

SPRING 2008

Making a Difference

Advocates Brave Rain at 10th Disability Day

Healthcare Access
a Barrier for All

Creating an
Accessible World

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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.

GOVERNOR'S
COUNCIL ON
DEVELOPMENTAL
DISABILITIES

Tom Seegmueller
Chairperson
tms@dhr.state.ga.us

Eric E. Jacobson
Executive Director
eejacobson@dhr.state.ga.us

Valerie Meadows Suber
Editor-in-Chief &
Public Information Director
vmsuber@dhr.state.ga.us

2 Peachtree Street NW, Suite 26-246
Atlanta, GA 30303-3142
Voice 404-657-2126
Fax 404-657-2132
Toll free 1-888-275-4233
TDD 404-657-2133
www.gcdd.org

Valerie Smith Buxton
Managing Editor
O'Neill Communications, Inc.
val@oneillcommunications.com

O'Neill Communications, Inc.
Design & Layout

Brandon D Hunt
Cartoonist

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Medicaid, Managed Care Present Challenges

For years, we in the disability community have advocated against a medical model for providing supports to individuals with disabilities. This made sense since the social services that people need such as housing, personal supports and employment do not fit well when examined through an X-ray or a stethoscope. Until recently the medical profession has not provided training to would-be doctors and nurses about the support needs of individuals with disabilities. In fact, the support needs contradict the reason many go into the medical profession – to fix or cure something or somebody. In the disability community, we believe that a disability is part of the natural human experience and doesn't need to be cured or fixed. These two philosophies have resulted in the disability community and the medical community being in conflict with each other.

This same conflict exists in the Medicaid program that was established in the 1960s to provide health care for low income people. The original purpose of the federal-state partnership known as Medicaid was to provide needed medical care to low income people. Advocates in the 1980s made the argument for using Medicaid funds to pay for home and community-based services as a counter-balance to Medicaid paying for congregate care such as nursing homes and state institutions. Even within those institutions it was primarily paying for healthcare services. Today, many within the federal and state Medicaid bureaucracy still view the program as a payor of health care services, not unlike a very large insurance company. This means that doctors know more than patients and costs are to be controlled.

A third dilemma has been with private insurance and public Medicaid and Medicare programs employing a model they call managed care. In the 1970s, managed care and the use of health maintenance organizations was synonymous with socialized medicine. It was the model that people in England and Canada used, and it created "one-stop shopping for all medical services." The American model of managed care evolved into a way of

minimizing costs, not ensuring that all medical care was provided in a centralized method. Now we see the state Medicaid program try and impose a model of managed care into Medicaid waiver programs that provide support services, not medical services, and it is used to try to control costs.

These are the dilemmas that many of us in the disability community have been fighting for many years. However, what we have forgotten throughout these debates is that people with disabilities have healthcare needs. People get sick and need to go to the doctor. The real question that we need to figure out is how to integrate healthcare and support services so that they work together not against each other. The focus of this issue of *Making a Difference* is healthcare across the age spectrum.

In addition, you will read about the over 2,000 people who stood in the rain for Disability Day at the Capitol to hear from the Ecuadorian Ambassador to the United States, the Honorable Luis Benigno Gallegos Chiriboga. This came at the beginning of the 2008 legislative session, and while it continues as this publication goes to print, we can report that it has been a very controversial session driven by economics and politics – not always about what is best for the people. Finally, don't forget to read about the ongoing story of Mia Nobbie's life and how she and her mom struggle with finding support.

We want to hear from you. Please call 1-888-275-4233 or e-mail eejacobson@dhr.state.ga.us



ERIC E. JACOBSON



TOM SEEGMÜLLER

"The real question that we need to figure out is how to **integrate** healthcare and support services so that they work together not against each other."

Eric E. Jacobson
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Executive Director, GCDD

Tom Seegmüller
Tom Seegmüller
Chairperson, GCDD



Slowing Economy Should Not Slow Waiver Progress

The following letter was shared with the Chairs of Senate Health and Human Services Appropriations and is reprinted here in a slightly edited version with the permission of Don Cole.

It is Easter Sunday morning, a day that reminds us of eternal life and hope. As I sit in my den reflecting on the meaning of this day, I think of those who face a future of challenge and hope because of a child with developmental disabilities.

When Governor Perdue appointed me to serve on the Board of Human Resources in 2003, I knew nothing about Mental Retardation/Developmental Disabilities (MR/DD) waivers. I quickly learned about the needs and felt a strong compulsion to stand up and speak for those who had the needs.

My political persuasion is conservative Republican. Government funded programs exercise the state's power to take the earnings from its people to use as the state sees fit. There must be compelling reasons to exercise this power. I see three fundamental reasons for the government to tax its citizens - (1) Protect its citizens, (2) Help those who cannot help themselves (3) Provide for the overall health, safety and welfare of its citizens.

The MR/DD waiver program addresses all three fundamental reasons. I know that the revenues in Georgia have slowed down. We go through these ups and downs in the economy. When the revenues slow, we know that one day they will come back up.

But you know, when a family learns that their child has a developmental disability, everything changes. Unlike our expectation for a return to a robust economy, there is little expectation for a return to a fully

“Those with special needs are not just a line item in a budget that goes up and down with the economy.”

independent, robust, healthy child. I don't mean to portray that families with children with developmental disabilities are lost in despair. On the contrary, these

families often find strength to face an entirely new future. Many of these families have invested their lives in a child and now are drawing to the end of their years wondering what will happen to their child who is now in his or her 40s or 50s but unable to function independently. The economy may have changed through those years but their son or daughter has the same needs.

“As Georgians we need to help our fellow Georgians who have children with developmental disabilities.”

I have no problem asking the legislature to continue to fund the MR/DD waiver program. I believe that the overwhelming number of Georgians would agree that this is a program for which they don't mind sharing the burden. As Georgians, we see ourselves as a part of a larger family. Those with special needs are not just a line item in a budget that goes up and down with the economy. They represent a valuable investment in our state. When we step up to help those families with children with developmental disabilities through the waiver program, we are going to see the rewards that come with the inspiration, motivation and hope for a future.

A single family cannot do it alone. As Georgians we need to help our fellow Georgians who have children with developmental disabilities. They are part of our family.

In the past three years, we have met the challenge at the rate of reducing the waiting list by 1,500 slots each year. Let's keep our eye on the goal and keep moving forward.

Donald E. Cole, *Secretary,*
Georgia Board of Human Resources



Letters to the Editor

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

Contact Our Editor and Public Information Director:

Valerie Meadows Suber,
vmsuber@dhr.state.ga.us,
404-657-2122
Fax 404-657-2132

or: 2 Peachtree Street, NW
Suite 26-246
Atlanta, GA 30303-3142

Audio or Large Print Versions:

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GOVERNOR'S
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DEVELOPMENTAL
DISABILITIES

Court Compensates Child with Autism Symptoms

Hannah Poling was meeting developmental milestones until she was 18 months old, when she was administered vaccinations against nine different diseases on the same day.

Medical personnel at the Division of Vaccine Injury Compensation of the Department of Health and Human Services reviewed the case history of Poling and concluded, "the vaccinations Poling received on July 19, 2000, significantly aggravated an underlying mitochondrial disorder, which predisposed her to deficits in cellular energy metabolism, and manifested as a regressive encephalopathy with features of autism spectrum disorder."

**"This case echoes the stories
of thousands of children across the country."**

The U.S. Court of Federal Claims and National Vaccine Injury Compensation Program ruled February 29 to compensate Poling and her family for the incident. The National Autism Association (NAA) sees the ruling as confirmation of what so many parents have been saying for years. "This case echoes the stories of thousands of children across the country. With almost 5,000 similar cases pending in vaccine court, we are confident that this is just the first of many that will confirm what we have believed for so long, vaccines can and do cause children to regress into autism," says Wendy Fournier, parent and president of NAA. "We call on the Centers for Disease Control (CDC) to acknowledge that the current vaccine schedule is not safe for every child and as with the administration of any medicine, individual risks and susceptibilities must be considered for each patient."

Paterson Becomes First NY Governor with Visual Impairment

Gov. David Paterson (D-NY) became the first legally blind, and the first African-American governor of New York on Monday, March 17, 2008. Paterson, who served on the American Foundation for the Blind's Board of Trustees from 1997-2006, is nationally recognized as a leading advocate for people with disabilities.

"David Paterson has been making history since the beginning of his career and challenging public perceptions about what it means to have a disability," said Carl R. Augusto, AFB's President and CEO. "Paterson has shown the world that people with vision loss can lead full and independent lives – running marathons, being a great father and husband and becoming a major political leader."

In 2002, Paterson was elected minority leader of the New York State Senate, the first non-white legislative leader in New York's history. In Boston in 2004, he became the first visually impaired person to address a Democratic National Convention.



GCDD Announces New Organizing Institute Participants

After reviewing 70 exceptional applications, the Governor's Council on Developmental Disabilities has chosen the participants for its second Organizing Institute, that will begin April 19:

Betty Hasan-Amin, a resident of Clarkson, Ga., is a self-advocate who is active in a number of community advocacy organizations, including: Concerned Paratransit Riders, Interfaith Disability Connection, Georgia Library for Accessible Service, Inc. and Atlanta Alliance on Developmental Disabilities. Hasan-Amin is currently enrolled in the Georgia Voices That Count program.

Valencia Stinson works in the Fulton County Office of Disability Affairs where she works as a training coordinator. She started Dreamkeepers, a program to educate and empower young girls.

Jordan Schwartz is a self-advocate and the group's youngest participant. At 14, she is the founder of The Children's Bilingual Theater and responsible for producing, funding and managing the company. In 2005 She launched ugrowgirl.com that encourages and supports girls on a human growth hormone regiment and gives them a site to celebrate personal growth and development.

Sharon Chong is involved with the Wheat Mission of Atlanta, an organization that serves Korean-

American individuals with special needs. She has also worked in the Gwinnett County school system as a paraprofessional in special education classes.

Gloria Chamlee is a parent advocate from Flovilla, Ga. Chamlee is a contact for the Butts County Navigator Team that helps connect other parents to community-based services and supports. She is also a graduate of Partners in Policymaking and several other training and leadership programs.

Carrie Lee is a self-advocate and currently a student at Savannah Technical College, majoring in business administration. Lee is a Georgia Voices That Count graduate and a certified peer support specialist for Life, Inc. in Savannah, Ga.

Clarietha Allen founded the Georgia Employee Federation with her late husband. This organization was established in 2001 out of a need for advocacy on behalf of working families who are low-income, disenfranchised or whose family members are injured or have disabilities.



Against All Odds Conference Set for June

People with disabilities, their families, service providers, service coordinators and policymakers will come together to address challenges and best practices in person-centered support June 1-3 at the Against All Odds Conference in Athens, Ga.

"People with developmental disabilities and their families want good support so they can have what other citizens expect: a secure home, friends, places to belong, freedom to make choices, chances to learn and opportunities to contribute. In the past, they have had to struggle with an under-funded service system that is too often inflexible and controlling and too frequently enforces exclusion based on low expectations," explained Connie Lyle O'Brien, who is organizing the conference.

Against All Odds, sponsored by the Governor's Council on Developmental Disabilities and the Office of Developmental Disabilities will offer a forum where leaders from across the country will share what they've learned in providing and coordinating person-centered supports. Meanwhile, speakers from Georgia will discuss the assets the state has to build on and define potential challenges in implementing person-centered supports.



“People with disabilities have better lives when they have met allies among service workers who have joined them in creating good supports against all odds. Working together, with passion, hope, faith and courage, these leaders have invented effective supports for real lives,” O’Brien said.

Held at the Georgia Center for Continuing Education on the University of Georgia Campus, the three-day conference is \$125. Some scholarships are available for people with disabilities, their family members and direct support professionals.



GCDD Identifies Project SEARCH Sites

To help high school students become gainfully employed in an interesting and challenging job by the time they graduate from high school, the Governor’s Council on Developmental Disabilities is planning to replicate the successful metro Atlanta supported employment program, Project SEARCH, across the state.

Under the direction of GCDD’s Family and Individual Support Director Dottie Adams, the program will be expanded into eight areas, including:

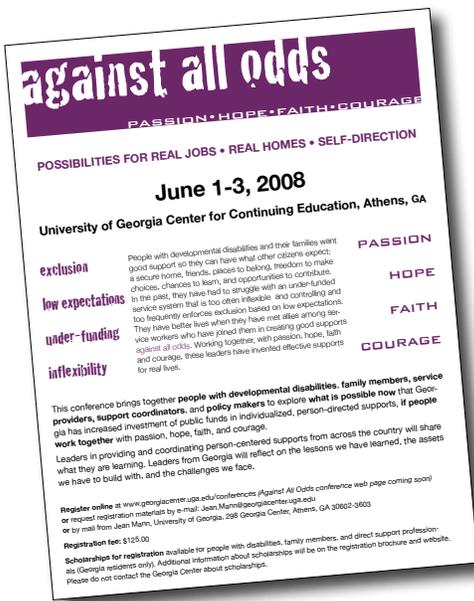
- Savannah**
Lead agency: Savannah Chatham County Public Schools
- Athens**
Lead agency: Clarke County School System
- Coffee County**
Lead agency: Coffee County School System
- Albany**
Lead agency: Dougherty County School System
- Cumming**
Lead agency: Forsyth County Schools
- Hall County**
Lead agency: Hall County School System

- Walton County**
Lead agency: Walton County School System
- Whitfield County**
Lead agency: Whitfield County Schools

These areas will develop and strengthen their collaboration with the school system, a supported employment agency, vocational rehabilitation and a business. The business will provide classroom space, and the school system will identify students and assign a teacher to work with those students within the business setting. This provides intensive learning opportunities and on-the-job support as students learn all the aspects of that business through rotating internships.



Omission Statement: Volunteer George Andl took the photos of the Georgia Voices That Count participants that illustrated last month’s article, “Advocacy Graduates Spur Change Across Georgia”. *Making a Difference* regrets the omission.



For more information or to register, visit www.georgiacenter.uga.edu/conferences or request registration materials by e-mail: Jean.Mann@gactr.uga.edu or by mail from Jean Mann, University of Georgia, 298 Georgia Center, Athens, Ga. 30602-3603.

Recapping the 2008 General Assembly

The Governor's Council on Developmental Disabilities agenda setting process engaged a broad constituency of organizations and individuals involved with disability advocacy. GCDD received input from more than a dozen organizations, and sought information from a few state agencies that were working on items that would affect individuals with disabilities. In addition, GCDD included activities from its work plan that are budget or legislative dependent. These activities got top tier priority status. Several things came up once the session got started as always, which made for a very busy winter.

Each year, advocates eagerly await the Governor's budget address to gauge the direction for the session. The Unlock the Waiting Lists! Campaign coalition voted to support 2,500 Mental Retardation Waiver Program (MRWP) slots keeping with the multi-year funding plan, 500 Independent Care Waiver Program (ICWP) slots in the Department of Community Health (DCH) budget and a 7% rate increase for waiver providers. The Department of Human Resources (DHR) proposed adding 1,500 MRWP slots, while DCH proposed 100 ICWP slots under Money Follows Person, and 50 ICWP slots for the community waiting list. DHR also requested a 7% rate increase for all home and

community-based service providers. However, the Governor's original proposals were more modest; 500 MRWP slots, 100 ICWP slots funded under Money Follows Person, 50 ICWP community slots, and no rate increase.

Then in mid-March, with the housing, mortgage and credit sectors of the economy teetering, the Governor reduced the revenue estimate and put both chambers on notice that he expected them to reduce both the amended 2008

In a four-page letter outlining his recommended cuts, the Governor stripped all the waiver support services from the budget.

and fiscal year 2009 budgets by over \$300 million combined. In a four-page letter outlining his recommended cuts, the Governor stripped all the waiver support services from the budget. Suddenly, disability advocates were working from ground zero. In the next week, House Appropriations restored the waiver services, and added a 2.5% rate increase for Medicaid providers. Two weeks later, Senate Appropriations kept the MRWP and ICWP Money Follows Person slots, added 50 ICWP community slots, and added another 2.5% to the rate increase. Then the budget went to conference committee to work out the considerable differences.

The following discussion reviews what was in GCDD's original legislative agenda and reports on the outcomes.

Tier I: GCDD Initiates

The following items are part of GCDD's five-year plan, and GCDD prioritized a substantial list of items this year.



**We couldn't
HAVE DONE IT
without your
SUPPORT!**



The final fiscal year 2009 budget includes 500 waiver slots for consumers on the MRWP waiting list, adults and children, totaling \$6,248,458.

Unlock the Waiting Lists! waiver package.

The Unlock campaign is guided by HR 1307, which sets out a five-year funding plan to reduce the list to a “reasonable pace.” We are in the fourth year of that plan and the legislature has done well in the past three years funding the recommended number of services; funding 1,500 in the FY 2007 session of a recommended 2,000. The final fiscal year 2009 budget includes 500 of the recommended 2,500 waiver slots for consumers on the MRWP waiting list, adults and children, totaling \$6,248,458. The federal match is \$9,372,687. The budget annualized the 1,500 services from the last fiscal year, a total of \$9,153,018 state dollars with a federal match of \$13,729,529. Advocates spent a considerable amount of time researching and asking about a budget action that transferred more than \$27 million from adult developmental disability services to adult mental health. In the end, the transfer took place, but the Chair of the House Subcommittee on Appropriations for Human Services, Rep. Mark Butler (R-Carrollton), forwarded a request to Department of Audits and Accounts for an audit of the transfer.

Provider Rate Increase. The House and Senate both included a rate increase for MRWP, ICWP and Community Care Service Program (CCSP) Medicaid providers. The compromise was 3%.

Independent Care Waiver Program. GCDD and Unlock requested 500 new slots for people with physical disabilities and brain/spinal injuries in

this home and community-based waiver. The end result in the budget was 100 new ICWP services under the Money Follows Person grant, which will enable individuals with physical disabilities to move from nursing homes to the community. This program will carry an 80/20 federal match for the Medicaid dollars. The budget also includes 75 ICWP slots for individuals on the community waiting list.

...100 new ICWP services under the Money Follows Person grant...

Family Support. GCDD worked on a \$6 million addition to state grant-in-aid funds for the purpose of providing small amounts of support to families to meet their immediate needs. Once the Governor reined in the budget, we had to focus on getting the waiver services restored, **so an addition to family support dollars will have to be reconsidered over the summer.**

HB 540. This legislation enables the custodial parent to apply for child support for children with physical or mental disabilities beyond age of majority. Last session, HB 540 made it to Rules, and then was stalled. Despite active advocacy, support from several legislators and receptive committee hearings this year, **HB 540 did not make it out of the House on crossover day**, and met its demise. Although more than half the states have some form of post-majority support laws for people with disabilities, Georgia is apparently not ready for this option.



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

GCDD voted to support organizations or agencies with these legislative or budget activities. Lead agency is in parentheses after the activity.

\$300,000 for the production of Braille books for post-secondary students (Federation for the Blind). This item is in the Board of Regents Budget. The House led the effort by putting the money in the budget. The Senate removed it, seeking clarification. Once they received answers, the money was restored. The Alternative Media Access Center will enhance its capacity to produce Braille for college students with these funds.

Deaf/Blind Service Funding (Georgia Statewide Coalition on Blindness). \$229,513 moved from the Department of Labor budget to the DHR budget for the Helen Keller Institute, to provide services such as interpreting and personal assistance.

Carve out dental services for children enrolled in PeachCare and Medicaid in DCH budget (Georgia Dental Association). A great deal of attention was directed at the Care Management Organizations providing healthcare to the Medicaid populations in Georgia in this session. Many legislators had heard from constituents about their issues with the CMOs. In hearings before joint House and Senate health committees, providers also expressed frustration with trying to get claims paid, patients served appropriately, complaints addressed. With the assurance that some of these issues would be addressed, the Dental Association decided not to push the carve-out.

HB 880. E-Text legislation (Learning Disabilities Association of Georgia). The proposed legislation would cover post-secondary students with Print Access Disabilities, at all public and private post-secondary institutions, including tech schools and proprietary schools who must be accommodated under the Americans with Disabilities Act or Rehabilitation Act. The legislation defines electronic version of instructional materials and requires structural integrity, including graphs, charts, tables. Students who had been trained to advocate on this bill met with Rep. Donna Sheldon (R-Dacula) who sponsored the bill. They showed her how they access college materials, talked to her about the benefits of the service and the challenges they

face in getting materials in a timely fashion. The academics, publishers and Regents still need to be brought together on this legislation, and advocates will have to start over again next session.

Real Homes Legislation to increase accessibility in new homes (Concrete Change and Coalition for Accessible Housing). **Advocates got SB 532 sponsored** by Sen. Nan Orrock (D-Atlanta) and Sen. Joseph Carter (R-Tifton). The legislation extends existing state law for including accessibility features to all new homes built on slabs. Sen. David Shafer (R-Duluth), Chair of Regulated Industries and Utilities, provided an opportunity to have the bill heard, and the committee was receptive to the needs expressed by the advocates. The Georgia Home Builders Association pledged to work on solutions, although their official position is that they

The Georgia Home Builders Association pledged to work with the advocates on solutions, although their official position is that they oppose legislative mandates for the building industry.

oppose legislative mandates. Shafer expressed his intention to work on the legislation. In the meantime, the House, led by Rep. Mark Butler (R-Carrollton) passed a study committee resolution, HR 1632, which authorizes five legislators to work over the summer on the issues, including considering possible tax incentives or tax breaks for the home building industry. A similar resolution in the Senate, SR 1244, passed April 2.

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

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

Life Sharing: SB 469 amends the state code to allow two persons with disabilities to reside in an owner occupied home without having to be licensed (DHR) This legislation did pass the final chamber on April 1, and is on its way to the Governor to be signed.



The Alternative MEDIA ACCESS Center will be able to enhance its capacity to PRODUCE BRAILLE for college STUDENTS with these funds.

GCDD supported these items that were not funded in the FY 2009 budget:

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

Aging and Disability Resource Center: Add \$350,000 to create two additional ADRC sites in Georgia

CCSP waiver program for Medicaid eligible elderly: \$6.7 million to maintain current recipients and serve new clients (GACOA, Co-Age)

CCSP program for 2000 non-Medicaid eligible elderly: \$4.0 million requested (GACOA, Co-Age)

Parent Protection Act: Would allow unpaid leave for parents to attend their children's school events (Georgia Job/Family Collaborative). This bill received a lot of attention, several hearings and a couple of columns by Op Ed page editor Maureen Downey of the *Atlanta Journal Constitution*, but it did not make it through crossover day.

HB 845 and SB 13: Raise Georgia minimum wage (Georgia Living Wage Coalition). The minimum wage bills did not pass.

HB 652 Braille Literacy Bill: This bill requires Braille instruction in the individualized education program (IEP) of a student who is blind or visually impaired, and provides requirements for the IEP, textbook publishers and certain teachers relating to Braille. The bill was not taken up by the Senate.

Other Important Accomplishments

EPSDT legislation: A significant step was taken to enforce the federal EPSDT (Early and Periodic Screening, Diagnosis and Treatment) Medicaid mandate. Two bills from last year were languishing in different chambers; HB 549 in Senate Rules after a House veto override vote, and HB 279 in Senate appropriations. GCDD, the Georgia Advocacy Office (GAO) and other healthcare advocates worked with Sen. Dan Moody (R-Alpharetta) and Rep. Doug Collins (R-Gainesville) to craft a piece of legislation that encompassed the prior authorization, definition of medical necessity and notice provisions that both prior bills had included. The Department of Community Health participated in discussions which eased the bill's passage. SB 507 passed the House, and went to the Governor for his signature. Advocates see this as the first of several steps to be taken to ensure children who are eligible for Medicaid receive the services their physicians prescribe.

HB 984: Children's Transition Homes: This is a piece of legislation GCDD worked actively with the GAO to oppose. The bill creates a licensing category for up to 16 medically fragile children to be housed in a transition facility, potentially in six-person homes. The transition facility would be used to prepare children to move to a permanent home from a hospital or nursing home, and to prepare their families to care for their special needs. However, GCDD, GAO and several families with medically fragile children are working with

DHR and DCH to develop the processes to move these children directly from hospitals and nursing homes to home, and felt it wasn't necessary to establish or fund a "place" in the middle. This bill passed both House and Senate despite aggressive opposition from the advocacy community, and will go to the Governor.

HB 535 Mental Health Ombudsman Bill: This legislation established an Ombudsman's Office in the Governor's Office to handle complaints, and sets up a patient advocate review board to investigate deaths in state hospitals and community residential placements. A developmental disability portion of the office will be established 12 months after the mental health portion has been operational. The Office received \$250,000 in funding to get started.

The fact that Unlock the Waiting Lists! prevailed with keeping some much needed services in the budget despite an economic downturn is a testament to the families, volunteers and self-advocates who wrote, called or visited their legislators to tell their stories. Despite the tension of the up and down days in the legislative session, we feel a sense of mission accomplished for many of the issues on which we worked so hard. Look for the last issue of *Moving Forward*, which will summarize all the legislation of interest, and other budget items that made it through the conference agreement. And thank you all. We couldn't have done it without your support. Be sure to thank your legislators! ●



Advocates see this as just THE BEGINNING of several steps that need to be taken ■ TO ENSURE ■ that children who are eligible for Medicaid receive the services that their physicians prescribe.

Crowd *Braves Rain* to Make *Voices Heard*

What started off as a cool and cloudy day gave way to a cold drizzle by mid-morning. The rain continued throughout the day, but failed to dampen the spirits of the nearly 2,000 advocates who turned out to make their voices heard as one.

Many wore red t-shirts emblazoned with the slogan: "My Vote is For Real." Some waved signs that declared: "Unlock the Waiting Lists." Still others had penned personal messages on hand-made posters.

The 10th Annual Disability Day at the Capitol, organized by the Governor's Council on Developmental Disabilities (GCDD), got underway with a breakfast at the nearby Georgia Railway Freight Depot meeting hall. There, a group of high school students from Hall and Barrow Counties' Partners Clubs gathered to learn how the legislative process directly affects them.

"A lot of people are talking about raising the sales tax right now," Irene Munn, legislative council to Lt. Gov. Casey Cagle (R), told the students. "Soon, when you buy a candy bar you may be paying sales tax. That's why it's important for you to talk to your legislator."

Supported by GCDD, the Partners Club program allows students with and without disabilities to form voluntary friendships with each other.

"People with disabilities can make a difference," observed Appalachian High student Michelle Maddox.

The pre-rally event also included demonstrations of Georgia's electronic voting machines. The Georgia Disability Vote Project is a statewide, non-partisan, grassroots project with

a purpose to close the political participation gap between people with disabilities and the general population.

"Basically we're here to make the community aware of voting information and education," explained Mary McShan of Fulton County Elections and Registrations. "We go into certain communities at large. We carry with us a demo machine at request. We go to schools and churches and seniors as well as nonprofit organizations."

Many of the advocates took a few moments to make their own personal signs to carry to the rally on the Capitol steps.

"I want my kids to see people with disabilities can do the same thing as everybody else. They just need a little bit of help."

"I want my kids to see people with disabilities can do the same thing as everybody else. They just need a little bit of help," said Cathy Fletcher, the state director for the Hearing Loss Association of Georgia. Fletcher, who has a profound hearing loss, was assisting her children, Stuart and Carissa, as they made posters for the rally. "[Persons with disabilities] can have an influence on our lawmakers and legislators who have the ability to make changes in our state."



"As people with disabilities and family members, we are

MORE THAN

49

- MILLION STRONG

in number and our vote should be heard and should be counted."





Ecuadorian Ambassador Champions Disability Rights

By Valerie Smith Buxton

When he was asked to chair a United Nations Committee to create a Convention on the Rights of Persons with Disabilities, Ambassador Luis Benigno Gallegos Chiriboga, who was then Ecuador's U.N. representative, thought, "Who can be against people with disabilities?"



"When our society becomes more integrated, we become better human beings."

Following the breakfast, the advocates made their way through an increasingly cold rain to the State Capitol steps for the main event. Chants of "My Vote is Real" and "Unlock the Waiting Lists" rose from the enthusiastic crowd.

"As people with disabilities and family members, we are more than 49-million strong in number, and our vote should be heard and should be counted," GCDD Chairperson Tom Seegmueller said in the opening comments. "All those running for office should understand that disability does not care if you're Republican or Democrat, black, white, yellow, male, female, Christian, Muslim or Jew. It is truly an equal opportunity condition of our society."

Although the power of the vote was the central theme of the day, this was also considered a day of advocacy, community and friendship, celebrating community, diversity and disability rights.

"Our work has just begun. Our resolve to make the rights of all a reality from Atlanta to the smallest rural village in our world will present us with a daunting challenge in this ever changing world," exclaimed keynote speaker Ambassador Luis Benigno Gallegos Chiriboga of Ecuador. "We need to provoke change in society. Not only to rectify past discriminations against persons with disabilities but also to create a society based on justice and equality. Let this be our commitment. Differences amongst individuals shall not hinder enjoyment for all of universally recognized human rights."

The annual event also focused on the diversity that exists in the disability community. Rev. Jea-Huy Choi, director of the Wheat Mission in Atlanta, led the crowd to chant the Korean phrase, "Oorenum Hannah," which translated means, "We are one community."

"I never thought it would become a matter of contention," Gallegos said. The convention defined the rights of people with disabilities and provided steps to follow to assure those rights, change perceptions and abolish discrimination.

But it took four years to finally have the convention pass. And though 126 countries have signed the convention, the United States still has yet to do so.

"People with disabilities make up 10 percent of the world's population. That's 650 million people," Gallegos said. "When our society becomes more integrated, we become better human beings."

Gallegos was in Atlanta as the keynote speaker for the 10th Annual Disability Day at the Capitol February 21. Before the rally, organized by the Governor's Council on Developmental Disabilities, Gallegos addressed the Georgia House of Representatives.

Rep. Judy Manning (R-Marietta) introduced Gallegos, who is now the Ecuadorian ambassador to the United States, to the House, which made a resolution commending Gallegos for his work as a disability rights advocate.

"If there is a cause worth fighting for, it is the respect for human dignity and the defense of the rights of the most vulnerable, those who need us the most, the minorities, women, children, indigenous, but most of all those who have a disability," Gallegos said to the members of the House.

"We want to make our societies a place for all, a world where all are equal: where segregation, exclusion, discrimination and fear of diversity should be banished.

"One may be born with a disability or acquire it during his life by accident, sickness or war, but surely as we age, we will have some type of disability. We are all in this together."

Gallegos ended his address to the House of Representatives by issuing a challenge to Georgia lawmakers: "I invite you today . . . that we swear that we shall not exclude, segregate or discriminate against any human being, for if we do so, we exclude, segregate and discriminate against ourselves."

**"I don't mind coming out in the rain
because it shows a commitment to the cause."**



**"Our issues
should be
national issues."**



"We are of many different racial, ethnic and religious backgrounds. We come in a variety of shapes, sizes, perspectives and physical abilities," said Sharon Chong, of Atlanta's Korean American Coalition. "Our disability is not only beautiful, but it's a strength."

Imam Furquan Muhammad of the Disability Interfaith Connection, offered a tribute to the fallen soldiers in the disability community "As we continue our journey with the grace of the Lord, the merciful and compassionate, we bring along the memory of those who came before us who left a significant impression on our work here at the Capitol, but more important, on the quality and direction of each of our lives."

But the overall theme of the day, "My vote is for real," was echoed again and again by both the crowd that braved the cold rain falling on the Capitol steps and by the event's key speakers.

"In 2006, Missourians with disabilities voted at a rate higher than the general public," challenged Jim Dickson, of the American Association of People with Disabilities Disability Vote Project. "Can you do that in Georgia? Will you do that in Georgia this November? Will you start organizing now and join the Georgia Disability Vote Project?"

Dickson outlined the power of a block vote in shaping the political landscape. "There are more of you in Georgia than there are in any other identifiable voting group. But we are under-registered, we do not vote in primaries. Primaries are where the policy gets shaped."

Helping to shape policy has always been in the forefront of Disability Day. Whether in the sunshine, snow or a cold rain, such as on this particular February day, the advocates who gathered at the Capitol were there to make

their voices heard by the legislators who gathered under the gold dome.

"I know you guys call yourselves the disability community," Rep. Roger Bruce (D-Atlanta) told the crowd, "But I also happen to be the VP of human resources for a company, and I choose not to use that word because I find you people are some of the most capable people I've ever seen."

"There are people in this building who are beginning to understand that life is not a simple 1-2-3 exercise," Rep. Doug Collins (R-Gainesville) explained. "It's not [about] simply sitting there saying you have to view it the way I do, because you have a disability you're different. Ladies and gentlemen, disability does not mean different... God created you wonderfully."

"For the past few years this house has been meeting its commitment of keeping its promise," offered Rep. Ben Harbin (R-Evans). "And we're going to continue to do that because it's the right thing to do. You've committed your time and your energies to lobby for something, not just because it's the right thing, but because you believe in it strongly, and it can affect you because you

**"You've committed your time
and your energies to lobby for
something, not just because it's the
right thing, but because you believe
in it strongly..."**

are helping people who just want to be at home, who want to live in their communities. That's what we're committed to doing. We're just small players. You're the big reason we do this."

The importance of the power of the disability community to effect change was echoed by Rep. Mark Butler (R-Carrollton). "You have friends in the House. The House has led the way in the past several years to make sure the promises we have made have been kept. We're going to do the same thing this year."

Rep. Mike Glanton (D-Ellenwood) remarked, "I don't mind coming out in the rain because it shows a commitment to the cause."

Beth Tumlin, an advocate who helped organize the first Disability Day in 1998, presented the Georgia Self-Advocate of the





Year Award in memory of her daughter, Natalie Norwood Tumlin, to Executive Director of Independent Living Council of Georgia Pat Puckett.

"I wore my angel earrings today because there are angels up here you can't see that made a huge difference in my life," Puckett said. "There are angels among us you can't see, but there are even more angels right around you," she told the crowd. "You are all angels. So, please go forth and do good work."

Although this day of celebration could have been dampened by the weather, the rain did not seem to affect the spirits and determination of any of the attendees. Dave Blanchard, director of public policy for the Atlanta Alliance on Developmental Disabilities said, "We are making a difference, because we show up rain or shine."

"Your presence here says a lot," said GCDD Executive Director Eric Jacobson. "The picture of everyone coming out in rain is powerful."

"If we can keep on working together, I think we can raise this thing to higher measures," offered Darius Weems, star of the independent film, *Darius Goes West*. "We need to keep fighting for something right we believe in."

"My vote is for real. It is very special to me," said Richard Heyman, a staff support employee of B & B Care Services who was celebrating his 8th Disability Day. "People say I can't do this or that but I can make it real."

Although impact of this Disability Day was yet to be measured, the event's coordinator focused on the challenges that lie ahead. "It's one of the most memorable occasions of my whole life, and I'm proud to be part of this, and I believe in this," said John Dallas of GCDD. "I would like to see some of the issues of the disability community reflected in the national elections. I haven't heard anything, and that silence is bothering me. Our issues should be national issues. The candidates need to speak up on this issue that affects over 50 million Americans." ●

Your Vote Is For Real

By Christy Rosell

Elections are won by the people who vote – not by the candidates by themselves. The candidates recognize the power voters hold. That's why they reach out to particular groups of people such as women, minorities, businesspeople, etc.

People with disabilities are another growing block of people that can wield significant influence on the outcome of the elections.

But only half of people with disabilities are currently registered to vote, according to Jim Dickson of the Disability Vote Project of the American Association of People with Disabilities.

"We're wasting half our voting power," he revealed to thousands of people at Disability Day.

He continued, "As a community, we do sophisticated begging – 'please fix it!' And we get crumbs. It is outrageous and wrong that there's a waiting list!"

But, he pointed out, if the disability community banded together to vote, the tables would turn, and legislators would listen.

Dickson told a story of a young woman with a disability who registered to vote for the first time several years ago. She was so nervous, her body shook when the time came to cast her vote. Afterwards, she said, "Now I know I'm as good as everybody else."

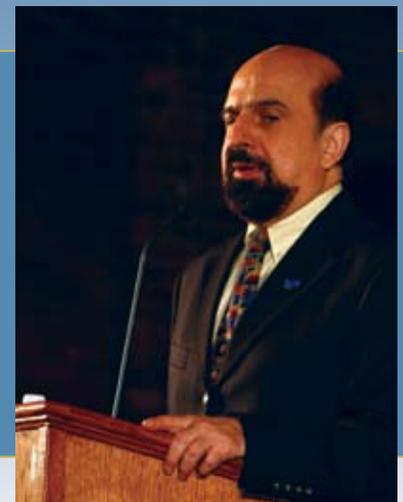
That feeling of pride is not the end of her story. Later, she met the governor of her state and she said to him, "I voted for you, so now it's time for you to listen to me."

She truly understood that her vote equaled power.

"You will have real power, not when you are asking legislators for something," Dickson concluded. "You will know you have real power when on election night, the candidates are calling you and thanking you and saying, 'Let's talk next week.'"

For contact information on election dates, polling locations, how to register, absentee ballots, and the disability vote, see the resource section on page 29.

We're
**WASTING
HALF**
our voting power.



Finding Physicians, Funding a Challenge for Mother

By Jill Alexander



Photo courtesy of Ruby Hodgman and The Herald-Leader

Jill Alexander is a disability advocate, an advisory member of the Governor's Council on Developmental Disabilities, a leader of the Ben Hill/Irwin Navigator Team and a graduate of Partners in Policymaking.

As a result of a traumatic brain injury at birth, my son has cerebral palsy. Making sure Gaven has the medical care he needs to ensure he reaches his full potential has been an uphill battle ever since.

When Gaven was younger, we had both private insurance and Medicaid coverage for him. But even with that much coverage, we always had a struggle on our hands to try to determine who was going to pay the deductible.

In 2006, we lost all of Gaven's coverage, and for four months, as we were waiting to see if he would qualify for the Deeming (or Katie Beckett) waiver, he had no coverage at all.

His therapy provider wouldn't see him without coverage, and he lost his occupational and physical therapy slots for three months. For a kid on a routine therapy schedule, this was a big disruption in his life. When he finally got covered under the Deeming waiver, he didn't want to go back to therapy and developed challenging behaviors in regards to therapy.

In addition to coverage problems, we live in Fitzgerald, in rural South Georgia. While Fitzgerald is a wonderful place to live, we don't have many choices in healthcare providers, and often have to travel 3.5 hours to Atlanta for specialists. Gaven has had 15 surgeries, all of which were in Atlanta or Tampa. We travel often for routine visits with his specialist.

While Gaven receives occupational and physical therapy through his school system, he recently had hip surgery and needs some extra physical work. The hospital has therapists on staff, but not equipment that is suitable for an 11-year-old. We have a great private therapist in town who has equipment for

children, but the therapist is almost always booked.

I used to take him for supplemental private therapy in Tifton, but that is a 60-mile round trip, and I can't afford to do that now with gas prices so high. We also have to travel for an hour to go to a dentist who accepts patients with developmental disabilities. Typical kids let dentists clean their teeth, but Gaven is scared to lay in the chair and have his teeth cleaned. Other specialty doctors are also hard to find. In my work with the Ben Hill/Irwin Navigator Team, I've met a lot of parents of children with autism who must drive 1-2 hours to see pediatric psychiatrists.

"Insurance and Medicaid wouldn't pay for it, so we had to do fundraisers to be able to afford the treatment."

Even with the Deeming waiver, some services are still not covered for Gaven, such as a treatment in a hyperbaric oxygen chamber combined with intensive suit therapy. It was unconventional, but after three weeks, Gaven went from walking in a posterior walker to walking with forearm crutches. Insurance and Medicaid wouldn't pay for it, so we had to hold fundraisers to be able to afford the treatment.

While getting treatment has been a struggle, we've managed to succeed so far. What worries me is that when Gaven gets older, he won't be able to get these therapies at all, even though they've helped him so much. ●

"We also have to travel for an hour to go to a dentist who accepts patients with developmental disabilities."

Two Mothers Share Their Children's Healthcare Challenges

Medical Transitioning Poses Challenges

By Norma F. Stanley

For most parents, keeping your child healthy and finding qualified, customized and readily accessible medical care, no matter what your child's age, is a given. However, for parents of children with physical and/or intellectual disabilities, it may not be that simple – particularly as their childhood transitions into adulthood.

In my case, finding a caring, patient and knowledgeable pediatrician for my daughter Sierra, who has cerebral palsy, was difficult. Now that Sierra is at a different stage in her development and is transitioning into needing adult medical services, we are faced with some new challenges.

At 19, she is small for her age – only 75 pounds, has physical and intellectual disabilities and is still seeing a pediatrician. She only speaks a few words, so we interpret for her the best we can. She also sees an adult doctor to address her specific medical needs as a maturing young woman. Her dad and I do the best we can to pre-diagnose the doctor or nurse practitioner's diagnoses, since they can't really understand what Sierra's saying - sometimes her yeses mean no and vice versa. She hasn't gotten to the point where we need to

“...transitioning to adulthood is a time of change that takes preparation – particularly for teens and young adults with disabilities.”

deal with any additional issues with her growing into full womanhood, but that day is coming, and I'm a bit concerned, as there are only certain things we can interpret.

At this time of her life, we are looking for a doctor to see about Sierra's general health needs and what we are finding is that we should have started the medical transition process long ago. Such seems to be the case with anything having to do with quality of life situations facing the disability community. According to a report from the American Academy

of Pediatrics' (AAP) National Center of Medical Home Initiatives for Children with Special Needs, transitioning to adulthood is a time of change that takes preparation – particularly for teens and young adults with disabilities. The AAP says it is very important for teens with disabilities to stay as healthy as possible, since good health promotes success in the adult roles of employment, lifelong learning and independent community living.

As with any other parent, those are certainly our goals for our daughter. But from the beginning, finding medical care wasn't easy. When we're not trying to find a physician with whom we feel comfortable, we're dealing with health insurance issues, such as when we can use her Medicaid and when we can't, as she is also under an HMO through her dad's employment coverage.

When Sierra does see a doctor, for the most part they generalize about what her illness may be and of course, depend mostly on what we tell them. Also because she's under an HMO, it's very rare we get in to see her primary physician, but so far, the physicians and/or nurse practitioners have been successful in keeping her healthy and all of us happy.

However, if there are chronic medical or behavioral issues, the transition from pediatric to adult-oriented healthcare for young adults with disabilities can get very complicated and can seriously affect their adult healthcare needs.

As they move into this new phase of life, young adults with disabilities and their parents can tap into resources that can be provided by their primary care physicians to help transition into adult healthcare. AAP says that while the physician's role throughout the transition process is to serve as a team leader, he or she cannot be the sole player throughout the healthcare transitioning. The physician can be a teacher to assist the youth and family in navigating the systems of care, but the ultimate research and implementation is still up to the parent and if able, the child, who has now become an adult. ●



Norma F. Stanley is a diversity marketing consultant and author of *The Elected Lady - Finding Victory in the Challenge* (Words of Faith, Reflections and Inspiration for Mothers of Special Needs Children and Other Moms).

Healthcare Access a Barrier Across AGE GROUPS



While people with disabilities are living longer, healthier lives due to many advances in medical care, the healthcare delivery system continues to pose obstacles.

“Children with developmental disabilities have a variety of medical, therapeutic, recreational and social needs that are provided by different agencies at different times and places. These services need to be coordinated and integrated to be provided in the optimal, most efficient way to help the family navigate services and provide important information from one provider to the next,” explained Dr. I. Leslie Rubin, president of the Institute for Study of Disadvantage and Disability, the medical director of Team Centers in Chattanooga, Tenn., co-director of the Southeast Pediatric Environmental Health Specialty Unit at Emory University, a member of the Department of Pediatrics at Morehouse School of Medicine, and a practicing developmental pediatric specialist in Atlanta.

“Healthcare, primary care, specialty healthcare, hospitals, therapeutic, recreational, social services and schools all need to be coordinated and integrated so families can tie it all together. Parents are often burdened with that role. Coordinating services can assure efficiency in the provision of services,” he continued.

In 1992, the American Academy of Pediatrics (AAP) established a model for providing services to children with disabilities called “The Medical Home.” The model states the medical care of children should be “accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective.” The AAP recommended The Medical Home be directed by a

“...the medical care of children should be accessible, CONTINUOUS, comprehensive, FAMILY CENTERED, coordinated, compassionate and culturally EFFECTIVE.”

“They are much more likely to have multiple medical needs. The doctors have to review multiple systems. It’s a more complex, delicate process.”

primary care physician who is known to the child and family and has a trusting relationship with them.

Rubin believes this model can help prevent service gaps, especially as children transition from pediatric care into adult care.

“Children with disabilities have special healthcare needs. They are much more likely to have multiple medical needs. The doctors have to review multiple systems. It’s a more complex, delicate process,” he said.

Add to that any communications barriers, and the need for coordinated healthcare delivery becomes apparent. “Older children may not be able to express the problem. They are more likely to have severe anxiety and behavior issues that may make examining them harder. Therein lie some of the issues of complexity,” he said.



“Barriers to care are funding for services and for reimbursement.”

Rubin supports The Medical Home concept and has tried to establish this model in his work at Hugh Spalding Children’s Hospital by working with Children’s Medical Service, Babies Can’t Wait, schools, rehabilitation facilities and physicians, but has run into some obstacles.

“It requires an outlay of funds. Each provider cares for its own income stream. In The Medical Home, everyone has to contribute to the coordinating element, or funding has to come from somewhere else,” he said.

Dr. Mark Swanson, senior medical adviser of the Centers for Disease Control (CDC) and Prevention’s Division of Human Development and Disability, also finds funding to be a problem as the patient ages.

“Barriers to care are funding for services and for reimbursement,” he explained.

Judy Hagebak, director of the Georgia Department of Health’s Long Term Care Division, agreed, saying her top challenge was having adequate resources to meet all the needs of people who prefer to be served in the community, not institutions. “All of our programs have waiting lists. You probably couldn’t get into services immediately. You have to wait until dollars are available to serve you,” she said.

“All of our programs have waiting lists.”

And even when services are available to support people’s healthcare needs in a community setting, finding doctors who accept Medicaid may be a problem. “There’s an overall shortage of qualified medical

APPROVED

CMO Bill Passed

Concern over the administrative practices of the care management organizations that took over Georgia’s Medicaid and Peach-Care programs 18 months ago prompted the House of Representatives to pass HB 1234 165-1 this session.

“There has been significant confusion and concern among Georgia’s health care providers related to CMO reimbursement policies and decisions.”

Rep. Mickey Channell (R-Greensboro) introduced the bill, called the Medicaid Care Management Organizations (CMO) Act. “There has been significant confusion and concern among Georgia’s health care providers related to CMO reimbursement policies and decisions,” he explained.

Channell said providers complained about a number of issues, including the high volume of claim denials, claims mispayments, duplicate payments, payment delays, communications issues, provider setup delays and contracting issues.

“The purpose of the Medicaid Care Management Organization Act is to clarify the obligations of CMOs in delivering healthcare services to Georgia citizens under the Medicaid program. Because this bill will benefit all health care providers and patients, it had broad support and passed 165 – 1,” Channell said.

The legislation gives Insurance Commissioner John Oxendine oversight of the CMOs and also defines a standardized method for reimbursing providers.

As of press time, the bill had been amended and passed by the Senate and sent back to the House to pass the Senate’s version.



providers for all persons, people with disabilities or not,” Hagebak said.

Michelle Law, of Southbridge, Ga., has had trouble securing occupational therapy for her 15-year-old son, Takoda, who has cerebral palsy. Law’s private health insurance covers the cost, and her son receives the Katie Beckett (or Deeming) waiver to help cover the co-pays, but her community simply has a lack of therapists.

“The two or three therapists we have are full, and the only times they may have open are during the day when he’s at school,” she explained.

“When it comes to finding some of these special therapists, I’d have to quit my job to drive him an hour or more, one or more times a week.”

She’s also experienced problems finding dental care for her son, whose wheelchair can prevent him from getting X-rays in some dental offices.

Dr. Theodore C. Levitas is a pediatric dentist at Children’s Dental Center of Atlanta and one of the few in the state who treat children with disabilities. The majority of his patients have disabilities.

Dr. Teddy, as he is known by his patients, has been practicing for 59 years and spends at least one day a week in area children’s hospitals. “Many children with special needs have to be treated in an operating room under anesthetic. Some have the inability to cooperate voluntarily.



“People with disabilities are forced to leave the pediatric healthcare system and struggle to find a place to go because adult healthcare is not set up for it.”

“Unfortunately, there isn’t a lot of enthusiasm for treating children with special needs. Most of them are Medicaid or PeachCare patients. Remuneration is minimal, and that’s why a lot of dentists have stopped seeing Medicaid patients in the past couple of years,” he explained.

Medicaid reimburses dentists about one-third of their usual fee, which often may not even be enough to cover overhead costs.

Reimbursement barriers may also be a cause for the lack of primary care physicians who are experienced in treating adults with disabilities, many of whom are on Medicaid. “Doctors see treating people with disabilities as an extra cost because it takes more time to be paid by Medicaid. It’s a disincentive,” Swanson said.

While doctors have an opportunity to specialize in developmental pediatrics, currently no comparable specialty is offered for treating adults with developmental disabilities.

“Families and individuals have a hard time finding physicians to take care of them as they grow into adulthood.”

“Families and individuals have a hard time finding physicians to take care of them as they grow into adulthood. People with disabilities are forced to leave the pediatric healthcare system and struggle to find a place to go because adult healthcare is not set up for it,” Swanson said.

Very few doctors are set up to treat patients with disabilities. Their offices, equipment or literature might not be accessible, they might not have training in how to assess someone who has trouble communicating or they might not have the training to examine an adult who is apprehensive about seeing a doctor.

Currently, most medical schools do not include training for primary care physicians to learn how to effectively treat adults with disabilities, though there are a few exceptions.

“At the University of Arkansas, family practice doctors have to take care of patients with disabilities during their training. But it’s not universal practice,” Swanson said.

The CDC advocates for physicians to take training and funds 16 state programs to train health professionals to take better care of people with disabilities.

“It’s hard to mandate changes in training because the programs are hard to change.

The program will provide direct financial assistance and support services for Georgia's medically fragile and special needs children and their families.

Families May Now Access Champions for Children Funds

Easter Seals Georgia Coalition was recently awarded the grant for the Champions for Children with Exceptional Needs Initiative. The Champions for Children Program is designed to assist children and families that no longer meet the eligibility requirements for the Tax Equity and Fiscal Responsibility Act (TEFRA)/Katie Beckett Medicaid program. The program will provide direct financial assistance and support services for Georgia's medically fragile and special needs children and their families.

An Easter Seals Champions Coordinator will work directly with families to determine eligibility, identify service needs as described by the family and connect them with resources and services.

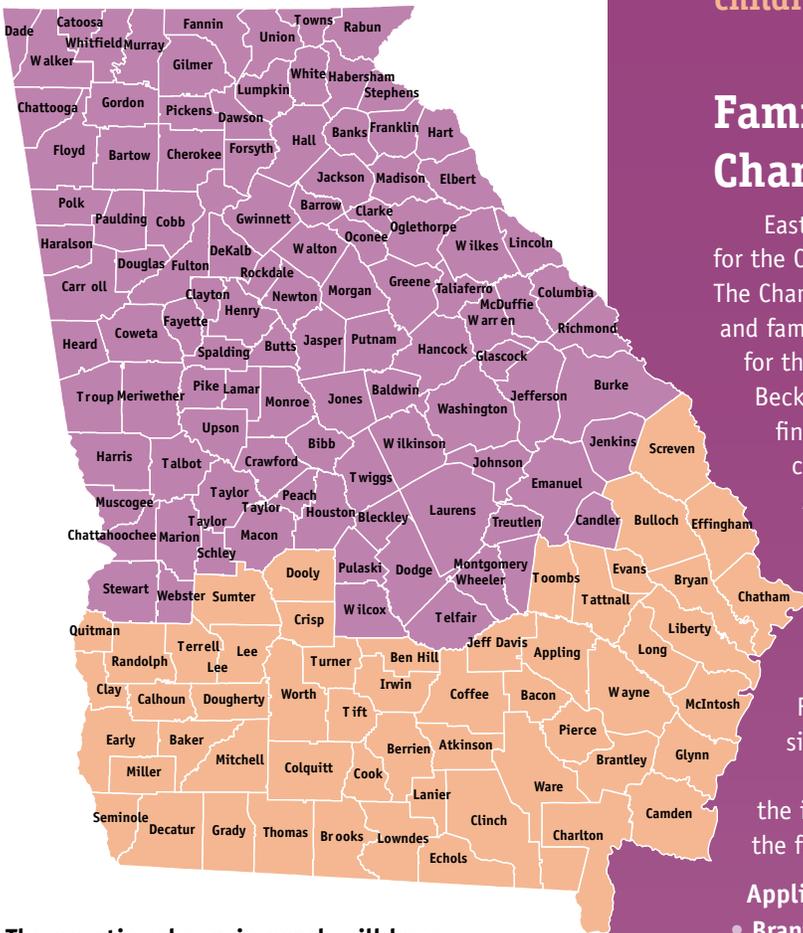
The Champions for Children Program is funded by a \$4.87 million five-year grant from The Community Foundation for Greater Atlanta. This grant was made possible by a one-time 2006 Georgia Legislature allocation.

The Easter Seals Georgia Coalition is pleased to announce the implementation of the Champions for Children Program in the following counties beginning April 1, 2008.

- Appling • Atkinson • Bacon • Baker • Ben Hill • Berrien
- Brantley • Brooks • Bryan • Bulloch • Calhoun • Camden •
- Chatham • Charlton • Clay • Clinch • Coffee • Colquitt •
- Cook • Crisp • Decatur • Dooly • Dougherty • Early • Echols
- Effingham • Evans • Glynn • Grady • Irwin • Jeff Davis •
- Lanier • Lee • Liberty • Long • Lowndes • McIntosh • Miller •
- Mitchell • Pierce • Quitman • Randolph • Screven • Seminole
- Sumter • Tattnall • Terrell • Thomas • Tift • Toombs • Turner
- Ware • Wayne • Wilcox • Worth

Families living in the counties served by Easter Seals North Georgia (metro Atlanta) will be able to access the program beginning July 1, and the program is expected to be available statewide by October 1. For more information on the Easter Seals affiliates and the counties they serve, please visit www.easterseals.com or call 1-866-584-3742.

The Easter Seals Georgia Coalition wants to ensure that a simple and effective process is put in place, which is why it is rolling out the Champions for Children Program in stages. The coalition realizes that many families will have specific questions about the eligibility criteria for the Champions for Children Program and the application process. However, the coalition respectfully requests that only families in the 54 counties listed above call the toll-free number until the program is rolled out into other areas.



The counties shown in peach will have access to the Champions for Children program as of April 1, 2008.

Training is the backbone of what will make the system better," Swanson explained.

The CDC is also working with specific disability groups, to help define solutions. "We're working with the spina bifida community to define best practices and gaps in knowledge and services. We can then apply what we learn to people with all disabilities," Swanson said.

One of the areas the CDC is looking at in the spina bifida community is transitioning from pediatric to adult care. "We have to prepare families from the beginning, when the children are small, that the children will have to be independent and responsible for their own care," Swanson said. "Doctors have children answer questions instead of their parents answering. This encourages them to



take responsibility for their own healthcare so when they're 21, they can go to a doctor and talk about their symptoms and condition."

Patients who are not verbal require a medical advocate throughout their lifespan. Law's son will eventually have to rely on others to help him.

"When we get too old, his twin brother will take over, or other family members," his mother revealed.

As her son ages, Law has begun to transition some of his services. "We used to get his wheelchair recommendations from the children's hospital, but we switched to the Shepherd Center for recommendations. He needs an adult chair now," she said.

Another concern Law has is that once her son becomes an adult, he will no longer be covered under his parents' private insurance. "He's automatically eligible for Medicaid when he becomes 18, but we want him to have private insurance as long as he can. We don't want him to live with the limits of Medicaid," she explained.

Adults with disabilities face a range of barriers, according to Dr. Mitch LaPlante, an associate professor of Sociology at University of California San Francisco.

"Working age people have much more difficulty getting services than older people with the same disabilities," he said. "Working aged people with disabilities have more unmet needs and suffer adverse consequences from unmet needs."

LaPlante has discovered people with disabilities in this age group rely more heavily on their families to help with activities of daily living than their older counterparts, and their families may not be properly trained or physically capable of helping them in and out of bed, into wheelchairs, etc.

And that's not the only barrier. "People with disabilities have much lower access to preventive healthcare and medical care. They are less likely to get mammogram screening and prostate screening. The equipment itself may not be accessible to everybody, or the treating professionals may not be attentive to their healthcare needs. That's a big problem causing more risk for other health problems," LaPlante said.

He feels access, appropriate medical services and sufficient quantity of care are top issues. "People with disabilities can be on the frontlines of having their healthcare restricted because of financial mechanisms to reduce costs."

Swanson agreed. "We need to have a healthcare system that gives everyone the financial means to access care. You need good health to work, have relationships and be in the community. It's people with disabilities' rights as individuals to have a quality of life like anyone else," he said. ●



Child Sues DCH for Services Based on EPSDT

Callie Moore is able to live at home with her family despite multiple and complex medical conditions and physical and cognitive impairments that resulted from a stroke she had before she was born.

If she didn't have access to skilled medical care and technology, Moore would need to move away from her family, friends and community into a hospital.

Under the Medicaid law known as "Early and Periodic Screening, Diagnosis and Treatment Services" (EPSDT), Medicaid-eligible children like Moore under the age of 21 are entitled to services like private duty nursing to be able to stay at home.

But Moore hasn't been receiving the nursing services she was prescribed by her doctor. The Department of Community Health (DCH), the organization that oversees implementation of Georgia's Medicaid program, routinely denies the hours she has been prescribed and keeps trying to cut them back. At one point, DCH told Moore's doctor that she could be institutionalized if he didn't lower the number of hours he had prescribed for her.

Congress enacted the Medicaid Act in 1965 with the aim of providing medical care for the nation's poorest people. Medicaid is a cooperative venture of the state and federal governments through which states that elect to participate receive federal financial assistance to furnish medical assistance to eligible people with low incomes. If a state chooses to participate in Medicaid, it is bound



to abide by the Medicaid Act and accompanying regulations.

Under the EPSDT provisions, if a doctor determines a treatment is necessary to correct or ameliorate a child's condition and the treatment is covered under one of 28 broad categories of services under the Medicaid Act, the state is supposed to pay for it, whether it is covered under the state's Medicaid plan or not.

"In Georgia, the problem is that the state has policies and procedures that place pre-determined caps and other limits on services. These get in the way of kids getting necessary services. For example, the state has limited private duty nursing hours. There should be no cap at all, but the state has a cap of one week of nursing hours at 16 hours a day. After that, the hours just keep getting cut back. The state's goal is to reduce nursing hours to no more than about five a day, no matter what the child's doctor has prescribed," explained Moore's attorney Josh Norris of the Georgia Advocacy Office.

"It's OK to have tentative limits in the state plan, but the limits can't frustrate the child receiving the services that her doctor prescribes for her."

"It's OK to have tentative limits in the state plan, but the limits can't frustrate the child receiving the services that her doctor prescribes for her. If the child needs services in excess of these tentative limits, the child should get those services without delay under EPSDT.

"EPSDT is unusual in that Congress created such a broad mandate for states to provide medically necessary services to children. Unlike other parts of the Medicaid program, the state has virtually no discretion to deny medically necessary services. Courts construing the EPSDT requirements have found that so long as a competent medical provider finds specific care to be medically necessary to improve or ameliorate a child's condition, EPSDT requires the state to cover it."

Moore is not receiving all the private duty nursing care her doctor has prescribed, so she is suing DCH Commissioner Rhonda Medows to receive the medically necessary services she is entitled to under EPSDT.

Her complaint says, "The provision of all necessary private duty nursing services to correct or ameliorate Plaintiff's medical and physical conditions are essential for Callie's well-being, and Defendant's denial of these services places Callie at greater risk of illness, hospitalization and death."

Norris said that part of the problem in Georgia is the narrowness of the definition of "medical necessity" being used by the state.

"Kids with disabilities have chronic conditions that aren't necessarily going to get better, but they can receive treatments to improve or maintain their functional capacities. It's a broader notion of medical necessity than is found typically in other contexts," he said.

Georgia's current definition of medical necessity is whether the omission of services would adversely affect the child's medical condition.

"That's a different concept than what will maintain or improve a person's medical condition," Norris said.

He maintains, "The state wants to drive down utilization of services like an insurance company so they can keep budgets in line."

A central issue in Moore's case is the definition of medical necessity. "The state has created policies around medical necessity, but the question is whether they comply with what was meant by Congress under EPSDT. We don't believe they do," Norris stated.

"This is an important case for Georgia," he said. In addition to defining medical necessity, it will determine whether the state can limit services when the physician says the patients need more services than are provided.

"The state has created POLICIES around medical necessity, but the question is whether THEY COMPLY with what was meant by CONGRESS under EPSDT."

Creating an Accessible World with the United Nations Convention

By Axel Leblois, Executive Director, G3ict



Axel Leblois is President and co-Founder of W2i, the Wireless Internet Institute. Prior to creating W2i, he spent over 20 years in leadership roles at several U.S. information technology companies. He is a Senior Special Fellow of the United Nations Institute for Training and Research.

W2i has developed programs with the United Nations ICT Task Force, InfoDev and UNITAR in the context of the World Summit on the Information Society. In 2006, the Global Alliance for ICT and Development selected W2i's proposal to form G3ict, the Global Initiative for Inclusive ICTs to facilitate a multi-stakeholder dialogue on ICT accessibility issues and develop a knowledge base and best practices sharing platform in support of the implementation of the new Convention on the Rights of Persons with Disabilities.

Basic human rights, taken for granted by so many, are often denied to people with sensory, mental, physical, developmental and intellectual impairments.

To assure basic human rights, the United Nations, under the leadership of its Department of Social Affairs and Ambassador Luis Benigno Gallegos Chiriboga of Ecuador, adopted the Convention on the Rights of Persons with Disabilities in December 2006, which has been signed to date by 126 countries, although not by the United States.

The principles of the Convention are simple:

- Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

The U.N. Convention recognizes that Information and Communication Technologies, or ICTs, could help signatory countries fulfill many of these principles, including non-discrimination, full and effective participation and inclusion in society, equality of opportunity and accessibility. The Convention specifically defines the obligations of countries regarding the development of ICTs in articles 9 and 4:

“Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage so that these technologies become accessible at a minimum cost.” (article 9)

“To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines.” (article 4)

To support the implementation of these dispositions, industry, non governmental organizations and public institutions have joined forces and created the Global Initiative for Inclusive Information and Communication Technologies – G3ict – under the auspices of the United Nations Global Alliance for ICT and Development. G3ict recognizes that simply creating legislation will not create change, unless accessible and assistive ICT products are readily available and affordable to people with disabilities. By promoting international ICT accessibility standards with industry participation, G3ict hopes to help countries create market conditions that will allow businesses to deliver required, accessible product features at an affordable cost; indeed, global standards are the foundation of cost reductions through mass production and economies of scale.

Personal computers, the Internet, telephones, televisions, radios and cell phones need to include features to make them accessible to people with disabilities to help countries meet the goals of the Convention. Technologies exist today which can achieve this goal, but are not widely implemented for cost or lack of awareness reasons.

Globally, more people own cell phones than any of the other communications devices. While miniaturization of cell phones presents a challenge to their accessibility, their widespread use, even in developing countries, and their unique features, make their improved accessibility highly desirable.

Smart phones and PDAs already cover many functionalities offered by personal computers, and other features could be easily adapted to assist people with disabilities, such as geographic positioning, which could help guide a person with visual disabilities; text displays for deaf persons, and voice recognition capabilities for people who may not be able to type.

In addition, certain functionalities could be added to cell phones to make them even more useful to people with

disabilities, such as remote control capabilities to allow them to control other devices with their cell phone, and radio frequency identification (RFID), which could be used as an interface with environmental services in buildings, public transportation or medical facilities. These features, combined with a simplified, universal device interface can significantly improve the lives of people with disabilities. Global standardization of these technologies has the potential to make them affordable.

The Convention urges countries to form public-private partnerships to accelerate the adoption of assistive technologies. Such partnerships already exist in some areas and have made a positive impact on the lives of people with disabilities.

One program is the Partnership in Opportunities for Employment through Technologies in the Americas (POETA), a Latin American initiative between the Organization of American States and the Trust for the Americas, established in 2004 with support from Microsoft.

POETA helps provide skills and opportunities to people with disabilities to find jobs and live independently. POETA established 39 technology centers across Latin America and serves about 12,500 people a year, with more than 100 public and private partners sharing knowledge, resources and infrastructure in 12 countries.

Each POETA center is equipped with adaptive technologies so people with disabilities can fully use the computers in the center. Adaptive technologies include trackballs which are a larger version of a typical computer mouse, but can be used more easily in conjunction with other adaptive technologies, such as hand wands and mouth sticks. The trackball can also be manipulated by the foot, for people who don't have use of their hands.

Other adaptive technologies include Dragon Naturally Speaking software that recognizes voice commands; an alternative keyboard called Intellikeys that helps people with physical, visual and cognitive disabilities more easily type; and Job Access with Speech, which reads the contents of computer screens to improve accessibility for people who are visually impaired.

Success stories like these can be found all over the world. With improved access to affordable information and communication technologies, people with disabilities across the globe will have more opportunities to gain employment, live independently and fully participate in their communities. ●

“To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines.” (article 4)

article 4

article 9

“Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early state so that these technologies become accessible at a minimum cost.” (article 9)

StraightTalk

Be Prepared BEFORE You Enter a Hospital



By Ashley Rhinehart,
MS, CRC

ICWP Coordinator at
disABILITY LINK

**I believe
KNOWLEDGE IS
power,
so arm yourself
and your loved ones
with this knowledge.**

As a child with spinal muscular atrophy (SMA), from the age of six until the age of 13, I was in and out of the hospital. Afterwards, I was blessed with few health related difficulties and no hospitalizations until my appendix decided to bail out at the age of 28.

From this and later experiences I have had, not only with myself as the patient, but also as an advocate for others, I have come to understand that not only has my perspective changed from that of a child to that of an adult, the world of personal healthcare has also gone through some major changes.

- Always carry a list of your medications, your doctors' phone numbers, your allergies and emergency numbers.
 - No matter how healthy you are, locate and "train" a primary care physician (PCP) and relevant specialists you like and trust. They need to know all about you, not just your disability, and you need to have regular contact and checkups. These relationships are important when you need orders for medical equipment, forms filled out, etc., as well as when you are sick. Give your PCP information about yourself, your medical history and other specialists that you see, therapies you are doing, etc. Make sure other doctors send records of your visits, lab tests, etc., to your PCP, and vice versa. Discuss hospital care, such as what/how you want it, and how they can be involved if the time ever comes.
 - Choose one or two medical powers of attorney. The form is on Georgia Legal Aid's Web site: www.legalaid-ga.org/GA/StateChannelResults.cfm/County/%20/City/%20/demoMode/%3D%201/Language/1/State/GA/TextOnly/N/ZipCode/%20/LoggedIn/0/iSubTopicID/1/iProblemCodeID/1330700/sTopicImage/g-health.gif/iTopicID/449/iChannelID/136/bAllState/0. These are people you trust to make medical decisions or advocate on your behalf, if you are unable to do so. Give them a list of your medications, doctors' phone numbers and your allergies, and keep it updated. Discuss your health and what you want them to do if you can't decide for yourself. These topics are not limited to "living will" kinds of things, but also disability-specific options like catheter or bedpan, options for ventilation, how often do I need to be turned, which side do I sleep on, things that haven't worked in the past and doctors to be consulted. Long-term care should also be discussed, especially alternatives to nursing homes.
 - Choose a financial power of attorney. The form is also on Georgia Legal Aid's Web site. Choose someone you trust to manage your affairs, such as paying rent, phone, water, etc. Tell them what to pay, when and how. Another way to do this is to give that person permission through the bank to operate your account, or have a joint account.
 - Choose an advocate/coordinator. This person needs to be good with details and should know at least some of the things listed under medical power of attorney. They may or may not be your medical power of attorney, but they must work closely together. This is an "unofficial" position, so there's no form. I have learned to never assume communication has taken place between any two medical entities. In other words, make sure someone keeps up with everything that is said, done and that you are told. Communicate with doctors and nurses, ask questions if you don't understand or it doesn't make sense and write everything down. It has been my personal observation that while staff members at hospitals work diligently and sincerely, there is a continuity that is missing. There is no one person looking at a person's complete picture.
- I believe knowledge is power, so arm yourself and your loved ones with this knowledge. Then take the time and energy you saved and spend it doing something you love. ●

APRIL

April 25 – May 2
The ADAPT Community:
25th Anniversary
25 Years of Activism
and Counting
 Washington, DC
 512-442-0252 • 303-733-9324

April 30
Taylor Family Foundation
Speaker Series
 Atlanta, GA
 404-961-9966

MAY

May 1 – 2
Interagency
Coordinating Council
 Macon, GA • 404-657-2726
health.state.ga.us/programs/bcw/

May 4
Teen Buddy Program
Habima Theatre's
Footloose
 Atlanta, GA • 404-961-9957

May 5 – 6; Augusta, GA
May 8 – 9; Kennesaw, GA
Redefining Disability
and Inclusion to
Transform Practice
 404-463-0796
www.cviog.uga.edu/training/dhr

May 8
Chatham-Savannah
Citizen Advocacy, Inc.
30th Anniversary Celebra-
tion at the Hellenic Center
 Savannah, GA
 912-236-5798
www.savannahcitizenadvocacy.org

May 26 – 29
International Conference
on Self-Determination
 Detroit, MI
 404-842-0556
cherangel_33@yahoo.com

May 28 – 30
The New Professional:
Leadership in Science,
Practice, Policy and
Advocacy

Washington, DC
 800-424-3688
www.aamr.org/events/2008_Meeting.shtml

May 29 – June 1
GPA Annual Meeting
(Georgia Psychology
Association)
 Jekyll Island, GA
 404-634-6272
www.gapsychology.org

JUNE

June 1 – 3
Against All Odds
 Athens, GA
www.georgiacenter.uga.edu/conferences

June 11
Georgia Aging and Disabil-
ity Resource Connection
2008 Regional Training
Conference
 Athens, GA
 Contact Lauren Burby at
burby613@earthlink.net

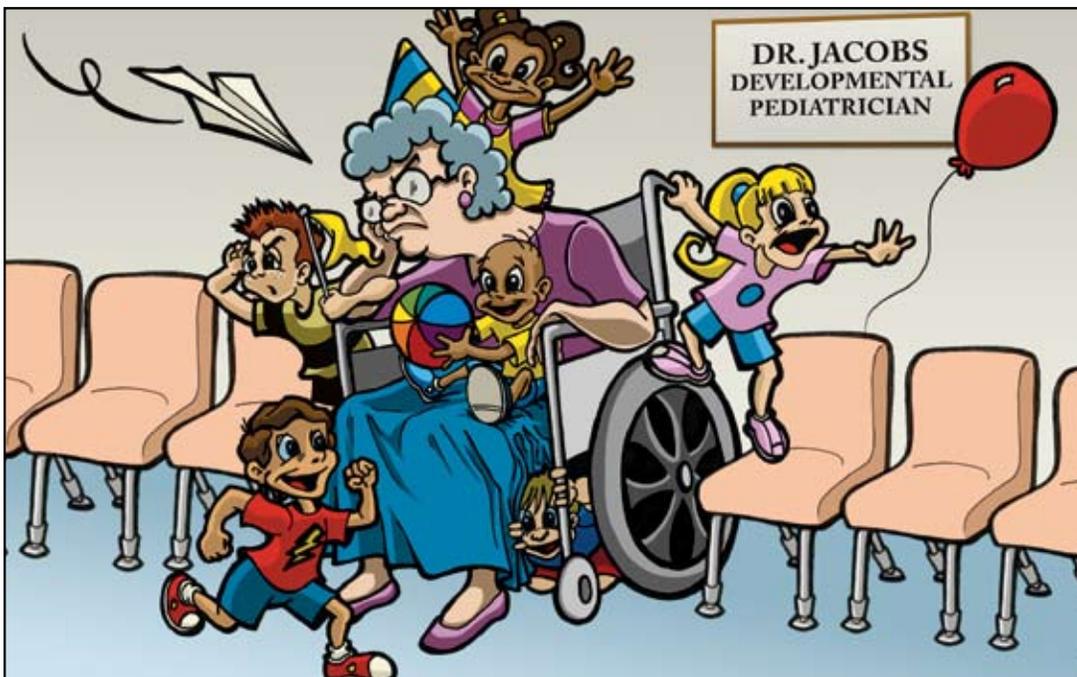
June 17
Georgia Aging and
Disability Resource
Connection
2008 Regional
Training Conference
 Augusta, GA
 Contact Lauren Burby at
burby613@earthlink.net

June 21 – 22
Long Road Home March
 Atlanta, GA
 404-657-2125
www.gcdd.org

June 25
Georgia Aging and
Disability Resource
Connection
2008 Regional
Training Conference
 Savannah, GA
 Contact Lauren Burby at
burby613@earthlink.net

JULY

July 17-18
Governor's Council on
Developmental Disabili-
ties Quarterly Meeting &
Awards Ceremony
 Atlanta, GA
 404-657-2126 • 888-ASK-GCDD
www.gcdd.org



Betty had to resort to drastic measures to find a physician who had experience treating people with developmental disabilities.

2008



Mia Waits Six Months for Support

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

In August, Mia and I knew we would need some personal support to help her get to work and activities. I got divorced, and my daughter went out of state for college, leaving me with no backup at home. Mia's UGA students couldn't do daily backup. So when the support coordinator began talking about Mia's plan renewal, I requested support to be in place at least by Christmas. I wanted a routine before the legislative session started in January. I requested only 20 hours of support a week, enough to get her to and from work, bowling, church activities, the gym and help to start the day with a healthy breakfast. August through December, five months, enough time to get it in place, right?

Wrong. Mia's Supports Intensity Scale and Individual Support Plan were written on time, but in the two months it took to hold three meetings and sign off on the goals for support, we went through two support coordinators. Mia met with Georgia Options, told them what she liked to do, where she liked to go, what she liked to eat, etc.,

if she didn't have to work and snacking, despite our efforts to restrict her access to certain foods. Her weight increased. Third weekend of January, we went to interview workers. Mia got along with both of them, and we let the provider make the final decision. Then they needed mandatory training. It was mid-February before Mia had support in place.

Mia is competent to stay home and manage her day for short stretches as long as someone can check up on her. My children Annie and Christopher were able to do that. But as a result of the delay, her support worker and I are spending a lot of time UN-doing the couch potato habits she acquired when her days were unscheduled. She's resisting the efforts. This wouldn't have happened if support had been put in place in a reasonable time frame. We could have lived with 90 days, but the six-month wait caused problems we now have to resolve.

Why did it take so long? Breakdown in support coordination was one factor. Mia's had 9? 10? support coordinators in the past three years. Waiting on the Regional Office for funding approval was another issue. I got a call from a parent who has been waiting nine months for approval of an enhanced rate so her daughter can stay in her home with decent support. If the money's there, what's the hold up? We need to spend the money expeditiously so when we go to the Legislature for new waiver money each year, we can show them results, that every hard-won penny has been assigned to support a family.

When it comes to Mia, I'm just a parent, but a pretty well connected one, so what happens to the average parent elsewhere in Georgia with more challenges than I have trying to get what they need? We must simplify and expedite the process of getting support to people. It's not rocket science, is it? ●

"We could have lived with 90 days, but the six-month wait caused problems we now have to resolve."

but we could not hire anyone until funding was approved December 23. Because of Christmas, nothing happened for a few more weeks. When the legislative session began, instead of knowing Mia had a supported daily routine, I was fielding numerous daily phone calls from the third floor of the Capitol between Mia, her job, her siblings (who fortunately provided some backup) and the job coach, coordinating her day from 70 miles away. Without a routine in place, Mia had started staying up late, sleeping late, watching TV all day



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DISABILITY DAY 2008



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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
 404-657-2126 or
 888-275-4233 (ASK-GCDD)

State Government

**Department of Community Affairs
 Georgia Housing Search**
www.georgiahousingsearch.org
 877-428-8844

Department of Community Health
www.dch.state.ga.us/
 404-656-4507

Department of Human Resources
www.dhr.georgia.gov
 404-656-4937

Department of Labor
www.dol.state.ga.us

General Information
www.georgia.gov

Georgia General Assembly
www.legis.state.ga.us/

Georgia House of Representatives
www.legis.state.ga.us/legis/2003_04/house/index.htm

Georgia Senate
www.legis.state.ga.us/legis/2003_04/senate/index.htm

Georgia Governor's Office
www.gov.state.ga.us/
 404-656-1776

Georgia Lieutenant Governor's Office
www.ltgov.georgia.gov/02/ltgov/home/0,2214,2199618,00.html
 404-656-5030

Global Accessibility

G3ict
www.g3ict.com
 404-446-4169

United Nations Enable
www.un.org/disabilities

Healthcare

Apply for Medicaid
dfcs.dhr.georgia.gov

Centers for Disease Control & Prevention
www.cdc.gov/ncbddd/dd/default.htm
 404-498-1515

Institute for Study of Disadvantage and Disability
www.isdd-home.org/
 678-595-4854

Medicaid
www.cms.hhs.gov/home/medicaid.asp

PeachCare (Medicaid for Children)
www.dch.georgia.gov
 877-427-3224 (toll-free)
 (877-GA-PEACH)

Pediatric Environmental Health Specialty Unit – Emory University
www.sph.emory.edu/pehsu/html/faculty.htm

Voting

Disability Vote Project
www.aapd-dc.org/dvpmain/dvpindex.php
 202-457-0046
 800-840-8844

People First
www.disabilitylink.org
 404-885-1234
 p1stofga@yahoo.com

Register/Polling Locations/Absentee
sos.georgia.gov/elections
 404-656-2871

Vote Smart
www.vote-smart.org

Disability Day

Wheat Mission – Atlanta
 770-717-0790



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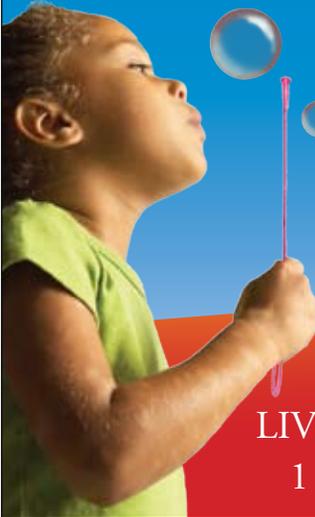
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- the Children 1st Coordinator at your local health department at **800-822-2539**
- Parent to Parent of Georgia at **800-229-2038** or in Atlanta at **770-451-5484**



Division of Public Health
Family Health Branch
Office of Children with Special Needs
www.dhr.state.ga.us

Babies Can't Wait Program

Who?

- Birth to age three
- With disability or developmental delay

What?

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

Children's Medical Services Program

Who?

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

What?

- Coordinates/provides specialty medical evaluations/treatment

High Risk Infant Follow-Up Program

Who?

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What?

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www.YourToolsForLiving.org

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Thousands Brave Rain for Disability Day at the Capitol February 21 (see story, page 12)



2008

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