

SPRING 2006

Making a Difference



Disability Day Draws Record Crowd

Direct Support Professional
Workforce Development

Life is Better All Together

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1,600 Voters Rally for a Better Quality of Life

A record number of people with disabilities advocated for themselves and others during GCDD's eighth annual Disability Day at the Capitol.



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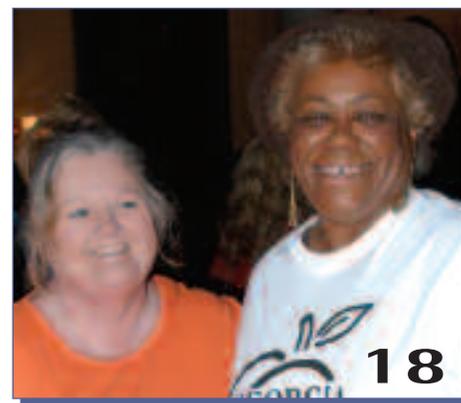
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A quarterly magazine of the Governor's Council on Developmental Disabilities

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

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

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To Georgia's Disability Community,

Georgia has become the first state in the union to adopt the Supports Intensity Scale (SIS) which helps provide support services to citizens with developmental disabilities based on their individual needs. This is a historic breakthrough for people with disabilities who will now receive support services based on an in-depth understanding of their individual lives and interests.

Georgia's new approach to defining service needs is being applauded by the American Association on Mental Retardation. This association developed the SIS to help case managers and other professionals focus on the specific needs and goals of each individual.

Dr. Stephen Hall, Director of the Georgia Office of Developmental Disabilities, in the Department of Human Resources' division of Mental Health, Developmental Disabilities and Addictive Disease, is overseeing the deployment of SIS, which he expects to help provide a fair, equitable and transparent system of funding based on a person's exact support needs. Under his direction, the state of Georgia began using SIS last November and expects 12,000 citizens with disabilities to benefit from this new approach.

Part of this improved service delivery method will be finding appropriate support staff for people with disabilities. Georgia's Department of Technical and Adult Education and the Governor's Council on Developmental Disabilities have teamed up to offer certification programs for direct support professionals to ensure people have access to quality direct support staff. The curriculum behind these programs focuses on person-centered planning and is expected to improve the quality and professionalism of support throughout the state.

The many advocates for people with disabilities continue to have a very positive and dramatic effect on state policies and programs designed to serve the disability community. Your stories and passion for your cause have been crucial during the legislative sessions over the past three years.

Providing support services on the individual level is critical to improving the quality of life for people with disabilities, and we need to continue working together to ensure the continued improvement of state programs. I look forward to our continued partnership in improving the services provided to Georgians with disabilities.



Sonny Perdue
Governor



Good Direct Support Professionals a Key Disability Issue

Shortly before this edition of *Making a Difference* was sent to you, the Georgia General Assembly finished the 2006 legislative session. Legislators spent the last 40 days debating budget proposals and legislation about how best to govern and support Georgia's citizens. While many predicted a short session because of the

upcoming elections, the session dragged on to the closing days of March. Unlike the past few years there were bits of hope as a growing economy added millions of dollars to the tax base.

For us in the disability community, it was a session highlighted by new funds for home and community-based services for people with developmental disabilities and physical disabilities. And while this session found us once again fighting to make sure those children who receive support through the Katie Beckett Waiver continued to get supports paid for through the Medicaid program, this time we hope we have ended the debate about their needs and the role of

Medicaid. All of this and more were celebrated on Disability Day at the Capitol which saw over 1,600 people from across Georgia converge on the Capitol in a spirit of camaraderie and great expectations. Elected officials, chants and remembrance of those who passed away during the last year filled the day. A new award was presented honoring the leadership of those with disabilities. Beth and Bill Tumlin presented the first Self-Advocate of the Year Award in memory of their daughter Natalie who passed away October 1, 2005. It was no surprise that Mark Johnson was the first recipient of this award. We hope this award will continue to be a Disability Day at the Capitol tradition for many years to come.

The Tumlins also helped accentuate the growing need for those who provide support to people with disabilities. The House of Representatives unanimously passed House Resolution 1401 recognizing Natalie Tumlin's spirit that led many advocacy efforts in Georgia. This resolution also recognized the role that direct support professionals played in Natalie's life and in the lives of thousands of people with disabilities and older adults. The resolution recognized the "need, importance and significant impact of a qualified,

available and adequately compensated direct support professional work force as critical to the support of people with disabilities living in their communities."

We first began writing about the growing need for direct care professionals in 2001 shortly after a conference sponsored by the Georgia Alliance on Staffing Solutions. At that conference, Robyn Stone, former assistant secretary of Health and Human Services and Amy Hewitt with the University of Minnesota Institute on Community Integration, presented state and federal statistics that supported the need to find better ways of recruiting and retaining direct care professionals. Both suggested that the solution does

"The need for qualified direct support professionals will become more apparent as Georgia moves toward more self-directed supports..."

not exist in any one approach but instead must include (1) direct care professionals feeling that they are valued by both their employers and by individuals receiving support, (2) an ongoing training program that includes both curriculum-based training and hands-on support, (3) opportunities for advancement and (4) fair wages for the quality and quantity of the work accomplished.

The need for qualified direct support professionals will become more apparent as Georgia moves toward more self-directed supports for individuals and families. As people are more in control of who provides supports and can choose non-traditional outlets, we expect an increased need for training and support for those providing personal care. We highlight two projects that the Governor's Council on Developmental Disabilities has funded over the past several years to address this issue. The Direct Support Professional Certification Program has been implemented in five technical colleges, with several others waiting to come on board. This project allows those already providing direct support or those thinking about choosing this as a career to better their skills and knowledge through both classroom and hands-on experience. In addition, GCDD funded the Alliance of Direct Support Professionals as a way for direct support staff to meet, discuss issues of concern and work together to find solutions.

As always, you can reach me at 1-888-275-4233 or you can e-mail me at eejacobson@dhr.state.ga.us.

Eric E. Jacobson
Executive Director, GCDD





Advocates Make a Difference on Disability Day

Some wise sage once declared, “If we continue to do what we have always done, we will continue to get what we always got.” For someone who has everything they need, continuing to stay the course may make sense. However, for those of us who have been involved as advocates in the legislative process, maybe it’s time to make a change in our approach.

Fortunately for us, Disability Day at the Capitol has evolved into the perfect platform to deliver our “new & improved” message. On February 23, more than 1,600 Georgians with disabilities, their family members, friends, neighbors and support professionals crowded into the Capitol and the Georgia Freight Depot to meet with legislators regarding a wide array of issues affecting their lives and the lives of those they love and care for.

The Governor’s Council on Developmental Disabilities, Georgia Direct Support Professionals Alliance, Unlock the Waiting Lists!, The Children’s Freedom Initiative, People First, Atlanta Alliance on Developmental Disabilities, Georgia ARC and local chapters, Atlanta ADAPT as well as Katie Beckett parents were just a few of those in attendance.

“What if next year when this eclectic group once again gathers under the gold dome we came united around 10 common goals and expressed them with the solidarity of a unified message?”

A quick glance at those in attendance at the depot attests to the fact that the event has become the largest of its kind during the legislative session, drawing not only a record number of advocates, but an impressive collection of legislators as well. Lieutenant Governor Mark Taylor, Speaker of the House of Representatives Glenn Richardson, Senate President Pro Tempore Eric Johnson, Chairman of Appropriations Rep. Ben Harbin

and Chair of the Subcommittee on Appropriations for Health and Human Services Rep. Jeff Brown spoke with those in attendance after addressing the gathering. Other legislators could be seen meeting with their constituents throughout the day.

Mark Johnson of Alpharetta was recognized for his role as a pioneer and leader within and beyond the Georgia disability community during the morning ceremonies at the Capitol where he received the first Georgia Self-Advocate of the Year Award.

At the depot as Terry Langley, Nandi Isaac and Heidi Moore put a very personal perspective on the issues facing Georgia’s disability community, I began to reflect on a concept that has been kicked around for a number of years. How often have we said that what we want and need for ourselves and those we love are no different than those things that everyone wants and needs if true quality of life is to be realized? What if next year when this eclectic group once again gathers under the gold dome we came united around 10 common goals and expressed them with the solidarity of a unified message? Would this shared mantra allow lawmakers to grasp not only the extent of our need but the potential strength of our unified vote as well?

For years we have believed that if we spoke and voted as a “bloc” we would move from the perceived status of a political minority to the potential status of one of the nation’s largest political majorities. I believe it’s time we prove our point.



Tom Seegmueller
Chairperson, GCDD

By Valerie Meadows Suber

People With Disabilities Go On Record To Make History



ALAN DUVALL & CHARLES HOPKINS



KATE GAINER



GAIL BOTTOMS

"This is big, really big," were Al Duvall's heartfelt words when he arrived to make history at the StoryCorps mobile recording trailer parked at the Martin Luther King Jr. National Historic Site in March.

Duvall, who is part of the Institute on Human Development and Disability (IHDD) Experts On Disability Speakers Bureau, was one of five individuals selected by the Governor's Council On Developmental Disabilities (GCDD) to participate in the nation's largest oral history project. The process calls for a close associate to pose questions to draw out the storyteller. Duvall's friend, Charles Hopkins of the Department of Human Resources, interviewed him.

StoryCorps has gathered 5,000 of the 250,000 oral histories it plans to record by the year 2013. The American Folklife Center at the Library of

"I have so many things I want to say that are stirring in my soul."

Congress will house the stories, and some will be broadcast on National Public Radio or local affiliates.

Kate Gainer, of disABILITY LINK, rushed home from a meeting in Nashville to be interviewed by her niece Felycia Thornton. "I'm glad GCDD managed to reserve time in this project for people with disabilities," she remarked. "This is too important to miss."

Reservations on a first come first serve basis filled up fast. GCDD called the StoryCorps office to explain that an oral history of America would be incomplete without the stories of people with disabilities. StoryCorps agreed and made reservations for people with disabilities.

Suggested questions were

AMARI & ANIL LEWIS

provided, but not required. Mia Nobbie, 21, and her mom, GCDD's Deputy Director Patricia Nobbie, D.P.A., used photographs to help spark Mia's memory of important parts of her story they wanted to include.

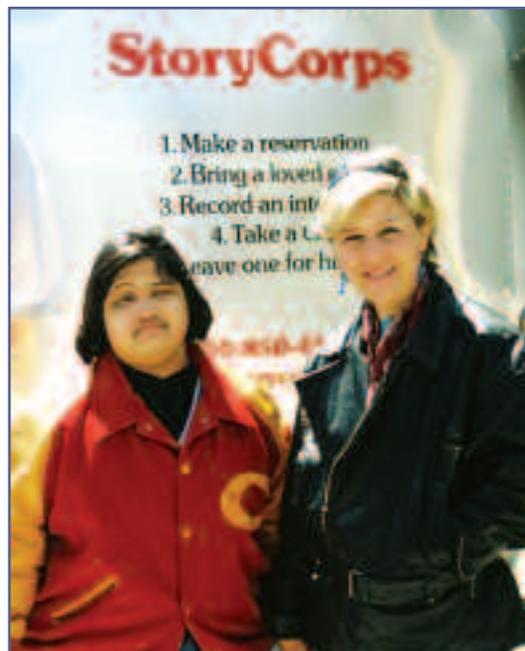
StoryCorps agreed to lower the age limit to allow 8-year-old Amari Lewis to interview his dad, Anil Lewis, chair of the Statewide Independent Living Council (SILC) and president of the National Federation of the Blind (NFB) of Georgia.

IHDD coordinator Jenny Manders interviewed poet Gail Bottoms, former GCDD council member and an IHDD expert speaker. Bottoms was pleased to learn that the scope of her conversation would not be limited to answering a set of prepared questions. She said, "I have so many things I want to say that are stirring in my soul."

StoryCorps' facilitator Jonah Engle described the stories as, "one of a kind, rich and rewarding. I am glad I was here to record them. They opened up another view of life for me." Engle thanked GCDD for making the special effort to ensure people with disabilities were represented.

Lisa Janicki, of StoryCorps headquarters, said, "Partnering with GCDD has allowed StoryCorps to celebrate and honor stories from a community of great strength and spirit that has unfortunately been historically under-represented. We thank the GCDD for introducing us to the truly inspiring individuals who participated." ●

MIA & PAT NOBBIE



Photos by Julius Suber



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.

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**GOVERNOR'S
 COUNCIL ON
 DEVELOPMENTAL
 DISABILITIES**

GCDD Welcomes New Team Members

The Governor's Council on Developmental Disabilities is pleased to introduce the two newest members of its staff:



DEE SPEARMAN: As GCDD's new public information assistant, Dee Spearman will provide administrative and program support in the areas of communication, marketing, promotion and media relations. She will coordinate public forums and media roundtables, produce and disseminate information materials and assist the public information director with publishing duties for *Making A Difference* magazine, planning and execution of the Making A Difference Discovery Day Tour and monitoring GCDD's organizational message and response to issues. Spearman worked previously as an administrator for learning support and academic affairs at a local college. She has assisted with the development and design of promotional materials for a marketing firm, served as office manager for a radio broadcasting group and planned special events for the Rock and Roll Hall of Fame and Museum in Ohio. Spearman can be reached by calling (404) 657-2121 or through email at dyspearman@dhr.state.ga.us.

SUSANNA MITCHELL: Susanna Mitchell joins GCDD as the new program associate. She will provide program support to the advocacy director and the individual and family support director. Mitchell previously worked as an advocate for homeless individuals and families at a nonprofit agency in Atlanta. Mitchell has a real interest in housing issues and is leading the strategic planning work group on Real Homes. She will also take on duties of the partnership fund, planning for Disability Day 2007 and assist with the production of *Moving Forward* newsletter. She can be contacted at (404) 656-6593 or through email at sumitchell@dhr.state.ga.us.



Gov. Perdue Appoints GCDD Members

Gov. Sonny Perdue (R) reappointed Lenora Maynard and appointed Julia Bowen to the Governor's Council on Developmental Disabilities March 20.

Bowen has previously served as an ex-officio member of GCDD.

"We look forward to continue working with these respected members of the disability community," announced GCDD Executive Director Eric Jacobson.

Medicaid Increases Disability Spending

The Deficit Reduction Act of 2005, recently signed into law by President George W. Bush, includes Medicaid programs for people with disabilities that will receive new funding over the next few years.

"The statistics we have indicate these programs will receive...\$11.808 billion in funding over the next 10 years," explained bill sponsor Rep. Nathan Deal (R-Ga.).

The Medicaid Reform Bill includes four programs designed to improve the lives of people with disabilities:

FAMILY OPPORTUNITY ACT This act allows families who have children with disabilities and are earning up to 300% more than the poverty level to qualify for Medicaid programs. Often, these families are struggling because of the extraordinary expense for their children's care, according to Deal. \$6.856 billion over the next 10 years.

MONEY FOLLOWS THE PERSON "This is designed to keep people out of institutions," Deal said. This legislation allows grants to be made to states on a federal match basis to improve access to home and community-based services.

Under the initiative, the first year a person moves into the community, the federal government will cover a higher percent of the cost of their services and states will pay a smaller portion. After the first year, the match rate will return to the regular rate. \$1.975 billion over the next 10 years.

EXPANDED ACCESS TO HOME AND COMMUNITY-BASED SERVICES "This is my primary focus," Deal said. He explained he knew of many situations where people could have avoided going to nursing homes or institutions, had community services been available.

In this legislation, states will no longer have to get a waiver to pay for these services; it will be built into Medicaid that they can offer home and community-based services as an alternative to institutions. \$2.615 billion over the next 10 years.

CASH AND COUNSELING This program will use the self-directed care model and allow recipients to have control over who they hire and what services they use. "This will overcome the institutional biases built into Medicaid," Deal revealed. \$360 million over the next 10 years.

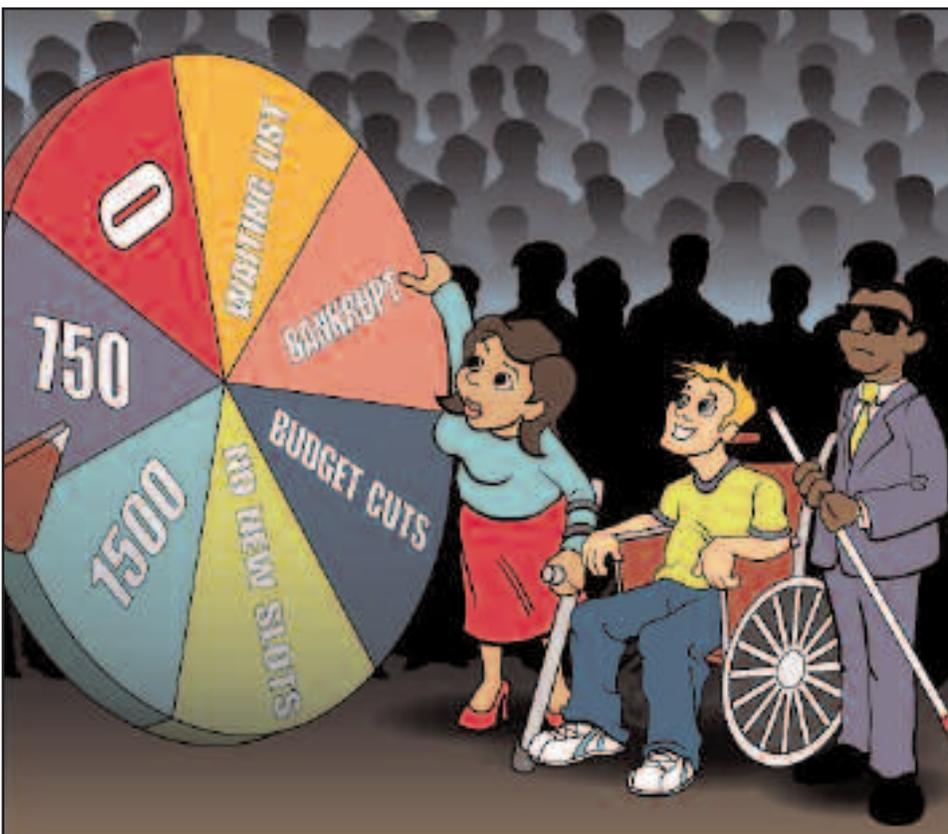
While the Deficit Reduction Act was designed to save \$40 billion over the next five years, these programs all represented spending increases. "In the long term, these additional expenditures could generate services that are more cost effective than institutional care," Deal concluded.

Atlanta Hosts Low Vision Project

The Centers for Medicare and Medicaid Services and the U.S. Department of Health and Human Services have selected Atlanta as one of six locations across the nation to participate in a national low vision rehabilitation services demonstration project. Beginning April 1, 2006, the project will study the impact of standardized Medicare coverage for vision rehabilitation services for those with a diagnosis of moderate to severe visual impairment that cannot be corrected.

The demonstration project will provide for Medicare-reimbursed vision rehabilitation services from certified specialists who can teach effective ways to enhance remaining vision for completing everyday tasks. As a result, people with vision loss will be able to function more independently and safely at home and in the community, thereby reducing their individual health care and dependency costs.

For additional information about the national Medicare project, call 404-875-9011 and ask for Medicare information. ●





By Patricia Nobbie, D.P.A.
GCDD Deputy Director

Disability Advocates, Legislators Forge Relationships

This session has been a very successful and rewarding one for advocates working on behalf of individuals with developmental disabilities. Many solid relationships were built with legislators in key positions, and advocates look forward to resuming the work during the summer and following the general election in November. This is the end of a two-year session; anything that didn't get passed this session is dead.

The most significant accomplishments were in the budget. The Unlock the Waiting Lists! Campaign worked very hard with legislators on the intent of the multi-year funding plan to sustain a long-term effort to reduce the waiting lists. Gov. Sonny Perdue funded 750 services in the Mental Retardation Waiver Program (MRWP) in his recommendations, but did not include any slots for the Independent Care Waiver Program (ICWP). Through meetings, testimony and targeted visits from individuals utilizing or waiting for services, Unlock succeeded getting the MRWP allocation increased to 1,500 services

"The Unlock the Waiting Lists! Campaign worked very hard with legislators on the intent of the multi-year funding plan to sustain a long-term effort to reduce the waiting lists."

funded for six months, and getting 152 slots funded for the ICWP program. The MRWP allocation included funding to build community capacity through extraordinary rates, person-centered planning, home startup costs for individuals moving out of institutions and enhanced funding for support coordination. Legislators understood the necessity of funding infrastructure to enable the Department of Human Resources (DHR) to implement the services successfully. The 152 ICWP slots will nearly eliminate the known waiting list for that program. These two items were huge wins for the

campaign, and for Georgians waiting for services.

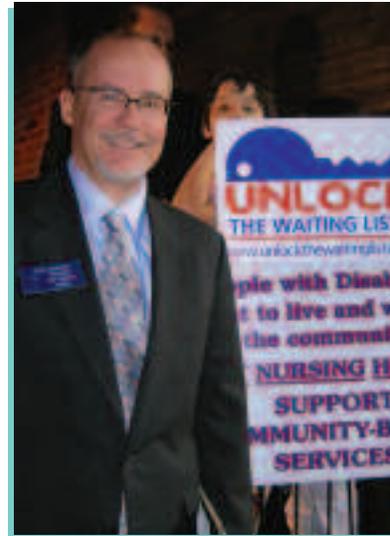
Another significant achievement was the action on the Katie Beckett waiver program. Legislators responded to the groundswell of concern expressed by parents by putting \$7.6 million in the FY 06 budget to be used in the last quarter of this year, and included language in the FY 2007 budget to ensure continuance. The funds constitute a one time allocation of state dollars to provide services for families who no longer meet the eligibility requirements for Medicaid through the Katie Beckett waiver, and who will also not qualify for any other government-funded services. DHR was authorized to contract with a fiscal intermediary to distribute the funds in the remainder of 2006 fiscal year, and to establish a foundation with fundraising capability to ensure the sustainability of the funds for the future. Many details remain to be worked out, but there is hope that parents who are no longer eligible for Medicaid will have an option to help them care for the significant needs of their children at home.

This year, the Governor's Council on Developmental Disabilities (GCDD) structured the legislative agenda in tiers, reflecting its priorities and the course of action to be taken on each item. Following is a review of each item in the original agenda, and a report on its status.

Tier I: Initiate: GCDD is lead agency

- **Amendments to the Election Code:**

Representative Sue Burmeister (R-Augusta) sponsored HB 1435 which incorporated most of the changes the advocates wanted. Beginning January 1, 2007, people with disabilities will no longer have to sign an oath specifying the nature of their disability to receive assistance at a polling place. The person assisting them will merely have to sign the voter's certificate stating that they assisted the voter – this creates a record that could be used to verify fraud. There is no longer a separate oath requirement for individuals with visual impairments. An individual's personal assistant can now deliver an absentee ballot for a person



Sen. Eric Johnson (R-Savannah) serves as president pro tempore of the Georgia Senate and showed his support on Disability Day.

Photos by Beth Tumlin

Lt. Gov. Mark Taylor (D) and GCDD Chair Tom Seegmueller discuss disability issues.



with a disability without penalty. HB 1435 is on its way to the governor for signature. The governor has 30 days to sign any legislation.

- **Money Follows the Person legislation:** Conversations were held with legislators and drafts of possible resolutions were circulated, but the coalition determined the effort needed to be refocused, and potentially combined with budget rebalancing efforts between hospitals and community funding.

“Many solid relationships were built with legislators in key positions...”

Tier II: Actively Support:

GCDD testifies, disseminates information, speaks with legislators about the issue

- **HB 898: E-Text Legislation:** This would require publishers to provide electronic versions of texts to post-secondary students with a print access disability. The Chair of the House Committee on Higher Education was reluctant to call a committee meeting on the bill without consensus among advocates, the Board of Regents and the publishers. The position of the publishers appears to be the primary sticking point. Discussions will continue, and legislation will be reintroduced next year.
- **Georgia Qualified Medication Aide Act, SB 480:** This would allow direct support staff trained as medication aides to administer routine medications to individuals in Community Living Arrangements in three metro area counties. The advanced practice nurse prescribing act was attached in the House, and the bill passed and is on its way to the

governor to be signed.

- **Budget Items:** Aside from the Unlock items described above, other allocations in the budget included:
 - Annualization of 925 waiver slots, in the FY 2006 budget; state: \$3,284,597, total funds: \$8,302,823.
 - 10 ICWP waiver slots in the FY 06 Department of Community Health (DCH) budget: \$53,038.

In the FY 2007 budget, to begin July 1, 2006

- 1,500 MRWP waiver services, funded for 6 months: \$11,589,794. The slots include moving 44 children from state institutions, 19 dually diagnosed adolescents from NW Georgia Regional Hospital and 40+ individuals from Allen Hall at Central State Hospital.
- 152 ICWP waiver slots in the DCH budget; 10 slots annualized from the FY 06 budget and funds for 142 new slots. State: \$3,286,957, total: \$8,535,333.
- Provide dental coverage for pregnant women; state: \$2,500,000, total: \$6,491,280.
- Additional funds to DHR to coordinate dental hygienist programs at accredited dental schools to provide services to consumers with developmental disabilities: \$50,000.
- Fund accessibility modifications to homes of persons with disabilities, through the Department of Community Affairs (DCA): \$300,000.
- Board of Regents budget, support funding for the Alternative Materials Access Center. This funding was not accomplished through a legislative allocation.

Tier III: GCDD allows use of name,

but otherwise no activity.

In this tier, the following items passed:

- DHR budget, 1,000 slots for the Community Care Services Program (CCSP); state: \$3,615,330, total: \$4,314,375.
- \$125,000 for naturally occurring retirement community (NORC).
- Aging and Disability Resource Center: \$700,000.
- SB 208, Central Registry for Brain and Spinal Cord Injury Trust Fund passed, on to governor for signature.

Other Notable Bills:

The legislative agenda is a moving target, and several issues and legislation came up that affect constituents. A few are noted below, and the final issue of *Moving Forward*, to be sent April 6, will report the final summary of pertinent legislation passed.

Language directing the Department of Community Health to research and plan for a Medicaid buy-in program was put in the FY 2007 budget.

HR 1401: Remembering Natalie Tumlin and her contributions to the advocacy movement for people with disabilities; recognizing the contributions of direct support professionals in supporting people with disabilities to live, work and participate in their communities.

HB 959: Mallory's Act: relating to parking permits for persons with disabilities, and to provide for permits issued to minors with permanent disabilities, passed both chambers by March 27.

HB 728: Mattie's Call, to provide for a state-wide alert system for missing adults with disabilities, was passed on March 31, after being amended by the senate to include Kimberly's call. This would enable law enforcement to use the "Amber Alert" system to help locate missing people with disabilities.

HB 695: Disabled Assistants Act, authorizes the issuance of permits for animals to assist persons with disabilities under certain conditions, such as service monkeys.

- Restoration of Peachcare Dental Funding that had been previously reduced (using funds in the Care Management Organization rates).
- Increase in the personal needs allowance for all nursing home residents, \$20 per person, state: \$2,288,002.

As Tier IV is a neutral position, and GCDD didn't oppose anything (Tier V), there is nothing to report on those areas. However, in the "Items to Watch" category, the following occurred:

- SB 500, the 2006 Georgia Accuracy in Elections Act, passed and is on its way to the governor for signature. The bill requires three precincts to pilot a paper ballot backup system in the next election.
- Plans for Medicaid Modernization through an 1115 waiver were put on hold indefinitely.
- HB 1223, referring to the duties and powers of Community Service Boards, was passed.
- The administrative services organization (ASO) that serves a gatekeeping function in the Medicaid and DHR budgets, requested proposals in early April, and ASO functions will be applied to waiver programs, SOURCE and Katie Beckett populations.
- Finally, the Senate surprised advocates by doubling the number of waiver slots in the MRWP with this language, "Provide 12 months funding for an additional 1500 slots in the Mental Retardation/Developmental Disabilities waiting list. This will bring the total number of

slots to 3,000. (Senate: offset \$24,147,199 state funds with funds previously used to cover the deficit for state hospitals.) (Conference committee: Reflect community service funding used in prior years to cover hospital deficits to be spent on community services only.)" While DHR may not be able to implement an additional 1500 services because no "new" funds were allocated, it has been directed to use funding allocated for community services for community services only, not to cover the deficits in the state hospital system. This language will support advocates in the future as they work toward moving all individuals with developmental disabilities from state hospitals to the community.

Advocates and their family members can be proud of the work accomplished in this session. Advocates are on firm footing toward achieving the goals of the multi-year funding plan, and they thank legislators for their work on disability issues. Stay tuned to state legislator races, and let them know of disability concerns and interests, and be prepared to contribute ideas toward the 2007 Legislative Session! ●



1,600 Voters Rally

FOR A BETTER QUALITY OF LIFE

Natalie Tumlin and 100 of her fellow advocates gathered at the Georgia Capitol to kick off the Unlock the Waiting Lists! campaign in 1998. Eight years later, on February 23, 2006, a record-breaking crowd of more than 1,600 Georgians with disabilities, their family members, friends, neighbors and support professionals gathered in the same place for what has become known as Disability Day. They joined to ask legislators to support initiatives affecting their quality of life.

The disability community took a few minutes to remember Natalie Tumlin, who died last October. In honor of her masterful advocacy efforts, Rep. Judy Manning (R-Marietta) sponsored H.R. (House Resolution) 1401, saluting Tumlin's contributions to the disability movement and recognizing the direct support professionals who help people with disabilities to live, work and participate in their communities. "Rep. Manning knew how important Natalie's staff was to her ability to be a mover and a shaker, so we decided to draft a resolution that both honored Natalie and recognized the importance of direct support professionals to the lives of people with disabilities and their families," said Governor's Council on Developmental Disabilities (GCDD) Deputy Director Patricia Nobbie, D.P.A.

GCDD Chairperson Tom Seegmueller welcomed the swelling crowd in the south wing of the Capitol building, emphasizing the power of voting, the theme of the 2006 Disability Day. "Imagine the real power we would have if every person with a disability and their families voted and participated in their communities," he said. "Together we're

strong; we have real power!"

Intensifying from a low rumble to a booming roar, the crowd's powerful words, "We Vote! Unlock the Waiting Lists! We Vote!" soon penetrated the walls of the House and Senate chambers.

Once again, the focus of the eighth annual Disability Day was the request for the House and Senate to increase the number of new Mental Retardation Waiver Program (MRWP) slots. Dave Blanchard, advocacy director for the Atlanta Alliance on Developmental Disabilities, and coordinator of Unlock the Waiting Lists! explained that there is a five-year funding plan to close the gap between the number of people on the waiting list and people receiving waivers. This year, the goal is to fund 1,500 more slots for Fiscal Year (FY) 2007. He also explained that if the state doesn't approve a minimum of an extra 1,100 slots each year, the waiting list may outpace funding increases.

Rep. Ben Harbin (R-Evans), appropriations Chair, addressed the crowd. "You have given us the opportunity to do what we need to do anyway, with your support," he said. "The House will stand firm to approve or increase it."

Lt. Gov. Mark Taylor (D) discussed the positive outcomes for disability advocacy that he has witnessed in Albany, his hometown. He said, "You're making a difference! The waiting lists are shorter thanks to advocacy."

Advocates asked legislators to approve funding 152 more Independent Care Waiver Program (ICWP) slots to the FY 2007 budget so that more Georgians with disabilities are able to leave institutions and move into their communities.

Blanchard explained that legislators funded an additional 10 ICWP slots during the supplemental budget period for FY 2006, even without a request from advocates. "It's an important symbol of their support," he said. The supplemental budget mid-year adjustment is also made during the legislative session, separate from appropriations for the upcoming fiscal year.



Rep. Ben Harbin promises his support in approving or increasing MRWP slots.

"DID YOU VOTE?
OUR VOTE COUNTS?"



During the adjustment, the Senate was also responsible for allocating an additional \$3.6 million for families who had been denied the Katie Beckett (Deeming) Waiver. The House added an additional \$400,000, bringing the total to \$4 million (after further discussions, the total was raised to \$7.6 million). The waiver assists families with children who have long-term chronic medical conditions and disabilities to receive Medicaid assistance for support not covered by typical insurance. "Very few people can understand the financial responsibility of raising children with special needs. The Katie Beckett Waiver has been a lifeline," said Heidi Moore, a parent advocate from Alpharetta. "We should be grateful to legislators for addressing our concerns."

Advocates marched to the Georgia Freight Depot, where some enjoyed lunch with their legislators, and all were encouraged to keep advocating and get involved in the elections.

Self-advocate Nandi Isaac of Macon talked about how unlocking the waiting lists would help

"No child belongs in an institution with a paid staff."

her and many others work and live in the community. "Please unlock the waiting lists for the state, for the U.S.," she said.

Terry Langley of McDonough discussed the importance of the Children's Freedom Initiative, H.R. 633, sponsored by Rep. Manning. "No child belongs in an institution with a paid staff," she said. If the FY 2007 item is passed, it will allow more than 40 kids to move out of institutions and into the community by June of 2007.

"The way that happens is to make sure there is plenty of community support," commented Eric Jacobson, GCDD executive director. The initiative also calls for pay increases for direct support professionals in the community.

Speaker of the House Rep. Glenn Richardson (R-Hiram), Sen. Eric Johnson, Senate President



First "Self-Advocate of the Year"

Shepherd Center Director of Advocacy Mark Johnson, of Alpharetta, was the named the 2006 Georgia Self-Advocate of the Year at Disability Day. An advocate for people with disabilities for over 30 years, Johnson has a reputation as a leader and pioneer of the modern day disability movement, and is the first to be honored with this award.

Fellow advocate Beth Tumlin presented the honor, established in loving memory of Natalie Norwood Tumlin, her daughter, and the self-advocate who was the driving force behind Unlock the Waiting Lists! "The first recipient is always there when advocacy is needed," she said. "He is a role model for self-advocates - he's taught people how to effect change in their own lives."

An emotional Johnson accepted the inaugural award from Tumlin and Governor's Council on Developmental Disabilities Executive Director Eric Jacobson saying, "This is really special." He concluded his acceptance by leading the crowd in a wall-shaking chant about Money Follows the Person (MFP) legislation. "I've learned you've got to make noise if you want something," he said.

"I've learned you've got to make noise if you want something."

Pro Tempore (R-Savannah), and Rep. Jeff Brown (R-LaGrange), chair of the subcommittee on Appropriations for Health and Human Services made remarks supportive of the disability community. "We actively support your issues," Brown said.

Other legislators spotted with their constituents among the crowd were Rep. Jay Neal (R-LaFayette), Rep. Steve Tumlin (R-Marietta), Rep. Carl Von Epps (D-LaGrange), Rep. Clay Cox (R-Lilburn), Rep. Tommy Smith (R-Nicholls), Rep. Jane Kidd (D-Athens), Sen. Vincent Fort (D-Atlanta), Sen. David Adelman (D-Decatur), Sen. Dan Moody (R-Alpharetta) and Sen. Michael Meyer von Bremen (D-Albany).

More than 1,600 advocates can be sure they were heard loud and clear at Disability Day. Sporting bright red t-shirts that asserted, "Our Votes Make A Difference," they were hard to miss. Until the session is closed and the budget is finalized, they are continuing heavy advocacy efforts, encouraging legislators to approve or improve the budget, and make a difference. And they hope Georgia's senators and representatives' ears are still ringing from the chants, remembering the real people who want real lives in red t-shirts declaring, "Did You Hear Us? Our Vote Counts!" ●

UNITS!

Lana Hardy discusses the need for more resources for aging and disabilities.



Looking Towards the 2006 Election

2006 PARTICIPANTS

Jeremy Sloan – Macon
Michael Turner – Athens
George Bell – Commerce
Joy Norman – Columbus
Greer Anderson – Stone Mountain
Barbara McRae – Atlanta
David Hardy – Atlanta
Renita Bundrage – Decatur
Lana Hardy – Atlanta
Susan Edwards – Alpharetta
Tim McClention – Gwinnett Co.
Liliana Garcia – Dunwoody
Dr. Karen Carter – Augusta
Cher Forman – Alpharetta
Mike Jackson – Commerce
Cheryl Rhodes – Atlanta
Kevin Carter – Augusta

After the rally at the Capitol and lunch with legislators during Disability Day 2006, a focus group was facilitated by Dottie Adams, Governor’s Council on Developmental Disabilities family and individual support director, to discuss disability issues to bring to the attention of candidates during the 2006 elections. Participants discussed topics affecting the lives of people with disabilities and the people who support them.

George Bell and Mike Jackson of Commerce felt candidates in their districts should assist people with disabilities to become employed. Bell said he would want them to support “start up money for people to have their own businesses, customized employment, supported employment and incentives” (for companies that hire people with disabilities). “We need to revamp the service system so that there are opportunities for all people to go to work, regardless of their disability,” Jackson agreed.

Many in the focus group agreed that a candidate should be supportive of people moving out of institutions and into the community, and should support community-based waivers and Money Follows the Person (MFP) legislation, to get their votes. “We should increase funding to all home and community-based waivers and decrease the dollars that go to fund institutions and nursing homes,” said Renita Bundrage of Decatur.

“It should not take years to be able to get affordable, accessible housing,” said Susan Edwards of Alpharetta. She has been on a waiting list for an apartment for 1 1/2 years because it is hard to find available wheelchair accessible apartments.

“Why are services good in Atlanta but not in the rest of the state?” is a question Tim McClention

of Gwinnett said he would have for legislative candidates.

Parent advocate Greer Anderson of Stone Mountain said, “We want broader options and choice in who delivers services.” She often spends more money on approved services than she would if she was permitted to buy unauthorized products or services directly.

Barbara McRae of Atlanta would like her legislators to support funding for family support while on the waiting list instead of support coordination services.

Participants said they would also educate candidates on aging and disability resource centers, problems with discontinued service hours and the need for services like Meals on Wheels for people whose direct support professionals get sick and can’t provide services for short periods of time. “Aging and disability is a growing issue,” said Lana Hardy, assistant executive director at the Atlanta Alliance on Developmental Disabilities (AADD).

Karen Carter, M.D., at the Department of Pediatrics at the Medical College of Georgia said, “The process to determine what accommodations and adaptations are needed for a child should be done in a timely manner.” Joy Norman of Columbus felt publishers should be required to provide texts for students in alternative formats.

Cheryl Rhodes focused on what happens to students when they leave high school. “There needs to be funding available so that parents don’t have to quit work or have the student just go home to watch television,” she said. “Programs need to be community-based and should enhance the person’s quality of life by helping them get better connected into the community.”

David Hardy said candidates should support higher education for people with disabilities by eliminating testing requirements and by funding accommodations. However, to become available for higher education, the special education diploma would also need to be modified.

Jeremy Sloan of Macon discussed the need to build provider capacity in Georgia, and help people



George Bell, Renita Bundrage, and other disability advocates discussed accessible housing, real jobs and becoming legislators themselves.

Advocacy Begins

.....> With You!

with disabilities maintain good personal care attendants by allocating more dollars in services and higher rates for waiver services. "I lost a lot of good attendants because they go elsewhere for money and medical benefits," he said. Cher Forman, a direct support professional in Alpharetta, agreed. "We need to equalize the pay for direct support professionals who work in the community with those who work in state institutions," she said.

Sloan also said his candidates should want to help improve transportation systems in Georgia, with better buses and more routes. Sloan said often none of the buses he waits for have functioning lifts.

Many in the group expressed a need for a more accessible and supportive health care system. Sloan and David Hardy said Medicaid and Medicare don't always cover prescription medications that are needed, and Carter said the process for obtaining health care resources should be simplified.

Liliana Garcia, Spanish statewide project coordinator of Parent to Parent of Georgia said that Medicaid is being taken away from Hispanic/Latino children who are U.S. citizens by birth because some family members are illegal immigrants. She said the children should be treated as U.S. and Georgia citizens, regardless of their parents' legal status.

"We need to equalize the pay for direct support professionals who work in the community with those who work in state institutions."

David Hardy shared concerns that the current legal system penalizes people by removing certain benefits when they are married. "This is discrimination, and the rules should be changed so that the benefits are based on the needs of the individual, and not on their marital status," he said.

Michael Turner said he would talk to candidates about the law enforcement and justice systems, and the need to look at more creative sentencing and appropriate services and supports for people with disabilities so they are not mistreated and abused in the criminal justice system.

Lastly, Bundrage said she would need to be convinced that her legislative candidates are champions for disability issues. She said if elected, the candidate should be willing to call upon her for advice when a disability issue arises. ●

On the morning of Disability Day, Governor's Council on Developmental Disabilities Deputy Director Patricia Nobbie, D.P.A., held an advocacy training class on how to educate legislators in a meaningful way. Self-advocates gathered at the Capitol Education Center and received a legislative overview and tips on communicating with senators and legislators from an expert advocate who spends most of her time at the Capitol.



Patricia Nobbie D.P.A. explained that waiting list slots that are approved in the budget become part of base funding next year. "We are really advocating for new money."

"Legislators know very little about a whole lot – if you want them to know something, you need to educate them," she said.

She explained that during the session, senators and representatives work hard on the fiscal year budget for the upcoming year and the supplemental budget for the current fiscal year. Thus, long-term communication is more beneficial than trying to contact them once they are already in session.

"Successful advocacy is a year-round process," Nobbie explained. "Legislators want to know what you think, and they are very approachable."

Nobbie gave the following tips on how to effect change and educate the state's decision makers:

- Find out what other states are doing about the issue.
- Know the opposition's platform.
- Communicate with the legislators in your district – they focus on constituents first, lobbyists second.
- Form relationships with your legislators and their assistants outside the legislative session.
- Discover legislators' preferred modes of communications (email, snail mail, telephone, etc.).
- Write "constituent" at the top of your letters or other communications.
- Tell legislators your story – keep it to one page or under 500 words.
- If advocating with an organization, always relay the same message.
- Speak the truth – if you don't know the answer to a legislator's question, it's okay to get back to him or her.
- Find out about legislators' personal lives – it's a good icebreaker to talk about the last football game their team played.
- Invite your legislator to community events or meetings of your organization.
- Don't be afraid to ask questions.

Nobbie encouraged advocates to try to talk to their legislators that day, but to make sure to continue the relationship over time. "The real influence begins with you," she said. ●

My Life with a Direct Support Professional

By Andreena Patton



Andreena Patton works as a peer supporter at Disability Connections, a center for independent living in Macon. She graduated from Mercer University with a B.A. in early childhood education and program and leadership services and obtained a M.S. in rehabilitation counseling and case management at Fort Valley State University. She is involved with the Georgia Peer Support Project, Unlock the Waiting Lists! and the Brain and Spinal Cord Trust Fund Summit. She serves on the GA Independence Plus Initiative Stakeholder's committee.

After becoming a quadriplegic from an automobile accident 11 years ago, my life changed drastically. One of the most difficult challenges was being dependent on someone else for activities of daily living (ADLs) like; bathing, dressing, transferring and cooking. At first, my family assisted me with ADLs but it became increasingly overwhelming as everyone began returning to work. As a family, we realized we needed help. As an individual, I realized I wanted to be more independent.

A new world opened up that I never knew existed. It was the world of attendant care. I was very nervous and did not like the idea of a stranger coming into my bedroom and assisting me with my personal care. However, deciding to use attendant care was the best decision I made towards becoming more independent. When my family assisted me, I would have to do things around their schedules. For example, I would have to get up when my mother could get me up or go to bed when she could assist me. In a sense, attendant care gave me my independence back.

“Deciding to use attendant care was the best decision I made towards becoming more independent.”

Independence is very important to everybody, especially to someone who loses it. Attendant care allowed me the independence to make my own decisions on how my schedule worked by deciding when I wanted to get up or go to bed,

eat, get dressed and take a shower. It enabled me to go to college, graduate school, obtain a job, maintain a social life, spend quality time with my family and most importantly live in my own apartment.

While using attendant care has permitted me to accomplish many things, it has been a taxing process to work with an attendant care agency, find compatible attendants and keep good quality people. One of the first questions I ask an agency that I am interviewing is, “Can I hire my own attendants?” To me working with agency attendants is a headache because I may get four or five different attendants in a week that I have to train each time. Whereas, when I find and hire an attendant, they work with only me, and I can train them once about my specific needs. I do try to hire attendants that have been certified under the Certified Nursing Assistant program, but I do not necessarily expect that as a requirement. It is important for me to be a major part in hiring my attendant due to the fact that I am with this person every day, all day and to foster a positive relationship, I want to have a say as to who comes into my home.

Attendants become more than attendants, they become family. I have had the same attendant for eight years, and I am as much a part of her family as she is mine. I go to her children's parties, sports events, school plays and she attends my family events. We have a close relationship and have developed a friendship. Without her and my other attendants, I would not be able to get out of bed, be a contributing member of society or have a meaningful independent life. ●

Direct Support Professionals and Their Clients Enrich Each Others' Lives

My Life as a Direct Support Professional

By Alice Tiner

Four years ago, when I was working with Athens Shuttle, I was introduced to several people with developmental disabilities. Previous to this position, I had never had the opportunity to build any form of relationship with anyone with a developmental disability. As my involvement increased, I decided that I was very interested in working more closely with people with developmental disabilities. I contacted the agency we served and applied for a position.

“My life has been enriched by helping the people I support and realizing the importance of assisting them to achieve a life as good as my own.”

When I first started in this profession, I never realized the impact it would have on my life. My life has been enriched by helping the people I support and realizing the importance of assisting them to achieve a life as good as my own. I have found in this field that the public is very uneducated on how to relate to individuals with disabilities. Many times, I have been out in the community with one or more consumers and people will address me with questions that are intended for the consumer(s). My response is, “Why don’t you ask them?” Most people with developmental disabilities are overlooked, devalued and do not get to make their own choices in life, even about where they live and with whom. I believe it is extremely important for me to advocate on the behalf of the people I support. Someone has to be their voice so changes can occur.

To expand my knowledge and the capabilities I can provide to the people I serve, I am taking the Direct Support Professional Certification Program.

During the course, our assignment was to choose a learning partner. The person I chose was Juanita, and she has no family, only paid support. This can make for a very lonely holiday season. On Thanksgiving Day, I invited Juanita to spend the day with my family. When we arrived at my grandmother’s house, she was greeted with a warm welcome. I introduced her as my friend, Juanita. As wonderful as my family may be, I found out just how uneducated they still are. I was fixing a plate for myself and someone whispered to me, “Can she talk?” I just laughed and said “Why don’t you ask her?” Then I realized that as much as I had advocated for people with developmental disabilities, I had not even made an impact on my own family! As the day passed, we watched the children run and play. We talked and laughed as we shared a part of our lives with Juanita all the while she opened up and shared her life with us. That evening as I was taking Juanita home, she reached over and said, “You know Alice, I love you.” A tear fell down my face as my heart smiled. I had been able to give just a little of my time to help someone’s life be more meaningful, if only for a moment. I knew then that my job is to educate anyone who will listen, and if they don’t choose to listen, continue until they do.

The experiences I have encountered led me to become an active member of the Georgia Alliance of Direct Support Professionals. As a direct support professional, I have witnessed a lack of support and recognition in this profession by the general public. Many consider us as just caretakers, attendants and even “warm bodies.” We are much more than this! We are mentors, advocates, community builders and person-centered planners. We strive to make a difference in the lives of the people we serve. The Georgia Alliance strives to raise community awareness, and that is why I became a part of this organization. ●



Alice Tiner has worked for Advantage Behavioral Healthcare Systems in Athens for the past four years as a community resource coordinator and a social service coordinator. After growing up in Oconee county, she attended Athens Technical College and the University of Mobile. She is married and has one child.

GCDD Responds to Need for Direct Support Training

The rallying cry of the direct support professional class at Athens Technical College was, “If it doesn’t work, try it another way.” This is exactly what the Governor’s Council on Developmental Disabilities (GCDD) did when it decided to tackle the lack of training options available for direct support professionals (DSP).

Lynnette Bragg, GCDD council member and former chairperson, explained, “We wondered how to give people the support they need so they really support people with disabilities, instead of just doing tasks. The training program evolved from conversations we had about what role we could play in facilitating this education.”

So GCDD embarked on a fact-finding mission, traversing the state to talk to DSPs and their clients to determine their needs, as well as interviewing people across the country about programs in other states.

Joy Eason Hopkins, president of Collective Alternatives, Inc., helped develop the curriculum

for what has become Georgia’s Direct Support Professional Certificate Program. “Before, training varied from provider to provider. Some service providers

had training coordinators, others had no-one. No training was standardized. It was just left up to the providers to do what they could.

“With budget cuts in services, that’s understandable – training is usually the first to get cut,” she explained.

“With more people moving out of hospitals into community life, direct support staff who have been supporting people in facility-based programs now must offer support in the community. It may seem like a natural thing to do, but it requires a lot of skill, and we weren’t acknowledging that,” Eason Hopkins said.



Lori McGee and her learning partner, Rocky Hunt, enjoy their time together during Disability Day at the Capitol.

Bragg explained that the training would emphasize building relationships to help people with disabilities feel more comfortable receiving help with intimate tasks, such as bathing. “It’s humbling to say, ‘I need help with tasks I would normally do myself,’” she said.

Next GCDD looked for a forum in which to offer the certificate course and determined partnering with the Department of Technical and Adult Education (DTAE) would be the best avenue.

“(DTAE) is a community resource – not just in the field of disabilities. The Hope Grant is available to students, and like the Hope Scholarship, can be used to pay tuition,” Eason Hopkins explained.

The six-month program, which included two

“We wondered how to give people the support they need so they really support people with disabilities, instead of just doing tasks.”



courses, was rolled out in September 2004 at North Georgia Technical College, Central Georgia Technical College and East Central Technical College, and in 2005, the program has been

“We have to be these people’s voices. We have to speak for them or else no-one will, or we need to teach them to speak for themselves.”

attended by students at Athens Technical College and Central Georgia Technical College’s Milledgeville campus. Eason Hopkins hopes to further expand into Savannah Technical College, Lanier Technical College, and eventually some metro-Atlanta technical colleges.

The first course consists of 50 hours of class time and 60 hours of practical experience. The competencies students are expected to learn in the first session include the changing role of support; systematic instruction; discovery process; individual accomplishments; person-centered thinking, planning, action; community exploration; representation; family support; personal assistance; social capital/social networks.

In the second course, the practical experience hours are increased to 90, while classroom hours remain at 50. Competencies learned in the second half of the program include systematic instruction in natural settings; motivation, encouragement and challenging behavior; rights, safeguards, confidentiality and documentation; personal wellness; medications; conduct and expectations; learning organizations; and Georgia’s services system.

While the course is comprised of 100 hours of classroom learning, the real emphasis of the program is on the practical experience. “Students

are paired with a learning partner. Each student maintains a portfolio of projects and products they work on with their learning partner,” Eason Hopkins explained.

Learning partners are people with disabilities who already utilize the services of a direct support professional. Depending on the circumstances, sometimes students choose a learning partner who they already know and work with, or the teacher may assign a new learning partner to a student.

“So far, it’s worked both ways,” Eason Hopkins said.

Linda Hazinski of Advantage Behavior Health Systems in Athens taught this year’s class at Athens Technical College. “The students learn how to listen to their focus person as well as how to advocate for them. We’ve seen them really grow in that way.”

The course emphasizes the importance of person-centered planning. “I think they get the whole philosophy of providing person-centered planning services to people, and how to train or support people in the community, as well as how to connect people to the community,” Hazinski said.

“The people we serve don’t always have choices,” explained graduate Crystal Brown, of Unlimited Services in Monroe, Ga. “We have to be these people’s voices. We have to speak for them or else no-one will, or we need to teach them

Barbara Reed and George Bell celebrate Reed’s graduation in Athens.





to speak for themselves.”

Students are encouraged to help their learning partners obtain new skills. “We put a lot of emphasis on where learning happens – it should happen in the community. There should be an emphasis on relationships and supporting and creating networks of support in more than one place in the community,” Eason Hopkins said.

“We’re learning what our clients’ dreams really are and helping to make them happen. We’ve got a new spirit about us.”

As part of the course, students must really get to know their learning partners and help them identify and fulfill one of their dreams. “The student has to determine

with their learning partner what to work on. It has to be something they can’t just do themselves. It has to be something that requires participation and involvement from other people; therefore bringing in a network of support,” Eason Hopkins said.

In the Athens class, for example, Hazinski said one student is helping her learning partner reconnect with her family.

George Bell, one of the learning partners in the Athens class, was teamed with Barbara Reed of Jackson Creative Community Services in Commerce, Ga., who helped him work on his dream.

“I’m more quiet. I learned to open up a bit and be more vocal. I never experienced anything

like this. We learned a lot about each other,” he said.

New graduate Jackie Johnson, of Gro Industries in Greensboro, Ga., said, “We’re learning what our clients’ dreams really are and helping to make them happen. We’ve got a new spirit about us.”

The course is structured so the instructors aren’t simply lecturing during class time. “Class time is spent on discussing what the students have experienced in their practicum projects,” Eason Hopkins said.

“One of the beauties of this program is that the learning partners aren’t limited to any population of people. They could be people with developmental disabilities, mental illness or those who are aging. I like that a lot because there are 16 students in a class and 16 different learning partners with 16 different stories and life circumstances,” Eason Hopkins explained.

Rep. Nathan Deal (R-Ga.), who has aging parents, said he has had a difficult time finding support staff to assist his parents. “They can’t afford home health care,” he said.

He appreciates the new course because it will produce trained professionals at a more reasonable rate. “It provides a valuable service and a good job opportunity for those individuals,” he said, and he is looking for ways the federal government can help support the development of direct support professionals.

The course is structured



to give back to the learning partner. "We couldn't do it without the learning partner – they should get something out of it. The learning partner gets a life profile for themselves, a written document that the student and learning partner complete together," Eason Hopkins said.

Learning partners can use this life profile to take to planning meetings to help determine supports. Because the class emphasizes community supports, the learning partner also is able to participate in more community activities as part of the course.

Both Eason Hopkins and Hazinski have noticed the students who complete the course feel more self-confident. "In the first class, a DSP said she learned about the medications her learning partner was on and how they were affecting her. She took her learning partner to the doctor and challenged the doctor on the medications. She said she never would have felt strong enough to challenge the doctor before this class," Eason Hopkins said.

Hazinski said she has heard comments from other service providers on how the program is affecting their staff. "Someone from another agency noticed how a student speaks out more for programming and community supports for her client."

While there currently are no classes in her area, GCDD's Lynnette Bragg, who is also a service provider, said, "I'm very interested in encouraging our staff to go through the training.

"My son has significant disabilities. He needs help bathing and eating. His relationship with his direct support professional is the most important in his life. Matching him with someone who respects him is vital.

"It's a great time in Georgia that we're recognizing how valuable these professionals are. They let people with developmental disabilities live life to the fullest," Bragg declared. ●



Linda Leopard and Harry Thornton learned more about each other during the six-month class.

Bright Outlook For Direct Support Graduate

by Christina Rosell

At her graduation on March 14, direct support professional Linda Leopard marched forward with enthusiasm and practical knowledge from her expert professors.

The ceremony marked the end of a six-month certification class for direct support professionals (DSPs) and the beginning of positive change – for DSPs, and the people they support.

"Not only did I gain friendship, but I will be able to use this class in what I do every day," she said.

At the beginning of the class, Leopard and her fellow students were asked to choose a "learning partner," and Leopard decided to work with Harry Thornton, a 53-year-old man who had been on her caseload at the day habilitation center where she had previously worked.

"He and I have traveled a journey together," she said, thinking back on her assignments and portfolio she worked with Thornton to assemble.

Throughout her time spent in the classroom, she learned about person-centered planning and mapping; behaviors and what they really mean; and many other topics from industry experts.

Then, she had to put her knowledge to practice with Thornton, and assemble a portfolio on everything they discussed. At the end of the class, Leopard and her classmates handed over their portfolios to their learning partners. "It will be beneficial to him," she said.

"I enjoyed working with her in this class," Thornton said at Leopard's graduation. "She helped me do a lot of things."

Leopard found the class to be so beneficial, she thinks it should be a requirement to work as a direct support professional, and hopes there will be more in-depth classes for graduates in the future.

And the future is already looking brighter for one of the first Direct Support Professional Certificate holders. Leopard was promoted to Community Resource Coordinator One on April 1, 2006.

"It means a lot," she said. "Not because you're getting any rewards, but because I love what I do." ●

"Not only did I gain friendship, but I will be able to use this class in what I do every day."

Graduates of the Athens class marked their achievement with a ceremony that included their learning partners.

Direct Support Professionals Take a Stand

By Christina Rosell

Direct support professionals (DSPs) across Georgia have joined forces to stand up for their rights – and the rights of the people they serve. Thirty DSPs founded the Georgia Alliance of Direct Support Professionals (GADSP) at the Timber Ridge Conference Center in Mableton last May, and drafted a three-part mission statement:

1. Promote recognition of DSPs.
2. Promote freedom of supported people through person-centered direct support training.
3. Advocate for a living wage and benefits for DSPs, and the people they support.

According to Bruce Blaney, GADSP project director, the alliance’s work includes helping “reorganize” provider agencies. He explained that agencies are typically managed in a hierarchal structure, with DSPs at the bottom. They don’t often make decisions about the people they serve daily, but simply carry out orders from the top.

“We don’t think that works very well because direct support professionals know the people they work with the best, and the people assigning tasks aren’t spending 40 hours a week with the people supported,” he said.

In a person-centered team structure however, Blaney said the DSPs take a more active role in the life planning of the people they support, and client service becomes more effective.

Lisa Robinson, GADSP chair and job coach at Supported Employment Specialists, explained how raising DSP wages benefits consumers, too. “Usually there is a turnover rate because the pay is low,” she said. “Clients can’t have a relationship if there is constant change. That’s really why the living wage is needed.”

Blaney maintained that there is a drastic difference between the wages of a DSP in the public sector, an institution

and in the private sector. Essentially, the state subcontracts private support providers in the community, and mandates the salary of the DSPs they employ. Therefore, the individual providers have little control over the wages of their employees, and need the state to award higher rates that directly benefit the DSPs.

The first piece of legislation that GADSP is supporting is the Children’s Freedom Initiative. The resolution calls for the transition of children from state institutions into homes with families. They would still need direct support in the community.

The resolution also requests pay increases for direct support professionals working for providers in the community. Without a pay increase, DSPs transitioning from an institution into the community would not be compensated as in the institution, forcing many to change professions, or take second jobs to counteract extreme pay cuts.

Johnnie Boddie, a GADSP Steering Committee member, is working hard on recruiting direct support professionals across the state to join the alliance. “This is for everybody; this is to make it better for all direct support people,” she said.

GADSP was created for people who provide support, and want to further improve the lives of their clients or family members, and has recently affiliated itself with the National Alliance for Direct Support Professionals (www.nadsp.org). In less than a year, GADSP’s membership has grown to 150, with regional chapters in Tifton, Macon, Atlanta and the newest in Athens. There are no membership fees.

Direct support professionals are encouraged to take a stand and join the GADSP by submitting their name, agency name, address, phone number and email to Lisa Robinson in writing. Fax 678-354-2670, email lrobinson@bellsouth.net or send the information to her in a letter addressed to Supported Employment Specialists, 615 Roswell Rd., Ste. 160, Marietta, GA 30060. With questions, call her at 678-886-8009. ●



Lisa Robinson accepts a House Resolution honoring DSP professionals on Disability Day.

“Clients can’t have a relationship if there is constant change. That’s really why the living wage is needed.”



(left to right) Joy Perry of the GADSP Steering Committee; Tom Kohler, a conference presenter; Lisa Robinson, the GADSP chair; and Mary LaLiberty, GADSP member.

Attendees Find Life is Better All Together

By Katie Bishop

Full inclusion at all stages of life is key for people with disabilities, and more people than ever are embracing this goal, as the seventh **Better All Together: Inclusion Works!** conference drew 724 people, its largest number of attendees ever.



Mary Kissel and Clara Berge share their children's experiences after high school (above). Audience members are inspired by Fred Pinson's battle for independence (right).



Organized by the Governor's Council on Developmental Disabilities, the conference was held March 1 – 4 in Athens, Ga., and featured 114 speakers from all over the country who enlightened attendees on topics ranging from including children in community living and person-centered planning, to employment options.

Speakers included professionals and people with disabilities and their families, who shared their personal hardships and ultimate triumphs as they moved toward full inclusion in their communities.

One man's fight to live in his community after

high school was an uphill battle. Through years of advocating, Fred Pinson, Jr., who has cerebral palsy, is successfully and happily living in the Avondale Estates community. Pinson, 44, spoke during the conference about the transition period after high school. Pinson encourages the person-centered planning model for people who want to live in the community because it allows individuals to make their own decisions.

Consumers have case managers who focus on providing quality care and direct support

professionals to help with personal needs such as running errands, cooking, bathing and maintaining a clean home. A doctor or nurse, who serves as an assistant in nursing homes, is not necessarily needed every day. Family members, friends and direct support professionals can learn to help with the tasks. Pinson says, "I taught my brother, who is nine years younger than I, to help me with those things before he was in fourth grade."

Pinson offered suggestions for ways to get involved and keep busy after high school graduation. He said, "Your high school friends, especially those with disabilities, will probably stay in touch with you." However, he says that other friends will gradually drift away. Pinson said, "To relieve the isolation, join a church or other religious organization and develop relationships there." Pinson himself is a member of a church and he is also very involved in his community as an activist for independence.

Mary Kissel, Clara Berge and Candee Basford have spent years encouraging their children to make the most out of every day and achieve their goals. The mothers, who spoke at the "Dreams We Never Thought Would Come True" seminar during the conference, shared how their children each have established a life full of enjoyment and hope since high school graduation.

"To relieve the isolation, join a church or other religious organization and develop relationships there."

When speaking of her son Eric's many accomplishments since high school graduation, Kissel's face lights up with joy. Eric Kissel, 38, lives in a house in Athens that his parents built. Through supported living, he is able to participate around the community. He volunteers at the Athens food bank, and his mother said that the people who receive the food give him the greatest gift. "It gives him the chance to be a contributor," she said.

"Katie has taught me the art of possibility, to move beyond what we think is possible and appropriate and enter into that realm of what is possible."



Candee Basford shared how she helped her daughter realize her dream of going to college.

The latest venture in Eric Kissel's life is as an artist. As a result of a supported employment grant by the University of Georgia, he is now president of his own company, Splashes by Eric, selling his artwork on note cards via his web site.

Mary Kissel said that as an entrepreneur, Eric Kissel is given the opportunity to make important business decisions and perform various jobs for the

business. He also gives back to the community by donating a percentage of his earnings to Georgia Options, a local community organization that supports people with disabilities to live in their own home. "Seeing him happy and healthy keeps us going," Mary Kissel said.

Clara Berge shares the same joy for her son, Kenny. When her son was 17, Berge, from Queens, N.Y., began looking for ways that he could get involved in the community. She discovered a farm close to their home where he could volunteer a few days a week. Kenny Berge, now 25, began working in the chicken coop collecting eggs. His mother said when they first walked into the farm, his face lit up with a huge smile. "You could see that all that dust, and the smell and all that motion was exhilarating," she said.

While the task was difficult to learn, Kenny

Berge enjoyed volunteering and later began to perform other tasks around the farm. After graduation, Clara Berge refused the idea of adult services and had her son live at home through person-centered care. With the help and encouragement of an assistant, Kenny Berge works at the farm every day. "I do not have enough words to say thank you to the people from the farm for the way they adopted Kenny as one of them," she said.

Candee Basford, another mother, has been dreaming about her daughter Katie's future since she was born. After learning that her daughter had Down syndrome, Basford was unsure of what the future would hold. However, after watching her play and learn with other children in her Head Start preschool classroom, Candee Basford realized that her daughter's future would be just as promising as anyone else's.

Candee Basford, from Seaman, Ohio, says that her daughter has known all along what her dreams are. At 16, she boldly told her mother that she wanted to go to college. Candee Basford was shocked at first and didn't see how it would be possible. However, after listening to what her daughter really wanted, she fought for her right to attend college. Katie Basford, now 27, is a student at Southern State Community College in Ohio where she has a grade point average of 3.25.

"Katie has taught me the art of possibility, to move beyond what we think is possible and appropriate and enter into that realm of what is possible," her mother said. Katie Basford takes every science class offered, because she wants to be a lab assistant once she receives her associate's degree. Candee Basford said that she hopes Katie's presence on campus will make people more welcoming and open-minded. While it has been a struggle to gain support for her daughter to go college, Candee Basford said that all she can do is listen to her daughter and help her accomplish what she wants to do.

These mothers' eyes are filled with pride as they each speak about their children's determination to create happiness and success. While life after high school can be a struggle that includes applying for waivers, waiting for services and making multiple decisions, it is a struggle worth fighting. With the help and encouragement of family and the community, people with disabilities can continue living inclusive lives long after high school. Pinson said it best, "Push away, push as hard as you can to live on your own because it's worth it." ●



By Lindy Dugger
and Valerie Smith Buxton

Putting the PERSON

Back in Person-Centered Planning

Advocates agree that the person-centered planning model is the best way to determine needed services, supports and outcomes for people with developmental disabilities. But a few top disability experts are concerned that more emphasis is being put on the process, instead of where it should be – on the person.

During the recent Better All Together conference in Athens organized by the Governor’s Council on Developmental Disabilities, experts Dr. Beth Mount, Michael Smull, Lynda Kahn, Jack Pearpoint and John O’Brien shared their thoughts on person-centered planning and their concerns that the process, which brings together service providers, people with disabilities and their families and community members has become institutionalized.

The panelists felt too much focus was put on the planning process, and not enough on the people for whom plans were being developed. In addition, standardized forms were being used to facilitate the process, taking away the personalized nature of the process.

“If we think it’s just another form, just another tool, we’re missing the point,” Pearpoint said.

“I think you could have a brilliant set of steps in a process and you could entirely miss the point,” agreed Kahn.

Another worry was that more emphasis was put on the process than actually listening to people and producing outcomes.

“When people are talking about their dreams, it’s fundamentally important to talk about questions such as why is that important to you? Why would that bring meaning to your life? Without those types of questions, you could end up with really superficial kinds of dreams or goals,” Kahn said.

“I developed a PowerPoint slide that said a plan is not an outcome, and it did not stop people from behaving as if it were,” revealed Smull.

Mount agreed, saying, “Planning is such a small part. Making it happen is what’s

important. That’s why it’s important to have the family,

the person with a disability, the community and direct support staff involved – they’re more likely to move (the plan) along.”

O’Brien said while it was essential for people with disabilities and their families to be involved in the process, “Every time we recognize the reality of people with disabilities and their families as having an expert voice, we undermine the system that supports them. So it’s no wonder that the system is acting as a not very smart, but cunning collectivity that wants to grab hold of this and turn it into something dead and routine.”

Smull suggested, “What we need to do is see if we can escape from teaching people to write plans and start teaching people who are implementing the plans how to think about people and the way we do things and what we call a person-centered approach. How do we develop a set of activities... that give us the outcome we’re looking for?”

Because he feels the system is threatened by giving power to people with disabilities and their families, O’Brien said, “We know we’re making progress around person-centered planning if we’re getting into interesting kinds of trouble.” ●

“If we think it’s just another form, just another tool, we’re missing the point.”



(left to right) John O’Brien, Jack Pearpoint, and Lynda Kahn share their insights on person-centered planning.

The Importance of Belonging

David Pitonyak, Ph.D., *Imagine*

Most of what I do in my practice is not very complicated. I spend time with people in ordinary places and situations and try to get to know them. I always ask the person for permission to meddle, and most people, even those without a formal means of communication, let me know that it's OK. What I am most interested in is the person's story, the people and events that have shaped their lives, the highlights and disappointments, the ordeals and accomplishments. What often emerges is a very human story, one that is easy to identify with, one that is both extraordinary and ordinary.

Often, what I learn from these stories is that the root of the person's difficult behaviors is loneliness. Many of the people I meet have one thing in common – they have lost connections to the most important people in their lives. Some have no contact with their families, or if they do, the contacts are infrequent or tentative at best. Sometimes family members are there, but the person has no friends, depending instead on people who are paid to be with them.

Paid care givers can be wonderful company, but they frequently change jobs or assume new positions. The resulting instability can be devastating to someone who is fundamentally alone. In *Circle of Friends*, Bob Perske describes how a person whose life is devoid of meaningful relationships might feel: "We have only begun to sense the tragic wounds that so many [persons with developmental disabilities] may feel when it dawns on them that the only people relating with them – outside of relatives – are paid to do so. If you or I came to such a sad realization about ourselves, it would rip at our souls to even talk about it."

I believe that loneliness is the number one cause of difficult behaviors. We are relational beings, and the absence of meaningful relationships wears us down and makes us sick. Imagine yourself without the people you love for 30 days. You have no idea where they have gone. Now imagine being without them for 60 days... or longer. How are you feeling? Are you sleeping well? What is your mood? My bet is that you are falling apart, spiraling out of

control. You want to be logical about all of this, but reason has taken a back seat to longing.

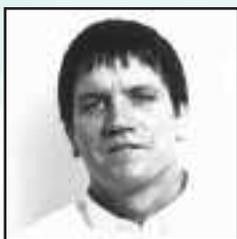
I met a man once who was very much alone. When he was a young boy, his family sent him to an institution. He had troubling behaviors, including self-injury, that would not go away, regardless of behavioral strategies or medications. He refused to do things with other people and preferred to isolate himself in his bedroom, wrapped tightly in blankets; they said he was "resistant to treatment." After getting to know him, I came to believe that his troubling behaviors and his resistance to relationships were the result of the trauma he endured when he was separated from his family, and from the systematic abuse he suffered at the hands of his "care givers," often in the name of treatment (e.g., time out, seclusion, over-correction). This is to say nothing of the constant turnover in his staff and losing people he cared about.

When I suggested that trauma and loneliness might be at the root of his difficulties, one member of his team said, "He's not lonely. He has one-to-one coverage." You can have ten-to-one coverage and be terribly alone. One way I like to explain the difference between coverage and relationships is to ask people to imagine that I have just returned home from a trip. I pull up in my driveway, and discover that my wife, Cyndi, is not home. Another woman is standing at the door and I ask, "Where is Cyndi?" She replies, "Cyndi is not home, but don't worry. We have you covered."

"There is a huge difference between 'coverage' and 'relationships.'"

People generally laugh at this scenario, but it is exactly what happens to people who experience our services time and again. There is a huge difference between "coverage" and "relationships." Our field keeps giving people coverage (and interventions) when what they desperately need is to belong.

There are many things we can do to help people find meaningful and enduring relationships. As a starting point, I like the questions posed by Mary Romer in her article, *Two is Not Enough*. They strike me as fundamental to anyone's success: "Are enough people engaged in the person's life?" "Are there people who are imbued with the belief and hope for a brighter, better future for the person?" and, "If not, how might such people be found or how might that sense of hope be instilled in those committed to walking with the person?" ●



David Pitonyak, Ph.D., is a behavioral consultant, dedicated to supporting people with disabilities who exhibit what some have called, "difficult behaviors." Pitonyak believes that what is most needed when supporting someone who engages in difficult behaviors is imagination, which is the name of his firm. His practice is based upon a simple idea: difficult behaviors result from unmet needs.



MAY

May 2-5
American Assoc. on Mental Retardation – International Alliance for Social Inclusion Summit
 Montreal, Quebec Canada
www.aamr.org

May 8-9
Easter Seals Project Action – People on the Move: Using All Transportation Options (ADA & Beyond)
 Alexandria, VA
www.projectaction.org

May 8-10
National Conference on Reuse of Assistive Technology Devices
 Georgia Tech Conference Center
 Atlanta, Georgia
 (703) 524-6686 ext. 305
nbailey@resna.org

May 22-25
National Council on Independent Living 2006 Conference, “Ending the Institutional Bias”
 Grand Hyatt • Washington, DC
www.ncil.org



May 25 - 28
8th Annual National Self Advocates Becoming Empowered (SABE) Conference
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www.sabe2006.com

May 25-27
2006 Georgia Psychological Association Annual Meeting
 Hilton Sandestin Beach Golf Resort & Spa • Sandestin, FL

JUNE

June 4-7
NACDD Annual Meeting & Technical Assistance Institute
 Baltimore, MD
www.nacdd.org

June 14-16
Career Opportunities for Students with Disabilities, 7th Annual National Meeting
 Atlanta, GA
<http://www.cosdonline.org/index.shtml>

June 21-22
Long Road Home March & Caravan, Georgia’s Annual Celebration of the Olmstead Decision
 Rome, GA & Atlanta, GA
ngainer@msn.com

June 28-30
APSE: The Network on Employment – 17th Annual National Conference on Supported Employment
 Marriott Copley Place
 Boston, MA
<http://www.apse2006.org>

JULY

July 18-22
Association on Higher Education & Disability Annual Conference

San Diego, CA
www.ahead.org/training/conference/index.htm

July 20-21
Governor’s Council on Developmental Disabilities Quarterly Council Meeting
 Atlanta, GA
 404-657-2126
www.gcdd.org

July 21-23
National Annual Down Syndrome Congress Convention
 Atlanta Marriott Marquis
 Atlanta, GA
 800-232-6372 or 770-604-9500
www.ndscenter.org

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Never Give Up!

By Phillip Modesitt, a ninth grader at North Atlanta High School

Agatha Christie said a really smart thing, "I like living." She thinks life is wonderful. And I think so too. Agatha Christie also said that life is not always fun and happy. She has been really, really sad. She has even felt "acutely miserable." But even though life is hard sometimes, you cannot give up. That is an important message – don't give up. Life really is great. She wants us to understand that everyone has bad days. She wants everyone to like living.

I also like living, but my life is not easy all the time either. There are many challenges in my life that I have to overcome. Sometimes it is hard having cerebral palsy. Sometimes I get very sad too. Sometimes homework is really hard. The most recent, big challenge I had was when I got diabetes.

I got diabetes at age 15 on November 29, 2004. My parents took me to the Children's Health Care of Atlanta emergency room that night. They were so sad and scared. I felt really sad too. They said, "Phillip Modesitt, now you are at Children's Health Care of Atlanta." I asked my mom what was wrong with me, but she said, "I don't know, Phillip. The doctors will help you."

Maxim: "I like living. I have sometimes been wildly, despairingly, acutely miserable, racked with sorrow, but through it all I still know quite certainly that just to be alive is a grand thing."

-Agatha Christie

The nurses stuck needles in me. The hospital didn't smell very good. I could smell my mom's perfume. The LPNs (licensed practical nurses) gave me blood sugar checks all day and all night, all day and all night. The needles hurt when they touched my skin. I could not walk at all. I was sick in bed and I cried all day. The tears tasted salty.

I stayed at the hospital for five days. After I

got home I learned how to deal with diabetes. Now I have the pump. The pump is like a fake pancreas. It gives me insulin. My blood sugar numbers stay better, and I feel better. I have a better chance of living a healthy life now. I also eat better. But what I really learned is that I wanted to live. I wanted to get out of the hospital. I wanted to go home and have my normal life.

I still deal with diabetes every day, and I still have to take blood sugar tests a lot. Even though I am good at it, my numbers still go up for unknown reasons. But I am dealing with it all.

Diabetes is a serious thing. Having diabetes taught me a lot. It is important to take care of your body, because you only get one. I learned to take care of myself in order to stay healthy. I also learned also how my body works. It is even more important now that I have diabetes because if I don't I could become very sick and maybe even die. I learned to control my diet to live a healthier life. I learned that exercise is important too.

This experience has taught me all this and more probably. I have many challenges, but I just have to accept them and live. I know that the sick times and the sad times will not be forever. I have a lot of very happy times in my life too. Like for example, I have great times with my friends and family. Even with diabetes and cerebral palsy I will persevere. I'll keep going until I succeed.

Mostly though, I am just happy to be living this life. Life really is "a grand thing." ●



Phillip Modesitt with his sister, Greta



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

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

State Government

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

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

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

General Information
www.georgia.gov

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

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

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

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

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

Advocacy

Atlanta Alliance on Developmental Disabilities
 Legislative Action Center
<http://www.ciclt.com/aadd/>
 404-881-9777

Georgia Advocacy Office (GAO)
www.thegao.org
 404-885-1234 • 800-537-2329

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