

# Making a Difference

WINTER 2010

## Travel and Tourism the Focus for Discovery Day 2009

**Parent Protection Act:  
Employers, Employees  
Explore Benefits**

**Real Communities Initiative  
Gets Underway**

**Be Counted: Census 2010**

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

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A quarterly magazine of the Georgia Council on Developmental Disabilities

The Georgia 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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## Change Does Not Always Equal Improvement

In the 1960s, Bob Dylan sang "the times, they are a-changing." However, in 2009 it seems change is not all good. It began with implementation of the new support waivers that required an individual budget using the supports intensity scale completed by their birthdays. The leadership in the system was turned upside down with the creation of the Department of Behavioral Health and Developmental Disabilities. A new commissioner appointed a new assistant commissioner for developmental disabilities who was working to fix the many problems with the NOW and COMP Waivers. Following our theme of change, the assistant commissioner left that position and there is a vacancy in this much needed leadership role.

On top of these changes, Georgia's economy remains in crisis as each month reveals less revenue and more unemployment. This and other issues will be discussed as the General Assembly begins to meet. Many believe very little will occur during the session because of the economy and elections in November. Others think that shrinking revenues will require lots of action by legislators as they work to determine the state's budget. As the legislators meet, many anxiously await recommendations from Perdue's appointed Olmstead Commission. The Commission has met for some time but little has been publicly reported, and a full-time Olmstead Coordinator was only recently appointed. While Olmstead is about moving people out of public institutions and other facilities, the Department of Behavioral Health and Developmental Disabilities pushes ahead with its efforts to improve those same institutions, proposing to spend approximately \$100 million. In 2009, 19 states have either closed their state institutions or have fewer than 150 people still residing in them. Why are Georgia and one other state (South Carolina) proposing to pour millions of dollars into those institutions that other states are closing?

**In 2009, 19 states have either closed their state institutions or have fewer than 150 people still residing in them.**

the best outcomes possible for individuals with developmental disabilities and their families. We should disinvest from low-value and high-cost services such as institutions and look for new models that support open markets and the use of nontraditional providers.

This edition of *Making a Difference* magazine highlights the 2010 legislative session and the legislation that the Georgia Council on Developmental Disabilities hopes to pass, including the Parent Protection Act, which will assist parents who need to take time off to attend IEP meetings, and our continued effort to Unlock the Waiting List!. You can also read about the United States Census Bureau's effort to make sure that people with disabilities are counted during this decennial, and GCDD's ninth annual Discovery Day, which took place on December 16, is featured as well. Finally, we include a registration form for the upcoming Disability Day At The Capitol, scheduled for Thursday, February 25, 2010.

We hope you enjoy reading *Making a Difference* and we want to hear from you. Let us know what you like or don't like by writing to [vmsuber@dhr.state.ga.us](mailto:vmsuber@dhr.state.ga.us). ●



ERIC E. JACOBSON



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## A Message to Georgia's Disability Community

By Andy Phillips, Olmstead Coordinator

Olmstead has been an inspiration to the disability community for 10 years. The community movement that was underway for decades has stalled. Too many people continued to be admitted to hospitals and nursing homes, and remained there for long periods of time when better local treatment options and supports were what they needed. For all of these people, the *Olmstead* settlement represented needed change.

The *Olmstead* settlement is deeply rooted in ideals that are commonly held. People want to choose where and with whom they live. They want a place that is accessible and affordable and that they can call home. People with disabilities want to choose who assists them with their personal care. People want the opportunity to work and be contributing members of their communities. Essentially, Olmstead members require those accommodations to live a full life in their communities.

Georgia's *Olmstead* settlement is referred to as the Voluntary Compliance Agreement (VCA). It is a partnership between the state that administers the disability service system and the people with disabilities who benefit from those services. Both parties agree that people with disabilities need not receive services in an institutional setting when the person demonstrates that:

- They want to live in the community;
- The state's professionals agree that the person is able to reside in the community;
- The state can reasonably accommodate the person's disabilities in the community.

Once these criteria are met, it is Georgia's responsibility to provide the person with an integrated placement. The VCA requires the creation of a multiyear Olmstead Plan that sets forth concrete and realistic annual goals. The plan describes where the state is going over the next five years, how it is going to get there and how it will measure success. The Olmstead Planning Committee

was expected to approve the Olmstead Plan by the end of 2009 or early 2010.

There have been a number of important Olmstead developments that occurred this year. In May, Gov. Sonny Perdue signed into law the formation of the new Department of Behavioral Health and Developmental Disabilities (DBHDD) to better serve Georgians with disabilities. There continues to be support in the budget for Money Follows The Person, [a program] which provides

funding to move people with disabilities out of state hospitals and nursing homes. The challenge before us is to expand community services for all people with disabilities, even in the toughest budget year we have seen for decades. We are in the early stages of creating a system of care that reduces the need for treating people in institutional settings and eliminating it for some.

The gains that people with developmental disabilities have made this year must continue. People with serious mental illnesses and people with disabilities in nursing homes have moved only slightly past the starting line. Many community-based services need to be built, developed and maintained in order to provide for the appropriate support that people with mental illness and physical and developmental disabilities need to live successful lives in the community. In addition to clinical follow-up, the individual need for supportive housing, supported employment, case management and peer supports must be addressed. The chances for recovery or for a high-quality life in the community increase significantly when people have these supportive services available. Putting these services in place is a priority for Georgia and the Olmstead Planning Committee.

Many of you have been engaged in making the *Olmstead* decision a reality for the past ten years. As the Olmstead Coordinator, I am looking forward to continuing this effort with you. This is work worth doing. ●



**“People with disabilities want to choose who assists them with their personal care. People want the opportunity to work and be contributing members of their communities.”**

■ **The challenge before us is to expand community services for all people with disabilities, even in the toughest budget year we have seen for decades.**



## Georgia Mental Health Institutions Spark More Controversy

The state of Georgia has been ordered to improve the conditions of the state's remaining institutions by the U.S. Department of Justice, but a recent evaluation brought to light by the *Atlanta Journal-Constitution* shows that little progress has been made.

"The one thing all hospitals should be able to provide is a safe environment for the people in their care," said Elynn Jeager, director of public policy and advocacy of Mental Health America of Georgia. "This is not true now, and has not been true for too many years."

The previously mentioned AJC article stated that Dr. Frank Shelp, appointed as commissioner of the state Department of Behavioral Health and Developmental Disabilities (DBHDD) in July 2009, inherited a problematic system. The Department of Justice has reported that "Georgia has done little to stop the patient-on-patient assaults, suicides and other problems."

**"The Department of Justice has reported that "Georgia has done little to stop the patient-on-patient assaults, suicides and other problems."**

"Changes are taking place," Jeager countered. "[Shelp's department] is moving forward on making changes. A partnership with the Medical College of Georgia will provide clinical services at East Central Georgia Hospital in Augusta." Jeager continued on to say that hopefully these partnerships will serve as a good role model system to other hospitals across the state.

The biggest problem right now, it seems, is overcrowding. "Of course the hospitals are still too crowded," Jeager said. "The DBHDD is working with advocates and with the Department of Community Affairs to address the lack of housing."

**It will take political will and a lot of advocating to move people out of hospitals and into communities.**

In the end, Jeager seems cautious but hopeful that the tide is soon to turn for Georgia's hospital system – if politicians and advocates move forward in working together. "It will take political will and a lot of advocating to move people out of hospitals and into communities," she stated.



## Darius Weems Continues to Inspire, Engage

Darius Weems, the star and inspiration behind the popular documentary "Darius Goes West," is continuing the fight to find the cure for Duchenne Muscular Dystrophy. DMD is an aggressive form of muscular dystrophy, a degenerative disease that primarily affects voluntary muscles. Weems was diagnosed with DMD as a young child.

DoSomething.org, a Web site dedicated to inspiring teenagers and young adults to make a difference in their communities as volunteers and advocates, recently announced Darius as a runner-up for its annual awards program. In a ceremony in New York City (where Darius met celebrity Nick Cannon), he was presented with \$10,000 for DMD research.

In a separate presentation, popular television station MTV surprised Darius with two pieces of news – first, that MTV would be donating \$10,000 to DMD research as well, and that the film "Darius Goes West" would show on both MTV2 and MTVU. The world television premiere was held September 27, on Darius' 20th birthday.

As an extension of DoSomething.org winnings, Weems and an abbreviated version of his story have been featured on the back of Doritos® packages. "It's pretty cool to see that," Weems said. "I'm mostly happy that there's \$20,000 going to DMD research."

Additionally, proceeds from DVD sales of "Darius Goes West" go to DMD research. DVDs are \$10 each, and can be purchased online at [DariusGoesWest.org](http://DariusGoesWest.org). ●



**As part of his DoSomething.org winnings, Weems and an abbreviated version of his story have been featured on the back of Doritos® packages.**



## Zilles Joins “Unlock the Waiting Lists!” Campaign

Dave Zilles has been announced as the legislative assistant for Pat Nobbie, deputy director, for the 2010 legislative session. “Zilles will assist me in legislative initiatives,” explained Nobbie.

Zilles, along with wife Linda, are advocates for son Jonathan who has been diagnosed with Friedreich’s Ataxia, a form of muscular dystrophy. “When Jon graduated from Auburn University, he came home and lived with us, but I know this was not what he really wanted to do,” Zilles explained in a previous interview with *Making a Difference*. “In the process of looking for a residence for Jon, I realized how important independence is for young adults with disabilities.” Zilles then began the long journey of advocacy, leading him to his newest role with the Georgia Council on Developmental Disabilities.

“My goals will include focusing on budget issues, namely trying to get the funding for Medicaid waivers,” said Zilles. “I will also be working on the Nurse Practice Act, and on new legislation that will provide for new homes to be built that meet accessibility requirements.”



Dave Zilles (far right) was honored with an Advocacy Appreciation award at the 2009 Making A Difference Appreciation Ceremony. Here, Zilles stands with GCDD Executive Director Eric Jacobson (far left), Council Chair Tom Seegmueller and Pat Puckett, executive director of the State Independent Living Council of Georgia.



## Ruth Wright Recognized as Direct Support Professional of the Year

Ruth Wright, Housing Opportunity Program Coordinator at All About Developmental Disabilities (AADD), recipient of the 2009 Direct

Support Professional of the Year award, was recently recognized at the In Support of Each Other Conference, co-sponsored by GCDD and the DSP Alliance.

## Ninth Annual Discovery Day

The ninth annual Making a Difference Discovery Day took place on December 16, 2009. We’d like to thank the Council members who were in attendance: Tom Seegmueller (chair), Glen Friedman (advisory member), Tifiny Nash (advisory member), Dan Crimmins, Rene Feldman, Stacey Ramirez, Rhonda Page and David Glass (advisory member.)

Enjoy these images from the event, and for a full recap turn to page 18 of this issue.



From left, Richard Warner (moderator), Francesca Cesa Bianchi (G3ict director, external relations), Valerie Meadows Suber (GCDD public information director and Discovery Day project coordinator) and Tom Seegmueller (GCDD chairperson). ●



Luz Borrero (above), deputy chief operating officer in the Atlanta mayor’s office, pledges to continue to work on making travel information accessible to citizens of and visitors to the city of Atlanta.

Bill Curtis-Davidson (right) of IBM, one of the partners for Discovery Day, is also co-chair of the Georgia Alliance for Accessible Technologies.

Karen Bennett (right), of InterContinental Hotels Group converses with Richard Warner, moderator.



Nerissa Serrano-Okiye (above far left) moderated the Inclusive Travel & Tourism Synergies Panel which was made up of Robert Kennedy, Subie Green, Eric Lipp and Mark Johnson.



GCDD Executive Director Eric Jacobson (left) acted as a member of the Community Perspective panel.

# Make 2010 Count: Be Counted in the 2010 United States Census

**I**t's an event that's almost as American as baseball and apple pie – every 10 years the American population is counted to determine the allocation of Congressional seats, electoral votes and what government programs take precedent. This decennial event takes place in 2010 – and advocates are asking the disability community to be sure that their voices are heard.

“States that have grown in population since 2000, such as Georgia, could gain a seat in the electoral college after this 2010 census,” explained Edward Davis, partnership and data services coordinator at the U.S. Census Bureau. “Plus, over \$400 billion in federal tax money is distributed every year to states and communities based in part on census population data.” Davis continued to say that if people don't participate in the census, then their community can miss out on receiving the full share of federal dollars, meaning less funding that can be used for transportation, emergency response services and housing development among many other projects – projects that particularly effect the lives of people living with disabilities.

“There is certainly that desire to make sure that the disability community is included in the final number,” said Eric Jacobson, executive director of the Georgia Council on Developmental Disabilities. “I know that this year in particular the census department is working to ensure that everyone is counted.”

“In September, the Atlanta region held a Census Summit involving representatives directly from and those working with agencies serving Americans with disabilities,” Davis said. “Through this partnership program, we continue efforts in our outreach.” Individual regions throughout the country have

developed Complete Count Committees to reach out to and educate the citizens in their particular area.

As Davis points out, it's not just important to your community to fill out the census form – it's the law.

“Taking the census is required by the United States constitution in Article One, Section Two. Every person residing in the country must be included in the census count,” he said.

So how can a person participate? According to the U.S. Census Bureau Web site, you can download the official form at [www.census.gov](http://www.census.gov). The form will also be mailed to all American residences. (Community locations such as your local courthouse and library may also provide copies.) The form must be completed and mailed by March – if you have not returned the questionnaire by then, you will most likely be visited by a census taker who will ask you the same questions that are on the form.

“A lot of people think it is a long form and will take a long time to fill out,” said Davis. “The 2010 form has only 10 questions, and will take about 10 minutes to answer.”

“To make things more accessible, then the obvious way would be to figure out how people could respond electronically,” Jacobson added. (According to the census bureau's Web site, this option is currently under consideration but is not available.) “But it's a very simple form and if you do have difficulties, a person from the census bureau will come out and help you fill it out.”

Jacobson concluded by saying that while GCDD is not currently involved with the Complete Count Committee, he encourages the disability community to take an active involvement. ●

**There is certainly that desire to make sure that the disability community is included in the final number.**



*The census bureau home page provides information and a way to download the official 2010 census form.*

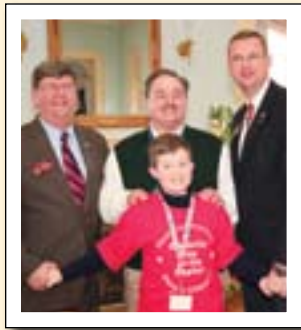
# 12th Annual Disability Day at the Capitol

Thursday, February 25, 2010



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 12th 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!**



**LEGISLATORS:** Please join more than 1,800 disability advocates from across the state on the Capitol steps February 25.

- 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 Georgia Council on Developmental Disabilities, the day will also feature opportunities for you to visit with your constituents over breakfast or lunch.

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.

# Count Me In. Count My Voice



Count Me In. Count My Vote. Count My Community.



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

**ATTENDEE RSVP FORM**

Disability Day at the Capitol • February 25, 2010  
Please register to attend the breakfast OR luncheon.

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:**  
Georgia Council on Developmental Disabilities  
Disability Day registration  
2 Peachtree St. NW, Ste. 26-246  
Atlanta, GA 30303

Please note special accommodations we should be aware of: \_\_\_\_\_

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404-657-2126,  
Toll Free 888-ASK-GCDD,  
FAX 404-657-2132

RSVP

ote. Count My Community.

# A Perfect Storm:

## Georgia's 2010 Legislative Session

**T**his time last year, I wrote: “By some reports, the 2009 Legislative Session will be dealing with the worst state budget crisis in 35 years.” I went on to say that we would see 10 percent cuts to all agency budgets, or \$2.5 billion dollars less than the prior year, and that the monthly revenue collections during summer 2008 were running six to seven percent behind those months a year ago.

Unbelievably, the state's economic situation has declined further and will get worse before the session starts. Since January, monthly revenue collections have averaged 15.1 percent, bringing in \$225 to \$260 million dollars a month LESS in comparison to the same time period a year ago. Revenue declines are TWICE what we experienced last year. October's figures indicated a 17.8 percent decline over October of last year. And it's not over yet. The week before Thanksgiving, the Chairman of House Appropriations Rep. Ben Harbin (R-Evans) announced that another \$350 million would have to come out of the budget once the legislative session started, and no agency would be spared.

Against this backdrop of scarce resources, human needs have grown as we would expect in a rapidly growing state. Outside forces are putting pressure on the need for resources to be provided NOW, not when the economy recovers – an Office of Civil Rights Voluntary Compliance Agreement for implementation of an Olmstead Plan to move people from state hospitals and nursing homes to the community, and a Department of Justice settlement agreement to address the egregious conditions in the state hospitals and build a community-based mental health system. Add in the waiting lists for aging, developmental disabilities and physical disabilities

waivers, along with transportation, trauma care, education and water, and you've got some serious obligations to weigh against a diminished pot of dollars.

### Remember the Restructuring of DHR

The needs for people with developmental disabilities and mental health concerns will be addressed within the newly created Department of Behavioral Health and Developmental Disabilities of which Dr. Frank Shelp is the new commissioner. As of this writing, the Department is lacking heads of the developmental disabilities and mental health sections. There is a newly appointed board of directors, but not all of the spots have been filled. The ICWP waiver program is still administered out of the Department of Community Health, but since public health has been moved under DCH, the Babies Can't Wait program is in the DCH budget.

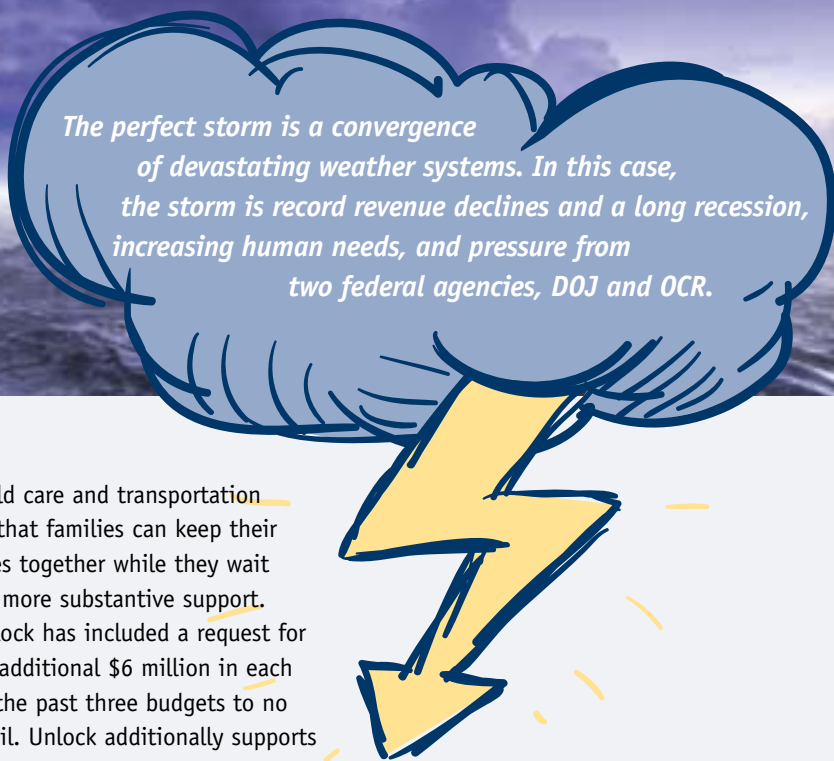
### Setting the Agenda

Each year prior to the start of the legislative session, the Georgia Council on Developmental Disabilities invites the community of interest to submit their legislative agendas to the Council for their consideration for support. During the October quarterly meeting, Council members review the issues of interest from the wider community. Decisions to support are based on four criteria:

- Issues must directly or indirectly affect our constituents or the Council itself;
- Supporting or opposing the issue is in concert with our mission, vision and values;
- The issue draws upon our knowledge and expertise as an organization;
- We have the capability to develop a realistic plan for how to implement the policy stand, communicate the plan to the appropriate people and make use of the stand in our work.



Revenue declines  
**ARE TWICE**  
what we experienced  
last year.



*The perfect storm is a convergence of devastating weather systems. In this case, the storm is record revenue declines and a long recession, increasing human needs, and pressure from two federal agencies, DOJ and OCR.*

After discussion, the Council votes on each issue, assigning it to one of five tiers:

**Tier I:** Council initiates, is the lead agency

**Tier II:** Other agency is the lead, but Council assists

**Tier III:** Council allows use of name, but otherwise, no action

**Tier IV:** Council has neutral position, won't fight or support

**Tier V:** Council opposes, fights against

### **Tier I Initiatives:**

The requests for the Unlock the Waiting Lists! budget are always the priority in the Tier I activities. As of this writing, DBHDD and DCH have proposed waiver budget packages to the Governor's office, but we have no guarantee that the proposals will get through the budget vetting process with the Office of Planning and Budget. DBHDD proposes 1,500 NOW/COMP waiver services – six months worth of funding including 150 COMP waivers for individuals moving out of the state hospitals (known as the Money Follows the Person initiative). The package includes the necessary infrastructure of staff, support coordination, transportation and transition expenses that have been in previous budgets. The DCH budget includes 100 ICWP waivers for individuals moving out of nursing homes (MFP) and 176 ICWP waivers for individuals in the community needing support, which is most of the known waiting list. We hope by the time this issue of *Making a Difference* is released, we will know that funding for these services has been included in the Governor's budget recommendations.

The Unlock the Waiting Lists! initiative also supports an increase of state dollars for family support. These dollars provide modest discretionary funds for families to meet their immediate needs (the average per family is \$2600). An increase in family support would provide services like respite,

child care and transportation so that families can keep their lives together while they wait for more substantive support. Unlock has included a request for an additional \$6 million in each of the past three budgets to no avail. Unlock additionally supports a developmental disabilities division and provider request to conduct a rate study of the waiver reimbursement rates, with no cuts to rates or services while that is being completed. This will supply the system with a comprehensive analysis of whether funding is adequate to attract high quality providers and keep them in the network.

Finally, the multiyear funding plan needs to be updated. HR 1307 provided a useful blueprint for the departments of DHR (now DBHDD) and DCH to project funding necessary to move the waiting lists at a reasonable pace. Although actual appropriations fell short of the plan overall, the DBHDD did use the projections as a guide for funding requests. We need to update the plan for the next five years, effective with the 2011 legislative session. In the spirit of *Olmstead*, we want to include funding projections for community-based mental health systems and provider rate increases.

### **Tier II:**

In the second tier, the Council provides support to another organization for specific legislation. The items in Tier II are carryovers from the first year of the session. The first is SB 247, the New Home Access Act, sponsored by Sen. Nan Orrock (D-36). The bill would increase accessibility in all new single family homes by requiring one zero-step entrance to the house, wide interior doors for easy mobility inside and blocking in the bathrooms so grab bars can be installed if needed. People with mobility challenges have a difficult time finding housing that accommodates their limitations. Older people have a





fall or a stroke, go into a nursing home for recovery and then cannot return home because they cannot safely get in and out of the house. We are also experiencing the return of veterans from the Iraq and Afghanistan wars who have experienced bombings and amputations, and they too will have a hard time returning to some of their former residences. Most of the resources that pay for home modifications are exhausted just months into each fiscal year. It's time to start building accessible housing stock. We work alongside Concrete Change and the Housing Coalition on this legislation.

The second item is state Individual Development Account legislation. Eligible low-income individuals deposit money in the account, and the deposit is matched by an outside source. It has a fixed-match rate (usually four to one), a fixed time frame and specific purchase requirements. Federal IDA legislation enables individuals to save for homes, businesses or higher education. The legislation that we are working on with the Center for Financial Independence and Innovation (CFII) would authorize savings accounts for the purchase of assistive technology such as home and vehicle modifications, communication devices, hearing aids and more, which are very expensive and not completely covered under other government programs. CFII and GCDD are seeking private foundation funding to provide the match – we just need state legislation to establish the new spending categories and adjust the poverty level eligibility requirements.

**Exception Amendment to Nurse Practice Act:** Concerted effort by a multi-stakeholder group of human service providers and leadership from the Governor's office has finally resulted in legislative language approved by the Georgia Board of Nursing, and the State's Attorney General. The exception would enable a trained, unlicensed caregiver of a person with disabilities to provide health maintenance activities for that person under written doctor's orders and supervised by a nurse. Caregivers will receive health maintenance activities training specific to the individual they support. Many of these activities can be safely provided by an unlicensed person at reduced cost to the state. This piece of legislation is on the Governor's legislative agenda.

**Parent Protection Act, HB 37:** GCDD will work actively with Atlanta's division of 9 to 5, a grassroots membership organization that focuses on supporting

family-friendly policies in the workplace, on this legislation, which would provide 48 hours of unpaid leave from work for family concerns. Parents are required by law to immunize their children, register them for school and attend IEP and disciplinary meetings. Many working mothers are caught between caring for children and their parents. Parents cannot be put at risk of being fired for taking care of family responsibilities, some of which are required by law.

**Promote Changes to the Medicaid Buy-In to increase pool of eligible workers:** Georgia has a Medicaid Buy-in program that enables workers with a disability who need personal assistance to buy-in to Medicaid so they can keep their assistance even when earning above the asset and income threshold. The program criteria are so restrictive that few have been able to take advantage of it. The Statewide Independent Living Council (SILC) will work with the DCH on the eligibility requirements so that more individuals can earn livable incomes, advance professionally and not lose the benefits they need in order to live and work independently.

*"We rely on our fellow advocates, and the voices of people with disabilities, their families, friends and communities to communicate with their legislators."*

**Tier III:**

The following is the list of legislative items that the GCDD will sign on to, or allow our name to be used in supporting literature:

- Blind Persons Braille Literacy Rights and Education Act to ensure teachers of the blind are literate in Braille. Some revisions need to be made. (Coalition for the Blind).
- Efforts to restore funds to undo the 20 percent cut to durable medical equipment prosthetics and orthotics provider rates in the DCH budget.
- Appropriations for the CCSP and non-Medicaid home and community-based services (Co-Age).
- Legislation for the Coordinating Council for Human Services Transportation (Co-Age).
- SB 207, the Tax Expenditure Report, to catalogue the tax breaks and incentives awarded to



**"The great disability rights leader and thinker, Jacobus tenBroek, said that the most FUNDAMENTAL right for people with disabilities was 'the right to live in the world.'"**



businesses by legislators each year and assess their cost-benefit to the state budget.

- Revisions to the Elections Code: Remove 'physical' from the definition of disability describing who can seek assistance at the polls (The Arc of Georgia).
- Respectful Language Legislation: Removal of words like *moron*, *imbecile*, *retarded*, and *idiot* from the Official Code of Georgia (The Arc of Georgia).
- SB 292, revisions to the Juvenile Code (JUST Georgia). GCDD is concerned with the chapters addressing the definition of disability, assessment and determination of competency.
- HB 290: Raise the state minimum wage (Atlanta 9 to 5). Several categories of workers in Georgia are exempt from federal minimum wage guidelines. People with disabilities disproportionately are paid minimum wage.
- Legislation to modify the Estate Recovery requirements: This legislation would modify the estate recovery statute to provide a specific hardship exemption from estate recovery for unrelated caregivers who have cared for the Medicaid recipient in the home for at least two years prior to the Medicaid member's admission to a long-term care facility. (Co-Age).
- Legislation carried by DBHDD to allow the placement of youth found to be incompetent to stand trial in a community-based youth facility for evaluation and treatment instead of a state hospital bed.

#### Tier IV:

There are currently no issues that the Council is neutral on, but there are a few issues that may not need state action if efforts on the national level succeed. The removal of the two-year wait period for Medicare eligibility and legislation to mandate insurance coverage of autism spectrum disorders are among these issues.

#### Tier V:

Other than opposing any more cuts to human service providing state agencies, the Council has no items in this tier at this time.

### Why Do We Advocate?

Deputy Assistant Attorney General Samuel Bagenstos, Department of Justice, Washington, DC, made the following remarks at The Arc 2009 Annual Convention in Pennsylvania:

"The great disability rights leader and thinker, Jacobus tenBroek, said that the most fundamental right for people with disabilities was 'the right to live in the world.'" The right to live in the world means that people with disabilities – all disabilities – have the right to be full members of our Nation's civic and economic life. It means the right to live, work, shop, and move about in the community."

This is why we advocate – to support an individual's "right to live in the world" – with an accessible house, appropriate educational materials, funding for community support, opportunity for economic advancement and stable care. This is a pretty ambitious agenda. We rely on our fellow advocates and the voices of people with disabilities, their families, friends and communities to communicate with their legislators. We encourage you to share the stories of your challenges and contributions, and let your needs be known. Sign up for Capitol Impact to get updates on the legislative activities, make sure you are on the list to get Moving Forward and put Disability Day at the Capitol on your calendars – February 25, 2010.

See you there! ●

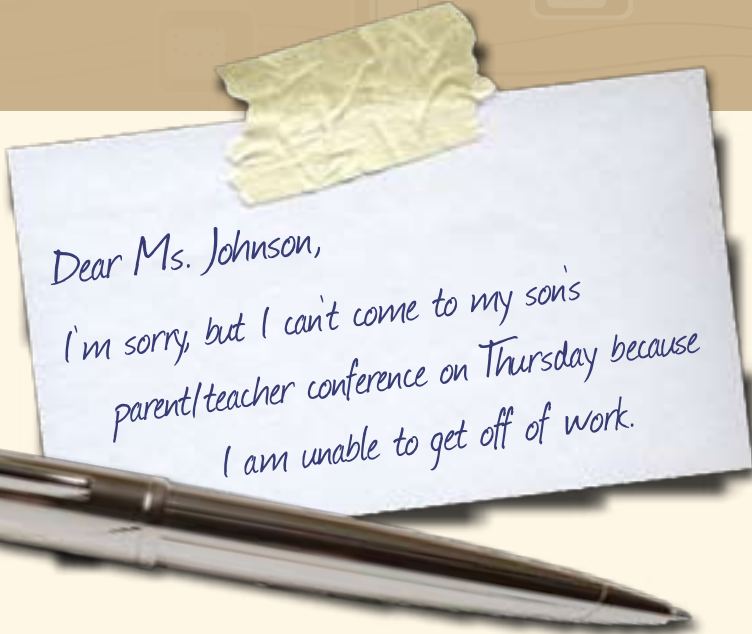


### By the Numbers

Individuals on the DD waiting list .....	6,409
Individuals on the ICWP waiting list .....	189
Approximate number of individuals with DD living with a caregiver over the age of 64 .....	17,000
Amount of federal stimulus money received for FY 2009 .....	\$672 million
Amount of stimulus money to be used in FY 2010 .....	\$1.4 billion
Shortfall in State budget as of July 1, 2009, beginning of 2010 Fiscal year .....	\$3,364,858,578
Reduction projected for 2011 .....	\$3,989,238,026

# Parent Protection Act

## What It Is and How It Can Affect You



Dear Ms. Johnson,  
I'm sorry, but I can't come to my son's  
parent/teacher conference on Thursday because  
I am unable to get off of work.

It could be a note like that, or a phone call, or simply a 'no-show.' In a scene repeated daily at schools across Georgia, parents have a tough decision to make: Do I risk my job status by asking my employer for time off, or do I just not go? How do you choose between being a caregiver for your family and a loyal, hardworking employee?

**"Parents with children with disabilities really do need to be at those parent/teacher conferences to make sure their children are in the appropriate classes, with the appropriate teachers and technology."**



The answer may very well lie in HB 901, which is under consideration in the Georgia House of Representatives and is better known as the Parent Protection Act (PPA). In a nutshell, the PPA is designed to provide up to 24 hours of unpaid, job-protected leave per year to attend school conferences, the employee's own medical appointments or to take a child, parent or spouse to their medical appointments.

The bill was introduced by Rep. Roger Bruce (GA-64). "The intent of this bill is to give people a sufficient amount of time to take care of the realities of life," Bruce explained. "Going to your

child's school is not something you should have to lie to your employer about to take care of that business, or to take a dependent parent to the doctor."

Cindia Cameron, Organizing Director of 9 to 5, the National Association of Working Women, concurs, pointing out that most families in Georgia have parents in the work force. Nationally, less than one in five children are in a family where there is one working parent and one stay-at-home parent.

The idea for PPA actually came from a fifth grader at A. Phillip Randolph Elementary School in Fulton County. Bruce had been asked to come speak about how a bill becomes law. The principal called him a few days later and said one of her students had a bill for him to introduce. The student explained that he wanted his parents to be able to come to classroom activities, go on field trips and be at parent/teacher conferences, but they couldn't because they were afraid of losing their jobs.

The original name of the legislation was "Time Out for Schools." But as other groups saw the benefit of its provisions for not only children but other family members as well, it grew into the current Parent Protection Act.

One of those groups was the Coalition of Advocates for Georgia's Elderly (Co-Age). "The major issue for us is that over 75 percent of the care for elders in this country is delivered by family members, yet there are a number of caregivers who don't have adequate protection on their job to be able to get paid or [get] unpaid leave to be able to take whoever they're taking care of to doctors' appointments and so forth," Kathryn Fowler, Executive Director of Co-Age, said.

Writing in support of the PPA, Co-Age said that "flexible family leave policies strengthen families, businesses, schools and the economy by increasing the ability of employers to recruit and retain the best people, improve productivity and moral, and decrease turnover and absenteeism."



## Extra beneficial for parents who have children with disabilities

"Often, children with disabilities have more doctors' appointments, they need more medical attention. Sometimes you can get a doctor's appointment during the evening or your day off, but often those are during the workday," said Cameron. In fact, it's not just good parenting, but it's the law.

"Under Georgia law, there are at least 12 different mandates that require parents to be at school to register their child and to bring proof of immunization. Parents of children with disabilities have to be at the IEP meetings, as well. Parents are required to be at school by law and they can have legal repercussions if they aren't, but there's no legal protection for them to take off work."

**"We're asking for people who don't have leave to be able to take some unpaid leave, and know they're not going to lose their job."**

Kimberly Brown-Mack from the Fulton County school system sees that disparity, and explains how the PPA could alleviate the pressure. "The Parent Protection Act would give parents a little more security. It would allow them to take time off for their children.

"Parents who have children with developmental disabilities already have a lot of issues and they learn how to cope with these disabilities. It often means they have to take a little more time off of work, but right now they can't."

## The effect on business

Bruce feels the PPA would be beneficial to businesses. "The bill provides for 24 hours per year, and you have to make those arrangements in advance. So to me, that's good for business."



There is some opposition to the PPA, but it's mainly a question of legalities. "Georgia has a Doctrine of Employment At Will," Bruce said. "An employer can fire someone for any reason or no reason. The opposition feels it would be an infringement on that right."

Some also think the Family Medical Leave Act covers this situation, but that's not necessarily the case. "The Family Medical Leave Act does not apply because it only covers businesses of 50 or more and only for medical situations," Bruce pointed out.

According to Co-Age: "The Parent Protection Act will provide a much-needed complement to the FMLA. Allowing individuals to take up to 24 hours of unpaid leave per year to take themselves, children or a parent to routine preventive medical appointments will keep the family unit healthy, seniors better able to stay in their homes and the business community strengthened."

"We're asking for something minimal," Fowler added. "We're asking for people who don't have leave to be able to take some unpaid leave, and know they're not going to lose their job."

As of this writing, the PPA is in the Industrial Relations Committee for review. When the legislature convenes again, Bruce is hopeful the bill will be voted on in committee and sent to the House for discussion. "I don't think there's anybody that's walking around that doesn't have some issue that they are dealing with personally. And people need to search within themselves and say if they were in a similar situation – would they not want help? If they can say 'no' to that, then I can understand the opposition. But I don't think there's anyone out here that doesn't have something they're dealing with internally." ●

**Working families need some flexibility just to make sure they can balance their responsibilities to bring home a paycheck and take care of the family members. People shouldn't be put in a squeeze between being responsible at work and being responsible for their family.**

## Flexibility in Hours Leads to Improvement in Overall Work Performance

By Carol Richard, AIA, LEEDAP • Partner, Richard Wittschiebe Hand



*Carol Richard has directed a wide range of project types and sizes as principal, project manager and designer within the architectural industry since 1980. As founder of the firm, she brings a diversity of experience to the practice and has been instrumental in providing direction for the firm.*

**R**ichard Wittschiebe Hand is a women-owned architectural practice that was founded in 1991. The firm has grown to over 20 people representing a diversity of race, age, gender and sexual orientation. Seventy percent of our staff is female, representing an unusually high proportion in the architectural profession. Our extended “family” includes numerous children under the age of 10.

We’ve had a number of female staff members work with us through their pregnancies and, after maternity leave, have returned to us under flexible work hours. Currently, we have a female project manager who is a single mom. She works reduced hours and a flexible schedule so that she can care for her son when he gets home from school. When he is sick, she works from home. She is invaluable to us. Another female project manager has three young children, two of whom are in elementary school. She needs to have the time to go to school

**We have found that providing our staff with flexibility in schedule and hours has allowed us to maintain our staff with minimum turnover.**

conferences for her kids. She adapts her schedule to be able to attend those conferences, and we are happy to accommodate her. Two of the men in our office have working wives with infants at home and

they each took leave after their babies were born. They came back feeling good about having had a chance to spend time at home with their newborns.

We have found that providing our staff with flexibility in schedule and hours has allowed us to maintain our staff with minimum turnover. We value the constancy of staff – it is crucial

in our industry to have individuals with project knowledge and experience stay with the project from beginning to end.

To us, it makes good business sense to make sure our staff is taking care of their own needs as well as their family needs. When basic needs are taken care of, they can concentrate on their work. We have a young female architect who was recently hit by a car while riding her motorcycle. She has undergone months of physical therapy. It would have been a hardship for her to get the therapy she needed without flexibility in her schedule and in the long run it may have taken longer to heal. Those unpredicted absences would have been detrimental to our company.

We believe that the Parent Protection Act provides basic rights for working families and that it makes good business sense, too. We support the passage of the Parent Protection Act. ●

**When basic needs are taken care of, they can concentrate on their work.**



# The Parent Protection Act positively impacts both employer and employee.

## Mother and Daughter Believe Parent Protection Act will Ensure Needs Are Met for All

By Linda Allen and Jennetta Allen

**M**y daughter Jennetta is a college student. What an incredibly exhilarating statement to make. As a parent of a child with disabilities each and every milestone is celebrated and achieving the seemingly impossible is pure joy. It took determination, hard work and a strong support system that included flexible employers that understood the importance of parental participation at school. My employers worked with me, allowing me to attend IEP meetings where Jennetta and I developed strong goals and objectives.

We weren't always so lucky. When Jennetta was first diagnosed with Spino-Cerebellar Syndrome my employer fired me because they were concerned I would miss too much work caring for her. How would I provide for my family? How would I make sure Jennetta received the attention, services and education she deserved? Eventually I found a job that allowed me the flexibility to support my family while ensuring Jennetta's needs were met.

**When Jennetta was first diagnosed with Spino-Cerebellar Syndrome my employer fired me because they were concerned I would miss too much work caring for her.**

The Parent Protection Act will give parents 24 hours a year to attend school meetings and doctor's appointments without costing their jobs or ability to provide for their families. Just 24 hours a year can make a difference in the life of a child.

Every day in my work as a family advocate of children with emotional behavioral disorders I am reminded of the struggles of balancing work and family. Teachers tell me that their biggest obstacle is lack of parental involvement while at the same time parents tell me they want to be involved, but

are at risk of losing their jobs if they take time off from work.

The Parent Protection Act is good for Georgia. It will give parents the ability to be involved with their children's education, take them to doctor's appointment and give our children the chances they need to succeed.

### Jennetta's Story

My name is Jennetta Allen and I am a sophomore at Strayer University. I am a success story of what is possible with strong parental involvement at school.

I was diagnosed with Spino-Cerebellar Syndrome when I was five. At first, school was very hard. I can remember getting sick at school one day and waiting for my mother to pick me up. I waited all day. Finally, the principal drove me home because my mother's boss would not let her leave the job. I remember how angry I felt and I remember my mom crying. She was fired a few weeks later.

My mom did not work for the next few years until she found a job that allowed her to take the time she needed for me. Every year, my teachers and my mother and I prepared for my IEP (Individualized Education Plan) as mandated under No Child Left Behind.

My mom never gave up on me. Through a collaborative approach to my education I was able to achieve a high school diploma and acceptance into an accredited university.

I want all children in Georgia to have the same opportunities and support that I had. The Parent Protection Act will allow parents to be involved with their children's education without worry of losing their jobs. With strong parental involvement and a collaborative approach to education, anything is possible. ●



*Linda Allen has been an advocate for parental rights in the workplace since daughter Jennetta was diagnosed with Spino-Cerebellar Syndrome, a progressive, degenerative disease that primarily relates to muscle control.*



*Jennetta (left) with proud mom, Linda.*



# Leaving On A Jet Plane: Ninth Annual Discovery Day Focuses on Travel, Tourism

**E**veryone loves to go on vacation – whether it’s a tour throughout Europe or a weekend spent exploring beloved local attractions.

However, travel for the 11 million people with disabilities who spend \$13.6 billion in the U.S. annually can be fraught with obstacles. This is why national, state and local industry experts gathered in Atlanta for the ninth annual Making a Difference Discovery Day Executive Briefing – Making Accessible Travel and Tourism a Reality in Georgia, presented by the Georgia Council on Developmental Disabilities (GCDD) in collaboration with G3ict and Hartsfield-Jackson Atlanta International Airport. This year’s theme departed slightly from previous years’ emphasis on employment by focusing on making accessible

travel and tourism a reality in Georgia – and in making Georgia a model that the rest of the country and world follows in creating accessible travel situations.

“Everyone ready to get airborne?”

Richard Warner, host of GPB-TV Georgia’s Business, CEO of What’s Up Interactive and the official host of the ninth annual Discovery Day, joked with the crowd.

“This day will affect you in ways you’ve never expected,” he continued on a

more serious note, recalling his participation as host for the 2008 Discovery Day. In fact, when keynote speaker Eric Lipp mentioned that he had

difficulty finding the accessible options on the Georgia Aquarium’s Web site, Warner (whose company is responsible for the aquarium’s Web design) immediately shot off an email to his designers. “The next time you go to the Aquarium’s Web site, you won’t run into those accessibility problems,” Warner said. “See? That’s how effective this Discovery Day is!”

“Today is about profiling the best practices of inclusion,” said Tom Seegmueller, chairperson of GCDD. “Our ultimate goal is to bring together the diverse spectrum of Georgia citizens and use their talents to create an inclusive society.”

Lipp, executive director and founder of Open Doors Organization in Chicago, was diagnosed with Von Hippel Lindau disease one day before his 30th birthday leading to traumatic surgery on his spinal cord.

**“I thought to myself ‘Hey, here I am – a young guy with a big mouth. Why don’t I do some good?’”**

“I’ll never forget my first time out in public with a manual wheelchair,” he said. “We were going to a restaurant, and I saw a revolving door. My family went through the revolving door, and I managed to find a side door – only for it to be blocked. I couldn’t find a way in. I remember being so angry.”

It was this encounter with not one but two doors that he literally could not go through that led to the founding of Open Doors Organization (ODO), created in 2000 with a mission of making all consumer goods and services accessible for people with disabilities. “I thought to myself ‘Hey, here I am – a young guy with a big mouth. Why don’t I do some good?’” Lipp said.

After conducting studies in 2002 and 2005 about the spending and travel behaviors of people

Below: Attendees listen attentively to the program.

Below right: Keynote speaker Eric Lipp addresses accessibility issues.





**“The world is a book,  
and those who do not travel  
read only one page.”**

– St. Augustine

with disabilities, researchers with ODO discovered that people with disabilities book travel options such as flights and hotels online more than any other population. “This means that Web sites need to be accessible! They need to provide the information in a way that’s easy to find,” Lipp said. “If your Web site is not accessible, you might as well put up a big flashing sign that says ‘We don’t want your business.’”

Upon learning this information, ODO set out to create “Easy Access Chicago,” an online and supplementary print guide that describes accessibility features at popular destinations such as restaurants and hotels in Chicago (EasyAccessChicago.org). “What surprised us the most is that the guide was flying off the shelves for people who were citizens – the users weren’t strictly travelers or tourists,” Lipp said. “The initial 10,000 guides flew off the shelves and the guide is in its second printing.”

The guide is unique in that it provides sensible information that people with a wide variety of abilities could find helpful. For example, it provides a detailed guide of city transportation, from the airport to the subway to the bus system. “What we’ve set out to do is to tell you everything,” Lipp said. “When we talk about inclusion, we mean for everyone.”



Salimah Major (far right) asks keynote speaker Eric Lipp a question.

Lipp challenged Atlanta and the state of Georgia to become leaders as one of the most accessible places in the United States, and the world. “Atlanta has so much to offer, and has a strong and proud disability community,” he stated. “Atlanta ranks eighth in top locations to visit in the United States, and in the south Atlanta ranks second only to

**“We need to make sure that all citizens have a good quality of life, and travel is a component of that.”**

Orlando.” Lipp suggested that the state of Georgia’s economic development Web site (Georgia.org) undergo a revision to detail the accessibility of locations, and also challenged individual attractions across the state to provide that information in as much of an upfront way as possible.

Later in the program, Georgia Department of Economic Development Commissioner Kenneth Stewart detailed the great assets that Georgia has – from natural environments to Hartsfield-Jackson Atlanta International Airport. “It’s a right of ours to travel,” he said. “We need to make sure that all citizens have a good quality of life, and travel is a component of that.” Stewart continued to say that all citizens have a clear vested interest in the outcome of Discovery Day. “The Georgia Council on Developmental Disabilities is a significant asset in the state,” he said. “By getting the right people involved, there’s no telling what can be done.”

Attendees each received the “Georgia Inclusive Travel & Tourism Concept Paper,” the debut piece from the Georgia Alliance for Accessible Technologies (GAAT). GAAT is a working group currently led by G3ict. GAAT is co-chaired by Bill Curtis-Davidson of IBM and Arthur Murphy of Aeolian Solutions, who also served as co-chairs of this year’s organizing committee.

**Atlanta ranks eighth in top locations to visit in the United States, and in the south Atlanta ranks second only to Orlando.**

**“And let’s ask ourselves – how do we think about this issue beyond government compliance? How do we bring together community leaders and see what accessibility in our city and state really looks like?”**

“GCDD’s annual Discovery Day presents the perfect opportunity to partner with like-minded organizations such as G3ict and GAAT,” said Valerie Meadows Suber, GCDD’s public information director and project coordinator for Discovery Day. “We’re very glad Discovery Day turned out to be the vehicle for the official release of the G3ict-GAAT white paper and this groundbreaking discussion.”

“It’s important to read this paper,” said Mark Johnson, director of advocacy at the Shepherd Center and member of the Inclusive Travel & Tourism Synergies Panel. “It provides candid information on tourism in Georgia, along with what’s NOT working and how advocates can make the difference.”

“Who has better resources than the state of Georgia?” said Axel Leblois, executive director of G3ict, GCDD’s major collaborator for Discovery Day. “This state can be a source of a lot of solutions.” Leblois continued on to enumerate the many reasons why focusing on accessible travel and tourism is important. “It just leads to better business throughout the world,” he said. “That helps our local economies.”

Leblois also provided good news on the Convention on the Rights of Persons with Disabilities, a treaty sponsored by the United Nations and which provides a universal legal framework on accessibility. “The United States signed the convention in August of 2009,” he reported. “Over the next few years you will see many countries adopting new resolutions and ways on how to become accessible and inclusive.”

A starting point on creating an accessible world is here in our own backyards. “Let’s create places in our state that are accessible,” Eric Jacobson, executive director of GCDD



*Dr. Bruce Walker of Georgia Tech updates the group on technological advances.*

and part of the community perspectives panel for Discovery Day, agreed. “And let’s ask ourselves – how do we think about this issue beyond government compliance? How do we bring together community leaders and see what accessibility in our city and state really looks like?”

**“It’s great to look at what the disability population currently spends in travel, but I like to ask what are the untapped dollars that could be spent?”**

Anisio Correia, also a member of the community perspectives panel, serves as vice president for programs at the Center for the Visually Impaired. As a frequent traveler and avid user of assistive technology, Correia brought a unique perspective to the panel. Acting as a voice of cautious optimism, he encouraged attendees to acknowledge how far that the global community has come. “A lot of the success we’ve achieved in accessibility is due to the Internet, and with new technologies,” he explained.

Dr. Bruce Walker, associate professor and director of the Sonification Lab at the Georgia Institute of Technology, took things one step further. “It’s great to look at what the disability population currently spends in travel, but I like to ask what are the untapped dollars that could be spent?” he said to attendees.

Representing Delta Air Lines on a panel of industry experts was David Martin, director of the office of disability and outreach programs. “Our goal is to make Delta the carrier of choice for people with disabilities,” he said. To achieve that goal, the airline has developed an advisory board on disability, as well as provide sensitivity training to staff. “Delta is the







only airline that has Complaint Resolution Officials. These employees are trained to handle complaints and inquiries from all passengers," Martin continued. "We believe it's just good business to show honor, dignity and respect."

"Making something easier for certain people can make it more difficult for others," John Kemp, executive director and general counsel of the U.S. Business Leadership Network, further explained. "Someone's accessibility is another person's barrier." Kemp continued to state that's why it is important to promote inclusion for all.

Luz Borrero, deputy chief operating officer in the Atlanta mayor's office, echoed those sentiments by voicing Atlanta's pledge to making travel information more accessible.

The day wrapped up with a panel on inclusive travel and tourism synergies, moderated by Nerissa Serrano-Okiye, who is the director of research in the tourism division for the Georgia Department of Economic Development. "Our mission is to get people into Georgia, and to make sure that they are having an enjoyable time," she said. Robert Kennedy, who is the assistant general manager of Hartsfield-Jackson Airport, agreed.

"Many times the resources are available," he said. "But people just don't know about it. That's what we have to get better at – utilizing

technologies like Web sites and social networking sites like Twitter."

"It's up to all of us now to move up one step from where we are now," said Subie Green, another member of the panel and executive director of CVI. Discovery Day attendee Salimah Major works with Wireless RERC (Rehabilitation Engineering Research Center), which promotes equal access and promotion of technologies to the disability community. "We're interested in learning how we can make technologies even more innovative," she said. "Designing technologies for a niche audience moves into being desirable by wider populations."

Deidre O'Brien, executive director of The Arc of Georgia and Discovery Day attendee, was looking forward to the change from a focus on employment to one on travel for Discovery Day. "Travel is difficult to near impossible," she said, referring to her experiences traveling with her twelve-year-old daughter. "I'm looking forward to learning how we can advocate to make these experiences better."

Making A Difference Discovery Day 2009 was presented by GCDD in collaboration with G3ict, Hartsfield-Jackson Atlanta International Airport and the Renaissance Concourse Airport Hotel, with support from AIRSERV, Delta Air Lines and IBM. "We're very appreciative to all the parties who played a key role in today's success," said Valerie Meadows Suber. "One day we might be able to look back on this event as the pivotal point at which the Georgia model for accessible travel and tourism really took off."

Leblois helped close the 2009 Discovery Day briefing by requesting attendees once again to review the GAAT concept paper. "This meeting was very instrumental in making progress," he said. "We've heard some very encouraging comments from our panel."

Jacobson encouraged everyone to use Discovery Day as a springboard to further action. "Let's not leave this meeting thinking 'Great stuff!' and then not see each other until this time next year," he said. "What do you do for next steps? Let's continue this exploration." ●



Above: Axel Leblois of G3ict (left) chats with Ben Lippincott of Wireless RERC.

Below: David Martin of Delta Air Lines reviews their efforts to serve the disability community.



Above left: Robert Kennedy of Hartsfield-Jackson Airport (left) speaks with co-panelist Mark Johnson of the Shepherd Center.



Above right: Kenneth Stewart (center) joined host Richard Warner (left) and GCDD Chair Tom Seegmueller.

**We believe it's just good business to show honor, dignity and respect.**

See "Georgia Inclusive Travel & Tourism Concept Paper" at [www.gcdd.org](http://www.gcdd.org) and link to Discovery Day.

# Real People, Real Lives, Real Communities: How Advocates are Getting Real

**T**he Georgia Council on Developmental Disabilities kicked off their Real Communities Initiative with a collaborative meeting on Wednesday, October 28, 2009 that inspired participants to become more involved in coordinating community discussions to promote and foster inclusion.

John O'Brien, a disability advocate and co-author of "When People Care Enough to Act" along with Mike Green and Henry Moore, led the day's activities by instigating several workshop-style, communicative activities between participants. "In order to lead conversations among communities, we need to be comfortable in conversations with each other," he suggested, handing out various worksheets and pieces of literature with leading questions to inspire and instruct conversation between meeting attendees.

The activities are just a larger part of what is known as the Real Communities Initiative, a program designed to open up conversation between advocates and their communities in becoming fully inclusive of all, regardless of race, gender, age, disability, creed or any other identifying factor.

"This project has been in planning for about a year," confirmed Caitlin Childs, organizing director for GCDD. "The Council is looking to expand the focus from individuals to include the entire community."

The Initiative was born out of advocacy efforts that were more individualized, as the Council spent years funding training to teach people to be self-advocates. "The framework of the prior training led to a more individualized approach to advocacy that was personalized for specific persons," Childs continued. "It is important, particularly for self-advocates, to discuss those personal issues that are often pushed aside, but we began to see the need for advocacy that involved the entire community."

**"It is important, particularly for self-advocates, to discuss those personal issues that are often pushed aside..."**

Phillip Jay, commission chair of Ben Hill County in south Georgia and a driving force behind a transportation initiative in his location, agrees with Childs' assessment. "If we can get people involved in more generic issues related community-wide, then people with disabilities would also be a recipient of that work and effort," he explained. "The Real Communities Initiative benefits the entire community and makes the community stronger."

The Real Communities Initiative is designed to spark a conversation within communities, by following a basic step-by-step approach as part of an assets-based community development model.

## Identify the Issue

Jill Alexander, a Council member and program assistant of Communities in Schools of Fitzgerald-Ben Hill County, is a member of the aforementioned core group in Ben Hill County



**"In order to lead conversations among communities, we need to be comfortable in conversations with each other."**

**“In every segment of community life there is a new understanding: when a growing circle of people work together in community partnership, they have the power to address important problems and to achieve the goals they want. Strong communities know that they need everyone to give their gifts if the community is to thrive. It is true: there is no one we don’t need.”**

*- Excerpt from “When People Care Enough to Act,”  
by Mike Green with Henry Moore and John O’Brien*

focusing on a transportation initiative along with Cam Jordan, Fitzgerald Community Development Director, and Shirley Brooks of the Jessamine Place. “Ben Hill County has no transportation at all,” Alexander said. “Initially, a group of us went to Washington D.C. for a conference on transportation issues last summer. Since that time, we’ve been having meetings that look at the transportation issues closer to home, in our county.”

Transportation is but one core issue that groups around the state are discussing. “I’m working with a group that is working toward the goal of Koreans with disabilities becoming as inclusive in society as possible,” said Sharon Chung. Chung is the immigrant outreach coordinator of the Asian Community at Disability Resource Group. She continued to explain that the Korean community is really just the first step, as she is already looking forward to reaching out to other communities across the state that may feel excluded or have that need for inclusion. “It helps because I speak Korean!” she laughed. “So one of the main issues I am finding in reaching out to other communities is that I need to find interpreters.”

**“...one of the main issues I am finding in reaching out to other communities is that I need to find interpreters.”**

Participants in the October 28 meeting also discussed what issues they are involved with outside of disability advocacy. “Something I am very proud of is my work in taking marijuana-flavored candy off of store shelves in the state,” said George Crawford, the director of

the community capacity building unit in the Office of Chronic Disease Prevention and Wellness in the Health Promotion and Disease Prevention Program. “The candy, usually in the form of a lollipop, was really endangering the youth of our communities. There was even a marijuana leaf on the packaging!”

The Real Communities Initiative, while working toward the goal of inclusiveness for people with disabilities, really has an overall goal of complete community health and participation from all community members. “We’re still working on identifying groups,” explained Childs. “For example, Project Access in Clarkston has been doing a lot of work in the past year with refugee communities in the Clarkston area.

All initial dialogues are planned to wrap up in January 2010, so the core groups can make a plan of action and move forward from there. “It’s really after these initial dialogues are complete when the Council will identify our first groups that we will definitely be working with,” Childs said.

### **Begin the Dialogue**

Once the initial groups are defined, the dialogue can be started in many ways. While people are encouraged to strike up conversations anywhere from their workplace to the checkout line at the grocery store, there are also less obvious yet just as effective (if not more so) ways to reach out. “I have at times written articles,



**While people are encouraged to strike up conversations anywhere from their workplace to the checkout line at the grocery store, there are also less obvious yet just as effective (if not more so) ways to reach out.**



and put together one-day informative seminars to help educate parents,” Chung said. “Additionally, in the Korean community, church is a very social activity, even for those who are not particularly religious. So, to me, it makes sense to reach out to the community via churches.”

**“We try to work with a variety of agencies to ensure that all communities are involved, particularly those with disabilities or the elderly.”**

Alexander agrees that it takes several different methods to fully reach out to people. “We try to work with a variety of agencies to ensure that all communities are involved, particularly those with disabilities or the elderly.” Crawford’s task force also held several community meetings, as well as meetings with local shop owners who were selling the marijuana-flavored candy in their stores.

“Trying to get people’s schedules lined up can be difficult,” Childs said when asked about the challenges of initiating dialogue. Another difficulty that coordinators have run across is not just any disability barriers, but also any cultural and/or language barriers. Despite these difficulties, Childs and the Council still impress upon others the importance of maintaining communication.

“The dialogue process is important because it’s part

of our very intentional approach. We’re not trying to just run out and begin doing things,” she said. The idea behind the Initiative is to learn from what others have done before in previous organizing efforts.

“It can be difficult to step back and take things slowly when you’re energized and motivated to do something,” Childs said. “But this part of our approach is actually very important so that we don’t waste resources, and can use all resources and talents wisely and effectively.”

### Gather Feedback

After conversing back and forth with the community, both Chung and Alexander remarked on the importance of collecting information in a concise way. “We put together a survey for the community to try and find out their needs, and to see if a transportation system would be utilized and supported,” Alexander explained. The survey was made available in both a print and online format. After collecting the responses, the results were made available to the public before a community forum.

“We wanted to know how to guide the discussion and content of the forum, and sharing our preliminary survey results with the community was a great way to do that,” Alexander continued. “And partially due to that, we had great turnout at the community forum! Seventy people attended, which we were really pleased to see.” Alexander also explained that the survey does not have a specific end date, as they are trying to gather as much input as possible from as many people as possible throughout the entire process.

**“People below a certain income level very much recognized the need [for community-wide transportation] and were interested in making something happen.”**

The results confirmed what Jay expected. “People below a certain income level very much recognized the need [for community-wide transportation] and were interested in making





something happen,” he said. Jay is enthusiastic to see that there is an interest in Ben Hill for a transportation system, particularly for what it might mean in terms of members of the community being able to find employment or to further their education at the nearby technical college.

As far as when gathering feedback would be considered complete, advocates don’t feel comfortable putting a due date on it. “For example, the survey will remain open because we want to make sure we get as much response and as many people’s thoughts and opinions as possible,” Alexander explained.

“We will continue to have these dialogues for years,” Childs said. “One of the things we want to do is make sure we are checking in and seeing what others are doing in different parts of the state and country.”

**“It’s nice to see the people we’ve already been talking to about this get excited. People are ready for something new. We’re ready to try something different.”**

## Make the Move

However, a discussion can only go so far before people act. Alexander says that the group she is involved with is planning to do some asset mapping in order determine where the county’s resources lie. “We are also initially going to try promote a carpool system at local industries on the outskirts of town,” she explained. “From there, we hope to have positive results that can then draw in more resources.”

Jay agreed. “We’re looking around and seeing some other communities that have a good transportation system in place. We’ll also be doing an assessment on what we already have out there.”

Though it is very early in the history of the Real Communities Initiative, the Council is expecting positive results, particularly after the initial outcome of the program in Ben Hill County. “We’re getting everyone involved, from

the mayor to the commission chair,” Alexander said. “It’s very exciting to see so many involved in our planning.”

**“I really hope that this idea of using this asset-based community development and community organizing model for people with disabilities really spreads...”**

Jay agreed. “I initially got involved because Jill told me to!” he chuckled. “She represents a very credible voice in our community.” After getting involved and learning about the issues, Jay began to see the very real need for a transportation system in his community. “I’m glad that the Council has set up [the Real Communities Initiative]. I think it’s going to be very helpful across the state, and Ben Hill is moving along.”

Chung is excited to see what issues are identified within the Atlanta Korean community. “We’re still in the early stages, and we’re kind of feeling people out as to what issues they are concerned about.”

The Real Communities Initiative is still in its infancy, Childs confirms. “I really hope that this idea of using this asset-based community development and community organizing model for people with disabilities really spreads, and that we’ll see people across the state and country using these strategies,” she said. “Any effort to improve the lives of all people in a community means full inclusion.

“It’s nice to see the people we’ve already been talking to about this get excited. People are ready for something new. We’re ready to try something different.” ●



*"The tourism industry still fails to adequately realize our desire to get out of the house and see the city, state, country and world."*

## Planning an Accessible Vacation

By Eric Lipp, Executive Director for Open Doors Organization



Eric Lipp

**W**e all know that vacation planning can be pretty overwhelming. You need information for flights, hotels, car rental, attractions, restaurants – and the list goes on. For “family” vacations, you also have to take into account the needs and desires of children and sometimes grandparents as well. If one or more people with disabilities are included in your travel plans, this is an even more daunting challenge.

As a person with a disability, I know that it takes careful, precise planning for me to travel. Sometimes I need the vacation just because of all the grueling time I put in on the Internet and phone trying to prearrange as much as possible. I have restricted mobility so I wear my disability like the scarlet letter, but millions with developmental disabilities have nonapparent disabilities that can make it all the more difficult. How many times have you tried to convince the airline that your loved one is capable of traveling alone? Alternatively, how many have never even attempted this because they fear something may go wrong?

Certainly I wish I had all the answers but I do not. However, I and the staff at Open Doors Organization ([www.opendoorsnfp.org](http://www.opendoorsnfp.org)) continue to advocate on behalf of people with disabilities in travel and tourism. There is a lot that needs to be done and not enough buy-in from corporate America to get it done quickly.

Open Doors Organization believes that every city should have a comprehensive access guide similar to the one we authored for Chicago (learn more at [www.easyaccesschicago.org](http://www.easyaccesschicago.org)).

The tourism industry still fails to adequately realize our desire to get out of the house and see the city, state, country and world. There are just too many obstacles and not

enough services to make travel easy. Detailed access guides need to be available so people can readily get the information to make good, informed decisions. For instance, our Easy Access Chicago guide includes everything from resources for adult daycare, to exact specifications – even down to bed height – for many hotel rooms. The guide has been out over two years and, to my amazement, the bulk of the users are citizens of Chicago and the Chicago-area.

In an effort to make your travel experiences easier, here are my top 10 tips for your travel:

### For Air Travel

1. Book non-stop flights
2. Think “safety for everyone” before you let someone with a developmental or other cognitive disability fly alone
3. If a problem arises, ask for the airline’s Complaints Resolution Official

### For Hotels

4. Request rooms on the ground floor
5. Ask very specific questions concerning accessibility
6. Provide an orientation to the hotel including elevators, guest room, exits, etc.
7. Notify the front desk so in case there’s an emergency, they will understand that a person with a disability is on the premises

### For Cruising

8. Request rooms that adjoin or are in close proximity
9. Notify your room attendant so they are aware and may help
10. Call the cruise line to see if they offer any other special services ●

**If one or more people with disabilities are included in your travel plans, this is an even MORE DAUNTING challenge.**





# StraightTalk

## ADAPT Action Recap: The Issues That Matter

By Barbaraann Bongiovanni

Imagine over 300 people with disabilities walking or rolling single file as it rained cats and dogs along the main streets of Atlanta heading toward the Georgia State Capitol. We were well over a half-mile long – people with every type of disability! What an awesome site to see and this was my first experience! The chanting continues: “Our homes, not nursing homes...solutions, not institutions...nothing about us, without us...end institutional bias!” Horns are honking, and police arrive and direct the traffic. What you just pictured was the national group, ADAPT, combined with our local chapter advocating in Atlanta for all people with disabilities.

Over 300 ADAPTERs from 30 states came to support the Atlanta disability community from October 10 through 15 at the Omni Hotel in downtown Atlanta. Linda Pogue, director of Advocacy at disABILITY Link, facilitated and organized the local planning committee. Bernard Baker and Pat Puckett were Day Leaders; Margo Waters and Kate Gainer were Color Leaders; and Shelly Simmons and I served on the Media Committee.

**Imagine living in an institution  
and not being able to go outside  
or plan your day for yourself.**

**PLEASE VOTE FOR CHOICE!**

On Sunday, October 11, everyone gathered around Centennial Olympic Park for a great lunch; afterwards we walked or rolled single file to the Martin Luther King Center’s Rose garden for a rally. Mark Johnson, director of advocacy at the Shepherd Center, hosted the rally; Delores Bates, Andrew Jones, Andrea Patton, and Bodie Watkins were highlighted as the ceremony continued. They

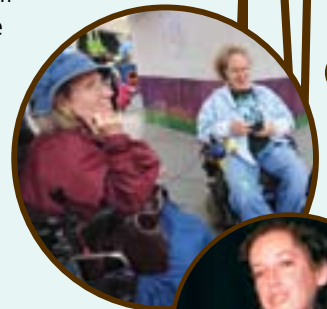
gave speeches on what it was like to get out of an institution and to have their freedom back in their life – the freedom that we, as people, take for granted! It was such an uplifting experience to attend the rally!

On Monday morning ADAPTERs lined up again to follow their leaders and marched the streets, this time to the Georgia State Capitol! Once we were at the Capitol, people moved right in through security and into the corridors. We wanted a meeting with Gov. Sonny Perdue. After four hours of waiting in the rain, the negotiators had reached an agreement and would have a meeting with the Atlanta leaders! These surprise visits go on throughout the week. We surprised the Office of Civil Rights, the Office of Housing and Urban Development, and the CNN Center!

ADAPT’s main purpose for this Atlanta action is to gain support to pass the Community Choice Act (CCA) in Congress and the Community First Choice (CFC) for the state of GA ([www.adapt.org](http://www.adapt.org)). The CCA provides people with disabilities and senior citizens, who are living in nursing homes and other institutions, to have a choice to live in the community. In addition, people would not be forced into institutions; they could choose where and how their community services are provided. The CFC would support the Olmstead decision by giving people the choice to leave facilities and institutions for their own homes and communities with appropriate, cost effective services and supports. It would also help address state waiting lists for services by providing access to a community-based benefit within Medicaid.

Currently, people with disabilities are trying to get the word out to everyone to vote for the Community Choice Act and the Community First Choice. Imagine living in an institution and not being able to go outside or plan your day for yourself. Please vote for choice! ●

Barbaraann Bongiovanni





# Presence, Memory, Vision

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

## PRESENCE

Mia turned 25 the same week that the fall 2009 issue of *Making a Difference* came out. She had a sleepover with three young women she knew either from camp or high school: Ruthie, Jessica and Hannah. They spent the morning at a camp event, and then came to the house Mia shares with Laura, Joe and their son Owen. The girls got settled on Mia's floor, took out pictures and cell phones, magazines and other trinkets that they gabbed about and shared. Mia served "d'oeuvres," carrots and dip and little bowls of chips. Over the next few hours they watched movies, talked about other camp friends, and called the Jonas Brothers fan club. After pizza, birthday cake and a viewing of "Enchanted," they settled down in sleeping bags and on the couch. The next morning, they all took showers, put on church clothes and the moms picked them up.



In the past few weeks I've tried to relate this picture of a life to several people at public meetings who have spoken in support of congregate facilities.

I was there but didn't need to be except to pay for the pizza. They were just four friends hanging out, talking girl talk. In the past few weeks I've tried to relate this picture of a life to several people at public meetings who have spoken in support of congregate facilities. I struggle with this discussion because Mia is relatively easy. She does not have behaviors or health issues that would make it challenging to support her. Some of the families that I have talked with have had exhausting and heartbreaking experiences trying to support their member with a disability. There are people in Georgia who know how to provide support for individuals with challenging needs in the community, but probably not enough of them, so I always come back to this question – how

do we make this presence in the community possible?

## MEMORY

Three memories fueled me in envisioning a life for Mia. In 1998, I heard Mary Kissel talk to a nonprofit class about her son, Eric, and starting Georgia Options. Mia was only 13, but I had my first "AHA!" moment. Mia could live in her own place and with a family who was invited to be part of her life.

The second memory was Robin Berger telling me about her daughter, Lori, who was working in a day care center. A few days prior to that, a high school special education teacher had told me that Mia could never work with children because she could not take the tech school classes to get certified. But Robin helped me see it despite the professional's withering assessment.

The third memory was of a presentation I saw by a young woman with Down syndrome who lived in her own house with a support person, and some of her slides were of her slumber party. It was a typical house in a regular neighborhood and I thought, "How do I get that for Mia?"

## VISION

Mia has it now - a typical house in a regular neighborhood, a regular job, a Sunday school class of toddlers and a family who stepped up to share a life with her. This was my vision, and she is thriving. How do I share this vision with other families? Pat Puckett has the idea to create a "Supported Living Academy" where families and the people they love and support come together with the providers that know how to support people's presence in the community to help everyone 'see' what's possible. If we can get people to 'see' it, we can create the presence. If we keep at it, in 10 years it will be what we all remember as life in the community for people with disabilities – and all of us. ●

## JANUARY

**January 14-15**  
**GCDD Quarterly Meeting**

Atlanta, GA  
[www.GCDD.org](http://www.GCDD.org)

**January 23**  
**23rd Annual**  
**Educational Conference**

Dunwoody, GA  
[www.focus-ga.org](http://www.focus-ga.org)

**January 25**  
**Service Providers**  
**Association for**  
**Developmental Disabilities**  
**Board Conference**

Atlanta, GA  
[www.SPADD.org](http://www.SPADD.org)

**January 28-29**  
**4th Annual Leadership**  
**Forum on Accessibility**

Orlando, FL  
[www.ATIA.org](http://www.ATIA.org)

## FEBRUARY

**February 25**  
**Disability Day**  
**at the Capitol**

Atlanta, GA  
[www.GCDD.org](http://www.GCDD.org)

## MARCH

**March 1-2**  
**6th Annual ASA-GGC**  
**Autism-Asperger**  
**Conference**

Atlanta, GA  
[www.ASAGA.com](http://www.ASAGA.com)

**March 10**  
**GA Options Workshop**

Athens, GA  
[hr@georgiaoptions.org](mailto:hr@georgiaoptions.org)



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## Letters to the Editor

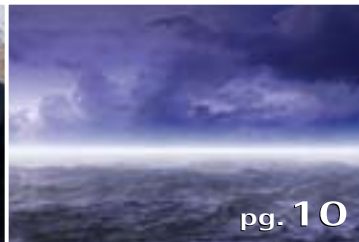
Have something to say about one of the issues discussed in *Making a Difference*?

Please send your "Letters to the Editor" to [vmsuber@dhr.state.ga.us](mailto:vmsuber@dhr.state.ga.us) by March 15, 2010 for inclusion in the Spring 2010 issue of *Making a Difference*.





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

### Georgia Council on Developmental Disabilities (GCDD)

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

## State Government

**Georgia Senate & House of Representatives**  
[www.legis.state.ga.us](http://www.legis.state.ga.us)

**Georgia Governor's Office**  
[www.gov.state.ga.us](http://www.gov.state.ga.us)  
404-656-1776

**Department of Community Affairs**  
[www.dca.ga.gov](http://www.dca.ga.gov)

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

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

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

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

## Real Initiatives

**Georgia Council on Developmental Disabilities**  
Caitlin Childs, Advocacy Director  
404-657-2125 (direct)  
404-657-2126 (main)  
[cpchilds@dhr.state.ga.us](mailto:cpchilds@dhr.state.ga.us)

Ben Hill County Commission  
Phillip Jay, Commission Chair  
229-426-5100

**Ben Hill County Transportation Initiative**  
Jill Alexander  
229-423-1036  
[jillralexander@hotmail.com](mailto:jillralexander@hotmail.com)

**Korean Community Initiative**  
Sharon Chung  
[sharon.chung1@gmail.com](mailto:sharon.chung1@gmail.com)

## Parent Protection Act

**Representative Roger Bruce**  
[rogerbruce.net](http://rogerbruce.net)  
404-656-0314  
[rbruce@legis.state.ga.us](mailto:rbruce@legis.state.ga.us)

**9 to 5, the National Association of Working Women**  
Cindia Cameron  
**9to5.org**  
414-274-0925 (main)  
[9to5@9to5.org](mailto:9to5@9to5.org)

**Coalition of Advocates for Georgia's Elderly (Co-Age)**  
Kathryn Fowler, Executive Director  
**GCOA.org**  
404-657-5343 (main)  
[kdfowler@dhr.state.ga.us](mailto:kdfowler@dhr.state.ga.us)

**Fulton County Schools**  
Kimberly Brown-Mack  
404-245-7804

**Discovery Day**  
**G3ict – The Global Initiative for Inclusive ICTs**  
[www.g3ict.com](http://www.g3ict.com)

**The Georgia Alliance for Accessible Technologies**  
Francesca Cesa Bianchi  
[fcesabianchi@g3ict.com](mailto:fcesabianchi@g3ict.com)

**Open Doors Organization**  
Eric Lipp, Executive Director and Founder  
**opendoorsnfp.org**  
773-388-8839 (main)

**Center for the Visually Impaired**  
Subie Green, Executive Director  
**CVIGA.org**  
404-875-9011 (main)

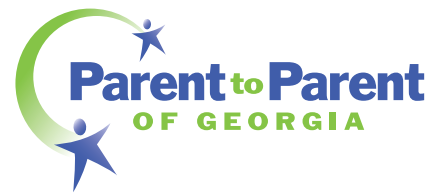
**Shepherd Center**  
Mark Johnson, Director of Advocacy  
**shepherd.org**  
404-352-2020 (main)

**Delta Air Lines**  
David Martin, Director of Office of Disability and Outreach Programs  
**delta.com**



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GCDD would also like to thank the many people who came out for Discovery Day 2009!