart then offered her a job as a janitor for less than half of her original pay scale. Huber sued under the Americans with Disabilities Act, asserting she deserved to be hired for the router job as a reasonable accommodation.

The ADA states: "Job restructuring, part-time or modified work schedules, reassignment to

a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities" are reasonable accommodations.

Wal-Mart argued its nondiscrimination policy to hire the most qualified applicant did not entitle Huber, under ADA, to be assigned to the router position without competing for the position.

The district court ruled for Huber, but the U.S. Court of Appeals, Eighth Circuit, reversed the decision, stating, "We are faced with an unanswered question: whether an employer who has an established policy to fill vacant job positions with the most qualified applicant is required to reassign a qualified disabled employee to a vacant position, although the disabled employee is not the most qualified applicant for the position."

The Supreme Court will rule on the case in 2008. ●

**"The district court ruled for Huber, but the U.S. Court of Appeals, Eighth Circuit, reversed the decision on appeal..."**



By Valerie Smith Buxton



# Advocacy Graduates *Spur Change* Across Georgia

**When Jacobina McNair discovered her daughter, Kendra, had autism and severe learning disabilities, she didn't know where to start to give her daughter a rich, full life.**

Becoming involved in Partners in Policymaking, one of Georgia's three premier advocacy training programs, helped her see the possibilities for her daughter and prepared McNair to become an effective advocate for both her daughter and the greater disability community.

"Partners opened my eyes that I was not by myself. It totally changed me and gave me confidence," McNair said.

The Governor's Council on Developmental Disabilities funds Partners in Policymaking, as well as two other training programs, Georgia Voices That Count and the Organizing Institute.

Partners in Policymaking was begun by the Minnesota Governor's Council on Developmental Disabilities to train participants, who are people with developmental disabilities or family members, to become advocates and members of organizations that serve this population.

**"If we want to create policy, legislative or community change, we have to have people who are knowledgeable about issues and have the tools necessary to create the change we're looking for."**

GCDD created Georgia Voices That Count to create a self-advocacy program specifically for people with developmental disabilities. It recently also started the Organizing Institute to move beyond advocacy training and give people tools

to organize members of their local communities around disability issues.

"GCDD funds programs that support the development of advocates as part of its charge from the Developmental Disabilities Act. One of the projects we must fund is self-advocacy," explained GCDD Executive Director Eric Jacobson.

He feels the three programs are necessary in the state. "If we want to create policy, legislative or community change, we have to have people who are knowledgeable about issues and have the tools necessary to create the change we're looking for. GCDD, with its 11 staff and 27 members, is never going to be able to create and sustain change without the assistance of people living in local communities. Without the folks who participated in these programs, we would not have been as successful in creating system-wide changes," he said.

While advocacy at the state level has a big impact on government assistance for the disability community, Jacobson believes the real advocacy work begins at the local level.

"Organizing conversations between people with disabilities and their families, friends, neighbors and local business leaders helps create a welcoming community in Georgia for all citizens," he said.

## Partners In Policymaking

The oldest of the three programs, Partners in Policymaking, first launched in Georgia in 1992. "We take 35 participants every year from all across the state. We have over 435 graduates of the program," explained Rita Young, training and advocacy manager for the Atlanta Alliance on Developmental Disabilities (AADD), the organization that administers the class.

Partners in Policymaking helps both self-advocates and parents of children with





disabilities become subject matter experts on the issues that affect the disability community, such as school inclusion, housing, employment and disability law. The program is in place in 35 states and two countries.

“We expect a lot of participants. We give them monthly assignments tied to the speakers. We also track their advocacy every month – how many meetings or conferences they attended and what contact they’ve had with legislators or the media,” Young said.

Class members also must complete a project during the nine-month course. This year, for the first time, the participants have the opportunity to contribute to an existing project, such as volunteering to work during GCDD’s Disability Day at the Capitol.

The class meets one weekend a month and features nationally renowned speakers that have been through a screening process. AADD also brings in local speakers when appropriate, such as speakers from the Georgia Advocacy Office, ADA Exchange, direct service providers and legislators.

AADD’s Director of Public Policy Dave Blanchard explained, “Partners in Policymaking builds on the principle of bringing people together to strengthen relationships and partner to create solutions. We are strengthened by the different perspectives of parents, people with disabilities and professional and personal speakers.”

One of the big events during the year is a mock testimony at the Georgia capitol in January, according to Young. “This gives the members an opportunity to present testimony on a specific

disability issue to a panel of volunteer legislators who give feedback. We encourage the participants to invite their own legislators,” she said.

Jacobina McNair, a 2001 graduate, said, “I think the experience I had during our mock interview before representatives at the State Capitol was a memorable one. It helped me to understand how important it is for us to share our stories and lives with the persons we put into office. Unless they live similar lives, they do not understand what daily life can be like for a person living with a disability or their caregivers.”

While McNair created a five-year plan for her daughter, who has autism and learning disabilities, during the class, her training has enabled her to help many other children as well.

Since taking the class, McNair, who lives in Gwinnett county, has helped many other parents of children with disabilities navigate the special education system. “I introduced myself to other special needs parents and helped them get more prepared for their IEP (Individualized Education Plan) meetings,” she said.

**“I introduced myself to other special needs parents and helped them get more prepared for their IEP meetings.”**

Now, McNair works in the Parent Mentor Program in Gwinnett to give the educators the parents’ point of view and help parents understand their role in their child’s education.

She also works with the Gwinnett Interagency Transition Council that helps plan for children’s transition out of school into life; the Gwinnett Navigator Team that brings resources together in one place for parents; the Autism Society of America’s Georgia Chapter; and the Gwinnett Early Childhood Interagency Council.

**“We are STRENGTHENED by the different perspectives of parents, people with disabilities and professional and personal speakers.”**

Fellow Partners graduate Karen Addams graduated in 1995 and has been using what she learned in the class to create a better life for her daughter, who has profound intellectual disabilities, cerebral palsy, hearing and vision impairment and hypomelanosis of Its, and other children with disabilities.

"The most important thing I learned was how disability advocacy is important throughout the person's lifetime. A lot more than just school is important to a person with disabilities," she said.

Addams has been a parent educator for Babies Can't Wait, lobbied for the Unlock the Waiting List! Campaign and Medicaid issues, served on a state advisory panel for special education and currently works for the Parent Training and Information Center of Parent to Parent of Georgia.

She also started the Georgia Parent Network listserv for parents of children with disabilities. "I'm most proud of bringing 700 families together in a forum where they can help each other.

"If I hadn't taken Partners in Policymaking, I wouldn't have done all those things. It's given me a whole different perspective about my daughter and what her life could be like," she said.

Partners in Policymaking will begin accepting applications for the next class in the spring.

Visit [www.aadd.org/newsite/programs/partners.html](http://www.aadd.org/newsite/programs/partners.html) for an application or call 404-881-9777, extension 220. Participants are asked to pay for as much of the training and travel as they can; however, scholarships are available on an individual basis to help class members offset costs such as transportation, support, respite care for children at home, etc.



## Georgia Voices That Count

Georgia Voices That Count is an advocacy training program specifically designed for people with disabilities, according to Linda Pogue, the program manager for the class, which is administered by disABILITY LINK, a center for independent living.

"All our participants are people with disabilities, and about 80 percent of the

presentations, teaching and activities are facilitated by people with disabilities," she said.

The year-long class meets about three or four weekends a year and focuses on history of disability rights, community living, employment and leadership. The class graduates the evening before GCDD's annual Disability Day at the Capitol, then participates in the rally. The only requirements for applying is that the person live in Georgia, have a disability and have an interest in disability rights. Class size varies from 10 - 16 members a year.

**"We like diversity. That's how people learn from each other"**

The selection committee values diversity and chooses people from both urban and rural areas, as well as some class members who currently live in institutions. "We like diversity. That's how people learn from each other," Pogue said.

Because many of the participants may have intellectual disabilities, the class uses more innovative ways to teach, such as music, poetry, field trips and discussions.

"One of the weekends we go to Warm Springs to the Little White House. This leads to great conversations and insights about Roosevelt hiding his disability. Why did he do that, and what does it mean? It also leads to discussions on disability pride and the origins of the Social Security system," Pogue explained.

During the year, participants have to undertake an advocacy project and must complete some part of the project by the end of the year. "Lots of people recognize some of the issues but don't know where to start or how to make a difference. Picking a project is a lot of pressure. But once they do it and are successful to a degree, it's a real barrier breaker," Pogue said.

Samuel Mitchell, a 2003 Georgia Voices That Count graduate, advocated for the timing of a traffic light in front of his Riverdale apartment complex to be adjusted.

"The intersection near the apartment I was living in didn't give you time to cross the street. People walking would have to run across the



**“Lots of people recognize some of the issues but don’t know where to start or how to make a difference.”**



street, dodging cars. Using a wheelchair made it really dangerous,” Mitchell reminisced.

“At first, I couldn’t get any type of action. The county took a while to get back to me, then said the state was responsible for Highway 85. But the state never answered any of my inquiries. Finally, I had to contact my senator, and she pulled some strings and applied some pressure and got people from the state to call me back. Finally they came out and put crosswalks down and adjusted the light to where it would hold longer to give you time to cross the street,” he said.

Post graduation, Mitchell continues to work on pedestrian and transportation issues. He became president of the Atlanta chapter of ADAPT, a national disability advocacy organization that recently played a role in making sure MARTA did not stop selling the unlimited ride card for paratransit users.

“We protested a number of times outside of MARTA headquarters and attended meetings and board meetings. We pointed out that canceling the card for people with disabilities to use paratransit, but allowing able bodied people to continue purchasing unlimited ride cards would be discrimination. MARTA listened and made the decision not to cancel the card,” he said.

Recent graduate Craig Tucker of Fort Valley exhibits subtle leadership, according to Pogue. “Craig is a quiet and determined advocate for

himself and the disability community,” she said. “He’s helping people move out of nursing homes.”

Tucker said, “I visit people to get ideas how to help them and get people to care. I try to help them speak for themselves. I try to find new ways to get the world to listen.”

One of the ways Tucker is trying to communicate is through a quarterly newsletter he writes that tells the stories of the people he talks to in the disability community.

“The greatest disability in the world is ignorance,” he said.

Georgia Voices That Count is currently accepting applications for the next class through the end of January. The class is free to participants. For information, contact Linda Pogue at 404-687-8890, extension 114 or [www.disabilitylink.org](http://www.disabilitylink.org).

## Organizing Institute

While Georgia Voices That Count is a self-advocacy leadership program, and Partners in Policymaking is a systems advocacy leadership program, the Organizing Institute, which began in 2006, is a movement building program.

“We like to think of the Institute as the graduate advocacy program,” explained Governor’s Council on Developmental Disabilities Advocacy Director Kate Gainer.

“The Institute teaches people to make their community aware that an issue exists and how they can help, using the collective efforts of all





the people in the community to help solve a problem," she explained.

Another difference is that the Organizing Institute also includes some participants with no prior connection to disability, in hopes that the disability community will join with related organizations and come together with a united voice on issues that affect both.

"If you expose Joe the grocer, Frank the fireman or Linda the mailperson to the issues you're working on, they might have a

new take on the issue and a new solution. GCDD wanted to teach people how to do that," Gainer said.

The initial process for the Organizing Institute was developed by GCDD, who then contracted with Project South, an organization that teaches leadership development for movement building. GCDD and Gainer remain actively involved in the running of the year-long Institute.

"We're having a much more hands on experience with the Organizing Institute in that our staff are not just managing a grant, but are actually creating and supporting the institute," explained Jacobson.

The first five months are spent learning about how to organize and the next five are spent in paid fellowships within existing organizations, implementing a project that impacts the disability community.

"I am proud of all the accomplishments of our first seven graduates. Some of them had no background in disability and completed their projects with enthusiasm," Gainer said.

Graduate Jane Grillo, whose son has cerebral palsy, a visual impairment and a seizure disorder, originally planned a respite program for her rural White county community.

Through a volunteer organization called Stepping Stone Farm, Grillo hosted three respite

events. However, while parents brought their children to the events, many of them ended up staying.

"Parents are not looking for us to help with respite care. Families with adult children with disabilities seemed to be the ones who needed the most help," Grillo said.

After realizing this, Grillo partnered with Better Hometown of Cleveland to do a downtown beautification project.

**"Families with adult children with disabilities seemed to be the ones who needed the most help."**

"We did container gardens all around the square in 27 planters," she said. "It connected people with disabilities with downtown business people and basically the whole community because they would see us out there planting flowers."

Grillo hopes that having a higher profile in the community will help lead to jobs for the people she serves.

In addition to adults, she works with students in high school and the ninth grade academy to do different community service projects. She partners with other local agencies to have students work. They have prepared newsletters for mailing and a theatre space for a performance, which Grillo said they particularly enjoyed.

She also started an email penpal program with the senior center. "The kids are used to email, but letter writing can be unbearable for kids with cerebral palsy. The older folks learn how to use email. The kids get to be companions to the folks at the senior center and bridge the generation gap a little," she said.

The next Organizing Institute begins in February. For information on joining the 2009 class, contact Kate Gainer at 404-657-2125 or [nkgainer@dhr.state.ga.us](mailto:nkgainer@dhr.state.ga.us). ●



## Basic Advocacy Tips

By Kate Gainer, GCDD Advocacy Director And Georgia's 2007 Self-Advocate of the Year

**Research** Learn everything you can about the issue you are pursuing.

**Friends** Make a list of the people and organizations that might agree with your point of view. Contact them and see if they've ever done any advocacy around your issue. It is not necessary to reinvent the wheel each time. If they have, they will be able to tell you what worked and what didn't. It is also always good to work in groups. That way your point of view cannot be dismissed as just one person's issue.

**Foes** Make a list of people and organizations that might not agree with your point of view. If there is disagreement, they might actively work against you. This is where research comes into play. You need to know who your opponents are and what their motivation is for disagreeing. If it is an organization, you need to know if the disagreement is coming just from their leadership or if the entire membership disagrees with you.

**Group Dynamics** If you are working in a group, there needs to be a decision on what the group really wants to happen around a given issue. You can't please everyone, but you can get consensus. Groups sometime break up because people feel decisions are being made without input from the group. It is always important for people to feel that their point of view has been heard. It is vital

the entire group knows what the group is advocating for and why. The group should decide on the methods of advocacy to be used.

**Speak with One Voice** If you are working in a group, especially a large group, there needs to be a decision made as to who the spokesperson will be on this issue. No one person knows everything about every issue. Some people can speak about a given issue better than others. The group leader may not be the best spokesperson for a given issue. If there are one or two people designated as the spokespeople, it is easier for the news media and the people you're negotiating with to understand your point of view.

**"The People United Will Never Be Defeated"** If you're working within a group, and you're trying to get a meeting with someone opposing your efforts, never agree to meet with them alone. They may try to stroke your ego by saying they will meet with you. But this is a group effort, and the more ears you have listening to what's being said, the better. People hear different parts of a conversation. You might pick up on something important that the others didn't hear, or vice versa. ●



“**Make a list of the people and organizations that might agree with your point of view.**”

**Relax,  
Remain Flexible,  
Have Fun**



## Advocacy Was Life or Death for Mother

By Laurie Faulk

Laurie Faulk is a mother and advocate who lives in Hawkinsville, GA. She has advocated for her son and other children like him who are currently living in nursing homes and institutions, but want to move back home to their families.

**W**hen my son, Donald, was six years old, his father placed him in a nursing home. I couldn't afford a lawyer to fight my ex-husband and keep Donald, who has cerebral palsy and a visual disability, at home.

For six long years, my son stayed in that nursing home. He developed bed sores, and his back now has an angle in it because he was left in one position for so long. He was admitted to the hospital on numerous occasions because the nursing home neglected to give him enough water, or didn't insert his feeding tube properly. The emergency room doctor at the hospital never knew if he would survive his visit. He wasn't bathed regularly. I could only visit him once a week because the home was located more than an hour away from me.

I didn't have the resources I needed to get Donald out and take care of him at home. Then one day, the Georgia Advocacy Office (GAO) found me. They called and asked if I wanted my son back. I said, "yes!"

It wasn't more than a few months, and he was back home!

GAO gave me a lawyer to help fight for Donald's rights. And I began to tell his story. I sat down with legislators to give them a good look at what we were going through.

**"I sat down with legislators to give them a good look at what we were going through."**

I'm a very country girl from Hawkinsville, and being up there in Atlanta with all those legislators and folks from the Department of Human Resources made me nervous. I stuttered, but I made it through it for Donald and kids like him. It felt really good to let everyone know my story and that many other mothers want their kids home, but don't know how to get them

out of nursing homes. Without GAO, a lot of those kids would STILL be in nursing homes.

These kids don't need to be in nursing homes. Before Donald went in, he could speak some words, but he deteriorated in there. We need to stand up and fight for these kids.

Because of my advocacy efforts, Donald now receives waivers to help me support him at home. He has an aide who comes in eight and a half hours a day, five days a week to help take care of him. I also got support to get the equipment he needed, like a special bed that doesn't cause bed sores and suction equipment to help me clear out his lungs.

Donald is 14. He no longer has bed sores, and he hasn't been in the hospital since he left the nursing home. A teacher comes to the house to home school him. Now he uses his hands more – he made me a cup. We just got back from a trip to Pigeon Forge, where he got to enjoy the shows at Dollywood and feel a snowball for the first time. He gets excited every time he gets to go somewhere because he no longer has to lie around in bed.

Best of all he is surrounded by his family. His baby niece keeps him on his toes, and he loves his dog and cat. I know my advocacy is what helped Donald move home. It doesn't matter if you're country; those legislators will sit there and hear you out, then help you find the support you need to bring your child home. ●



# Legislators, advocates work together for a better Georgia

## Advocates Help Educate Legislators

By Rep. Judy Manning (R-Marietta)

Legislators are asked to support many causes. While advocates are focused on one issue, legislators must weigh that issue with others. But advocates should not become disenchanted with the process if legislators can't give their issue their full attention.

For example, in regards to the waiting list and the children's freedom initiative, no one in the world would say that people shouldn't be in the community. Lots of things have to happen to get people moved into community, like housing, transportation, providers, services, staff, etc. Some pieces just aren't there yet. We may never get 100 percent of what we need, but we are making progress. The hardest thing for advocates and legislators both is to realize the complexity of all the needs that are out there, to approach the problem in a balanced way and keep working on it.

One thing advocates can do to really help legislators is sitting down and talking to us, to help us understand what the problems are. Many issues are not just about money. Advocates should understand that legislators get frustrated also. We want to help, to solve problems, especially things that affect large groups of people, like those with developmental disabilities. But the next call we answer is another issue, equally important to that advocate, and it's hard for us to balance all the needs. If I could just wave a wand, I could do a whole lot!

Even if you don't have the same perspective as your legislator, try to understand where they're coming from without becoming angry or disagreeable. Even among legislators there are disagreements in perspective, but we try to understand why issues are important to those individuals, and work with them to come to a solution.

We have made a great deal of progress to help Georgians with developmental disabilities live better lives. We used to get only 10 slots [services] or 30, just a drop in the bucket. Last year, 1,500 slots were funded. When we got the waiting list passed [Multi-year funding plan resolution] we still had to advocate for the money. We may never completely end the waiting list. But thanks to the passionate advocacy efforts of the disability community, we have made real progress, and that's important. ●

**“The hardest thing for advocates and legislators both is to realize the complexity of all the needs that are out there, to approach the problem in a balanced way and keep working on it.”**



Rep. Judy Manning has served House District 32 for six terms. She is the Chairman for the Children and Youth Committee, the Vice Chairman for the Interstate Cooperation Committee and a member of the Appropriations and Natural Resources & Environment Committees. She is a loyal supporter of the Unlock the Waiting List! Campaign and has obtained funding for services for people with developmental disabilities even during the tightest state budgets. She co-sponsored HR 1307, the multi-year funding plan for services for developmental disabilities, HR 633, the Children's Freedom Initiative, as well as legislation to ensure Braille literacy, expansion of PeachCare and other legislation. Manning is a two time recipient of the Legislator of the Year award.

## GCDD Sets

# Legislative Priorities

## for 2008 General Assembly

**J**anuary 14th, we will embark on the second year of the two-year legislative session. At the October Governor's Council on Developmental Disabilities meeting in Gainesville, members were briefed on issues submitted to GCDD for consideration and determined their priorities.

GCDD's agenda-setting process engages a broad constituency of organizations and individuals involved with disability advocacy. In September, letters were sent to about 35 agencies and organizations, inviting them to submit budget or legislative issues on which they would be focused during the legislative session. The issue had to have some impact on the disability community, be in concert with the GCDD mission, vision and values, effectively employ the expertise of GCDD, and it had to be an issue on which GCDD could constructively use its limited resources. We received input from more than a dozen organizations and sought information from a few state agencies we knew were working on items that would affect individuals with disabilities. These items were presented to GCDD members, and through a ballot process, were separated into five tiers of action: initiate; active support; support by name; remain neutral; and, oppose.

In addition, GCDD includes activities from its work plan that are budget or legislative dependent. These activities are assigned top tier priority status.

The following discussion presents the items on GCDD's legislative agenda to date and the recommended level of support. Keep in mind the activities of the legislature are a moving target, and our attention to particular issues is always subject to change. For that reason, an ad hoc Public Policy Committee was established of GCDD members, who will meet by phone each week to review the events of that week, make adjustments to the agenda and advise me of those adjustments. GCDD will be supported at the Capitol by several individuals who are working on particular budget items or legislation.

We begin each season prior to the session with the Governor's budget instructions to the agencies, and his revenue projection, as that allows agencies and the public to know the level of discretionary dollars available. This year, the Governor's instructions to the agencies was to create a budget with flat funding, a 2 percent cut, and to submit a white paper requesting and supporting any necessary enhancements. As of this writing, the revenue estimate had not yet been set.

### Tier I: GCDD Initiates

The following items are part of GCDD's five-year work plan. GCDD has prioritized a pretty substantial list of items.

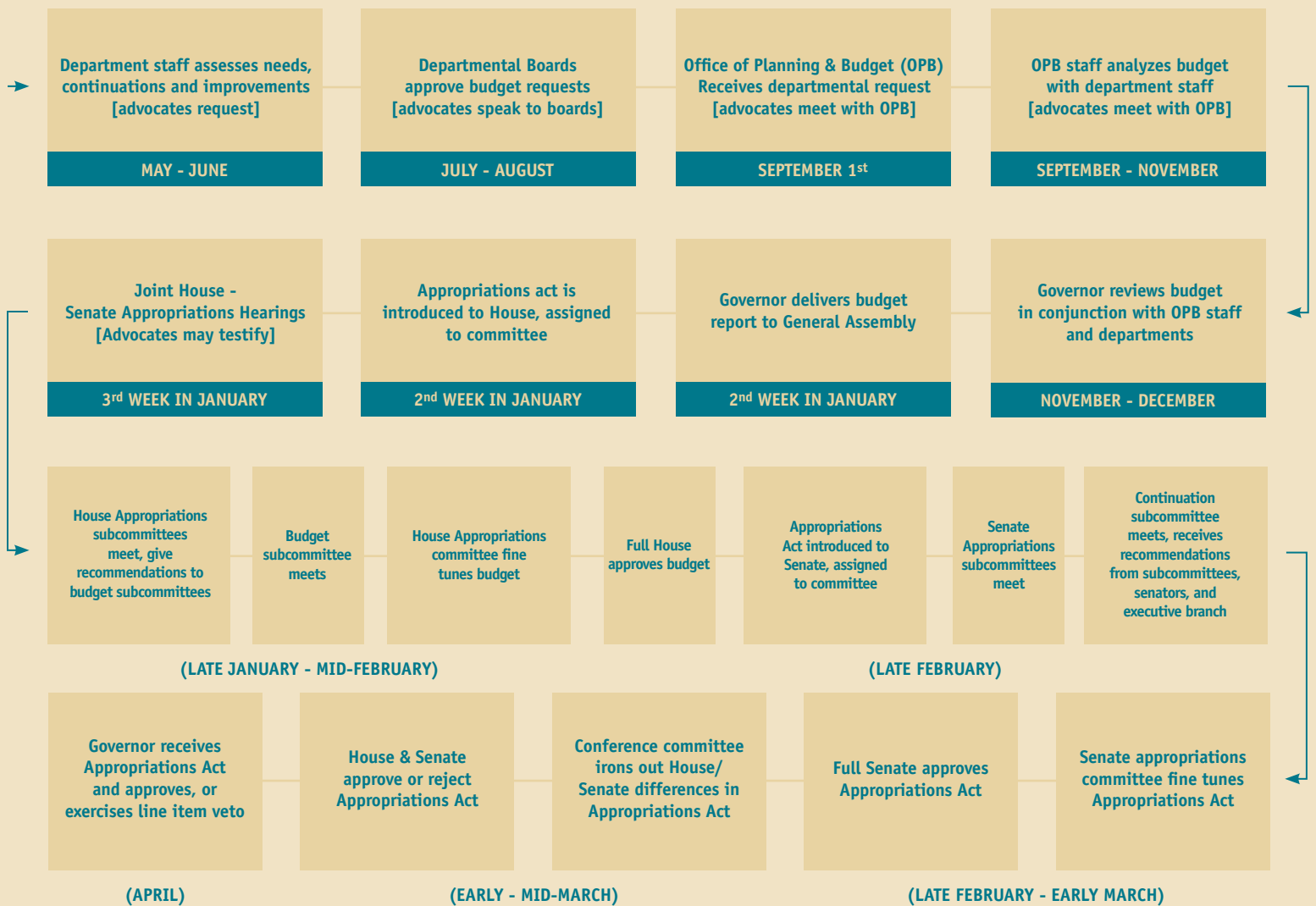
**Unlock the Waiting List! Package:** 2,500 waiver services; provider rate increase and Independent Care Waiver Program (ICWP) slots. The Unlock campaign is guided by House Resolution (HR) 1307, which sets out a five-year funding plan to reduce the list to a "reasonable pace." We are in the fourth year of that plan, and the legislature has done well in the past three years funding the recommended number of services: 925 of the recommended 1,000 the first year; 1,500 services funded for six months last session of the recommended 1,500; and 1,500 in the FY 2007 session of a recommended 2,000. This year, the recommendation is 2,500 services. We know this will be an uphill effort, but the Unlock Steering Committee decided to continue to use the multiyear funding plan as a guide, so that is the official request. This package includes resources for support staff and for institutional transitions.

**Provider Rate Increase:** GCDD and Unlock are supporting a 7 percent rate increase for all Medicaid waiver service providers in developmental disabilities. The providers were not given a rate increase last year, and the continued expansion to the Developmental Disabilities Waiver Program requires a stable, high quality workforce with the capacity to provide needed services.



**In September, letters were sent to about 35 agencies and organizations, inviting them to submit budget or legislative issues on which they would be focused during the legislative session.**

# Georgia's Budget Process



**Independent Care Waiver Program:** GCDD and Unlock are supporting a request for 500 new slots for people with physical disabilities and brain/spinal injuries in this home and community-based waiver. There are significant challenges with determining how many individuals would be eligible for, and need this waiver, but based on the number of individuals with traumatic brain injury and people with physical disabilities between the ages of 21 - 64 living in nursing homes, 500 slots is a reasonable start.

**Children's Freedom Initiative:** HR 633 urges Department of Human Resources (DHR), Department of Education (DOE), Department of Juvenile Justice (DJJ), Department of Community Health (DCH) and Department of Labor (DOL) to work together on a comprehensive plan over five years to move all children out of institutional facilities, and establishes an Oversight Committee to advise and assist the agencies

in the planning and implementation process. GCDD will continue to support this work.

**Transition:** GCDD directed staff to explore legislation that would require agencies to work with families toward transitioning their teens and young adults with disabilities to successful post-high school activities. This will require mostly research this year.

**Amendments to HB 1435:**

This bill was passed during the 2006 General Assembly, and made some major improvements to the voting process for people with disabilities, particularly those who requested assistance at the polls. Some corrections need to be made to the section of the code affected by this legislation, and we are still working toward a less restrictive definition of disability.

**Family Support:** GCDD proposed a \$6 million addition to state grant-in-aid funds for the purpose of providing small amounts of support to families to meet

*The Governor's Council on Developmental Disabilities' legislative agenda does not necessarily reflect the views of the Office of the Governor.*



immediate needs. State-funded resources are more flexible, do not need to meet Medicaid guidelines and can offset families' needs to request more expensive or extensive services. States that have a solid home and community-based service system usually have a robust pool of state-funded family support. These funds would be included in the DHR budget under the Division of Mental Health, Developmental Disabilities and Addictive Diseases.

**HB 540:** This piece of legislation enables a custodial parent to apply for child support for children with physical or mental disabilities beyond age of majority. HB 540 advanced to Rules last session, but was stalled. We will be seeking its successful passage this session.

## Tier II: Other organization is the lead, GCDD actively supports

GCDD voted to support organizations or agencies with these legislative or budget activities. The lead agency is in parentheses following the activity.

**\$500,000 for the production of Braille books:** for students at the post-secondary level (Georgia Chapter of the National Federation of the Blind). This item will be in the Board of Regents Budget. Students who are blind and literate in Braille are provided with Braille books in K-12, but not when they reach colleges in the University System of Georgia. Instead they must listen to them on tape, or postpone coursework until the book becomes available. The Alternative Media Access Center would like to be able to enhance its capacity to produce Braille for college students, and needs additional funds to build this capacity.

**Carve out dental services for children in PeachCare and Medicaid:** line item in DCH budget (Georgia Dental Association). Provision of dental services has been in turmoil under the Care Management Organizations (CMO) due to numerous and arbitrary contract changes. This item would separate money for dental care from general Medicaid and PeachCare funding, restoring administrative consistency, improving efficiency and oversight and ensuring children receive prompt, adequate dental care.

**HB 880: E-Text legislation:** (Learning Disabilities Association of Georgia) The proposed legislation would cover students with Print Access Disabilities, who are students on the secondary level at all public and private postsecondary institutions, including tech schools and proprietary schools, who must be accommodated under the Americans with Disabilities Act or Rehabilitation Act. The legislation defines electronic version of instructional materials and requires structural integrity, including graphs, charts and tables. HB 880 was dropped near the end of last session; this is the third year we will work on this.

**Updating Georgia Code:** to remove language disrespectful to people with developmental disabilities (Atlanta Alliance on Developmental Disabilities). Over the years, the Georgia State Code has accumulated references to people with disabilities such as "moron," "imbecile," "feeble-minded," etc, which are artifacts of earlier times. A coalition of advocates will seek legislation to remove these disrespectful references from the code.

**Real Homes Legislation:** increase accessibility in new homes (Concrete Change and Coalition for Accessible Housing). The coalition proposes legislation to include three accessibility features in all new homes constructed on slabs: one zero-step entrance, 2'10" doors which allow 32" clear opening and a half bath on the main with reinforced walls for grab bars. These features make homes more accommodating and marketable to people with disabilities, especially those with mobility impairments, but also to the aging population, and even families with young children.

## Tier III: GCDD allows use of name, but otherwise no action

For the following list of initiatives, GCDD will allow its name to be used as a supporter of the initiative, but will otherwise take no direct action.

**Naturally Occurring Retirement Communities:** Restore the \$40,000 cut from last year's request, and add \$125,000 (Jewish Federation of Greater Atlanta, Georgia Council on Aging GACOA).

Students who are blind and literate in Braille are provided with Braille books in K-12, but not when they reach colleges in the University System of Georgia.

## How a Law is Passed in Georgia

### Aging and Disability Resource Center

**(ADRC):** Add \$350,000 to create two additional ADRC sites in Georgia.

### Community Care Service Provider (CCSP) waiver program for Medicaid-eligible elderly:

\$6.7 million is requested to maintain current recipients and serve new clients (GACOA, Co-Age).

### CCSP program for 2000 non-Medicaid eligible elderly:

\$4 million requested (GACOA, Co-Age).

**Parent Protection Act:** Would allow unpaid leave for parents to attend their childrens' school events (Georgia Job/Family Collaborative).

**HB 845 and SB 13:** Raise Georgia minimum wage (Georgia Living Wage Coalition).

**Life Sharing:** Amend code to allow two persons with disabilities to reside in an owner-occupied home without having to be licensed (DHR).

Currently, GCDD has no items in the "neutral" or "oppose" tiers. We will also be watching several issues on the healthcare front: the continued implementation of the CMOs and the provider issues that have arisen; prior authorization for therapies for children in the Babies Can't Wait and Katie Beckett populations; and any action that may occur in PeachCare. We will also follow several tax reform proposals to be able to share that information with the disability community. And, as always, we never know what might come up!

Weekly updates on the legislative session are provided in *Moving Forward*; make sure you are on the mailing or e-mail list to receive it. The e-version of *Moving Forward* will be distributed through Capitol Impact, our new legislative tracking system. Log on to Capitol Impact through [www.GCDD.org](http://www.GCDD.org). There, you can check bill status, read analysis of legislation and be alerted to actions to take. Find out who your legislators are on [www.vote-smart.org](http://www.vote-smart.org) by entering your 9-digit zip code. Contact your legislator, and share your perspective as a family member or self-advocate. Lastly, mark your calendars for February 21, Disability Day at the Capitol, the biggest advocacy day during the session. Hope to see you there! ●

- 1 Legislator decides to introduce a bill for a new or changed law.
- 2 Office of Legislative Counsel attorney advises legislator on legal issues and drafts bill.
- 3 Legislator files bill with the Clerk of the House or Secretary of the Senate.
- 4 Bill is formally introduced on the next legislative day after filing. Bill's title is read during period of first readings.
- 5 After first reading, presiding officer assigns bill to standing committee.
- 6 In the House, the Clerk reads the bill's title on the next legislative day (second reading), though the bill is now in committee. In the Senate, second reading comes after bill is reported favorably from committee.
- 7 Bill considered by committee. Author and other legislators may testify. Public hearings may be held.
- 8 If bill is favorably reported by committee, it is returned to Clerk or Secretary.
- 9 Clerk/Secretary prepares General Calendar of bills favorably reported by committee. The House presiding officer calls up bills from calendar for floor action for the first 15 days of the session, while the Senate does the same in the first 10 days.
- 10 For the last 25 days of the session, presiding officer calls up bills from the Rules Calendar for floor consideration.
- 11 Once bill is called up from Rules Calendar, Clerk conducts third reading of the bill. It is now ready for floor debate, amendments and voting.
- 12 After debate, main question is called and members vote. If bill is approved by majority, it is sent to the other house.
- 13 If second house passes bill, it is returned to original house with any changes. If changes are accepted by first house, bill goes to next step. If first house rejects changes on which the second house insists, a conference committee may be appointed then submits a report. If report is accepted by both houses, the bill goes to the next step.
- 14 Bill is enrolled and sent to the Governor, if requested. Otherwise, all enrolled bills sent to Governor following adjournment sine die.
- 15 Governor may sign bill or do nothing, and bill becomes law. Governor may veto bill, which requires 2/3 of members of each house to override.
- 16 Laws enacted at the session are incorporated into the Official Code of Georgia Annotated. An act becomes effective the following July 1, unless a different effective date is provided in the act.

# GCDD Petitions State for \$6 Million for Family Support

By Carmel G. Hearn



**H**annah Cooper and her family live in a small north Georgia community. The 7-year-old is a cheerful first grader with a beautiful smile. She also has a very rare chromosome disorder called Tetrasomy X, which is associated with developmental delays, cognitive disabilities, asthma and bone problems.

"As of now we have no available in-home respite care. There is no way we could pay for this out of pocket," explained her mother, Angela Cooper. "Hannah has a low tolerance for big groups and loud noises and she tires very easily. We as a family could benefit from respite care in the home because we would feel more comfortable leaving her at home while we were out."

The Cooper's situation is common in Georgia. Because of governmental regulations that restrict access to funding based on financial need or the severity of a disability, some families receive little or no financial assistance. Others spend years on waiting lists. They're often living on one income, as one parent is typically a stay-at-home caregiver. Having just a little financial relief to help pay for diapers or respite care would make a tremendous difference to these families.

"Hannah requires expensive adult size diapers for naps every day, and she is incontinent at night time," Cooper said. "The expense of those diapers costs us about \$60 a month or \$720 a year. A program to help cover those [costs] would help us tremendously."

The Governor's Council on Developmental Disabilities is requesting \$6 million be added to the State Department of Human Resources Division of Mental Health, Developmental Disabilities and

Addictive Diseases (MHDDAD) budget for State Funded Family Support, which is double the amount requested last year. The additional funding will help provide limited support to families with a member who has developmental disabilities. The funding is more flexible than Medicaid and can be used to meet the needs of the family member so he or she can remain at home. Potential uses include respite care, after school programs, summer camp and other items. Many families only ask for a one-time allocation to help cover the cost of recommended therapeutic equipment or products.

Some families have applied for alternative means of support but are kept on waiting lists, often for years. Others simply don't know where to turn for support. There may be thousands of Georgia families simply unaware of programs that could help.

"Our families need respite care. Some of our families are in a bad situation. There is a high level of divorce," explained Ann Collett, founder of a Dawson County family support group. "We're in it for the long haul. I tell people with younger kids, get on a list. You need to have a break. You don't want to get to the point where you get depressed. It affects the whole family."



Collett's son, Sean Collett, has a severe form of autism. Currently the family receives about \$2,000 a year in waivers, which they use for adult diapers and occasional respite care. Collett started her support group ([dawsonsupportgroup@yahoo.com](mailto:dawsonsupportgroup@yahoo.com)) to share information and resources, and to encourage other families to think about preparing for the future, when their children become adults.

"I wonder if people realize when our kids get out of school it's hard," Collett added. "You want your child to have a quality of life. A lot of them, with assistance and job training, can work."

**“Some of our families  
★★ are in a ★★  
bad situation.  
There is a HIGH  
level of divorce...”**



## Champions for Children Provides Uncomplicated Funding

by Carmel G. Hearn

**M**ore than \$2.5 million of assistance will begin funneling to Georgia families with medically fragile children this spring.

The "Champions for Children" program initially will release \$500,000 per year to families whose children don't qualify for other programs or have medical needs that are not being met through other funding resources.

Unlike programs that have tight regulations based on diagnosis or family income, Champions for Children provides support dollars to families with children who have disabilities, regardless of income.

The program is coordinated by The Community Foundation for Greater Atlanta. The Foundation was charged by the Georgia Department of Human Resources to convene an Advisory Committee to work on implementation of the legislative intent for a \$7.6 million appropriation from the 2005 legislative session. The group met during the summer and fall to create a Request for Proposal, and review the applications. The Foundation will present the results of the RFP process to legislators when the 2008 session begins, and then the name of the grantee will be made public.

"The Champions for Children Advisory Committee decided they wanted this program to be available to any child 21 or younger diagnosed with a cognitive, physical or mental disability, explained Lita Pardi, program officer for The Community Foundation for Greater Atlanta. "We wanted to follow the original intent of the legislature, to provide funding for children no longer eligible for Katie Beckett."

The Katie Beckett, or Deeming, waiver provides access to Medicaid so children who qualify for an institutional level of care can be cared for at home.

One of the top priorities was to include the families who are affected, as well as service providers, in structuring the program. "It was absolutely essential that we had their involvement and buy-in, said Lauren Welsh, vice president of marketing & communications for The Community Foundation.

After filling out a simple application, families will work with a coordinator to determine needs, then the grantee will pay providers directly for services or tangible items.

The money comes from a \$7.6 million appropriation designated by the legislature in 2005 to help families who had become ineligible for Medicaid under the Katie Beckett waiver to help pay for therapy, respite care, diapers and other supplies. A little over \$5 million was made available in the form of debit cards at that time.

Champions for Children was formed to manage the remainder of the funding, as well as any unspent funds and plans to release \$2.5 million for direct financial assistance for families over the next five years.

Meanwhile, the remainder will be set aside as a trust, with earnings going toward family assistance beginning in 2013. ●

But funding for training and therapy programs has also begun to run dry.

"Hannah no longer gets private speech or occupational therapy, and those are the ones she needs the most," said Cooper. "It's a sad world for our kids in this state."

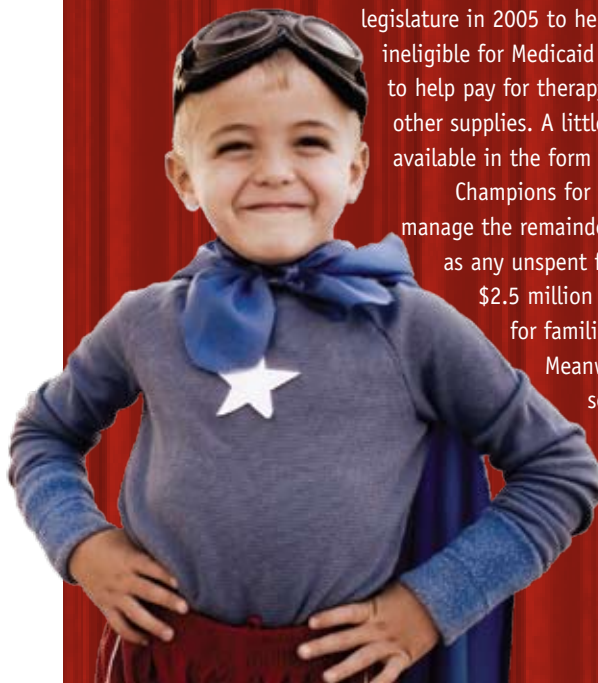
Additional family support dollars could provide a mechanism for young people with developmental disabilities to transition from school to work through job carving, job training and supported employment programs.

"There are over 17,000 people with developmental disabilities at home being taken care of by caregivers over the age of 62," revealed Dave Blanchard, director of public policy for the Atlanta Alliance on Developmental Disabilities. "We need to catch up on the past neglect of support."

In making its recommendation for increased funding in 2008, GCDD pointed to research on past family support in Georgia and five other states. The study revealed that families used dollars sparingly, with the average cost per family per year of only about \$2,500. The research further showed that very little fraud was perpetrated. Plus, families delayed their needs for more expensive services and were very satisfied with their decision-making abilities.

"If the money can pay for a fence to keep a child with autism from running away, then that's what you need," explained Patricia Nobbie, Ph.D., GCDD deputy director. "When we don't have that money, then those people go on a waiting list for waivers, which is more expensive."

The state legislative session extends for 40 days from mid-January usually through late-March. For the Cooper and Collett families, as well as thousands of others across the state, it will be 40 days of waiting and hoping that could make a lifetime of difference. ●



## Women with Disabilities:

# *Desirable and Desiring* SHATTERING STEREOTYPES



**"I'm a whole woman, and my disability is only one part of me."**

**B**eing viewed as asexual is a problem many women – and men – with disabilities face. "One of the major forms of discrimination is to assume women with disabilities are not objects of desire or subjects who have desire," explained Dr. Rosemarie Garland-Thomson, a professor of women's studies at Emory University.

Minna Hong, who uses a wheelchair as a result of an injury she had in 1999, is frustrated by the stereotype. "People think if you're paralyzed and can't feel it, why would you want to have sex?" she said. "Sex for me isn't about how much I feel, but the intimacy you share with one person."

Tameeka Hunter recently performed in Georgia Tech's production of *The Vagina Monologues* to show the audience that women with disabilities are sexual beings.

"I wanted people to see me walking out there on my crutches and talking about sex. I'm a whole woman, and my disability is only one part of me," Hunter, who has cerebral palsy, said.

While most women with and without disabilities may experience some concern about how a new partner will see her body in an aesthetic sense, a woman with a disability has the added concern about how her lover will view her body from a functional viewpoint.

"Men think, 'Am I going to hurt her?'" Hong said. "People have to have knowledge.

Having good communication skills is key."

And this discrimination is felt everywhere, even in the medical community.

Pam Fordham, who works with a project called Breast Cancer Screening for All, was diagnosed with breast cancer and opted for a double mastectomy with reconstruction. "I heard the doctor say, 'She can't see very well, why does she want the reconstruction?' What I look like matters to me. I care what I look like in my clothes, and I didn't want to come out of surgery without what I went in there with," she said.

Women with disabilities sometimes have to fight for things able-bodied women take for granted. "After my accident, I went to my beautician, and she chopped off all my hair, thinking it would help me because it would be easier to style. It made me feel worse because I felt ugly," Hong said.

She makes sure she displays her femininity. While she has given up skirts because her leg muscles have atrophied, she still likes to wear pearls, perfume and soft clothes.

And while Fordham is legally blind, she buys her makeup from a department store, picks out her own clothes and gets her hair cut once a month.

The way women with disabilities are portrayed in popular culture also has an impact on how they feel about themselves. "Healthy and vibrant is how women are portrayed in the media. Before I was injured, I was extremely fit. I had a difficult time for the first two years until I came to grips with my new body. I decided, why can't I be considered attractive or confident? The more you see diversity, the more people are open minded to differences," Hong said.

Garland-Thomson said media is starting to portray women with disabilities in more positive ways. "In the mid 1950s, charity campaigns began to use images of women and girls with disabilities to generate sympathy and make donors more willing to give money," she said.



# Women with Disabilities and Reproductive Health

Women with disabilities often have negative experiences when they go to the gynecologist and may avoid going more than their able-bodied counterparts.

"I went to the gynecologist not too long ago, and I think they were so involved in why I was paralyzed I don't think they were paying attention to what my needs were," said Minna Hong.

"They don't know People First language. I have to ask for someone to lift me to the table and hold my legs. Getting a mammogram is also difficult," she said.

Pam Fordham, of Breast Cancer Screening for All, said up until a few years ago, there weren't any resources available to women with disabilities about cancer screening.

"People with disabilities are 98% more likely to die of cancer than people without disabilities," she said.

**"People with disabilities are 98% more likely to die of cancer than people without disabilities."**

"Oftentimes that's because more medical problems are present than just the cancer. But also, it's a lack of resources, resource materials, transportation and access to medical care for those who are uninsured."

So Breast Cancer Screening for All got a grant to put breast cancer screening information and how to do breast self-exams in accessible formats. It also identified accessible mammography machines and where to go for low or no cost screenings.

Fordham, who has a visual disability and survived breast cancer herself, works with other women with disabilities to make sure they have the information they need to live healthier lives. "I tell them my story, then motivate them to take charge of their own medical care, set goals of what they need to have checked and how they'll do it. Then we pair up to hold each other accountable for doing it," she said.

Breast cancer survivor Rita Harrison added, "Don't allow anyone in the medical area to downplay the importance of your illness, and ask questions! Don't feel intimidated."

Harrison volunteers two days a week with Breast Friends, an organization that provides one-on-one support online or on the phone.

"Our founder, Lyn Wasserman, a two-time breast cancer survivor, wanted to

**Don't allow anyone in the medical area to downplay the importance of your illness, and ask questions!**

make sure women had someone to talk to after their diagnosis. She also recognized that a lot of times people were in a situation where they didn't have transportation," explained Harrison, who has a visual disability and is a member of Leadership Atlanta.

So in addition to offering peer support from survivors, Breast Friends offers women in the metro Atlanta area transportation to medical appointments.

Harrison also recognizes the need for accessible information about Breast Friends and has translated some materials into Braille and large print.

For more information, visit [www.gaada.info](http://www.gaada.info) or contact Nancy Duncan of the Disability Resource Group at 770-451-2340. To contact a breast cancer survivor or for transportation assistance, contact Breast Friends at [www.breastfriends.org](http://www.breastfriends.org), 404-843-0677 or toll free at 888-718-3523.

But images of women with disabilities are slowly becoming more positive. With the identification of people with disabilities as a viable consumer market, they are appearing in more advertisements. "Advertisements are presenting people with disabilities as having valued lives. It's quite radical presenting life with a disability as valuable and desirable. Ads are only intended to sell things, but they can be politically and socially progressive," Garland-Thomson said.

However, Garland-Thomson points out that many of the women with disabilities portrayed in

the media conform to other standards of beauty, such as model and landmine activist Heather Mills and model, athlete and actress Aimee Mullins, both beautiful blondes who have had one or both legs amputated.

"Older women with disabilities or women with bodily variations that are radically different from valued bodily standards don't fare as well in representations," she said. ●

# StraightTalk

## Voting *is* IMPORTANT!

By Cheri Mitchell



### **Voting is important for people with disabilities!**

In People First, one of the key beliefs we have is self-determination. Self-determination means having a voice and a choice.

Our government is a democracy. Democracy is a form of government in which the people have a voice and a choice in who runs our government. Voting is how we elect people in our country. No one person's vote is more important than your vote. It is equal with your vote. Voting makes you equal with everyone else.

People who are elected make important (often life and death) decisions about how our government will spend or use its resources and the restraints or limits it will place on people.

We must take up our responsibility and ensure that the people elected into government best reflect what we feel.

If we think people with disabilities should be independent, then we should vote for someone who thinks people with disabilities should be independent.

If you feel you should have a choice, then you should vote for someone who thinks people with disabilities should have a choice.

When you vote, you are expressing your opinion, how you feel and what you think the government should do, who will be in our

government and how our government will operate this country. With a system in place such as this, the more people who vote, the more people will be heard. No matter who is victorious in an election, your vote is still important because it shows support for your country. You cannot think that your vote won't make a difference in an election because history has proved this wrong. The narrowness of the presidential election in Florida a few years ago just begins to show how much a few votes can swing an election one way or the other.

When choosing not to vote, you give away your self-determination. You give away your voice and your choice. Justin Dart is recognized as the father of the Americans with Disabilities Act and the godfather of the disability rights movement. He said, "Vote as if your life depended on it, because it does!!!"

People First and the Georgia Advocacy Office started Project Vote in April 2007 to assure people with disabilities have their voices heard. We trained key leaders in the disability community from across the state so they can go back to their communities and organize voter education outreaches and voter registration using the motor voter forms.

Training focused on why voting is important, what the law, and what our rights are and tips on how to vote. The Governor's Council on Developmental Disabilities and disABILITY LINK also provided support.

**"It is becoming clear that people with disabilities can make a difference."**

The disability community has been called the sleeping giants of the voting populations. It is becoming clear that people with disabilities can make a difference. We have fought hard to be heard and to have a choice. Don't give that away! Make sure you vote!

If your group would like to host a voter education outreach or registration drive, contact me at 404.885.1234 or p1stofga@yahoo.com. ●

# VOTE



# Simple Changes Could Make New Homes More Accessible

By Eleanor Smith

**R**enee R. wanted to move her mother down from Ohio to Georgia to live with her after swiftly worsening arthritis caused her mother to need a walker. But an architectural assessment of her house showed it would cost tens of thousands of dollars to renovate for usability, so placement in a nursing home became the option. Ricky L. ran his dirt bike into a tree on a downhill run and three months later left a rehab facility in a wheelchair. In the interim his low-income, two-working-parents family had to leave their inaccessible rented house and scramble to find another rental, unfortunately with higher rent and farther from the parents' work. William M., at age 84, developed balance and weakness problems, and he fell trying to manage the screen door and entry step of the home he and his wife have lived in for 40 years, breaking his hip and shoulder. How common are these usually-uncollected stories?

The startling data is in: conservatively, 25 percent of new houses built today at some point will have a resident with severe, long-term mobility impairment. Using a second data set – the number of people who report difficulty lifting, carrying, reaching, walking or climbing stairs – the probability rises to 60 percent.

**“Currently, at least 98% of new single family houses have steps at every entrance and narrow bathroom doors.”**

Researchers at the University of Florida projected these rates by analyzing data on the average number of years a house serves as a dwelling, average number of people in a household, number of people reporting a mobility impairment in the 2000 U.S. Census, the projected rate of mobility impairment in an aging society and the number of households occupying a house over its lifetime.

Obviously it's not possible to predict in which house a resident will have a stroke or a child with cerebral palsy will be born. If we know that at least one in four houses, and plausibly more than half of all houses, at some point will have an occupant with a severe long-term impairment, the need for a widespread change in construction practices and housing policy is clear.

New multi-family apartments and condos, public or private, are covered by federal access requirements, but

single family houses are not. Currently, at least 98% of new single family houses have steps at every entrance and narrow bathroom doors. These barriers are so fundamental they often keep people from returning home from the hospital with mobility impairments. Yet our current practice is to build houses with barriers and then pay high prices to remove the barriers after impairment occurs.

Reliable cost estimates state less than an additional \$100 to incorporate a zero-step entrance and wide doors for a new house built on a concrete slab and less than \$600 for a house built over a basement or crawl space. Yet \$700 is a typical estimate to widen just one existing narrow door, and \$3,300 to create a zero-step entrance on an existing house. Nor does this begin to tell the whole economic story. Many people who could otherwise be at home instead enter a nursing home because when injury occurs they don't have time or resources to renovate their house. Total U.S. spending on nursing home care reached \$122 billion in 2005, 67% of which was paid with public dollars.

The waiting lists for publicly assisted home renovations are long. Many people who can't afford or arrange renovations are living in houses that endanger their health, unable to exit their home or enter their own bathroom. Then there's the vital matter of social connection. Our current home-building practices isolate people who acquire disabilities (and often, in practice, their other family members as well) into their own homes. The party they would like to attend, the book club they would like to join, the homes of their extended family, become off limits.

The Governor's Council on Developmental Disabilities is supporting a bill in the 2008 legislative session that would require one zero-step entrance and wide interior doors on all new houses in Georgia built on a concrete slab (with exemptions for topographically unfeasible lots.). If you want to help work on this bill, please email Barbara at [bar30032@yahoo.com](mailto:bar30032@yahoo.com). ●



**25%**  
of new houses  
built today  
at some point  
•• will have a ••  
**resident**  
with severe,  
long-term mobility  
impairment.

Eleanor Smith is the director of Concrete Change. Concrete Change is an organization that focuses on convincing homebuilders to make all new homes visitable through no-step entrances and wider interior doors.

Visit [www.concretechange.org](http://www.concretechange.org) for more information.



# More Restful Nights Help Mia Perform in New Job

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

I have learned so much about sleep in the last few months. Those of you who have been following our story know that Mia was diagnosed with severe sleep apnea. When we went for our first sleep clinic appointment, a month after receiving a Continuous Positive Airway Pressure (CPAP) machine, I found out just how severe. During her initial sleep study, the technician recorded six hours of sleep. During those six hours, Mia's brain woke her up 800 times because her breathing passages collapsed! According to Angela at the sleep clinic, this is "off the charts apnea." Mia was being woken up an average of 130 times an hour. Obviously, this is not sleeping, so no wonder she couldn't keep a job!

The body's reaction to lack of sleep is even more remarkable. First, the brain blocks the release of a chemical that suppresses appetite, so you don't ever feel satisfied after you eat. As a result, people with severe apnea always feel hungry, and tend to snack all day long. This is definitely the case with Mia. She harbors an entire snack store in her room at times, and if we don't intercede, will eat small, but unhealthy tidbits all

calories as fat. This is why the apnea and obesity are so closely intertwined, and also why people who finally get control of their apnea start to lose weight naturally.

So armed with this information, we began the CPAP therapy in earnest, and after the first month, for the hours that she wore the mask, she reduced her waking-up incidences to 12 to 17 times per hour. For someone with Mia's level of apnea, the therapists aim for waking between 7-10 times per hour. So we are on the way.

The next good piece of news is that she got a job! She is working as an office assistant at the Alternative Media Access Center at the University of Georgia that provides accessible materials to students with diagnosed print disabilities. The AMAC serves any campus in the state that purchases membership with the AMAC and the center then provides audio, large print or Braille texts for students who need them. The Governor's Council on Developmental Disabilities knows several people at the AMAC through some prior legislative activities, so Mia is among friends. Crystal Kitts from Briggs and Associates is supporting her on the job, and we have all decided that Mia is capable of more than she owns up to, so we hope the job responsibilities will increase over time and we can get back up to a part time schedule.

We have also applied for personal support so Mia has assistance to get to work, the gym and her other activities. With two of my adult drivers gone, I need back-up at home, especially with the legislative session looming. Knowing what I would be facing, I made this request in August, but as of December 13th, we still don't have approval from the Regional Board for the funds. Why does this process take so long? See the next column! Happy New Year Everyone! ●



**"...after the first month, for the hours that she wore the mask, she reduced her waking-up incidences to 12 to 17 times per hour."**

night long. Second, the body produces a hormone that enhances the storage of fat in the body, so not only do you feel hungry and overeat, your body has an added tendency to store those extra



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**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](http://www.gcdd.org)  
 404-657-2126 or  
 888-275-4233 (ASK-GCDD)

## State Government

**Department of Community Affairs**  
**Georgia Housing Search**  
[www.georgiahousingsearch.org](http://www.georgiahousingsearch.org)  
 877-428-8844

**Department of Community Health**  
[www.dch.state.ga.us/](http://www.dch.state.ga.us/)  
 404-656-4507

**Department of Human Resources**  
[www.dhr.georgia.gov](http://www.dhr.georgia.gov)  
 404-656-4937

**Department of Labor**  
[www.dol.state.ga.us](http://www.dol.state.ga.us)

**General Information**  
[www.georgia.gov](http://www.georgia.gov)

**Georgia General Assembly**  
[www.legis.state.ga.us/](http://www.legis.state.ga.us/)

**Georgia House of Representatives**  
[www.legis.state.ga.us/legis/2003\\_04/house/index.htm](http://www.legis.state.ga.us/legis/2003_04/house/index.htm)

**Georgia Senate**  
[www.legis.state.ga.us/legis/2003\\_04/senate/index.htm](http://www.legis.state.ga.us/legis/2003_04/senate/index.htm)

**Georgia Governor's Office**  
[www.gov.state.ga.us/](http://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](http://www.ltgov.georgia.gov/02/ltgov/home/0,2214,2199618,00.html)  
 404-656-5030

## Family Support Bill

**Capitol Impact**  
[www.capitolimpact.com](http://www.capitolimpact.com)

**Unlock the Waiting List!**  
[www.unlockthewaitinglists.com](http://www.unlockthewaitinglists.com)  
 1-877-WAITLIST

**Champions for Children**  
**The Community Foundation of Greater Atlanta**  
[www.atlcf.org](http://www.atlcf.org)  
 404-688-5525  
 champions@atlcf.org

## Women's Health

**Breast Friends**  
[www.breastfriends.org](http://www.breastfriends.org)  
 404-843-0677 • 888-718-3523

**Breast Cancer Screening for All**  
[www.gaada.info](http://www.gaada.info)  
 770-451-2340

## Advocacy

**Partners in Policymaking**  
**Atlanta Alliance on Developmental Disabilities**  
[www.aadd.org/newsite/programs/partners.html](http://www.aadd.org/newsite/programs/partners.html)  
 404-881-9777 x220

**Georgia Voices That Count**  
**disABILITY LINK**  
[www.disabilitylink.org](http://www.disabilitylink.org)  
 404-687-8890  
 404-687-9175 TTY  
 800-239-2507 (V/TTY)

**Organizing Institute**  
**Governor's Council on Developmental Disabilities**  
[www.gcdd.org](http://www.gcdd.org)  
 404-657-2125 • 888-ASK-GCDD

## Voting Education and Registration Outreach

**People First**  
[www.disabilitylink.org](http://www.disabilitylink.org)  
 404-885-1234  
 p1stofga@yahoo.com

**Vote Smart**  
[www.vote-smart.org](http://www.vote-smart.org)

**CHILDREN'S SPECIAL SERVICES, LLC**  
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**For information call 770.677.9379 or email**  
**DisabilitiesServices@jfcs-atlanta.org**  
**www.YourToolsForLiving.org**

Jewish Family & Career Services is a proud partner of the Jewish Federation of Greater Atlanta and of the United Way of Metropolitan Atlanta



## JANUARY

**January 17 – 18**  
**Governor's Council on**  
**Developmental Disabilities**  
**Quarterly Meeting**

Atlanta, GA  
 404-657-2126 • 888-ASK-GCDD  
[www.gcdd.org](http://www.gcdd.org)

**January 31 – February 1**  
**Assistive Technology**  
**Industry Association**  
**Leadership Forum on**  
**Accessibility**

Orlando, FL  
 312-321-5172 • 877-OUR-ATIA  
[www.atia.org](http://www.atia.org)

## FEBRUARY

**February 20 – 23**  
**International Conference**  
**on Aging, Disability and**  
**Independence**

St. Petersburg, FL  
 352-273-6099  
[www.icadi.phhp.ufl.edu/](http://www.icadi.phhp.ufl.edu/)

**February 21**  
**Disability Day**  
**at the Capitol**

Atlanta, GA  
 404-657-2126 • 888-ASK-GCDD  
[www.gcdd.org](http://www.gcdd.org)

## MARCH

**March 2 – 4**  
**2008 Disability**  
**Policy Seminar**  
**Advancing Disability**  
**Policy in an Election Year**

Washington, DC  
[www.thearc.org/NetCommunity/](http://www.thearc.org/NetCommunity/Page.aspx?&pid=1642&srcid=183)  
[Page.aspx?&pid=1642&srcid=183](http://www.thearc.org/NetCommunity/Page.aspx?&pid=1642&srcid=183)



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## Find Meaningful Employment for People with Disabilities

The Cobb-Douglas Community Services Board offers customized employment and system change training that allows you to:

- Learn from Georgia's most successful employment program
- Discover proven methods and how to overcome obstacles
- Choose from one or two-day sessions, on or off-site



The program is led by Doug Crandell and Nancy Brooks-Lane who have an extensive history of customizing employment for individuals with disabilities and have provided technical assistance for similar programs in 13 other states, as well as training in 25 states.



Call 770.434.7911 or email [dcrandell@cobbscb.com](mailto:dcrandell@cobbscb.com) or [nbrooks@cobbscb.com](mailto:nbrooks@cobbscb.com) to set up a session or for more information.





## Children with SPECIAL NEEDS

Offering integrated, comprehensive, family-centered services for:

- children with special needs and
- their families

A child with special needs (from birth to age 21) can be referred to a Public Health Program that serves these children by calling:

- the Children 1st Coordinator at your local health department at 800-822-2539
- Parent to Parent of Georgia at 800-229-2038 or in Atlanta at 770-451-5484



Division of Public Health  
Family Health Branch  
Office of Children with Special Needs  
[www.dhr.state.ga.us](http://www.dhr.state.ga.us)

### Babies Can't Wait Program

**Who?**

- Birth to age three
- With disability or developmental delay

**What?**

- Provides evaluation, assessment, and service coordination at no charge
- Offers early intervention services, based on an Individualized Family Service Plan, using sliding fee scale

### Children's Medical Services Program

**Who?**

- Birth to age 21
- With chronic medical condition and family income eligibility

**What?**

- Coordinates/provides specialty medical evaluations/treatment

### High Risk Infant Follow-Up Program

**Who?**

- Birth to age one
- With medical conditions requiring intensive follow-up services from Public Health

**What?**

- Provides direct follow-up services (i.e., in-home nursing assessment and parent training)

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or call 770.677.9379

[www.bregman.org](http://www.bregman.org)

# STRIVE TO THRIVE

The Selig Center  
1440 Spring St.  
Atlanta, GA 30309



# Disability Day 2008



.....  
FEBRUARY 21

2008

My Vote  
is for  
**REAL**



Join advocates from around the state  
to meet your legislators and rally for  
disability rights and issues!

Contact GCDD for registration information:  
[www.gcdd.org](http://www.gcdd.org) or (800) ASK-GCDD.



Governor's Council on Developmental Disabilities  
2 Peachtree Street, NW, Suite 26-246  
Atlanta, GA 30303-3142  
404-657-2126, [www.gcdd.org](http://www.gcdd.org)

Address Service Requested