

SPRING 2010

# Making a Difference

**Advocates gather in Atlanta  
for Disability Day 2010**

**Safe Schools Initiative:  
Your Child's Safety on the Line**

**Student-Led IEPs Secure a Bright Future**

**State Legislature Wraps Up Session**

[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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## State Budget Crisis Leads to Questions about Funding for Vital Programs

Since January, we at the Georgia Council on Developmental Disabilities have spent much of our time monitoring the Georgia General Assembly to make sure that the budget and legislative process work to improve the lives of people with developmental disabilities and those who care about them. This is why we sponsored the 12th annual Disability Day at the Capitol on February 25, 2010. Even the cold weather could not keep almost 2,000 people from shouting "Count Me In, Count My Vote! Count My Community!" Another awesome day for the disability community!

However, all is not well. Georgia is mired in an economic downturn and the amount of money available to support state government continues to decline. Some have suggested the state needs to look at new sources of revenue including a tobacco tax, hospital bed tax or raising fees, while others suggest that revenues are not the answer and instead Georgia should downsize government services to reflect the dollars available.

What is the answer? We know there are ways to make services for people with developmental disabilities more cost efficient. We have heard suggestions that the Department of Behavior Health and Developmental Disabilities reduce its workforce. Others suggest that services should change to support employment over workshops, home and community-based services over institutions, self-directed over provider-directed services. All of these could save money.

We might make up the deficit in 2011 and maybe in 2012 if every department made these kinds of changes. However, unless the economy rebounds very quickly, (some estimate we need 14 percent monthly growth to maintain what we had before the economic downturn) all of us will suffer. This includes those who need services and supports because we have a disability, have children in school, need police and fire services, have elderly parents or grandparents, are unemployed (10.5 percent unemployment is a record in Georgia and it means more people need public support) and need health care or food stamps, or drive on the roads.

Do we make do with less? Are you willing to give up personal care services or respite care? Are you willing to have your grandchild in a classroom with 30 other students or attend school four days a week? How do you tell your employer that you need Fridays off because your child doesn't have school and you have to stay at home? Are you willing to watch your neighbor struggle to get the medicine she needs because she recently lost her job? Or are you willing to pay more for tobacco (if you smoke), higher fees when you go to a state park or see tax breaks for some businesses reduced or eliminated?

These are the questions each of us should be thinking about and prepared to discuss with those now running for local, state and federal offices. Now that the General Assembly has ended its 40 days, the race is on for your vote. Take this request very seriously and ask those running for office how they will, if elected, help meet the growing needs of our state. Make sure your vote counts.

This edition of *Making a Difference* provides an overview of what took place during the 2010 legislative session, how to conduct student-led IEPs and the need to end seclusion and restraints in our schools. We hope you enjoy reading this magazine 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) ●

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Excerpts from:

## A Course Correction: The Power of Vulnerability

By Philip Jay, Commission Chair in Ben Hill County

**I**t was 1970. After 13 months as a Marine in Vietnam, disenchanted by my government’s commitment to a war we could not win and painfully confused by my country’s scorn of anyone in military uniform, I embraced the peace movement with the enthusiasm of the newly converted – on one occasion, even meeting Jane Fonda.

In 1969, upon my return from what Mama Jay calls “my war,” I experienced first-hand the reception of being spit at and jeered followed by a double life as a stranger among students obsessed with untested idealism. These experiences left me certain of one thing: I wanted to spend the rest of my life committed to work truly valued by communities – work which was unlikely to be challenged or doubted, much less mocked or derided. It was a naïve ambition, as it turned out, ironic in the extreme given my eventual career choice.

pliers, saws, restraints, even some primitive electroshock devices. Third-world torture chambers would be envious.

Accompanied by hospital staff as guides, we continued on to another building. This one was called a ‘Ward.’ Its door opened to a room filled with women. Some danced to tunes of their own making, a few played cards or checkers. Some slept while others, though awake, didn’t seem to know we were there.

**What are the influences that charted the courses that condemned these patients to the institution? I can’t speak to their own decisions or those of their families and communities.**

What are the influences that charted the courses that condemned these patients to the institution? I can’t speak to their own decisions or those of their families and communities. Nor shall I judge them. I can only grieve at the difficulties they all must have faced.

Almost 40 years later, while writing this story, I was told that only about 300 patients remain at Central State Hospital excluding, of course, the 25,000 who remain in its cemeteries. Those released are back in communities throughout Georgia; each one fully capable of lighting the way to reconciliation for anyone who sees them as strangers.

For those remaining in cemeteries, they continue to serve. I’m reminded of the charge Lincoln assigned the nation over another graveyard in 1863, Gettysburg. American, having not listened to “our better angels” was in the middle of a war that would fill cemeteries across the country with 620,000 casualties; many of whom lie buried in the battlegrounds on which they had died.

Our nation’s journey, like my own, is not finished. As Lincoln so eloquently reminds us, we can never forget what we did at Gettysburg; nor, I submit, at Central State Hospital.

For Philip Jay’s complete story, visit [www.GCDD.org](http://www.GCDD.org). ●

**These experiences left me certain of one thing: I wanted to spend the rest of my life committed to work truly valued by communities – work which was unlikely to be challenged or doubted, much less mocked or derided.**

An opportunity to move in this direction presented itself in a course at Mercer called, appropriately enough, Abnormal Psychology. Several of us were offered a chance to intern at the largest mental institution in the world: Central State Hospital in Milledgeville. At the time there were 13,000 patients with every psychiatric label known to man warehoused in conditions that can only be described as deplorable. Our focus was developmental disabilities. Our task – toilet training.

Our initial visit consisted of tours of the grounds and various buildings. As if to lend credence to the legends of medical experimentation at the hospital, one of the most memorable buildings housed laboratories with walls of shelves filled with assorted pieces of old, maybe even antique, surgical equipment including scalpels,



## House Bill 901 – Parent Protection Act – Remains in Industrial Relations Committee

A Winter 2010 article detailed the Parent Protection Act, a bill sponsored and supported by Representative Roger Bruce (GA-64). The Parent Protection Act provides up to 24 hours of unpaid, job-protected leave per year for parents to attend events and activities for their children or anyone they may provide support for. “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,” Bruce said to *Making a Difference*.

Bruce remains discouraged by the lack of progress. “There’s still resistance from the business community,” he said. “We’re attempting to move it from one committee to another.” The bill remains in the Industrial Relations Committee for review.

**“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.”**

“It’s really ironic because the business community says that they recognize that parental involvement is important to a child’s educational development, but at the same time they won’t allow a bill that promotes parental involvement,” Bruce continued. “It’s a contradiction!” Bruce expects that the bill will have to wait until the legislature convenes again before any movement is made.

## DBHDD Releases “Quality Management Systems” Annual Report for Developmental Disabilities

The Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) released its first-ever Quality Management System Annual Report for developmental disability services in February.

“The report is the first of its kind in Georgia,” said Beverly Rollins, executive director for the Division of Developmental Disabilities.

The report looks at the effectiveness of service delivery from the perspective of the individuals served and measures providers’ compliance with the department’s policies, procedures and training requirements.

**“A key goal for our division is gathering and sharing more information in better ways.”**

“A key goal for our division is gathering and sharing more information in better ways,” said Rollins. “We now have in place the tools we need to do that.”

The report is the result of interviews with over 1,200 individuals receiving services as well as reviews of provider records, on-site observations and interviews with providers conducted throughout 2008 and 2009.



## United States Census Kicks Off, Disability Community Encouraged to Participate

It takes 10 minutes to fill out, and can very well mean the difference between funding for the programs that matter most to you and no funding at all. 2010 marks another decade that has gone by since the last United States census – meaning that you’ll either receive a phone call, survey in the mail or a personal visit from a census taker to make sure you are counted.

Additionally, while every household receives a census form to fill out, a random sampling of houses will receive an American Community Survey – this is to provide an even deeper perspective on American households.

For more information on the United States census, visit [www.census.gov](http://www.census.gov) or the Georgia regional office at 404-730-3832. ●

## GCDD Presents Two Grants to Georgia Tech and BlazeSports America

Two innovative grants have been developed for two very deserving programs – the first is going to Georgia Tech for a series of webinars to encourage teachers to take advantage of developed materials called SciTrain. The materials with SciTrain help teachers learn how to integrate students with developmental disabilities into mainstream science, math and computer science classes. SciTrain’s courses are available online for free.

BlazeSports America is developing a youth leadership training program that targets youth in low-income communities, providing leadership skills through peer-led activities. The pilot program was completed successfully in 2008, and includes interactive workshops and experiential learning opportunities for attendees to practice leadership.

## Real Communities Initiative – A Process of Exploration

The Winter 2010 issue of *Making a Difference* magazine provided an update on GCDD’s Real Communities Initiative, a program encouraging communities to get involved in discussions that promote and foster inclusion.

Caitlin Childs, organizing director for GCDD, says that the process of identifying the five communities is still ongoing. “It’s an exploration,” she said.

“Incorporating different programs and communities into this initiative will be done on a case-by-case basis.” Childs also explained that part of this process is to decide whether or not the model that the Real Communities Initiative is going after will be a good fit for the final communities.

In the beginning of March, the Department of Community Health Development (ABCD) training in Warner Robbins for GCDD and communities that have been participating in the program so far, including representatives from Ben Hill County, the Georgia Korean community and the city of Milton.

Childs looks forward to really kicking the Real Communities Initiative into gear. “We hope to have an announcement on our official communities within the coming months.”

## GCDD Staff Honored

Eric Jacobson, GCDD executive director, has been honored with the 2010 Webb Spraez Award which was created in 2003 by Jewish Family and Career Services (JF&CS) to honor an individual, group or corporation whose dedication and energy promote growth and success of the Larry Bregman MD Educational Conference. Each year the Bregman conference offers adults with developmental disabilities, their families and their care gives the opportunity to learn about topics that might not be addressed in other venues.

GCDD Deputy Director, Pat Nobbie is the recipient of the annual Heart of Gold Tom Graf Award. The Tom Graf Award, awarded by All About Developmental Disabilities (AADD), recognizes an individual whose efforts, in a professional capacity or advocacy role, represents an outstanding achievement or contribution that has benefitted people with developmental disabilities.

Dottie Adams, GCDD Individual and Family Support director, is a finalist for a 2010 Community Impact Award, sponsored by Parent to Parent of Georgia. The Impact awards recognize individuals whose actions demonstrate, support or lead to inclusion of individuals with disabilities so they can meaningfully participate in all aspects of life. Impact award winners will be announced in late April. ●



*Those involved with the Real Communities Initiative met in Warner Robbins in early March 2010 for a workshop involving Asset Based Community Development. (Back row, l-r) meeting facilitator Mike Green, Milton mayor Joe Lockwood, Milton city manager Chris Lagerbloom. (Front row, l-r) Stacey Ramirez of the Real Communities Initiative, Noel Keilhauer of the Real Communities Initiative, Radha Vettrai of Community Action Pioneers in Gwinnett, Ann Coggins of the Milton Disability Awareness Committee, and Caitlin Childs of GCDD.*

# “I for Inclusive”: Inclusive Adult Education Program Stirs Interest

**I**nclusion is the name of the game at Kennesaw State University (KSU), where a pilot program sponsored by the Georgia Council on Developmental Disabilities is shaping up to serve as a model for colleges and universities across the United States.

“There’s been a lot of interest,” said Jill Sloan. Sloan is the program coordinator of KSU’s Academy for Inclusive Adult Education. The program is set up to act as “a bridge” between high school and the “real world,” so students with developmental disabilities can increase their education and chances of employment, as well as learn vital social skills.

Participants attend college courses for two years, and receive a KSU Certificate of Social Growth and Development upon completion. Students audit two classes per semester. “For example, the very first semester includes ‘Fitness for Living’ and ‘First Year’ classes. Second semester classes are ‘Arts in Society’ and ‘Self-Defense,’” Sloan said.

**“They can use these skills to go on and get college credit, earn their GED or get started in the workforce.”**

After that, the possibilities are endless. Students are able to choose classes that fit their interests and desires. “Students are responsible for showing up to class, being on time, paying attention – they’re students,” Sloan said.

Parent Kim Tilford’s daughter, Kelsey Bizzell, attends KSU under this program. “Kelsey’s big dream has always been to go to college,” Tilford said. “But one of her teachers in high school said something to Kelsey about how she could just forget that dream. Kelsey was crushed.” Tilford went on to explain how she connected with Sloan to learn more about the KSU program.

Student Christopher Hunnicutt had a similar path. “One of his goals was to go to college,” said his father, Chris Hunnicutt. “I learned that GCDD had thrown their support behind this program, and we applied for him to do this.”

“I love Kennesaw,” said student Christopher. “It’s great to see that kids with disabilities are coming and learning. And it’s not based on their disability, it’s based on their education and their qualifications.”

“Kelsey is definitely planning on being back for next year,” Tilford said. “She loves to read and she wants to work with children to teach reading. So Jill enrolled Kelsey into classes on early childhood and teaching reading in the elementary grades.”

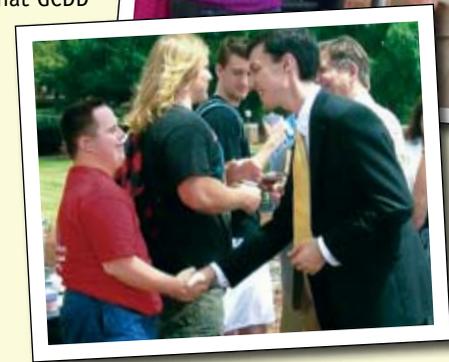
“I see this program as a bridge to further endeavors,” Sloan said. “They can use these skills to go on and get college credit, earn their GED or get started in the workforce.”

Students are integrated into on-campus jobs. “Their first semester is spent job shadowing employees in various departments across campus,” Sloan said. “Based on evaluations, we’re able to match them up with an on-campus job.”

“Kelsey works in the bookstore,” Tilford said. “This is a life skill she can take with her.”

Kennesaw State University is the first in the state to develop a program like this one – but Sloan is optimistic that more will soon follow. “Other colleges and universities are interested,” she said. “One of our goals is to participate in creating a consortium of colleges across the state, developing a program.”

In the meantime, the program is expected to grow to at least five entering students in Fall Semester 2010. ●



Above: Students Mary Minotto (right) and Christopher Hunnicutt (left) make the rounds at a meet-and-greet with KSU administration.

Below: Kelsey Bizzell will move on next year to take education courses, combining her love for children and for reading.



# Nine Days and Counting: an Update from the Capitol

**I**t's always nice when the legislature cooperates and is ready to wind down by the time this update goes to press, but for the last few years we haven't had such closure and this year is no exception. The information reported here is current as of "Crossover Day" which is the thirtieth day of the session. Legislation that doesn't clear either one house or the other is "dead" after Crossover Day (barring bills being attached to other bills which are still active) so in effect, they have "cleaned house," reducing the amount of legislation that we need to track.

So, what's left?

## **Tier I:**

**In the Council's legislative agenda, Tier I always includes the Unlock the Waiting Lists! budget requests.** As we reported in January, this is a brutal year for the state budget. As of this writing, the FY 2010 budget has not yet been conferenced to resolve the differences, and

**The FY 2011 budget was further reduced by \$442 million, triggering another round of three percent cuts to most state agencies, and some other significant reductions.**

Governor Sonny Perdue had to lower the revenue estimate again, reducing the 2010 budget by another \$342 million dollars, which was replaced with stimulus funds from the American Recovery

and Reinvestment Act money originally allocated in the 2011 budget. Then the FY 2011 budget was further reduced by \$442 million, triggering another round of three percent cuts to most state agencies, and some other significant reductions. In the midst of these budget reductions, negotiations were ongoing regarding cigarette

**We retained the funds for 150 COMP waivers to transition adults from the state hospitals to the community, but no new services for adults on the community waiting lists were included in Governor Perdue's budget.**

tax, hospital bed tax, and other fee increase legislation. As of Crossover Day, a 1.45 percent bed tax was accepted by the hospitals (with some exceptions) in lieu of a 10.5 percent provider rate cut. However, the cigarette tax appears to be dead at this point. Several bills to increase fees for government services or documents were passed by the House. We are waiting on an analysis of these and their impact on the budget.

In the background of this precarious budget situation, the negotiations with the Department of Justice and the Office of Civil Rights regarding the CRIPA lawsuit are still ongoing, with no definitive indication of the impact of that settlement on the budget. The House held appropriations committee meetings Tuesday, March 30 and passed out their respective budgets with few changes from what we knew in the beginning of the session. We had no further detail on the use of \$42 million in new money proposed by the Department of Behavior Health and Developmental Disabilities to address the CRIPA lawsuit. As of this writing, we retained the funds for 150 COMP waivers to transition adults

**Most agency heads would acknowledge that we are well beyond cutting the fat and are now cutting into the bone. Further reductions will now result in diminishing returns in the ability of agencies to maintain services.**



from the state hospitals to the community, but no new services for adults on the community waiting lists were included in Governor Perdue's budget.

**The other Tier I item was a new multiyear strategic planning and funding plan resolution to replace HR 1307 which expires at the end of this session.** HR 1713 was introduced by Judy Manning, with co-sponsors Gardner, Houston, Walker, Channell and Rynders. This resolution expands the request to the Departments of BHDD, DCH and DHS to include strategic planning and funding projections for the NOW/COMP waivers, state-funded family support, community-based mental health services, ICWP waivers and funds necessary to support rates that will increase provider capacity.

**The legislation authorizes savings accounts for the purchase of assistive technology such as home and vehicle modifications, communication devices, hearing aids and more...**

## **Tier II:**

**Individual Development Account legislation: HB 1314, sponsors Sheldon, Hill, Kaiser and Mosby, passed the House.** Eligible low-income individuals deposit money in the account, and the deposit is matched by an outside source. Federal IDA legislation enables individuals to save for homes, businesses, or higher education. The legislation authorizes 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. Individuals' public benefits would not be affected. As of this writing, the legislation was assigned to Senate Health and Human Services Committee.

**Exception Amendment to Nurse Practice Act: HB 1040,** sponsors Pruett, Cooper, Cole, Ramsey, Cheokas and Byrd, was put through the grinder (four passes through Non-civil Judiciary Subcommittee, and then full committee of Judiciary Non-civil, before going to Rules) but emerged successful on Crossover Day with a House vote of 162 to 0. 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, after training by a nurse. Many of these activities can be safely provided by an unlicensed person at reduced cost to the state.

**The New Home Access Act, sponsored by Sen. Nan Orrock (D-36) in last year's session got a new life as HB 1395,** sponsored by Rusty Kidd and others. 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. 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. Although



**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.**



**The Parent Protection Act, HB 37, did not advance.**

this bill did not cross over, we are planning a hearing in House Regulated Industries to air the issue and let the builders know we are not giving up.

**The Parent Protection Act, HB 37, did not advance.** A scaled down version, which would require that employers who award sick leave allow their employees to use their acquired days toward caring for sick children also did not advance.

**Tier III:**

The following is the list of legislative items that the GCDD signed on to, or allowed our name to be used in supporting literature, and its status as of print time.

- **Blind Persons Braille Literacy Rights and Education Act** to ensure teachers of the blind are literate in Braille. Did not cross over. Coalition for the Blind will regroup over the summer.
- **Appropriations for the CCSP and Non-Medicaid Home and Community-based services (Co-Age).** CCSP Money follows Person budget was eliminated. Other aging services were reduced.
- **Legislation for the Coordinating Council for Human Services Transportation (Co-Age).** SB 22 passed the Senate, in House Transportation committee.
- **SB 207, the Tax Expenditure Report, to catalogue the tax breaks and incentives awarded to businesses** by legislators each year and assess their cost-benefit to the state budget. Passed the Senate, House recommitted to negotiate content of the tax report.

- **Revisions to the Elections Code:** Remove 'physical' from the definition of disability describing who can seek assistance at the polls (The Arc of Georgia). This legislation was not pursued.
- **Respectful Language Legislation:** Removal of words like moron, imbecile, retarded, idiot, from the Official Code of Georgia (The Arc of Georgia). Legislation to change the code was stalled due to technicalities. SR 1324 urged restraint of use of the term mental retardation in official code and language, and passed the Senate.
- **SB 292,** revisions to the Juvenile Code (JUST Georgia). This legislative work is ongoing.
- **HB 290:** Raise the state minimum wage (Atlanta 9 to 5). This legislation did not move.
- **Legislation to modify the Estate Recovery requirements:** This legislation did not become active.
- **HB 391:** 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. Passed Senate, now in House Judiciary Non-Civil.

**This will reduce administrative costs for dental services by more than 10 percent, hopefully enabling Medicaid to retain better reimbursement rates for dentists in the program.**

**Other Legislation of Note:**

- **HB 1407** requiring a single payer for dental services provided to children in PeachCare through the CMOs passed the House. This will reduce administrative costs for dental services by more than 10 percent, hopefully enabling Medicaid to

retain better reimbursement rates for dentists in the program.

- **HB 565**, Commission for the Blind and Visually Impaired: Representative Howard held a meeting for information and plans a legislative hearing in committee. The Coalition for the Blind will continue working on this issue over the summer.
- **HB 1311**, sponsored by A. Scott, Kaiser, and Dempsey: Removes the means test for eligibility for services under VR. Georgia is one of the few states with a means test for some services under the Division of Vocational Rehabilitation which is not required under the federal rehab act. House Industrial Relations will hold a hearing on the issue before the end of the session.

**Many options for establishing a balanced approach to the budget, including examining existing tax credits and exemptions for their value, revising the tax code to update it to the profile of our current economy, and a variety of revenue enhancements need to be considered.**

## Making the Case for a Balanced Approach

Casting long shadows over this session is the state's weak economic situation and fears of the effects of further reductions on state agencies' ability to provide critical services. Most agency heads would acknowledge that we are well beyond cutting the fat and are now cutting into the bone. Further reductions will now result in diminishing returns in the ability of agencies to maintain services. Many options for establishing a balanced approach to the budget, including examining existing tax credits and exemptions for their value, revising the tax code to update it to the profile of our current economy, and a variety of revenue enhancements need to be considered.

## By the Numbers:

Individuals on the DD waiting list ..... **4,917**

Individuals on the ICWP waiting list..... **187**

Approximate number of individuals with DD living with a caregiver over the age of 64 ..... **17,000**

Original FY 2010 Revenue Estimate..... **\$20,193,974**

Revised Revenue Estimate for the FY 2010 amended budget..... **\$17,074,653**

Revised Revenue Estimate for the FY 2011 budget ..... **\$17,713,512**

On Friday, March 26, the House passed legislation to establish a Tax Code review commission to revise and update the existing tax code. There was some opposition because the make-up of the commission appeared to be favored toward corporate interests, so consumers and citizens need to watch the work of this commission closely in the interim to ensure that changes to the tax code are balanced among the interests and needs of Georgia's diverse citizenry.

Further updates will be provided in future issues of *Making a Difference*. ●



# “It’s Time to Stand Up and be Counted!”:

## DISABILITY DAY 2010

**T**he 12th Annual Disability Day in front of the Capitol was a spirited affair, with advocates from across the state – and across the country – coming together to let the Georgia government know that they are ready...ready for the waiting lists to be cleared; ready for legislation to be passed for more readily available accessible housing options; ready for employers to recognize the value that employees with disabilities bring to the workplace...ready for change.

“I came today because, as a self-advocate, I can help myself better,” said Krishna Goel. Goel came with the Brain Injury Support Group of Augusta, and held a sign that translates to “Count Me In, Count My Vote, Count My Community” in Hindi.

Disability Day is for advocates to have a tangible connection to their government representatives. As a parent advocate, Phyllis Kahn has been to many Disability Days.

“Who is going to take care of my children when I’m gone?” she asked. “That’s my biggest fear. That’s why I’m here today. I do whatever I can to make sure that others, including my own, receive services.” Her son, Jeffrey, lives in a group home and daughter Amy lives on her own with support.

While Kahn has been to many Disability Day events over the years, the 2010 rally was Mary Jackson’s first. Jackson, a provider outreach specialist for APS Healthcare of Atlanta, was working with coworker Roslynn Miller-Rivers on creating signs with different languages. “Disability does not discriminate,” Jackson said. “That’s why we’re making signs in these different languages. Disability can



Council Chair Tom Seegmueller and Executive Director Eric Jacobson encourage participation and advocacy.



happen to anyone regardless of age, race, gender, religion – doesn’t matter.”

The over 2,000 demonstrators flooded the streets in the march to the state Capitol, where they braved frigid temperatures. Eric Jacobson, executive director of the Georgia Council on Developmental Disabilities, gave an order to attendees. “Your job is to make sure that they,” he emphasized, gesturing to the Capitol building and meaning government officials, “come knocking on your door and asking for your vote. Your job is to make sure that they know what issues you care most about.”

Tom Seegmueller, chairperson of GCDD, welcomed the sea of advocates. “I know it’s cold out here,” he joked. “But your presence here truly makes a difference in the lives of all Georgians – it’s not just for you, but for the countless people that weren’t able to make it today.”

Throughout the day, Jacobson and other speakers led the crowd in a roaring chant: “Count me in. Count my vote. Count my community.”

“In an April 2008 speech, President Barack Obama said ‘We must build a world with no barriers,’” Jacobson stated to a cheering crowd. “It’s time to hold our government officials to that promise!”





**The right to work is for everybody. At the Office of Disability Employment Policy, we're working on developing jobs with actual promotions, retention and satisfaction.**

Kathleen Martinez was nominated to be the third assistant secretary for Disability Employment Policy, and was confirmed by the U.S. Senate in June 2009. Martinez spoke at the 2010 Disability Day, encouraging attendees to hold their elected officials accountable in the fight for inclusion.

Georgia Department of Labor Commissioner Michael Thurmond delivered a short speech, welcoming attendees to the state Capitol. "I want to ensure that every Georgia citizen has access to all educational and employment opportunities in the state – let's knock down those barriers."

"UNLOCK THE LISTS!" Thurmond encouraged the crowd to shout. "Say it so they can hear you in the

**"I want to ensure that every Georgia citizen has access to all educational and employment opportunities in the state – let's knock down those barriers."**

Capitol! Say it so they can hear you in Savannah, in Augusta, in Athens!" After his rousing speech, Thurmond introduced one of the keynote speakers, Kathleen Martinez.

Kathleen Martinez, the assistant secretary for U.S. Department of Labor's Office of Disability Employment Policy (ODEP), was the co-keynote speaker for Disability Day. "The right to work is for everybody," she said. In speaking about employment opportunities for those in the disability community, Martinez said "We get what we're willing to accept."

"It's easy to get channeled into a job with low to no expectations," she continued. "At the Office of Disability Employment Policy, we're working

on developing jobs with actual promotions, retention and satisfaction."

Martinez also discussed the aging of American citizens. As the 'baby boom' generation grows older, the rate of Americans with disabilities will continue to increase. "As we become an increasing part of the workforce, the stigma will be reduced," she said. "Exposure helps reduce stereotypes and negative responses."

"Don't stop holding your elected officials accountable," Martinez continued. "Michael Thurmond?" she said, gesturing back to where Thurmond stood. "Keep him accountable. Pick up the phone. Write letters. Come to events like Disability Day. Make your voice heard."

Martinez also informed the crowd of an event – at the end of April there will be a "hiring extravaganza" in Washington, DC, which will be very much like a job fair for people with disabilities to connect with employers. "We're hoping that this will be a successful event with strong response, that could potentially go 'on-the-road' and extend to cities across the country," she said.

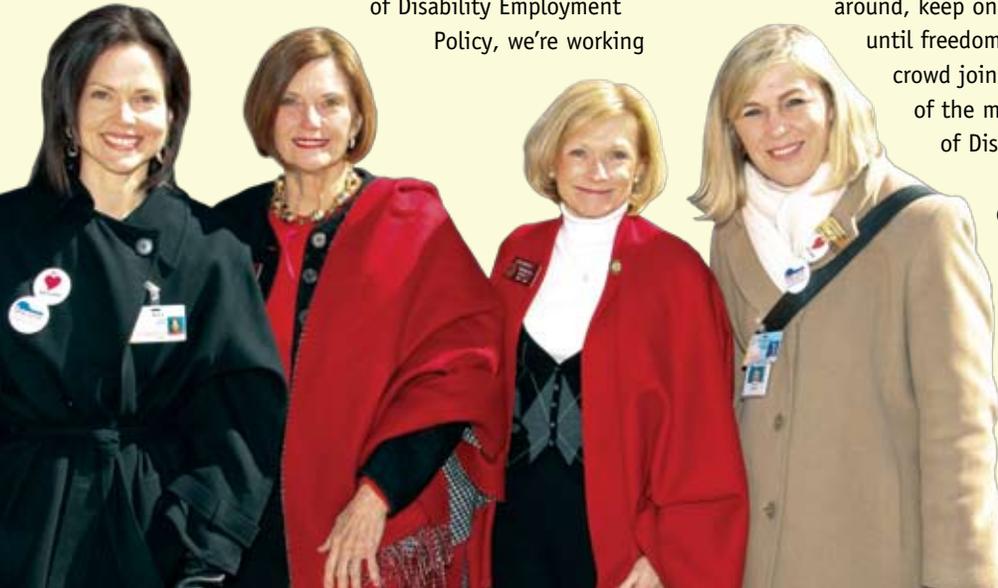
Following Martinez's speech, Thurmond took the podium and led the crowd in a version of a song that was popular during the Civil Rights movement in the 1950s and 1960s: "Ain't gonna let nobody turn us around, keep on marching, marching until freedom come," he sang as the crowd joined in. It was truly one of the more poignant moments of Disability Day.

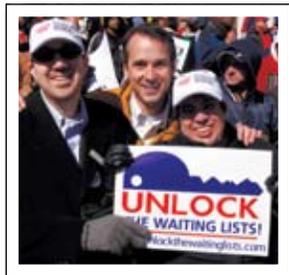
Pat Nobbie, deputy director with GCDD, introduced Bill Janes, the new Olmstead coordinator. "Unlocking the Waiting Lists! isn't just about moving

**"Ain't gonna let nobody turn us around, keep on marching, marching until freedom come."**



Michael Thurmond, commissioner of the Georgia Department of Labor, led the crowd in a song popular during the Civil Rights movement.





**Unlocking the Waiting Lists! isn't just about moving people out of institutions and into communities ...once people are moved to the community, we must figure ways to sustain them.**

people out of institutions and into communities," he said. "Once people are moved to the community, we must figure ways to sustain them. That is another vital part of the committee's charge."

Janes explained that a new Olmstead Plan would be available in a few months. He formerly served as the director of Florida's Office of Drug Control and as assistant secretary of Substance Abuse and Mental Health in Florida's Department of Children and Families.

Dorothy Harris of People First of Fitzgerald, Georgia, introduced co-keynote speaker Julie Petty of Self Advocates Becoming Empowered (SABE). As at all Disability Days, Petty emphasized the point that disability rights are not "partisan issues."

"The great thing about our country is that we can talk to our government, engaging our elected



Co-keynote speaker, Julie Petty of Self Advocates Becoming Empowered, encouraged younger advocates to become more involved with the issues.

officials in conversation," Petty said. "I'm excited to see the diversity and the wide spectrum of people with different types of disabilities attending today."

Petty was also enthusiastic to see a great amount of younger adults and children in the crowd. "They are our future, after all," she said. "They have totally different perspectives, which is great. It's exciting to see young advocates getting involved."

The way Petty explained things, it made disability advocacy seem pretty simple. "We want



Tracy Allardice (right) and Jennifer Garrett, sisters of the late self advocate Natalie Tumlin, present the Self Advocate of the Year award to Rebecca Ramage-Tuttle.

society to give us the help we want when we need it," she said. "We can – and want to – give back to our communities. We don't want to be assigned to a bed. We want support for our family members. We want what everyone has."

The final act of business was in presenting the Self Advocate of the Year award, an annual tradition in honor of the late Natalie Tumlin. Her sisters, Tracy and Jennifer, were on hand to present the award to Rebecca Ramage-Tuttle. Tuttle was recognized for her role in bringing 400 advocates to Atlanta for the October ADAPT rally.

"It's a great honor to be recognized," Tuttle said. "But advocacy is always a group effort." Tuttle also talked about her friendship with Tumlin. "She lived the life we strive for every day," she said. "I miss my friend, but am honored to receive this award, and to continue being a self-advocate."

Reaction to Disability Day was overwhelmingly positive. Britt Anderson with Just People, who was attending for the first time, was impressed with the organization of the day. "I really liked it!" he said. "It's good. I liked hearing from people who are advocates."

Joellen Hancock, a parent advocate, also enjoyed the camaraderie and spirit of the day. "Children with disabilities are just like everyone else," she said. "They want to be with their peers. Today is well-organized and very informative – just cold!" she finished cheerfully. ●

**"We can – and want to – give back to our communities. We don't want to be assigned to a bed. We want support for our family members. We want what everyone has."**



# 'Listening Tour' to be Springboard for Action

by Carly Sharec

## DISABILITY DAY



On Wednesday, February 24, the U.S. Department of Labor's Office of Disability Employment Policy (ODEP) stopped in Atlanta on their six-city 'Listening Tour.' This tour will play a key role in forming future endeavors, as advocates work to break down barriers and increase employment opportunities for people with disabilities.

Assistant Secretary of Labor for Disability Employment Policy, Kathleen Martinez, was joined by representatives from the U.S. Department of Labor, U.S. Department of Education and the Social Security Administration in listening to a variety of opinions. The day was conducted as an open forum, with the panel of government representatives listening to advocates from across the state as they shared their stories, and their beliefs in what will help the system.

"We want to create a true strategic plan for how to move forward," Martinez said. "Listening to what people truly desire, as well as listening to positive stories that show certain models working, is what helps us create a plan."

Martinez noted that in the six-city tour (which also visited Dallas, Philadelphia, Chicago, San Francisco and Boston), she noticed several themes emerging. "People mostly want the federal government to walk the walk," she explained. "They want more opportunities provided by government agencies."

She also mentioned that she was disappointed that more employers did not attend. "A change in attitude starts at the top," she said.

Indeed, the numbers are staggering. In January 2010, the overall unemployment rate in the country was 10.4 percent; however, the overall unemployment rate was 15.2 percent for people with disabilities. More sobering is that 70

percent of unemployed people are actively seeking work, but only 21.8 percent of unemployed people with disabilities are actively seeking work – a number that suggests that the employment situation is so frustrating, people are giving up their employment search.

Eric Jacobson, executive director, and Pat Nobbie, deputy director, represented the Georgia Council on Developmental Disabilities in speaking to the listening tour panel. Nobbie shared her experiences in being an advocate for her daughter, Mia. Mia expressed a desire to work, but was initially told that she was not ready for employment.



Pat Nobbie (left) shares her story with the Listening Tour panel, as Eric Jacobson listens in.

**"When we talk about community, we recognize that all people want to participate in their communities."**

"In high school, Mia was the manager of several sports teams, was involved with several regular education classes, and taught Sunday School," Nobbie said. "But her initial assessment was that she was not ready for employment. We requested another assessment, and she found a job where she is successful and that she enjoys."

"The reality is that I'm connected," Nobbie said, referring to her connections as a part of GCDD. "Good for me. But that doesn't help others trying to advocate for their children. As a

parent myself, I know the process of employment needs to be easier."

Jacobson provided information on the background and role of GCDD, along with introducing the Real Communities Initiative. "When we talk about community, we recognize that all people want to participate in their communities," he said. "Employment remains our priority."

Maia Santamaria with the Centers for Independent Living (CIL) in Rome, shared her story with the panel. "Northwest Georgia is very, very rural," she explained. "The national average for people with disabilities is one out of five. In northwest Georgia, that spikes to two out of five people. So it's very important for our area to have access to programs that aid in employment and accessible housing."

Donna Baxley, who was attending from CIL with Santamaria, discussed President Barack Obama's proposed budget. "It means money will go to the states rather than directly to programs

like CIL. We don't want this to happen." She encouraged Martinez and the participating panel, to fight against this proposed budget change.

A report of the findings during this tour will be shared with advocates and government officials. "The involvement of

everyone is critical," Martinez said. "There's no way we can work in a vacuum. To be successful, we need collaboration with all."

"I think it's impressive how Georgians collaborate," Martinez continued.

"That's why I wanted to speak at Disability Day. People with disabilities are a big market. I've been impressed with the work that Georgia has done in disability advocacy, and look forward to future initiatives." ●



**Listening to what people truly desire, as well as listening to positive stories that show certain models working, is what helps us move forward in creating a plan.**

# PERSPECTIVES

## Positive Behavior Support:

### The long-term solution to the problem of seclusion and restraint

By Daniel Crimmins, Ph.D.



*Daniel Crimmins, Ph.D. is the director of the University Center for Excellence in Developmental Disabilities program (UCEDD) at Georgia State University in Atlanta. He also is a professor in the Institute of Public Health. In this role he oversees a range of training and technical assistance programs that have the goal of improving services for individuals with disabilities of all ages. Crimmins received his B.A., M.A., and Ph.D. in psychology from Binghamton University, and completed an internship in clinical psychology at the University of Mississippi Medical Center.*

New regulations are an important first step toward limiting the use of restraint and seclusion in the schools. But regulations by themselves are not enough. If we eliminated seclusion and restraint tomorrow, and did nothing else, there is a very good chance that schools would increase their use of suspension, expulsion, calls for law enforcement and recommendations that students be evaluated for medications to control their behavior.

I am certain that school personnel genuinely want to do the best thing for their students. But schools are complex organizations with dozens of written rules and procedures related to behavior, and an equal number of unwritten ones. When faced with challenging behaviors, teachers, paraprofessionals, therapists and administrators typically respond by doing what their schools have always done – usually some form of reprimand or punishment, and even at times restraint and seclusion. If we take away what they've always done, we must be sure that there is training and support in positive approaches to challenging behavior.

There is a long-term solution to this dilemma – the approach called Positive Behavior Support (PBS). PBS has the goal of building a school-wide culture that promotes behavioral competence, including the following five components:

- Define clear, concrete, easy-to-understand behavioral expectations for all students
- Demonstrate these expectations and have all students practice them in all settings
- School personnel monitor student performance and reward appropriate behavior
- School personnel provide corrective consequences for behavior problems
- Teachers and administrators continually review, evaluate, and improve the system

This approach is now being used in over 10,000 schools across the United States, including more than 150 schools in Georgia.

There is a growing body of research that says PBS works! We know that children do not learn positive behaviors through negative consequences, such as restraint and seclusion. Children do learn positive behaviors through clear expectations, direct instruction, modeling, positive reinforcement and practice. Last but not least, we know that schools that adopt PBS show improvements not just in student behavior, but also in measures of school climate, staff morale and academic achievement.

**If we take away what they've always done, we must be sure that there is training and support in positive approaches to challenging behavior.**

So will this approach work for all kids? The answer is a qualified “yes.” We expect most students to respond to school-wide PBS. We also know that there are always some children who learn differently and need extra support to master critical skills – the PBS framework says that 15 to 20 percent of children will require some extra time and attention from teachers and counselors. Finally, we also expect that a smaller number (often only two or three percent of all students) will need intensive, individualized attention and support from school personnel to look at persistent behaviors, understand why they continue and develop an individualized positive behavior plan to replace it.

If I had one wish for Georgia, it would be that all schools would adopt the PBS model. I say this with the understanding that doing so requires a commitment of staff time for planning, training, implementation and monitoring of many years. I also say this with the heartfelt belief that it will save the lives of a few, drastically change the lives of many, and dramatically improve the lives of all. This is why we do what we do! ●

With forethought and proper procedures put in place,  
schools can become truly safe environments for learning.

## Tragedy Leads to Advocacy

By Don and Tina King

Our son, Jonathon, was a very outgoing boy – a typical teenager. He loved sports and being outside. He loved baseball and swimming – we called him a typical outdoorsman. He was a good kid; very happy-go-lucky.

We would ask him how his day was at school. Often he would not tell us, and other times he would tell us he had to go to time out. To me, time out meant you had to go sit in a corner for a short period of time, so I never thought to question him on it.

It turns out that time out was very different for our son. He was being locked in a jail cell – there was no light. He had no access to food or water. Plus, he was claustrophobic, so the whole experience was very traumatic for him.

After Jonathon passed away, we were shocked when we learned exactly what he had been going through. And the school did nothing. Nobody was fired. The courts have said, so far, that Jonathon's rights were never impinged upon. They swept it under the rug.

**Even if there were no physical marks, the emotional harm of secluding or physically restraining a child remains with that child for his or her lifetime.**

So we started attending forums and talking to people. It was shocking to learn that this has happened before, to countless families. Even if there were no physical marks, the emotional harm of secluding or physically restraining a child remains with that child for his or her lifetime.

The rule that's being passed in May is a great start. It's too late to help our son, but it's going to help thousands of other children. You shouldn't have

to go to school and be afraid for your life. Our only hope is that nothing happens until it is passed. It only takes one moment to forever change a lifetime.

**We realize that every situation with every child is different, so one blanket rule is not going to prove helpful to students, parents or teachers in the long run.**

Our main goal, though, is to ensure that teachers have the proper training in dealing with children with behavioral issues. The teacher watching over Jonathon had just started at the school. He wasn't even trained in CPR. So we want to make sure that proper training is mandatory. We realize that every situation with every child is different, so one blanket rule is not going to prove helpful to students, parents or teachers in the long run.

That's why it's important for parents to become better informed. Schools need to work more with the parents. At the schools Jonathon attended previously, they knew that if they called us with any problems, we would have come to pick our son up. When incidents happen, parents must be notified. Also, seclusion rooms need to be done away with. If a child must be placed in a separate location from his or her class to calm down, then that child must be supervised and treated with respect.

We're currently waiting for word from the United States Supreme Court on whether or not they will hear our case. In the meantime, we urge parents to be involved. When you ask your child what he or she did in school that day, ask follow-up questions. Don't ever assume "time out" means what you think it means.

Our main goal is that no parent has to go through what our family has gone through. ●



John Bazemore, AP

*Don and Tina King reside in Dahlonega. Don works with Georgia Power, while Tina is a medical professional. To learn more about the Safe Schools Initiative and Jonathon's story, turn to page 18.*

# Safe Schools Initiative

## Taking Restraint and Seclusion out of Schools

**E**very day parents across the United States, including the state of Georgia, send their children off to school, thinking that their child will come home safely and more knowledgeable than the day before. A quality public education is part of the American dream, after all.

However, for many families, that dream has turned into a nightmare.

"The issue of seclusion and restraint in schools is really of national concern," said Leslie Lipson, director of the Parent Leadership Support Project in the Georgia Advocacy Office. "But it's especially relevant in Georgia because of the Jonathon King tragedy."

**"These are children. They deserve respect and the knowledge that adults will take care of them."**

Jonathon King was an eighth-grader in Gainesville who had been entered in what is known as the ALPINE Program after his behavioral issues worsened in sixth grade. This program is in place to serve students with severe emotional or behavioral disabilities, as well as students with autism. Its Web site states that "the program provides educational services to the students, consultation services to schools, and training and support services to families." The Web site also continues to state that the program utilizes

a social skills curriculum called the Student Achievement Model.

Throughout his eighth-grade year, however, Jonathon was kept in a small seclusion room for hours on end. He eventually threatened suicide. According to news reports, his teachers also reported that he often threatened suicide – however previous threats were deemed empty.

**"The issue of seclusion and restraint in schools is really of national concern."**

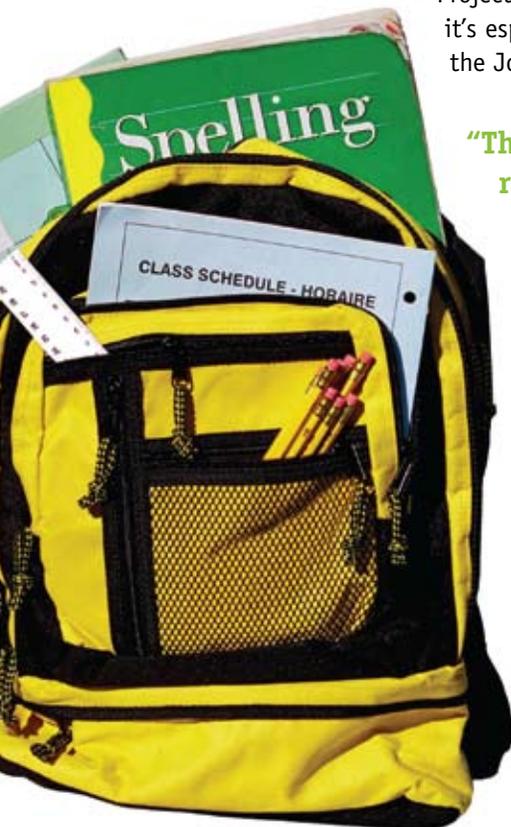
One day, in 2004, a teacher handed Jonathon a rope to hold up his pants. The teenager was then sent to the seclusion room, where he was found later.

"You have a young boy that was literally given the rope he used to hang himself in an unmonitored seclusion room," Lipson said. "The worst part is that his parents had no idea. He was so used to being in the seclusion room, he didn't even report it to anyone outside of the school.

"His parents sent their child to school on a bus in the morning, and he died," Lipson continued. "That shouldn't happen. Ever."

While terribly sad, this situation does seem to be extreme – until you read the reports from neighboring states. A January 2009 report by the National Disability Rights Network (NDRN) stated that 41 percent of states and territories have no laws, policies or guidelines concerning restraint or seclusion use in schools. Nearly 90 percent still allow prone restraint, which is the most dangerous way to restrain a person.

"Prone restraint is inherently more harmful," explained Lipson. "When you're holding someone down, and they're face up, you can tell if they are breathing. In prone restraint, the person is





held face down. The person conducting the hold can't tell if the person can breathe or not." The NDRN report states that prone restraint can lead to sudden fatal cardiac arrhythmia or respirator arrest, cerebral and cerebellar oxygen deprivation, lacerations, abrasions, bruising and blunt trauma among other injuries. Consider the seven-year-old girl in Wisconsin who died after several adult staff at a mental health day treatment facility pinned her to the floor.

"The use of seclusion and restraint originated in psychiatric care facilities as an emergency mechanism," informed Lipson. "It's not regulated in our schools. There's no spotlight on this issue."

Parents, students and advocates across the United States, including Georgia, are urging their departments of education to limit or regulate the use of restraint and seclusion. For example, the Georgia proposal (which is the version expected to be passed in May) outlines and specifies the prohibition of seclusion in Georgia public schools along with prohibiting prone restraint, mechanical restraint, chemical restraint or any other use of physical restraint except in situations with the student is an immediate danger to himself or to others.

"We're in the process of developing a rule on the use of restraint and seclusion," explained Kim Hartsell. Hartsell is the director of Special Education Supports for the Georgia Department of Education. "We've obtained input on the rule from a diverse group of stakeholders, and we are planning to initiate the rule at the state Board of Education meeting in May." Hartsell explained that this means the rule, which prohibits the use of restraint in Georgia schools unless a child is deemed to be an immediate danger to himself or others, will be in effect in time for the start of a new school year in fall 2010.

The Department of Education (DOE) began thinking about regulating the use of restraint and

seclusion in 2008. "We disseminated guidance on the use of seclusion and restraint in October '08 to the Georgia Network for Educational and Therapeutic Support (GNET) programs," Hartsell said. "Then in the spring of 2009, we began the development of this rule."

The rule also states that, in the case of restraint and removal from a classroom being used, the school must notify the parents of the student in question immediately (within one school day of the event in question.) "The goal is to keep students – all students – safe," Hartsell said. "It creates a safe school climate for students and staff, which ultimately supports a positive learning environment. It's not really a rule about discipline – it's a rule about student safety and what to do in a situation when a student's behavior is truly dangerous."

There is a question as to what is the alternative when a student does act up or disrupts a class, posing harm to himself or to others. Daniel Crimmins of the Center for Leadership in Disability at Georgia State University explained that the alternative is a Positive Behavior Support System. "We know that children are not born with bad behaviors," Crimmins said. "We also know that children do not learn positive behaviors through negative consequences – they learn positive behaviors through direct instruction and positive reinforcement."

**"It's not really a rule about discipline – it's a rule about student safety."**

Crimmins also explained how while school-wide procedures should be in place for all students, students with chronic behavioral problems may need individualized plans for positive behavior supports. "This is when school

**There is NOTHING educational about RESTRAINING a child.**



Leslie Lipson, Director, Parent Leadership Support Project.

staff and parents have to work together,” he said. “The student, as well, plays a vital role in coming up with a workable plan that keeps everyone safe.”

Currently in the state of Georgia, there’s no required training for school officials in the practice of restraint, though most schools that practice restraint do offer training. “It is highly encouraged,” said Hartsell. “Training for school and educational program staff was addressed in the initial guidance issued to GNET in 2008 and training is required in the proposed rule on seclusion and restraint.”

Lipson is encouraged by the DOE’s regulations. “A lot of schools throughout the state have adopted these regulations when it comes to training their teachers and staff,” she said. “What we’re finding is that when schools adopt these methods, and work on positive behavior supports, there is an incredible reduction in the time that administrators take in working with students who need behavioral supports.”

While the DOE passing the rule is a good start, advocates in Georgia still do not have time to rest – there’s more they are after in this debate.

**“We want schools to be smart and thoughtful in how they work with students. There are methods that will work for an entire school, and also methods that will work for individuals.”**

“That’s not entirely what we’re looking for,” explained Lipson. “We’re looking for a cultural change. We want schools to use positive support behaviors. We want schools to be smart and thoughtful in how they work with students. There are methods that will work for an entire school, and also methods that will work for individuals. So while the rule change plus guidelines on how to properly restrain a child are a good start, we’re still seeking that cultural change.”

Some opponents of the Safe Schools Initiative attempt to point out that a child in danger of harming himself or others is a

disruption to the educational system. Lipson politely disagrees. “We don’t want these problems to go masquerading around as educational, because they are not,” said Lipson. “There is nothing educational about restraining a child.”

Another frustrating point for many advocates of the Safe Schools Initiative is the lack of reporting when an incident of seclusion or restraint occurs (a point that, hopefully, should be made moot in Georgia when the new rule is passed in May.) “The lack of data is one of the most frustrating things,” said Lipson. “The data we do have shows that these incidences mostly happen to younger children, and there is some evidence that there may be more incidents for children with autism or who are non-verbal.”

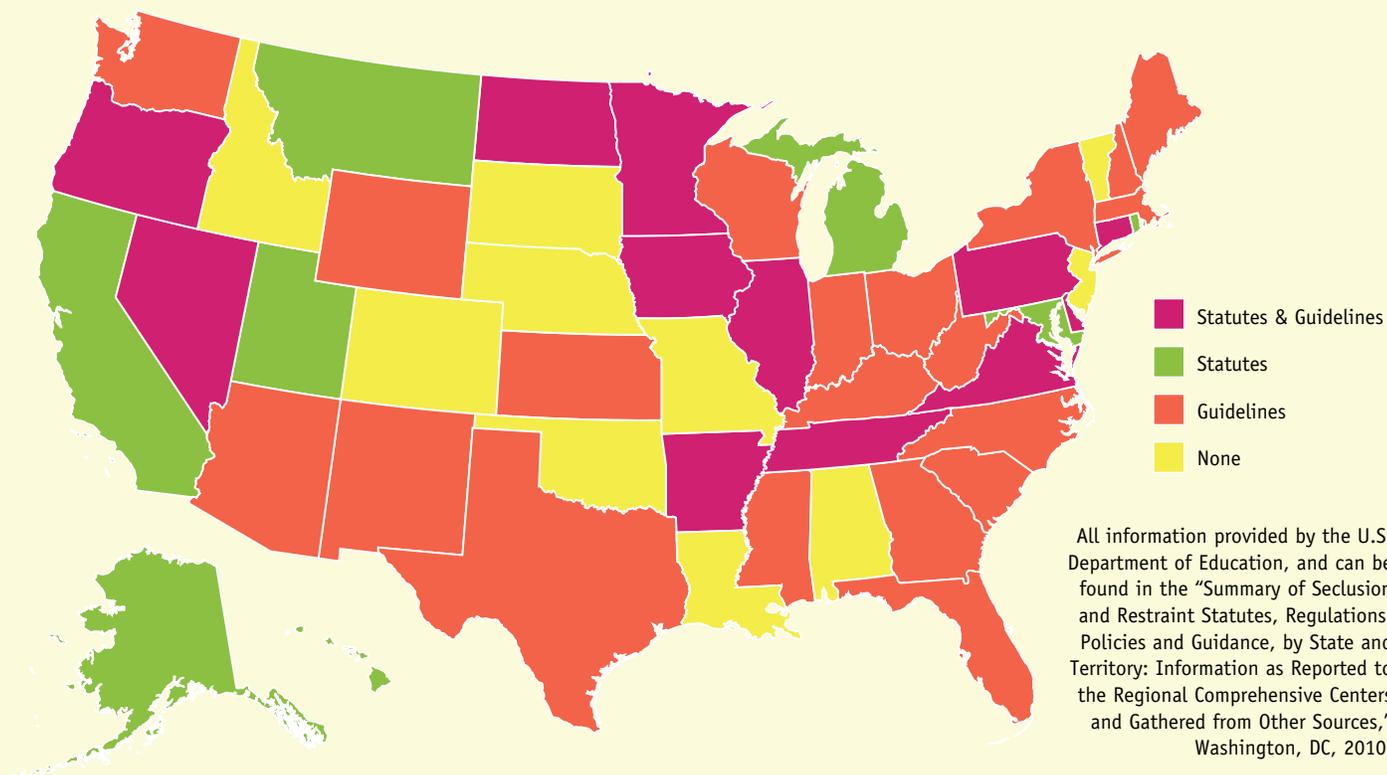
Hopefully, the lack of data won’t be an issue for too much longer. In 2009, the United States Secretary of Education Arne Duncan, began research on each state’s laws, regulations, guidance and policies regarding the use of seclusion and restraint in schools across the United States.

The report, released in February 2010, revealed that 23 states and territories currently have no specific restrictions on restraint and/or seclusion in pre-K or K-12 settings (though suggested guidelines may be in place in those locations.) News releases from Duncan suggest that this report will be updated and verified at repeated intervals throughout the coming years.

For the first time, federal lawmakers have acted on legislation that would prohibit restraint and seclusion in most circumstances and require training for educators on effective behavior management. The bill passed the U.S. House of Representatives and is now in the U.S. Senate for formal review and approval.

In the meantime, advocates are hopeful that the new Georgia rule will prevent any future tragedies in the state, such as what happened to Jonathon King. “These are children,” Lipson said. “Children. They deserve respect and the knowledge that adults will take care of them.” ●

**A declaration supporting the end to seclusion and restraint in schools is being circulated now. If you are interested in signing the Safe Schools Declaration please visit <http://tiny.cc/5ge6X>.**



## A State-by-State Look at Seclusion and Restraint in Schools

By Carly Sharec

The "Summary of Seclusion and Restraint Statutes, Regulations, Policies and Guidance" was released by the U.S. Department of Education in February 2010. The report, one of the first of its kind, detailed which states offered guidelines on seclusion and restraint, which ones had statutes or regulations, which ones had both and which ones had none. For example, a state may have a statute on restraining a child, but offer no guidance on when that situation may be appropriate or how that student should be restrained.

Also, the report was quick to point out that while a state may not currently have guidelines and/or statutes, they still may be considering developing that legislation. For example, Georgia currently has no regulations addressing seclusion or restraint but that will change once the state Board of Education approves the new rule in May. Louisiana is another state that

has no regulations or guidelines, but the state is considering putting those into place.

All information in the report was verified by each chief state school officer (or a representative). All states reviewed and confirmed the information gathered.

**"In the case of seclusion and restraint in schools, it's a 'Wild West' out there."**

The wide variety in the map shows Leslie Lipson's point when she says "In the case of seclusion and restraint in schools, it's a 'Wild West' out there." Different states have different policies, and many states leave the decision of seclusion or restraint up to the individual schools. In certain instances, teachers and school officials with no training in proper restraint are restraining their students, with methods that at times include items such as duct tape or wire.

In an official press release sent out by the Department of Education, Secretary of Education Arne Duncan said that he is "pleased that many states and territories have begun to work with their stakeholders to develop or revise current practices. The Department will continue to serve as a resource throughout the process to ensure that all students are safe and protected."

What the map does not show are the many territories of the United States that offer no regulations or policies, with no plans to do so. This includes Guam, the Republic of the Marshall Islands, the Federated States of Micronesia and Puerto Rico (among others).

According to the report, it will be updated regularly as states revise their guidelines and laws. For a full copy, it can be found on the U.S. Department of Education's Web site at [www.ed.gov](http://www.ed.gov) (search for 'seclusion and restrains').

# Students Take the Lead in Educational Success



**“It makes me feel like I’m the star.”**

**T**hat’s the straight-forward answer one North Hill high-schooler gave when asked why he liked his student-led IEP (Individualized Education Plan) so much.

Funded by a grant from the Georgia Council on Developmental Disabilities entitled Partnerships for Success, student-led IEPs are starting to take a firm foothold in some pilot-program Georgia schools.

What was formerly a sit-down discussion among teachers, parents and administrators aimed at addressing a child’s needs and putting together a program for that child, has now become something much more valuable. Students themselves are putting together information, attending the IEP meetings and making a personal presentation to all concerned.

“The student’s presentation makes it personal to every person who’s there,” says Nancy O’Hara, interim associate superintendent of Innovative Instruction at the Georgia Department of Education. “The student controls the pace. It often is less contentious.”

One big advantage to the student-led IEP meetings is that a teacher usually works with the student on a one-to-one basis putting together the presentation, giving a teacher the opportunity to provide technology learning along with presentation skills.

“The student actually sets the pace for the meeting,” says O’Hara. “He presents the facts about himself – this is what I’m good at, this is what I’ve had success with this year, this is what my struggle has been.”

**“In a student-led IEP, the student actually sets the pace for the meeting.”**

Will Crain, fifth grader at Spout Springs Elementary, discusses options with his IEP team.



Paul Smith, a Hall County high schooler, and his job coach Tammy Ellis prepare for his IEP team meeting.

The law requires that a student must be invited when transition planning is going to be discussed. In Georgia, transition must be discussed by the time a student enters high school or turns 16, whichever comes first. In the past, though, most of the time there was little if any student involvement in those meetings.

And with Partnerships for Success, not only are high school students becoming more involved, elementary students are participating in the planning program too.

**“We’re teaching these students a skill they need in the rest of their life.”**



Cindy Saylor and Colleen Lambert are program directors with Partnerships for Success. They’ve launched initial student-led IEPs in several counties, including Hall County schools, where the program is in its second year.

“Last year, we found when the elementary school students did it as well as high school students, they were beginning at the same place, on the same level,” Saylor said. “We hope by starting with the elementary students, each year they will participate a little bit more and they will gradually increase their level of participation, so by the time they reach high school, they are fully participating in their IEP meetings.”

“We’ve seen some progress between last year and this year. The students are participating more, and we’re seeing more teachers express interest,” Lambert added.

Susan Wright, special education and transition coordinator for Hall County School System, said “It’s powerful to see the student actually facilitating or leading their IEP as far as who they are and what they want to do, what they’re really good at, what’s their favorite subject, what’s something they’re not really good at. Because of the help that one elementary student was receiving from both teachers



**One of the missions of the student-led IEPs is to bring self-determination to the students through the teachers.**

and parents, he was actually seeing the connection of that circle of support.”

“In addition, we’re teaching these students a skill they need in the rest of their life,” O’Hara explained. “It’s a kind of self-advocacy, self-determination skill. How to look at their own needs and assess it. Figure out what supports they do or don’t need.”

The response to the student-led IEPs has been positive for everyone concerned. “The kids love it, the parents love it,” says Laura Stephens, special education teacher at North Hall High School. “One thing with the parents is it makes them see that their kids are going to be out in the real world and we probably do need to listen to what he wants to do. Also, the kids realize they have some control over their own lives, and the parents realize they need to give up some of their control.”



Denise Grogan, Special Education Teacher at Spout Springs Elementary School, is in her second year utilizing the student-led IEPs. She says the students, “now understand that the IEP process is not a scary thing. It’s about them and it’s about their future.”

**“The kids realize they have some control over their own lives, and the parents realize they need to give up some of their control.”**

Caitlyn Patrick is one of Grogan’s students. Caitlyn is 14 and has Down syndrome. Last year was her first student-led IEP. She’ll be involved in her second one in the early part of 2010 before moving on to middle school in the fall.

Through her presentation, Caitlyn was able to tell her teacher that, “I love the computer and having everyone together.”

Caitlyn’s mother, Gail Patrick, said she was amazed at what she saw. “We come in and she is sitting there smiling from ear-to-ear and she is doing her own little PowerPoint production. We started out with who she is and what she likes and she’s showing the things that interest her.

And she’s up there having just the best time of her life, with her face saying to me, ‘Look, look what I did.’ And her speech therapist said, ‘Well, this is a side of Caitlyn I have never seen.’ Even he enjoyed seeing this other bubbly, giggly side of her.”

Perhaps more to the point about students leading their own IEPs, Patrick said, “I didn’t realize how much we were missing until she was there with us.”

Patrick gives a great deal of credit to Grogan and Caitlyn’s other teachers. “It’s a lot of work for the teachers to sit down and get it ready with the kids. It’s also a learning tool for the kids. It’s a continuation of their learning from the classroom.”

Especially important in this budget-conscious time is that student-led IEPs are not expensive to implement. As O’Hara pointed out: “It’s just a different way to prepare the students. We’re really trying to provide, as a state, some direct technical assistance to a pilot group of schools this year, and then what we learn from that pilot group, I think what we’re going to do is replicate some kind of “how-to” booklet that can be distributed statewide.”

When student-led IEPs are put in place, the results can be extraordinary. Patrick says the results speak for themselves. “To see the self-esteem in the children speaks so much for them.”

Grogan echoes those sentiments exactly. When asked how effective student-led IEPs had been, she summed up her experience best by saying “My students soared!” ●



Above, top: Julissa Interiano of Hall County presents ideas to her IEP group.

James Dickerson, an 11th grader at North Hall High School, leads his IEP by sharing activities he is involved with.

Caitlyn Patrick (far left) shared her enthusiasm for music and Miley Cyrus with her IEP group.

# Sharing Stories Through Art

By Carly Sharec



GCDD Family & Individual Supports Director, Dottie Adams.

**Art has long had the ability to motivate, inspire and bring together people from many different walks of life – and the Georgia Council on Developmental Disabilities is now using art as a way of story telling.**

The perfect time to debut this method was at a gathering of professionals in the disability community in December 2009 at St. Simon's Island. "People come together often in professional conferences, and we talk about our professional selves," said Joy Hopkins, president of Collective Alternatives in Marietta. "It was a surprise to a lot of people to come together and talk about ourselves, as human beings and individuals.

"There are a few different reasons we've decided to use this style instead of just words," said Dottie Adams. Adams is the family & individual supports director for the Council.

"Some of the people we support and those who attend our meetings find it easier to follow a photographic report of goings-on rather than something that is written down. This way, we can make sure that everyone in attendance understands what's taking place, as well as knows that whatever they said was noted and considered."

**"Some of the people we support and those who attend our meetings find it easier to follow a photographic report of goings-on rather than something that is written down."**

Carol Perkins, advocate and formerly of Avita Community Partners in Flowery Branch, explains. "During those two days, we learned that our work

is not so much about disability as it is about community. We came to realize that everyone has a story to share. Our obligation is to share ours and listen with our hearts to others."

Illustrations along with notes also help to ensure that everything that gets said gets noted. "Sometimes we get these brilliant, profound things – if you don't capture them, they're just gone," Adams said. "By organizing thoughts via drawings, we're more likely to make sure everyone's voice is heard. It's just a very effective way of getting things done," she summed up.

Bruce Anderson of Community Activators in Washington was the facilitator for the event. "Storytellers would say that the



story of a person with a disability is, at its most important level, not a disability story," he said. "It's the story of a person who is trying

to figure out how to belong. In that way, a person with a disability has a similar story to every other person who lives in a community."

The method of drawing to capture stories has been well received. "There's a very positive reception," Adams said. "People seem to appreciate it. After every evaluation, we get comments from people that they like having it."

"I'm sure this will become an annual thing," said Hopkins. "People seemed drawn to be there – which was very interesting to me." Hopkins explained that the day the event began, a series of storms swept through Georgia. "People could've easily stayed home, but they got in their cars and drove. It was great."

Adams expects that this method of using illustrations as a communicative method will be continued in the future as well. "I've done this for years," she said. "It's a tricky skill, but very useful." ●



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JOIN - BE PART OF COMMUNITY

# SUPPORT RELATIONSHIPS

LISTENING



Love



Don't forget what is already there



Don't use a cookie cutter approach



Reciprocity

# HISTORY / TRADITION



Visualize a positive future



Try Another Way  
Marc Gold

Put fire into our work  
Showed us possibilities



Challenge our thinking



CITIZEN ADVOCACY  
Standing with People



Take time for small group reflection



Dottie Adams, Family & Individual Supports director for the Georgia Council on Developmental Disabilities, assists the Council in capturing ideas at meetings through the innovative use of illustrations. This method ensures all meeting attendees can see that what was discussed at the meeting was captured. Adams used this method at the December 2009 event at Epworth by the Sea in St. Simon's Island. "We plan to use this a lot in the future," Adams said.

# Understanding the Cultural Differences Through Life Experiences

By Aarti Sahgal



*Aarti Sahgal coordinates diversity programs for the Georgia Council On Developmental Disabilities and for Parent to Parent of Georgia. Sahgal holds an MBA from Mumbai, India and has 14 years experience in marketing and advertising. Sahgal lives in Marietta with her husband, Amit and two sons (Arjun and Angad) and their dog Abby. Angad has Down Syndrome.*

I grew up in New Delhi, India where everyone is of the same color (but still practices color discrimination, where less brown is considered “fair”), speaks almost the same language (there are 22 official languages and 2,000 different dialects) and has similar sounding names (the largest secular democracy with many different religions). Then I worked in the advertising industry on different global brands and traveled within and outside the country. So, I guess, I understood diversity. But what I did not understand was the concept of being a “minority.”

Who is a minority? Minorities can be defined as “people experiencing social pressure and lessening of their opportunities for health, success and other virtues in comparison with the rest of the society.”

I became a “minority” when I had a son with a disability. I became a “minority” when I moved to Atlanta with my family five years ago and struggled to find “my place” in the American society.

The important question is: how do we stop the marginalization or isolation of individuals who are different (different in color, caste, race, culture or abilities) from us?

**The important question is: how do we stop the marginalization or isolation of individuals who are different (different in color, caste, race, culture or abilities) from us?**

The discussion is really simple as it begins and ends with us. What is important in a diversity initiative is our openness to difference. This openness begins in the workplace, with acceptance of others who do not necessarily think, perceive or plan in the same way that is comfortable for each of us as individuals. If our responsibility is to help produce better outcomes for individuals with disabilities, then it is worth examining our own values and biases and exploring how we discuss these differences with

co-workers, managers and staff. Yes, this is very basic and fundamental, but these can be volatile topics of discussion.

How can we become more conscious and not fall into the “stereotype trap?” Here is a quick test – fill in the blanks:

All women are \_\_\_\_\_.

All Hispanics are \_\_\_\_\_.

All Muslims are \_\_\_\_\_.

All people with cognitive disabilities are \_\_\_\_\_.

What words did you use to fill in the blanks? Were these words stereotypical based on your perception of reality? Are you sure? Why?

**What we see is defined not by what we are looking at, but by how we perceive what we are looking at.**

We need to be aware of our own perception when assisting families. What we see is defined not by what we are looking at, but by how we perceive what we are looking at. This view is a product of our own cultural training.

A feature of nearly every culture is its instinct for self-preservation, often reflected in the perception that “ours” is the right way to think, act or believe – which makes alternative ways of thinking, acting or believing wrong. It is the understanding of and ability to think flexibly about the preferences of others that is the hallmark of cultural competence.

The best way to understand a different culture is to experience it. Look for similarities and not differences. Look for strengths and not deficiencies. Let’s begin to learn and appreciate the strengths of families who have learned to adapt to all that affects and shapes their daily lives and have, in their own unique ways, supported their members in the process. ●

# StraightTalk

## Self Advocate of the Year Speaks of Progress, Looks to the Future

By Rebecca Ramage-Tuttle of disABILITY Link

I've been asked many times what does receiving Georgia's Outstanding Self-Advocate of 2010 award mean to me. I have been a lifetime self-advocate for disability rights and it is great to be recognized by my peers in the field, but what means the most to me is the work and how it has the possibility of affecting every American life – not just those who currently have disabilities, but those who will have disabilities due to aging and those yet unborn who will have disabilities.

I was born with spina bifida in the days where doctors told parents to take their babies with this disability home and let them die. I was blessed to have some pretty amazing doctors that I am forever thankful to for my life, but there were others who told my parents that I would never walk, talk or think for myself. Well, except for the walking part, they got it all wrong. When I was a child, I did not have the legal right to go to school and when I finally started at the age of six, I went to a segregated school for children with disabilities (and believe me, my thoughts on mainstreaming is a whole other article on its own), and I went to the same school from kindergarten through 12th grade. I had teachers in high school that would not teach us geometry because they felt there were not enough students who were capable of understanding and they also felt that the majority of us were going to end up in nursing homes – heck, some of us were already in nursing homes while attending high school.

Did you know that there used to be a law known as the “ugly law?” This was a law that prohibited “unsightly” people with disabilities from being on public streets. Many U.S. cities had these laws and Chicago was the last in the nation to strike down the law in 1974. 1974 is not that long ago when you put things into perspective.

While we have made progress since the “ugly laws,” we still have a very long way to go. Our community tends to want to celebrate our civil rights milestones like the Americans with Disabilities Act and the Olmstead Decision, but I don't think we have anything to celebrate until all of our brothers and sisters in nursing facilities and other institutions have been liberated and are living the lives they choose.

**I don't think we have anything to celebrate until all of our brothers and sisters in nursing facilities and other institutions have been liberated and are living the lives they choose.**

I'm calling on my brother and sister advocates to put the work that goes towards our celebrations to getting the mission accomplished. The late Mark Smith, advocate extraordinaire, once told me that “all God's children just wanna be free.” I believe no truer words were ever spoken and I carry these words with me through my daily work. So, what does this award mean to me? It means that we still have a lot of work left to do before there will be FREEDOM FOR ALL. Support your local ADAPT chapter. Contact [www.adapt.org](http://www.adapt.org) for more information. ●



*Rebecca Ramage-Tuttle is executive director of disABILITY Link, and the 2010 recipient of Georgia's Outstanding Self-Advocate Award.*

**Did you know that there used to be a law known as the “ugly law?” This was a law that prohibited “unsightly” people with disabilities from being on public streets.**



## Do You See Me?

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

**C**harles Hopkins, veteran advocate and recently retired from the DHR's Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD), spoke at the Georgia Options' annual banquet and talked about his recent trip to Uganda. He described how he collected an entourage of children as he walked through the village, and this phenomenon did not seem to be the result of being the tallest or whitest person within 100 miles, although he probably was. It was something else that made him so approachable. The others in his group also wondered about it, and asked Charles what he thought about this reaction. He too had been thinking about it, and finally responded, "They know I see them."

He shared this with the nearly hundred families, caregivers and clients of Georgia Options. He had also been thinking about what had made Georgia Options so successful in the very difficult niche of the world they have sought to occupy – to support people to live in their own homes and have typical life experiences. Sounds simple, but so many things can get in the way – rules and guidelines and funding formulas and limited housing and attitudes. Still, they support some people that the powers-that-be have said could never live in the community, and Hopkins said that Georgia Options has succeeded because they 'see' people.

**Mia has an uncanny ability to see people. I have learned to value her knowledge and trust what she sees, and not make the assumption that because she is 'intellectually disabled' that she can't see people for who they are.**

Mia has an uncanny ability to see people. I have learned to value her knowledge and trust what she sees, and not make the assumption that because she

is 'intellectually disabled' that she can't see people for who they are. Mia hardly ever meets a stranger, but there have been a few times in her life that she has been put off by someone. Sometimes a perfectly acceptable, socially appropriate person has been hurt that they have not earned Mia's favor. When we run into this situation, I have had to really think about what it was they did or said that put her off. The only conclusion I come to is that they really didn't get her. They treated her appropriately, but they really didn't 'see' her, and she could sense that right away.

**Mia demands acknowledgement of her right to live in the world – she wouldn't recognize anything else.**

What is it she sees? What did the children in Uganda see? Is it a glimpse of the soul perhaps, or absolute trust? Is it unconditional love and acceptance of their being? Is it the acknowledgement of their "right to live in the world" as Paul Bagenstos from the U.S. Department of Justice said in a speech to the ARC of Pennsylvania? Maybe the children of Uganda glimpsed Hopkins' acceptance, in spite of the culture and language barriers, of their right to live in the world. Mia demands acknowledgement of her right to live in the world, she wouldn't recognize anything else. So if someone hesitates, or tries to correct her world view – she dismisses them.

Over the weekend, we got to visit some old friends in Athens. Taylor and Mia went to school together and were good friends. Taylor doesn't talk much, but that never stopped Mia from communicating with him. It had been a couple years since they had been in each other's company. When they met on the street, it took Taylor a good moment to process who she was. Then he reached out his hand and took hers and said, "Mia."

He saw her. ●

## APRIL

**April 20-23**

**Social Role  
Valorization Workshop**  
Georgia Advocacy Office  
Atlanta, GA • 404-885-1234  
[dchampion@thegao.org](mailto:dchampion@thegao.org)

**April 25-29**

**ADAPT Action**  
Washington, DC  
[www.adapt.org](http://www.adapt.org)

**April 26**

**Federal Hiring Event for  
People with Disabilities**  
Office of Disability  
Employment Policy (ODEP)  
Washington, DC  
[www.usajobs/disabilityhiringevent.asp](http://www.usajobs/disabilityhiringevent.asp)

## MAY

**May 10**

**Long Road Home**  
Georgia Advocacy Office  
404-885-1234 • [cmitchell@thegao.org](mailto:cmitchell@thegao.org)

**May 20**

**People First of  
Atlanta General Meeting**  
404-885-1234 • [cmitchell@thegao.org](mailto:cmitchell@thegao.org)

## JUNE

**June 4**

**Vote Training**  
People First and the  
Georgia Advocacy Office  
678-755-6015 • [cherimitchellg@gmail.com](mailto:cherimitchellg@gmail.com)

**June 8-10**

**21st Annual APSE National  
Conference People First:  
Not Just a Slogan**  
Atlanta, GA • 301.279.0060

**June 24-25**

**Annual Technical Assistance Institute**  
National Association of Councils on Develop-  
mental Disabilities (NACDD) and Administra-  
tion on Developmental Disabilities (ADD)  
Arlington, VA  
202-506-5813  
[www.nacdd.org](http://www.nacdd.org)



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## JULY

**July 10-14**

**Toronto Summer Institute 2010:  
Inclusion, Community and Diversity**  
Inclusion Press  
Toronto, Ontario  
416-658-5363  
[www.inclusion.com/inclusionnetwork.html](http://www.inclusion.com/inclusionnetwork.html)

**July 15-16**

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

**July 26**

**20th Anniversary  
of the Americans  
with Disabilities Act**



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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

### KSU Academy

Kennesaw State University  
Jill Sloan  
[www.kennesaw.edu](http://www.kennesaw.edu)  
678-797-2036

### Annual Disability Day

Georgia Department of Labor  
Michael L. Thurmond  
[www.dol.state.ga.us](http://www.dol.state.ga.us)

U.S. Department of Labor – the Office of Disability Employment Policy

Kathleen Martinez  
[www.dol.gov/odep](http://www.dol.gov/odep)

Self Advocates Becoming Aware (SABE)

Julie Petty  
[www.sabeusa.org](http://www.sabeusa.org)

### Safe Schools Initiative

The Georgia Advocacy Office  
[www.thegao.org](http://www.thegao.org)  
[info@thegao.org](mailto:info@thegao.org)  
404-885-1234

Georgia Department of Education – Special Education  
Kim Hartsell  
[www.doe.k12.ga.us](http://www.doe.k12.ga.us)  
404-656-3963

### Student-Led IEPs

Partnerships for Success  
[www.partnershipsforsuccess.org](http://www.partnershipsforsuccess.org)

Georgia Department of Education – Special Education  
Nancy O'Hara  
[www.doe.k12.ga.us](http://www.doe.k12.ga.us)  
404-656-3963

### Georgia Community Dialogue

Georgia Council on Developmental Disabilities  
Dottie Adams  
[dxadams@dhr.state.ga.us](mailto:dxadams@dhr.state.ga.us)  
404-657-2129

### Collective Alternatives

Joy Hopkins  
[ceahopkins@mindspring.com](mailto:ceahopkins@mindspring.com)  
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800.229.2038  
www.parenttoparentofga.org



## DISABILITY DAY 2010



## 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 June 10 for inclusion in the Summer 2010 issue of *Making a Difference*.



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# Making a Difference

The quarterly magazine of the Georgia Council on Developmental Disabilities

Volume 10, Issue 4 • Spring 2010

## DISABILITY DAY 2010: Count Me In, Count My Vote, Count My Community!



The Georgia Council on Developmental Disabilities thanks the state legislators, sponsors and advocates who supported and made the 2010 12th Annual Disability Day a success.

Turn to page 12 of this magazine for more information.

