

Making **a** Difference

SPRING
2004

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Georgia's First Lady
Mary Perdue

Mary Perdue Knows

**Babies
Can't
Wait**

**Katie Beckett Waiver
Advocates Statewide
Fight Proposed Premium**

**Point/Counterpoint
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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.

Email us at:

makingadifference@gcdd.org

Call us at: 404-657-2127

Fax us at: 404-657-2132

Or you can visit us at:

2 Peachtree Street, NW, Suite 8-210
Atlanta, GA 30303-3142

Sponsorship:

For sponsorship opportunities contact:

Gordon O'Neill at
770-578-9765 or

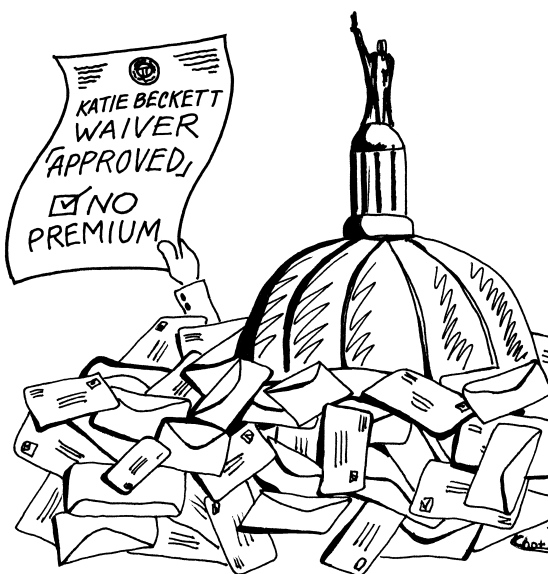
gordon@oneillcommunications.com

Subscriptions / Back Issues

Visit us at our Web site: www.gcdd.org

or call us: 404-657-2126

It is the policy of *Making A Difference* to publish readers' comments. Contents do not necessarily reflect the opinions of GCDD, the editors or state government.



Disability advocates statewide sent a "few letters" to the legislature regarding the Katie Beckett Waiver premium proposal. Their advocacy reversed the DCH recommendation.

A Service to the Community

All too often we get caught up in the rush of things, and don't slow down long enough to give pats on the back or tell folks what a great job we think they have done. Well, it's the middle of the night and I'm slowing down, and I just want to say what an incredible service I think the Governor's Council has given the DD community through the publication of *Making A Difference!* There has not been one issue that I didn't read cover to cover and truly appreciate the contents! I particularly liked this past issue on Self Determination, and thought your article, "Self Determination is Not an Option," was absolutely right on target. I just wanted you to know that I think this is one of the most (among many) outstanding contributions that GCDD makes to help folks with disabilities and their families be more informed and better prepared to deal with the complex world of "systems" in which they live. And what an education for those who don't live it! Great job!

Thank you and your staff for ALL that you do with all your programs. Where would Georgia be without the strength, support and leadership of the Governor's Council on Developmental Disabilities!?

Beth Tumlin (Natalie's Mom)
President, *The Arc of Georgia*

Fills Important Need

It is with great pleasure I write a letter of support for the excellent quality of *Making A Difference* magazine. The magazine is interesting, accurate and thought provoking.

There is a real need for more communication between families caring for adults with disabilities and for the people with disabilities themselves.

Families have few resources, especially when children reach adult age. This magazine is a great resource to the families I work with across the state. I look forward to continue working with you in the future.

Patricia Solomon
Georgia Department of Education



Special Olympics
Georgia

Great Source of Information

Special Olympics Georgia offers year-round sports training and competition to athletes age eight and up with intellectual disabilities, so we sincerely support any efforts to inform the constituency that we serve of available resources, advocacy issues, personal accomplishments and legislative agendas. The editors and staff of *Making A Difference* have done a good job keeping important issues top of mind and promoting the visibility of individuals with all kinds of disabilities from all around the state of Georgia.

Georgia Milton-Sheats, *Executive Director*
Jennifer Daniell, *Project/Office Manager*
Special Olympics Georgia

Putting Faces to Names

I wanted to let you know that I just read the Winter 2004 magazine that I got while we were in Atlanta at the joint SICC/SAC meeting and really appreciate all the effort you all put into it. I learned a number of things, some small and some big, that helped make other bits of knowledge that I have make sense. The most profound was being able to put a face to Eric Johnson and to know that the letter parents are receiving saying that the Senate Appropriations Committee has restored the funding to the 2004 budget is from someone who has listened to us and is someone who can make our voice heard. Thanks for helping to guide us.

Ruth Masciarelli
Parent, *State Interagency Coordinating Council (SICC)*





Georgia's State of Disability: Funding is No Priority

Borrowing from the English author Charles Dickens, "It is the best of times, it is the worst of times." As we examine the disability agenda, coupled with requests for priority funding, hard choices are being made, resulting in cuts in important programs and the scaling back of vital services.

As I write during the twilight of this legislative session, we in the disability movement reflect positively on "Disability Day at the Capitol," where more than 600 advocates braved a "school snow day" to demonstrate their enthusiasm and commitment for "systems change" through the legislative process. This event remains one of the largest annual activities during the legislative session.



We are in the worst of times when once again we experience a void of leadership concerning the publicly funded system of supports for people with developmental disabilities and their families. It begins with the Department of Human Resources that still does not have a commissioner and filters its way down to the Division of Mental Health, Developmental Disabilities, Addictive Diseases (waiting for a director too) and the Office of Developmental Disabilities, which many of us thought had selected an administrator, only to have the offer withdrawn at the last minute. A car can't drive without a driver and an airplane can't fly without a pilot . . .

It is the worst of times, when for the first time in many years, there was no new money in the budget to address the Waiting Lists for home- and community-based services. The Waiting Lists continue to grow at an ever-increasing pace. As of February, there were over 4,500 people waiting for services.

It is the worst of times when once again there is no increase in the reimbursement rate for home- and community-based providers. In the last 10 years, the providers have received only one increase. Who would want to work for the same compensation over a 10-year period?

Families dependent on the Deeming (Katie Beckett) Waiver to help manage the cost of caring for a child with a disability have fought and won a hard battle to keep unfair monthly premiums from being implemented without their input.

While we have experienced the worst of times, I have to be an optimist and think about what happens when it is the best of times. It is then that we have a publicly funded system that is built on a vision where individuals with disabilities and families are the driving force in the decision-making process. During those best of times, we annually expect and receive new funds in annual budgets to address the Waiting Lists as well as additional Georgians with disabilities being served. Our providers should receive the same annual cost-of-living increases that doctors, hospitals and nursing homes receive from state budgets.

Perhaps, more importantly, during the best of times, we anticipate more people having their chains removed as adequate supports are put in place so that more Georgians can leave institutions and nursing homes living free in home- and community-based facilities.

In the best of times, from the time a child is born until he dies, there are supports available based on need, not money.

*In the best of times,
from birth to death,
there are supports
available based on
need, not money.*

Finally, I would like to direct your attention to our new *Making A Difference* magazine editorial team, O'Neill Communications. We think you will be pleased with their improvements and enhancements as we expand to new markets focused on disability issues. Please share with me your thoughts concerning our publication and what you would like published in the future. I can be reached at eejacobson@dhr.state.ga.us or 1-888-275-4233.

Eric E. Jacobson

Eric E. Jacobson
Executive Director, GCDD

**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.

Lynnette Bragg
Chairperson
lynnettebragg@aol.com

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

2 Peachtree Street NW, Suite 8-210
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

Yao Atiim Seidu
Editor-in-Chief
yaseidu@dhr.state.ga.us

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

Janice Nodvin
Consulting Editor
May South, Inc.
jnodvin@mayinstitute.org

Daemon Baizan
Photography - Cover Feature

Jeremy Chotiner
Cartoonist

Nancy O'Neill
Design & Layout
O'Neill Communications, Inc.



Art donated by a
self advocate

THE LONG ROAD HOME



Johanna Burton 1-28-04

Olmstead Anniversary Spurs March and Freedom Rally

The fifth anniversary of the U.S. Supreme Court's Olmstead decision, that found keeping people in nursing homes and state hospitals against their will is unlawful, will be marked in Georgia with an eight-day march and freedom rally June 14-22, 2004, from Milledgeville to Atlanta.

According to Samantha Renfro, of the Brain Injury Resource Foundation, "There are over 4,500 people with developmental disabilities waiting for home- or community-based care. Some have been waiting for 10 years."

The "Long Road Home March" will begin at the Central State Hospital in Milledgeville June 14 and go through Lake Sinclair, Eatonton, Monticello, McDonough, Stockbridge and Forest Park before ending in Atlanta June 22 with a rally at the state Capitol.

The march hopes to:

- Make the public aware of people who are still in state hospitals and how Georgia is implementing the Olmstead decision.
- Send a message to state officials that there are real people depending on Georgia's compliance with the Olmstead decision.
- Empower people with disabilities to know that their voices count and their votes make a difference.

For more information, visit www.longroadhome.org or call People First of Atlanta at 404-687-8890, x 115.

March the *Long Road Home* June 14-22

Inclusion Conference Presents Seminars from Early Childhood through Adulthood

To illustrate how inclusion works and provide strategies to support inclusive communities, Georgia's Governor's Council on Developmental Disabilities (GCDD) held its sixth **Better All Together: Inclusion Works!** Conference March 17-20 in Peachtree City, GA.

The conference offered sessions on a wide variety of topics to encourage inclusion in every stage of a person's life, from early childhood through graduation from high school and beyond.

A special session for school administrators and several presentations on adult services were added this year. The Superintendents Summit and Principals Academy featured guest speakers such as Georgia State Superintendent of Schools Kathy Cox and Assistant Secretary, U.S. Office of Special Education and Rehabilitative Services Robert Pasternack.

Adult services sessions included higher education, homeownership, how to get and keep a job, self-employment and several other important topics. Several adults with disabilities also shared their experiences of becoming included in their communities.

Early childhood and school inclusion, curriculum modifications, community-building, teaching strategies and person-centered planning sessions were presented by leaders in the fields. Educators, parents and students had access to key information to help them continue to move toward full inclusion in schools, work places and communities.

The conference was co-sponsored by the Georgia Department of Education - Division for Exceptional Students; Office of Children with Special Needs; Division of Public Health; Community Developers Association of Georgia; Institute on Human Development and Disability;

Center for Excellence in Developmental Disability Education, Research, and Service; Project WINS; the Georgia Advocacy Office; and The University of Georgia Center for Continuing Education.

GCDD Plans Awards

The GCDD is presently surveying advocates, policy-makers and lawmakers in preparation for the 2003 Annual Legislative and Advocacy Awards Program held in conjunction with the July Council meeting in Atlanta. This year's program will be held July 15-16 at the Georgia Tech Conference Center and Hotel.

Traditionally, GCDD recognizes Legislators of the Year, Advocates of the Year and Media Professionals of the Year.

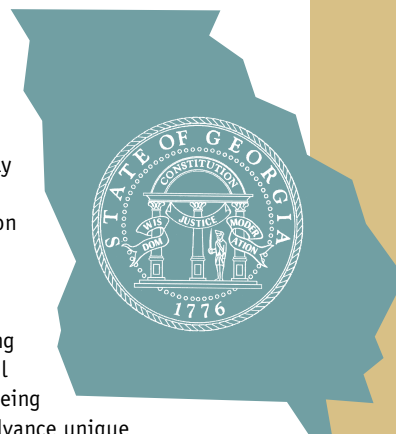
At the just concluded April meeting, held in Cartersville, GCDD's focus was on employment and leadership development within the disability community.

Doug Crandell, Cobb County Community Service Board, presented an overview of successful efforts in job placement and training in the community just northwest of Atlanta.

Renn Doyle and Dave Blanchard of the Atlanta Alliance on Developmental Disabilities presented a comprehensive report on the past, present and future of the Partners in Policymaking Program, a GCDD funded initiative.

"Partners" has just recently organized a graduate division to track the activities of its past graduates, now approaching 200. Additional graduates are being organized to advance unique opportunities that will advance the disability movement in the state.

Visit the Web site at www.gcdd.org for info and upcoming meetings. ●





GCDD Advocates Against Proposed Budget Cuts

by Pat Nobbie, D.P.A.

To fulfill its commitment to the disability community, the Governor's Council on Developmental Disabilities (GCDD) sets a prioritized agenda for each legislative session. This year, the budget deficit greatly influenced legislative actions; however, despite cuts to many programs, the disability community helped restore funding slated to

be cut, and even accomplished a few legislative victories.

Two fiscal year (FY) budgets were tracked: the FY'04 supplemental budget that adds funding for the remaining months of this fiscal year, and the FY'05 budget that authorizes funding that starts July 1. The FY'04 budget, House Bill (HB) 1180, was passed by both House and Senate March 22. The state's

\$16.2 billion FY'05 budget was adopted by the House March 15, and was passed by the Senate March 25. As of press time, the final budget was being conferenced by three members each from the House and Senate.

First Priority Legislative Items

Monitor the Department of Human Resources (DHR) budget.

Status: The House originally proposed adding \$654,105 for 25 more slots in the "Unlock the Waiting Lists" Home- and Community-Based Services Waiver Program for adults with developmental disabilities; however, in the final appropriations vote, 15 slots were removed, and the committee's recommendation was \$218,035 for 10 slots. The House also removed \$1.16 million to transition 20 consumers with development disabilities from Columbus and Savannah Regional Hospitals to the community; however, the Senate voted to restore that money (Olmstead budget item). The Senate added \$100,000 back in for five slots in the Independent Care Waiver Program (ICWP).

Monitor the Department of Community Health (DCH) budget.

Status: GCDD supported the grassroots efforts of hundreds of parents of children with severe disabilities to fight a proposed premium on the Katie Beckett Waiver. As a result of parent participation in the legislative process, the House and Senate restored the funds to the Katie Beckett program in both the FY'04 and FY'05 budgets, thus removing the requirement for a premium. (see article, page 18). House version of FY'05 budget includes:

- \$4.9 million to restore Medicaid coverage for those with incomes over 185% of the federal poverty level up to 200% which will maintain coverage for 15,000 women and children who would have been cut off (Senate lowered to 195% of poverty level).
- \$5.6 million to continue adult dental coverage in Medicaid (Senate kept restoration).
- \$1.6 million for Medicaid coverage of orthotics and prosthetics (Senate reduced by \$200,000).
- \$1.5 million for the Katie Beckett waiver program to prevent premiums (Senate kept restoration).

Monitor the Department of Education (DOE) budget.

Status: The DOE budget was threatened with huge losses to the Quality Basic Education (QBE) formula that represents per pupil funding across the state. The House added \$278 million, but the Senate only approved \$156 million.

- Georgia Learning Resource System (GLRS), the technical assistance (TA) system for special education, lost \$1.129 million, and the Regional Educational Service Agency (RESA) system lost \$1.6 million. GLRS and RESA will be consolidated to maintain an education resource and TA function. Advocates are concerned GLRS will lose its capacity to deliver TA to the special education system and parents of children with special needs. Senate did not restore.
- House restored \$5.8 million to the DOE for vocational lab supervisors. The Senate cut \$3 million.

Propose a Money Follows People resolution to create initiative for institutional dollars to follow people transitioning to home and

community-based settings.

Status: Early conversations with Senate leadership on the proposal to work with two nursing home providers to transition people to the community with their financial support ran aground. However, certain Senate members are still interested if the effort does not cost the state more than nursing home care.

Support revenue generating options that surface during the session.

Status: In his State of the State and Budget Address in January, Governor Sonny Perdue said to Georgia families, "If you have to live within your means, state government will, too. We will not raise taxes to balance this budget." Although the Georgia Coalition United for Responsible Budget (CURB) advanced several revenue generating proposals, neither House nor Senate, nor the Governor's office, acted on them.

Secondary Priority Legislative Items

Work with the Secretary of State to amend election code legislation to remove voting process barriers for people with disabilities.

Status: GCDD, with a disability rights attorney, worked with the State to draft language that would amend the elections code by:

- Amending the oath procedure and making it uniform across all disabilities
- Requiring public information directed at voters to be in accessible formats
- Amending absentee procedures so personal assistants can deliver ballots for people with disabilities without threat of prosecution; and defining personal assistant
- Allowing poll workers to assist people with disabilities in all elections

Several barriers emerged during the process, and advocates decided to postpone



GCDD Public Policy Director Pat Nobbie, D.P.A., monitors the legislative session.





Disability Day at the Capitol

A snow storm didn't keep hundreds of advocates and people with disabilities from rallying at the Georgia State Capitol during the Sixth Annual Disability Day, sponsored by the Governor's Council on Developmental Disabilities February 26.

At the Capitol, attendees and legislators heard compelling stories about how the Multi-Year Funding Plan (MFP) and Katie Beckett Waiver programs positively affect families and how ensuring these programs continue, without cuts or premiums, is imperative for people with disabilities.

After the rally, attendees and legislators enjoyed a barbecue lunch and heard from several state politicians, including Sen. Eric Johnson (R-Savannah) who announced the Katie Beckett Waiver premiums had been removed from the state's fiscal year 2004 budget, thanks to the lobbying efforts of advocates and people with disabilities. ●

Sen. Sam Zamarripa (D-Atlanta) shared the story of his sister who was transitioned out of an institution and now lives in her own home down the block from him.



Lt. Gov. Mark Taylor (D) receives a gift made by patients at Children's Healthcare from Annette Bowling, Exec. Dir., Albany ARC. Sen. Eric Johnson (right) announced proposed premiums on the Katie Beckett Waiver were deleted from the budget.

Legislative Update

introduction of the bill until early next session. The Voting Coalition will work with the Secretary of State's Office to draft and prefile a bill prior to '05 legislative session.

Support the movement of self-determination legislation (SB 170 and HB 701).

Status: Advocacy groups promised the Governor's Office they would give DHR and DCH an opportunity to work out processes for self-determined service delivery. Both bills received preliminary committee hearings, but neither passed. Both can be reintroduced next session if the agencies fail to make adequate progress.

Monitor HB 498 for amendments or other legislation to change the regional system.

Status: Nothing happened this year. However, the Healthcare Audits Div. of the Dept. of Audits and Accounts submitted the results of Phase I of a study of the Community Service Board System to the Governor that cited serious criticisms of the system. Based on the findings, some changes may be made in the next legislative session.

Educate legislators on direct support worker issues, especially the planned training program with the Dept. of Technical and Adult Education (DTAE), and in the area of compensation and benefits. *This is an education and information item only this session.*

Status: Due to the necessity of paying close attention to the budgets, this issue was not addressed. GCDD will talk to legislators about the issue over the summer, coinciding with the introduction of the Direct Support Worker Curriculum that will be in place in several DTAE campuses in July.

Support proposed registry legislation on behalf of the Brain and Spinal Injury Trust Fund (BSITF).

Status: HB 869, which threatened to amend the procedures for funding the BSITF was successfully amended and retained the procedures and percentages that currently fund BSITF. This bill passed the House and Senate. The Central Registry bill, SB 582, which would give the BSITF direct access to information on individuals with brain and spinal injuries, passed the Senate, and is assigned to the Healthcare Facilities

Subcommittee of the House Committee on Health and Human Services.

Other Legislation

There is other legislation of interest to people with disabilities that GCDD has been following. Below is a brief review of bills, resolutions and budget items whose final passage will affect the community.

Multi-year Funding Plan – This resolution supports developing a multi-year funding plan to create more Medicaid waivers for home- and community-based services for adults with disabilities. The plan should address Waiting Lists, which include over 4,500 people waiting for services. House Resolution 1307 passed after a unanimous vote. Its twin, Senate Resolution 784, awaits passage. The next step is to work with DCH and DHR to develop the plan and create an appropriations package for the Waiting Lists for next legislative year.

For the latest news and updates, visit www.gcdd.org, and check weekly issues of *Moving Forward*, the legislative newsletter. ●



Mothers & Babies Can't Wait

*Children With Special Needs
Program Provides Early
Intervention*

By Yao Atiim Seidu

Augusta parents Doug and Leslie Mann were at their wits' end. Just being the parents of quadruplets could have that effect on anyone.

Now, multiply their frustration and desperation with the news that not one, but all four of their toddlers have medical and developmental disabilities, including autism. The family became more vexed when they learned that state early intervention support is only available until the two-year-old quads celebrate their third birthday.

Families like the Manns are not unusual. Even today, parents who give birth to an infant with complex medical and developmental delays are often told "wait, pray and hope for the best."

For more than a decade, Georgia has had an alternative, an early intervention program for infants and toddlers – Babies Can't Wait (BCW).

BCW is a family-centered approach to identifying early intervention services for infants and toddlers with known disabilities or developmental delays. A multidisciplinary team, consisting of a service coordinator, parents and various professionals work together to develop a plan of action, the Individualized Family Service Plan (IFSP), and to identify the supports that are necessary to help the child reach his or her full potential. Services are funded through Medicaid, Peach Care, private insurance, personal family resources or BCW.

Experts know that BCW works through independent early childhood research that shows

effective early intervention can substantially reduce the need for specialized services later in life. For example, one study documents for every \$1 spent on early intervention, \$7 is saved on special education and related support systems.

Perhaps the greatest benefit of early intervention is that families increase their ability to interact successfully with their child. That knowledge and training results in children experiencing fuller, more meaningful lives with family and community.

Nygil Mann (not related to the Mann family in Augusta) is a two-and-a-half-year-old who has beaten all the medical odds against him and is today thriving in the BCW program.

Nygil was born nearly two-and-a-half months early with hydrocephalus, cerebral palsy, chronic lung disease and severe visual and hearing impairments. "Nygil wasn't supposed to survive, and if he did, they predicted he would be blind, unable to hear or speak and have severe mental retardation," his mother, Tameka Lipson, said. "They told me not to expect much from my son."

As a premature infant, Nygil's prognosis was a lifetime of immobility, dependency on supplemental oxygen and feeding and little more than existing in a vegetative state, his mother reflects.

"May I tell you that last week, for the first time, Nygil began independently drinking from a 'sippy cup'," his proud mother said.

Enrolled as an infant, Nygil and his family currently receive support from physical, occupational and speech therapists twice a week. He has made such advancements in mobility, speech and manual dexterity that his family can't recall a time without smiles, toys and learning devices.

"Nygil is just an unusual child; he's a real



Sloane Nguyen provides occupational therapy to toddler Nygil Mann who has been enrolled in the program since infancy.



Mary Perdue Has a "Special Love" for All Children

Georgia's First Lady Mary Perdue and speech therapist Joyce Chaney work with toddler Ashley "Chi-Chi" (2) who receives speech, occupational and physical therapy.

Georgia's First Lady Mary Perdue is perhaps the state's most visible and vocal advocate of children's issues that include Babies Can't Wait (BCW) and foster care for children with disabilities.

"I just really have a love for young children. Perhaps it's that special love and care I have for those who are overlooked (in foster care) or those who are considered not as lovable as others," the First Lady said. "I believe it's because I have something I can give them – unconditional love. Deep within me, no matter what a child looks like or how they act, or if they have a family like the rest of us, I feel they still need love and attention from the people

they care about and those who care for them."

Mrs. Perdue is a trained speech therapist who began her certification at the University of Georgia and graduated from Ohio State Univ. The former Georgia educator said most of her exposure to children with disabilities has been limited to her training in speech pathology. She recently attended a therapy session with Ashley and Nygil, two children in the BCW program.

"I went into speech pathology with the idea that I could and would be helping children who have disabilities," Perdue said. "Meeting Ashley and Nygil was special for me.

"Ashley gave me a big smile from the beginning; she is certainly very responsive," Perdue said. "She has a lot of work ahead of her

to reach her full potential, but those are just challenges and opportunities. I just think these children are a blessing, and I would encourage people not to shut their hearts just because they are not what we consider average.

"Nygil is fortunate to have such a supportive family. I enjoyed interacting with him and with meeting his mother, father and older sister," said Perdue. "With his support team and the kind of services he's receiving, Nygil's developmental delays will lessen significantly. That does make a difference."

Georgia's BCW Director Stephanie Moss agrees. "Our program is designed for therapists to work with the parents so they learn techniques, methods and procedures to help their child perform desired activities and tasks," Moss said. "The services and therapies we recommend are focused on giving families the support and skills they need to be there for their kids for the long-haul as lifelong advocates."

Nygil, Ashley, their therapists and families were impressed with the interest and relationship the First Lady has with disability.

"She looked me straight in the eye and said she understood what I was doing," occupational therapist Sloane Nguyen said. Joyce Chaney, a speech therapist said, "She referred to us as 'Sisters in the Profession;' that warmed my heart. You know she was successful in the classroom, as a foster parent and now with her special causes as First Lady."

Nygil's mother Tameka, a parent advocate, said, "I hope when she spends time with the governor, they talk about cuts in the program and how expansion will further reduce services."

Not mixing politics with her love for children, Perdue said, "When I look at people, children or adults, I see a person. I value them as a person. For me, their ability or disability is not most important. We all have disabilities to overcome in our lives. To me, what's important is the value of the person. We have to understand in society that there is value in every life, and everyone can make a contribution." ●

fighter," says his occupational therapist Sloane Nguyen. "He has shown tremendous improvement and achievement over two years primarily because he has this 'can-do' attitude." His mother agrees. "He's like many children his age: playful, affectionate, compassionate, aggressive and loves to meet strangers. He doesn't feel sorry for himself."

Nygil's success can be attributed to his strong family support says Georgia's First Lady Mary Perdue, who met Nygil's dad, Carlos, mom, and sister, Nydia, last month.

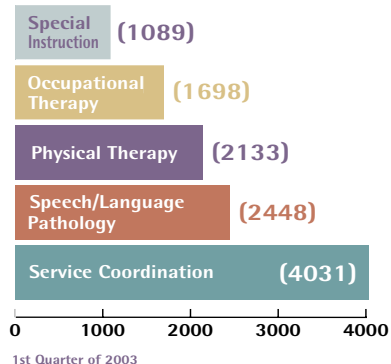
"I was impressed with their closeness and how well they communicated with each other," Mrs. Perdue, a former speech pathologist said. "Nygil is

going to do just fine. I think he has a bright future considering the family's close working relationship with therapists and their commitment to him."

Ashley "Chi-Chi" (last name withheld as she is a ward of the state) also receives physical, speech and occupational therapy at home twice weekly.

"Chi-Chi," a Mexican-American, was abandoned by her mother within 48 hours of birth. She has spina bida, chromosome seven deletion (hands on backward with no bones in the hand), atopic kidneys (one organ is in her upper

Most Commonly Accessed Services



Babies Can't Wait FAQ

What's new?

- About 6,000 to 8,000 more children in Georgia will be screened as a result of CAPTA.
- BCW will establish better relationships with physician and DFCS offices to improve referrals.
- BCW will provide increased referral training to the Georgia Chapters of Family Practitioners and the American Academy of Pediatrics on early identification and early intervention of children with delays in development or special needs.



Who is eligible?

Any child from birth to three years old who is high risk or is experiencing significant delays in one or more of the following areas of development: physical, cognitive, communication, social/emotional or adaptive, or has been diagnosed with a mental or physical condition that will have a high probability of resulting in significant delay. *There are no income eligibility requirements.*

How do children enter the program?

- BCW personnel conduct an initial intake visit with parents and family members.
- A team evaluation is performed by people representing at least two of the following: early childhood education, occupational therapy, physical therapy, speech/language or nursing.
- The team will discuss the results with the family and determine if the child is eligible.

How do I contact the program?

- Visit your local county health department
- Call the state Babies Can't Wait office, 404-657-2726 or toll free, 888-651-8224, or on the Web, <http://health.state.ga.us/programs/bcwl/>

(Pictured above) Mary Perdue with Nygil Mann (center), his family and therapist Sloane Nguyen.

chest) and is unable to swallow.

Evola Allen, 73, has provided foster care to Ashley since she was released from the hospital. The former pediatric medical technician has cared for nearly 60 foster children and has a long-term agreement with the Department of Family and Children Services (DFCS) to care for Ashley until she becomes an adult.

"The therapists really make a difference in her life. We are able to go places today that we never dreamed possible," Allen says.

The BCW program also provides families with ongoing evaluations. Each family's service coordinator works to support the family into the

state's educational system or other early childhood settings, such as Head Start, private preschool, private therapies, or child care, as the child nears his or her third birthday to ensure a continuum of services. After the age of three and through age 21, services and supports are provided through the Department of Education.

The majority of children in BCW are referred by their parents. Physicians and medical personnel are the second leading referral source, but that is soon to change.

In June 2003, Congress passed the Child Abuse Prevention and Treatment Act (CAPTA), requiring every child under three who has a substantiated case of abuse or neglect to be referred to early intervention. That mandate called for implementation within 12 months. In Georgia, that means that BCW will be working to screen up to 8,000 children who will be referred to the program and may be eligible for early intervention supports and services.

"It's always a challenge locating kids who are not being served," explained Stephanie Moss, state director of BCW. "Our program is going to expand even more rapidly as we implement CAPTA."

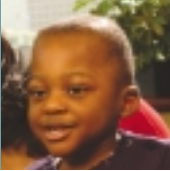
Currently, BCW serves 1.35 percent of all infants in the state. Nationally, the objective is 2.11 percent. With federal mandates to screen and add more

children, and state coffers stretched to the limit and now constricting, BCW officials are bracing themselves for changes in the program. One new procedure is the requirement of "prior authorization from the Georgia Medical Care Foundation" for Medicaid and Peach Care children who receive the highest level of service.

"That's bound to have a devastating effect on some children and their families," says Nguyen. "With more children in the program, more infants and toddlers are going to go without services or will experience a reduced level of services."

Easter Seals, along with other BCW providers statewide, indicate a growing deficit in trained and experienced therapists to accommodate an expanded program.

For every \$1 spent on early intervention, \$7 is saved on special education and related support systems.



Georgia's First Lady Mary Perdue was impressed with the closeness between Nygil Mann and his therapist in the BCW program, Sloane Nguyen.

"It takes at least five years of education, training, a national certification and state license," Nguyen says, describing typical therapists. "I fear that we are not going to be able to provide the necessary therapy children and their families need and have grown accustomed to. That's going to result in children not making the progress we know is possible without adequate funding."

Still, officials have redoubled their efforts to attract more children to the program, performing more with less.

The BCW program, operating under Part C of the Individuals with Disabilities Education Act, identifies more than 16 services that are to be made available to children and families if a multidisciplinary team determines they are necessary to address goals and outcomes on IFSPs. The most frequently utilized and accessed services are provided by speech, occupational and physical

Perhaps the greatest benefit of early intervention is that families increase their ability to interact successfully with their child.

therapists along with special instruction.

A larger program in the state will mean more eligible and enrolled infants and toddlers, therapists, administrators and support staff.

"We are not there yet, but we are growing, improving," Moss said. In 2000/01, BCW was serving less than one percent (0.98) of the state's population, as reported to the U.S. Office of Special Education Programs. "Based on

the 2000 census, we should be serving about 7,000 children," she said. "We are at about 5,000 now, but just two years ago we were at 3,500. We have to make the referral process more of a priority at the district health level."

Joyce Chaney, a speech language pathologist, works with occupational and physical therapists to provide services to infants and toddlers in their natural environments with love, care and attention.

"It's a humbling experience to provide services to children who have special needs. You see that they are so talented and aware of their circumstances and situation. Where they don't have normal functions, abilities and talents, the Lord gives them other capabilities that we can harness to help make them more successful at home, in school and later in their private lives," Chaney said. "Without Babies Can't Wait, many of these children would be in state institutions or at home, receiving no therapies, help or assistance."

Some children have problems eating, swallowing, sitting up and even allowing their teeth to be brushed.

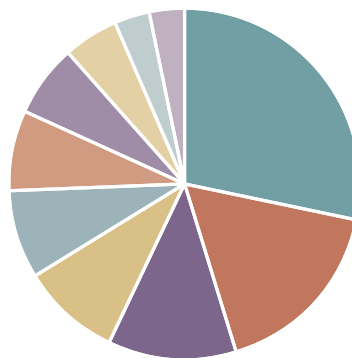
Through early intervention, a speech therapist may be able to transition an infant from gagging and babbling to forming simple oral motor movements that are essential for rudimentary speech.

"One of the many wonderful things that has happened with the Babies Can't Wait program is that we can now identify problems and get children help when it's most beneficial to them," explained Keith Fields, a BCW service provider in Dublin, GA.

Fields says another major difference in early intervention for infants and toddlers can be found in socialization.

"If a child has significant delays, they are going to see speech, occupational and physical therapists each week. Those are adult contacts outside of the family," he said. "That has to promote socialization, with advances and treatment that weren't available just a short time ago." ●

10 Most Commonly Served Diagnoses



- Down Syndrome (340)
- Seizure Disorder (204)
- Cerebral Palsy (142)
- IVH Grade III or IV (110)
- Hydrocephalus (98)
- Microcephaly (89)
- Severe Hearing Impairment (80)
- Autism/PDD (61)
- PVL (39)
- Dandy Walker (39)

1st Quarter of 2003

IV - Intraventricular Hemorrhage

PVL - Periventricular Leukomalacia

PDD - Pervasive Developmental Disorder

The Search for “Best Practices” Is Global

By Gordon O'Neill

The Governor's Council on Developmental Disabilities' (GCDD) search for “best practices” will be focused on China in June as the China - U.S. Conference on Educating Students with Special Needs takes the world stage in Beijing.

The conference hopes to expand understanding among American and Chinese counterparts who deal with government policy, technology and the professional practices and standards for people who care for and educate students with special needs.

The conference is a forum for the exchange of “best practices,” and two people involved in the GCDD are particularly interested in the outcome.

GCDD Public Policy Director Patricia D. Nobbie, D.P.A., serves on the conference's steering committee, and Licheng Tian, M.D., Ph.D., a GCDD council member, moved from China in 1985. He hopes

for great things from the conference.

“At the time I left, China was still quite far behind - they had some schools for children with disabilities, but it was not standard, and they were not in every province and city yet - there is much to do there.

“The United States has better resources, especially for people with disabilities. China is a poor country and cannot compete,” Dr. Tian said. “In China, people with disabilities still hide in their homes, and families are shamed - thinking they did something wrong. This will change gradually.

“China provides special education and special care but are still far behind - they are opening their eyes through exchange programs and conferences with the United States and other countries,” Dr. Tian points out. “The United States is the richest country in the world and should continue

moving people with disabilities into the community where they can have close to a normal life.”

In the search for “best practices,” Dr. Nobbie said, “I am going with my eyes wide open. I don't know what to expect, as policy is quite different in China. It will be interesting to see how they have addressed disability issues over there.

“I am really excited about going and hope that a longstanding relationship with China will be developed between the disability communities,” she said.

“As I understand it, China has a lot of inclusion in education but no special curriculum or instructional support for those with disabilities,” Dr. Nobbie said. “We will visit a number of Chinese schools and institutions - I have a lot of questions.”

But, based on Dr. Nobbie's research, it appears China is on the move and getting ready for the Olympics. “China is really thinking about disability and accessibility issues. It seems China opened up after the women's conference that included a lot of people with disabilities from around the world.”

Dr. Nobbie believes that China has a strong sense of family and community and not a lot of state supported help. “China puts more of their people with disabilities to work because everyone is expected to contribute.” And with the emphasis on community-based jobs in the U.S., a great deal could be learned from the Chinese approach.

Although Dr. Tian is unable to attend this year's conference, he hopes Dr. Nobbie's attendance will allow him to develop contacts in China and that he will somehow be able to help China better serve their disability community.



Global Interactions is coordinating the conference that will explore special education options for Chinese and American children.

“The United States is the richest country in the world and should continue moving people with disabilities into the community where they can have close to a normal life.”

June 2004 – China - U.S. Conference on Educating Students with Special Needs takes the World Stage in Beijing.



When comparing China to the United States, Dr. Tian noted that many states are different. He came to Georgia after living in New York and Minnesota, and he said, “New York is better, much better, and Minnesota has progressed much further in improving life for people with disabilities. They moved most of their people with disabilities into the community.”

The United States has the most progressive public policy on people with disabilities because of Civil Rights laws and regulations, but as Dr. Tian noted, “How these laws and regulations are implemented from state to state is another question.”

China is faced with the same daunting task, administering disability policy in a huge country, and the Chinese are interested to see how the U.S. implements its programs across the country. There are other issues to be studied, as Dr. Nobbie pointed out, “China has a ‘one-child’ policy,” and she wonders how this impacts public policy for those with disabilities in China.

The conference is just one part of an ongoing exchange program between China and the United States, and there was a similar conference on disabilities in 1988.

The conference offers three days dedicated to the presentation of papers on topics expected to include professional development and standards, technology, early childhood development, public policy and law and integration into the community. Speakers from both countries will address each topic and, in the end, conference participants hope to improve understanding between the two countries and serve as the impetus of real change – on both sides of the ocean.

Twenty-six organizations are co-sponsoring the conference including the Council for Exceptional Children, National Association of Councils on Developmental Disabilities and a wider variety of state, regional, disability and education-related associations and councils.

The conference is an interactive learning experience, and each participant will play a role in the dialogue as they work to clarify differences and

Doctor Treats Patients with Profound Disabilities

As part of the “best practices” movement in Georgia, Dr. Licheng Tian and the East Central Regional Hospital in Augusta are moving more and more people who have been institutionalized into community-based homes.

“For many years, we have put them into those institutions; we now know it is better to put people with disabilities in the community – so they can be part of the community with close relationships with family and friends.

“We now have eight houses, each serving four clients,” Tian said. “It is the first step; we have not done so on a large scale, but we are hoping to expand.”

Currently Dr. Tian works with 500 to 600 clients who have severe or profound disabilities, and many have been “institutionalized” for as many as 40 to 50 years. In addition to cognitive disabilities, his patients and clients have medical problems and most are unable to speak.

“They require a lot of care, and

because they cannot talk, the entire staff must watch each client closely to monitor their health – to see if they look sick, weak or have pain,” Dr. Tian explained.

While he regularly treats people with disabilities, Dr. Tian also has a personal connection with the disability community – his son has autism.

Dr. Tian’s vast professional and personal experience with people with disabilities makes him uniquely qualified to communicate with and treat people with profound disabilities.

For example, if a patient becomes angry or has behavior problems, Dr. Tian might determine a medical problem is causing the patient discomfort or pain and triggering tantrums or seizures.

Serving as an internist for those with disabilities requires the special sensitivity of Dr. Tian who notices subtle changes in his patients’ bodies and routinely screens them for new medical problems.

(Pictured above) Dr. Licheng Tian with a patient at the State Hospital at Gracewood.

similarities while broadening their individual perspectives.

As Dr. Nobbie said, “There is a lot to be learned from both sides.” But the biggest ray of hope is that Chinese and American counterparts can carry on conversations and even visit each other to sustain the momentum of the conference and improve the lives of people with disabilities around the world. ●

Summer Camps for All Kids



Finding the right summer camp for a child can be difficult for every parent, and when a child has a disability, the task becomes even harder. A wide variety of camps are available in Georgia for children with disabilities, from inclusive to those specifically for medically fragile campers.

Lucy Cusick, Executive Director for FOCUS GA, suggests parents consider several criteria when searching for the right camp for their child. "There are several questions I ask when I'm looking for a camp: What is the ratio of adults to campers? Do youths assist with the camp? Is toileting and/or feeding assistance available? Does the camp have a lot of outdoor activities that might exclude my child?"

The importance of these characteristics will depend on each child's abilities and medical needs, and there are several camp options available for children who are medically fragile or have developmental disabilities, from day programs to overnight camps.

Although many parents are reluctant to send their children to overnight camp, it provides campers with disabilities the opportunity to learn to live in harmony with others and fosters independence – a primary long term goal – while also providing respite for the family.

Camp Hollywood

*A Week-Long Day Camp,
Several Metro Atlanta Locations
(medically fragile)*

For children who are medically fragile and their siblings, Camp Hollywood is a day camp in the metro Atlanta area that is hosted by Families of Children Under Stress (FOCUS). "Camp Hollywood is fun, and the kids love it. Each day is themed after a children's movie

from that year. For example, this summer we'll have a day themed after Spy Kids, and the children will do activities with a spy theme," Cusick said.

The camp features five activities each day, including cooking, art, recreational movement, music and science. "Our camp is based on indoor activities, and there's not a lot of moving around," Cusick explained. "We have a nurse at all locations and provide toileting assistance for those who need it."

The camp usually accepts 32 campers at each location. The campers are divided into four groups of eight, according to their ages. "The children with disabilities and their siblings aren't necessarily in the same group, unless they request it," Cusick said. "Usually about 90% of the kids have disabilities, and 10% don't."

Each group has two adults, providing a one to four ratio of adults to campers. "This is the tenth year of our camp, and we have a great reputation for care," Cusick said. Camps are held for one week throughout the summer at various locations in metro Atlanta. "We try to keep the price low, about \$125 per week," she said.

For more information about Camp Hollywood, visit www.focus-ga.com or call 770-234-9111.

Finding the Right Camp

A wide variety of camps are available for children with disabilities. To find a camp suited to your child's abilities, consult these valuable resources:

Atlanta Parent Magazine Camp Listing
www.atlantaparent.com/campexpo.html

Georgia Learning Resource System
www.glr.org or 404-657-9958

Children's Camp Web Site
<http://KidsCamps.com>



One of Camp Twin Lake's newest activities is its completely wheelchair accessible putt putt golf course, which is the only known course of its kind in the country.



Camp Barney Medintz

A Month-Long Residence Camp, Cleveland, GA (inclusive)

Camp Barney Medintz offers children with disabilities the opportunity to go to overnight camp with children who do not have disabilities. "This is a hybrid program," explained Camp Director Jim Mittenthal.

Those who participate in the Chalutzim program for children with disabilities are grouped together, but still have many opportunities to interact with children with no disabilities. "They live in the same village with other kids, they eat with other kids, and they're on stage in front of 600 other campers for our weekly talent show," Mittenthal said.

Grouping the Chalutzim campers together allows a nearly two to one camper to staff ratio and allows the staff to tailor activities to the group's needs. Campers choose from a variety of activities including horseback riding, boating, backpacking, swimming and much more.

Because the camp lasts for a month, all campers must be somewhat independent from their families, Mittenthal said. "We would expect them to have the ability to manage their hygiene, maintain their possessions, follow instructions from adults and seek help if they need assistance."

Like campers without disabilities, as Chalutzim campers grow older, they have the opportunity to participate in an apprenticeship program that allows them to help the staff and give back to the camp community. In addition, some former Chalutzim campers are now staff. "They work in the office, the kitchen and dining hall, the camp store and the infirmary. Some work in program areas," Mittenthal revealed.

While Camp Barney Medintz is a culturally Jewish camp sponsored by the Marcus Jewish Community Center of Atlanta, children of all faiths

and from all over the country are welcome. For more information, visit www.campbarney.org or call Jim Mittenthal at 770-395-2545.

Camp Twin Lakes

A Week-Long Overnight Camp, Rutledge, GA (brain injuries)

Camp Twin Lakes was specifically designed to serve children with medical conditions, such as cancer, HIV or brain injuries. "Our camp is special and unique to this area. Not many camps have these facilities," explained Executive Director Larry Melnick.

Built on flat ground, with buildings that are close together, Camp Twin Lakes also has a medical director and a counselor-to-camper ratio of either one to one or one to two, depending on the child's needs. The camp can accommodate up to 330 children and provides toileting and feeding assistance when necessary.

"We try to offer all the activities of camps for children without a medical condition, such as arts and crafts, tennis, horseback riding, swimming, biking, boating, nature programs and more," Melnick said. "The camp gives children with brain injuries the opportunity to try things they wouldn't ordinarily do.

"We had one child here last year who couldn't walk in a straight line, but completed our high ropes course," he said. "The camp allows parents to see that their children can participate in activities on their own."

Two sessions for children with brain injuries are scheduled for this summer, including Camp TBI (To Be Independent), sponsored by Walton Rehabilitation Hospital in Augusta, and Camp Hardgrove, sponsored by the Brain Injury Resource Foundation in Atlanta. For information on Camp TBI, call 706-724-7746 or visit www.wrh.com. For information on Camp Hardgrove, call 678-937-1555 or visit www.birf.info. ●

Snapshots from Summer Camps: Campers enjoy a popular waterslide at Camp Twin Lakes, which hosts the Brain Injury Resource Foundation's Camp Hardgrove; Camp Barney Medintz (center) allows campers with disabilities to share activities with children without disabilities; and themed indoor activities are the focus of Camp Hollywood.



Monitoring the Progress of Students with Disabilities Essential to Academic Achievement

By Representative Johnny Isakson

Two years ago, the President signed the No Child Left Behind Act (NCLB) into law, a historic piece of legislation with the goal of ensuring that every single child in this country receives a quality education. The law has given unprecedented flexibility to states and local school districts, allowing them to target funds and resources to meet the needs of their students and teachers.

At the same time, the law requires states to establish their own tests to measure how successfully students are learning. Through

made available to the families of students with special needs and offers supplemental services for students who are not making progress. The families of students receiving special education have high expectations for their children. They want them to graduate from high school and go on to find gainful employment or participate in post-secondary education. It is vital that our schools have the same expectations and measure each student's progress toward these goals.

There is no doubt that for some students "proficiency" looks much different than it does for other students. The law recognizes this fact and the Department of Education is constantly working with states and local school districts to ensure that the goals of NCLB are in line with the day-to-day realities of the classroom.

In December, the Department released a new provision that allows schools to assess students with the most significant cognitive disabilities with an alternate test that is appropriate to their intellectual development. This allows states to more accurately gauge the progress of these special needs students.

The new provision is a great example of how we can use the law's flexibility to not only realign policies with the practical implications of the classroom, but also increase the academic achievement of students with special needs, including those with the most significant challenges.

As Chairman of the State Board of Education, I learned firsthand that the most important thing we can do for our children is give teachers the freedom to teach, principals the freedom to lead and superintendents the flexibility to make changes that suit the needs of their schools. No Child Left Behind gives the responsibility for excellence in education back to the local level. All that the law asks is that we measure our progress and work to better respond to the needs of every child. Together, I am confident we can accomplish this goal. ●



Representative Johnny Isakson

(R) represents Georgia's Sixth District in the U.S. House of Representatives. He serves on the House Education & Workforce Committee and was one of the original authors of the No Child Left Behind Act. Before being elected to Congress, Isakson served as Chairman of the State Board of Education under then-Governor Zell Miller.

disaggregation of the test results, schools are also required to show progress in the academic proficiency of certain subgroups of their student population, such as minority students, English-learners and special education students. I believe the accountability provisions in NCLB are a critical component of the law and are based on the worth and intelligence of every child, including those with disabilities.

In public education, too many students with special needs have been subject to what President Bush calls "the soft bigotry of low expectations." These students are often passed along from grade to grade with no true assessment of what and how they are learning. For the first time, NCLB requires the academic progress of every single child to be measured.

The law also requires that the test results be





Children with Disabilities May be Hurt by Standardized Testing

By Jennifer L. Stapel, Psy.D.

Standardized testing may not be the best way to measure the effectiveness of a school in educating children. Among numerous issues related to standardized testing for all, specific concerns for children with disabilities include: fair access, the purpose the test results serve and accountability.

Despite inclusion, children with disabilities often do not have equal access to the curriculum on which a test is based. They also do not have equal access to the test. While numerous, the accommodations and modifications allowed are insufficient. For example, a test may tell us that a child cannot read. However, it does not tell us the same child understands and utilizes the information appropriately when the content is read or signed to him or her. Some children do not read well enough to answer grade level comprehension questions but could answer if given the content in a way not allowed under the acceptable accommodations for the test.

From an individual child viewpoint, standardized information that conveys how a child compares with same age peers is likely already available, and hopefully an effective IEP has been written. From a policy point of view, the standardized testing of a child who has been identified, and has an educational plan, is redundant and potentially hurtful to the child, school and community depending on how testing information is interpreted and used.

The advent of the No Child Left Behind Act (NCLB) has demanded the educational system devise a standardized testing program to measure progress and create accountability for schools. However, the tests being used are less than perfect. Many children score lower on standardized tests for reasons unrelated to their ability. In addition, tests may not be adequately normed for all children. Finally tests may not be measuring the same thing in all groups. We do not have all this information, and yet the consequences for the individual and collective educational systems are significant.

Children with disabilities should be evaluated in a way that is meaningful to their personal

educational outcomes and to the effectiveness of the educational system. Parents, teachers, clinicians and legislators want to see that public education systems are accountable for the education of all children. But accountability can't be achieved with an imperfect system that is unlikely to take account of the interplay of complex dimensions. How do we apply a standard without truly understanding the impact of disabilities on a child's ability to: (a) understand the test content and respond to it with an equal chance as any other child; (b) complete the test in its prescribed length and with specific



Dr. Jennifer L. Stapel

is Director of the Marcus Evaluation Project at the Marcus Institute, an affiliate of the Kennedy Krieger Institute at Emory University and Asst. Professor at Argosy University-Atlanta. She is a licensed pediatric psychologist with a specialty in neurodevelopment and assessment, whose areas of interest include children and adolescents with developmental disabilities.

demands for writing, reading or math; and, (c) access their way of learning?

The current testing system is meant to identify schools that are in danger. However, this type of standardized testing is blind to differences in how children learn. Applying this test data to inform a course of action is ill-founded. This data is often irrelevant to improving the performance of students as a whole and to improving the performance of students with disabilities.

IEPs and evaluations tell us more about children with disabilities than any current test. The testing system propagated by NCLB does not help children, potentially robs them of the attention and energy needed to learn and does not even provide an accountability standard that we can feel good about.

The question we need to ask is: should ANY child have to undergo this type of testing? ●

Putting a Premium on The Katie Beckett Waiver

A passionate outcry from parents prevented a proposed premium on Medicaid's Katie Beckett Waiver for Georgia's 2004 supplemental budget and 2005 budget.

The Department of Community Health (DCH) proposed the cost-sharing requirement on the waiver, also known as the Deeming Waiver, in response to Governor Sonny Perdue's call for a five percent decrease in every state agency budget.

The Katie Beckett Waiver allows families with children who have long term chronic medical conditions and disabilities to receive Medicaid funds to pay for services and supports not covered

by typical insurance. These families would not normally qualify for Medicaid assistance because they make too much money to receive Supplemental Security Income (SSI). The DCH proposal would have required each family receiving the waiver to pay a monthly premium toward the cost of the waiver, similar to the fee for private insurance.

Georgia's House of Representatives passed the supplemental 2004 state budget, with the proposed premiums included, February 17, but the Senate removed the premium proposal from the 2004 budget February 26. Both

Houses recommended restoring funding to the DCH to support the waiver in the 2005 budget in March. The final budget had not been approved as of press time.

Premiums were to be based on the parents' total income, according to their most recent federal income tax return and ranged from \$21 per month to \$458 per month. A \$600 per child deduction would have been allowed, and families with more

than one child receiving the waiver would have paid only one premium.

The Georgia Governor's Council on Developmental Disabilities (GCDD) advocated against the premium to allow those receiving the waiver to work with the DCH to come to a solution that meets everyone's needs.

Patricia Nobbie, D.P.A., Public Policy Director for GCDD, voiced three main concerns with the premium concept. "A child's Medicaid coverage could be terminated if the premium isn't paid; there is no variance for undue hardship; and, it could be terminated if the primary insurance lapses."

Julie Beckett, whose daughter, Katie, was the first waiver recipient in the country, said, "These families take on an incredible amount of work because they love their kids. Having these children home allows them to participate in their communities, and saves states the expense of hospitalizing or institutionalizing them."

GCDD held press conferences around the state to raise awareness of the issue in Atlanta, Athens, Columbus, Dublin and Savannah. In addition, Dr. Nobbie and about 20 parents attended the February 11 board meeting of DCH to voice their concerns about the proposed premium.

Many of the parents had similar stories; though

"Having these children home allows them to participate in their communities, and saves states the expense of hospitalizing or institutionalizing them."

Advocates Statewide Fight Proposed Premium on Waiver



Mary Beth Morris (above) and Phillip Riley (right) explain to the DCH board how the premium would affect their families.





“The (disability community) has one of the most heartfelt and strongest lobbies at the Capitol. It’s an important message to bring”

their income seemed high on paper, some of them were spending up to \$11,000 a year on non-covered supplies and supports such as special diet needs,

diapers, speech and other therapies and more. Most reported driving cars that were more than five years old, only buying clothes at second hand stores or discount stores, living paycheck to paycheck and not being able to afford to go to the movies, out to dinner or on vacation.

Phillip Riley, the father of a seven-year-old girl with autism said, “Emma doesn’t hurt herself any more, and she is more self-sufficient thanks to her therapies. I won’t be able to afford those therapies any more if I have to pay this premium.”

Members of the volunteer DCH board were sympathetic to the parents, but because they had already sent the recommendation to the governor, felt they could not withdraw the proposal and voted to proceed with it. Chairman Carol Fullerton suggested parents lobby their legislators to have the proposal removed from the budget.

Dr. Nobbie and many of the families who had attended the DCH meeting subsequently met with several state legislators, including Rep. Jay Shaw (D-Lakeland), the Chair of the House Subcommittee on Appropriations for Community Health.

The group also spoke with Senator Jack Hill (R-Reidville) who is the Chairman of the Senate Appropriations Committee. Sen. Hill expressed his support for removing the premiums from the budget. He had heard from many families and GCDD about the impact the fee would have.

Senator Tommie Williams (R-Lyons) said, “I got more emails on the Katie Beckett issue than any other this session. The (disability community) has one of the most heartfelt and strongest lobbies at the Capitol. It’s an important message to bring.” ●

Evans Worry Premium Will Strain Family Finances

Gene and Cindy Evans have three children: Wesley, Jessica and David, who has Down syndrome. Currently they receive financial assistance for David’s therapies through Medicaid’s Katie Beckett Waiver, also known as the Deeming Waiver.

David, who is 26 months old, receives physical, speech and occupational therapy at an estimated cost of \$1,000 a week, and the Evans rely on the waiver to cover what their own private insurance does not cover. Thanks to these therapies, David is progressing well, and the Evans hope he’ll be walking in four to six months.

tion. He also receives his occupational therapy there,” Mrs. Evans said.

In addition, the Evans are still paying for diapers and don’t expect David to be toilet trained until he’s at least four years old. They are living paycheck to paycheck, and Mrs. Evans, who used to work part time and as a substitute teacher, can no longer work due to David’s extraordinary needs.

“I don’t want to cut our budget by taking away things from our other kids. Jessica wants to take gymnastics, and Wesley wants to play piano and take soccer,” Mrs. Evans said. “If we have to start paying \$125 a month for a premium, we may have to do that,” Gene Evans said. “This premium is adding financial stress to the emotional stress families are already facing.”

The Evans feel there are better ways to cut from the DCH budget than charging a premium. “Every year we have to re-file for the Katie Beckett Waiver. David has Down syndrome, and he is always going to have developmental delays. The state could save a lot of money if they didn’t have to process that paperwork every year,” Mrs. Evans said.

The Evans are concerned that children whose families cannot afford the premium may end up in institutions. “It’s ironic. The bottom line is that the cost to the government for the children to be at home is much less expensive than the cost of putting them in an institution,” Mr. Evans said.

“We pay state tax, and now we’re being asked to pay the state again because we have a child with a disability. I feel like we’re being discriminated against,” Mrs. Evans said. ●



The Evans children: Jessica (8), David (2), Wesley (9 1/2).

“I don’t know where he’d be without his therapies,” Cindy Evans said. “If we hadn’t had the therapists, I wouldn’t have known what exercises he should do to help his low muscle tone (hypotonia).”

The Evans have incurred other costs not covered by insurance or the waiver to pay for David’s care. “David goes to Therapy Works that brings together children with and without disabilities to help with his socializa-

Julie Beckett: Advocating for All Children

While Katie Beckett was born three months prematurely in 1978, she was in better shape than her mother Julie after the birth. “I had toxemia and kidney failure, and the doctors had to do an emergency C-section, but Katie was pretty healthy,” Julie Beckett revealed.

After a couple of months, Katie came home from the hospital healthy and weighing in at five pounds. She continued to thrive until four months later when her doctor suspected she had contracted encephalitis and admitted her to the hospital.



Julie Beckett explains to State Senator David Adelman and the committee what her life was like before the waiver.

The next day, Katie had a grand mal seizure while drinking water from a bottle. As a result she aspirated some of the water, resulting in respiratory distress. Later that afternoon, she had a second grand mal seizure, lapsed into a coma, and stopped breathing.

Three weeks later she woke up completely paralyzed except for her face, and Katie would spend two and a half more years in the hospital, slowly improving.

“It was very stressful at first, but it became routine. We celebrated birthdays, Thanksgivings and Christmases in Katie’s room,” Beckett said. “She would get sick every few weeks from being in the hospital and being around all the germs, though.”

Katie eventually was able to move, and when she was two she started to breathe on her own, though she was still dependent on her ventilator for part of the day. “By her third birthday, she was getting stronger, and we

could take her outside and take her home for short periods of time, then she’d have to come back to the hospital to get on the ventilator,” Beckett said.

During the time Katie was in the hospital, she had reached her insurance cap of \$1 million dollars, so Medicaid took over the cost of her hospital care. In 1981, after she was able to breathe on her own for some of the day, Beckett, and her husband, Mark, wanted to bring Katie, and her ventilator, home.

“At that time, Medicaid would not pay for home care. They would pay \$15,000 - \$18,000 per month to keep Katie in the hospital, but would not pay the \$3,000 a month it would take to pay for the supplies and medication she needed at home,” Beckett said.

Beckett determined she could apply for an exception to this rule, although exceptions had never been granted, and contacted her congressman Tom Tauke (R-Iowa), who assigned one of his staff members to collect information about home care options to support her case. Unfortunately, her application for exception was rejected.

But Beckett had found a powerful ally in Tauke. Shortly after the rejection, he was on a plane with then-Vice President George H.W. Bush. “He told Vice President Bush about Katie’s situation and how having her home would help her have a more normal life while also saving the government money. Bush went back to Washington, talked to President Reagan about Katie, and less than a week later Katie was released from the hospital.”

Having Katie home was just the beginning for Beckett, who had been teaching high school history. “During the Reagan and Bush years, I worked with a group who was trying to get other kids home. States were hesitant to start waiver programs at first, until we showed them how the families could get what they needed while saving the states money,” Beckett said.

Because Katie was brought home and not hospitalized for over 90 days, Beckett was able to have Katie’s insurance reinstated, as well, saving her state even more.

In 1984 Beckett went to work for the University of Iowa. “The Katie Beckett Waiver was like a best kept secret. Through the university, I let families know

“The Katie Beckett Waiver was like a best kept secret. Through the university, I let families know how they could get their kids home.”



Dawn Shepherd testifies at the DCH meeting.

Funds Would Be Stretched Even Thinner for Shepherd Family

Dawn Shepherd resigned from a good paying job with BellSouth to take care of her son Garrison, who is two and has cerebral palsy. Shepherd, who lives in Marietta didn't have the time to commute to Buckhead and still keep Garrison's many doctor and therapy appointments.

In addition to cerebral palsy, Garrison has a seizure disorder and sensory problems that cause him to be frightened of movement, light and noise. "Just riding in the car would make him scream with terror," Shepherd said.

As a child with high muscle tone (hypertonia), Garrison's screaming made him burn a lot of calories, causing him to lose weight.

With help from his occupational therapist, Garrison is able to ride a little more comfortably in the car and can take a bath

without screaming. He sees each speech, occupational and physical therapist two times per week, and they are not covered by the Shepherd's private insurance.

"The Katie Beckett Waiver covers all his therapies," Shepherd said.

Garrison needs other supplies that are not covered by insurance or Medicaid that Dawn, and her husband Greg Shepherd, pay out of their own pockets, such as a hearing aid, weight gain powders, PediaSure, flavored dental exam gloves, dental swabs to teach Garrison how to chew, diapers and more.

"His therapist recommends certain toys for him that are available on loan through the Babies Can't Wait library, but they are often not there when we need them, so we buy them," Shepherd said.

Even without the premium, expenses are

really starting to add up for the Shepherds. "We have to build a house that is more accessible for Garrison, and we had to buy a special van," she said.

Shepherd said she and her husband are struggling with emotional and financial stress due to Garrison's extraordinary needs. "Greg works an average of 85 hours per week trying to keep us up financially. He stays perpetually behind and under pressure, and his blood pressure has shot up to stroke level," she said. "Our life has been turned upside down."

Shepherd firmly believes the state should find other ways to increase revenues instead of charging a premium on the Katie Beckett waiver. "Cuts can be made in areas where there is less pain and heartache than the area these families of special needs children dwell." ●

how they could get their kids home. I also urged health care providers to encourage families to participate in their children's health care so they could eventually bring them home."

"Now people who are medically fragile, have developmental disabilities or who are elderly can live at home and be happy, healthy . . ."

Now, Beckett is the National Policy Director for Family Voices, a group that advocates for family-centered, community-based care, as well as promoting respite and family support.

Katie, who is now 25, has graduated from college with a degree in English and creative writing, and is planning for a career in journalism. "Katie lives in her own apartment and is healthy now," Beckett said. "She's making her own footsteps, serving on a Senate advisory panel about getting people with disabilities to work."

Beckett is glad her fight to bring Katie home has positively affected others. "Now people who are medically fragile, have developmental disabilities or who are elderly can live at home and be happy, healthy and accepted by the community," she concluded. ●



Julie Beckett meets with Georgia State Legislators and GCDD to discuss disability issues. (Pictured from left to right) GCDD Chairperson Lynette Bragg; State Senator David Adelman (D-Decatur); State Representative Sally Harrell (D-Atlanta) and her daughter Salena; State Senator Don Thomas (R-Dalton); Julie Beckett and GCDD Executive Director Eric Jacobson.

Making the Most of the IEP Meeting

By Ijeoma Ajoku, Stacey Ramirez and Judith Steuber, Special Education Parent Mentors

Cobb's School District is only one of the counties teaming up with the Georgia Department of Education's (DOE) statewide Special Education Parent Mentor Network. In this program, parents of children with disabilities are employed by local school systems as mentors. Because of their personal experiences, they understand the issues that arise when navigating the special education process. The goal of the program is to nurture communication among parents, educators and community agencies, ultimately leading to greater success for students with disabilities.

Parent Mentors Help Navigate IEP Process

workshops to explain the procedure and assist parents in the preparation for the IEP meeting. To find out which Georgia counties participate in the Special Education Parent Mentor Network, call the DOE's Division for Exceptional Students at 404-656-3963 or visit www.parentmentors.org.

An integral part of student success is parental understanding of the IEP process. Parent Mentors conduct



Parent Mentor Stacey Ramirez, Parent Liaison Judy Harvey, Parent Mentor Judith Steuber, Special Ed Director Rhonda Thompson, and Parent Mentor Ijeoma Ajoku

About the Authors

Ijeoma Ajoku is the mother of three children, one of whom has Asperger's Syndrome. Her goal as a mentor is to reach out to economically disadvantaged families to increase awareness of special education services. BA in Business Administration; diploma in Information Systems

Stacey Ramirez volunteers for her children's teachers and the PTA's Exceptional Children Committee. Her third grader has mild to moderate autism and is doing well in a partial inclusion setting. Her kindergartner has an expressive speech delay. BS in Secondary Education/Chemistry

Judith Steuber joined the Parent Mentor program after a career in health insurance management. She has two boys with moderate to severe autism. Judith's goal is to help students and parents understand and prepare for pre-school through post-secondary transitions.

Tips from Special Education Parent Mentors



Individualized Education Program (IEP) meetings give parents and educators a chance to work together to design a customized learning plan for children with disabilities who are eligible for special education. The goals and objectives, or benchmarks, are the core of the IEP. Parents play an important role in deciding what will be written.

After years of attending IEP meetings for their own children, Cobb County School District Parent Mentors Ijeoma Ajoku, Stacey Ramirez and Judith Steuber have compiled the following suggestions for maximizing the experience.

This important meeting should be scheduled at the parents' convenience, and they should come prepared to be team players. A professional appearance, a positive attitude and a willingness to work together will assure a successful collaboration for the student. Parents should be willing to listen to all points of view, as many will be shared. Collecting and organizing the student's evaluations, observations, notes and goals in a binder will give parents quick access to information. The purpose of this binder is to help parents formulate questions and concerns before the meeting. This is not only a time saver but helps parents focus on what should be addressed. The binder should include:

- A list of the child's abilities and interests
- Work samples
- Recent medical or education records
- List of questions and concerns
- The parents' goals and objectives for the child
- Copies of previous IEPs
- Any other helpful information



To ensure a successful IEP meeting, parents should:

- Remember the IEP process is meant to be beneficial for the child.
- Use the child's present level of functioning to help develop the IEP goals and objectives. Plan for the child's placement based on these.
- Be willing to offer appropriate modifications and accommodations.
- Ask questions about parental rights and issues they don't understand.
- Inquire about resources that explain school terminology and special education acronyms.
- Take good notes and make sure the child's strengths and weaknesses are presented during the IEP discussion and understood.
- Assess some of the child's abilities with his/her present goals in the home environment before going to the IEP. S/he may not be generalizing the skills learned at school.
- Remember an IEP meeting can be called at any time and may be reconvened. An IEP is a living document and can be changed.
- Develop trust in the process. The goal for everyone at the meeting is to provide the most appropriate educational plan for the child.
- Offer suggestions for strategies that work best with the child.
- Think of long-range transition goals as early as elementary school and bring them up during the IEP meeting.
- Adding phrases of acknowledgement or thanks go a long way toward future success.

For more information about the IEP process and a list of child's rights, visit www.doe.k12.ga.us/curriculum/exceptional/iep.asp ●

Disability Community Loses Passionate Advocate Roy Brown

With deep regret and sadness, the Governor's Council on Developmental Disabilities announces the death of one of its members, Roy Brown, 48, a long-term disability rights advocate from Rossville, GA.

"Roy was a community activist who was willing to share his knowledge with others and help those who were less fortunate than him," GCDD Executive Director Eric Jacobson said. "He was a great human being, a loving husband and father and a staunch advocate for the civil rights of people with disabilities."

As a GCDD member, Brown was elected chairperson of the Advocacy and Information Committee. "Roy took his position very seriously and saw it as his civic duty to improve the lives of people with disabilities. Even when there were barriers in the way, it was his drive and desire to see that all people with disabilities had the opportunity for independence, productivity, inclusion and integration," Jacobson said.

Brown received many awards for his service to people with disabilities in Georgia, including the "Service to Mankind" award by the Sertoma Club of East Hamilton County; the "Most Distinguished Role Model" award by the Amputee Coalition of America; and, the "Advocate of the Year" and "Volunteer of the Year" awards by GCDD.

He is survived by his wife, Elizabeth, and daughters Kristina, Pickabo and Rory. ●



GCDD Council member Roy Brown (right) with Charles "Chuck" Ware, vice president, state legislative committee, AARP (American Association of Retired Persons).

CROSSWORD PUZZLE



Have fun testing your knowledge of MAD magazine! Enter to win tickets to Six Flags, Whitewater or American Adventures. To enter, mail or fax in your answers by May 10. Visit www.gcdd.org for more details.

ACROSS

- 2) Governor's _____ on Developmental Disabilities.
- 3) What percent of GA's population was being served by BCW in 2000/01?
- 4) Acronym for No Child Left Behind.
- 5) The search for "what" is global?
- 7) A customized learning plan for children with disabilities.
- 8) Babies Can't _____.
- 9) Katie _____ Waiver, also known as the Deeming Waiver.
- 10) Type of camps for kids profiled.
- 14) First Lady of GA, Mary _____.
- 16) Disability community calls to *Unlock the Waiting Lists* at _____ Day at the Capitol.

DOWN

- 1) Diagnosis most commonly served by BCW program.
- 3) Subject of the Medical Update.
- 5) _____ All Together, Inclusion Works!
- 6) Person who works to raise awareness for a cause.
- 10) Standardized _____.
- 11) Georgia's First Lady's profession - _____ therapist.
- 13) _____ Follows People - Resolution proposed by GCDD during this year's state legislative session.
- 15) Asian country holding Conference on Educating Children with Special Needs in June.

Answers will be in the next issue and on the Web site after May 15, 2004.

APRIL

NATIONAL AUTISM AWARENESS MONTH

**April 14-17
Council for Exceptional Children Convention**

New Orleans, LA, 888-232-7733
www.cec.sped.org

**April 15-16
GCDD Quarterly Meeting**

Cartersville, GA, 404-657-2126
www.gcdd.org

**April 19-20
Best Practices for Surveying People w/Disabilities**

Washington, DC, 202-205-5633
Email: David.Keer@ed.gov

**April 19-20
Asperger's Syndrome/ Autism Super Conference**

Autism Society Greater GA Chapter
Atlanta, GA, 800-489-0727
www.asaga.com

**April 22
State Interagency Coordinating Council Children with Special Needs - Babies Can't Wait**

Tifton, GA, 404-657-2726

**April 28 - May 1
Immersion Learning about Self-Determination Conference**

Center for Self-Determination & GCDD, Atlanta, GA, 734-213-5220
www.self-determination.com

**April 30 - May 2
Special Olympics Georgia Family Camp**

Hampton, GA, 770-414-9390 x 110
jennifer.daniell@specialolympicsga.org
www.specialolympicsga.com

MAY

**May 2
Arts for Independence**
Jewish Family & Career Services - Independent Living Program
Atlanta, GA, 770-677-9329
www.artsforindependence.org

**May 2
FOCUS at Six Flags (Families of Children Under Stress)**
Atlanta, GA, 770-234-9111
www.focus-ga.org

**May 3-6
2004 National Association of ADA Coordinators Conference**
Las Vegas, NV, 800-722-4232
<http://janweb.icdi.wvu.edu/naadac/>

**May 10-11
COSD 5th Annual National Meeting: (Career Opportunities for Students with Disabilities)**
Chicago, IL
www.cosdonline.org

**May 21-23
2004 State Summer Games**
Special Olympics Georgia
Atlanta, GA, 770-414-9390
www.specialolympicsga.org

**May 27-30
National Self-Advocacy Conference: Live the Dream**
People First of California
Anaheim, CA
www.peoplefirstca.org

**May 28 - June 1
Association for Behavioral Analysis Convention**
Boston, MA, 269-492-9310
www.abainternational.org

**April 19-20
Asperger's Syndrome/ Autism Super Conference**

See nationally renowned Asperger's Syndrome expert Tony Attwood, PhD, plus other experts on autism. Medical and intervention options, self care, puberty and personal safety issues will also be discussed.

**May 21-23
2004 State Summer Games Special Olympics Georgia**

Join in the fun of the State Summer Games at Emory University in Atlanta! Sports include athletics, artistic gymnastics, aquatics and more.

**July 26-27
ADA 14th Anniversary Celebration**

This two-day event will feature seminars on ADA Law by Nancy Duncan, kids activities, a puppet show and more.

JUNE

**June - July
Blaze Camps**
Blaze Sports Programs
770-850-8199, Email: blazesports@blazesports.com
www.blazesports.com

**June 1-4
AAMR's 128th Annual Meeting (American Assn. On Mental Retardation)**
Philadelphia, PA, 800-424-3688
www.aamr.org

**June 9-12
National Council on Independent Living Conference**
Your Vote Counts for Freedom
Washington, DC
800-833-1354 x 102, www.ncil.org

**June 14-22
Celebration of 5th Anniversary of Olmstead**
People First, 404-687-8890
Email: ngainer@msn.com
www.longroadhome.org

JULY

**July 7-10
Nat'l Conference on Autism Spectrum Disorders**
Seattle, WA
www.autism-society.org

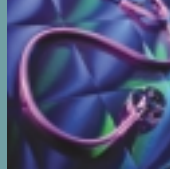
**July 15-16
GCDD Quarterly Council Meeting**
Atlanta, GA, 404-657-2126
www.gcdd.org

**July 22
State Interagency Coordinating Council Children with Special Needs - Babies Can't Wait**
Macon, GA, 404-657-2726

**July 22-25
National Down Syndrome Society Conference**
Washington, DC, 800-317-7554
www.ndss.org

**July 26-27
ADA 14th Anniversary Celebration**
Augusta, GA
Gerald Powell, 706-724-6262 x 303

Send in your organization's events to val@oneillcommunications.com to be added to the calendar!



Conquering Obesity in Children and Adults *by Susan Burns*

Some people with developmental disabilities are faced with the same struggle as many other Americans - being overweight. More than half of all adults are overweight (64.5%) and nearly one-third is obese (30.5%). In addition, approximately 15% of children are overweight. A study conducted by the University of Georgia and the Department of Human Resources found that 20.2% of Georgia's children were overweight, five percentage points higher than the national data. The study measured height and weight of 3,473 Georgia children in the 4th, 8th and 11th grades.

Obesity is associated with medical conditions such as type 2 diabetes, hypertension, heart disease, depression and asthma. It is estimated that unless health habits change for the better, one in three U.S. children who were born in 2000 will develop Type 2 Diabetes. The Centers for Disease Control and Prevention (CDC) estimates that U.S. obesity medical expenditures for 2003 were approximately \$75 billion.

A variety of factors cause obesity, including genetic, metabolic, behavioral, environmental, cultural and socioeconomic influences. While some factors cannot be changed, behavioral and environmental factors, the largest contributors to obesity, can be addressed. Families should create and maintain a healthier lifestyle.

The dramatic increase in obesity over the past 20 years has been impacted by the change in lifestyles and environments. About 45% of household budgets are spent eating meals outside of homes that are often high in calories and fat. Plus, food portion sizes have increased. For example, 20 years ago a three-inch diameter bagel had 140 calories, and today bagels are six inches in diameter and 350 calories.

Not only are people eating more, they are consuming more calories from beverages. Soft drink consumption has increased 300% over the past 20 years, and serving sizes have increased from 6.5 oz in 1950 to 20 oz in the late 1990s. This is an increase from 85 to 250 calories. A 160-pound person will have to work for 35 minutes gardening to burn those extra calories.

Society has also become less active. Modern conveniences like remote controls, elevators, car washes, leaf blowers and drive-through windows all mean less physical activity. Children and adults are spending more time sitting in front of televisions and computers and playing video games. A national survey reported children watch at least four hours of television per day, and those who watched five or more hours a day were four times more likely to be at risk for being overweight.

Physical education (PE) in schools, which gives kids a chance to be physically active, is declining. Only a quarter of high school students participate in daily PE, down from 42% in 1991. In fact, half of high schoolers are not enrolled in PE at all.

Finally, the environment has changed, and there are fewer opportunities to be physically active. The perceived danger of neighborhoods discourages people to take a walk. Many suburban neighborhoods are structured for the convenience of cars and not for families to take walks or ride bikes.

Motivating children with developmental disabilities to exercise can be even more difficult, especially if they have physical limitations. However, achieving energy balance is a good way to improve overall health and self worth, so ensuring children with disabilities get enough exercise is very important. The message is clear for all individuals and families: maintain a healthy lifestyle to decrease the risk of becoming overweight. ●



Susan Burns

is a registered dietitian currently working with the Georgia Chapter of the American Academy of Pediatrics as the WIC/Nutrition Coordinator. Her work gives her the opportunity to provide education to physicians throughout the state on issues such as infant feeding practices and childhood obesity. She has also worked with Georgia's Department of Human Resources (DHR), the Georgia Women Infants Children (WIC) Program for eight years and was a clinical dietitian at Egleston Children's Hospital with the Cystic Fibrosis Center.

Education: B.S. Nutrition Management, Georgia State University

Healthy Eating Tips

- **Serve regularly planned meals and snacks and a wide variety of healthy foods.**
- **Eat more slowly and enjoy the food.**
- **Drink more water.**
- **Eat fewer high-fat foods.**
- **Eat more fruits and vegetables.**
- **Eat a healthy breakfast.**
- **Drink less soda and sweetened fruit drinks.**
- **Choose skim or reduced fat milk.**
- **Eat together as a family.**



Healthy Exercise Tips

- **Choose activities the entire family can do together.**
- **Keep activities fun, simple and non-competitive.**
- **Try short periods of vigorous activity – 10 minutes 3 times a day is a great way to start.**
- **Reduce TV time to less than 1-2 hours daily.**
- **Limit video games.**
- **Reduce computer time (except for homework!).**
- **Move around during "breaks" at work or school.**



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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

www.gcdd.org
404-657-2126 or
888-275-4233 (ASK-GCDD)

State Government

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

Babies Can't Wait

Division of Public Health,
Department of Human Resources
www.ph.dhr.state.ga.us/programs/bcw/index.shtml
404-657-2726



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"Best Practices"

China - U.S. Conference on Educating Students with Special Needs
www.globalinteractions.org/2004-Students/Students-home.htm

Disability Law and Policy Center
www.dlpcga.org, 770-270-9964

Olmstead Decision
www.accessiblesociety.org/topics/ada/olmsteadoverview.htm

Olmstead March and Freedom Rally
www.longroadhome.org

People First of Atlanta
404-687-8890

Statewide Independent Living Council of Georgia
www.silcga.org
770-270-6860 or 888-288-9780

Unlock the Waiting Lists!
www.gcdd.org/programs/unlock/

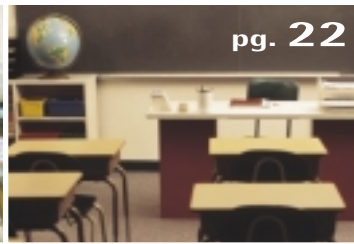
IEP Meetings

Awesome Library
www.awesomelibrary.org/Library/Special_Education/Individualized_Education_Plans/Individualized_Education_Plans.html

Georgia Advocacy Office
www.thegao.org/advocatiep.htm

(IEP) Individualized Education Program
www.doe.k12.ga.us/curriculum/exceptional/iep.asp

Kids Health
<http://kidshealth.org/parent/growth/learning/iep.html>



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LD OnLine
http://www.ldonline.org/ld_indepth/iep/iep.html

Special Education Parent Mentor Network
www.parentmentors.org

IEPs and the Law
Atlanta Legal Aid Society
www.law.emory.edu/PI/ALAS/schoolrights.htm

Reed Martin
www.reedmartin.com/iepgoals.htm

Special Education

Council for Exceptional Children
www.cec.sped.org
888-CEC-SPED (232-7733)

(FAPE) Families & Advocates Partnership for Education
www.fape.org, 952-838-9000

Georgia Advocacy Office
www.thegao.org
404-885-1234 or 800-537-2329

IDEAPractices
www.ideapractices.org
877-CEC-IDEA (232-4332)

IDEA Hotline
now PSEA Interactive
800-944-7732, x 7327

National Dissemination Center for Children with Disabilities
www.nichcy.org, 800-695-0285

No Child Left Behind
www.nclb.org

Special Education Rights Advocacy
www.wrightslaw.com



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State of Georgia
Department of Education - Exceptional Students
www.doe.k12.ga.us/curriculum/exceptional, 404-656-3963

World Institute on Disability
www.wid.org, 510-763-4100

Summer Camps

Atlanta Parent Magazine Camp List
www.atlantaparent.com/campexpo.html

Camp Barney Medintz Residential Camp (inclusive)
www.campbarney.org
770-396-3250

Camp Hollywood Day Camp (medically fragile)
www.focus-ga.org, 770-234-9111

Camp Twin Lakes Overnight Camp (brain-injured)
www.camptwinlakes.org
Winter: 404-231-9887
Summer: 706-865-1495

Children's Association for Maximum Potential
www.c-a-m-p.org, 210-292-3566

Find Camps Across the U.S.
<http://KidsCamps.com>

Georgia Learning Resource System
Division for Exceptional Students
www.glsr.org, 404-657-9958



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(404) 508-7796
Fax (404) 508-6443

AlbanyARC

Albany Advocacy Resource Center
Albany ARC, serving our community since 1963, promotes the general welfare of people with disabilities and fosters the development of programs on their behalf.

(229) 888-6852
(24-hour on-call)
www.albanyarc.org

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- Family Support
- Day Programs
- Job Training
- Summer Camp

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404-634-4222
WWW.GACOMMUNITY.COM

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Understanding Disabilities Creating Opportunities

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email: info@ucpga.org
(770) 676-2000
1-888-UCP-WILL
www.ucpga.org

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Easter Seals

Beth English, Director
1906 Palmyra Road
Albany, Ga 31701
(229) 439-7061

ARC COBB
(770) 427-8401
www.arccobb.org



Disability Day at the Capitol

Hundreds of advocates for people with developmental disabilities brave snow and ice to make their voices heard at the Georgia State Capitol in February.



Governor's Council on Developmental Disabilities
2 Peachtree Street, NW, Suite 8-210
Atlanta, GA 30303-3142
404-657-2126, www.gcdd.org

Address Service Requested