

# Making a Difference

SUMMER  
2005

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

## Advocates Work to Free Children

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Against Institutions*

*Perspectives:  
Two Mothers Share  
Their Struggles*

*The Search for  
Integrated Recreation*

Jerilyn Leverett  
and her daughter  
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Photos by Harris Hatcher.

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

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

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

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### To Georgia's Disability Community,

**W**hen people are given the opportunity to reach their fullest potential, amazing things happen. A good example of this theory occurred last month when the Federal Government recognized Georgia for its development of the Mental Health Peer Specialist Program. Consumers involved in Peer Specialist Programs have accomplished goals in education, employment and independent living that few believed could ever happen. When barriers and biases are removed, the human spirit takes over, which results in great things happening to improve the quality of an individual's life.

Georgia's Mental Health Peer Specialist Program will be used as a national model to pave the way for other states to follow in the area of Consumer Driven Service Delivery. By utilizing Peer Specialist Programs as a catalyst, we must now challenge ourselves to ensure that as many Georgians with disabilities as possible have the same opportunity to reach their potential in community-based settings within a Consumer Driven Service Delivery System.

To facilitate this transformation, two initiatives have originated within the Governor's Office. First, the Commission for New Georgia's task force on Behavioral Health and Disabilities Service Delivery is charged with developing recommendations in service delivery that will promote better long-term outcomes by using evidence-based or best practices to become more efficient. Our second initiative is transformation of our Medicaid system. We are in the beginning stages of this exciting, but difficult work, aimed at transforming our Medicaid program in a way that educates consumers to make better health care choices. Many people wonder if Medicaid consumers can make better health care choices. I believe that they can with educational strategies targeted to their specific needs; too often, people live up to the expectations that public assistance programs place upon them. When given the proper tools and obtainable goals, Medicaid consumers and providers in the "New Georgia" will be expected to make informed choices based upon quality of care and cost effectiveness, with the ultimate goal of improving individual health outcomes.

I am proud of the work and dedication the Mental Health and Disability Community has put into this transformation effort. Supporting individuals in the community is the right thing to do for people, communities and our State's economy.



*Sonny Perdue*  
Sonny Perdue  
Governor



## Community Living is the Best Choice for Children

**A**s this edition of *Making a Difference* goes to print, we in the disability community celebrate two landmark events: the sixth anniversary of *Olmstead v. LC and EW* and the 15th anniversary of the Americans with Disabilities Act. Both advance the values that all people have gifts to share in neighborhoods, towns and cities across this country. Both reinforce the belief that all people should live in real homes rather than in segregated places like state institutions or nursing homes.



Today, there are over 140 children under the age of 22 living in nursing homes, private and public facilities in Georgia. Georgia remains in the top 10 in the number of children living in institutions. Six years after *Olmstead*, we still have children living away from their families for no crime other than having a disability. This cannot be acceptable. We have the experience of closing Rivers Crossing and showing how to support children in real homes rather than institutions.

The Georgia Advocacy Office, Institute on Human Development and Disability, People First of Georgia, Statewide Independent Living Council, members of the State Alliance for Full Participation Team and the Governor’s Council on Developmental Disabilities have joined together to focus on creating a Georgia where children are prevented from going into institutions or are brought safely home from facilities into homes and families.

We are committed to continuing to ask the questions: “Why are kids living in institutions?” “How can we get them out?” and “What will it take so that no child from Georgia ever has to live in an institution or nursing home again?” Over the next few months and years, you will hear a lot about this issue. Together, we are producing a video and publications to tell the story of those who have left and those who remain. We will be meeting with policymakers, legislators and the media to discuss how we can find ways to get children home.

### “What will it take so that no child from Georgia ever has to live in an institution or nursing home again?”

We have heard too many stories like the one about a two-year-old who had never been outside because the institution staff did not think she could go out and had to wait for a doctor’s permission. We won’t be able to tell every story because some want to keep it secret in the name of confidentiality. But you can be sure this coalition will persevere and grow stronger in its desire to meet our goals.

This edition of *Making a Difference* is dedicated to these children and telling their stories. It’s about what is needed so that every child has a safe and loving home outside the walls of any institutional setting. We will need your help, and I encourage you to contact any of the organizations involved and ask how you can get involved.

Let us know what you think about the magazine or any issue concerning people with disabilities and their families. We welcome the opportunity to print thoughtful responses to specific articles published in *Making a Difference*. You can reach me at 1-888-275-4233 or you can e-mail me your thoughts at [eejacobson@dhr.state.ga.us](mailto:eejacobson@dhr.state.ga.us).

Eric E. Jacobson  
Executive Director, GCDD

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

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



A **TREMENDOUS** thanks and ACCOLADES to the devoted **GCDD staff** for the **untiring** work that is done **EVERY** day in **advocating** for systems **change** and **improving** the lives of **families** and **PEOPLE** with **disabilities**.

Lynnette Bragg  
Chair, GCDD

## Supporting Families Key to Helping Children

**T**his quarter's magazine is devoted to children's issues. We all know that our future is in the hands of our children. Our main focus, as a society, is to build the next generation to be better than ours. To do this, we must focus on some important issues.

The most important issue for children is supporting families. The family unit is the core for all our values, where we are taught love and the basic skills of survival. Families who have children with developmental disabilities have challenges beyond those of families without disabilities. When our son Matthew was 12, he said families of children with disabilities are blessed because the family has to have more love in it than other families. It requires a level of devotion and determination that is so very different from families who do not have children with disabilities.

However, the divorce rate among families of children with disabilities is very high. Randy and I have been married 32 years, and there have been times when it was very stressful. Scott took so much time to care for, it left no time to build and maintain a relationship. Without the support of Scott's grandparents, I don't know if we could have survived. Randy often said that Scott was a wedge and Matthew was the glue that held us all together. Family support must be a priority. We did not have the availability of family support 20 years ago when I was diagnosed with lupus and was in need of major surgery and Pappaw had a heart attack. We were advised that Scott would need to live at Gracewood. We opted instead for the Autism Group Home in Riverdale. After living there for a while, it took Scott four years before he would sit next to me and show me affection. With just a little bit of support for our family, Scott would not have gone to the group home. We must stay devoted to the task of supporting families through Family Support and Natural Support Enhancements and continue working with the Family Connection Collaboratives in each Georgia county.

The second most important thing we can do for our youth is to educate them. Throughout my last 13 years with GCDD, education has been a priority. Real education, the kind that not only teaches the skills of living independently, but also teaches the basics, is imperative. A woman from Macon told us she went to school until she was 21 and upon leaving school found she could not get a job or further training because she was never taught to read. She learned to cook, make her bed and clean her home, but not to read. She enrolled in adult literacy classes, went on to the vocational technical school where she learned to read and is now successfully employed. We need to recognize the No Child Left Behind program needs a lot of support and educators need a lot of flexibility in teaching children with differing ways of learning. This is not a cookie cutter program, and our teachers need all of the help we can give to help our children succeed and learn.

As my term as chair of the Governor's Council on Developmental Disabilities comes to a close, I challenge each of you and the great state of Georgia to continue supporting families, children and adults with disabilities to **lead Real Lives, have Real Learning Opportunities, work in Real Jobs and have Real Homes, Real Friendships and Relationships, while maintaining Choice and Control over their lives.**



## Grants Help Children With Disabilities

**T**he Georgia Governor's Council on Developmental Disabilities has recently awarded grants to organizations that provide information on advocacy and resources for children with disabilities to the community. There were four large grants distributed this year, the Georgia Advocates for Rights for Children's Healthcare, the Baldwin Service Center, the Flint River Area Barrier Busters and the Southern Juvenile Defender Center. All of the organizations used the grants to provide knowledge and information to the community about developmental disabilities.

Georgia Advocates for Rights for Children's Healthcare provides support to medically fragile children. Beginning as a small group who has always been assisted by the Georgia Advocacy Office, the Georgia ARCH has been learning the ways of advocacy as they go. With the grant money from GCDD, Georgia ARCH was able to reach legislators with informative DVDs and inserts about medically fragile children and the need for Medicare to care for the children.

Pam Moore at Georgia ARCH, said, "We never could have reached out to the legislators like we did without the funding."

The 300 DVDs that were sent out have received an enormous amount of positive response. The money helped the Georgia ARCH get rolling with advocacy, and they now are able to take the next step to forming legislation.

The Baldwin Service Center in Milledgeville used its grant to form an alliance called the No Boundaries Club that works closely with students who are in sororities and fraternities at Georgia College and State University. The students and the center are currently working together to perform puppet shows in third grade classrooms. The child size puppets teach third graders about developmental disabilities and how to respect people with disabilities. The puppets have various disabilities and also each have a sibling puppet that demonstrates what life is like if a family member has a disability. With the money from the GCDD grant, the Baldwin Center and the college students have been able to obtain the materials needed to begin the puppet shows in the upcoming fall school year.

The people of Cordele and Crisp County are isolated due to physical and attitudinal barriers. The Flint River Area Barrier Busters (FRABB) recruited and trained high school students with and without disabilities to promote awareness of disability issues and create a more accessible community. FRABB members modeled leadership and self-advocacy skills and provided opportunities that promote students as future leaders.

The Southern Juvenile Defender Center at Emory University used its GCDD grant to create a specialized web site to disseminate information about best practices to individuals with disabilities and their families. They also worked to increase

information and support about consumer-directed care and family support programs.

With the GCDD grants, the organizations worked hard to promote acceptance and support for people with disabilities by focusing their time on advocating for others and educating the community about developmental disabilities. ●

**"We never could have reached out to the legislators like we did without the funding."**

## Awards Bestowed on Those Who Make a Difference

Many Georgians advanced the causes of people with disabilities this year, through advocacy, leadership, the media and politics. The Governor's Council on Developmental Disabilities recognized the following people for their extraordinary contributions to the disability community July 21 in a ceremony during its quarterly meeting.

**C. Anthony Cunningham Leadership Award**  
*Lynnette Bragg*



### Advocates of the Year Awards

Recognizes individuals active in Independent Care Waiver Program efforts:  
**Greg Harry • Kiley Hayes • Edwin McWilliam • Andreena Patton • Samantha Renfroe • Ashley Rhinehart • Cindy Saylor**

### Media Professional of the Year

**Tom Corwin from the Augusta Chronicle**



*State Sen. Sam Zamarripa (left) at Disability Day*

### Legislators Leadership Awards

**State Rep. Jeff Brown (R-LaGrange)**  
**State Sen. Sam Zamarripa (D-Atlanta)**

**Read the next issue of Making a Difference for more information about these award winners.**



# ADA Has Changed Children's Lives

By Nancy Duncan, Executive Director  
Georgia ADA Exchange

This year, as we celebrate the 15th anniversary of the passage of the Americans with Disabilities Act, we decided to review some of the provisions of the ADA that have positively affected the lives of children with disabilities.

## Childcare

Childcare programs now may not exclude children just because they have a disability. Just how much the provider must do to accommodate a child depends on the resources of the provider. There have been several important court cases wherein large childcare chains have been required to provide even such extensive accommodations as tube feeding or catheterization.

Smaller firms have to do "something." If they are very small, they may not be able to afford to make their building wheelchair accessible, but there is no reason why they cannot make program alterations that meet the needs of children with Down syndrome or a hearing loss. If the centers have a place for changing toddlers who wear diapers, they must be willing to change older children whose disability requires them to continue to wear diapers.

These requirements apply to day care and after school care programs. Georgia has an excellent network of inclusion specialists for childcare providers who can work with individual children, care providers and families. For more information on these specialists call 404-463-0009 or visit [www.decal.state.ga.us](http://www.decal.state.ga.us).

## Recreation Programs

Both private and public recreation programs are covered by the ADA and are required to serve children with disabilities. Organizations such as the YMCA or county parks may have special programs just for children with disabilities such as wheelchair basketball or swimming for children with developmental disabilities. However, these special programs do not give the recreation provider an excuse to bar children with disabilities from their regular programs.

Private programs must provide accommodations based on their financial resources. So a small rural baseball league might not have to build a fully accessible field, but it must figure out ways of including children with disabilities in their program. As for county and city-run programs, size is not important. If they can afford to have any recreation programs, they must include children with disabilities in these programs. Both the ADA and Section 504 of the Rehabilitation Act require city and county programs to serve all children. This holds for summer camps, leagues, classes, recreation centers, etc. All of the programs offered by a city or

county must be available to and inclusive of people with disabilities.

The excuse of "too dangerous" cannot be used unless there is a high probability of danger. This probability must be applied to each individual child based on his/her specific abilities. So, a program cannot say "Children with visual impairments cannot participate in the summer program since they might get hurt during physical activities." That policy is too broad, and thus, is a violation of the ADA.

## Medical Facilities

Doctors' offices are covered under the ADA in the same category as restaurants and hotels (Title 3). This means that a doctor cannot exclude children just because they have disabilities. Obviously, a doctor may not be an expert on a particular disability, but they can serve as a primary care doctor consulting with other specialists as needed. A practice cannot say, "we do not take children with disabilities." Based on the size of the practice, wheelchair access should be provided from the parking lot throughout the office, including the examining table. Sign language interpreters must be provided, when appropriate, and paid for by the doctor's office. The staff must accommodate the child's need for more time, more explanations, etc. Hospitals too, are covered by the ADA and must make special accommodations as needed by the individual child.



**"All of the programs offered by a city or county must be available to and inclusive of people with disabilities."**

For more information on the ADA, please contact the Georgia ADA Exchange at 770-451-2340 or [www.gaada.info](http://www.gaada.info), or the Southeast Disability and Business Technical Assistance Center at 800-949-4232 or [www.sedbtac.org](http://www.sedbtac.org). ●



*Special Olympics participants enjoy a day of sports and activities where everyone left a winner (photos at left and bottom left).*

*Photos courtesy Andrew Kornylak.*

## Special Olympics Georgia a Success

Nearly 2,000 athletes competed in Olympic-style events at this year's Special Olympics State Summer Games at Emory University June 3-5. With the help of over 1,000 volunteers, the 35th anniversary games were a huge success. Patrick Kerney and Jim Mora of the Atlanta Falcons encouraged the athletes, while the mascots Maximus of the Gwinnett Gladiators, Thrash of the Atlanta Thrashers and Homer of the Atlanta Braves performed for the audience and athletes.

The athletes competed in aquatics, artistic gymnastics, badminton, volleyball



and table tennis. Unified sports where people with and without disabilities compete together included volleyball, soccer and tennis. Athletes proudly showed off their medals, but as always, everyone left as a winner.

**For more info on the Special Olympics, visit their web site at [www.specialolympicsga.org](http://www.specialolympicsga.org) or call 770-414-9390.**



## Full Participation Advocates Meet in Washington

The Alliance for Full Participation (AFP) will host the first ever Summit 2005 in Washington DC September 21-23. The Many Voices, Many Visions campaign will bring together 3,000 people including lawmakers, advocates, families, people with disabilities and advocacy experts who are committed to making the

Developmental Disabilities Act for Americans a reality.

The summit's mission is to create a social agenda for the dream of full participation. The theme for this year's conference emphasizes leadership, self-determination and community membership. This year's summit is designed to be a groundbreaking event and will encourage greater awareness, debate, discussion and unity among the multiple groups in attendance.

Renee Pietrangelo, chair of the founding steering committee, said, "We weren't really sure how big of a turnout we would get, but it looks as if it is going to be a huge event!"

Teams of stakeholders have been developed to represent each state at the convention. Once they have established a social agenda for the nation, the stakeholders will implement the plans within each state. The teams are critical to helping the summit achieve its larger goals of building consensus within states about necessary actions and policies at the state and national level to improve the lives of people with disabilities.

The AFP has collaborated with the Safe Advocates Becoming Empowered (SABE) Executive Council to develop a plan to move forward together to assure that the AFP Summit 2005 planned for September fully integrates self-advocates throughout the process. This collaboration assures that the Alliance for Full Participation is a productive, long-term process, before and after the September meeting, which will significantly improve the quality of life for all people with disabilities.

**Registration for the summit is available online. For information on attending the summit, please visit [www.allianceforfullparticipation.org](http://www.allianceforfullparticipation.org).**



## Family Cookout Offers Workshops and Fun

All Children Are Special is hosting a family cookout and outing on August 20 that will bring together organizations that want to enhance the quality of life for children and those transitioning to adulthood with cognitive and physical disabilities and the family members.

Attendees will receive critical information about programs and resources for their children available throughout metro Atlanta. Workshops will host speakers from Georgia Community Support and Solutions, Georgia Parent to Parent, Atlanta Alliance on Developmental Disabilities, disABILITY LINK and the Governor's Council on Developmental Disabilities.

In the afternoon, families will enjoy food, fellowship and entertainment with jazz and gospel performances. Celebrity Olympic Gold Medal Winner Curtis Lovejoy will also be in attendance. All proceeds will benefit All Children Are Special, a nonprofit advocacy organization.

**For more information on the event or volunteering, contact Helga Moore at 404-429-5901 or Norma Stanley at 770-873-3245.**

## Georgians Celebrate 15 years of the Americans with Disabilities Act

This summer marks the 15th anniversary of the landmark passing of the Americans with Disabilities Act (ADA). To commemorate this important milestone, Georgians are participating in the "Spirit of the ADA" campaign.

The campaign is a 22-day celebration of events throughout the state, ending with a bang on July 26 in downtown Atlanta. The celebration, which will take place from 10 AM - 2 PM, begins at The King Center with a torch race and concludes at Centennial Olympic

Park and the Georgia World Congress Center with a commemoration.

The day will be filled with educational training, disability awareness and fun and games! All ages of people with and without disabilities are welcome to attend the exciting celebration. Marc Wilkerson with the State ADA Coordinator's Office said the event is "really targeting the youth and senior citizens because they can both benefit from the education training and awareness as well as the resources available." Children without disabilities will have an opportunity to experience working with assistive technology and senior citizens will be trained in how to cope with disabilities they may experience in the future.

In addition to learning and advocacy, sporting events, arts and crafts and entertainment are planned. To celebrate the momentous occasion, local guest celebrities will make an appearance to join in the fun. Wilkerson said the event is meant to be "fun-filled as well as serve a purpose."

**For more information, contact Mark Wilkerson, 404-657-7313 or mwilkerson@gsofic.ga.gov.**



*"Freedom" is a communal piece of artwork created by Bridge to Community.*

## Art Exhibit Includes Disability Group

The Spruill Art Gallery in Atlanta recently hosted an exhibit titled "Looks Good on Paper." The display ran from

May 5 to June 25 and included 150 pieces of work on, of and about paper. Two of the pieces of art were done by people with developmental disabilities. The first piece entitled "Freedom" is a communal piece of artwork created by Bridge to Community, a group supported by the Cobb-Douglas Community Service Board. The group's instructor, Jim Slattery, also has developmental disabilities and created the second piece of artwork titled "Beginning of Forgiveness."

All works were hand selected by Ben Apfelbaum, the gallery director and curator of all shows. The gallery focuses only on the pieces of work and does not segregate artists. Apfelbaum said, "All works are judged by their artistic quality only; I am not interested in the artists' biography."

**The Spruill Gallery is located at 4681 Ashford Dunwoody Road in Atlanta. For more information, visit [www.spruillarts.org](http://www.spruillarts.org).**

## Apply for the 2006 Parent Public Policy Fellowship Program

The Joseph P. Kennedy Jr. Foundation, which supports the creation of national programs for persons with intellectual disabilities and their families, is seeking parents of persons with intellectual disabilities for an intensive, one-year Public Policy Fellowship in Washington, DC.

During this fellowship, the applicant will learn how legislation is initiated, developed and passed by Congress and will actively participate in public policy development. Kennedy fellows receive first-hand knowledge and experience in the development of public policy in key areas such as special education, health care and mental health care to improve the quality of life for individuals with intellectual disabilities.

**For information on the application process, please contact Jill Fosse at 301-565-5476. All applications must be postmarked by Sept. 1, 2005. ●**

# Advocates, State Work to Free Children from Institutions

**W**hen disability advocates at the Georgia Advocacy Office discovered 141 children under the age of 22 were still living in state-run institutions, intermediate care facilities, nursing homes and a private facility, they knew something had to be done.

"The GAO knew of some children and had asked the state of Georgia for a list of children in state-run facilities," explained Patricia Nobbie, D.P.A., deputy director of the Governor's Council on Developmental Disabilities (GCDD).

Once the GAO received the list, it joined with its federal partners, GCDD and the Institute on Human Development and Disability (IHDD). "It was a big effort, and we wanted as much influence as possible to help us change the policy," explained GAO Project Director Gillian Grable. "Some states have ended the institutionalization of children. We wondered, 'How can we help the state of Georgia become one of those states?'"

The federal partners, along with People First and the Statewide Independent Living Council (SILC) helped successfully lobby for a resolution in the Georgia House of Representatives in the 2005 legislative session.

The Children's Initiative Resolution (House Resolution 633) urges the Department of Human Resources (DHR), the Department of Community Health (DCH), the Department of Education (DOE), the Department of Labor (DOL) and the Department of Juvenile Justice (DJJ) to present the General Assembly with a plan to provide home and community-based supports to children under the age of 22 who are currently living in state-run facilities and to implement the plan within five years. The resolution

also calls for the Speaker of the House to appoint an oversight committee to help develop the plan that includes people with disabilities, members of the legislature and members from GAO, GCDD and IHDD.

Georgia Rep. Judy Manning (R-Marietta), who is the chairman of the Children and Youth Committee, brought the resolution to the House. "Children don't need institutions. They need their families and their communities. They need attachments so they can bond and gain independence.

"This committee will work together to make solutions for these kids. The resolution asks these groups to come together to come up with solutions to the waiting list problems.

The committee will take the lead to offer the state departments solutions to solve problems and get kids out of institutions and back into their communities."

*"Some states have ended the institutionalization of children. We wondered, 'How can we help the state of Georgia become one of those states?'"*

Gillian Grable, GAO

Grable stressed that once children leave institutions it is important to place them in "permanent, loving homes where there is a significant adult who loves them."

## Support for the Children's Freedom Initiative

Nobbie said support for the Children's Freedom Initiative already exists in some of the state departments. "Gwen Skinner (director of DHR's Mental Health, Developmental Disabilities and Addictive Disease division) has said publicly that she is committed to moving these children into the community."

While the advocacy organizations know at least 141 children are in state-funded care, they do not



Participating in the Long Road Home March II in June, Victoria Leverett confirms that children with disabilities make valuable contributions when they live and thrive in their communities instead of institutions.



*“Children don’t need institutions. They need their families and their communities. They need attachments so they can bond and gain independence.”*

GA Rep. Judy Manning

## A Powerful Coalition

Advocacy organizations came together in Georgia to provide a unified voice for children with disabilities who are living in state-run institutions, hospitals, intermediate care facilities, nursing homes and a private facility.

**GCDD** - The Georgia Governor’s Council on Developmental Disabilities is the state planning council mandated by Congress through the Developmental Disabilities Act. GCDD provides resources and a forum for people with disabilities and their families to increase inclusion, independence and integration within the community.  
[www.gcdd.org](http://www.gcdd.org)

**GAO** - The Georgia Advocacy Office is a private nonprofit corporation that works with people with developmental disabilities to secure their protection and advocacy. GAO, mandated by Congress through the Developmental Disabilities Act, has been designated by Georgia as the agency to implement protection and advocacy within the state. [www.thegao.org](http://www.thegao.org)

**IHDD** - The Institute on Human Development and Disability, mandated by Congress through the Developmental Disabilities Act, works with others to improve the quality of life for people with developmental disabilities and their families through education, research and public service within the community.  
[www.ihdd.uga.edu](http://www.ihdd.uga.edu)

**SILC** - The Statewide Independent Living Council of Georgia is a nonprofit organization that provides disability information and assistance to seven Centers for Independent Living (CIL) around the state. The CILs are nonresidential, community-based organizations that offer a wide variety of services to people with disabilities and their families including peer counseling, independent living skills training, individual and systems advocacy and information and referral. [www.silcga.org](http://www.silcga.org)

**People First** - People First is a self-advocacy group that is based on the principles of self-determination and freedom to make individual choices. Members of the group support each other while advocating for important issues and learning about their rights and responsibilities.  
[www.disabilitylink.org/docs/people.html](http://www.disabilitylink.org/docs/people.html)



Brad Thompson enjoys spending time with his mom Denise Fuller.

## Living in a Residential Home

**Who:** Brad Thompson

**Age:** 17 years old

**Support:** Mental Retardation Waiver Program (MRWP) - a home and community-based waiver for people with developmental disabilities

**B**rad Thompson lives in a residential home in the community and is quick to give his mom a smile when she visits. When he was a young child, he had behavioral problems stemming from a brain injury from meningitis and encephalitis which caused him to act out against his siblings. His mother, Denise Fuller, decided that it was best for him to live with another family until his behavior was under control.

"When I left him – it was horrible," she remembers. "In the beginning, I visited him daily, sometimes twice. I drove his caregivers crazy! But they were real patient with me." Now, Brad has adapted and enjoys living in the community and so he still lives in a residential home, even though he and his siblings are older now.

Brad was one of the very first children placed in a home by the Jessamine Place in Fitzgerald, GA. He has lived with various families for the last eight years with frequent visits from his own family. The Jessamine Place screens and trains all applicants, or "live-in companions" before Brad moves in with them.

"We've had hard times . . . he's been with families where it didn't work out," Fuller remembers. Now, she said, he's doing much better.

"This family has made remarkable differences – he's progressed so much," his mom said. "He does sign language, he asks for things, dresses himself, puts on his socks." She explained that although Brad doesn't communicate his feelings verbally, he smiles most of the time and is loving and caring.

Fannie Johnson, Brad's live-in companion, said he has improved his self-degrading behavior since he moved in seven months ago. "He likes to hug and smile at you," she observed. ●

*"When I left him – it was horrible . . . In the beginning, I visited him daily, sometimes twice. I drove his caregivers crazy!"*

know all of the children's names or circumstances, Nobbie said. The children could be medically fragile or have mental illness or developmental disabilities.

GAO is gathering information on the children. "Over the last number of months, we started to meet these children and get to know their



MHDDAD Director Gwen Skinner and Dr. Steven Hall, director of the Office of Developmental Disabilities, share advocates' commitments to moving children out of institutions with Mark Johnson, director of advocacy at the Shepherd Center (left to right).

families," Grable said. "Essentially, their stories are – 'When I needed help – either with physical or emotional support for my child – there was no place to go. That's when I was advised to place her into an institution! No one is asking the parents what supports they would need to keep their children at home.'"

Nobbie said DHR's eventual role will be to assess the children and identify providers in the community who can support them and their families.

Pat Puckett, the executive director of the Statewide Independent Living Councils of Georgia stressed how important being in the community is.

"We strongly believe people with disabilities should be integrated into society and included in the world around them. It is especially important to start young because everybody gets used to them and understands that's how it should be. Separate is never equal," she emphasized.

## Summit to Raise Awareness

The three national advocacy groups – GAO, GCDD and IHDD, will not only provide input into the planning process, they will also help fund it, starting with the Children's Freedom Initiative: A Summit For Change, to be held August 25-26 at the Atlanta Community Food Bank. "The summit will raise awareness of the initiative, set forth the problem and start the work plan," Nobbie said.

The groups will facilitate meetings between the state agencies and pay for oversight committee meetings, respite care and travel reimbursement for committee members. "We expect the planning process to cost about \$100,000," Nobbie said.

In preparation for the summit, IHDD is collecting stories about children who currently live in state-run facilities, according to its director

# Living with a Birth Family

Zolinda Stoneman, Ph.D.

"We're collecting stories across the state that feature families and children who have been caught in this situation and been hurt by it so people can have an idea how this affects real children and their families," Stoneman explained.

While DHR will serve as the lead state agency, the other agencies will also have important roles, and each agency has different funding streams that may help support the implementation of the plan.

"The DOE wants to be prepared for 141 new students, and the Department of Labor's Vocational Rehabilitation department will need to offer job support to the teens," Nobbie said.

As part of the resolution, the state agencies will have to report to the legislature and the oversight committee every year on their progress. And Nobbie said they have to consider the future. "We have to close the back door so more kids don't go into institutions and nursing homes," she said.

Stoneman added, "Families really don't want their children to leave them. But the state isn't providing the support they need to keep the children at home. One of the things we learned when we began collecting stories was there were things that could have happened to keep the families together like behavioral support, medical and health support or information. None of the families wanted to give up their children."

## Importance of Community

Nobbie feels living in the community is very important for children. "It's a human right for a child to live in a family and have the same experiences that other kids have. Institutions don't do that. Children who live in institutions don't have contact from significant loving others. In many cases parents can only visit on the weekend, and the children don't have any toys, pictures or any personal things there," she stated. "Some children are even living on a locked unit.

"These children want jobs and a high school education. They shouldn't be confined in an institution where opportunities are so limited," she stated. "Institutions are no good for people."

In addition, some children who are currently living in institutions leave the institution to go to school every day. "If they can go to school, why can't they live in a family?" Nobbie asked.



Chad Roberts with friend Charlie Coleman, working on leisure and community skills.

**Who:** Chad Roberts  
**Age:** 13 years old  
**Support:** MRWP;  
**Natural Support Enhancement - a flexible service for getting people out into the community.**

Generally a happy kid, Chad Roberts lives at home with his mom, Kellie Roberts. Chad has autism, is nonverbal and significantly delayed in all areas. Communication has been a large problem until recently, when he got a device that helps him communicate with the world.

Roberts feels that home is the right place for her son to live until he is older, but admits she wouldn't be able to raise him alone if it weren't for the Natural Support Enhancement. "Because of Charlie Coleman at the Emory Autism Resource Center Family Program, we've had success in planning Chad's day so he can be successful," she explained.

Since he's had support from the program at Emory, Chad has followed a structured schedule. When he gets home from school, he refers to a picture schedule which is easier for him to process than words. If Chad decides he doesn't want to do an activity that's on the calendar, he is able to replace it with other pictures that symbolize what he would prefer to do. "He has done beautifully with his picture schedule," his mom said. "He's almost independent and will complete 'Grooming Boot Camp' this week." A year ago, he couldn't complete the most basic daily living tasks.

Chad is also working with Kim Pisor, an independent behavior specialist, at home and at school. "We still deal with behavioral problems; he has rages, and sometimes I know the trigger and sometimes I don't," Roberts explained. Using swimming, horseback riding, gymnastics and country music videos as rewards have helped her son make behavioral progress. He's even earned several rewards at his school this year for "Most Improved Student" and "Student of the Month."

"He's going to camp this summer; it will be his first time for overnight camp," Roberts said, excited and nervous at the same time. "We've set up a social story with pictures from the camp and have made a calendar for everything so he knows when he's going and when he's coming home."

Roberts works part time at a group home but doesn't think now is the time for Chad to live in that kind of setting. "They're wonderful folks, and I see Chad living there when he's older, but he's in school right now. Our goal is for him to finish school while he's here at home," she commented. "While Chad has very complex issues, he's my son - he's part of a family and we love him."

According to Roberts, her son enjoys learning, going to school and even waiting for the bus. Although frustrated at times, he's proud that he's learning how to take care of himself and is responsive - rewarding praise with hugs and smiles.

"He's doing better now," she stated. "This is a team effort though. I couldn't have done this without the waiver. Chad probably would be in an institution if I didn't have the help I have." ●



Membership in a community pool allows Roberts to swim year round.



## Living with an Adopted Family

**Who:** Christopher Hanes

**Age:** 15 years old

**Support:** Katie Beckett Waiver - families with incomes too high for Medicaid receive funds for children with chronic medical conditions and disabilities

Christopher and his mom share many interests, including travel.

Christopher Hanes' birth family made a tough decision – a decision to find another family for Christopher who has Kabuki Make-Up syndrome, a seizure disorder, a heart defect and mild autism. Evelyn Hanes, a single 37-year-old woman also made a decision – a decision to make a family and a home for herself and for Christopher.

Even having contemplated adopting a child with physical disabilities in the past, when the opportunity of adopting Christopher appeared to Hanes out of nowhere, it was quite shocking. "It took me about a month to decide whether it was the right thing to do and what was God's plan for me and Christopher? Did this meet my needs and not his needs?" she remembers. "I tried to look at it in a way to know if it was the right thing for both of us."

If the adoption had not worked out, Christopher may have been one of many other children with disabilities who end up in impersonal institutions. However, after miraculously working out insurance issues that seemed impossible, Hanes took her nine-month-old son home and never looked back. A nurse, she was able to give him the daily care he needed by working weekend shifts and staying home with him during the week until he was ready to go to school some four years later.

"I had a girl that took care of him for a year [on the weekends] and then when she went off to school, her parents became like a second set of parents," she said. "They are very special to us."

Several years after the adoption, Hanes applied for the Katie Beckett Waiver. It helps cover medications and health treatments that her insurance doesn't cover. "I haven't had to spend money on medication for several years, and that is really a blessing," she commented.

Now a teenager, Christopher enjoys traveling, swimming for the Special Olympics and is a food connoisseur of sorts. According to his mom, his charm will get him far in life.

Christopher, who was not yet an eighth grader, was not invited on the eighth grade end-of-year field trip. On the day of the trip, he convinced the teacher in his sweetest voice to let him go with the class. Soon after, his mom received a phone call from the teacher letting her know they were on the way to Stone Mountain. "He talked his way right into it," Hanes laughed. "And he had a ball and he climbed a mountain!"

"We have a great life," she said. "I can't imagine him being in a situation where he can't just get up and go. If I woke him up and told him we were going on vacation, he'd be in the car before I could pack." ●



Christopher enjoys spending time with his granddaddy.

The main challenge to implementing the plan, according to Nobbie, is building a good provider community. But she has faith that the state agencies will work hard to do that. "We feel (DHR) Commissioner (B.J.) Walker is committed to seeing this plan through. So is Gwen Skinner and (Director of Developmental Disabilities) Steve Hall."

Stoneman hopes people realize how important the Children's Freedom Initiative is. "These children are the future of Georgia. We need to figure out what these families need to make sure their futures are bright." ●



## A Conversation with GAO's Ruby Moore

By Valerie Meadows Suber

What does it really mean to a child not to have the presence of even one parent who is consistently there to love them in a home that is a safe place, a sanctuary, a place where a child can learn and can make mistakes, and where people love you just because you are you?

In an interview with *Making a Difference* magazine, Georgia Advocacy Organization (GAO) Executive Director Ruby Moore spoke on the need for a Children's Freedom Initiative Summit to end the institutionalization of children in Georgia. "If not now, when? If not us, who?" she asked.

### Can an institution ever be a suitable substitute home for a child?

A staff member just brought home a baby from an orphanage in Russia. She was growing up not knowing how to feed herself – how to use a spoon, knife or fork. She didn't know what it felt like to eat a meal with a family. She was always fed by staff who plopped a metal tray in front of her and fed her. When staff left they went home to their families. This child didn't go home with the staff.

There is nothing within an institution that will give children the love; there are staff there that care but they don't take these children home where they can learn how to do simple things and make simple choices.

### What triggered passage of the Children's Initiative Resolution (HR633)?

Locking people up because of a disability. This needs to be changed – this is one of the most urgent issues today. The resolution came about because we felt this needed to be brought to the attention of the legislature.

### How did the Children's Initiative Resolution evolve into the Children's Freedom Initiative?

Three federal partners, the Georgia Advocacy Organization, the Governor's Council on Developmental



Disabilities and the Institute on Human Development and Disability, got together and said we need to bring the children home – we thought about the words that describe what we are doing – we are freeing children who have been institutionalized.

***What is the intended outcome of the Georgia Children's Freedom Initiative: A Summit For Change and beyond?***

To bring home the children of Georgia who are currently institutionalized and change the way we think about supporting children and their families so that we don't send any more kids to institutions.

Beyond the August summit the Children's Freedom Initiative will be a major focus in Georgia for five to 10 years or however long it takes.

***The Children's Freedom Initiative: A Summit For Change will offer what program highlights?***

People telling their own stories of how they personally came to be institutionalized and ultimately freed. From a family perspective, what it would have taken or what it did take to bring their child home.

We have nationally and locally known speakers. We will have representation from Georgia's First Lady Mary Perdue's Children's Cabinet. Harriet McBride-Johnson, internationally known activist who was in an institution as a child will come. We found a three-year-old at Central; a three-year-old at Gracewood; a baby at Egleston in the intensive care unit. All of these babies have families that want them.

Plus – key people who have a clear vision of what families and permanent homes look like for kids, all kids, including kids with disabilities.

***Why is this issue important to you?***

I am a mom to three daughters; one has a disability. I feel that no child should be institutionalized because they have a disability. Any person who would have to spend a day in an institution would be shocked beyond comprehension. In institutions kids stop crying, they stop walking and they stop talking. This happens to people that don't grow up with at least one loving adult who was there to create a loving home. This is something most people cannot fathom.

All you have to do is picture your child in that setting and I cannot.

***What will it take to make it possible for all Georgia children to be in permanent homes with a family?***

Citizens need to know that there are children growing up in institutions. Policymakers need to recognize this too. We already have everything we need to make sure children currently residing in congregate facilities live with families and that in the future no child will be institutionalized. That's the outcome we want, and we want it quickly, but we need to find the political will.

When you look at this issue through the eyes of a child it's clear: why wouldn't everybody be coming home to live with a family? ●



*Elizabeth Rhodes during a recent visit to her mom's house.*

## Leaving an Institution

**Who:** Elizabeth Rhodes

**Age:** 19 years old

**Support:** MRWP - a home and community-based waiver for people with developmental disabilities

Almost four years ago, Elizabeth Rhodes went from living with her family to living in an institution a few hours away. Elizabeth was having behavioral problems that required professional attention. “[The institution] had a behavior specialist that worked with her on self-care and self-control. She really needed a lot of one-to-one care,” said her mom, Cheryl Rhodes.

However, when Elizabeth was approved to receive Medicaid through the MRWP last April, the search for an appropriate community placement began. “She was on the list for years!” Rhodes emphasized. According to Rhodes, it was a tedious process to find a provider for her daughter. “I keep joking that the highlight of 2004 was getting Elizabeth settled,” she said. “It took a lot of time to get the pieces in place.”

This past December, Rhodes moved her daughter, who has moderate mental retardation and a seizure disorder, out of the institution and into a community setting. Since she moved back into the community, Elizabeth's problems have noticeably decreased. “She's so happy all the time!” her mom said. “She is more involved in her community and has more choices for leisure time activities. [Her caregivers] value her as an individual instead of a consumer.”

Elizabeth was placed into a residential home operated by the Consumer's Care Corporation. She lives with a couple, another “consumer,” and the couple's young child. According to her mom, Elizabeth loves her new home where she gets to go out to dinner, Home Depot, or wherever the family goes, and she especially enjoys playing the big sister.

Rhodes is appreciative of the fact that Elizabeth's live-in companion takes the role of a mother. “She takes pride in Elizabeth's accomplishments,” she said. It also turns out that Elizabeth's caregiver used to be a special education teacher and is comfortable with being a liaison for Elizabeth, her school and her mom.

Rhodes admits that it wasn't easy parting with her daughter in the beginning, but things are much better now. “It was very hard at first,” she remembered. “There is good communication though, and a sense of trust. I really feel like they have my daughter's best interest at heart.” ●

*“She's so happy all the time! . . . She is more involved in her community and has more choices for leisure time activities.”*

# The HUNT for Inclusion-Oriented Recreation

By Christina Carlton



Chessa Birrell earned the Small Craft badge by giving others instruction.

**M**any parents of children with disabilities feel frustration that there is not enough out there for their kids to do. Other parents make a sport of finding recreation for their children.

Dr. Cheryl Marko, a parent of a child with Spinal Muscular Atrophy in Acworth, GA, knows a lot about recreation-hunting. Her daughter, Chessa Birrell, plays soccer, hockey and football, she sings and dances, is a Girl Scout and has a blast at different camps throughout the summer including Girl Scout Camp, Aviation Camp at the Fernbank Center and Summer Safari Day Camp at Zoo Atlanta.

Most of her sport activities are specifically designed for kids with disabilities but others are inclusive – that is, they weren't necessarily designed with disabilities in mind but the leaders have come up with ways to make sure she can participate.

**“ . . . many parents feel that kids with mixed abilities who play together are better prepared for future integration into the community.”**

## A License to Participate

Many parents feel that kids with disabilities who play in a mixed abilities setting are better prepared for future integration into the community. However, many of them don't realize that there are inclusive activities for their kids in their communities.

Parents should know that the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of a disability. According to the National

Center on Physical Activity and Disability (NCPAD), this means people with disabilities have:

- 1. The Right to the Most Integrated Setting**
- 2. The Right to Participate:** The right to register and participate in recreation or leisure activities so long as the participant meets “essential eligibility requirements” required of all registrants such as registering before the program is full and paying the same fee that others pay. Other essential eligibility requirements may be the ability to serve in a tennis match or the ability to swim if the participant falls off a kayak.
- 3. The Right to Reasonable Accommodations:** Reasonable accommodations (modified play rules or extra staff for management of the activity) should be provided by the activity organizer to enable participation as long as the accommodation does not result in an unfair competitive advantage.
- 4. The Right to Adaptive Equipment**
- 5. The Right to the Same Fees:** No sport or recreation provider shall charge a higher fee, or surcharge, for the cost of accommodations for a participant with a disability.



Archery instructor Barb Bonham pulls the arrow back as Chessa Birrell aims and presses the release button at Girl Scout Camp.

For a more complete list and explanation on the rights to recreation, visit [www.ncpad.org](http://www.ncpad.org).

## Don't be a Lonely Hunter

The first place for parents to start looking for inclusive activities is with their children's interests – just like most parents would. Family-



*With a few modifications, Birrell (center) can enjoy the same activities as the other Girl Scouts at Dream Catcher Day Camp.*

*Photos by Harris Hatcher.*

focused publications feature camps and activities for children on a regular basis.

Parents who network with other parents and disability professionals often find what they need for their children without as much hassle.

"I do a lot of networking in the disability community," Marko said. "Someone will mention something, and I'll jot in down and file it away for future reference." She also finds out about camps that are relevant to her daughter's disability from parents and speakers at Muscular Dystrophy Association clinics and Spinal Atrophy conferences. An organization called Parent to Parent of Georgia offers an online forum for people to discuss a large range of topics related to their kids and a place to network at [www.parenttoparentofga.org](http://www.parenttoparentofga.org).

## Recreation Tactics

According to Marko, two tactics matter the most once she has sighted the target activity: 1) Be open and honest about a child's abilities and disabilities, and 2) Don't take "no" for an answer.

"Some organizations give an immediate response – 'of course she's welcome' and with others – you have to work at it," Marko said. "As time moves on and people become more aware, we get better accepted. With Fernbank, there was no hesitation."



For several years, Chessa has attended day camp with her Girl Scout troop. The counselors were aware that this year, her age group would be required to do physical activity to earn a Small Craft badge. Jeanine Adams, the canoeing instructor at Dream Catcher Day Camp, contacted

**“Through their [mixed abilities] performances, they, in turn, demonstrate to our audiences that differences can not only be overcome, they can be complimentary and celebrated.”**

the Girl Scout Council of Northwest Georgia to have the badge modified so that Chessa could earn it

by giving instruction instead of paddling and throwing life rings. These modifications were made without Chessa’s mom ever having to make a

suggestion. “We don’t turn anybody away,” said Kristie Walden, director of the day camp.

The Georgia Dance Conservatory in Marietta, GA is also very accommodating. “We were inspired to offer mixed ability classes after Alex Spitzer, who is a wheelchair dancer and choreographer, along with an able bodied dancer, performed an original piece of his at one of our recitals a few years ago,” said Lisa Touns, artistic director and owner. “Through their [mixed abilities] performances, they, in turn, demonstrate to our audiences that differences can not only be overcome, they can be complimentary and celebrated. Every year Chessa’s been in our recitals, her number has been one of the most appreciated in the entire performance.”

Another community organization across the state of Georgia that offers inclusive activities is the YMCA. Each branch is independent so the programs are not the same across the board, but they share the same philosophy – to be open to



*Lindsey Armstrong and Chessa Birrell recently performed a choreographed recital together.*

# INCLUSIVE RECREATION For Kids

- ALTA Tennis •••••
- Boys & Girls Clubs •••••
- Boy & Girl Scouts •••
- City/County Recreation Programs
- Gymnastics/Exercise Centers
- Martial Arts Centers •••••
- YMCA ••

and to serve people of all abilities.

“We try to go out of our way to accommodate any and all people that we come into contact with,” said James Mercer, vice president of communications at the YMCA of Coastal Georgia. “It’s not as much a set program as [existing] programs that we adapt to the particular needs of the individual.” Delaine Truman of the Northwest Cobb YMCA tries to develop classes for specific disabilities, like autism and Down syndrome, but does as much as she can to accommodate anybody for the other 28 children’s programs her branch puts on each year.

The Atlanta Lawn Tennis Association (ALTA) provides free wheelchair instructional clinics for children in the spring and fall. Wheelchair tennis rules are the same as standard tennis rules except that the wheelchair tennis player is allowed two bounces of the ball. Kids 16 and up are able to join a mixed abilities league in the summer. The league is comprised of doubles matches where each team includes one player in a wheelchair.

Marko explained that looking for things her daughter can be involved in is sometimes tiring and discouraging, but well worth the effort. “If you think the answer is no, you might stop asking,” Marko advised. “It’s an attitude of let’s see what they can do.” ●

## After Leaving Institution, Man is Living His American Dream

by Katie Bishop

**T**welve years ago, a court decision ordered Alan Duvall to leave the institution he had called home for the past 19 years. While he did not advocate for himself, Alan understands the importance of living in the community and believes the court decision was the best thing that ever happened to him.

Currently, home for 33-year-old Duvall is a personal care agency residence in Chamblee, GA. He spends his days working at the International House of Pancakes, playing video games, going to the mall, listening to music and attending church. He takes the bus to and from work, spends time with his family in Gwinnett, and has a witty sense of humor. Cheri Mitchell at disABILITY LINK said that not only is Duvall a fun loving guy, but “a great dancer who can do the worm!”

With his good humor and strong heart intact, Duvall described his moving out into the community as a positive experience that gave him the ability to control his own life. Duvall explained control over your life is the hardest adjustment; however, it is the most fulfilling part of living within the community. For example, Duvall chooses to pay his own rent. He believes that paying rent, making his own choices and working make him more of an American citizen than when he lived in the institution.

At the time, it was extremely hard for Duvall to leave the institution, the only home he really knew. However, he fully believes in letting people lead their own lives in a community of their choice. He spends much of his time advocating for others and sharing his personal

experience as a message that if he can do it, anyone can. Duvall also notes that “communities are much more cost-effective.”

Duvall said that while his personal inspiration comes from God, he hopes that he can be an inspiration to others by sharing his story and making people smile. A graduate of Berkmar High School, Duvall has spoken on several occasions to groups of people with and without disabilities about the importance of living in a community. Duvall said a dream come true “was speaking at the University of Georgia, I love the Bulldogs.” He believes his calling is public speaking and enjoys fulfilling his purpose while making a difference in others’ lives.

Once out of the institution, finding a place to call home was difficult. He moved several times all over the state until finally settling in Chamblee. He said the assisted living home he is in now is “the best one by far!” Duvall has been living with his personal care assistant, Edward Williamson, since 1998. Williamson works hard to let Duvall live an independent life and make his own decisions.

It is because of Duvall that Williamson has stayed in this profession. Williamson admires and respects all that Duvall has accomplished, saying, “He is my hero.” ●

***“Duvall believes paying rent, making his own choices and working make him more of an American citizen . . . ”***



Linda Pogue and Alan Duvall at the sixth annual People First Conference.



# MARCHERS Demand Those Be Released in Institutions

By Valerie Smith Buxton  
with contributions from  
Katie Bishop

**D**isability advocates from across Georgia resorted to civil disobedience in their efforts to meet with Governor Sonny Perdue on the last day of the four-day Long Road Home March II June 22 in Atlanta.

The march marked the sixth anniversary of the Supreme Court's landmark Olmstead decision which found that states were required, under the Americans with Disabilities Act, to provide services to people with disabilities in the most appropriate integrated setting. Marchers hoped their action would call attention to the

continued need for funds and legislation mandating more community-based living to hasten the end to the inhumanity of institutionalized existence.

Advocates were disappointed the governor had not followed through on promises he delivered after last year's Long Road Home March, according to Samuel Mitchell, one of the leaders of the march.

"Governor Perdue said he or someone from his staff would meet with us four times a year. Sonny Perdue – do what you said you would do!" Mitchell exclaimed.

While the governor's office did meet with disability advocates once following last year's march, no further meetings followed. Zen Garcia, march leader and ADAPT organizer, couldn't understand why the governor did not meet again with the advocates. "We're just as important as all the other citizens in Georgia. Our issues are everybody's issues – anyone can become disabled," he said.

After a rally at The King Center, the group of about 100 disability advocates marched to the Capitol for another rally outside. The group then moved indoors, where Abel Ortiz, the governor's policy adviser for health, human services, juvenile justice and veteran's affairs addressed the group in the rotunda.

Ortiz revealed he was unable to attend earlier march events in Augusta and Athens because he was meeting with the Center for Medicaid and Medicare Services to try to reform the process in Georgia. "If it's better to live in the community, why don't we pay for it with Medicaid dollars?" he asked. As part of the reform effort, the state is trying to make costs more predictable, and will also include quality rankings for doctors. "This will help people make better decisions based on quality and cost," he explained.

In addition, Ortiz is hoping to take money currently spent on institutions and move it to community care options. "We are committed to working to get more people into the community," he stated.

Ortiz was then asked when all these reforms would take place. "We don't know the dates for implementation," he said.

***"Our issues are everybody's issues  
– anyone can become disabled."***

**March Leader Zen Garcia**

Advocates responded by chanting, "Set the date! Set the date!"

Kate Gainer, another march leader asked, "Where is the governor?"



Advocates marched from The King Center to the Georgia State Capitol in Atlanta.

Atlanta photos by Harris Hatcher.





Ortiz responded, "We are busy doing the work we need to do to get people out of institutions."

Marchers then began chanting "We want Sonny Perdue!" and "Sonny Perdue, where are you?" as they approached the governor's office. Several people who use wheelchairs positioned themselves outside the governor's door. The crowd chanted "Free our people now!" and "Get us out! Keep us out! Don't put us in!" while hoping for an audience with the governor.

***"We are busy doing the work we need to do to get people out of institutions."***

**Governor's Policy Advisor Abel Ortiz**

After 20 minutes of chanting and blowing whistles, one demonstrator, Gwen Evans, of Atlanta, was taken away in handcuffs after falling down in front of the governor's doorway. She was subsequently released without charges being filed.

Ten minutes later, the civil disobedience paid off when the governor's office set two appoint-

ments, one July 5 and one October 5 to meet with the advocates to discuss their demands (*see sidebar at right*).

The march began June 19 with two days in Augusta with rallies and a trip to a state-run institution.

"Marchers tried to visit residents at Gracewood Regional Hospital, but staff



*Marchers rallied and met with the mayor in Athens.*

*Athens photos by Bob Herrin.*

# community services, R\*E\*C\*O\*G\*N\*I\*T\*I\*O\*N HIGH ON LIST OF DEMANDS

Georgia disability advocates brought public awareness to two federal bills during the Long Road Home March II June 19 - 22: MiCASSA (S. 401, HR 910) – the Medicaid Community Attendant Services and Support Act and MFP (S.528) – the Money Follows the Person Act. In addition, marchers demanded from the governor and legislature:

- 1 That a money follows the person initiative be instituted in Georgia for the purpose of aiding people in nursing homes and institutions, who want to live in the community, to do so.
- 2 That the state of Georgia provides multi-year funding to the centers for independent living for the purpose of such transitions.
- 3 That the Governor of Georgia takes a position of support for the federal legislation known as MiCASSA.
- 4 That 1,000 (MRWP - Mental Retardation Waiver Program) waivers for students aging out of school, adults already on the Waiting List and people in institutions be funded. That the ICWP (Independent Care Waiver Program) receive funding for 173 waivers. That the CCSP (Community Care Services Program) receive funding for 2,000 waivers. We request these be included in the 2007 budget.
- 5 That the Governor recognizes and proclaims June 22 as Olmstead Decision Day.
- 6 That Georgia institute a policy which states any person in a nursing home or institution that expresses a wish on the Minimum Data Set to live in the community, be given information on what's available and the contact information for the local center for independent living.
- 7 That the names of facilities along with the number of persons in the individual facility who have expressed interest in community living on the Minimum Data Set be supplied to the centers for independent living and disability advocacy groups upon request.
- 8 That an immediate and permanent moratorium is implemented on the starvation/dehydration of people with disabilities.

moved the residents inside and closed the doors,” according to march participant Mark Johnson, director of advocacy at the Shepherd Center.

The march moved to Athens June 21, where participants rallied and met with Athens Mayor Heidi Davison. The day ended with a reception and candlelight vigil at the Institution for Human Development and Disability, which is housed in the former institution for children, Rivers Crossing.

Parents of children who lived at Rivers Crossing recounted how they were only permitted to see their children on weekends and how hard that was on their families.

This year’s march was dedicated to Georgian Elaine Wilson, one of the Olmstead plaintiffs, who died last year.

Fellow plaintiff Lois Curtis was honored for her role in the groundbreaking decision with an award during the rally in Atlanta, which was attended by self-advocates from all over Georgia, and even from other South-eastern states.



March activities in Athens included an Americans with Disabilities Act celebration and a candlelight vigil at the Institute for Human Development and Disability (above). Kate Gainer made the wishes of the disability community clear to the governor’s office (right).



State Senator David Adelman (D-Decatur) addresses marchers outside the Capitol.

Matthew Barnes, of People First in Albany, marched in the first Long Road Home March last year and came again this year. “We wouldn’t miss it, being with other individuals for a single cause,” he said.

***“We need more awareness and support for people who are in institutions. Everyone deserves the same quality of life . . . ”***

**March Participant Peggy Chavis**

Dawn Alford, who lives in Carroll County, but currently attends Georgia Tech, said, “I’m a supporter of MiCASSA because it enables me to live independently.” MiCASSA is the Medicaid Community Attendant Services and Support Act that would provide support to people with disabilities so they could continue to live in the community, instead of in an institution or nursing home.

Provider Peggy Chavis, who is visually impaired, came from Athens, where she is director of the Multiple Choices Center for Independent Living. “We need more awareness and support for people who are in institutions. Everyone deserves the same quality of life. I’m here to help create awareness that will hopefully make a difference.”

The Long Road Home March II was sponsored by the DeKalb Chamber of Commerce, DisABILITY LINK, Georgia Advocacy Office, Georgia Voices That Count, Governor’s Council on Developmental Disabilities, Handicapped Drivers Services, Institute on Human Development and Disability, People First of Atlanta, Statewide Independent Living Council and Walton Options. ●



# Olmstead: How *Far* Has GEORGIA Come?

**W**hen Atlanta Legal Aid attorney Sue Jamieson first met Lois Curtis, she had no idea her new client would take her all the way to the Supreme Court.

The case, in which Curtis, then later co-plaintiff Elaine Wilson, sued the state to receive services in the community instead of an institution, became famous across the country as the Olmstead decision. "Not in our wildest dreams did we expect the case to go to the Supreme Court," she said.

The issue that caught the eye of the Supreme Court was a clarification of a clause in the Americans with Disabilities Act, which states people with disabilities must be served in the most integrated setting available. The state of Georgia argued that it had no obligation to serve Curtis and Wilson in the community, while Jamieson argued forcing Curtis and Wilson to live in an institution in order to receive services was discriminatory.

The Supreme Court agreed with Curtis and Wilson, and the Olmstead decision was born.

Six years later, states all across the country, including Georgia, are moving people from institutions into their communities to comply with the decision, but it has been a slow process.

Jamieson said instead of moving small groups of people into the community, she hopes Georgia will create a plan to move everyone who is eligible and wants to move into the community.

Currently, there are about 1,096 people with developmental disabilities living in state-run



*Lois Curtis was honored for her role in the Olmstead decision during the Long Road Home March II. The march was dedicated to co-plaintiff Elaine Wilson.*



institutions and intermediate care facilities. Georgia's Division of Mental Health, Developmental Disabilities and Addictive Disease has helped 310 people move into their communities as a direct

result of initiatives funded to implement Olmstead.

"Georgia's Department of Human Resources is doing all it can with available dollars so people who live in institutions can move to the community," said Dr. Steve Hall, director of DHR's Office of

**Currently, there are about 1,096 people with developmental disabilities living in state-run institutions and intermediate care facilities.**

By Christina Carlton



Bobby Henslee happily greets his former foster mother in a courtyard at the hospital.

## what does FREEDOM SOUND LIKE?

When most people hear the word lawsuit, they hear the sound of coins clanging. But when Bobby Henslee hears the phrase Olmstead lawsuit, he hears the Backstreet Boys, a car engine starting up and the sound of his feet pounding on gravel during a morning jog. To him, these are the sounds of freedom. They are sounds he does not hear often because he lives in an institution.

A 38-year-old man with mild mental retardation, Henslee has lived at Central State Hospital since he was 16 years old. He hopes to leave the institution as part of Georgia's Olmstead Plan and has been waiting several years to do so. To live in the community, he will need 24-hour support and someone to help him manage his finances.

"I don't like it here," he said. "I'm independent and should have rights." He explains that it's important to be able to do the things he wants to do when he wants to do them, not when somebody

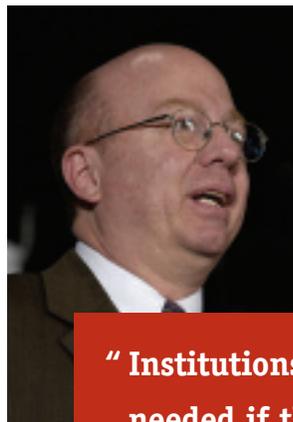
else schedules (or doesn't schedule) an activity for him.

Henslee, a graduate of Georgia Voices that Count, recently attended the annual People First conference. He spoke up for himself as well as for his fellow residents at the hospital who couldn't speak for themselves. "They should have more rights to do what they want to do – to take control of their own lives!" he said passionately.

Ann Resseau, director for the Developmental Disability Division at Central State Hospital, commends him for his self-advocacy. "Bobby's very good about assessing people to see if they have power or clout – to see if they can help him."

While he waits for the support he needs to live in the community, Henslee dreams of moving into a house or an apartment and working as a mechanic. He also looks forward to jogging, listening to music and singing along to his favorite songs whenever he wants to. ●

Dr. Steve Hall, director of the Office of Developmental Disabilities is working to ensure supports are in place across Georgia so people who want to move into their communities have what they need to make a successful transition.



Developmental Disabilities. "The key to success is to build an effective, efficient and excellent community provider system.

"Institutions would not be needed

**"Institutions would not be needed if the community system was as good as we want it to be."**

if the community system was as good as we want it to be," he said.

Jamieson said that without good providers, "It will be an ongoing challenge to keep people in the community."

Hall stresses that successful implementation of Georgia's Olmstead Plan (which can be found at

<http://dhr.georgia.gov> – type "Olmstead Plan" in "Search" box and press enter.) depends on a number of factors, including separating Georgia's waiting lists into those who live in the community and those who live in institutions and ensuring money follows people from institutions to the community.

Jamieson agrees that money must follow people. "Nothing will be solved until states redirect money away from institutions," she said.

Hall described Georgia's current funding of services like this: "Imagine if you get your paycheck and \$200 is missing," he said. "Your boss says he gave the money to the grocery store where you normally shop. So you go there to shop, but they say to you, 'We already have your groceries picked out for you.' You may get some things you don't need or want and not get some things that you do need."

Hall said because of the way Georgia's funding is structured, this scenario is happening daily to people with developmental disabilities, especially those who live in institutions. To combat this problem, the state is rewriting its Medicaid waiver and plans to submit it to the federal government in December, in hopes that it will be accepted and put into practice in July of 2006.



*Sue Jamieson is concerned the pace of implementing Georgia's Olmstead Plan is too slow.*

**“They should be defining what supports are needed and who will develop them.”**

The new waiver will allow people with developmental disabilities to have the power to choose what they need and want, not what someone else thinks they need. If accepted, the new waiver will help more people move from institutions into their communities because the people will have more control over how their funds are being spent.

In the meantime, a change to the current waiver went into effect July 1, 2005 that will grant waiver recipients a little more flexibility to self-direct their services.

“It’s the natural way in a capitalist democracy that people should be able to choose what supports and services they want. When people can freely choose their providers, that can create new services and supports in communities that can benefit everyone,” Hall explained.

Services would be determined based on a person-centered planning process that involves the person with a disability and members of his circle of support, such as a family member, doctor, friend, etc. Some planning has already been done for people who are living in institutions.

Jamieson feels person-centered planning is a step in the right direction, but that many of the resulting plans are too vague. “They should be defining what supports are needed and who will develop them. The plan doesn’t say when or how it will be implemented,” she said.

According to the state’s Olmstead plan, after the planning process, “. . . the individual should receive services as specified in the assessment report or be placed on the waiting list for those services.” However, Jamieson is concerned that this is not happening. Instead, she believes people are participating in planning sessions, but never find out when or if their plan will be implemented.

“The state is obligated to serve people in the

community who want to live in the community,” Jamieson said. Since the Olmstead decision, she has brought three lawsuits on behalf of people in institutions who were waiting for services, and after filing the suits, each client was served in their communities.

As people wait for services, state institutions and communities are starting to work together to integrate people with developmental disabilities more fully into their communities. “Someone may work all day at a job in their community, but live in the institution,” Hall commented.

While this scenario may not exactly fit the goals of Georgia’s Olmstead Plan, it does set the stage for people who are living in institutions to begin to develop natural supports in the community, which are vital to people as they move permanently into their communities.

“The enemy is loneliness. Being in the community is not the same as participation in the community,” Hall stressed.

The partnership between the institution and community support systems can also help family members overcome their fears about their loved one living in the community, which Hall said is one of the biggest challenges to implementing the Olmstead plan.

“Families are afraid their brother, sister, son or daughter won’t be safe in the community. We need to assure them their relatives will receive 100% of the same benefits they get in the institution in the community and that they will be safe, happy, have friends and competent help and support in the community.”

Hall thinks a few more years will pass before everyone who wants to move out of institutions is served, but the state will continue to develop a good network of services and natural supports. “We want to make sure people have good choices in their communities so they don’t end up in private nursing homes,” he stated.

“We don’t want people to spend their lives surrounded by people who are paid to be around them. We want them to have all the gifts and joy we take for granted in ordinary community life,” Hall said. ●

**“Families are afraid their brother, sister, son or daughter won’t be safe in the community.”**

**Director of the Office of Developmental Disabilities Steven Hall, Ph.D.**

# PERSPECTIVES

## Woman Fights for Appropriate Education for Son

By Karen Diamantstein

**M**y son, Michael, was born June 21, 1995. Following his autism diagnosis in 1997, we established a discrete trial teaching program in our home. We hired a team of therapists who were trained to implement his uniquely tailored program. He made steady progress and, though he struggled to produce speech, his strong visual and motor skills showed promise. His ability to interact with teachers and therapists developed nicely. We continued our home program, plus private speech and occupational therapy, until we ran out of money.

In 2000, Michael entered The Model Classroom (TMC) at Faith Lutheran. Despite his ability to adapt and enjoy his play with other children, his functional communication skills were not improving. The school's director, Marian Joiner, told us TMC could not provide enough intervention to meet his needs and suggested public school so Michael could have daily access to therapy services.

Marian attended our first IEP meeting and spoke about Michael's need for daily therapy. She suggested he was an ideal candidate for errorless learning and discrete trial teaching of specific skills. She also emphasized the need for professionals who were qualified to teach and use PECS™ and augmentative communication devices so Michael could develop a functional communication system.

It was my understanding that the IEP committee would follow these suggestions, but little of what Michael needed was ever provided by the Cobb County School System. I am grateful that, after a bumpy start in a terribly inappropriate placement, Michael eventually joined a wonderful classroom with a loving and caring teacher. But that didn't ensure the provision of appropriately designed educational programming and services.

Designing a successful teaching program for Michael requires a coordinated team of experienced specialists. He has unusual scatter in his profile of skills and learning styles, making implementing a good discrete trial teaching program challenging. Any program lacking the required level of frequency and intensity will not be sufficient.

Since the school system became responsible for Michael's education, various skill regressions have become obvious to everyone who knows him. The concepts presented to him in school seemed to get simpler, and I felt school employees wanted me to accept his limitations and be satisfied with their well-intentioned efforts.

Michael has lost skills because he has not used those skills in any consistent, well-managed educational program. Discrete trial teaching, when properly implemented, has been documented to be effective for him.

I provided our school system with evaluations, documentation binders and tapes containing data and video of Michael demonstrating mastery of many skills no longer apparent. I encouraged school system employees to review this history and explore why he lost these skills.

I have never asked for anything that even begins to resemble the "best" services money can buy in regards to Michael's IEP. I have been forgiving when mistakes were made by system employees. After years of struggling with the system, I have no reason to believe that future services would be based on his needs. Our situation may represent a growing problem in public schools.

In spring 2004, I had an opportunity to place Michael with an educational specialist who managed our first intervention plan. This plan showed more promise in its ability to help Michael master cognitive functions than any instruction designed by the school system. I asked the system to fund this program over the summer and until Michael could be transitioned to an appropriate classroom placement. The request was denied.

I think Michael should be in school because it adds a rewarding dimension to his life. However, I have no way to verify the appropriateness of his education, and he has no way to tell me what happens during his day. Without unlimited and inconspicuous opportunity to observe him at school, I am at a disadvantage and can hardly participate as an equally knowledgeable member of his IEP committee.

Given Michael's profile, I doubt any competent educator or health care professional would disagree that he needs a full-day, year-round service program. Further, a service plan that fails to provide sufficient intensity or consistency by qualified instructional staff is, at best, limiting Michael's potential and, at worst, interfering with his ability to derive educational benefit from his services.

If I lived in some other states, my school system could place him in a comprehensive, full-day, year-round program at no expense to me. I don't want to move away from friends and family, but I'm considering it. He deserves appropriate services, and I need to work with school administrators who will explore ways to meet his needs.

Cobb County School System's three years of failure to design and implement an appropriate educational plan for Michael motivated me to withdraw him from school. I felt he would be unlikely to make any meaningful progress in the absence of appropriately targeted educational services.

Michael's educational needs have been neglected since he entered public school in 2001. I believe the system's efforts to "not leave Michael behind" are in need of scrutiny. ●



*Karen Diamantstein is a 40-year-old single mother of a child with autism who is nonverbal, has no independent toilet skills, rarely sleeps through the night and has some behaviors that require constant monitoring. His father takes him every other weekend and for dinner three evenings a week, which is her only respite. She is physically and emotionally overwhelmed by her son's needs, but said his smile and the sound of his laughter give her reason to get out of bed in the morning.*

# Two Mothers Share Their Struggles to Find Supports for Sons with Autism

## Joey World

By Reneé Pullen

**E**ight years ago our family eagerly welcomed the adoption of two special boys. The youngest, Joey, was a beautiful, curly haired four-year-old. We were told that Joey was globally developmentally delayed. We thought that with love and the proper educational care Joey could catch up on what he had missed in his early developmental years. If we had seen the big picture in the beginning we would have run as fast as we could to the far corners of the earth. Instead, we now find ourselves running to the far corners in search of help for Joey and so many others like him with families who are in crisis. Joey's present diagnosis is autism and mental retardation. In our rural area in Southwest Georgia, we have no support or overnight facilities available. Just finding a respite provider for a child like Joey is a major challenge – we've been through six since Christmas. Our family has literally shut down our world and we live in what I lovingly refer to as "Joey World."

Joey goes to bed about 7:30 PM. The first wake up is around midnight, then around 2:00 AM and then again between 4:30 and 6:00 AM. He is turning on the lights, running the water in the bathroom, or watching Barney on the television. I have learned to sleep with one eye open in order to redirect Joey back to bed so that he and I can get a few hours of sleep before the new day begins. Someone has to get up immediately or the damage Joey can do in a short amount of time is shocking. We put a lock on our pantry to prevent boxes of cereal and any other food items from being poured all over the bar and floor. Joey then moves to the refrigerator where he opens jars of condiments or leftover food and digs his hands or utensils in the jars.

Once we dress Joey for school, he has to be watched closely or he will strip naked in seconds. The ride to school is usually manageable. When we arrive at school I hold my breath as he and his brother walk to the outside door of his classroom. If he sees other students, especially females, he will run after them to pull their hair, expose himself or curse at them. I verbally thank God that we made it and pray that Joey can cope through the day. The afternoon ride home is usually chaotic. Joey is

stressed to the highest point and often goes into a full rage. He slaps and kicks any part of my body that he can reach. He snatches my hair, spits on me and urinates in his seat. I have had numerous narrow escapes while driving.

While Joey is at school, he is restrained for most of the day. While his teachers are willing to learn how to best reach Joey, there aren't any places nearby that offer training for autism. I probably know more about autism than anyone in this county!

In May, Joey experienced a rage at school and attacked his teacher. As a result, he was sent to Central State Hospital, where doctors warned us to fight to get him out or he might regress. And he did start to regress – at home he wears pull ups at night, but in the hospital, he had to wear them all day. He was kept medicated most of the time, and just wasn't himself there.

Luckily, Joey was accepted by the Marcus Institute in Atlanta for a 16-week program that will help him learn how to better deal with his rages. I'm looking for good results from Marcus. Unfortunately, since it is a day program, he will have to stay with a host family while he's there instead of at home with us. We'll only be able to see him on weekends. We'll get training there too about how to handle his rages. We're worried that because we don't have any follow-up care available nearby, he might have trouble retaining what he learns at Marcus.

My husband and I take turns spending time with our other children and new grandson. Joey's brother also has some learning disabilities, and we are not able to spend as much time as we'd like with him because Joey demands so much of our time. We are physically and mentally drained and have little time for each other.

We sacrifice ourselves daily for our love for this special child. He is the love of our life, and we absolutely don't want to put him in an institution. All we need to keep him home with us is some respite care once in a while so we can spend time with each other and our other family members and some follow-up care after he finishes at the Marcus Institute.

Joey did not grow in my womb, but he certainly grew in my heart, and I'm afraid his needs will one day be beyond what we can do at home without help. ●

**Our family has literally shut down our world and we live in what I lovingly refer to as "Joey World."**



*Reneé Pullen and her husband adopted Joey and his brother eight years ago and live in Blakeley, GA. Pullen teaches at the local elementary school during the day, and she and her husband take turns watching Joey in the evenings and on weekends. She feels if she could have respite care just once in a while, she would be able to keep Joey at home. Currently, none is available in her area.*

## AUGUST

**August 20**  
**"All Children Are Special"**  
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**August 25 - 26**  
**Children's Freedom**  
**Initiative: A Summit**  
**For Change**  
*Atlanta Community Food Bank*  
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 on Developmental Disabilities  
 (GCDD) and the Institute on Human  
 Development and Disability (IHDD)

## SEPTEMBER

**September 21 - 23**  
**Alliance for Full**  
**Participation's National**  
**Disability Summit**  
**Washington D.C.**  
*www.allianceforfullparticipation.com*

**September 29 - October 1**  
**Kennedy Center's**  
**Accessibility Conference**  
*Scottsdale Center & Mesa Center*  
*for the Performing Arts*  
*Scottsdale, Mesa, Arizona*  
*Eileen Bagnall at ARTability at*  
*602-757-8118 or 520-631-6253*

## OCTOBER

**October 7 - 9**  
**Special Olympics GA**  
**State Fall Games**  
*Albany, GA*  
*www.specialolympicsga.org*

**October 16 - 18**  
**National Black Child**  
**Development Institute**  
**Annual Conference:**

**Bridging Culture in a**  
**Changing World**  
*Wyndham Palace Resort & Spa*  
*Orlando, FL*  
*www.nbcdi.org/conference/35ac*

**October 20 - 21**  
**GCDD Quarterly Meeting**  
 Athens-East Central Region  
 Holiday Inn, Athens, GA (Tentative)  
 Contact Kim Person 404-657-2130  
*kaperson@dhr.state.ga.us*  
*www.gcdd.org*

## NOVEMBER

**November 1 - 3**  
**2005 US Business**  
**Leadership Network**  
**Annual Conference**  
*Pittsburgh, PA*  
*www.usbln.com/events/conference*  
*2005.htm*

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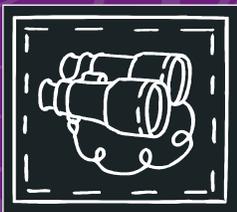
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## UPCOMING CONFERENCES

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**Alliance for Full Participation**  
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 promises in the Developmental  
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 State of GA Contact: Eric Jacobson,  
*eejacobson@dhr.state.ga.us*  
[www.allianceforfullparticipation.org](http://www.allianceforfullparticipation.org)



# Emory's Specialized Genetics Clinics

By Stephen T. Warren, Ph.D., Chairman

**T**he Department of Human Genetics (DOHG) at Emory University is bridging benchmark genetic research with clinical treatment. This department of the Emory University School of Medicine was founded in 2001, through restructuring the existing Department of Genetics and incorporating the entire Division of Medical Genetics. The DOHG believes that gaining insight into a disease by identifying a causal gene can lead to new approaches with therapeutic interventions.

The majority of our research focuses directly on human disease, and the Department has major strengths in neurogenetics, and translational research. The DOHG is home to both the National Down Syndrome Project and a National Fragile X Syndrome Research Center (with Baylor College of Medicine), constituting the largest research program on this disorder in the nation. This year the DOHG has received a National Institutes of Health grant to support Genetic Autism research.

The Emory Genetics Laboratory (EGL) provides testing and management guidelines for the Newborn Screening Program of Georgia. Approximately three percent of all living newborns have a birth defect or health problem. These conditions may be evident shortly after birth or later in the child's life. EGL provides diagnostics for hundreds of genetic diseases, receiving over 28,000 patient specimens per year from all over the country and is the major national referral center for several genetic disorders.

Children who are not reaching developmental milestones or have characteristics of a genetic condition may be referred to one of Emory's Genetics Clinics. Specialty clinics are held for patients with inherited metabolic

disorders, Down syndrome, Fragile X syndrome, neurofibromatosis, lysosomal storage diseases, and craniofacial disorders. Our medical staff includes Board Certified Pediatricians Paul Fernhoff, M.D., Medical Director, Margaret Adam, M.D., Daniel Gruskin, M.D., and Jeannie Visootsak, M.D., who is also Board Certified in Developmental-Behavioral Pediatrics.

The Department holds numerous weekly clinics for children and adults and is responsible for all in-patient consultations and management of genetic diseases in six metro Atlanta hospitals. In addition, several outreach clinics are held throughout the state. A number of clinical research protocols are conducted by the Department, including enzyme replacement trials for Fabry's and Gaucher's diseases carried out by the Center for Lysosomal Disease.

Our clinical genetics team also evaluates adults at risk to inherit an adult-onset genetic condition or those seeking treatment for a pre-diagnosed genetic disorder. A strong family history of cancer, heart disease, diabetes or other potentially inherited conditions may warrant an evaluation with a geneticist physician or counselor.

The Emory Metabolic Clinic and Nutrition Program, administered by Rani H. Singh, Ph.D./R.D., is a nationally leading program, offering complete services to manage metabolic disorders. The program also includes an annual weeklong metabolic camp for young women with phenylketonuria (PKU) and maple syrup urine disease (MSUD); [www.metcamp.org](http://www.metcamp.org).

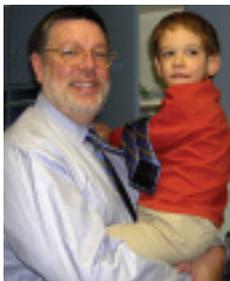
Our unique combination of a cutting-edge research program in conjunction with a comprehensive clinical genetics division is revolutionizing patient care.

To learn more about the DOHG at Emory University, please visit us online at [www.genetics.emory.edu](http://www.genetics.emory.edu). ●

**"Approximately three percent of all living newborns have a birth defect or health problem."**



*The Department of Human Genetics at Emory University holds specialty clinics for patients with inherited metabolic disorders, Down syndrome, Fragile X syndrome, neurofibromatosis, lysosomal storage diseases and craniofacial disorders.*



*Dr. Warren with patient Hunter Wilhite.*

## DR. STEPHEN T. WARREN

*received his Ph.D. in Human Genetics from Michigan State University and worked at the University of Illinois College of Medicine and at the European Molecular Biology Laboratory in Heidelberg. In 1985 he joined the faculty of Emory University School of Medicine where he holds the William Patterson Timmie*

*Professorship of Human Genetics, as well as Professorships in Biochemistry, Pediatrics and the Winship Cancer Institute. Warren is a Full Investigator of the Howard Hughes Medical Institute, and he founded the Department of Human Genetics at Emory School of Medicine.*

*A Diplomat of the American Board of Medical Genetics with specialty certification in*

*clinical cytogenetics and clinical molecular genetics, Warren is a member of the American College of Medical Genetics, the Human Genome Organization and the American Society of Human Genetics (ASHG). Warren has won numerous awards, including the ASHG's William Allan Award, considered the highest award in human genetics.*

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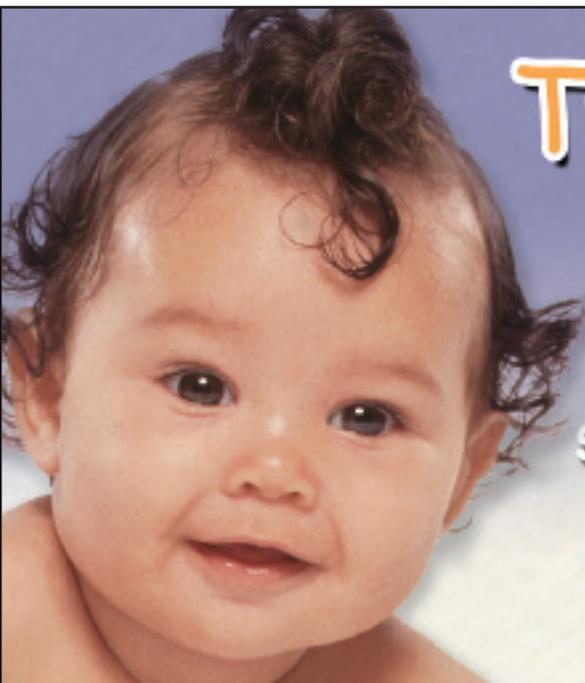
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Below, please find further resources of information related to the articles in this edition of *Making a Difference* magazine.

**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

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

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

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

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

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

**GA Lieutenant Governor's Office**  
[www.ltgov.georgia.gov/02/ltgov/home/0,2214,219618,00.html](http://www.ltgov.georgia.gov/02/ltgov/home/0,2214,219618,00.html)  
 404-656-5030

**Dept. of Community Health**  
<http://www.dch.state.ga.us/>  
 404-656-4507

**Dept. of Human Resources**  
<http://dhr.georgia.gov>  
 404-656-4937

## Olmstead

**State of GA's Olmstead Implementation Plan**  
<http://dhr.georgia.gov>  
 Type "Olmstead Plan" into the "Search" box and press enter.

**The Olmstead Decision Overview**  
[www.accessiblesociety.org/topics/ada/olmsteadoverview.htm](http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm)

**The Supreme Court's Olmstead Decision**  
<http://www.findlaw.com/cascode/supreme.html>  
 Type "Olmstead" into the "Party Name Search" box and press enter. Select "Olmstead v. L.C."

**Atlanta Legal Aid**  
[www.atlantalegalaid.org](http://www.atlantalegalaid.org)  
 404-524-5811

## Children's Freedom Initiative

**GA House Resolution 633**  
[www.legis.state.ga.us/legis/2005\\_06/pdf/hr633.pdf](http://www.legis.state.ga.us/legis/2005_06/pdf/hr633.pdf)

**Children's Freedom Initiative Summit and Georgia Advocacy Office (GAO)**  
[www.thegao.org](http://www.thegao.org)  
 404-885-1234  
 800-537-2329

**Institute on Human Development and Disability (IHDD)**  
[www.ihdd.uga.edu](http://www.ihdd.uga.edu)  
 706-542-3457

**Statewide Independent Living Council of GA (SILC)**  
[www.silcga.org](http://www.silcga.org)  
 770-270-6860, 888-288-9780  
 TTY: 770-270-5671

**People First of Atlanta**  
[www.disabilitylink.org/docs/people.html](http://www.disabilitylink.org/docs/people.html)

**Alliance for Full Participation (ALP)**  
[www.allianceforfullparticipation.org](http://www.allianceforfullparticipation.org)  
 301-706-6252

## Inclusive Recreation

**Atlanta Lawn Tennis Association (ALTA)**  
[www.altatennis.org](http://www.altatennis.org)

**Boy Scouts of America**  
[www.scouting.org](http://www.scouting.org)

**Boys & Girls Clubs**  
[www.bgca.org](http://www.bgca.org)

**Georgia Dance Conservatory**  
[www.ruthmitchelldance.com](http://www.ruthmitchelldance.com)  
 770-426-0007

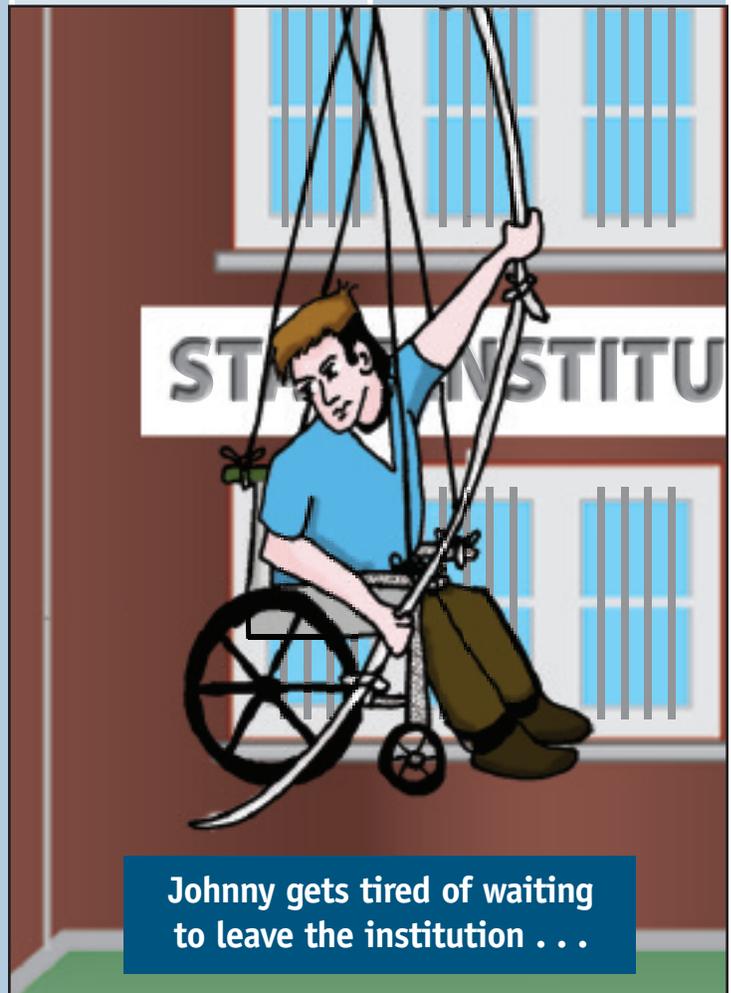
**GA State Soccer Association**  
[www.gasoccer.org](http://www.gasoccer.org)  
 770-452-0505

**Girl Scouts of the USA**  
[www.girlscouts.org](http://www.girlscouts.org)

**Parent To Parent of Georgia**  
[www.parenttoparentofga.org](http://www.parenttoparentofga.org)  
 800-229-2038

**YMCA**  
[www.ymca.net](http://www.ymca.net)

**Zoo Atlanta**  
[www.zooatlanta.org/family\\_fun\\_summer\\_safari\\_camp.htm](http://www.zooatlanta.org/family_fun_summer_safari_camp.htm)



Johnny gets tired of waiting to leave the institution . . .

## Long Road Home March II

*Advocates took part in the Long Road Home March II, June 19-22, ending with a rally at the Capitol to celebrate the sixth anniversary of the landmark Supreme Court Olmstead Decision, a turning point for people with disabilities that opened the door to a life of freedom in the community.*



Atlanta photos by Harris Hatcher. Athens photos by Bob Herrin.



**Governor's Council on Developmental Disabilities**  
2 Peachtree Street, NW, Suite 8-210  
Atlanta, GA 30303-3142  
404-657-2126, [www.gcdd.org](http://www.gcdd.org)

**Address Service Requested**