GEORGIA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

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Advocates Influence Legislators to Fund Key Initiatives

Should the State Fund Faith-Based Initiatives? New Waiver Slots Mean More Choices

Real Homes. Real Jobs. Real Education. Real Choice.



Features

Disability Community Reveals Hopes for Future

State officials, parents, selfadvocates and service providers offer their opinions on what the future should hold for people with disabilities.



About Our Cover: Stakeholders are beginning to share a common vision for Georgians with disabilities. Pictured clockwise from top: new self-advocates Sarah Galloway, Robert McNamara, Stephanie Koch and Director of the Office of Developmental Disabilities Dr. Stephen Hall; self-advocate Tameeka Hunter; mom Theresa Christian with son Kevin and daughter Meaveen Sullivan; therapist Sloane Nguyen with client Nygil Mann; Speaker of the House of Representatives Glenn Richardson (R-Hiram).

In Each Issue

- 3 Letter from Governor Sonny Perdue
- **28** Resources
- **30** Calendar Editorial Cartoon



18 Waiver Recipients Have Choices to Make

Experts give tips on finding the right service providers for new waiver recipients.

22

Person-Centered Planning

Methodology focuses on abilities while planning for jobs, lifestyles for people with disabilities.

Departments

6

8

Around GCDD

Learn about projects

funded by GCDD and

recent staff changes.

News & Events

IDEA: DHR unveils

Advocates comment on

supported employment

program; entrepreneurs

exhibit at expo; Georgia

committed to self-determi-

nation in waiver spending.

4

GCDD Viewpoint

Georgia's Disability Community Starts Down the Right Path Advocates, politicians and state officials finally share a common vision.

5

From the GCDD Chair What if it Works?

Lynette Bragg is optimistic about the 925 waiver slots.

24

Advocates Influence Legislators during Disability Day

More than 1,300 self-advocates, family members and service providers packed the Capitol to make their voices heard.

7 Leonard Roscoe: Self-Advocate to the End

Small in stature, Leonard Roscoe leaves big shoes to fill.

10

Legislative Update

The outcome was very positive for advocates in the developmental disabilities community as the first fully Republican-controlled legislative session came to a close.

16

Point/Counterpoint

Should the State Fund Faith-Based Initiatives?

27

Straight Talk

Shannon Barnes now has the job of her dreams.

29

Legal Update

IDEA 2004 contains significant changes of which people should be aware.



Making**®** Difference

Volume 5, Issue 4 Spring 2005

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

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

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

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To Georgia's Disability Community,

y now, many of you may be aware of the recommendations in my 2006 budget that go to support Georgians with disabilities. These recommendations, which include adding 925 slots to our waiver programs, over \$2.3 million for provider rate increases and almost \$3.8 million for treating children in community settings, have all been sent to the General Assembly.

These are the first steps in providing an opportunity for individuals with disabilities to have a choice in their health care. While funding is a necessary and important first step, the next steps are just as important.



The next steps involve developing strong partnerships committed to doing the right thing for each individual with a disability and the disability community as a whole. Creating natural support systems for people with disabilities by providing them an opportunity to become a part of our communities and neighborhoods must also be achieved. Establishing trust between people with disabilities

achieved. Establishing trust between people with disabilities, their community providers and the state is also critical for nurturing an environment that promotes personal choice and responsibility in health care for Georgians with disabilities.

In my time as governor, I have met many of our citizens with disabilities and the individuals who are assisting them to live independent lives. I know firsthand of your commitment and passion for doing the right thing. I also understand that we can create solid partnerships to improve the quality of life for Georgia's citizens with disabilities.

Thank you for your courage, and thank you for your commitment towards this very difficult work.

Sonny Fundace Sonny Perdue

Sonny Perdue Governor

Georgia's Disability Community Starts Down the Right Path

here is an old Chinese Proverb that says, "a journey of a thousand miles begins with a single step." I believe we have begun the thousand-mile journey toward repairing the system that provides supports to people with developmental disabilities and their families. The first steps began in January with the hiring of Dr. Stephen Hall as the director of the Office of Developmental Disabilities. Our journey must include a new vision about (1) what people with developmental disabilities want in their lives; (2) what families need to care for their loved ones; (3) the role of providers and direct support professionals; and,



(4) the role of the state-funded system of services and the people who manage the system.

The first steps will be rough as everyone gets to know each other. There has been so much distrust between all those involved, and it will take time to mend the differences that exist. Each will have to listen and understand what the others say and find ways to reach compromise. During the recent legislative session, conflicting proposals about how to maximize a provider rate increase were resolved by deciding to sit down after the legislative session and have discussions about rates for all services. There is no end to what can be accomplished if individuals, family members, providers, advocates and state agencies work together as equal partners to create change.

Once we move past these first steps, I am sure that we will agree that what people want is the opportunity for real affordable and accessible homes, real jobs that allow them to be productive members of their communities and real choices to make decisions about their own lives.

The people who are now in place can make this vision come true. Advocates asked for leadership to help build and implement a new vision for people with developmental disabilities and their families. It was the leadership of the ARC of Georgia and other advocacy groups that said, "We want more emphasis on developmental disabilities in the Division of Mental Health, Developmental Disabilities and Addictive Diseases, and we want a leader who understands the issues and can There is no end to what can be accomplished if individuals, family members, providers, advocates and state agencies work together as equal partners to create change.

change the direction." These new leaders will need our support, guidance and patience. It may take a while for us to get further on this journey, and we may have to take steps backward before we move forward. However, I think now is the time for us to undertake this most important journey together.

This edition of *Making a Difference* is focused on this vision. We asked people from around the state to give us their thoughts about what they want in their lives. They were among the more than 1,300 people who attended this year's Disability Day at the Capitol.

I look forward to this new journey and hope that you enjoy reading this magazine. Let us know what you think about the magazine. In addition, "Letters to the Editor" are encouraged. We welcome the opportunity to print thoughtful responses to specific articles published in *Making a Difference*. You can reach me at 1-888-275-4233 or you can e-mail me your thoughts at eejacobson@dhr.state.ga.us.

Eric E. Jacobson Eric E. Jacob

Eric E. Jacobson Executive Director, GCDD

FROM THE GCDD CHAIR





Recently, Department of Human Resources Director B.J. Walker gave a speech in Albany, GA that resonated with GCDD Chair Lynnette Bragg, whose son has disabilities. The excerpted passage below is reprinted with Walker's permission:

"We start with our values. Each of us is given a precious resource – it is a lifetime. For us the gold standard question is: 'What would you like to do with your lifetime?'

"As a society, we take certain things for granted, but people with disabilities do not – cannot.

"So:

- We believe that dependence on government is not good enough for our consumers. We value independence and self-determination.
- We believe that working people and their families are always better off than nonworking people. We value self-sufficiency.
- We believe that institutions are not the best places for people to live and grow in. We value community.
- We believe that government has to be a resource to families; not a substitute for them. We value helping families support their loved ones.
- We believe that people with the support of family – should make the important decisions that affect their lives. We value individual dignity and personal freedom."

What if it works?

cott Bragg turned 30 in November! WOW! That means that we, his family, have been navigating "systems" for 30 years! The majority of that time, we have not "navigated" as much as been made aware that there are "no services" or the ones that are available do not "fit" or are not "appropriate" for him or there is a "waiting list." Scott has also had a lot of "plans" over the last 30 years.

During a Governor's Council on Developmental Disabilities public forum in Macon, a man stood up and said "my son has had many plans, IEPs, ISPs, so many I cannot count them. I tell you my son has been "p'd" on enough! All we want is a little bit of service!" I think he summed up the frustrations that many of us have had with the system over the years.

We have cried, fought, advocated, educated and tried to convince the powers that be to change and to fund the support systems in the community.

So, what have we done? We have cried, fought, advocated, educated and tried to con-

vince the powers that be to change and to fund the support systems in the community. We have had our "plans" and have made baby steps in changing systems. Lois Curtis and Elaine Wilson were very successful in getting a big "plan," not only for changes in Georgia, but changes throughout the United States with the "Olmstead Plan."

I am privileged to have met B.J. Walker, the Department of Human Resources commissioner, and discuss her thoughts and plans for disability services in Georgia. Somehow, I was not quite prepared for a speech she gave at the Albany Resource Center. (See sidebar at left.)

I will be honest; during her speech I cried and had chill bumps. I asked myself, does she know she is in Georgia and how hard it will be to implement these values throughout the system? It was very surprising when she submitted her budget to Gov. Sonny Perdue and it included funding for **925** people on the waiting lists.

It was then very invigorating when the governor's budget was presented and it included funding for supporting **925** people! Both the House and Senate have continued to show their support for **unlocking the waiting lists.** We have fought and fought to **Unlock the Waiting Lists** for so many years, to take this brain child of Beth Tumlin and the hard work that she and Grace Fricks began, and to actually see these numbers included in a budget is almost unbelievable!

Our questions then become, What if it works? What if we get the opportunity to provide services for this many people? Do we have the infrastructure in the community to provide the supports needed? How fast can the current system/structure process the applications for these people? Will the funding be taken away as it was in previous years?

A special thanks to each of you who attended Disability Day at the Capitol! It is the energy you bring that has resulted in our elected officials funding the waiting lists!

Lynnette Bragg Chair, GCDD



AROUND GCDD

GCDD People

Doughman Becomes Advocacy Director

Danielle Doughman has been promoted to



advocacy director for GCDD. Her primary responsibilities are to support the development and implementation of leadership, education and advocacy initiatives that lead to increased quality of life for people with developmental disabilities and their families. Doughman has been with GCDD since 2002 and previously worked

as a social worker at a nonprofit agency serving the urban poor of Atlanta.

Goodman Fills New Position

Aimee R. Goodman has been hired to fill the new project manager position. In this role, Goodman will be working with Council members, providers and



staff on grant and contract management, evaluation and reporting. Goodman previously worked at Hillels of Georgia where she served as the associate director for Emory and the director of development. Prior to that she worked at the Jewish Federation of Greater Atlanta, where she oversaw the Business and Professions Division of the Annual Campaign.

Kim Person Named Executive Secretary



Kim A. Person has joined GCDD as executive secretary. She will provide administrative support to the executive director and will be responsible for assisting GCDD in office operations, travel arrangements, secretarial support and coordinating/arranging Council meetings. She will also supervise support staff. Person's

previous experience includes customer service, event planning, staffing and sales.

Nobbie Promoted to Deputy Director

The Georgia Governor's Council on Developmental Disabilities Public Policy Director Patricia Nobbie, D.P.A., has been promoted to deputy director.

In her new role, Nobbie will have three primary responsibilities. First, she will continue to track legislative and policy issues on the state and federal level, which will entail taking the pulse of the disability community and state and national trends; preparing a legislative agenda for GCDD to consider; working with legislators to write legislation; and, seeing legislation through the process. It also entails tracking the state budget process by working with state agencies to create budget recommendations and tracking the progress of budget items through appropriations committees to the final vote.



projects and the outcomes of projects GCDD funded, plus develop methods to conduct evaluation that is meaningful and informative for the types of projects that GCDD does.

Third, Nobbie will use the information she gains in her research and legislative work to develop long and short-term strategic goals, with the input of GCDD members, then create a work plan that is built on good research and supports good policy. "In this capacity, I will also be more involved with the GCDD budget as we try to balance resources with the 'wish list' of things we want to accomplish," Nobbie explained.

"I am very excited about the focus of this new role, and I appreciate the director's and Council members' confidence in me to do the job!"

Second, she will evaluate research

GCDD Grant Project Highlights

The Governor's Council on Developmental Disabilities funds a wide variety of deserving projects designed to improve the lives of people with disabilities in the state of Georgia:

Partnership Funds offer more than 1,500 scholarships each year so people can receive training and education at conferences and other advocacy events.

Successful Innovative Proposals

The Institute for the Study of Disadvantage and Disability received a grant for students from three Atlanta universities (Morehouse, Emory and Georgia State) to develop projects that address the circumstances of children with developmental disabilities who also live with social and economic disadvantages.

Credit-Able helps people with disabilities and their families establish a credit history, join a credit union and learn the basics of finance and budgeting. The project provides financial education and makes low-interest loans to people with disabilities to purchase assistive technology. Visit *www.gatfl.org* for more information.

The Aging and Disabilities Coalition

assessed the needs of aging people with developmental disabilities and their aging caregivers as a result of Senate Resolution 822. After researching and developing recommendations, a statewide symposium was held and the results of the work are documented in a final report to policymakers.

Learn more about GCDD's grant programs during an informational conference call on April 19 at 3:30 PM or August 3 at 9:30 AM. RSVP online at www.gcdd.org or by calling (888) ASK-GCDD.

Leonard Roscoe: Self-Advocate to the End



Leonard Roscoe (1970-2005)

dvocate, musician, friend and family man are just a few words that accurately described Leonard Roscoe. He died March 6 while participating in an American Disabled for Attendant Programs Today (ADAPT) Action, during the National Governor's Association Convention in Washington, DC. He was 35. Roscoe and other advocates hoped to persuade the governors to sign a resolution that would provide resources for people with disabilities to live independently in their own communities. Roscoe's passion for self-advocacy was fueled by his own experience living over 20 years in an institution.

A native Atlantan, he was born with Osteogenesis Imperfecta, also known as brittle bone disease. As a result of this rare disability and lack of information and resources, Roscoe spent most of his life in an institution. That experience gave him the motivation and ammunition he needed to fight the battle for independent living and self-determination. "He could knock down any wall," said Samuel Mitchell, president of the Atlanta chapter of ADAPT. "He used that fighting spirit to help get the Atlanta chapter back up and running," Mitchell reflected.

Over the years, Roscoe has actively participated in advocacy projects and organizations. He was a member of the disABILITY LINK Board of Directors and MARTA's Elderly and Disabled Advisory Committee. He has participated in several ADAPT actions; including the Long Road Home and the Free Our People March. His tireless involvement and feisty spirit show his desire to help people with disabilities stand up for their rights and live in the community. "We had a kindred spirit because of formerly living in institutions," said Mitchell. "When I was moving out of a nursing home, he gave me that additional push that was needed to take it over the top."

When he was not working as an advocate, Roscoe performed as a disc jockey for weddings, parties and disability-related events. He began

playing music while still living in an institution and cultivated it into a successful business after leaving. "One of my most memorable moments was when Leonard asked me to help with his music career," said Bernard Baker, self-advocate and friend. "I want to keep his dream of music going by continuing to play his mixed tunes."

Roscoe used that same zeal for advocacy and musicmaking to build a family and

close friendships. He and Renee Peak, his high school sweetheart, fought to adopt their son Nigel from Calcutta, India. "We had some challenges because both of us have disabilities," said Peak. "We specifically wanted a child with a disability because we could empathize." Often the entire family would travel to participate in advocacy projects, and were by his side the day he died.

Roscoe was also known as a great friend and threw lavish parties with an atmosphere of fun and laughter. "Last Thanksgiving we sat and talked in his beautiful home," said Mitchell. "I was amazed because here was this confident little guy with a big heart." Roscoe cherished people and had long lasting relationships.

"To others he was a friend, but to me he was a brother," said Baker. "When I was down and out, he always lifted up my spirits. He will be greatly missed."



"I was amazed because here was this confident little guy with a big heart."



Roscoe shared his love of music by providing entertainment at many disability-related events.

"When I was down and out, he always lifted up my spirits. He will be greatly missed."





Disability Community Comments on IDEA Changes

A standing-room-only crowd of disability advocates and educators waited patiently to offer their thoughts on the new Individuals with Disabilities Education Improvement Act (IDEA) of 2004 with Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS) John H. Hager February 15. Advocates from as far away as Texas

came to the meeting at Frederick



Cathy Everett, a Georgia Partners in Policymaking graduate, was concerned that short-term goals were no longer emphasized.

Douglass High School in Atlanta to voice their concerns, which ranged from specifying certain therapists in the list of approved therapists to larger issues such as a perceived weakening of parental input into the child's Individualized Education Plan (IEP).

Attendees were concerned that administrators and teachers could be excused from the IEP process. "It weakens the IEP to allow team members to pop in and out," said Connie Hawkins, director of the North Carolina Parent Training Information Center.

Cathy Everett, a Georgia Partners in Policymaking graduate, was concerned that short-term goals were no longer emphasized. "Short-term goals are necessary, especially for kids with specific disabilities," she said.

The Governor's Council on Developmental Disabilities has identified several areas of concern for the proposed changes to IDEA and has submitted the following suggestions to OSERS:

- Transition planning and services that formerly began at age 14 are now delayed until age 16. The Council recommends this process begin no later than five years prior to a student's anticipated graduation.
- Disciplinary protections have been weakened for students whose disability may manifest itself in inappropriate behavior. The Council supports establishing written regulations which would place the burden of proof on school districts to show such behavior is not a result of the disability and prohibit authorities from withholding instruction as a form of punishment.
- Parents should be informed in advance and in writing that they can decline to excuse an IEP team member from participating in a meeting. The Council suggests that parents also be entitled to "reconsider and require" the attendance of an IEP team member, even if previously excused.

OSERS will hold more meetings this spring and summer so the public can comment on proposed regulations to implement IDEA. Cities and exact locations have not yet been determined.

For a copy of the law, visit the Office of Special Education Programs (OSEP) web site, www.ed.gov/about/ offices/list/osers/osep/index.html, and go to the Individuals with Disabilities Education Improvement Act of 2004.



Disability advocates and educators from as far away as Texas came to the meeting at Frederick Douglass High School in Atlanta to voice their concerns with IDEA 2004.



Assistant Secretary of the Office of Special Education and Rehabilitative Services John H. Hager (left) and Larry Wexler listen to comments on the new IDEA changes.

DHR Promotes Supported Employment with Project Search

The Department of Human Resources' (DHR) Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) is supporting innovative programs to integrate people with disabilities into mainstream work settings. One program is Project Search, the first program of its kind in the state of Georgia, which matches talents of people with disabilities to career paths that can lead to independence and unimagined opportunities.

DHR serves approximately 14,000 people with disabilities who are most in need – including those affected by autism, Down syndrome, cerebral palsy and mental retardation. Gwen Skinner, MHDDAD division director states, "As a society, we have to progress in our thinking to integrate people with disabilities into environments where they can advance and progress in their work of choice. Self-determination should be a right afforded to every individual."

Of those with disabilities who receive DHR employment services, 62% receive community-based job development and training. With support from career coaches, people with disabilities find opportunities, market their skills, complete the interview process and compete for jobs that pay competitive wages.

Project Search currently works with two Atlanta area hospitals, North Fulton and Crawford Long. Routine work that is generally part of a nursing job description is now handed to Project Search participants.

Jennifer Briggs, president of the

NEWS & EVENTS



company that manages Project Search states, "There is dignity in earning a living. We cannot assume that people with disabilities will be seen as equals if we continue to train and act with a separate but equal mentality. We are pleased to have DHR as a funder and partner in demonstrating the value of people with disabilities."

Zelyna Cano, a MHDDAD consumer, currently works at Crawford Long Hospital as a materials management clerk. When asked how she feels about her job, she says, "My parents are very proud of me, and I am too. I want a career in health care and hope to do a good job."

For more information on services provided by MHDDAD, please access www.mhddad.dhr.georgia.gov.

Entrepreneurs With Disabilities Turn Out For Expo

Business men and women with disabilities came together to promote their businesses at an Entrepreneurial Expo January 18 at Chattahoochee Technical College, held by the Cobb-Douglas Community Services Board and CobbWorks! Workforce Development System.



Dr. Chris Button (right) talks enthusiastically about the various businesses represented with Bill Cheeks, chairman of CobbWorks!

Project Exceed, Project Access and Jobs For All – three initiatives funded by the U.S. Department of Labor (USDOL) promoting customized employment for people with disabilities – enabled



Entrepreneur Ronnie Smith promoting his laundry service, Keep It Klean.

entrepreneurs in Cobb and Douglas counties to start the businesses of their dreams with encouragement, employment services and monetary support.

USDOL Director of Policy & Research Susan Parker was impressed with the initiative which began in Cobb County and is branching out across the state.

"All too often we think disability is a social program. Heck no! It's very clear that people with disabilities have the ability to keep the U.S. economy healthy and growing," she asserted. "This program in Cobb County is cutting edge. It ought to be statewide, nationwide – no – worldwide!"

Dr. Chris Button, the USDOL supervisory policy advisor agreed.

"I find myself using Georgia as an example for meetings (about customized employment) across the board," she said.

One entrepreneur in attendance was Ronnie Smith, a young man with autism. He was given a grant for his enterprise – Keep It Klean – an exclusive laundry service for beauty salons and barbershops. With his start-up money, he was able to put a working engine in his Jeep for pickups and deliveries, set up a washer and dryer in his garage and buy detergent, towels and bags.

A self-employed, "shredder technician," Anthony Fuller was also promoting his business. Fuller, deaf and with a serious visual disability, can shred papers for businesses without breaching confidentiality. "I happen to be legally blind, but that hasn't stopped me from fulfilling my dreams," he said.

For more information on customized employment, see the Summer 2004 edition of *Making a Difference* magazine or visit *www.cobbcsb.com*.

Georgia Working to Establish Self-Determination in Waiver Spending

The state of Georgia is currently designing its Independence Plus initiative that will allow people with disabilities to have more control over how their waiver money is spent. The goal is to develop a comprehensive system of self-directed home and community-based services and supports for those receiving waivers through the Community Care Services Program, the Mental Retardation Waiver Program, the Community Habilitation Services Program and the Independent Care Waiver Program.

Key components include:

- Individual Budgeting develop a uniform, person-centered methodology to calculate all individual budgets in the state and create an easy-to-read guide for consumers.
- Quality Assurance/Improvement Systems – adapt these systems to assure necessary safeguards for health and welfare of participants in the self-directed service delivery system by revising the current incident manage-ment system and developing emergency backup systems.
- 3. Key Operations/Master Plan design key operational functions of the selfdirected service delivery system and develop a self-determination master plan that incorporates components of the self-directed service delivery system. This would be accomplished by defining prerequisites, selection procedures and training requirements for support personnel; evaluating financial management services; and, developing an implementation plan. Each of the key components has a

corresponding stakeholder group that includes representatives from state departments, provider agencies, consumers and family members.

For more info, visit http://www.hcbs. org/files/31/1515/GAip03.htm.



Legislators Vote to Fund Key Disability Initiatives

By Pat Nobbie, D.P.A.

The first fully Republican-controlled legislative session came to a close March 31, and for advocates in the developmental disabilities community, the outcome was very positive. Advocates forged relationships with new legislators and new leadership, laying the groundwork for productive work on the multi-year challenges facing the development of adequately funded and quality-driven services for families and individuals with developmental disabilities.



GCDD's Deputy Director Pat Nobbie (left) with Speaker of the House of Representatives Glenn Richardson (R-Hiram) during Disability Day at the Capitol.

The Governor's Budget

Many of the cuts that were feared were removed in the governor's budget proposal, and some very positive budget items were included. That enabled the community to focus its efforts on a few specific items. Here is a review of the legislative agenda passed by the Governor's Council on Developmental Disabilities (GCDD) in October, a summary of the actions taken by advocates during the session and the results.

First Priority Legislative Items

Oppose cuts to Medicaid services **for people with disabilities** in the Department of Community Health (DCH) budget. Status: The list of targeted cuts was much longer originally, but in the governor's budget, only the **fixed expenditure cap for** the Independent Care Waiver Program (ICWP) turned out to be a concern. The intent of the cap was to garner some savings to place another 46 people on the Independent Care Waiver Program. This trade-off effectively put some higher-cost individuals already being served by the program in jeopardy of losing services so that some new individuals could come on the program. Consumers representing the State Independent Living Council and its network of Independent Living Centers, the Shepherd Center and Unlock the Waiting Lists! testified before the House and Senate Appropriations Committees, visited their legislators, met with the governor's office, shared information with Speaker of the House Glenn Richardson (R-Hiram) and made dozens of phone calls. Advocates held a press conference in the rotunda of the Capitol February 7 that was attended by nearly 70 people and several news outlets. As a result of these efforts, the House Subcommittee on Appropriations for Health and Human Services (Jeff Brown (R-LaGrange), Chair) recommended removing the cap, and put \$1.1 million in the budget to fund the additional 46 slots. The Senate subsequently stayed with the House recommendation.

Support budget request for waiver slots in the Department of Human Resources (DHR) budget.

Status: The governor's budget proposed funding for 925 slots, which meant \$3,284,957 in state dollars. By the time the session began, the well-oiled Unlock the Waiting Lists! machine made sure that legislators and the governor's office knew that advocates appreciated the big addition to the budget, and that they were watching it closely. For the remainder of the session, this budget item never seemed in question. Legislators received over 1,500 messages of thanks and appreciation for this large bite out of the waiting list.

Support increase in provider rates for services currently reimbursed below the Southeastern average.

Status: The governor's budget provided for a 3% increase for all Mental Retardation Waiver Program (MRWP) community providers, but then cut 30% of the room and board allocation, which would negate the rate gain for some residential providers. Quick thinking by the provider community recognized the entire room and board allocation (a flat rate, monthly, state dollar allocation that was not applied equitably to all individuals in residential services) could be matched with Medicaid funds, resulting in a greater pool of dollars which could then provide a rate adjustment to the residential providers, and an overall rate increase of 4.5% to all community providers. The House Appropriations Committee accepted this proposal, and as of press time, there was only some dissent on the language to be included in the budget document.

Secondary Priority Legislative Items

Oppose premiums for the Katie Beckett (Deeming) Waiver (access to Medicaid for families with medically fragile children) (\$1.5 million)

Status: This year, the proposal was to charge a premium of \$200 per month only to families who made over \$100,000 per year. The well-prepared parents of children who benefited from the waiver fought it early and hard, working their legislative contacts developed from last year and educating new legislators. Again, the House Subcommittee on Appropriations for Health and Human Services recommended removing the premiums, and the Senate agreed.

> Many of the cuts that were feared were removed in the governor's budget proposal, and some very positive budget items were included.

GCDD LEGISLATIVE AGENDA REVIEW





Advocate Justin A. Pressley found legislators such as Rep. Amos Amerson (R-Dahlonega) (right) receptive to disability issues during lunch at the Depot on Disability Day.

Medication Administration: Support amendments to the Nurse Practice Act that would enable direct support staff to administer certain routine medications to the consumers they support.

Status: This agenda item came off the table right away. The Division of Mental Health, Developmental Disabilities and Addictive Diseases decided not to pursue this legislative change this session.

Support Amendments to the Election Code.

Status: As reported in January's Making a Difference, a number of changes to the election code would remove barriers to voting faced by people with disabilities. Representative Alan Powell (D-Hartwell) drafted a bill. Different strategies to move the bill were not successful because they would have required it to be attached to other, more controversial voting bills that included a requirement that voters show a photo ID at their polling place. After numerous conversations with House and Senate committee leadership, advocates agreed to wait until next session so it could be introduced as a separate piece of legislation. Legislators have expressed support for these changes.

Other Happenings:

Every session also brings its share of unexpected budget-related items and legislative issues. Other gains in the budget were the replacement of lost federal social service block grant funds that are used to serve consumers with developmental disabilities; conversion of 166 consumers from state-supported developmental disability services to Medicaid eligible waiver services; additional funding for children with

behavioral disorders and developmental delays; services to 600 additional elderly clients on the non-Medicaid home and community-based waiting list and an additional 200 slots in the Community Care Services Program (CCSP). Funds were also restored to the Centers for Independent Living, Family Connection and GCDD.

Disease Management

Despite a concerted effort by advocates and providers to remove the high cost consumers with developmental disabilities from DCH's disease management initiative that proposed to serve 100,000 individuals, the conference committee decided to keep the governor's proposal. There is some language to "explore the feasibility of engaging" an Administrative Services Organization to use the SOURCE model, but no funds were attached. The conference committee also included implementation of utilization review for the waivers; savings resulting from the ICWP are in the DCH budget (\$2,000,000) and savings from the MRWP and the Community Habilitation and Support Services (CHSS) (affecting 4,000 people with developmental disabilities) are in the DHR budget (\$2,400,000). Utilization review is a retrospective look at how services were used over the previous year; concurrent review, which SOURCE promotes, is present time management of consumers' medical needs. The advocates hope that some combination of these two approaches can be negotiated over the coming year that will result in savings AND better care management.

The Children's Initiative

Late in the session, the Georgia Advocacy Office (GAO), the Institute on Human Development and Disability (IHDD) and GCDD worked with Rep. Judy Manning (R-Marietta) to pass resolution (HR 633) that "urges" DHR, DCH, Department of Education, Department of Labor and Department of Juvenile Justice to cooperate on a plan to identify, assess and plan the development of home and community-based services for the over 150 children under the age of 22 who

> Advocates made great strides for the coming fiscal year, but the waiting list is a multi-year problem that requires strategic, proactive, aggressive fiscal policy.

are currently living in institutions, nursing homes, private Intermediate Care Facilities for the Mentally Retarded (ICF-MRs) and even hospitals. The resolution also enables the speaker to appoint an oversight committee composed of three legislators, representatives from IHDD, GAO and GCDD and others, of whom 60% will be people with developmental disabilities and/or their family members. The plan will be delivered to the speaker by July 1, 2006, with the first budget proposal for implementation for FY 2008.

Advocates found legislators to be receptive and attentive to disability issues. Unlock representatives have requested meetings with the speaker after the session to review the multi-year funding plan and discuss strategy for next year. Advocates made great strides for the coming fiscal year, but the waiting list is a multi-year problem that requires strategic, proactive, aggressive fiscal policy. Advocates look forward to working with legislators to address the remaining issues of the community of people with developmental disabilities.

For the latest news and updates, visit *www.gcdd.org*.



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

Stakeholders Reveal Hopes for the Future

Disability Advocates Dream of Better Services

By Valerie Smith Buxton

hile disability advocates across the state cheered the large number of waiver slots being proposed in the Georgia budget, 14 advocates came together during Disability Day to discuss their vision for a brighter future for people with disabilities.

Facilitated by Dottie Adams, family and individual support director for the Governor's Council on Developmental Disabilities, the group of advocates touched on a variety of topics that affect people with disabilities from birth through old age.

Pat Ellis, a parent from Commerce, said learning about services and supports as soon as a diagnosis is made is crucial. "Parents need mentors as early as possible." Gary Mize, a service provider in Elbert, agreed. "We need to seek out parents to let them know services are available."

Several participants felt if agencies knew about each other, that would help people with disabilities get the services they need. "It would be great to have a one stop shop for services," said Vicki McCletion of Lutheran Services in Atlanta.

"I'd like to see a referral system for all early intervention programs – an 800 number people could call and get information," said parent

Theresa Christian of Griffin. "Churches are missing an

opportunity to minister to young parents," Bobby Holcombe, a parent in Carrollton commented.

"We need circles of support in the community that are linked with agencies already in place, like churches," Augusta parent Geneice McCoy said. Everyone agreed respite care was important at all ages, and educating families about respite services was critical.

"People may not know it's out there," said

Mandy Griffin, a parent mentor and former judge from DeKalb County.

Mother Bobby Goldberg said giving information to siblings of people with disabilities is important too, because currently "We need circles of support in the community that are linked with agencies already in place, like churches . . . "

Geneice McCoy

all materials are designed with the parents in mind, but not other children.

Once children with disabilities enter school, the advocates said they would like to see a number of changes. George Bell, of People First in Commerce, said, "Schools should have support for different learning styles of their students."

McCoy was concerned about children in school *(continued on page 14)*



"We need to seek out parents to let them know services are available." Gary Mize

Self-advocates, parents and service providers share their hopes for the future with moderator Dottie Adams (standing) of GCDD (photo at right).



State Leaders Say Community Integration Key

ith proposed funding for 925 waiver slots and new leaders in the Department of Human Resources (DHR) who are committed to community integration, Georgia is showing a renewed commitment to improving the lives of people with developmental disabilities.



"We want to work to create an array of services so there's real choice, not just additional service providers." Gwen Skinner

Director Gwen Skinner, of the DHR's Division of Mental Health, Developmental Disabilities and Addictive Diseases, is impressed with the support the governor and legislators have shown for the proposed waivers. "I'm so pleased and excited that we've pushed that initiative forward and found the legislators extremely receptive," she said.

Skinner knows, however, there is still work to be done. "We're going to aggressively pursue unlocking the waiting lists," she said. Skinner and Dr. Stephen Hall, the new director of the Office of Developmental Disabilities of DHR are working to do that.

Hall, who directed a communitycentered board in Colorado that provided service systems for people with developmental disabilities, is adamant that the best way to serve people with disabilities is in their natural communities.

"I want a future where people with developmental disabilities are a part of their community, not apart from their community," he said. "You don't have to imagine that in Georgia. It's already happening right now in some places, where local leadership is creative and has gone through hoops to achieve community integration."

He wants to remove some of the hurdles so everybody with developmental disabilities can be more integrated into their communities.

Hall feels one way to do that is to offer a more flexible funding mechanism. "Services should be individualized so each person gets exactly what they need."

In less flexible funding situations, people with disabilities may receive services they do not need simply because of rules and regulations that are in place. Hall is also a believer in well-trained service personnel.

"The enemy of people with developmental disabilities is staff turnover. The only way to reduce costs and achieve superior outcomes is to pay to help good professionals do their best work," he said. "We can drive down the cost of delivery and help people become more independent if we have direct service staff who are better paid and well trained."

Skinner and Hall have begun to forge

partnerships with other agencies, such as the Departments of Labor and Education to ensure people with disabilities have access to quality services. "Public education matters a lot. If kids have access to good transition programs and relationships, it lessens their dependence when they graduate," Hall said. "We have some schools in Georgia that deliver the best you'll see in special education, while others are just meeting the requirements."

Hall hopes to bring some consistency throughout the network of service providers in the state. "We need to expand what they're doing right. If the quality of care is good in our communities, institutions will no longer be needed."

"I want a future where people with developmental disabilities are a part of their community, not apart from their community." Dr. Stephen Hall



In addition to quality care, Skinner wants Georgians with disabilities to have more choices. "We want to work to create an array of services so there's real choice, not just additional service providers," she said.



Dr. Stephen Hall talks to (left to right) Sarah Galloway, Robert McNamara and Stephanie Koch during Disability Day about how they want to live their lives.

r. Stephen Hall has brought passion and a commitment to facilitating community living to the Department of Human Resources' Office of Developmental Disabilities.

The new director, who was executive director of Colorado's second largest community-based service board has been integrating people with developmental disabilities into the community for the past several years and is proud of Colorado's progress. "Colorado only has 140 people with developmental disabilities in institutions," he said.

Hall pointed out that Colorado's

Hall Brings Community Focus to DD Office

service system is run through private profit and nonprofit agencies. "This gives people with disabilities more choices at the local level and safer, better outcomes," he said.

While he feels funding 925 waiver slots is a wonderful start for Georgia, he feels there still is work to be done. "We're not using the natural community as it should be," he said.

Making waiver money more flexible is one of Hall's goals. "People with disabilities and their families should make the choice of where the money should be spent, and if they are satisfied with those services," he said. He also emphasizes

that improving the skills of direct support

professionals will help cut costs in the long run because support will be delivered more efficiently. He believes with proper support, many people with developmental disabilities will be able to find employment. "The key to moving people into their natural community is to make

"People with disabilities and their families should make the choice of where the money should be spent, and if they are satisfied with those services."

sure they have the supports they need," he explained.

Hall said that while Georgia has a lot of challenges ahead in the delivery of services to people with disabilities, he has also been very impressed with some of the programs he's seen.

"Throughout Georgia, you find many services and supports that are among the

best in the country. They are the perfect use of taxpayers' resources. We need to bring a system of consistency throughout the system so that the good services expand what they're doing right," he said.

After only a few months at his job, Hall says, "Very little has changed yet. But I've seen a willingness in people to make changes. I want the leadership from

this office to do the best work possible for people with developmental disabilities," he said.

Division of Mental Health, Developmental Disabilities and Addictive Diseases Director Gwen Skinner has confidence he will do just that. "I feel Dr. Hall is going to be outstanding," she said.

whose disability may cause behavior issues. "The public doesn't believe disability causes certain behaviors, and kids may get kicked out of school." Christian, whose young son has autism, said,

"Parents are afraid their kids will be locked up for behavior issues."

Holcombe agreed, saying, "IDEA provides some protection from behaviorrelated punishment. We need to educate teachers about the behaviors to expect." McCoy and Holcombe also felt that

parents aren't always equal partners in the Individualized Education Plan (IEP) process, which needs to be changed.

"Parents are intimidated by the IEP. They feel like they're not allowed to participate as they want," McCoy said. "We need a training process for the IEP," Holcombe said. Rincon parent Vicki Sumner said, "We offered IEP training, but people wouldn't come."

As children with disabilities enter their teens, a whole new set of challenges awaits, such as transitioning, recreation and graduation. The group's wish list for leisure activities included summer camps, more inclusive recreational opportunities and after school programs.

Johnnie Boddie, of the Atlanta Alliance on Developmental Disabilities in Atlanta stressed the need for students with disabilities to show their academic abilities. "Instead of a special education certificate, these kids need diplomas, or they can't get into technical schools," she said.

Planning for life after school was also a big issue. "Transition planning should be started from an early age, and we need to involve kids in the IEP process," Griffin said.

"Transition planning should be started from an early age, and we need to involve kids in the IEP process . . . "

Mandy Griffin

ADVOCATES DREAM OF BETTER SERVICES



Geneice McCoy



Bobby Holcombe

"Students need a smooth transition from school to life," Ellis said.

Once students leave schools, the group hoped they would find a job they enjoy, just like every other kid who finishes high school. "We need more resources to support people with disabilities to find jobs they want, not just the jobs they can find," Mize said. "We should partner with employers to help people find jobs," Holcombe said.

"Older parents with older children with developmental disabilities need help . . . " Pat Ellis Some group members felt more supported employment options were needed, while others liked the idea of self-employment programs. Everyone agreed jobs encouraged independence, a key goal for the group. Transportation,

housing and lack of trained support workers and health care providers were listed as other obstacles for people with disabilities.

Dr. Licheng Tian, who works at Gracewood Hospital in Augusta, said, "We need to train health care providers to care for patients with developmental disabilities, especially as these patients age."

Aging people with disabilities were a big concern for some. "Older parents with older children with developmental disabilities need help," Ellis said.

Overall, the group's vision for the future included better

trained direct support professionals, more community involvement and independence for people with developmental disabilities.

"Parents are afraid their kids will be locked up for behavior issues." Theresa Christian



Theresa Christian



Janet Deal



George Bell

Focus Group Members

pecial thanks to the disability advocates who took time to share their viewpoints on the future of developmental disability services:

George Bell

People First and Voices that Count graduate – Commerce

Johnnie Boddie

Direct support worker with Atlanta Alliance on Developmental Disabilities – Atlanta

Theresa Christian Parent – Griffin

Janet Deal

Rescare and president of SPADD (Service Providers Association for Developmental Disabilities) – Atlanta

Pat Ellis Parent – Commerce

Bobbie Goldberg *Parent* – Atlanta

Mandy Griffin

Parent mentor and former juvenile judge – DeKalb County

Bobby Holcombe

Parent and representative of the ARC of Carroll County – Carrollton

Mike Jackson

President of Region III People First Chapter and Voices that Count graduate – Commerce

Vicky McCletion Lutheran Services – Atlanta

Geneice McCoy Parent – Augusta

Gary Mize Advantage Behavioral Health and Hart County commissioner – Elbert

Vicki Sumner Parent – Rincon

Dr. Lee Tian Parent and physician at Gracewood – Augusta



The focus group discussed the issues that affect people with disabilities across the age spectrum.

Proposed Amendment Would Put Civil Liberties at Risk

By Maggie Garrett, American Civil Liberties Union of Georgia

uring this legislative session, Gov. Sonny Perdue introduced a "Faith & Family Amendment," with the stated purpose of aligning Georgia's Constitution with current practice. But, the amendment does much more, which is why the resolution has garnered criticism from religious, education and civil liberties groups.

Under the current Georgia Constitution, religiously affiliated social service agencies can and do receive state funds under certain conditions. These conditions, which also apply to secular organizations, include: taxpayer money may not go



Maggie Garrett

works on constitutional issues as the legislative counsel/staff attorney for the American Civil Liberties Union of Georgia. She has a special expertise in separation of church and state law and has been involved several cases, including Turner v. Habersham County and Glassroth v. Moore, and she is currently involved in litigating Doe v. Barrow County.

directly to a house of worship; may not be used to discriminate in hiring or in the delivery of services; may not be used for proselytizing or religious activities; and is subject to government audit.

These partnerships have successfully operated under our current constitution for decades, and there are no pending lawsuits that challenge the arrangement. An amendment is unnecessary.

Even if an amendment were needed, this resolution is not tailored to fix the alleged problem. The resolution does much more than amend the constitution to coincide with current practice. The resolution would actually repeal our state constitutional provision, providing the state with no guidance or restrictions on the money that government gives to religious organizations. And, the resolution is written so broadly that it would threaten our current public education system by allowing state public school funds to be spent on private religious schools.

One controversy that could erupt if the amendment were to pass is whether the state government could fund religious discrimination. Religious organizations are exempt from portions of the Civil Rights Act and thus can hire and fire based upon a person's religious beliefs. A religious organization can deny employment based upon a candidate's religious affiliation, marital status, sexual orientation, gender or any other characteristic that a religious organization finds objectionable.

Disturbingly, there are many, including the Bush Administration, who advocate that religious organizations could maintain this exemption even while using taxpayer dollars. Georgia's current constitution protects against this. The proposed resolution does not. The proposed plan also would not prohibit a state-funded religious provider from refusing a service to a beneficiary because of his or her religious beliefs. For example, could a state-funded religious provider refuse to serve a person in an HIV program because he is gay? Another problem would arise when the only available state provider advocates beliefs counter to a recipient's beliefs. The person who sought the service either would be forced to forgo the services or attend a program that compromises his or her religion. The current constitution protects against these problems. The proposed amendment does not.

An issue that should be of particular concern to the developmental disability community is that religious entities are exempt from the Americans With Disabilities Act. What will happen when the only available state provider of a service in the county has no ramp for entrance? The current constitution protects against this problem. The proposed amendment does not.

There is no reason to open this can of worms when our current provision has served us well for decades.

Public Funding Would Expand Services for Those in Need

By Chris Hunnicutt, Lutheran Services of Georgia

or centuries, organizations of faith have been in the forefront of public service, combating social ills, leading humanitarian causes and meeting the needs of people challenged by circumstance. In Georgia, a faith-based community established the state's first home for orphaned children which produced the state's first elected governor in 1777 – Gov. John A. Treutlen. Historically, faith groups created programs and institutions to educate and provide individuals with exemplary services, without public oversight. Out of their hearts, volunteers dedicated themselves and their resources to the well-being of others.

Over time, the government gained influence and became a larger, more prominent source of social service funding through taxation. Yet faith communities have continued to offer hope and help to individuals, groups and entire communities needing assistance. In some instances, organizations that began as faith-founded, faith-focused, dare I say, faith-based entities have established outreach services that are recognized for effective, efficient management of social programs. The Jewish Federation, the Salvation Army, the YMCA and Lutheran Services in America name only a few. They meet people's needs out of their beliefs. They consider service a fundamental tenet of their faith. They provide food, shelter, clothing, education and re-education, adult literacy, refugee resettlement, care for abused and neglected children and adults and support for women in crisis. Are such efforts unworthy of public resources simply because they are offered out of a faith-based perspective?

Those who object to public funding of faithbased initiatives often cite the following concerns: inherent religious activities; potential for discriminatory practices; independence of faith-based organizations and assurance of requirements for services.

 Require separation between activities such as worship, religious instruction and proselytizing from the services being offered. I believe meeting people's needs is universally the driving agenda, not conversion to faith or politics. Moreover, a clarification that restricts the use of public funds for these religious activities would address these concerns and could meet the Establishment Clause of the First Amendment.

- Prohibit restriction of services on the basis of religious belief or practice, or lack thereof.
 Discriminatory practices can be monitored and avoided by establishing rules and reviewing the organization's mission statements and bylaws.
- Independence of faith-based organizations is fundamental to sound implementation of services.
 Yet, the characteristics of these institutions include their mission, practices and beliefs and should be permitted because they are fundamental to the



Chris Hunnicutt

is the State Program Manager of "FACES for People with Developmental Disabilities," a program of Lutheran Services of Georgia, that focuses on individualized residential supports. He is a graduate of Partners in Policymaking, serves as the President of The Arc of Georgia and is on the Governor's Council on Developmental Disabilities. His son, Christopher Aaron, is a developing self-advocate.

individuals who work to serve.

 Finally, procedural rules and regulations to ensure compliance are in place. Whether faith-based or not, guidelines already exist to provide a framework for the delivery of supports for those who provide services and those who receive services.

Human services, largely the arena in which faithbased services exist, are matters of the heart. Surely we acknowledge people of faith have shown their hearts and have improved others' lives through their service. We have an opportunity, perhaps even a responsibility, to expand services by expanding resources to include communities of faith who are capable and interested in meeting those needs. This is the time and place to put aside the barriers to expanding supports to those who need them.

Waiver Recipients Have Choices to Make

ith the proposed 925 Mental Retardation Waiver Program (MRWP) and additional Independent Care Waiver Program (ICWP) slots waiting to be unlocked, many Georgians may soon have the ability to make their own choices.

Living in Georgia, a state committed to selfdetermination for people with disabilities, people with waivers will get to decide which services they

need and who will perform them, as well as finding their own places to live rather than being placed into uncomfortable, unhappy situations. Soon, if the waiver slots are unlocked, many people will enter the world of self-determination, a world of choices and as Gov. Sonny Perdue once said, a world of freedom. They will choose whom to hire, where to live and possibly whom to fire.

Finding Providers

Self-determination is about choice – that means no one should ever feel they have only one service provider from which to choose. A good place to get a list of providers is a regional Department of Human Resources (DHR) office. Providers can be great sources of information about other service providers. It also doesn't hurt to seek the opinions of

people with disabilities who live in the community. Jamaica Miller, 26, of Athens, has another

method of finding personal care assistants. She and her mother, Dianne Miller, run employment ads in the paper and interview personal care assistants themselves, as well as hiring through word of mouth. Jamaica has had the ICWP waiver about two years. "We don't always get certified nursing assistants (CNAs) because they already tend to have a mindset about how to treat someone with a disability," her mother said. "We want her to have a life in the community, not sit with a CNA at home." One of their recent ads read:

Friend and companion needed for 26-year-old female who is blind. She enjoys singing, attending church activities, swimming, working on the computer, volunteering, meeting new people. Applicant must be dependable and organized, fun and motivating. Nonsmoker. Duties include assisting with personal care and housekeeping tasks, cooking healthy meals, promoting a consistent exercise program and providing support for participation in various community activities. Part time. Must have reliable transportation. Basic computer skills desirable.

Once waiver holders learn about the service providers in their communities, it's important to investigate further. Carol Perkins, director of services for Georgia Mountain Community Services said that there would be many people she'd talk with in addition to the administrator who is the initial contact. "I'd want to talk to the local manager, staff and other people who are receiving services," she said. "I suggest looking for a provider who is going to really get to know the person, who demonstrates proof of accessing community resources, will support the person in creating a stable living plan, recognizes the importance of choice, is financially stable and demonstrates person-centered values. I'd also want to look at any kind of customer satisfaction data the organization might have." As with any business, another place to see how the organization treats customers is the Better Business Bureau. Complaints filed against a service provider as well as how the organization dealt with the complaint can tell a lot about what kind of service to expect.

Top Three Pointers for Provider Shopping

- 1. Interview, interview, interview!
- 2. Ask for references.
- 3. Take your time.



Jamaica Miller (center) prefers to hire sociallyinclined assistants like Ragan Pennington (right), who accompanied Jamaica and her sister, Dixie Miller (left), to a neighborhood Bunco party.

26-year-old woman in Athens named Jamaica Miller has a dream to live independently one day. She has been unable to see since birth and experienced a head injury about three years ago. She had already applied for the ICWP before her accident and received it afterward in 2002. She exercises her right to make choices by placing ads and interviewing her assistants, or "companions" as she calls them, with the support of her mother, Dianne Miller.

At home, her assistants help prepare meals, do laundry and shop for groceries. However, Jamaica

"We look for people who are energetic, fun, young, like to go out and do things." Miller also wants assistants who like to get out of the house. "We look for people who are energetic, fun, young, like to go

Jamaica Miller, Waiver Recipient

out and do things," her mother said. "One of her companions came with music and added a lot of joy to her life." Since Jamaica Miller's recovery, her waiver allowed her to start volunteering at South Jackson Elementary School and St. Mary's Outpatient Rehab. She also serves as an assistant Girl Scout leader. Before receiving the waiver, she couldn't have worked or volunteered because she wouldn't have been able to get to her jobs without her assistants.

Socially, she has blossomed. Her companions take her to church, where she loves to sing at a college service. Afterward, she usually goes out to a restaurant and mingles with the students. She also enjoys going to local venues where musicians play.

Her first time out was to see one of her companions play guitar on his night off. When he saw her there, he dedicated a song to her and according to her mother, it made her night.

"She's at a point in her life where normally there would be a separation from mom and dad, and she's not ready for that yet, but the service providers give her a degree of control that she would never have without the waiver," Dianne Miller said. "She gets to do things even if mom's too tired to take her." When Jamaica Miller interviews prospective assistants, she lights up if they are musically-gifted. She enjoys singing along when her friend and companion Joe Guerzo plays the guitar.



Interviewing Personal Assistants

Perkins suggests it's important to interview potential personal care assistants, not just the organizations they work for. Some personal care assistants help with daily tasks like cooking or doing laundry while others may assist waiver holders at their jobs.

John Chandler, director of Star Choices, Inc. in Macon explained that finding a personal care assistant is a lot more personal than most people assume, and finding the right one requires a lot of homework. "It's almost like doing an online dating questionnaire," he said. "The important thing is compatibility. What TV shows do you like? Are you a night person or a morning person? Do you like sports?" He explained personal care assistants often end up integrating into the person's home, and it's important that they are able to be part of the family without taking advantage of that close relationship. "Do they have the ability to be your buddy and respect the relationship and what the appropriate tasks in the relationship are? It's rare to find someone who can really walk that tightrope," he said.

Trish Farnham, executive director of Georgia Options agreed. "When you receive waiver services, it should be a partnership," she said. "It is a marriage of a whole lot of different people – the person receiving support,

"It's almost like doing an online dating questionnaire . . . The important thing is compatibility." "The more they can mesh their life with yours and they're happy, the more likely they'll stay."

the family, the coordinator, the state." The Miller family is a good example of how intimate the relationship can be. Because Jamaica Miller's assistants have become family, they are not referred to as personal care assistants.

"We call them friends and companions," her mother said.

Dianne Miller said that the questions she and her daughter ask when interviewing potential "companions" have evolved over the years. After one assistant got sick and had to quit due to animal allergies, they started

asking whether or not the prospect likes cats. Jamaica Miller had such strong reactions to the smoke on another assistant's clothing that she had to let her go. Now, smoking always comes up toward the beginning of an interview. A singer, she also enjoys personal care assistants who have musical inclinations, although it's not required. "We ask them to tell about themselves – degrees, age, hobbies, animals – and usually they tell us without having to ask too much more," Dianne



A consumer of waiverfunded services, Anthony Maynard (right) exercises selfdetermination through membership in the Star Choices Human Rights Committee, as he discusses various issues with Richard Keil, a family counselor and chairman of the committee. Miller said. "The more they can mesh their life with yours and they're happy, the more likely they'll stay."

Dianne Miller also asks, "How do you feel about working with a person with a disability?" This question can reveal potential "companions" for who they really are. Dianne Miller said she knew one man was not a good fit when he responded, "I could take care of somebody like that." She also thinks it's a good sign when

potential employees ask to speak with her daughter because it shows they want to get to know her.

After the interviews, the women discuss the prospects as a team. "We get up to 50 phone calls after an ad, so we keep detailed notes on each one," Dianne Miller said. "Then, after we interview them, we give them a score of one to ten."

Here are some other good questions that service providers suggested asking:

- What are your interests?
- Do you participate in any clubs or organizations in the community?
- Do you consider yourself a creative person?
- What do you do for fun?
- What part of the day are you at your best?
- What's your outlook on life?



T.J. Redding (center) works on a copier at ColorQuick with his supervisor, Denise Arnold (right), a job he secured with assistance from waiver-funded services and his job coach Don Boughton (left).

The interview questions for potential assistants vary depending on the support needed. However, there are some common qualities to look for in an assistant. "I think they need to be good listeners, respectful of the person they're working with, resourceful and connected to the community," Perkins said. "They need to recognize the uniqueness of each individual and tap into that uniqueness, helping the person to recognize their gifts and talents and see how to be part of the community. They need to be creative in finding strengths, skills, abilities and what they have to give, and at the same time, not inflicting personal standards on the person – it's a hard job and it's a wonderful job for people who are good at it."

Choosing Where to Live

Self-determination is also about choosing where to live – not being told where to live. Many providers will help the waiver holder find housing. However, Perkins pointed out that finding housing and roommates for people with disabilities isn't too different than finding housing for anyone else. "In an ideal situation, you would hope that the person would be well-connected enough with the community that they would find one just like anyone would," Perkins said. "You'd look at finances and compatibility, regardless of ability or disability."

Chandler said that sometimes money gets in the way of his customers getting everything they want, as is the case with most people, but he has a few guidelines when helping someone find a house or a roommate. "Would I live there? Would I be willing to have this person live with me? Would I feel comfortable with this?" he questioned. "Ninety-nine percent of the time, the service provider's feelings will be the same as the individual's. We're not all that different."

Farnham's organization usually matches people that the organization serves as roommates. "We spend a lot of time making sure the two potential roommates get to know each other before they become roommates," she said. Oftentimes when housing isn't available in someone's price range, Chandler and his organization, Star Choices, get creative. They often "retrofit housing for people with physical issues such as wheelchair access and shower conversion." But when there's not enough money for these needed renovations, the organization asks a church to volunteer to help fix it or asks someone to donate money toward the project.

Freedom of Choice

People with waivers should remember that they are consumers like everyone else and have a right to freedom of choice.

"Some people think the only choice people get is to choose the provider, and from then on, the provider drives the choice. I don't think that's the idea," Chandler said. "People need as much choice as bureaucratically possible in terms of what service they receive, when they receive it, who their contact is in the agency and who provides the service."

Many programs don't operate with this philosophy. Some service providers see the parents of a person with a waiver as the main customer and see the person with the waiver as the secondary customer. Sometimes, the person holding the waiver doesn't get things done his or her way because someone else has the last say.

Chandler pointed out that, as with any industry, there are good providers and bad providers. A waiver equals money, so some providers will promise anything to get the waiver, even if they can't keep their promises, such as good service down the road if a problem occurs, or funding for housing or transportation that doesn't exist. "The biggest way to make sure this doesn't happen is to do your homework on the front end and talk to their customers," Chandler advised. "Have a conversation with someone being served by them; you

may find they were really attentive and reasonable when they had a problem." He also pointed out that although it's sad that some organizations care more about the money than the person holding the waiver, more service providers – good and bad – mean competition.

"Consumers have more choices because of competition," he said. "That's a good thing, but only if consumers are good shoppers."

"Consumers have more choices because of competition. That's a good thing, but only if consumers are good shoppers."

Questions to Ask Potential Service Providers

Provided by Trish Farnham, Georgia Options in Community Living

Person-Centered Supports

- What's your definition of person-centered supports?
- How do you get to know a person before supporting him/her?

Recruiting/Hiring Staff

- How do you recruit your staff?
- What role does a person play in determining who supports him/her?
- How predictable are the staffing patterns? Will the same person typically work the same position?

Teaching Staff

- Who initially teaches staff when supporting a new person?
- How much teaching is your staff required to have before supporting a person independently?
- Who else in the organization (other than direct support staff) will know a person's needs well?



Tailor your questions for service providers to meet your specific needs. The questions that Dianne Miller (left) and her daughter Jamaica ask when interviewing potential "companions" have evolved over the years.

Meaningful Days

- What are your thoughts on supported employment?
- How do you support a person to build a meaningful day?

Personal Finances

- Do you require that you become a person's Supplemental Social Security Income (SSI) representative-payee?
 - How are personal finances safeguarded?
 - Who chooses the person's bank?

Health and Safety

- What is your oversight of behavior support plans and psychotropic medications?
- Does the person choose his/her own doctor?

Organization Accreditation

- Who accredits you?
- What is your organization's vision for people with disabilities?

Continuity

- If a person discontinues services, must he/she leave the home?
- How do you ensure emergency backup?

Person-Centered Planning: By Christina Carlton Focusing on Abilities

eciding on a career path is difficult for most people especially for people with disabilities who have been told what they can't do over and over again. Many of them don't realize they have a choice to work, to volunteer, to contribute to society.

But what if people with disabilities had networks of support and encouragement that came together to talk about their skills and how to apply them? People with positive support can accomplish a lot. And they are accomplishing a lot already through personcentered planning.



O'Brien explained that all people who have a connection with the person such as family members, service providers, schoolmates, teachers and friends from church, should be considered part of the team.

First, the group maps out the person's life who they spend time with and where they go. All too often, the map reveals that all of the person's activities are focused on service providers. "We try to get them more into the community rather than just service places," O'Brien said.

Next, the group discusses what situations put the person at his or her best and worst. "What makes them alive, energetic, excited? What doesn't? I ask this to get very explicit directions about the person. This is key to designing a plan that works for them," O'Brien explained.

This methodology came in handy for a young man attending Salem High School in Rockdale County. Ryan Shadrix, an 18-year-old student who has microcephaly and moderate developmental delays, participated in a person-centered planning group. Yard work was immediately identified as something that "works well" for Shadrix. However, when the possibility of working with a landscaper was explored, someone pointed out that he doesn't like sudden changes in his schedule,



something common to the landscaping business due to weather. So the focus was guickly changed to other opportunities.

Next, someone pointed out that he likes working with children. Shadrix had attended My Special Friends

Daycare for seven years. The owner, Carolyn Peacock, suggested he could help out with a Thanksgiving feast in November.



Jessie Solomon (center) with her team mapping out strategies to meet her goals of being more social and comfortable with new people.

Ideally, in person-centered planning, a group comes together to discuss a person's abilities - not deficiencies - and develop an executable plan to support the person's goals. According to Connie O'Brien, an

internationally renowned expert on person-centered planning, a job is usually the most common goal. "Most people with disabilities want to work, earn

Ideally, in person-centered planning, a group comes together to discuss a person's abilities – not deficiencies – and develop an executable plan to support the person's goal.



"Ryan helped carry the food out, set up tables and chairs, played with the kids, and he helped clean up and take care of the garbage," said his mother, Sharon Potts. "He had a great sense of accomplishment that day." After the event, Shadrix proudly told his mother, "I was in charge of the kids!"

Potts was enthusiastic about the session because others in the group pointed out skills that she had never known her son possessed. "It was a surprise to us that this was under our noses the whole time and we never thought of it," she said.

She was also glad to start thinking about his future before he graduated. "This workshop brought home to my husband and I that it's not too early to start thinking about this."

Jessie Solomon, a student at Alpharetta High School, is also in a person-centered planning group. A 19-year-old with autism who is nonverbal, her immediate goals are not to work, but to be more social and learn how to be comfortable getting to know new people.

"Most people with disabilities

want to work, earn money,

help other people . . . people

don't want to always be on

the receiving end of help."

However, her mother, Patti Solomon was hesitant about person-centered planning at first. By asking others to join her daughter's "circle of friends," she was risking rejection. But she took the chance. "This process showed me that lots of people were willing to give their time," she said. "I thought I was totally

alone and now I feel totally different."

Since the first planning session last fall, Jessie Solomon's circle of friends has worked with her to build up a large social network. She belongs to a dinner club, goes to sleepovers and church. Last year, over 100 friends came to celebrate her birthday.

Now that she is thriving socially, her mom isn't just sitting back. With a team of other parents in the community, she is forming a booster club to "find ways to have our kids working, socializing and living a full life without state funding." Patti Solomon said, "She's got two years of high school left and when she's done, she's not going to sit at home!"

Alex Simmons, a student in the Fayette County School System is reaping the benefits of personcentered planning. His mild intellectual disabilities have not stopped him from being an award-winning gymnast, and they won't stop him from working either. With encouragement from his circle of friends, he started volunteering at Gym South. Soon, he hopes to become a paid employee.

His mother, Opal Simmons, said that sometimes it's hard to let a child grow up. "It's very hard to let go, especially when they have a special need; oh God is it hard," she said. "There's a scene in the movie *Ray*... his mother is teaching him how to count steps, and he comes in the house and falls. He's crying out for her and she steps toward him but steps back because he has to learn how to do it on his own.

"That's what it's like to have a child with a disability – you want to help them but you have to step back. You've got to let them grow. That's part of person-centered planning – you've got to let them grow because they can do a lot more than you give them credit for."

Despite the great results for these families,

person-centered planning is not widely used in Georgia. "We don't have a lot of people who can facilitate person-centered planning, although there have been many efforts to train people to feel confident enough to do it," said Dottie Adams, family and individual support director for the Governor's Council on Developmental Disabilities.

However, Adams will work to train those interested in facilitating person-centered planning. To learn more, contact her by emailing Opal Simmons (center), and her son Alex (right) meet with his circle of friends to discuss his job opportunities.



Coached by Bobby Allen (left) at Gym South, Alex Simmons (right) won six medals in last year's Special Olympics and Nicholas Sanchez (center) won five. With encouragement from his circle of friends, Simmons started volunteering at Gym South and hopes to become a paid employee soon.

Advocates Influence Legislators During Disability Day

ore than 1,300 disability advocates gathered at the Georgia Capitol in Atlanta on February 24 to educate legislators on the issues that affect them the most. During the 7th Annual Disability Day at the Capitol, advocates cheered the governor's proposed 925 waiver slots and service provider pay increase, but were opposed to spending

caps on the Independent Care Waiver Program (ICWP) that might send some people back to nursing homes.

"No caps. No levels on the ICWP," the crowd chanted, along with "Our homes, not nursing homes!" Samuel Mitchell, president of People First of Atlanta led these chants, as well as "Free our brothers. Free our sisters. Free our people now!"

Speaker of the Georgia House of Representatives Glenn Richardson (R-Hiram) told the crowd he had recently broken his ankle, giving him a small taste of what life is like for those who use a wheelchair on a daily basis. "Thank you for making us aware of your issues. We are working through one of the toughest budget crises since the depression, but we look forward to releasing funding to unlock the waiting lists and meet your needs," he said.



The day also included speeches from federal officials. Dr. Margaret J. Giannini, director of the Office on Disability, U.S. Department of Health and Human Services, updated the crowd on disability issues at the national level. "This month is the fourth anniversary of

President Bush's New Freedom

Initiative, a bold plan to tear down the barriers of equality that affect the 54 million Americans with disabilities," Giannini said.

(continued on page 26)

Samuel

Mitchell, president of People First of Atlanta (1), Speaker of the GA House of Representatives Glenn Richardson (R-Hiram) (2) and Dr. Margaret J. Giannini, director of the Office on Disability, U.S. Department of Health and Human Services (3) spoke to disability advocates.

Legislators By Christina Carlton Work For You!

ver 150 people packed in like sardines at the Capitol for two advocacy forums during Disability Day. The forums opened with encouragement and advice for communicating with legislators from Sen. Sam Zamarripa (D-Atlanta).

"Welcome to the Capitol!" he said. "People here work for you. You put us here, and you are our responsibility. Don't forget that. They need to hear from you."

He encouraged forum attendees to find their legislators and tell their stories. "Your message moves people," he said.

Georgians from as far away as the Florida and Tennessee state lines and Savannah gathered around Dave Blanchard, advocacy director for the Atlanta Alliance on Developmental Disabilities and coordinator of the Unlock the Waiting Lists! campaign. He gave a seminar on what disability issues were hot buttons to discuss with legislators.

First, he explained how to call legislators off the floor and speak with them during their session. Anyone can go to the third floor of the Capitol where the Senate and House of Representatives meet, and write a note to them at the page desk outside of the respective chambers. A page carries the note inside and comes back with a reply. In the best case scenario, the legislator will come out and meet

with the advocate. However, sometimes he or she isn't there, or is in the middle of an important presentation that cannot be disrupted. Blanchard explained that this should not discourage anyone, and they should keep trying until they have success.

Next, he reviewed the messages to be communicated with them when they came off the floor. First, fund 925 waiver slots for people on the 5,000+ waiting list. Second, tell them to vote

"no" on the Independent Care Waiver cap. Last, he informed the crowd that their service providers are being paid the same wages as fast food employees. "Is that what we want?" he shouted. A woman in the crowd responded with "No sir! We're getting what we pay for!"

Blanchard noted that Disability Day was a great day to advocate, but people needed to

"An issue that is not on somebody's radar becomes an issue when they get eight letters about it."

that letters go a long way. "An issue that is not on somebody's radar becomes an issue when they get eight letters about it."

To find your elected senators and representatives, visit *www.vote-smart.org* and enter your zip code.



"Welcome to the Capitol! People here work for you. You put us here, and you are our responsibility. Don't forget that. They need to hear from you."



Sen. Sam Zamarripa (D-Atlanta) gives advice on communicating with legislators (4-left) to open the advocacy forums held during Disability Day. AADD Advocacy Director Dave Blanchard (5-far

left) gave a seminar on what disability issues were hot buttons to discuss with legislators.



After the speeches and rally at the Capitol, advocates marched to the Georgia Freight Depot.



focus on the disability

rights movement for

the long run, too. "We have long-term

care solutions that will take long-term

dedication," he said. He told advocates





More than 1,300 disability advocates gathered at the Georgia Capitol in Atlanta on February 24 to educate their legislators on the issues that affect them the most. Reporters from GPTV, WSB-TV, WABE 90.1, the Atlanta Journal/ Constitution and Augusta Chronicle covered the event. The New Freedom Initiative goals are to:

- Help people with disabilities enter the workforce
- Promote decent, safe housing and home ownership
- Expand transportation options
- Increase access to assistive technology and universal design
- Provide more access to community lifeImprove educational opportunities

Giannini said the federal government is taking

steps to reach these goals by offering Real Choice System Change grants to states to help fund programs. Funding the Ticket to Work program on the state level helps people with disabilities find employment without losing their (state provided) health care benefits; and funding new initiatives such as "Money Follows the Individual", a five-year demonstration to help people move from institutions into their communities.

"Georgia is receiving \$1 million plus in Real Choice System Change grant funding," she said.

Gov. Sonny Perdue's Policy Director Trey Childress updated disability advocates on strides Georgia is taking to improve the lives of people with disabilities. "We've recommended more waivers each year, despite the state's budget problems," he said. Childress said the

A Step Backwards

A bright young woman with dreams, plans and her whole life in front of her would be devastated if a cap was put on the ICWP. Dawn Alford, a student at Georgia Tech, recently moved into her first apartment with the assistance of the ICWP. However, the proposed cap would force her to move out of her apartment and into an institution – a step in the wrong direction for her and many others across Georgia.



state would continue to work on disability issues and assured the crowd, "Self-determination will be the model for all waivers in Georgia."

After the speeches and rally at the Capitol, advocates marched to the Georgia Freight Depot which was filled to overflowing, forcing dozens of people to find seats outdoors.

Arc of the United States Assistant Executive Director for Membership and Program Services Sue Swenson was the first to speak at the depot.

"You have a new day in the state of Georgia. Your governor is talking about self-determination. (Office of Developmental Disabilities Director) Steve Hall understands you have to listen to people. President Bush is trying to reorganize the government to serve each citizen. We have to rededicate ourselves to a government of the people, by the people and for the people so it doesn't perish from the earth," she said.

As part of Disability Day activities, Atlanta Alliance on Developmental Disabilities Advocacy Director Dave Blanchard updated advocates on budget items, noting that more than 5,600 people are still on the waiting lists, with 2,500 of those on the short-term crisis list. He also said the state House had voted to return money to the budget to prevent parents from paying a premium on the Katie Beckett, or Deeming waiver.

Blanchard urged advocates to oppose a proposed cap on the ICWP. "We have to keep the pressure on our legislators," he said.

New Department of Human Resources Director of the Office of Developmental Disabilities Dr. Stephen Hall said he had been asked about future plans for the department, and he responded, "Which vision do YOU want? We'll work together to put dollars toward that vision."

The more than 1,300 advocates who attended Disability Day were able to get their message across to a number of legislators at the Capitol and at the depot, an important task, according to Shepherd Center Advocacy Director Mark Johnson. "You must put a face

Straight**Talk**

The Job She Always Wanted

n artist, collector, athlete, music lover and scientist, Shannon Barnes has many choices in her life, many choices for her career. An aspiring 22-year-old Marietta woman with autism, she never let her disability (she would never even call it that) get in the way of her dream. Services Board (CSB) for job-hunting assistance. Through their office, she also received an Office of Disability Employment Program (ODEP) grant that helped her purchase a laptop and a microscope to use at her job. Along with her knowledge of science, resource ownership would help her become a valuable employee.



Assisting Dr. Rowell in surgery is one of Barnes' regular tasks at the Cat Care Hospital. Here, she helps prepare a cat for surgery.

"She doesn't let anything stop her," said James Barnes, her grandfather.

"Autism is beautiful, not tragic," Shannon Barnes explained. "We all have our strong points, our weaknesses, good days and bad . . . we have hopes and dreams, ideas and plans and goals."

In the fall of 2004, she received her degree from the School of Animal Science in Atlanta. Typically, students take six to 10 months to complete the program, but Barnes' love of science propelled her to finish within three months.

Toward the end of her program, she contacted the Cobb-Douglas Community

With the help of her job coach, Nicole Bass, Barnes found a job faster than it takes most college graduates to get their resumes together. She and Bass visited and networked with veterinary hospitals in the area after she received her degree.

Barnes was soon hired as an animal care specialist and quickly became an asset to the Cat Care Hospital in Marietta, working closely with veterinarian and owner Dr. Debra Rowell. "Shannon is very dedicated, very committed; she cares for the kitty cat and she has great selfesteem," she commented.

Barnes is responsible for assisting Rowell during surgery, doing lab work, taking x-rays, checking for ear mites, taking

blood and urine samples and administering medicine and shots.

"I love my job. I love animals and I know a lot about them," she said. "With the support and understanding of my boss, my job coach and my coworkers, my differences do not get in the way of my ability to do my vet technician job. I am very thankful to have the job I always wanted."

According to a paper Barnes wrote entitled *Me and My Autism: Who I Am and Who I Want To Be,* she had some rough years in school because her teachers didn't always understand her. However, she feels that her life is better now since people in her life make an effort to understand her. "Autism is beautiful, not tragic. We all have our strong points, our weaknesses, good days and bad . . . we have hopes and dreams, ideas and plans and goals."

"Once I got the right support, my life turned around," she wrote. "All people have got to do to live better and easier with autism and other special needs is easy. You need to relax, open up your mind, your heart and your eyes, and don't be afraid to take the time to know us and learn about us."

For more information about customized employment, call your local vocational rehab center or contact Cobb-Douglas CSB by visiting *www.cobbcsb.com* or calling 770-422-0202.



Barnes loves all facets of her job: doing microscope work, taking x-rays, checking for ear mites, administering medicine and shots and taking blood and urine samples.

www.gcdd.org



RESOURCES



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

Governor's Council on Developmental Disabilities (GCDD) www.gcdd.org 404-657-2126 or 888-275-4233 (ASK-GCDD)

State Government

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

Department of

Community Health http://www.dch.state.ga.us/ 404-656-4507



Department of Human Resources http://dhr.georgia.gov 404-656-4937

Customized Employment

Cobb-Douglas Community Services Board www.cobbcsb.com 770-422-0202

Finding Service Providers

Better Business Bureau www.bbb.org 703-276-0100

Georgia Dept. of Human Resources (DHR) Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD)

www.mhddad.dhr.georgia.gov 404-657-5737

To find your local DHR office or search for service providers in your county, click on "Services" then click on "Developmental Disabilities." Scroll down and click on "Find a Service Near You" or click on "Regional Office" for the DHR office serving you.

Georgia Mountain Community Services

www.gamtns.org 800-525-8751

Georgia Options, Inc. 706-546-0009

Star Choices 478-743-9801



Future of DD Services

Georgia Department of Human Resources (DHR) Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) http://mhddad.dhr.georgia.gov/ portal/site 404-657-5737





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Legal Update: IDEA 2004

Office of Special Education Programs http://www.ed.gov/about/offices /list/osers/osep/index.html 202-245-7459

Person-Centered Planning

APS Healthcare http://www.apshealthcare.com/ publicprograms/georgia/pcp/ georgia_pcp.htm

Parent to Parent of Georgia http://www.parenttoparentofga. org/roadmap/education/ educationinclusionperson.htm

LD Made Easy Specializing in organization, social skills, and handwriting problems. We solve "homework wars" Author of "Learning Re-enabled" Susan N. Schriber Orloff, OTR/L Occupational Therapist, Registered and Licensed CEO/Executive Director Over 30 years experience Former resource teacher



IDEA 2004: Changes May Affect Your Student by Dawn R. Smith, Esquire

n November 2004, Congress reauthorized the Individuals with Disabilities in Education Act (IDEA). The reauthorization followed many months of wrangling between the House of Representatives, who proposed sweeping changes to IDEA that severely limited parents' rights, and the Senate, who proposed a bill that was more limited in its changes to parents' rights. The final result was a compromise that rolls back some of the gains of IDEA '97 and aligns the law with the No Child Left Behind Act (NCLB).

While in the past, IDEA made reference to the importance of research-based methodologies in the instruction of students with disabilities, IDEA 2004 now is replete with references to the importance of the use of "scientifically-based programs" in reading, behavioral techniques and early intervention. In fact, the Individualized Education Plan (IEP) must now contain a statement of the special education services "based on peer-reviewed research to the extent practicable" to be provided to the child. While a discussion of methodologies in the IEP meeting should no longer have been taboo after IDEA '97, it is now explicitly a required part of the IEP meeting. Therefore, for a child who is not reading, the team should discuss what reading program is being used with the child and what other programs are there that have a track record for working with children like the one at issue.

Another significant change in IDEA is the elimination of benchmarks or short-term objectives.

While Georgia cannot develop regulations that conflict with IDEA 2004, Georgia can expand the minimal protections offered in IDEA 2004. It is important during the interim period . . . to gather questions and concerns on the implementation of IDEA 2004 for presentation to our State Board during the regulation process.

In the past, properly crafted objectives were important vehicles to periodically monitor a student's progress during the year toward meeting annual goals. Under IDEA 2004, only the IEPs of children with significant disabilities who are subject to

alternative assessments, rather than participating in system-wide testing, must contain short-term objectives. How individual school districts will handle the elimination of this important vehicle for measuring progress remains to be seen. There is no prohibition on the IEP team for each child agreeing to keep the objectives or on the Georgia Department of Education issuing regulations to implement IDEA 2004, which require objectives.

Other important changes include the requirement of a *complaint resolution meeting* prior to a due process hearing, which can extend the time within which a hearing and decision must be issued to 75 days. In addition, IDEA 2004 no longer requires the IEP team to complete a transition plan for a child prior to the age of 16 but does *require measurable transition goals* as part of the IEP for older students with disabilities.

IDEA 2004 becomes effective in July 2005. The U.S. Department of Education plans to issue regulations in December 2005 that should provide more guidance on the implementation of the new law. After issuance of the federal regulations, the Georgia Department of Education will take public input and develop its own implementing regulations. While Georgia cannot develop regulations that conflict with IDEA 2004, Georgia can expand the minimal protections offered in IDEA 2004. It is important during the interim period in which we have no Georgia regulations to gather guestions and concerns on the implementation of IDEA 2004 for presentation to our state board during the regulation process. Your Governor's Council on Developmental Disabilities is an important part of the regulation process and will be consulted by the Department of Education. Be sure to let GCDD know how you see implementation working, or not working, so that you can have a voice.



Dawn R. Smith. **Esquire**

is a partner with the firm of Zimring & Smith, LLC in Atlanta, Georgia. Her practice centers on education law with an emphasis on representing children with disabilities. She also represents plaintiffs in disability employment discrimination. She is co-author of A Georgia Manual for Parents and Advocates and a frequent lecturer on Special Education Law. Smith graduated from Georgia State University Law School. She is a board member of the Autism Society of America, Greater Georgia Chapter; a member of the Public Policy Committee for the National Board of Children and Adults with Attention Deficit Disorder (CHADD); and a board member for the Council of Parent Attorneys and Advocates (COPAA).

CALENDAR OF EVENTS

HOW TO REACH US

MAY

May 9-11 National Training Conference for Deaf and Hard of Hearing in Government (DHHIG) George Washington University Washington, DC www.dhhig.org/ntc

May 9-13

Nat'l Institute for People with Disabilities Network 26th Annual International Conference "Building Brighter Futures for People with Developmental and Learning Disabilities" New York, NY, Tina Sobel at 212-273-6457, Email: tsobel@yai.org www.yai.org

UPCOMING CONFERENCES

September 21-24 "Many Voices, One Vision"

Alliance for Full Participation Summit 2005 will bring together those committed to making the promises in the Developmental Disabilities Act a reality.

Washington Hilton, Washington DC Contact: Carol Walsh, 301-706-6252 walshworks@mindspring.com State of GA Contact: Eric Jacobson, eejacobson@dhr.state.ga.us

www.allianceforfullparticipation.org

JUNE

June 3-5 Special Olympics GA, State Summer Games Emory University, Atlanta, GA 770-414-9390 www.specialolympicsga.org

June 6

Georgia 400 Road Race – Special Olympics GA Atlanta, GA, Lindsey.adams@ specialolympicsga.org www.specialolympicsga.org

June 19-22

Long Road Home March Olmstead Decision 6th Anniversary

Kate Gainer, disABILITY LINK 404-687-8890

JULY

July 11-14 National Council on Independent Living 2005 Annual Conference Washington DC www.ncil.org

July 13-16

The Autism Society of America's 36th National Conference on Autism Spectrum Disorders – "In Tune with the Future" Nashville, TN www.autism-society.org or

http://asa.confex.com/asa/2005/ Julv 16-17

State Master's Bowling Tournament - Special Olympics GA Columbus, GA, 770-414-9390 www.specialolympicsga.org

July 21-22

GCDD Quarterly Meeting Evergreen Conference Center Stone Mountain, GA (Tentative) Contact Kim Person 404-657-2130 kaperson@dhr.state.ga.us www.gcdd.org

July 23

ADA Memorial Gainesville, GA www.adamemorial.com

July 26 "Spirit of the ADA" 15th Annual Festival

Atlanta, GA, Kimberly Davis 404-330-6023, kdavis@atlantaga.gov

AUGUST August 13

Dinosaur Dash 5K Road

Race - Special Olympics GA Fernbank Museum of National History, Atlanta, GA, Lindsey.adams @specialolympicsga.org www.specialolympicsga.org

Letters to the Editor

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

Contact us at: makingadifference@gcdd.org Valerie Meadows Suber, 404-657-2122, Fax 404-657-2132 Or visit us at: 2 Peachtree Street, NW, Suite 8-210, Atlanta, GA 30303-3142

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For an audio version of *Making a Difference*, please contact GCDD. A large font version is available for download at *www.gcdd.org*.

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For sponsorship opportunities contact: Christina Carlton at 770-578-9765 or christina@oneillcommunications.com

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Editorial Cartoon Ideas

If you have an idea for an editorial cartoon, please email it to val@oneillcommunications.com. If we use your idea, we will acknowledge your submission.





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Albany ARC

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A child with special needs (from birth to age 21) can be referred to a Public Health Program that

the Children 1st Coordinator at your local health department at 800-822-2539
Parent to Parent of Georgia at 800-229-2038

http://health.state.ga.us/programs/specialneeds/

DIVISION OF PUBLIC HEAL FAMILY HEALTH BRANCH

· children with special needs and

serves these children by calling:

or in Atlanta at 770-451-5484

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

-UCP

services for:

their families

United Cerebral Palsy of Georgia

Supporting people with all developmental disabilities throughout Georgia

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

Babies Can't Wait Program

William?

With disability or newelopmental delay

What?

Provides evaluation, assessment, and

 Offers sairly intervention services, based an art individualized Panily Service Plan, using sliding fee scole

Children's Medical Services Program

Who?

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

What

 Coordinates/provides speciality medical systemions/treatment

High Risk Infant Follow-Up Program

What

firth to age one:

 With medical conditions requiring intension allow-up services from Poblic Health

What

Provides direct follow-up services (i.e., in-Some ming assessment and parent training)

Making@ Difference

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

Volume 5, Issue 4 • Spring 2005



Disability Day at the Capitol



Over a thousand disability advocates packed the Capitol to make their voices heard at this annual GCDD-sponsored event.



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

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