

# Making a Difference

SPRING 2009

**Thousands  
Swarm Capitol  
to Advocate, Celebrate**

**Microboards Empower,  
Enrich Lives**

**Legislative Session Marked  
by Budget Woes**

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

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

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

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GOVERNOR'S  
COUNCIL ON  
DEVELOPMENTAL  
DISABILITIES

## Yoder Dedicated 33 Years to AADD

Civil rights and disability advocate Mary Yoder will retire from her post of executive director of the Atlanta Alliance on Developmental Disabilities at the end of June.

Yoder has worked with AADD since 1976, serving as advocacy specialist, director of project RESCUE, director of community services and assistant executive director.

"Being a part of AADD has provided me with many opportunities to work alongside truly remarkable people and to help develop and build strategies to strengthen our community," Yoder said.

Betty Dent has worked with Yoder for nearly 30 years. "She's the most unique director I've ever known. She brought to the agency the caring that all people should have. She always made AADD consumers her number one priority," the outreach specialist said.

Yoder came to Atlanta in 1966 to do civil rights work. "We were volunteers doing background support for the Southern Christian Leadership Conference," she said. "I did some tutoring in the neighborhoods."

While tutoring, Yoder noticed how disability and poverty were linked, and this was reinforced by her next job as a teacher at St. Vincent DePaul.

Later, Yoder worked at the Brook Run hospital. "I provided direct care and support there for about three years. It was frustrating because families wanted and needed things we couldn't provide because institutions operate from the lowest common denominator," she said.

While working at Brook Run, Yoder met Denise Shaw. "Denise was 4.5 or 5. She didn't talk or walk. I brought her home every other weekend and on holidays. Even after she moved into a foster home, we still brought her home. It was respite for the foster family, but fun for us," she explained.

Shaw and Yoder became lifelong friends, and in 1986, Shaw moved in with Yoder and her husband and began working at Georgia State University in 1987.

After Brook Run, Yoder taught adults skills to live in their communities at the Fulton County Mental Retardation Service Center, where she heard of Project RESCUE (Refer, Evaluate, Secure, Coordinate, Uncover, Educate), which later became AADD's program, Georgia Family Support.

"Project RESCUE was creative about creating supports around what the family wanted, when they wanted. It was really attractive to me. I was thrilled and delighted to come work here," Yoder said.

Now 33 years later, Yoder is proud of AADD's accomplishments, including demonstrating that women with severe disabilities could live in their communities; leading the Justice in Developmental Disabilities Coalition; creating a support group for women with cognitive disabilities who have been abused; providing leadership for Unlock the Waiting List!; and supporting mothers with intellectual disabilities so they can keep their families together.

"We have such a dynamite group of staff who are passionate about what they do. Some of our clients have had the same support professional for 26 years. This increases the quality of services so much," she said.

Her staff will miss her. "She has a heart as big as the world. She would work 15 - 20 hours a day trying to get services for people with disabilities. She is not replaceable," Dent said.





## Advocates Should Join Together for Stronger Communities

**2009** has started out as a very interesting year when it comes to our country, state and community. The current economic crisis has resulted in dramatic reductions in the revenue that the State of Georgia will have to allocate for goods and services. The federal economic stimulus package will help the situation if the funds make it to the areas where there is the greatest need. In the disability community, there is a growing waiting list of individuals already in the community and those who want to leave institutions and nursing homes. This waiting list for

services and supports will continue to grow unless our elected officials decide that meeting the needs of the people is their most important priority. This might mean forgoing tax cuts and credits or looking for additional revenues or taking the time to converse with constituents and better understand these growing needs. None of these choices are easy, but they may be necessary.

There may be tough decisions for us in the disability community as well. We may have to find ways to come together collectively and join with others who represent people who have been marginalized or exiled. We know how to come together. The more than 2,000 people who showed up for this year's 11th annual Disability Day at the Capitol tells me that we can bring the numbers. The question is can we use those numbers to create action and change communities and public policies? We are not sure this is quite as easy.

Think of the power if people with developmental disabilities, physical disabilities and mental illnesses; people who are poor; representatives of children and the elderly; and

populations of color all came together and identified common issues. Let's take housing as an example. We all know that with the banking and credit crisis, the availability of housing is at risk for many people. Fewer and fewer people have access to quality, affordable and accessible housing. We could change the policy and outcomes for many if the groups mentioned above came together and decided that housing was the most important issue, and they were going to work on the local, state and federal levels to make sure that every Georgian had a place to live. We might have to spend some time talking with each other, learning about the possibilities and recognizing that each person at the table has a gift, but in the end we could find that place where as a group we could make a difference. The power of collective action could spur other opportunities as well.

We may have to find ways to come together collectively and join with others who represent people who have been marginalized or exiled.

This edition of *Making a Difference* will report on the results of the 2009 legislative session. This was the first year of a two-year session and there were several victories for the disability community that will help us as we move into the second year. We also explore microboards which several families in Georgia are now using to manage the services and supports they receive which are paid for by Medicaid.

Finally, we will continue to monitor the impact of the new home and community-based waivers for people with disabilities on individuals, families, providers and the system. We hope you enjoy this edition of *Making a Difference*. We want to hear from you. You can reach our Public Information Director and Editor In-Chief, Valerie Meadows Suber at 1-888-275-4233 or [vmsuber@dhr.state.ga.us](mailto:vmsuber@dhr.state.ga.us).



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## Obama Names Disability Policy Special Assistant

President Barack Obama is demonstrating his commitment to disability issues by naming Kareem Dale as his special assistant who will focus exclusively on disability policies. Vice President Joe Biden announced the appointment while leading a Presidential Delegation at the 2009 Special Olympics World Winter Games in Boise, Idaho.

"The commitment that the President and I have to Special Olympics and people with disabilities is deep and abiding. And we are backing up those words with real action at the White House," Biden said. "This is our first step to ensure that we have a strong advocate for people with disabilities at the highest levels of our administration."

**"This is our first step to ensure that we have a strong advocate for people with disabilities at the highest levels of our administration."**

Dale, who is partially blind, will have direct access to the president in this role, and he will coordinate the administration's efforts to ensure that people with disabilities are on a level playing field with all Americans.

Originally from Chicago, Ill., Dale previously served as the national disability director for the Obama for America campaign. He also served on the Arts Policy Committee and the Disability Policy Committee for then-Sen. Obama.

Dale graduated from the University of Illinois at Urbana-Champaign with a Bachelor's degree in advertising in May 1995. He received his JD/MBA in May 1999 from the University of Illinois at Urbana-Champaign, graduating cum laude. While attending law school, Dale was also active in community service, including serving as president of two organizations, the Black Law Students' Association and Open Forum.



## Social Security Expands Fast-Track Disability Processes

Michael J. Astrue, Commissioner of Social Security, announced in January that improvements to the Social Security Administration's computer modeling system have increased the number of claimants receiving expedited approvals for disability benefits. Social Security's two-track system – the Quick Disability Determination (QDD) process and Compassionate Allowances – is now fast-tracking about four percent of all disability cases, a sharp increase from the 2.7 percent of cases fast-tracked last year.

"In practical terms, this means that this year 100,000 to 125,000 Americans – those with the most severe disabilities – will be approved for benefits in about 10 days instead of waiting the three to four months it typically takes for an initial decision," Astrue said. "These initiatives are truly a lifeline for those who need it most."

Under QDD, a predictive computer model analyzes specific data within the electronic file to identify cases where there is a high potential that the claimant has a disability and where Social Security can quickly obtain evidence of the person's allegations. Through Compassionate Allowances, Social Security expedites the processing of disability claims for applicants with medical conditions so severe that their conditions by definition meet Social Security's standards. These fast-track systems increase the efficiency of the disability process and also help free up resources so the agency can better cope with an increase of about 250,000 cases resulting from the current economic downturn.

"During these tough economic times, getting Social Security and Supplemental Security Income disability benefits quickly to Americans who are unable to work helps them and strengthens our economy. For SSI recipients, expedited approvals also ensure they immediately get the vital medical coverage they need," Astrue said. "It is critical that we continue to embrace innovative technologies in order to improve the services we provide to the public."

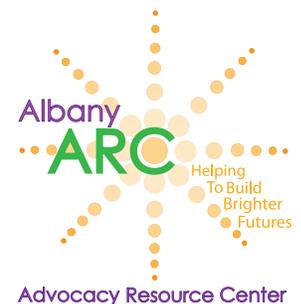
## Student Designs New Logo for Albany ARC

The Albany Advocacy Resource Center (Albany ARC) has a new look. The new logo and slogan reflect the essence of Albany ARC, and Albany ARC leaders hope it will help in the growth and recognition of their organization.

"We are very excited to reveal this new identity to our members and to the community of Southwest Georgia," said Sandy Edge, Albany ARC assistant executive director. "We feel the new logo and slogan help to unify Albany ARC's programs and services it offers to people with disabilities."

Designed by an Albany Tech Visual Communications student, Megan Warmack of Leesburg, GA, the logo, which includes the slogan, "Helping To Build Brighter Futures," will be displayed on everything from letterhead to brochures, and will be used for future marketing development through new forms of social media, and a new Web site design. Warmack's graphic identity was selected from other logos submitted by Albany Tech students in a contest.

"The slogan, 'Helping To Build Brighter Futures,' certainly indicates a relationship and helps differentiate Albany ARC," Edge continued. ●





## GCDD, SILC Create Samuel B. Mitchell Award

Samuel Mitchell was a tireless advocate for himself and all people with disabilities, so a group of advocates decided creating a lifetime achievement award that bears his name would be a perfect way to honor the man who helped so many.



“Sam was in the second graduating class of Georgia Voices That Count. That’s how he got started,” revealed Governor’s Council on Developmental Disabilities Advocacy Director Kate Gainer. “He was very active and encouraging. He became a surrogate father for a lot of people with disabilities he met through the years.”

Mitchell served on a variety of committees, organizations and boards, including as president of the Georgia chapter of ADAPT and vice president of People First of Atlanta, as well as sitting on the Long Term Care Ombudsman Advisory Committee, planning committee for the Long Road Home and on the board of disABILITY LINK.

Mitchell’s wife, Cherie Mitchell, was touched by the award. “I was really pleased and honored they chose to name it after Sam. He was a fabulous advocate, both at the state and national levels,” she said.

The first Samuel B. Mitchell Lifetime Achievement Award, jointly presented by GCDD and the Statewide Independent Living Council, was bestowed on Bernard Baker during

the 11th Annual Disability Day at the Capitol February 25.

“Bernard is the type of old advocate you can call on to do just about anything. And he’s not only there, he’s there enthusiastically,” Gainer said. “He is the type of advocate who can motivate a crowd of strangers. To me, he embodies self-determination.

“Sam really worked hard in the movement, and Bernard embodies that same spirit. Sam used to joke around and tell people he was a manly man. The second runner up to that would be Bernard,” she said.

### Organizing Institute Graduate Receives Computer from Community Center

While Patricia “Ajike” Williams was preparing to promote disability rights as a pro se litigant before an administrative judge, her home computer failed.

Undaunted, she headed to the Dorothy C. Benson Multipurpose

Complex in North Fulton County to use the center’s computers to complete her presentation.

“I didn’t realize the staff members were observing me at work. Little did I realize that the seemingly innocent questions they asked were out of more than mere curiosity,” Williams explained.

“Little did I know that others around me thought the work I was doing to increase employment opportunities for all members of the disability community in Georgia was important. However, I became fully aware of the unique spirit operating at the Benson Center on the day that Don Gurecio presented me with an entire computer system!”

Gurecio said, “Anyone sacrificing to do the work you are doing

**“Thank you for your effort to expand employment opportunities among the disability community!”**

deserves to have their own computer. Thank you for your effort to expand employment opportunities among the disability community!”

Williams was grateful for the generosity of the gift that would allow her to continue her advocacy work for employment for people with disabilities.

“There is a unique spirit operating at the Benson Center. The manner in which both volunteer and paid staff members deliver services is with a servant’s heart. On more than one occasion, I have watched as staff members have gone beyond the call of duty to uplift and improve the quality of life for all those who come to the center, transcending cultural and class barriers,” she said. ●



## Rolling Down Pennsylvania Avenue: Just Another Day for Devin Robinson

By Carly Sharec

**T**he South Cobb High School band, in Austell, recently took its place in history at the inauguration of President Barack Obama as it was one of only a handful of selected bands across the country to play at the event. For one student, it was an especially historical occasion, as he walked –no, rolled – down Pennsylvania Avenue.

“Devin Robinson is a freshman in our drum line,” said SCHS band director, Zachary Cogdill. “Devin has a degenerative neuromuscular disorder. We had to come up with a way for him to march with us – I was not going to let him miss out on an opportunity of a lifetime!”

Robinson has leukodystrophy, which is the progressive degeneration of white matter in the brain. Robinson particularly has trouble with muscular skills and speaking. “There is a lot of shaking and instability as far as his muscles go,” Cogdill explained. “But he’s a very smart kid, and a very talented bass drummer. We do what we can to accommodate his needs, and the inauguration event was no exception.

**“We had to come up with a way for him to march with us – I was not going to let him miss out on an opportunity of a lifetime!”**

“Several people called up, ready to donate wheelchairs or golf carts. While we were of course appreciative, we wanted Devin to blend in a little bit more,” Cogdill explained. “We initially set out to have something specially designed, something that wasn’t intrusive or too big so that it wouldn’t distract away from Devin or his performance.”

Just when it began to look impossible, things fell into place. Devan Seabaugh, the man who brought soapbox derby racing to the Atlanta area, contacted the band and offered a modification of a soapbox derby car.

Michael Feldberg from The Color Spot also offered his company’s services in creating the vinyl wrapping to go around the car with the band logo and colors. “Going back to the concept of inclusion, the car was mostly wrapped with black in order to blend in with the rest of the band, which wears black pants,” Cogdill said.

Seabaugh heard the need from his friend, Feldberg. “He sent out an e-mail explaining about Devin, and I just happened to have a soapbox that I built back in 2004. We took it to the high school and once the band director said it was exactly what they needed, we took it back to modify it for Devin’s drum and to accommodate an extra person.”

“I initially heard about the need from the Atlanta radio station Q100,” Feldberg explained. “This was a once-in-a-lifetime event for these students, and we wanted to do everything we could do to be a part of it. We’re just glad we could assist.”

“The car was redesigned to accommodate a back passenger, which was SCHS student Shanique Williamson,” Cogdill said. “She helped Devin keep time – after all, with drumming, it’s very important to be precise!”

“I know that he got a kick out of it...we had a blast,” Gerald Robinson, Devin Robinson’s father, stated. “But he also took his job seriously. Devin was there as a band member, not as an individual.”

Cogdill is appreciative of the overwhelming community support, not only for Robinson but also for the entire band. “My students learned so much about character and philanthropy through this experience,” he said. “As a teacher, I don’t think I could ask for anything more.” ●

**“As a teacher, I don’t think I could ask for anything more.”**



# Budget Issues

## Take Center Stage in Legislature

**T**he winter edition of *Making a Difference* reported that the 2009 Legislative Session was going to be a bumpy ride, and it was. As of this writing, the legislature is five days away from Sine Die, but legislators are still working on the FY 2010 budget, and the Department of Human Resources (DHR) restructuring legislation. These two moving parts, along with the addition of federal stimulus money from the American Reinvestment and Recovery Act of 2009 (hereafter referred to as ARRA) are challenging even the most seasoned advocates with keeping track of the latest developments.

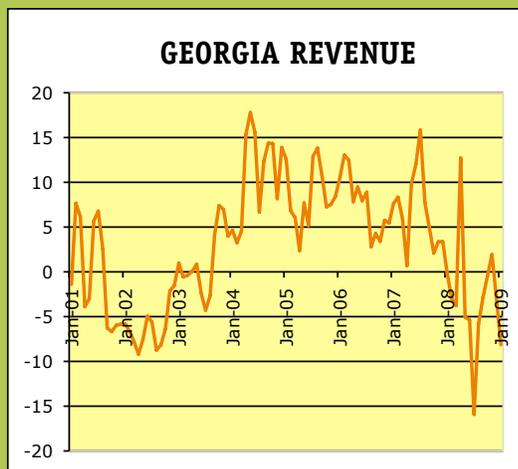
### Revenue: what did Georgia have to work with?

Revenue continued to decline as the session began. January's revenue collections were 16 percent less than the same month a year ago; February's revenue collections reflected a 34 percent decline over February of 2008. This scenario forced Governor Sonny Perdue to once again lower the revenue estimate by another \$1.6 billion. ARRA funds filled \$1.1 billion of the hole, along with a combination of the enhanced federal match for Medicaid, state stabilization funds in public safety and education, and Title IV-E funding for foster children and Temporary Assistance for Needy Families (TANF). Further reductions to state agencies provided another \$70 million. The rest of the funding came from reducing the motor fuel tax, adjusting the State Health Benefit Plan employer contribution rates, and other smaller items.

### ARRA funding

As complicated as it seems, it is important for advocates to understand how the Medicaid portion of the ARRA was used in the budget, so here's a little context. Prior to the passage of the ARRA, the state put up 36 percent state funds and the federal government matched it with 64 percent for Medicaid. This formula is called the Federal Medical Assistance Percentage (FMAP). The ARRA offered states an enhanced matching rate of 25 percent / 75 percent for nine fiscal quarters – from October 1, 2008 to December 31, 2011. The state generated savings in the budget by cashing out the difference between the 36 percent and the 25 percent, and using that cash to plug holes in the budget. For example, Georgia previously paid 36 cents for \$1.00 in Medicaid funding – the state match portion. Well, now that \$1.00 only costs

January's revenue collections were **16 PERCENT LESS** than the same month a year ago; February's revenue collections reflected a **34 PERCENT DECLINE** over February of 2008.



Aside from the **budget**,  
the next big moving piece was the  
**DHR restructuring legislation**.  
Again, this initiative had  
a lot of **moving parts**.

Georgia 25 cents, so the state now has an extra 11 cents. Multiply that 11 cents by all the Medicaid dollars in the budget, and the state has generated a windfall in extra cash. But instead of using the money for Medicaid-eligible people and services, the state used it for lots of other things, including the Homeowner's Tax Relief Grant, cuts in public health, etc. The executive branch contends that the ARRA money prevented even more drastic cuts to the

**...instead of using the money for Medicaid-eligible people and services, the state used it for lots of other things, including the Homeowner's Tax Relief Grant, cuts in public health, etc.**

budget, given the abysmal revenue picture, but this may have positioned the state to go from the frying pan to the fire. In 2011, when the enhanced match phase is up, the Medicaid dollar will again cost 36 cents, and Georgia will have to come up with the money it spent in other places to replace a huge hole in the Medicaid budget.

**Remember this:** The Medicaid enhanced match windfall totaled about \$731 million dollars. As of this writing, the House, Senate and Governor's Office were going back and forth about the use of

the funding for maintaining Medicaid provider rates at current levels versus funding the projected growth in Medicaid-eligible patients, but the home and community-based service providers were held harmless from the cuts. So the disability community didn't gain anything from that effort.

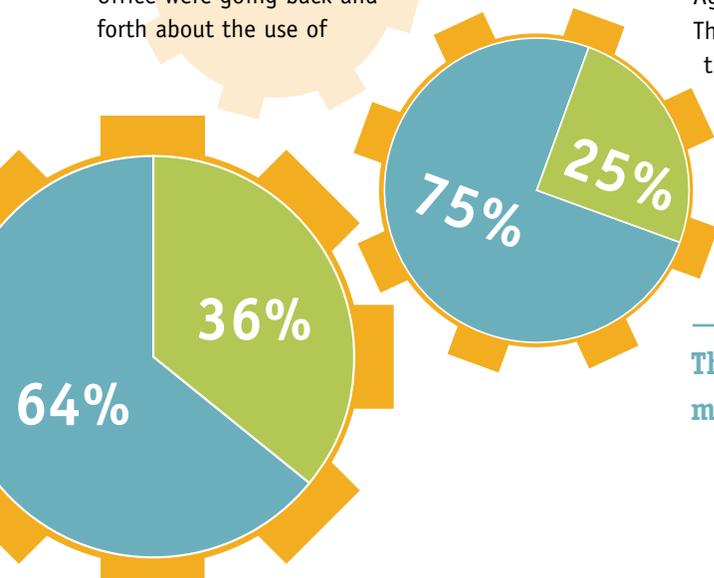
The cash out from just the adult and child and adolescent developmental disabilities program budgets was \$52 million dollars. It was taken from training, contracts, the funds for the 135 waivers traded out through attrition, and more. So in 2011, advocates and the state will have to find the money somewhere to replace that \$52 million. In the meantime, the only new money appropriated was for the 150 Money Follows Person slots to support people moving out of the state hospitals, and 100 Independent Care Waivers (ICWP) to support people moving out of nursing homes, and annualizing prior appropriations. These services are mandatory because of the Olmstead Voluntary Compliance Agreement and the Money Follows the Person Grant.

### **DHR restructuring**

Aside from the budget, the next big moving piece was the DHR restructuring legislation. Again, this initiative had a lot of moving parts. The Governor's Task Force recommended creating three departments out of two; the Department of Behavioral Health included Mental Health and Addictive Diseases services; the renamed Department of Human Services contained Aging Services, Developmental Disabilities and the Division of Family and Children's Services (DFCS)

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**The Federal Medical Assistance Percentage (FMAP) match increased from 64% to 75%.**





# FEATURE

[FY 2010 Budget not finalized as of writing]

## FUNDED:

### DHR, Adults and C&A

- 150 Money follows Person New Option Waiver (NOW) slots..... \$2,387,318
- Annualize the cost of 365 NOW waivers services..... \$3,309,899

### Department of Community Health (DCH)

- 100 ICWP waiver slots, Money Follows the Person program ..... \$1,572,750

### Education

- School nurses (cut reduced from \$30,000,000)..... (900,000)

## CUTS:

### Developmental Disabilities:

- Reduce funds to reflect the revised revenue estimate ..... - 5,391,480
- ARRA funding change in the Medicaid federal participation rate from 65% to 75%. ..... - 42,743,523
- Reduce training for MHDDAD .....- 510,534
- Provide for savings by reflecting the FY 2010 FMAP ..... - 2,010,969
- Reduce various contracts.....- 500,000
- House did not restore funds for 135 NOW waivers..... 0

### Aging:

- Reduce funds for Alzheimer's respite services.....- 190,281
- Reduce funds for non-Medicaid home & community based (HCBS) respite services through attrition ..... - 2,723,282
- Replace state funds for senior nutritional services (meals on wheels) with federal ARRA funds ..... +1,045,000

### Education:

- Preschool disabilities, low-incidence special needs, regional educational service agencies (RESAs), severely emotionally disturbed, etc ..... - 3,085,967

[ARRA funds replaced \$375,000,000 in state education funds]



...the Governor's Council on Developmental Disabilities will be renamed the Georgia Council on Developmental Disabilities.

and Child Support; and, the Department of Health contained Public Health, Healthcare

Financing and Office of Regulatory Services. The House substitute version, HB 228, moved Public Health into the Department of Behavioral Health with Developmental Disabilities. The Senate version, SB 222, moved Public Health back to the Department of Health, and kept Developmental Disabilities with the Department of Behavioral Health. At the time of writing, HB 228 was stripped and SB 222 was inserted, passed committee and the Senate and was transmitted to the House. House and Senate will disagree with the differences in the bills and appoint a conference committee to work out those differences. At this point though, Developmental Disabilities will be housed under the current Department of Behavioral Health, which will most likely take on a new name. In addition, the Governor's Council on Developmental Disabilities will be renamed the Georgia Council on Developmental Disabilities.

### Other legislative priorities:

**New Home Access Legislation, SB 247:** There is still a good bit of resistance to this bill, despite several good conversations with legislators about the need for these requirements. We did not receive a copy of the House Study Committee Report until March 19th, and the recommendations in the report were less than we hoped for. Sen. David Shafer (R-Duluth) held a hearing for the stakeholders on Friday, but not to vote the bill out. We will be working on this legislation next year as well.

### Individual Development Accounts (IDA)

**Legislation:** With the budget and the restructuring consuming most legislators'



attention, advocates decided to wait until the summer to talk to legislators about the potential for IDA expansion, and to get a bill drafted prior to the 2010 session.

**Unlock the Waiting Lists!:** As previously stated, the appropriation as of this writing falls far short of the need. The multi-year funding plan asked for 2,500 NOW and Comprehensive Supports Waivers (COMP), and 630 ICWP waivers. Funds were appropriated only for 150 developmental disabilities NOW/COMP, and 100 ICWP Money Follows Person waivers. Waiver funds appropriated in the last budget were annualized, but there were differences between the House and Senate intent as of press time. There was a net loss to the child and adult developmental disabilities budgets of \$52 million dollars.

**Deaf-Blind Agenda:** HB 565 proposes the establishment of a Commission for the Blind and Visually Impaired, and HB 566 renewed the Blind Person's Braille Literacy and Education Act from last year. Both bills will remain active next year.

**Autism Insurance:** SB 161 was tabled to continue work on it over the summer. In dispute are the services to be covered by private insurance and the estimated cost of covering the range of autism-related conditions. The House version of the bill did not make it out of committee.

**Resolution** to urge Medicare to eliminate the 24-month waiting period for Social Security Disability Income (SSDI) recipients passed the Senate.

**Parent Protection Act (HB 37)** which would allow 24 hours of unpaid leave for employees to attend their child's school events, medical appointments or to an elderly parent's doctor appointments without fear of losing their job, and the Minimum Wage legislation to raise rates from \$5.15 an hour to \$7.25 an hour didn't see any movement.

**Medicaid Issues:** DCH Commissioner Rhonda Medows agreed to take a meeting with advocates to address their concerns about the purpose, staffing and membership of the Medical Care Advisory Committee, which will happen after the session.

All other issues on the disability agenda were held in light of the budget and restructuring concerns, but can be moved forward next year. Although there is always a great deal of legislation dropped, very few substantial bills actually made it through the entire process. Advocates really struggled this year to keep the important issues in the forefront of the discussion at the Capitol. The dialogue on the need for increased revenues will continue with some urgency over the summer, as many policy-makers fear the state is not yet at the bottom of the economic downturn, and Georgia will have to figure out how to replace the federal money it used to shore up the FY 2010 budget. In terms of the advocacy community, since no new funding was appropriated for the waiting lists, the lists of people waiting for services are expected to rise above 8,000. We urge all of our friends, family members and advocates to communicate with your legislators on the need for the state to increase its income if we are to support services for our citizens in their own communities. ●

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**We urge all of our friends, family members and advocates to communicate with your legislators on the need for the state to increase its income if we are to support services for our citizens in their own communities.**

# Real Communities Make A Difference:

## 11<sup>TH</sup> ANNUAL DISABILITY DAY

**This year's annual Disability Day found thousands of disability advocates shivering on the steps of the state capitol, but the fire burning in their hearts was more than enough to combat the cold weather as they met once again to fight for issues affecting the disability community.**

"This is the day that we vow to look forward," Frank Ski, this year's host and popular V103 deejay, exclaimed to the crowd, galvanizing those gathered to cheer. "It's time to close and never, ever reopen those institutions!"

The grim reality of the current economic situation was also a point that could not be overlooked. "The fact is that this is not a partisan issue," said Governor's Council of Developmental Disabilities Deputy Director Patricia Nobbie, Ph.D. "We are facing some serious challenges as a community, state and nation. This year, the government is cutting 135 disability waiver slots. The 2010 budget has no additional services added. This is not enough."

But, Nobbie added, it's important to hold onto the small victories. There are 150 developmental disability waiver slots within the Department

of Human Resources' budget, and an additional 100 slots within the budget for the Department of Community Health. "These are important things to keep in mind, and we cannot underestimate the importance of these waivers." Nobbie continued to describe legislation that is currently being moved through the state government which requires little to no funding, yet can have a big impact on the lives of Georgians living with disabilities, including House Bill 228, HB 426 and Senate Bill 161. HB 228 deals with the restructuring of the Department of Human Resources, while HB 426 and SB 161 are about the Autism Insurance Bill, which, if passed, would require particular insurance coverage of autism spectrum disorders.

**"You have brought a face to the faceless and a voice to the voiceless."**

Several government officials joined the festivities, including long-time disability advocate Sen. Nan Orrock (D - Atlanta). "You have brought a face to the faceless and a voice to the voiceless," she said. Orrock in particular has been fighting for legislation that would require new homes to include at least one accessible entrance to the building and wide inside doors for wheelchairs. "It's time to change the culture," Orrock stated. "Anyone can experience a disability at any point in their lives, so why aren't our homebuilders taking that into consideration?"

A press conference was held for members of the media. "There are 7,000 people waiting for services in the state of Georgia," said Eric Jacobson, GCDD executive director. "We know that with the economy in its current situation, money is tight. But Georgia must be prepared to take action!" A later statistic shared by Dave Blanchard from the Atlanta Alliance on Developmental Disabilities, is that Georgia is

**"I was determined to become the TEACHER that I NEVER HAD."**



**"I don't have a disability because I think I have a disability. I have a disability because OTHER people think I do!"**

currently 49th in the country for providing community supports.

Shelley Simmons of the Statewide Independent Living Council also spoke at the press conference, citing a survey of Georgians. "58 percent of all Georgians are willing to pay higher taxes for more services for those living with disabilities," she said to cheers from the crowd. "It just makes sense, both morally and economically." The same survey also showed that over 60 percent of Georgians agree that new homes should be required to be built with accessibility in mind.

"We appreciate those of you who are out here today," said Rep. James Mills (R – Gainesville). "You are speaking for those who can't speak for themselves."

The theme behind this year's Disability Day was remembering the Olmstead Decision, which will be celebrated with a series of events in summer 2009. However, Kate Gainer of GCDD spoke in front of the crowd about the importance of the Olmstead Decision...and how far behind Georgia is in honoring the ruling.

"There are still so many people in institutions," Gainer said. "The Olmstead case was 10 years ago! It's time for Georgia to comply with Olmstead!"

Gainer then led the crowd in chanting, "Get us out! Keep us out! Don't let us in!"

Sen. Jack Hill (R – Reidsville) appeared at Disability Day to speak about the waiting lists for community support.



# THANKS

again to all the sponsors of  
GCDD's 11th Annual Disability Day!

- |  |  |
|--|--|
| Abilities Expo   | Institute on Leadership and Disability               |
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"We [the government] want to thank you for helping us help you unlock the waiting lists," Hill stated. "It's a fight that we are all in together."

Cobb County second-grade teacher, Brad Cohen, made an appearance as this year's keynote speaker. Cohen, who has been named state teacher of the year, is most recognizable for having his story featured as a Hallmark Hall of Fame Movie, "Front of the Class."

Explaining how family, friends and teachers ostracized him while growing up with Tourette's Syndrome, which makes him make noises out of his control, Cohen's story is one of triumph. "I was determined to become the teacher that I never had," he told the crowd. "I wanted to be that teacher who focused on strengths ... not weaknesses."

After graduating from college, it was on Cohen's 25th interview with the Cobb County School District that he finally got his chance. Hired as a second grade teacher, he knew what his first lesson would be.

"I sat on my rocking chair and told them about Tourette's Syndrome," Cohen said. "And I said there was only one thing we could never do in my classroom ... play Hide and Go Seek!"

That was 13 years ago, but Cohen still acts like he first started his job last week. "I live my life with passion!" he stated. "I don't have a disability because I think I have a disability. I have a disability because OTHER people think I do!"

Following Cohen's speech, awards were handed out to advocates in the fight for people living with disabilities. The Samuel B. Mitchell

Lifetime Achievement Award was given

to Bernard Baker, who led the crowd in a chant of "Free our people!"

"My reaction [to receiving this award] was one of total surprise," Baker said following his acceptance. "But my work is all for continuing the dream that Sam had, and I will continue the work."

Without sponsors, Disability Day at the Capitol would not be possible. The Governor's Council on Developmental Disabilities would like to thank its sponsors:

**SPONSORS  
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Legislators supported advocates' efforts.



## Government Officials Turn Out for Disability Day

The Governor's Council on Developmental Disabilities would like to thank the following state legislators who showed their support for the disability community at the recent Disability Day:

Rep. Jill Chambers (R-Dekalb) • Rep. Mike Jacobs (R-Dekalb) • Rep. Sean Jerguson (R-Chamblee) • Rep. Fran Millar (R-Dekalb) • Rep. James Mills (R-Hall) • Sen. Nan Orrock (D-Fulton) • Rep. Allen Peake (R-Macon) • Sen. Jack Hill (R-Reidsville) • Rep. Dan Moody (R-Alpharetta) • Rep. Doug Collins (R-Gainesville) • Rep. Carl Rogers (R-Gainesville)

Thanks for all of your hard work on behalf of Georgians living with developmental disabilities, and we look forward to seeing you at next year's Disability Day!

Bill and Beth Tumlin, along with daughter Tracy, presented the annual Self-Advocate of the Year award in honor of their other daughter, Natalie. "Thank you for keeping on keeping on," Beth Tumlin stated in presenting the award to Virginia Harris.

Ashley Turner from Carrollton, a personable young lady, was thrilled about her first time at Disability Day. "I'm excited to go and march!" she said. "I love the buildings [of downtown Atlanta.]" Following the program and march, Turner seemed tired but happy. "It was a good day," she summed up. Friends Melina Willingham and David Gray agreed.



**"Look around and see how we've grown!"**



Turner was just one of the new faces that Tom Seegmueller, chair of GCDD, noticed as he looked out over the crowd. "Look around and see how we've grown!" he commented on the attendance of Disability Day. "A few of you have been here for all 11 years, but there are so many new faces today, too. Good work! We look forward to seeing you back here next year."

Betty Hasan-Amin, who lives with a spinal cord injury, is a more seasoned veteran of Disability Day. "I have been for quite a few years, but was unable to come last year," she said. "I was really excited to come out this year."

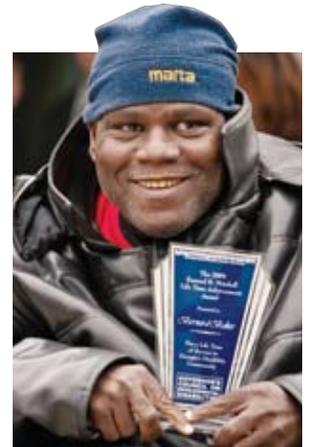
When asked why attending was so important to her, Hasan-Amin passionately responded, "We know the legislature is in session. Certain bills and programs need to be passed. Olmstead was passed 10 years ago, but there is still so much work to be done."

Tess Hailes, along with service dog Jake, was impressed with how Disability Day has grown. "I've been here before," she said. "It's grown and has made a big difference for many people living with disabilities." Hailes also enjoyed emcee Frank Ski. "He was phenomenal!"

Will Crain from Sprout Spring School in Hall County was particularly enthralled with keynote speaker Cohen, taking time to talk with him and even take some pictures. "It was awesome!" Crain enthused about his day at the capitol. "I loved that it was by the choo-choo train!" Lunch was served at the Georgia Railroad Freight Depot, and was catered by The Varsity.

The end of the program was used to inform people of next year's date – February 25, 2010. "Mark your calendars!" Jacobson told the crowd. Ski took the stand one final time, as well.

"Take the information you have learned today to go out there and make a difference in the lives of thousands of Georgians!" Ski said. ●



**"...my work is all for continuing the dream that Sam had, and I will continue the work."**

# PERSPECTIVES...

## Finding a Home Proves Difficult for Gracewood Resident

By Kathy Crowder



*Kathy Crowder is a 57-year-old woman with cerebral palsy who has been a resident of East Central Regional Hospital most of her life. She is a graduate of Georgia Voices that Count and a former member of the Governor's Council on Developmental Disabilities. When visiting her family, she enjoys going to church and catching up with old friends.*

I've lived at the East Central Regional Hospital's Gracewood facility for 40 years, since I was 17 years old and my mother could no longer support my physical needs.

I had an active life at Gracewood for many years. I made friends, joined a puppeteer group that performed all over the state and saw my family often. About seven years ago I decided I wanted to move back into the community because many of my friends had moved out, and my father was unable to make the trip to visit me as often as he got older.

**"I wanted to go where I function well, not where the service provider functioned well."**

I wanted to move closer to my family and friends near Warm Springs but was told by the service provider that support for my physical needs was not available there. After several fruitless years of trying to find support at home, I decided to look in other communities. This was frustrating because I wanted to go where I function well, not where the service provider functioned well.

Working with United Cerebral Palsy, I initially found an accessible home in Newnan that wasn't too far from my family. This seemed like a good compromise. Once we had identified the home, I applied for a waiver to move my support money from Gracewood to the community. But a year later, I still hadn't received the waiver funding, and UCP had to let go of the house. I was really disappointed.

Now a home in Mableton has been identified for me, but there are still a few obstacles to overcome. First, I won't be able to see my father as often because the home is further away. Also, the house needs to be adapted with a shower lift and raised tub to meet my needs.

In addition, I've discovered I can't bring the customized wheelchair I use at Gracewood to the community, though other assistive technology devices, like my Dynavox, will follow me there. Also, not all of my supports are in place yet. I'll need speech therapy, physical therapy, occupational therapy and day services in addition to direct support. An accessible van will also need to be in place before I can move.

I'll be sharing the Mableton house with three other people with disabilities, one of my friends from Gracewood and a woman from the local community. We have to find one more person with a disability who can move in with us and is ambulatory because the rules do not allow four people who use wheelchairs to be supported in the same home.

I hope I am really able to move out of Gracewood this time. I want to go to church with my family and do what I want, when I want. I want to get out more and eat at restaurants like Red Lobster.

I want my freedom. I think seven years is long enough to wait for it. ●

# Georgians struggle to find appropriate support in their communities

## Young Man Prefers Community Life after Living in Nursing Home

By Riley Buckmaster

When I was 32 years old, I had to move into a nursing home full of elderly people because my mother could no longer take care of my extraordinary physical needs.

My community in Thomaston, Ga., didn't have the support services I needed to live in my own home. Living in the nursing home didn't suit me because I was much younger than the other residents, and we couldn't relate to each other. But I had to live there for 13 long months before I found the community-based supports I needed and a place to live.

Now I live in Warner Robins, which is about two hours away from Thomaston. It was the closest place to my home county where support services were available. I live in a duplex with two friends, Calvin and Rodney, who also have disabilities, and we all get along great. There's nothing Calvin wouldn't do for me.

**"When I was 32 years old, I had to move into a nursing home full of elderly people..."**

The best thing about living in the community instead of the nursing home is that I can come and go as I choose, not as I'm told to. I'm free to do what I want, when I want. I like to read, watch TV and fiddle with computers.

Since I moved to Warner Robins a little over a year ago, I've started taking classes at Middle Georgia Technical College. I took classes in the fall, and I'm planning to take more this spring. I want to get my Cisco network certification. I wouldn't have been able to do this if I was still living in the nursing home.

My roommates and I each have our own staff. My direct support professionals come between 9-5 during the week and for 13 hours each weekend day. They help me dress, take my medicine, bathe, cook, clean and other general things I'm not able to do on my own because I use a wheelchair. They're wonderful, and they've bent over backward to make sure I get the support I need. They even help me get to school.

The only regret I have is that I don't get to see my mother as much as I'd like, but I did see her over the holidays, and she comes to visit periodically. I talk to her on the phone once or twice a week, too.

But overall, my life is much better. I'm living with my friends and have the freedom to do what I want, just like anybody else. ●



*Riley Buckmaster is a 34-year-old man from Warner Robins, who serves on the Governor's Council on Developmental Disabilities' Advisory Board. He attends Middle Georgia Technical College.*



# Microboards Empower, Enrich Lives



Carmine Vara

**C**armine Vara loves his job working as a senior information specialist at Stone Mountain Park. He likes meeting all the people who come into the park and helping them find their way around.

The 25-year-old has worked there for five years and has been promoted and received raises. But then his service agency said it couldn't support him at his job and suggested he go to work at a sheltered workshop for mere pennies on the dollar.

"We had a horrible time with the services he was receiving," his mother, Nancy Vara, explained. "It was hard to find providers that would meet Carmine's needs. He knows what he wants, and he doesn't want to go into a program he doesn't like. The plan needs to be individualized."

The Varas' frustration with services led to them incorporating a microboard for Carmine.

"A microboard is a small nonprofit organization created

to provide a circle of support to a person with a disability," explained Georgia Microboards Association (GAMBA) President Jayme Sickert.

The board is formed by the person with the disability along with members of his or her community.

The purpose is to identify and plan for the support needs of the individual

using person-centered planning ideals. In Georgia, microboards use the Planning Alternative Tomorrows with Hope (PATH) planning tool to identify the person's needs and create an implementation plan for meeting them.

"I think my board is awesome," Carmine Vara said. "The meetings are all about me."

His mother agreed. "We were worried about what would happen once mom and dad were gone," she said. "We have a life insurance policy that would pay a provider for services, but the provider wouldn't take care of Carmine's emotional needs, or take into account his family background or roots. Now we have seven people at the table who say they'll help. They've been to our home, they know who we are. They're aware of Carmine's needs and what to expect from his staff. They will support what he wants, not what the agency wants."

When forming the "All About Carmine" microboard, Nancy Vara turned to Dr. Ruthie Beckwith, who formed the Tennessee Microboards Association and has been instrumental in helping to set up GAMBA, as well.

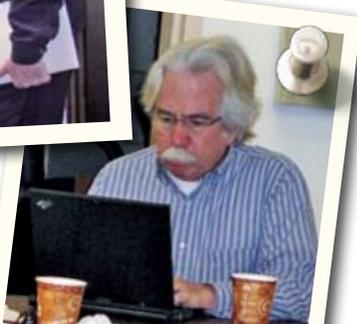
"We invited 20 people who might be interested in being on his board to our house. Ruthie facilitated the meeting," Nancy Vara explained. "It's taking a friendship and taking it one step further. Board members are saying I'll commit to Carmine's life and well-being."

From that meeting, seven members were appointed to the board. "We each have a role. Carmine is the president, and he has a vice president, two administrative assistants and a financial officer," she explained. In addition to Nancy and Carmine Vara, his sister Andrea serves on the board, as well as four members of his community.

**"It was hard to find providers that would meet Carmine's needs. He knows what he wants, and he doesn't want to go into a program he doesn't like."**



GAMBA allows members to share best practices.



*A microboard is a small nonprofit organization created to provide a circle of support to a person with a disability.*

Chris \*, who serves as the board's financial officer, has known Carmine Vara since 1997, when they met at an equestrian riding school. He said he volunteered because "I wanted to help out a friend.

"I handle all of Carmine's financial stuff. His mother and I have access to a bank account for him. I handle both his personal funds and any money he receives from state or federal organizations," Chris explained.

According to Sickert, microboards generally follow one of two models. "In some cases, the microboard becomes a licensed provider in the state for services for the person they support. This is a difficult, very labor-intensive process, with a big application. Once approved, the board becomes a licensed provider and receives waiver funds to directly hire staff and pay for services.

"The other model is one that simply uses board members as a natural circle of support for the individual with a disability. Another licensed provider provides the services," he said.

The All About Carmine board decided it would apply to become a licensed provider to assure he was receiving the individualized services he requires.

"We have petitioned the state for a waiver to become a personal care provider. Once it's approved, we can hire staff and pay Carmine's bills on our own. We'll be able to contract with who will be the best fit for Carmine. We'll conduct the hiring and firing process and training. We have a policy and procedures manual that details everything," Chris said.

In addition to training to learn how to properly support Carmine Vara's physical needs, his staff also needs to learn about his personal needs. His mother said, "When you come into Carmine's life, there's a whole other training involved about what Carmine wants in his life. If he wants to get



on MARTA and take it from one end of the tracks to the other, it's his choice, what he wants to do."

The board meets once a month and discusses a variety of topics. "Often, we coach Carmine on how to talk to his staff, if he's having any issues," Nancy Vara said.

He also talks about other issues, like planning trips, problems he might be having with his friends, or even his family. "Sometimes he says I'm being unreasonable - I tell him to call his board.

**"If something happened to the parents, these people would be institutionalized without an advocate."**

I try to hand over the responsibility - it's my ultimate goal not to be on Carmine's board, just to teach the folks on it and educate them about his life," his mother said.



*Top Photo: Nancy and Carmine Vara with Vara's direct support professional.*

*Lower Photo: GAMBA helps microboards become incorporated.*



*Microboards are a formalized circle of support.*

**“It’s a huge RESPONSIBILITY, and you can’t underestimate it.”**

One of the most important aspects of any microboard is having people outside the family who are committed to the individual.

“Families feel like they’re going it alone,” Sickert said.

And parents are concerned about who will have their child’s best interests at heart in the future.

“Carmine needs to know who he can call if I’m not here – people he trusts to turn to. He knows not to sign documents without talking to someone. In an emergency, I would be afraid of

**It’s a false sense of security to think a provider agency will take care of your child when you’re gone.**

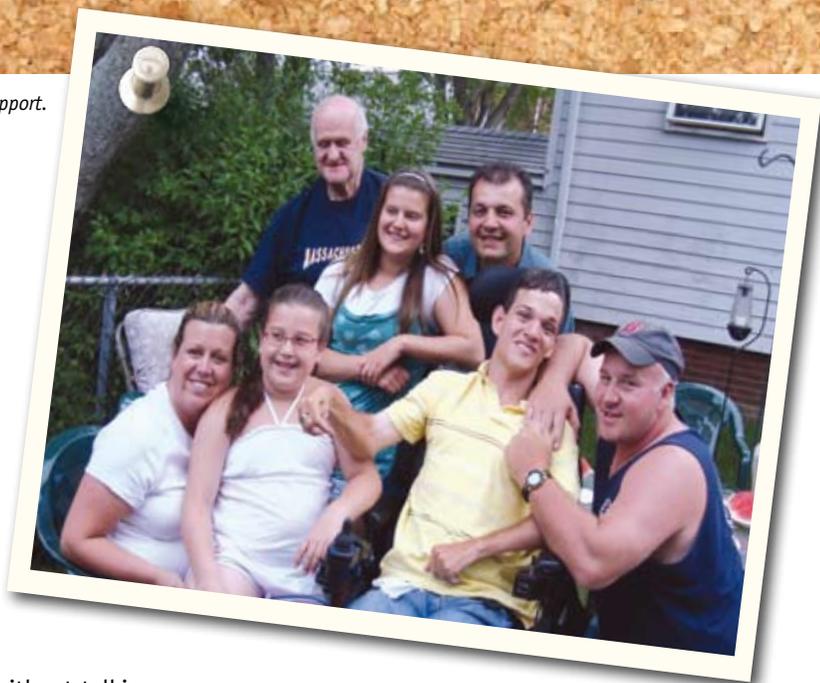
a provider sending someone over who didn’t know him. I wouldn’t want someone like that assisting him with decisions,” Nancy Vara said.

“If you don’t have anyone in your child’s life, then you need to start looking for those people. It’s a false sense of security to think a provider agency will take care of your child when you’re gone. His board members all know what to do,” she continued.

Chris agreed. “If something happened to the parents, these people would be institutionalized without an advocate. So many people with disabilities should have something like this in place, especially those who are in the baby boomer category and don’t have other family members to help them out.

It’s important for friends or church members to assist.”

Serving on a microboard is a two-year term, and Chris said serving is a big commitment of time and effort. “I always tell people, ‘This is somebody’s life, if something



were to happen to Carmine’s parents, these are the choices we’re making for this person.’ It’s a huge responsibility, and you can’t underestimate it.”

After two years, the board members can resign or ask to be voted in for another term.

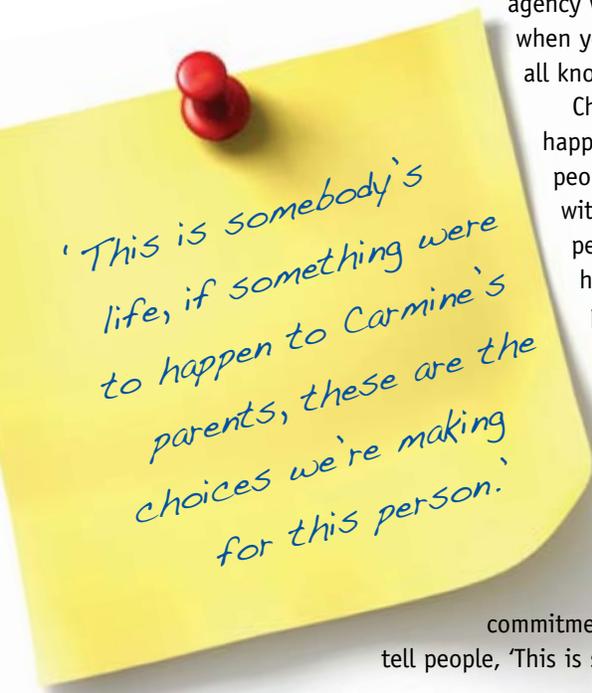
In addition to monthly meetings, board members have other duties, as well. Chris handles any financial needs that come up during the month, is currently working on business cards and T-shirts for the board and also socializes with Carmine Vara regularly, as do all the board members.

“I go bowling with Carmine, and take him to Hooter’s, to Las Vegas, to Stone Mountain. You name it,” he said.

Nancy Vara said the bylaws of the board state that her son receive at least three visits a month from various board members, whether they be outings or home visits, which helps members better assess how he is doing.

“If they see a concern with staff or Carmine, they call up the other board members and say, ‘We need to sit at the table because Carmine is not happy.’ They know what they need to do,” she said.

“Carmine is building true relationships with the board, and they support him in decisions he needs to make. The board takes the burden off the family, and we trust board members to help Carmine make decisions,” she said. ●



*‘This is somebody’s life, if something were to happen to Carmine’s parents, these are the choices we’re making for this person.’*



## Microboard Association Offers Support

By Valerie L. Smith

Formed in 2008, the Georgia Microboards Association (GAMBA) provides support and technical assistance to microboards, nonprofit organizations providing circles of support for individuals with disabilities.

From recruiting and training board members to providing support for navigating the incorporation process, GAMBA offers resources to Georgians with disabilities and their families who are looking to start a microboard.

Families and individuals usually start a microboard because they want to create an unpaid circle of support that will endure for as long as they need and desire; they want to have more control over who provides supports to them; and/or they want to build resources to be able to meet unexpected needs or desires.

Jayne Sickert, chairman of GAMBA, serves as his daughter Amy Sickert's board chairman and has found starting her board rewarding.

**“Individuals with disabilities or their parents many times feel like we’re the only ones who know what the needs are.”**

“Individuals with disabilities or their parents many times feel like we’re the only ones who know what the needs are. We need additional support people. We chose people for Amy’s board who were part of her life already. People from church, a nurse, a CPA and a lawyer all agreed to be on her board,” he said.

“Amy’s involvement in the community is greater and others have taken interest in her. Some of the ladies on the board have taken Amy to get her nails done or to dinner. She isn’t just interacting with mom, dad and her care staff. It’s been a real benefit. She has new opportunities and

a richer, fuller life than if she were just home with mom and dad. It’s a great concept,” he said.

Starting a microboard can be challenging, but GAMBA can help make the process a little smoother.

“We can help train the board, provide assistance with incorporation and organization and implement the PATH set up,” Sickert explained. PATH, which is short for Planning Alternative Tomorrows with Hope, is the process by which the microboard identifies the goals of the person it serves and devises a plan on how to achieve those goals.

In addition, GAMBA remains up-to-date on changes and rules in regulations of microboards and will disseminate that information to member boards. “It gives us an opportunity to network, share information and find out what’s working and what’s not for other boards,” Sickert said.

Nancy Vara, a GAMBA board member who sits on her son, Carmine’s, board, said she became involved because, “I want to network with other board members from other microboards to see what creative things they are doing that we can do with Carmine and his staff.

“GAMBA is working on outlining what the dues will pay for, such as networking events with other boards, talking to legislators, assistance with becoming a provider, how to build a board and those types of things,” she continued.

While most of the members are currently in the metro Atlanta area, Sickert hopes to expand GAMBA’s reach. “Our intent is to create board positions and have representatives for every region. We’re trying to get the concept out, answer questions, get people to meetings. We received a grant from the Governor’s Council on Developmental Disabilities to help us do some initial things like getting a Web site and hiring someone to go throughout the state to talk about microboards and the association.

“We’re starting to get some inquiries from Athens, Macon, Savannah and Rome,” he said.

Georgia is only the third state in the United States to form a microboard association, joining Tennessee and Virginia. The microboard concept originated in Canada in 1986. ●



**“I want to NETWORK with other board members from other microboards to see what CREATIVE THINGS they are doing ...”**

# The Olmstead Decision: We've Come So Far, But Have So Far To Go

Nearly 10 years ago, the United States Supreme Court made the famous *Olmstead v. L.C. and E.W.* ruling. The court's decision stated that segregating individuals with disabilities in institutions may be discriminatory and that according to the Americans with Disabilities Act, states should provide community-based services to their residents. This court battle instantly opened doors, literally and figuratively, for thousands of Americans to move into their communities.

Several organizations throughout Georgia, including the Governor's Council on Developmental Disabilities, will be marking the landmark case, which originated in Georgia, with several inclusive celebrations of how far the United States has come over the past 10 years, as well as looking forward to just how much further the country has to go.

"Our goal is to go to all of the institutions that are still open in the state of Georgia, and hold celebrations throughout the summer on their lawns," Kate Gainer, advocacy director for GCDD, stated. "These celebrations will be a part of our 'Long Road Home' event, and will

culminate in one big event in front of the state capitol."

These are not protests, though Gainer won't make any promises. "I can't say we won't be marching," she chuckled. "What we're trying to do is raise enough money to take as many people as we can to these events. The purpose of having them at an institution is so that people inside the institution can join, and have their voices be heard."

**"We understand that there are still several people living in institutions in this state that are just waiting to get out."**

Georgia State University will also mark the occasion with a symposium on October 23, 2009. "We will be holding it in conjunction with Atlanta Legal Aid and the Georgia Advocacy Office," Stacey Ramirez, of the Center for Leadership and Disability (another sponsor of the symposium), explained. "It should be an excellent day for advocacy! Lois Curtis, one of the plaintiffs from the *Olmstead* decision, will be joining us, as well as Judge Marvin Shoob, who ruled the original judgment of the case."

Topics of the symposium will explore the current rights of individuals in institutional living, as well as what the next steps should be in Georgia as far as implementing and expanding the *Olmstead* decision goes. "We understand that there are still several people living in institutions in this state that are just waiting to get out," Ramirez explained. "It's important for us not to sit back and accept that everything will work itself out. Ten years later, we need to ruminate on the *Olmstead* case every day, and search for ways

**"Our goal is to go to ALL of the institutions that are still open in the state of Georgia, and hold CELEBRATIONS throughout the summer on their lawns."**



EXCERPTS FROM:

## The Long Road Home March

By Samuel B. Mitchell

We came determined to make it known,  
that we want to live in our own homes.  
From many different walks of life we've come,  
concentrating our voices and efforts as one.

High spirits abound as we travel down  
to the old capitol at Milledgeville town.  
Ready to march for the dignity and release,  
of those locked away yearning to be free.

Free of the domination, pain, and abuse,  
free of nursing homes and state institutions,  
and free to take control and live as we may,  
deciding what directions our lives will take.

The sun glares down with fierce defiance,  
baking the earth as we push onward.  
To the questioning stares of each passerby,  
we give cards and leaflets that explain why.

At Central State we speak with those,  
who are trapped behind the wide glass doors.  
Take heart is the message, you are not alone,  
we'll keep on fighting until you are home.

The cemetery exposes Central States shame,  
with rows of markers with numbers for names,  
and with a prayer for the dead and what we've begun,  
we launch the caravan toward Brook Run.

To cheers and horns the caravan wounds,  
pass fields and meadows, hamlets and towns.  
At Brook Run we gather to hear of and see,  
a closed institution with the people set free.

The next day onward to Shepherd we go,  
to continue the march to the Capitol's door,  
and eating a hearty meal provided by friends,  
we prepare ourselves and the march begins.

Threatened by lightning, rain and storm,  
we steel our resolve, and steadfastly move on.  
Again we educate the public at large,  
by sharing materials that tell why we march

Get us out we've shouted from the start.  
Keep us out we've cried to each listening heart.  
Don't put us in we loudly state our plea,  
as we advance down wide and busy Peachtree.

We snake our way through old Underground,  
and reach the Capitol in the middle of town.  
Then gathering for the Candlelight Vigil we pray,  
thanking God for the safety provided that day.

“Ten years later, we need to  
ruminate on the Olmstead case  
every day, and search for ways on  
how to speed up the process of  
moving people out of institutions.”

on how to speed up the process of moving  
people out of institutions.”

Gainer agreed. “That’s the whole  
point of having our celebrations at the  
institutions,” she explained. “It was a  
landmark decision, but Georgia still isn’t  
doing enough to help people on the waiting  
lists get community support. So we’re both  
celebrating the decision, but also bringing  
attention that there is still a problem.”

Gainer explained that fundraising  
began last year for “Long Road Home,”  
but donations are always accepted by  
People First of Georgia, care of the Georgia  
Advocacy Office at 150 East Ponce de Leon  
Avenue, Suite 430, Decatur, GA, 30330.  
“The more donations, the more institutions  
we can travel to,” Gainer said. “The  
more institutions we travel  
to, the more awareness  
we bring up. And that’s a  
great thing.” ●

*Olmstead plaintiff Lois Curtis  
plans to participate in  
several anniversary events.*



# New Options Waivers: NOW Isn't Fast Enough For Some

**I**n the nearly six months since the New Options Waivers went into effect in Georgia, some families have not yet attained the support they received prior to November 1, 2008 (when the waivers went into effect), and are wondering when they will become a priority.

Jodie Key, along with daughter Chloe, are two Georgians affected by lack of support. Chloe Key was diagnosed with Sanfilippo syndrome at the age of three. Sanfilippo syndrome is a rare degenerative genetic disorder in which the child is missing an essential enzyme that breaks down a complex body sugar, which then slowly builds in the brain. The Key family initially used a service provider through the state with no problem. "We had someone come in twice a week to relieve my husband and me from supervising Chloe," Key explained. "We also received help with diapers, which was huge for us. Chloe's comfort level is huge for us, so of course we go through several diapers each day. It can be quite an expense."



**"We need help, and we're not getting it."**

But on November 1, that all changed. "Her service provider wasn't going to honor the waiver," Key said. "They just stopped coming. We don't get help with diapers anymore. Sometimes our support coordinator finds someone who might be interested in coming out to relieve my husband

and me at certain points throughout the week, but none of the suggestions pan out."

Another mother, Linda Dukes, has experienced a similar frustration when changing from her daughter's natural supports enhancement waiver to the NOW waiver. In a letter written to Dr. Stephen Hall, director of the Office of Developmental Disabilities through the state Department of Human Resources, Dukes expressed her initial reluctance to fully support the waiver. "...we can't use our current service provider for services any longer because the low pay rate for providers makes it impossible to find anyone I would trust to work at those rates," she wrote. Dukes felt forced into self-directing daughter Elena's care, and began the process of filling out paperwork in November 2008 to begin receiving services in January 2009.

**"The waiver nightmare continues, with mistakes, delays or miscommunications on every level."**

"The waiver nightmare continues, with mistakes, delays or miscommunications on every level," Dukes wrote in an updated letter on March 9. She explained how the original paperwork was lost, but her daughter was still approved for care by January 3. The two service providers that Dukes uses are still not being paid in full or on-time, which has caused frustration for Dukes and created uncertainty on the part of the service providers.

"We are also very frustrated that you said that good providers would not be hurt, but our GREAT providers are being hurt tremendously because they have lost a large portion of their clients due to the new rate plans," Dukes goes on to say.

"Some of the providers didn't understand how one service would be broken into five different services in a process called 'unbundling,'" responded Hall. "It's something that the federal government required us to do that has nothing to do with the waivers." Hall explained that some

# “Did they ever think about how it would affect real people?”

providers aren't seeing that they can bill for the other four services which will make up for any losses. “Also, we made an agreement with the Department of Community Health in August that any provider that had a cash flow issue could ask for and be paid whatever the discrepancy was.” Hall also said that only two providers had taken advantage of that service.

Eve Bogan, the director of Tools for Independence out of the Developmental Disabilities Services Division of JF&CS, thinks that the theory behind the waivers is solid. “My feeling is that given all the issues with the state budget and the waiting lists, the timing of such massive systems change is a bit unfortunate,” Bogan stated. Bogan also said that she has found that individual regions have been very responsive to any problems that come up. “The theory and vision of the waivers are solid, but the devil is in the details, which is the implementation,” she summed up.

Sherry Richardson, featured in last issue's New Options Waiver story, also has been experiencing some of the growing pains associated with the waiver. “Major process changes included how we would receive services, which providers we would use, and we had to decide which services to self-direct, use a co-employer, or use providers in a traditional manner,” she explained.

“Our family is just grateful that our son Micah has a waiver,” Richardson continued. “Children with autism have very specific needs to support their daily functioning. Without waiver services, Micah would not be where he is today.”

In the meantime, Key is optimistic that the New Options Waiver is just experiencing growing pains, and that she will soon be able to get back to fully focusing on her daughter, rather than worrying about how she and her husband will provide everyday needs. “Taking care of Chloe is a full-time job, one that my husband and I take on gladly,” she said. “But we need help, and we're not getting it.”

Richardson also remains positive. “Overall, I feel as if we have made it through the roughest patch of the New Options Waiver implementation,” she stated. “I look forward to things to come.” Richardson also went on to say that after attending the Office of Developmental Disabilities' community forums and advocate meetings, she feels better equipped to handle changes with the waiver.

Dukes has a specific approach that she suggested in her letter to Hall. “The department HAS to work with support coordinators and providers so that they really understand how the whole process works, from start to finish.” This way, Dukes explains, they can more accurately explain to parents how the system works and what their exact choices are. She also states that community guide training is not enough, as she is spending all of her time simply ensuring that her daughter's needs are being met.

**“Major process changes included how we would receive services, which providers we would use, and we had to decide which services to self-direct...”**



“Georgia didn't change its waivers for 25 years, unlike the other 49 states,” Hall explained. “Some states had changed their waivers as many as four times in that time frame. The change that happened on November 1 is a combination of three previous generations of waiver changes that, in my opinion, should have been done a long time ago.”

Some are still not impressed. “They spent so much time getting this to look good on paper,” Key sighed. “Did they ever think about how it would affect real people?” ●

## Microboards Offer Option for Self-Determination

By Dr. Ruthie Beckwith

**F**or people with disabilities, a small, nonprofit microboard offers an opportunity to create a formalized circle of support of friends, family and community members who know their wishes and will help them obtain the supports and services they need to live a full life of their choosing.

Ruthie-Marie Beckwith, Ph.D. is the founder and executive director of the Tennessee Microboards Association, Inc. an organization dedicated to helping people with disabilities self-manage their services and supports. Beckwith was previously a volunteer founder and executive director of People First of Tennessee. She has served as an adjunct professor of special education at George Peabody College at Vanderbilt University and Middle Tennessee State University. She provides consulting services across the United States in areas of self-determination, community organizing, leadership development and self-employment. She received her Ph.D. and M.S. degrees in Special Education from George Peabody College and her B.S. degree from the State University of New York at Geneseo.

Many individuals and their families form microboards to have more control over paid supports and build resources to meet unexpected needs or desires. However, the most fundamental benefit is a commitment from the volunteers on the board that they will be there for the person. This commitment serves as the basis for trust, respect and confidence in the microboard's capacity to assure long-term supports remain in place along with expanded community membership.

Four steps are followed in the formation of a microboard:

- 1 Basic information about microboards is provided to the individual and his or her supporters.
- 2 A person-centered plan is created using the Planning Alternative Tomorrows with Hope (PATH) process.
- 3 Board of directors training and assistance with incorporation and organization is provided.
- 4 The microboard helps the individual carry out his or her PATH.

Some microboards choose to become the service provider for the individual with a disability, allowing them to receive Medicaid waiver funds and disburse them directly to employees they hire to support the person. In these cases, three more steps are required:

- 1 The microboard completes an application to become a paid provider of services and supports for the Medicaid home and community-based waiver program.
- 2 The microboard develops the management and oversight needed to operate as a paid provider.
- 3 The microboard helps the individual carry out his or her PATH.

Another primary benefit of microboards is the contribution they make to the completion of activities identified on the person's PATH. Most microboards find that within two to three years, another PATH is needed to take advantage of the expanded opportunities the microboard helped create in the person's life.

Depending on the circumstances, establishing a microboard can take a year or more, especially if the board decides to become a service provider.

Microboards incur some basic establishment costs including fees for incorporation and background checks. To use the trademarked term "microboard," the group must join the Georgia Microboards Association (GAMBA), which provides technical assistance to start and maintain a microboard. GAMBA fees vary by the type of microboard and include membership in the association.

Starting a microboard can have a few challenges. Many individuals with disabilities may have a limited social network from which to recruit board members, and they may need to build self-confidence and belief that they are in control of their lives. Also, some individuals may be in crisis at the time they need to start the microboard and need to resolve that crisis before they have the energy to devote to the board.

To assure the microboard is successful, it should have a sufficient number of members to carry out the work; add members as time passes or the individual's needs change; have clear support for managing the funds it receives; ensure that one person is not responsible for or insists on doing all the work; develop an effective system for managing required paperwork; and, develop a good working relationship with its funder(s).

While starting a microboard can be challenging, its rewards for the person it serves are great. For more information, visit [www.gamicroboards.org](http://www.gamicroboards.org) or call GAMBA Chairman Jayme Sickert at 770.335.6178. ●

# StraightTalk

## Disability Day Energy Motivates South Georgia Advocate

By Virginia Harris, Executive Director of BAIN

Every year for the past 10 years, I've been coming to Disability Day at the Capitol with a group of people from my tiny south Georgia town of Bainbridge. I make the four-hour trip with BAIN staff, board members and people with disabilities because I know how important it is to fight not for just my own rights, but the rights of the whole disability community.

During the rally, I get so fired up and empowered, and I know it's important for other people with disabilities to see self-advocates making noise and coming together to get organized and make a difference. One thing my group always does when we're here is visit with the legislators from our area to let them know what issues are important to us and all Georgians. Writing my representatives and talking with them in Atlanta is always a great experience.

**I know it's important for other people with disabilities to see self-advocates making noise and coming together to get organized and make a difference.**

This year's rally allowed us to express outrage at the constant targeting of the disability community in the state budget process. This is the third year in a row that the funding for independent living for people with disabilities has been threatened, and we came together to say it must stop. We were the disability voice of Georgia coming together. We were people with all kinds of disabilities, family members, friends and workers all united in our common cause. This is what we can do when we ALL work together.

I was really surprised and honored during this year's Disability Day to be named Georgia's Self-Advocate of the Year. I've been working in the disability movement about 15 years, and it's been my objective to advocate on the state and local level for issues surrounding independent living.

I want my community to have fair housing and accessible transportation like Atlanta, so I serve on a local housing task force and transportation committee. I also organize political forums in my town so our legislators know what issues are important to people with disabilities.

I'm involved in advocacy on the state level by serving on the board for Georgia's Statewide Independent Living Council. It takes a lot of long hours, and I don't always see change for a year or two, but at least I know we're working on it.

In my community, I started BAIN (Bainbridge Advocacy Individual Network), which is our area's independent living center. Before BAIN, we had no agency advocating for services for people with disabilities in Bainbridge. We didn't have a voice. So I pulled together as many people with disabilities as I could on the local level so we could start doing changing that. I love the country and don't want to move. I think we can make a change in Bainbridge, when we work together.

Going to Disability Day at the Capitol helps keep us fired up. It gives people in Bainbridge the opportunity to come together with people across the state to celebrate our rights and feel united in our common cause.

Once you experience Disability Day once, you always want to come back. I get excited and want to bring the passion and advocacy spirit back to my local community. ●



Virginia Harris is the founder and executive director of BAIN, an independent living center in Bainbridge, Georgia, run by and for people with disabilities. She has served on the Statewide Independent Living Council and the State Rehabilitation Council and is a graduate of Partners in Policymaking.

— I GET —  
**excited  
and want to  
bring the  
PASSION  
and advocacy  
spirit back to  
MY LOCAL  
community.**



## Mia Helps Raise Funds in Pageant

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

When you hear the word pageant, you think 'beauty.' I'm not a big pageant person. Especially with children, I never felt comfortable crowning one winner, an outcome often determined by the resources and competitive behavior of the parents. I would inwardly suffer if someone was made fun of or hurt.

So I was hesitant when Mia's summer camp, Extra Special People, decided to hold a "Big Hearts Pageant" to raise money for the program. But I trust the staff because I know they love and respect the kids and would never put them in a vulnerable situation. Still, once you put kids with disabilities out on a stage, you don't know what to expect. I went along with faith and Mia's excitement.

Before I sat down to write this, I sought a better definition of pageant, because the Big Heart Pageant is NOT the stereotypical beauty contest. According to Webster, one of the definitions is "an elaborate drama, celebrating a historical event or presenting the history of a community." That last piece of the definition really rings true. The pageant is a reflection of the ESP community and its history. Cutler, one of the emcees, has been a counselor for eight years. Now he's a high school teacher. Another participant, Nicholas, started camp as an energetic, distractable child. Now he comes on stage in a formal tuxedo, six feet tall, styling and then pausing to deliver the recipe for his famous baked ziti, which he brings to every ESP potluck. Mia has attended for 13 years, as have several members of the "oldest unit." We can't graduate them. They have grown up together and shared sleepovers, Fair Day and Mall Day, mud and water wars, tubing, Camp Twin Lakes and prom nights in July. Kids learn to swim, walk and communicate. Parents get to breathe. Counselors graduate from college and go to work. Sometimes they bring their husbands or wives and babies back to camp.

Martha, the founder, and director for many years always said it was the community's responsibility to support ESP. She sought no grants or government funding. Businesses, schools and churches in seven counties contribute in large and small ways to the success of the camp. The campers and their friends and families are a beloved community that pays witness, supports and celebrates the campers' histories.

At the end of the show, the whole cast and crew and audience broke out in "Hip Hip Hooray," the signature camp cheer. I can support a pageant of community where everyone wins. ●

The experience showed me again that children and youth are amazing and full of joy and each will share something, no matter how subtle.

The experience showed me again that children and youth are amazing and full of joy and each will share something, no matter how subtle. In the inaugural year, a couple hundred people attended and \$4,000 was raised. Campers got flowers, tiaras and people's choice awards. Mia's sister Annie brought a whole row of her friends, and when Mia got on stage after being introduced, she took the microphone away from the emcee and said, "My sister Annie is here and all her friends" and threw them a big, diva-style wave. This year, the audience tripled and the camp raised nearly \$10,000.

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



# APRIL

**April 22**  
**GSU Disability Awareness Film Series, sponsored by the Center for Leadership in Disability**

*Her Name is Sabine*  
 University Center at Georgia State University  
 Atlanta, GA  
 404-413-1287  
[jhowell@gsu.edu](mailto:jhowell@gsu.edu)

**April 24 & 25**  
**Sibling 101: Brothers and Sisters of People with Special Needs**  
 DoubleTree Guest Suites – Galleria  
 Atlanta, GA  
[dhendric@kennesaw.edu](mailto:dhendric@kennesaw.edu)

**April 28**  
**PIN Support Group Meeting - Parent To Parent GA**  
**Medicaid Basics**  
 770-540-4479  
[scott.crain@hallco.org](mailto:scott.crain@hallco.org)

**April 29**  
**GSU Disability Awareness Film Series, sponsored by the Center for Leadership in Disability**  
**Autism the Musical**  
 University Center at Georgia State University  
 Atlanta, GA  
 404-413-1287 • [jhowell@gsu.edu](mailto:jhowell@gsu.edu)

# JUNE

**June 15**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Columbus, GA  
[longroadhomega-subscribe@yahoo.com](mailto:longroadhomega-subscribe@yahoo.com)

**June 16**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Thomasville, GA  
[longroadhomega-subscribe@yahoo.com](mailto:longroadhomega-subscribe@yahoo.com)

**June 17**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Savannah, GA  
[longroadhomega-subscribe@yahoo.com](mailto:longroadhomega-subscribe@yahoo.com)

**June 18**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Augusta, GA  
[longroadhomega-subscribe@yahoo.com](mailto:longroadhomega-subscribe@yahoo.com)

**June 19**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Central State Hospital  
 Milledgeville, GA  
[longroadhomega-subscribe@yahoo.com](mailto:longroadhomega-subscribe@yahoo.com)

**June 20**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Rome, GA  
[longroadhomega-subscribe@yahoo.com](mailto:longroadhomega-subscribe@yahoo.com)

**June 21**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Georgia Advocacy Office  
 Decatur, GA  
[Longroadhomega-subscribe@yahoo.groups.com](mailto:Longroadhomega-subscribe@yahoo.groups.com)

**June 22**  
**Long Road Home: 10th Anniversary of Olmstead**  
 Georgia State Capitol  
 Atlanta, GA  
[longroadhomega-subscribe@yahoo.com](mailto:longroadhomega-subscribe@yahoo.com)

**June 30 – July 2**  
**APSE 2009 - Employment For All**  
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[www.apse.org](http://www.apse.org)  
 804-278-9187  
[www.apse.org](http://www.apse.org)



**A winning PATH starts with teamwork.**



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

## Governor's Council on Developmental Disabilities (GCDD)

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

## State Government

### Department of Community Health

[www.dch.state.ga.us](http://www.dch.state.ga.us)  
404-656-4507

### Department of Human Resources

[www.dhr.georgia.gov](http://www.dhr.georgia.gov)  
404-656-4937

### 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

## Microboards

### Georgia Microboard Association

[www.gamicroboards.org](http://www.gamicroboards.org)  
678-546-9799

### Tennessee Microboards Association

[www.tnmicroboards.org/](http://www.tnmicroboards.org/)  
615-594-5899

## Inauguration March

South Cobb High School  
[www.cobb.k12.ga.us/~southcobb/](http://www.cobb.k12.ga.us/~southcobb/)  
770-819-2611

## NOW Waiver

Developmental Disability Services  
[mhddad.dhr.georgia.gov](http://mhddad.dhr.georgia.gov)  
404-657-2258

## Olmstead Celebration

People First of Georgia  
c/o Georgia Advocacy Office  
[www.thegao.org](http://www.thegao.org)  
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[olmsteadsymposium@gmail.com](mailto:olmsteadsymposium@gmail.com)



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

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

Volume 9, Issue 4 • Spring 2009

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