Making a Difference

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Real Homes. Real Jobs. Real Education. Real Influence.
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To Georgia’s Disability Community,

My vision for Medicaid in Georgia is health care that promotes healthy lifestyles. For individuals who have a chronic or persistent illness, this means services that teach and assist individuals on Medicaid to manage their own health care conditions. For individuals who are at risk for developing chronic or persistent illnesses, our Medicaid system should be structured to teach personal responsibility for lifestyle changes that are preventive, avoiding the needless suffering that conditions like diabetes, heart disease and obesity cause. For our children, prevention is the key. We must identify health concerns early, and begin teaching the child and their parents how to make wise choices about health care.

With these goals in mind, we need a new approach for providing health care; we need to bring the doctor/patient relationship back to the front and center of decision-making. This relationship should provide our Medicaid-eligible citizens the health care services they need, no more and no less. We need health care decisions to be made based upon what research shows is effective treatment, in the most cost efficient manner. When given information on the effectiveness of treatments and the costs of treatment, I am confident individuals on Medicaid can make the right choices for their health care needs.

I have heard from groups opposing changes to Medicaid, claiming the state is limiting federal funding, looking at cutting needed services and reducing eligibility. They even claim that our citizens on Medicaid cannot make their own health care decisions. None of this is true.

The truth is our Medicaid transformation effort is about improving health for Georgians on Medicaid while we also control unsustainable health care costs in ways that make sense. We know that health is improved by using prevention services, improving health literacy, making treatment available at the right time and in the right places and, when needed, assisting individuals to manage their health care. These are the same ideas we have heard from many of you who have joined us in this transformation work.

My hope is we will continue to work together to improve Medicaid because Georgians on Medicaid deserve to be involved in a health care system that will allow them to make decisions that will truly improve their health and quality of life.

Sonny Perdue
Governor
The Power of Advocacy

As we begin a new year and another legislative session, it is time to reflect on the past and prepare for the future. While we have had some successes during the past year, there is no time to simply declare victory and relax. We do not have that luxury. There is much work still to be done.

We must begin thinking about how we as the disability community are organized to create the social and policy changes that we desire. We need to begin thinking about not only how we advocate, but how we organize and create coalitions that include others with common interests. I recently attended a training session where I learned the principles of “direct action.” Direct action is about challenging the existing power relationships by changing what is happening and how people act together. It is about people with developmental disabilities and their families coming together to develop solutions to problems that meet their needs. They can do this by joining with others and using their numbers to pressure the system to change.

We can work together and with others to win real and immediate changes that improve people’s lives. During the legislative session, we will continue to work to Unlock the Waiting Lists! and support efforts to fund 1,500 new waivers for the Mental Retardation Waiver Program and 152 new waivers for the Independent Care Waiver Program. We can close buildings at Central State Hospital and move people into the community with Money Follows the Person legislation. We can make sure that the over 150 children currently living in public and private institutions come home to loving and stable families. These are changes that we can make happen during this legislative session.

We can work together so that all those involved have a sense of their power. There are many opportunities for you, your family and your friends to come to the Capitol and let your legislators and elected officials know what is important to you. You can join with direct support professionals in trying to get better wages and benefits. You can come to the Capitol on Disability Day (February 23, 2006) and be a part of the more than 1,300 individuals who will let their voices be heard.

We can alter the relations of power by making sure individuals, and when appropriate, their families, have control over their lives. The new waivers currently being written by the Division of Mental Health, Developmental Disabilities and Addictive Diseases will put individuals and families more in control over the supports purchased and who provides those supports. New options such as a Medicaid Buy In will allow people to work and continue using Medicaid as the payer for health care and supports. And, we can support legislation that will ensure that all places where people vote are physically accessible so that everyone can participate in our civic responsibility to vote during upcoming elections.

Nelson Mandela once wrote, “Our deepest fear is not that we’re inadequate, but that we are powerful.” We can come together and show that as a community we are indeed powerful. Make sure that you are among those in attendance at Disability Day at the Capitol AND also make sure that your legislators are in attendance and know about our issues. Call them today and tell them you expect to see them on February 23. Make an appointment to see them that morning and ask them to support the budget and legislative issues you will read about in this edition of Making a Difference. Finally, ask them to sit with you at lunch at the Freight Depot. You can help us win immediate improvements in your life, experience the sense of power when we all come together, and alter the relationships that will result in the system recognizing this is about YOUR life.

Finally, we encourage you to write thoughtful responses to specific articles published in Making a Difference magazine. Please allow us the opportunity to print your opinions by e-mailing “Letters To The Editor” at vmsuber@dhr.state.ga.us.

I look forward to seeing each of you at Disability Day at the Capitol, February 23. Your calls and e-mails are always welcome. 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
New Year Brings New Advocacy Opportunities

For many, the New Year brings thoughts of stereotypical resolutions and renewed commitment. For those of us living in the World of Disabilities, the New Year brings thoughts of political activism in the coming legislative session. For some, the political process and the thought of becoming involved are either unpleasant or intimidating. Others have little or no faith that their actions will make any difference.

However, to quote former Atlanta Mayor Maynard Jackson, “Politics is not perfect, but it’s the best available nonviolent means of changing how we live.” Therefore, for those of us seeking change, it is once again time to roll up our sleeves and become politically active.

In this issue of Making a Difference you will find GCDD’s legislative agenda for the coming session. We realize that this agenda does not address all the concerns that individuals across the state may have. However, our prioritization of these issues is directly related to not only their significance, but also the potential for positive change.

If you have never been a part of Disability Day at the Capitol, I urge you to come to Atlanta on February 23, 2006 and join disability advocates from all across Georgia for a powerfully unifying experience. Please look for the Disability Day at the Capitol registration form on page 7, fill it out and mail or fax it to our office. For more details on this, call GCDD or visit our Web site at www.gcdd.org. The site is also an excellent way to stay abreast of the progress relating to our agenda during the official proceedings of the general assembly. Our legislative fact sheet, Moving Forward, is updated weekly and available online to keep you informed.

“You CAN make a difference. Personal advocacy has had a direct impact on dramatic changes relating to waivers, the waiting lists and other issues during recent legislative sessions. I believe that it is worth reiterating that if those of us in the disability community all spoke up in unity, we would be one of the largest MAJORITIES in the political system today. Your involvement in this process can truly make a difference. Help us. Help yourself. Help those you love.

Tom Seegmueller  
Chairperson, GCDD
GCDD Hosts Seventh “Better All Together” Conference

Since 1994, the Georgia Governor’s Council on Developmental Disabilities has joined with students, parents and educators to learn how to successfully support students and school personnel so students could be successful, contributing members of local schools by hosting the Better All Together conferences.

Better All Together #7: Inclusion Works! on March 1-4, 2006, celebrates the past six conferences and continues to include topics about educational inclusion as well as inclusion and contribution in community life after graduation from school. The conference offers sessions that will help participants learn how to include young people with disabilities during their school years and provides sessions that demonstrate what is possible for young children before school age and for adults as they graduate from high school.

Many experts from Georgia and around the U.S. and Canada will present a wide variety of sessions on:

- Early childhood inclusion
- Curriculum modifications
- Supported employment
- Teaching strategies
- Person-centered planning
- School inclusion
- Supported living
- Community building
- Assets-based community development

Each day will include sessions on both education and adult issues from recognized experts, including Dr. Stephen Hall, director of Georgia’s Office of Developmental Disabilities of the Department of Human Resources, Division of Mental Health, Developmental Disabilities and Addictive Diseases. Cary Griffin, an expert in customized employment; Kathy Everett, a parent of a child with a disability and a special education teacher; and self-advocate Gail Bottoms are just three of the speakers who will reveal their strategies for success during the conference. In addition, students, adults with disabilities and parents of children with disabilities will share their experiences and lessons from school, work and community life.

The conference will be held at the University of Georgia Center for Continuing Education in Athens. For more information, or to register, call 706-542-2134 or 800-884-1381 or visit www.gcdd.org.

Co-Sponsors
- The Arc of Satilla
- The Arc of Walker County
- Bright from the Start: Georgia Department of Early Care and Learning
- Brain and Spinal Injury Trust Fund Commission
- CDAG: Community Developers Association of Georgia
- Department of Human Resources - Office of Developmental Disabilities
- GAO: Georgia Advocacy Office
- Georgia Department of Education - Division for Exceptional Students
- IHDDD: Institute on Human Development and Disability
Disability Day at the Capitol
Your Vote Makes a Difference!
February 23, 2006

Join the Governor’s Council on Developmental Disabilities at the Georgia Capitol for:
• Advocacy training from representatives of Partners in Policymaking and the Unlock the Waiting Lists! campaign
• A rally to let legislators know how their decisions affect people with disabilities
• Updates from local grassroots leaders
• Opportunity to eat lunch with legislators from across the state

For more information, visit www.gcdd.org or call 404-657-2126.

ATTENDEE RSVP FORM | Disability Day at the Capitol | February 23, 2006

Please register to attend the luncheon.

RSVP: 404-657-2126, Toll Free 888-ASK-GCDD, FAX 404-657-2132, TTY 404-657-2133, or www.gcdd.org

Name: ___________________________________________ Organization: __________________________ Total # attending: ________

Mailing Address: ___________________________________________ City: ________________________ Zip Code: ________

E-mail: ________________________________________________ Telephone: ________________________

Optional $10.00 donation per person to support luncheon is appreciated, but not required.
Total payment amount: ______________ Total amount enclosed: ______________

Please make check payable and return to:
Governor’s Council on Developmental Disabilities
Disability Day Registration
2 Peachtree St. NW, Suite 26-246, Atlanta, GA 30303.

Please note special accommodations we should be aware of: ________________________________________________________________

________________________________________________________________________________________________________________

________________________________________________________________________________________________________________

________________________________________________________________________________________________________________
GCDD hosts Disability Day at the Capitol each year to link people with disabilities with their local legislators. Your support helps people with disabilities tell their stories to policymakers and move Georgia toward a better quality of life for all citizens.

纪委 Yes! My organization will co-sponsor Disability Day at the Capitol (check desired sponsorship level):

纪委 $10,000: Full-page advertisement in Making a Difference magazine, name on banner and program, reserved VIP seating, exhibit space.
纪委 $5,000: Half-page advertisement in Making a Difference magazine, name on banner and program, exhibit space.
纪委 $2,500: Quarter page advertisement in Making a Difference magazine, name on banner and program, exhibit space.
纪委 $1,500: Name on banner and program exhibit space.
纪委 $500: Name on banner and program.
纪委 $150: Name on program.

纪委 Yes! I will attend Disability Day at the Capitol.

纪委 Yes! Other representatives from my organization will attend Disability Day at the Capitol.
I am attaching a list of the names of the people who will be attending.

纪委 Check enclosed 纪委 Please invoice

Name: ________________________________ Title: ________________________________

Organization name exactly as you wish for it to appear on event materials: ________________________________

______________________________________________________________________________________________________________

Address: __________________________________________________________________________________________

City: __________________________ State: __________ Zip: ______________

E-mail: ____________________________ Telephone: ____________________________

RETURN TO:
Governor’s Council on Developmental Disabilities • Attention: Disability Day
2 Peachtree Street NW, Suite 26-246 • Atlanta, GA 30303
Or fax to 404-657-2132
**Livable Lifetime Show House Opens in March**

The 2006 Livable Lifetime Show House, which showcases universal design features, will be open for tours every day but Sunday March 11 - April 1 in Fayetteville, Ga., in the Emory Springs Community on Hwy 54. Presented by the Universal Design Alliance, the home will highlight many design elements that produce a convenient, safe and flexible home that can meet the changing needs of individuals and families throughout their lifetimes.

The Universal Design Alliance is a nonprofit organization dedicated to educating the public on the benefits of both interior and exterior home features that promote lifetime enjoyment. It has teamed with Bob Adams Homes to create this show home that includes many examples of accessible features for people of any age or ability.

The Show House will demonstrate the talented skills of interior designers trained in “multiple life stage design” and will include many ideas not commonly available in homes at this time. In addition, workshops, seminars and special events are planned to help educate consumers on the benefits of a livable, lifetime home.

The Show House will benefit the EasyLiving Home Coalition and the Universal Design Alliance. Tickets are $5, groups of 20 or more are $4 each. [www.universaldesign.org](http://www.universaldesign.org)

**Olmstead Plaintiff Shows Art**

Lois Curtis, who took her fight to live in her community all the way to the U.S. Supreme Court, recently showed her artwork in her first exhibit called, Ms. Curtis, it’s a pleasure to meet you.

The exhibit, held November 11 - December 23 at the Temple Gallery in DeKalb County, celebrated Curtis’ journey from institutionalized isolation to community inclusion.

Curtis spent most of her adolescent and adult life as a resident in various state-run institutions for people with disabilities. After her repeated requests to reside in the community were denied, Curtis’ 1999 suit against the State of Georgia came before the Supreme Court. Victorious, the landmark Olmstead Decision became the national mandate to free tens of thousands of people with disabilities from unnecessary and unjust institutionalization.

Today, Curtis receives community-based support and makes art and advocacy her life’s work. With pastels and acrylics, Curtis’ expressions are bold and emotionally straightforward. Her remarkable insight into people and her joy for life are powerful reminders that everyone has dreams and contributions to make.

The Temple Gallery, sponsored by the DeKalb Council for the Arts, is a nonprofit gallery committed to bringing innovative art and artists to the community.

**New Autism Guide Available**

The Governor’s Council on Developmental Disabilities, in partnership with the Autism Society of America’s (ASA) Greater Georgia Chapter, has developed an updated version of the Autism Spectrum Resource Guide. The guide includes:

- Where to Find Resources in Spanish
- Where to Find Information on Getting A Diagnosis and/or Evaluation
- Where to Find Information on Professionals, Therapy and Treatments
- What to Expect After You Get a Diagnosis
- Where to Find Information on Providers, Respite and Other Resources
- Where to Find Information on Financial Assistance Sources
- Where to Find Information on Future Planning
- Where to Find Information on Supported Living and Residential Facilities

The new resource guide is available for download from [www.gcdd.org](http://www.gcdd.org). Alternative formats are available upon request.

**Magazine Now Broadcast**

The Governor’s Council on Developmental Disabilities is proud to announce Making a Difference magazine is now read and broadcast on the radio bandwidth of the Georgia Radio Reading Service (GARRS) weekly, every Thursday at 8:30 AM and on Saturdays at 10:00 AM and 10:30 AM. Listen online at [www.garrs.net](http://www.garrs.net) or call 404-685-2820 for information on how print-challenged individuals can receive a program guide and a special radio receiver free or for a nominal donation. The Georgia Radio Reading Service covers the entire state of Georgia and has approximately 20,000 listeners.
Natalie Tumlin: Advocated for Those Who Couldn’t

Even before she was liberated by assistive technology and could only make about 30 sounds, Natalie Tumlin was a self-advocate, according to her mom, Beth Tumlin. “When she was about seven or eight, her school wanted to put her in a classroom with children with profound disabilities. It was a quiet, isolated situation, and she said, ‘No, no, no, no, no.’ It was her first self-advocacy – she let us know she didn’t want to be isolated – she wanted to be with others,” Tumlin said.

Natalie Tumlin, 30, died October 1, but not before touching the lives of people all over the country, and lending her voice to help other Georgians with disabilities.

When Tumlin was 12, her world was changed by assistive technology (AT). “Her first Touch Talker opened the world up for Natalie, and Natalie up to the world,” her mom said.

Because Natalie Tumlin had such a narrow repertoire of sounds she could make, people assumed she didn’t understand what they were saying to her. But once she began using AT and started communicating with others, people realized she did understand.

While still in high school, Natalie Tumlin’s self-advocacy expanded to include advocating for others. She began attending meetings at the Cobb County Community Services Board about the lack of services for people with disabilities with her mother. “Natalie was at most of the meetings, adding in her two cents. That was important – it wasn’t just a group of parents, it was also a person with a disability describing what she wanted,” Tumlin said.

In 1997, the Tumlins became aware of the problem of waiting lists for services and a year later they started the Unlock the Waiting Lists! campaign. Natalie Tumlin became a spokesperson for that effort by visiting legislators and telling them what she needed. “All Natalie’s legislators knew her,” Tumlin said. “Natalie made the campaign real. She talked to people who lived in nursing homes and knew she didn’t want to live in one.”

As a result of her advocacy efforts, Natalie Tumlin received a Community Habilitation and Support Services (CHSS) waiver that allowed her to live in her own home in 1999. She also received a supported employment grant. “She was able to get a job coach. She took the CCT (Cobb Community Transit) bus to the interview. She started working for Windy Hill Hospital as a courier and earned a paycheck. She had a lot of independence,” her mother remembered.

“She couldn’t walk, talk, dress or feed herself, but she had two paying jobs and started her own company,” Tumlin said.

The waiver support allowed Natalie Tumlin to enjoy life in her community. “She loved doing what people took for granted. She loved going shopping, to the pharmacy and loved going to the dentist!” her mother exclaimed.

After receiving her waiver, Natalie Tumlin’s advocacy didn’t end. She continued to give a voice to those who couldn’t speak for themselves by participating in rallies, meeting with legislators and completing the Georgia Voices that Count class.

“Communicating was Natalie’s greatest achievement. It was something she couldn’t do for such a long time. Being able to talk for others put the biggest grin on her face,” Tumlin said.

Advocated for Those Who Couldn’t

It is so hard to bid you farewell. You have touched so many lives and had so many stories to tell.

I think we first met at Wheeler High when you were a student there. A person centered plan we developed…what future might you dare?

You made it very clear what you had on your mind. It didn’t take lots of words to know the life you wanted to find.

You used your Liberator to make sure that everyone knew. It really did give you freedom so your self-determination grew.

The ICWP came along after quite a wait. You moved into your own place and found a nice housemate.

Gina was the best at making sure your needs were met. She paid attention to the little details…on that you could always bet.

You found every opportunity to let the politicians know. That we needed more community services…so let the money flow.

Three governors of this state all knew you by name. Miller, Barnes and Perdue…on you they had no more fame.

I always loved how your mom would be introduced to others. It wasn’t Beth…or Mrs. Tumlin…It was always Natalie’s mother.

You were one of the most loved people I have ever seen. I know you never doubted it a moment…that must have felt serene.

The laughter, the joy, the good times that we all shared. Will make wonderful memories…no better ones will compare.

Too many of our self-advocate friends have left us this year. We will miss you along with Elaine, Teresa and Leonard’s rally cheer.

I am sure without a doubt that heaven is a better place. Because you are there now with your amazing grace.

Thank you, Natalie, for being you and sharing your life with us all!!!
The Governor’s Council on Developmental Disabilities (GCDD) revised its agenda-setting process for the 2006 session to engage a broader constituency of organizations and individuals involved with disability advocacy.

In September, letters were sent to 35 agencies and organizations representing a variety of disability-related activities, inviting them to submit the budget or legislative issues on which they would be focused during the legislative session. The issue had to have some impact on the community of people with developmental disabilities; be in concert with GCDD mission, vision and values; capitalize on the expertise of GCDD; and be an issue for which GCDD could use its limited resources constructively. GCDD received input from nearly a dozen organizations, and also sought information from a few state agencies. These items were summarized and explained to council members at the October meeting, and through a point system, were separated into five tiers of action: initiate; active support; support by name; remain neutral; and oppose.

The following discussion presents the items on GCDD’s legislative agenda to date. Keep in mind the activities of the legislative session are a moving target, and GCDD’s attention to particular issues is always subject to change.

Tier I: Initiate GCDD Is Lead Agency

- Amendments to the Election Code: This piece of legislation is carried over from last year. GCDD is awaiting a new draft from the vice chair of the House Governmental Affairs Committee. The legislation would make corrective changes to the following aspects of the code: definition of disability and attendant care; oath requirement; alternative means of voting; mental competence; requirements for accessible materials; assistance at the polls; and delivery of absentee ballots. The lead attorney at the Georgia Advocacy Office, Josh Norris, will be assisting GCDD with this piece of legislation.

- Money Follows People Legislation: GCDD will assist People First of Georgia with this initiative. Several states and the federal government have some version of Money Follows the Person legislation either in effect or pending. Georgia will be working on a draft that will authorize the transfer of funds that support individuals in institutional settings from the institution to their communities.

Tier II: Actively Support

GCDD will testify, help individuals testify, produce and disseminate information and talk with legislators about the legislation or budget issue.

- HB 898: E-Text Legislation: Requires publishers to provide accessible education information (an electronic version) to postsecondary students with a print access disability. The e-version must have
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Structural integrity. A coalition of the Statewide Independent Living Council (SILC), Association on Higher Education and Disability (AHEAD), Learning Disability Association of Georgia, Tools for Life and the National Federation of the Blind is supporting this legislation, which is assigned to the House Committee on Higher Education.

• Medication Administration Certification Program: Department of Human Resources (DHR) has received support from Governor Sonny Perdue’s office to proceed with legislation authorizing staff at Community Living Arrangements to administer certain medications and procedures to individuals with disabilities under the oversight, but not direct supervision, of a registered nurse. Staff must complete the Meds certification course, and the authorization will affect only homes in metro Atlanta at this point.

There are numerous budget items in the DHR budget that GCDD will actively support with the Unlock the Waiting Lists! coalition, under the leadership of Dave Blanchard, of the Atlanta Alliance for Developmental Disabilities. Most items are included in the Mental Health, Developmental Disabilities, Addictive Diseases portion of the DHR budget.

• 1,500 Mental Retardation Waiver Program (MRWP) waiver slots
• Transition 135 consumers with developmental disabilities from Central State Hospital Allen Building
• Transition 19 juveniles with dual diagnosis from NW Georgia Regional Hospital
• Transition 38 consumers from the Freeman Building at Central State Hospital
• Close West Central Georgia Regional Hospital in Columbus; serve consumers in appropriate settings

• Close Craig Nursing Home at Central State Hospital; serve 149 consumers in appropriate settings
• Support additional funding so providers can pay Direct Support Professionals fair and adequate wages, provide training and assure quality services (Service Providers Association for Developmental Disabilities - SPADD)
• Department of Community Health (DCH) budget: Medicaid – Fund a basic prevention and minor restorative treatment dental care program for pregnant women and adults with developmental disabilities. (Georgia Dental Association, GDA)

Tier III: GCDD allows use of name in support, but otherwise no activity. Organization supporting the item is listed.

• HB 369 and SB 159: Helmet Laws (with the Brain and Spinal Cord Injury Trust Fund - BSCITF)
• Grandchildren’s Caregiver Subsidy Act (Georgia Council on Aging - GCOA)
• Cause of Death Reporting Requirements (GCOA)
• Common Sense Initiatives for Safer Health Care (GCOA)
• Cruelty to Elder Person Act (GCOA)
• HB 142: Create a duty to provide child support for children with disabilities beyond age of majority
• SB 208: Modification of language for statute for Central Registry for BSCITF

Stay abreast of the happenings at the session in several ways:
• Find out who your legislators are. Go to www.vote-smart.org and enter your 9-digit zip code.
• Check the status of current bills, resolutions and the committees your legislator serves on at www.legis.state.ga.us.
• Make sure you are on the mailing list for Moving Forward, GCDD’s weekly legislative update, that summarizes critical bills and the status of budget discussions. Moving Forward is also posted to the GCDD Web site at the end of each week.
• Visit the GCDD Web site’s Public Policy Link and download position papers and one-page fact sheets that you can share with legislators on the issues you are concerned about. A constantly updated legislative agenda will also be posted there.
• Attend Disability Day at the Capitol. This is a great way to invite your legislator to meet you for lunch at the Depot and hear your concerns.
• Visit your legislator at the Capitol. There are always advocates on the third floor outside the double elevators who will be happy to help you meet your legislator at the ropes.
Budget Items

- Funds to continue expansion of Aging and Disability Resource Centers (Division of Aging-DOA)
- DHR: Medicaid funding for 500 elderly consumers who are nursing home eligible: $1.475 million (DOA)
- An additional $6,000,000 to provide services to individuals on the Community Care Service Provider waiver waiting list and $4,000,000 for 2,000 individuals who qualify for non-Medicaid Home and Community-Based Services (GCOA)
- Additional funding to expand the Naturally Occurring Retirement Community (NORC) replicable model of home and community-based services to help seniors age in place (Jewish Federation of Greater Atlanta-JFGA)
- Increase funds to provide critical respite support for caregivers (JFGA)
- Restore the Peachcare dental funding ($1.8 million) that was reduced in last year’s budget (GDA)

Tier IV:
Council Remains Neutral

- SB 78: Allow for exceptions of direct supervision of dentists to enable dental hygienists to provide prophylactic dental care to individuals with developmental disabilities in institutional settings
- Implementation of Administrative Services: Organization to oversee functions of Medicaid (The Requests for Proposals for this function have not been developed yet, so it is unlikely this will be a legislative or budget issue this session)
- Suicide Prevention: Proposed legislation for the Division of Public Health to create office of Suicide Education and Prevention

Tier V: Council Opposes

There are no budget cuts or legislation that GCDD needs to consider opposing action on at this time.

GCDD will track the development of several other issues, and should the deputy director feel GCDD needs to respond by stating its position or taking action, the ad hoc committee will meet to discuss the issue and advise the deputy director on the course of action. Items under watch include:

- Paper ballot initiatives: Possible legislation to require all electronic voting machines to have a mechanism for recording a paper receipt that will enable the voter to verify their input (Concern is whether the paper receipt will have accessibility modifications for people with disabilities)
- Use of Social Security numbers for voter registration
- Medicaid Modernization: watch for authorizing legislation or a joint resolution allowing the governor’s office to proceed with the proposed 1115 waiver.
- Request of state funds in the Department of Community Affairs budget to provide accessibility modifications to homes where a person with a disability lives
- Any legislation that would change the structure of the MHDDAD regional system
- Additions to the DCH budget for Independent Care Waiver Program waiver slots. Currently the DCH budget contains no money for additional slots for the waivers, but advocates have begun speaking to the Office of Planning and Budget and various legislators about meeting this need. The request is for 152 slots, which would require about $3.2 million in state funds. If funds are included in the governor’s budget request, the deputy director will request GCDD to consider active support.

This agenda does not include the bills and budget issues that arise once the session begins in January. The session begins Monday, January 9. GCDD expects the governor’s budget address the following week, and after that, GCDD will know how things stand with advocacy efforts for the funds that support the Unlock the Waiting Lists! and institutional transitions.

Advocates have the opportunity to meet with their legislators during Disability Day on February 23, 2006.
With higher medical costs and rising enrollment, Georgia’s Medicaid program is predicted to consume more than 50 percent of all new state revenue by fiscal year 2009.

The state is hoping to slow the growth in the cost of Medicaid by proposing a 1115 waiver to the Centers for Medicare and Medicaid Services (CMS) that will allow the state to try new approaches to health care delivery that are not included in Medicaid’s current regulations. In return, the state will agree to stay within a specified budget.

“It’s not clear what the impact of Medicaid Modernization will have on people with disabilities who rely on Medicaid for home and community-based services,” said Governor’s Council on Developmental Disabilities Executive Director Eric Jacobson.

Most of the changes appear to only affect people who rely on Medicaid for their health care, not those receiving home and community-based services.

“The enhancements we’re suggesting focus on prevention, care and disease management,” explained Abel Ortiz, Governor Sonny Perdue’s policy adviser for health, human services, juvenile justice and veteran’s affairs. “We’re proposing incentives to encourage regular health care through the medical home of the consumer’s choice.”

Ortiz hopes providing better preventive care will help Georgia save money by reducing the more costly trips to the emergency room or expensive treatments for preventable conditions. Plus, choosing a medical home can reduce costs by better coordinating health care services for the consumer and avoiding duplicated efforts.

Abel Ortiz, center, discusses disability issues with self-advocates.

The plan includes paying providers enhanced rates to provide better services, such as after hours and weekend hours or a nurse’s call line.

Cutting wasteful practices will also help curb costs. “We won’t bundle services that don’t make sense. We don’t need to pay for services people don’t need,” Ortiz said.

“We don’t want to restrict eligibility or reduce the expansion of services. We want to keep people healthy,” he said.

Another proposal is to subsidize the cost of employer-provided insurance for those who don’t make enough money to pay for the insurance themselves.

Perhaps the biggest change being proposed is the establishment of health opportunity accounts (HOA) for consumers. “If someone is at risk for diabetes, and their primary physician advises them to go to a nutritionist, and they do that, money will be deposited in their account. They can use the money to pay for medical items or services they need that Medicaid won’t pay for, such as dental care, transportation to the doctor, daycare while a parent is at the doctor and other health-related expenses,” Ortiz explained.

Money for the accounts would come from savings generated through the other changes, and charitable contributions could pay into the accounts as well.

The plan, originally slated to be submitted to
CMS January 31, 2006, may not be submitted as soon as intended, as stakeholders have proposed some changes the governor’s office is considering. “We are re-looking at the date,” Ortiz said.

Advocates Reaction Mixed

While the plan was developed with input from providers, consumer advocates and other stakeholders, some advocates have concerns about the plan.

“My fear is that the plan could be used as a tool to weed people off the rolls of Medicaid,” revealed Rebecca Ramage Tuttle, CEO of disABILITY LINK, an independent living center in DeKalb County. She is concerned that people who don’t follow their doctor’s prevention advice could be dropped from Medicaid.

Ortiz said that wouldn’t be the case. “If patients fail to follow their doctor’s advice, there is no penalty, but the patient would not be able to get funding added to their health opportunity account,” he explained.

In addition, Ramage Tuttle was disappointed that other items were not included in the proposal. “I would have liked to see more home and community-based services included,” she said. Jacobson agreed. “There’s no data on how people with disabilities fit into the Medicaid Modernization process. Are the MRWP changes (Office of Developmental Disabilities Director) Steve Hall is proposing our part of the Medicaid reform effort?” (see sidebar on page 17).

Georgia Legislator Recommends Federal Medicaid Reform

Georgia Rep. Nathan Deal (R) presented Medicaid reform recommendations to the U.S. House of Representatives that were passed in H.R. 4241 (Deficit Reduction Act) November 18. As of press time, the House and Senate were negotiating a final bill to reform Medicaid, but the House had passed its final budget version December 19.

Changes to the Medicaid program included in the House’s version of the budget included the Family Opportunity Act. The act, originally proposed in the Senate, allows low and middle-income families to access Medicaid for their children with disabilities. Medicaid is often the only program that provides the benefits needed by children with significant disabilities.

Some of the House’s other recommendations included:

- **STOPPING OVERPAYMENT FOR MEDICINE** – Change Medicaid payment rates for medicines so they are based on the average of actual sales prices for prescription drugs to avoid overpayment.

- **CRACKING DOWN ON ASSET TRANSFERS** – Restrict the ability of elder law attorneys to qualify wealthy clients for Medicaid by transferring assets by beginning a penalty period on the date the individual seeks eligibility for Medicaid rather than at the time they transfer the asset.

- **SHARING COSTS** – Increase the co-pays for health services from $3 to $5 for some Medicaid recipients.

- **PROVIDING FLEXIBILITY** – Allow states to modify Medicaid benefits so that they are equivalent to other health programs in the state with the largest enrollment.

The spring edition of Making a Difference magazine will provide more information on what Medicaid reform Congress passes once the House and Senate reach a consensus.
One part of the plan Ramage Tuttle liked was the health opportunity account idea. “The health opportunity accounts would be a great help to pay for dental needs, assistive technology and other durable medical equipment that Medicaid doesn’t pay for,” she said.

An objection shared by Ramage Tuttle and consumer health advocate Linda Lowe is that applying for a 1115 waiver has the potential to limit federal funds.

“There is a danger in accepting limits on Georgia’s access to federal funds. This plan will force us to negotiate with the federal government each year instead of receiving a guaranteed match rate,” Lowe said.

Ramage Tuttle agreed, “The state needs to take every opportunity to increase federal funds, not take the chance of decreasing them.”

Currently, for each 39 cents Georgia pays for Medicaid, the federal government pays 61 cents. “Under the waiver, the federal government pays 61 cents. ‘If the state goes over budget, we have to renegotiate with the federal government, and we may or may not get the extra money.’

Ortiz insists the plan will not have a negative impact on federal funds. “If the plan doesn’t remain cost neutral over the total time of the waiver, we could lose the benefit of the enhanced waiver services, but federal funding is not at risk,” he said.

The governor’s office has released a list of the changes they are proposing that would require the 1115 waiver, but Lowe feels many

### Medicaid Modernization Changes That Require 1115 Waiver

Governor Sonny Perdue’s office is recommending a number of changes to modernize Georgia’s Medicaid system. According to Abel Ortiz, the governor’s policy adviser for health, human services, juvenile justice and veteran’s affairs, implementing the following changes would require the state to apply for 1115, statewide waiver from the federal government:

- Exploring options for employer-sponsored insurance during eligibility phase.
- Allowing consumer to identify health care home, which may include physicians, pharmacy, mental health providers and/or dentists.
- Providing prevention or educational services for consumers who are at risk for chronic or persistent conditions and communicable diseases.
- Including prevention and education under existing disease management services.
- Educating providers about community services and resource opportunities and coordination.
- Giving medical home providers the ability to make a referral to a care management program that could include non-physicians who would be compensated for their services, such as peer supporters.

### Health Opportunity Accounts:

- Zero beginning balance; funding is added when consumers make responsible health care decisions.
- Funding added based upon an individual amount, or capped amount for families.
- Funds may be used as payment for health-related services not otherwise covered under Medicaid (i.e. adult routine dental care, chiropractic care, orthodontists, transportation to doctor’s appointments, etc.).
- Payments to providers for services funded from the savings account need to be made by the Medicaid payment system.

### Providers Received Enhanced Rates For:

- Developing/participating in education, prevention and disease management.
- Participating in price transparency and quality outcomes measures.
- Taking part in peer to peer evaluation of practice patterns.
- Adopting the use of technology in their practice.
- Establishing a medical home.

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The governor’s office has released a list of the changes they are proposing that would require the 1115 waiver, but Lowe feels many
After 15 years, Georgia’s Mental Retardation Waiver Program (MRWP) is getting a much needed tune-up, according to Dr. Stephen Hall, director of the Department of Human Resources (DHR) Division of Mental Health, Developmental Disabilities, Addictive Diseases’ (MHDDAD) Office of Developmental Disabilities.

“Georgia’s waivers for people with developmental disabilities are some of the oldest in the nation,” Hall said. “They are 15 years old, based on 18-year-old technology. It’s time for them to be changed.”

The Office of Developmental Disabilities is working on changes to the waiver that they will propose to go into effect July 1, 2006, if approved.

The most fundamental change is that the waiver will include the Money Follows the Person (MFP) philosophy, instead of giving funds directly to providers who then decide which services people will receive.

“When money follows the people, funding is fair, equitable and makes sense, and is based on their exact needs,” Hall said.

The MFP approach puts dollars where they are needed. For example, under the current structure, people might be receiving funding for transportation services they don’t need. “If a waiver recipient has a friend who will drive him to his services, the state won’t have to pay for that,” Hall said.

Under the proposed new waiver, each waiver recipient will undergo a universal assessment that incorporates the Supports Intensity Scale, that will let the state know the exact needs of each person.

“Our responsibility is to ensure those with the greatest needs receive a greater amount of help.”

Hall expects superior outcomes for people with developmental disabilities as a result of this proposed waiver. “When you give choices, recipients will make the right decision for themselves,” he said.

“Ninety percent of the recipients will choose the exact same program they had this year. The following year, the 10 percent of people who chose new services will talk about them, and about six years out, we expect more than half of the recipients to be choosing different services,” he said.

Jacobson felt the state should evaluate programs currently in place or already proposed before jeopardizing funding. “Managed care is supposed to start in April, and the state has already begun disease management for people with disabilities. The state hasn’t given these programs enough time to evaluate whether they are achieving the efficiencies they expect. Plus both programs are supposed to create the savings they’re proposing in the 1115 waiver,” he said.

“The state is thinking about it backwards – they are starting with ‘we want a waiver,’ not ‘where do we want to be with our program, and what authority do we have now to do those things?’” Lowe said.

The plan also proposes that some participants share in the cost of their health care. “When states increase cost sharing, people get worse care. They won’t buy their high blood pressure medicine if they have to choose between that and food,” Lowe said.

Lowe believes the only part of the proposed Medicaid Modernization Plan that would require the statewide 1115 waiver are the health opportunity accounts. “I understand the rationale for giving people rewards. But is it worth giving up access to federal dollars?” she asked. “I think the dangers outweigh the benefits.”

Ortiz maintains a number of the proposed changes would require the 1115 waiver, but appreciates advocates’ input. “Strong advocacy is good. Without advocacy, we wouldn’t be where we are now. But we need to be clear that there is a misunderstanding that there is a cap on federal funds. The plan will have no negative impact on federal funds,” he concluded.
Life could get exceptionally more fulfilling for 322 Georgians with developmental disabilities, mental illnesses and severe medical situations at Central State Hospital. But their quality of life is dependent upon the Georgia General Assembly’s approval of the Department of Human Resources (DHR) Fiscal Year 2007 Budget Proposal.

DHR has proposed that the state of Georgia: 1) Transition 135 individuals with developmental disabilities to the community; 2) Transition 38 adult extended-care individuals to community placements; and, 3) Close the Craig Nursing Home at Central State Hospital and serve the 149 individuals in appropriate community settings.

“When they came into the hospital, we weren’t able to offer the kind of support we can now,” said Gwen Skinner, director of the DHR Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD). “It’s time to look at our institutions very carefully.”

If approved, the proposal to transition individuals into a more integrated community setting would help fulfill Georgia’s commitment to implement the Olmstead Decision as mandated by the Supreme Court.

Quality of Life

HEALTH “People are much healthier when they’re out in the community,” said Renee Peek, remembering her deceased husband’s life in and out of Brook Run, a state-operated institution. With osteogenesis imperfecta, or brittle bone disease, Leonard Roscoe lived constantly with broken bones during his 23-year tenure in the institution. However, once he was in the community, he enjoyed five consecutive years without a broken bone.

His story was the same with pneumonia. After he left the institution, it was four years before he experienced a respiratory infection, something he suffered several times a year at the hospital.

“He would have died a long time ago if he had not gotten out,” Peek speculated.

Tracy Peterson also experienced better health once she moved out of Brook Run, a year before it closed in 1997. “When one person gets sick, they all get sick,” explained her mother, Valerie Schwartz. “By the time it makes the rounds, they start getting sick all over again.”

CONTENTMENT Schwartz compared institutional living to dorm living. “I think that first of all, even when people go off to college and live in the dorm – most people don’t want to be there the second year,” she analyzed. “They would rather be in their own place.” She pointed out many freedoms that most people enjoy daily are taken for granted: a private bedroom, personal belongings, a choice of what to do every day and what to eat for lunch.

“None of these exist in the institution,” Schwartz said. “Your personal things are not your personal things at the institution.”

Peterson shares her home with a friend she met at Brook Run. Although Peterson is blind and has severe mental retardation, she enjoys “watching” musicals with her roommate and listening to music. The two also participate in music therapy twice a week together.

They take pleasure in simple things like having
lunch on their deck outside, smelling the sweet aromas from the preparation of their favorite meals, having their own clothing that doesn’t get stolen and sitting in soft furniture – all luxuries that didn’t exist when they lived in the institution. “I don’t care how good an institution is, it’s still bad,” Schwartz concluded.

When Roscoe moved into the community at 25, he was finally able to lead his life the way he wanted to. He became a DJ and enjoyed circulating the clubs in Atlanta with his wife. According to Peek, they were approached at a show by Mary J. Blige, and the famous singer asked her if she was Roscoe’s wife. “Mary was one of the few people who said to us, ‘Is that his wife?’” Mostly, people assumed that Roscoe’s quality of life didn’t include a wife or family.

Five years ago, Roscoe and Peek adopted a son, Nigel. “He was the best father!” she said proudly. “We celebrated 10 years out [of the institution] in January and four years with Nigel in February.” A month later, Roscoe died. “I’m so glad he had those four years,” Peek said.

Skinner feels people are happier outside of the institution because of interactions with other people. “They have few, if any, relationships with people who are not paid to have relationships with them [in the institution],” she said. “It’s unnatural that everyone who spends time with you is paid to spend time with you. Having relationships enriches our lives, and it will do the same for these individuals.”

FEAR NOT When Brook Run was in the process of shutting down, many family members of the individuals living there were scared and concerned. They felt the individuals might not get support in the community or even that they liked living in the institution since they had been there for so long.

“People fear what they don’t know,” said Janet Deal, regional director of ResCare of Georgia, a service provider for people with disabilities and former employee of Brook Run.

“I moved to the community program when it closed, and I’ve seen individuals that I knew for years live in the community now and do well.” Like many parents at Brook Run, Schwartz was not in favor of the institution closing at first. Although she didn’t feel completely comfortable putting her daughter in the institution, she felt like she was safe there and her basic needs for food and shelter were met. “People who cling to an institution cling because that’s all they’ve been exposed to,” she remembered.

As she became more involved in advocacy however, she changed her mind about where her daughter would live a better life. Ron Cornelison of Options for Supported Living educated Schwartz on her choices, convincing her that the brick and mortar of an institution did not provide care as well as a community could. “I finally felt like it was the best thing for Tracy and everybody else,” she remembered. “I took the big step to let her come on out.”

Sometime after leaving the institution, Schwartz’ daughter experienced some general health problems that required medical attention. “I think that’s every parent’s fear – ‘If my child gets sick in the community, no one will take care of them’,” she explained. “This is a fear parents have, but it’s not founded. Tracy’s gotten really good care, and the doctors are willing to prescribe or treat her and be very patient.”

“Your personal things are not your personal things at the institution.”
Now that Peterson lives just 10 minutes away, her mom has more peace of mind. “I manage to see her more often. On the way to the grocery store I can drop by and give her a kiss and be on my way,” Schwartz said.

She also appreciates an improved quality of care by service providers. “I know when I call her home, I’m going to speak to the person that’s there everyday and that person knows what I need to know,” she said. “When you call an institution, it could be luck of the draw who you speak with.”

**BEHAVIOR** Some people worry about residents with behavior problems leaving the institution. Skinner says that it’s DHR’s job to work with them to transition to support and therapy.

As a mother of a daughter who was in an institution for 21 years, Schwartz talked of her own observances on behavior in and out of institutions. “Sometimes the behaviors are caused by the environment. If you had to be in a room with 28 other people who are yelling and banging and screaming, and you need attention, the only attention you are going to get is negative attention,” she said. “People who move into a smaller, more structured environment are going to improve their behavior.”

She referred to a study where a behavioral psychologist tried to work with patients in an institution. It failed because it was inconsistent. The day shift was made up of trained professionals who knew what the patients were trying to learn and how to interact with them properly. However, the night shift staff wouldn’t follow through with the program because for them, there was no incentive.

“The payoff is greater in the community than in the institution,” Schwartz pointed out. An individual’s behavior is more likely to change for the better when a care giver is in a living situation where his or her quality of life depends on the individual’s positive behavior.

According to Deal, behavior therapies are available to individuals who need them when they are living in a community. “There was a fear at the closing of Brook Run for medical needs or behavioral needs...with good planning, all of those needs can be met,” she said.

**THE TRANSITION** Skinner is aware that people with family members in Central State Hospital have concerns about the pending transition. “I understand worrying,” she said, referring to her children when they left for college. “Are they going to make the transition? Is someone going to be attentive to their needs? Is anyone going to care about them as much as us?” But, she insisted that if the proposal passes, people would receive sufficient support based on their needs. “What our work is, if this is approved, is to do a very individualized assessment of each individual and figure out what they need individually.”

Deal said, “When folks come together and look at the individual and plan based on the individual, things go well.” But she added that the transition would not be a fast or easy process, and it takes support and hard work. Importantly, communication between the hospital and provider network is key.

Peek worked to get her high school sweetheart, Roscoe, out of Central State Hospital when he was 25. “It’s important to have a good circle of support,” she recognized. Now she’s raising her son who has several mental and physical disabilities. “I’m raising a child on my own who is bipolar and has severe ADHD...it can be done with the proper supports,” she concluded. “I will die before my child goes into an institution.”

If the proposal passes, DHR intends to start analyzing living situations in the community for Central State individuals immediately. DHR plans to work with the individuals, their families and the staff at Central State to determine needs for support. Individualized supports could include job training and placement, help with cooking or assistance performing the activities of daily living, such as dressing or bathing.

Then, appropriate living situations and locations would be examined. In cases where individuals’ families are involved in their lives, appropriate support systems would be searched for or created in or near the communities of the family.
members. “We’re not going to move people until there is a good plan,” Skinner said. “We have to consider each person individually because we are talking about quality of life.”

Deal and Skinner both recommended that people who are concerned about their family members moving to the community should contact local advocacy organizations to meet others who have made a successful transition.

The Georgia Peer Support Project by MHDDAD, with support from the Governor’s Council on Developmental Disabilities and disABILITY LINK, gives people access to peers who share their own experiences. Some peer supporters offer the story of their moves from institutions to various community settings. This support is offered through Centers for Independent Living throughout the state. The centers can be found by visiting http://silcga.org/CIL_List.htm or by calling the Statewide Independent Living Council at 888-288-9780.

**THE WORKERS** Critics of the DHR proposal worry that there aren’t sufficient community supports and are concerned that people at Central State Hospital will lose their jobs if the proposal is approved.

As regional director of ResCare, Deal is well acquainted with hiring care givers to serve individuals in the community. She agrees that there isn’t a pool of provider staff just waiting for individuals to serve. However, she feels that workers will come forward as needed. “The provider network does have capacity to support people, and it grows as more people need services,” she said.

The care givers at Central State Hospital are the most obvious people to hire as care givers for individuals moving out of the institution. “There will be opportunities for direct support staff and leadership opportunities as well as opportunities to be a host provider in their own homes,” Deal said. “MHDDAD and local providers are always looking for new providers of support.”

After 16 years as an employee at a state-run institution, Deal started searching for another job when she found out the hospital would close in the mid-90s. She visited several community programs and was soon working for the DeKalb Community Service Board.

“I found that the transition was a good one,” she remembered. “I never will forget the first day I went out and visited individuals in their homes, and met people I had worked with at the hospital 16 years earlier. They were living well in their own homes in the community. I found it was very satisfying, and it was a continuation of my career.”

In her new role as a community provider, Deal observed the individuals’ higher quality of life and related with their sense of pride. She spoke of a unit of 16 men at the hospital and how their quality of life has changed, “…now I see them living in the community with roommates and going to the movies. I regret saying things like, ‘they are too medically complex.’”

When the hospital closed a year later, Deal hired several of the staff members she had worked with as direct support staff for people with disabilities living in apartments and group homes. Support staff were also needed for day programs and employment support.

She concluded that many workers at Central State Hospital have been there for many years and enjoy supporting people with disabilities. She felt that although the hospital is closing, they can continue working with people with disabilities in the community.

According to Skinner, the workers should not expect decreases in pay when they transition to community support roles because the state pay rate is set. Deal noted that the pay varies from private organizations to state jobs but as is with most jobs, the more highly experienced workers garner higher pay rates.

Skinner said the hospital workers will have assistance in transitioning into community support roles because DHR plans to coordinate with the Office of Human Resource Management and Development and the Department of Labor. “We don’t want to lose highly trained workers,” she said. She also said the hospital care givers would not need further training to go out into the community. “It’s more of a re-training as a mindset – you don’t need a hospital to help people get dressed.”
What Advocacy Means to Me

By Bernard Baker,
President, People First of Georgia

Advocacy means being able to get what you want done – done by any means necessary. Sometimes that means taking over a public official’s office by blocking the doors, blocking elevators or any other means necessary. Sometimes it may even mean getting arrested for a cause that you believe in.

There are also other means of getting your point across. You might hold a meeting, write letters, make phone calls or have discussions on certain issues you believe in. It may mean going to several different groups and organizations to sit down in a roundtable discussion about the issue you want to work on. But it means never giving up on your dreams, your goals or what you believe in.

Before I joined any groups, I was fighting my own personal issues as my own self-advocate. Self-advocating by myself was harder.

One thing my mom and I advocated for was accessible transportation so I could go to the doctor on the bus. Mom had to carry me on her hips on the bus, so we advocated for accessible transportation. We also advocated that I be put into a regular school classroom with kids without disabilities. That didn’t happen for a long time.

When I want to elementary school, I was put in a special class for kids with disabilities. I never went to a typical class until high school, when my homeroom teacher was determined I should attend regular classes. He carried me up the stairs so I could get to class. Without him, I wouldn’t have been able to take normal classes and be included at Walter F. George High School.

Advocacy also means finding a group of people who believe in the same issue because they have similar problems. The main goals are to get what you want changed and get your issue heard. It’s still hard to create change, but I have more support in groups than I had alone, and there’s more power in numbers.

I am now president of People First of Georgia. ADAPT and People First are teaming with other groups to work to convince legislators to pass Money Follows the Person legislation, so people can live in the community instead of institutions and nursing homes. We are also part of the Children’s Freedom Initiative so we can make sure children no longer have to go to institutions and nursing homes. I will not rest until I see people getting what they want, when they want and how they want it. I believe in self-determination.

Since I’ve been advocating as part of a group, I’ve helped convince Greyhound to put lifts on its buses, MARTA to purchase more buses with lifts and airlines to be more sensitive to the needs of passengers with disabilities.

There’s still a lot of work to be done. I’d like to see more accessible transportation for people with disabilities. We have MARTA in Atlanta, but I’d like to see more private companies be more accessible to people with disabilities and not be so expensive. I want to start my own transportation company and have it operated by people with disabilities. I’d like to convince tour buses to add lifts so people with disabilities can take tours. I’d also like more affordable and accessible housing with no-step entrances for people with disabilities.

Up until now, my biggest advocacy successes have been working on a committee for MARTA to help them change what they need to change and advocating with ADAPT to help get lifts on Greyhound buses.

“It’s still hard to create change, but I have more support in groups than I had alone, and there’s more power in numbers.”

That’s what self-advocacy means to me, and I’ve been a self-advocate all my life. If I had to give advice to new self-advocates, I’d say the best thing is to listen to older advocates, learn from them and work together as a team.
Advocacy: One Girl’s Voice

By Jordan Schwartz, Self-Advocate

At seven, my first try at theater was as a seagull. Fun, but hard work too, and with theater, my mother’s only rule was commitment. She said that if I got a part, then people were counting on me, and I had to do my best and could not quit midway. At the end I could choose to never do it again, but about 157 performances later, I guess that I decided to stick to it. It’s fun working with different casts and friends, and now I see that an early lesson in commitment was my first lesson in what advocacy means to me.

“Encouragement matters because individual effort, as small as it sometimes seems, can make a difference and will leave a legacy.”

I’ve learned a lot through theater, and I got to thinking about the “Whos” in Dr. Seuss’s Whoville, after seeing Seussical performed by my classmates at Atlanta Girls’ School. When one Who wanted to be heard, only Horton heard. No one else would help until all the Whos in Whoville committed to join together to be heard, then Whoville was saved. This play gave me an idea, and as a legislative page, I knew that there is a process to get the word out, to get information, to get answers and to be heard. My theater background gave me the confidence to go public with my message and reach out with my website, ugrowgirl.org as a way to be heard.

Advocacy is of value to many aspects of a person’s life, whether your reason to advocate is for a cause or for yourself, or as in my case, for both. Last year, at age 11, I found out that I had Turner’s syndrome, and after my health insurance denied medically necessary medication, I worked with my family to see if the Katie Beckett (Deeming) Waiver could help, but I was denied there, too. It was scary knowing that I only had a few years when the therapy could make a difference. I was running out of time, and it felt like no one was listening. The Governor’s Council on Developmental Disabilities was there to listen, and Sen. Judson Hill (R-Marietta) has asked me to page for him this session so I can listen, learn, improve my advocacy skills and be heard. Through ugrowgirl.org, I can build bridges between support systems while providing encouragement and a venue for expression.

Encouragement matters because individual effort, as small as it sometimes seems, can make a difference and will leave a legacy. I know that my advocacy and commitment can link together to form a strong bond so that I can work toward communicating an effective message of encouragement, compassion and tolerance, and this poem expresses my ideas on reaching my goal.

u grow girl

by Jordan Schwartz

u grow when you serve
u grow when you teach
u grow when you learn
u grow when you reach out to others and share who you are.

Live your life extending your arms in friendship and service.

Learn that when you give of yourself, U GROW GIRL!

To learn more visit: ugrowgirl.org and www.childrensbilingualtheater.org.

www.gcdd.org
Corporate America was recently cautioned of the effects of neglecting the disability market. “In the next few years in this country, you’ll see a war for talent and a labor shortage, and yet the disability market is untapped,” Emily Myers-Briggs of Briggs & Associates predicted.

Top executives from large corporations in Atlanta as well as owners of small and mid-sized businesses were invited to the 2005 Discovery Tour October 25, sponsored by the Governor’s Council on Developmental Disabilities (GCDD).

The fifth annual Discovery Tour began at the Martin Luther King, Jr. National Historic Site, and coincidentally, the day after civil rights activist Rosa Parks died.

Discovery Tour co-host Gloria Johnson-Goins, vice president of diversity at The Home Depot Corporation, said Parks should be remembered as “a symbol that everyone still needs opportunities to ride the bus.”

She went on to say that corporations should see people with disabilities as people who can be productive employees. “We want a Georgia that employs all its citizens who want to work.”

Disability Employment Today

Kate Gainer, disABILITY LINK advocacy coordinator, demanded businesses give people with disabilities a chance to work and be productive. “Ten years ago, we were told we would be saviors of the workforce, and yet today, the unemployment rate for people with disabilities is 70% – way below the national average!” she said. “It’s time the private sector kept its promise. I challenge you to provide us with the opportunities to become full, productive Americans.”

Discovery Tour Co-Host Dave Altman, vice president of corporate communication at the Southern Company, said his company was actively recruiting people with disabilities.

“There are ways to recruit and employ people with disabilities, but recruiting managers don’t know how. We’ve got to raise awareness with people in business,” he said.

Later, tour participants went to Emory Crawford Long Hospital and were introduced to a young woman whose main responsibility is to care for IV pumps and a man who stocks carts for anesthesiologists. Another young woman with a disability enjoys working with people. “I escort patients to the pre-surgery area and recovery area,” said Adetola Shobalolu. Although it is hard for her to remember routes because of her disability, she is able to navigate the hallways with a system of strategically placed American flags that point her in the right direction.

These workers were hired in the last year, after Diane Prindle, regional director of Briggs & Associates, a specialty employment agency, approached Chief Operating Officer Albert Blackwelder. She requested that Blackwelder fill one of the hospital’s business needs – a need for dependable employees – by hiring people with disabilities. The request was based on a successful hiring program called “Project SEARCH” at Cincinnati Children’s Hospital Medical Center. Prindle told Blackwelder, “We affect the bottom line.” She was pleased that he immediately grasped the idea and “took action.”

After nearly a year of employing people with disabilities, Blackwelder examined the program’s success. His original goals at the beginning of the program were met: 1) full time equivalents were not increased (a benchmark to measure against other
hospitals) and 2) costs had not increased. “One thing I didn’t ask for, we’ve gotten: an increase in quality,” he noted. “What [Briggs & Associates] was doing was no different than what we’ve been doing – when we have an empty job, we look for the right person to fill it. Unfortunately, we were excluding a whole group of people because they didn’t fit the description,” Blackwelder said.

Ultimately, he found that hiring individuals who love their jobs, enjoy the people they work with and feel respected in their departments as contributors actualized a measurable decrease in costs. “Our pump costs are a lot less than Emory University’s because the IV pumps here are cared for meticulously,” he said.

Blackwelder also found other employees were more satisfied. He noticed an increased appreciation for the new positions among the anesthesiologists. “Anesthesiologists have a toolbox – they are a tough thing to maintain and it’s a problem when one goes to pull out a tool, and it’s not there,” he explained. “We don’t have that problem anymore.” Blackwelder said Maurice Goodwine, who has a disability, meticulously ensures the carts are adequately and neatly stocked, allowing the anesthesiologists to better perform their jobs.

**Supported Employment**

Amidst a shortage of nurses and operating room (OR) technicians, Prindle suggested removing non-medical tasks from their daily responsibilities such as stocking carts or cleaning equipment. By removing these tasks and assigning them to other workers, the hospital could function more efficiently with less nurses and OR techs.

“I agreed to do this, but put some responsibility back on Diane,” Blackwelder said. “I can’t increase my costs – this is a low margin business.”

Briggs & Associates worked with the hospital staff to determine what roles needed to be filled. Then, they coordinated a work-study program with DeKalb County schools. The first class of eight students spent time in the hospital classroom and upon graduation, each student was hired to fill a position that fit his or her abilities.

The hospital provided a classroom, but Briggs & Associates handled all necessary training. “We didn’t have to pay for that!” Blackwelder said.

Because of the program’s success, Emory University Hospital currently has a class in session and plans to hire the graduates sometime this year.

**Assistive Technology**

The next stop on the Discovery Tour showed how assistive technology (AT) can make working possible for people with disabilities. Many companies see AT as a financial barrier to hiring employees with disabilities. However, in many cases, AT can be as simple as a piece of plywood to prop up a piece of equipment.

“Assistive technology plays a vital role in helping people with disabilities, their families and their employers,” Altman said.

Anil Lewis, president of the Client Assistance Program, demonstrated some of his AT. Lewis, who lost his eyesight in his mid-20s, earned an M.B.A. at Georgia State University and is currently working on a law degree with the help of handheld electronic devices with Braille and WebCT. Many institutes of higher learning now utilize WebCT, an internet-based system that allows professors to post notes and handouts online before class. This permits students with visual disabilities to read along with the rest of the students during class, something they were unable to do in the past.
Now he happily calls himself a “gadget man.”

Although some AT can be as simple and as inexpensive as jar opener grips, others can be more costly. ReBoot – Assistive Technology Resource Center (ATRC) in Tucker, Ga., offers a “try before you buy” option so people don’t make costly investments in the wrong technology.

Eric Krugg demonstrated his equipment for tour participants. He tested a device that helped him speak, a challenge since his brain was injured in an accident. His device was on loan for a month. “My primary goal is to get a job to have enough cash to have my own house,” he said with the help of the device. However, he wasn’t sure the equipment was worth the investment and thought he might try out other equipment before purchasing it.

Attitude

Discovery Tour participants learned about stereotypes and attitudes and how they affect people with disabilities in the workplace. Before becoming an attorney for the Georgia Advocacy Office, Crystal Beelner lost count of how many times she was interviewed. With her resume, she was able to land an initial interview, but once people saw her, a woman with dwarfism, she wasn’t called back for a second interview. “I’ve had everyone, including judges, make rude remarks,” she said. “That’s why it’s so important to cross attitudinal barriers.”

She realized she had to make others comfortable about her disability before they could see her for who she was – a qualified attorney. “Coworkers have to be comfortable,” she said. “They’re scared thinking, I might offend them. Chances are, you will. That’s just part of life.” But, she learned that being upfront with people about her disability on the phone helped increase their comfort level and her chances of getting a second interview.

Lewis discussed a different kind of attitude change. When he lost his eyesight, he thought he had lost his way of identifying himself. As a student, Lewis could read an unbelievable 750 words per minute. “I can’t do that with Braille or my fingers would explode!” he laughed, only half joking. “I had to conquer my attitude ... I learned the only thing that changed was I couldn’t see.” He soon realized he could still accomplish his goals, he would just need a little AT and a better attitude to do so.

Visitable Homes

Unfortunately, many Georgians in wheelchairs miss out on social activities because their family and friends have steps at the front, back and garage doors, skinny doorways and tiny bathrooms.

The last stop on the 2005 Discovery Tour was a “visitable” town home community in Decatur. East Lake Commons has simple features that allow people in wheelchairs to be able to visit, including no-step entrances (not necessarily the front door), wider doorways and bathrooms with room for wheelchairs.

Eleanor Smith, a community resident and founder of Concrete Change, a nonprofit organization dedicated to making homes visitable, said renovating a home to be visitable can cost thousands but building one from scratch might cost just a few extra dollars for a wider doorframe and door.

Employment Support

Among adults with disabilities ages 18-64, three out of 10 (29%) work full or part-time, compared with eight out of 10 (79%) of those without disabilities – a staggering gap. Compare this to the number of people (16+) with disabilities who are unemployed, 72% of which would prefer to work according to a 1998 Survey of Americans with Disabilities by the National Organization on Disability and Louis Harris & Associates.

“We can’t have help getting people into jobs without the support of the corporate community,” said Tom Seegmueller, GCDD chairperson. At least one tour participant connected with the disability community’s message by the end of the tour. “I’m seeing possible opportunities for small businesses,” said Pamela Goldstein Sanchez of Pam Sanchez Designs, Inc. in Atlanta. She concluded that someone with a disability might be able to help her organize her resource library or help clean her husband’s tools at his orthodontic practice.

“There are hundreds of individuals with disabilities who want to work,” said Beelner. “They have the ability to adapt to your organization.”

Crystal Beelner had many interviews before an employer saw beyond her disability and hired her.
JANUARY
January 27
Autism Workshop – A Conference for Parents & Professionals
Woodstock, GA
770-591-9552
www.behavior-consultant.com/ablss.htm

January 27-29
Division E Midwinter Conference – “The Illusion of Therapy: Discover the Magic Within”
Emerald Pointe, Lake Lanier Islands, GA

FEBRUARY
February 1
Healthy Mothers, Healthy Babies Coalition of Georgia’s 19th Annual Legislative Breakfast
“Sloppy” Floyd Veterans Building
Atlanta, GA
770-451-0020
www.hmhbga.org

February 2
Wright’s Law – Special Education Law & Advocacy Seminar
Gwinnett Convention Center
Duluth, GA
www.wrightslaw.com

February 3-4
Autism Society of America – Greater Georgia Chapter Annual Autism-Asperger Conference
Gwinnett Convention Center
Duluth, GA
conference@asaga.com

February 6
Mental Health Day
Georgia State Capitol
Atlanta, GA
404-656-8508

February 8-9
Poor People’s Day
Georgia State Capitol
Atlanta, GA
404-622-7778
info@gahungercoalition.com

February 14
Money Follows the People Day
Georgia State Capitol
Atlanta, GA
ngainer@msn.com

February 16
3rd Annual Under One Roof Housing Conference – The Nuts & Bolts of Georgia’s Housing Resources
478-825-6954
thomasb@fvsu.edu

February 23
Disability Day at the Capitol
Atlanta, GA
404-657-2126
www.gcdd.org

MARCH
March 1-4
Better All Together – Inclusion Works! Conference
University of GA – Continuing Ed. Center
Athens, GA
www.gcdd.org

March 3-5
The 2006 Josephine L. Taylor Leadership Institute

APRIL
April 17-18
2006 Multiple Perspectives on Access, Inclusion & Disability
Ohio State University
Columbus, Ohio

April 20 -22
Governor’s Council on Developmental Disabilities Quarterly Council Meeting
Public Forum - 7 PM
Albany, GA
404-657-2126
www.gcdd.org

To include events through mid-July in the next edition, please send to val@oneillcommunications.com by March 6.
Alternatives to Guardianship

By Kathleen Harris

Even though an individual may be found legally “incapacitated,” it does not necessarily follow that the individual needs a guardian. There are many other ways to assist individuals to make decisions without resorting to this legal process which removes fundamental rights.

Person-Centered Planning (PCP)

The best way to avoid guardianship is to assure enough support for individuals from families, friends and others so the individual’s preferences can be honored, respected and implemented. This is generally done through a process called person-centered planning (PCP).

Through PCP, individuals tell professionals and other interested people what they want and need. If the individual is unable to direct or participate in this process, the people closest to the individual confer about what they believe the individual wants and needs based on their knowledge and observations of the individual. They then assure implementation of the plan.

Family Consent

Hospitals and medical centers typically have family consent policies that address who can give consent for medical treatment if it is determined that an individual is not competent to give such consent. Usually, immediate family members are the ones who are authorized to give consent, followed by more distant relatives and close friends.

There are no legal reasons why other providers, such as mental health programs and school systems could not also implement family consent policies (and some do). As providers are beginning to address self-determination, choice, and are implementing person-centered planning, they are also implementing family consent policies.

Durable Powers of Attorney

Durable Powers of Attorney are executed through legal documents in which individuals give the power to authorize certain actions on their behalf to another individual if they become unable to make their own decisions. A variety of powers can be given in this way, but the most common are medical and financial.

Finances

When an individual is determined to be unable to handle money, a number of alternatives can be explored. For someone receiving government benefits, a representative payee may be appointed to receive and disperse the funds.

Durable Powers of Attorney for Finance can be effective if executed before the person becomes “incapacitated.” These are documents in which individuals designate someone to handle their money in the event they become incapacitated. If such a document was not executed in time (before the person became incapacitated), electronic deposits and automatic bill paying might be desirable. Or, it may be possible to hire a personal money manager to receive funds and pay bills.

If no trust was devised, and no power of attorney was executed, it is possible to have someone appointed a conservator or guardian of the property by a court to handle the estate. The guardian of the property would be accountable to the court and would not affect as many personal rights as guardian of the person under Georgia law.

For those with developmental disabilities or mental illness, however, a “special needs” trust may be the best route to handle money. Such a trust can be established to enhance the individual’s life while protecting eligibility for Supplemental Security Income (SSI) and Medicaid. These trusts are an excellent way for parents to plan and monitor their child’s life after they are gone. Parents can designate money to pay for a person or agency to visit and report to the trustee about the well-being of the recipient. Families can specify that the report include such things as whether their child is happy in their home, whether they are getting out into the community or whether they are given enough opportunities to live as independently as possible. By establishing such a trust, parents provide supplemental income to their child above SSI and Medicaid, and also achieve peace of mind about what will happen to their loved one after they are gone.

In summary, our goal is to assist people with disabilities build caring relationships among family, friends and others. This support circle helps assure through these alternatives that people’s preferences and wishes can be honored, respected and implemented without resorting to legal guardianship.

Kathleen Harris is a disability law attorney from Michigan who served on the Michigan Supreme Court Task Force on Guardianship and also on legislative work groups to reform guardianship law. Currently, she consults with states about alternatives to guardianship through her work with the Center for Self-Determination. She also serves on numerous boards of nonprofit agencies that promote civil liberties and self-determination for people with disabilities.
Below, please find further resources of information related to the articles in this edition of Making a Difference magazine.

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

State Government
Department of Community 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
disABILITY LINK
www.disabilitylink.org
404-687-8890

Georgia Voices that Count
http://www.disabilitylink.org/docs/voices/voices.html
404-687-8890, ext. 114

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

People First
www.disabilitylink.org/docs/people.html
404-687-8890
404-687-9175 TTY
800-239-2507 (V/TTY)

U Grow girl
www.ugrowgirl.org
info@ugrowgirl.org

Unlock the Waiting Lists!
www.unlockthewaitinglists.com
877-WAITLIST

Assistive Technology
ReBoot – ATRC
www.reboot-atrc.org
770-934-8432

Center for Assistive Technology & Environmental Access
www.catea.org
404-894-4960

Georgia Tools for Life
www.gatfl.org
800-497-8665
TDD: 866-373-7778
Atlanta Metro TDD: 404-486-6333

Civil Rights
The Martin Luther King, Jr. Historic Site
www.thekingcenter.org
404-526-8900

Community Support
ResCare of Georgia’s Options for Supported Living
www.rescare.com
770-908-2481

Medicaid Reform
Georgia Budget & Policy Institute
www.gbpi.org
404-420-1324

Georgia Coalition United for a Responsible Budget
www.gacurb.org

MRWP Changes
Department of Community Health
http://dch.georgia.gov/00/channel_title/0,2094,31446711_37280543,00.html

Peer Support
Centers for Independent Living
http://silcga.org
888-288-9780

Supported Employment
Briggs & Associates
www.briggsassociates.org

CobbWorks!
www.cobbworks.org
770-528-8072

Universal Design
Concrete Change
www.concretechange.com

EasyLiving Home
www.easylivinghome.org
404-723-5503

Universal Design Alliance
www.universaldesign.org
770-667-4593
If you are interested in being a sponsor for Making a Difference magazine, please call Christina Rosell @ 770-578-9765

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(770) 676-2000 or 1-888-UCP-WILL
www.ucpga.org

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(Individualized supports to find & maintain competitive employment)

*Day Program
(Creative alternative to supported employment)

*Transition Program
(Life Skills Development)

For more information call 770-677-9379 or visit us on the web at www.YourToolsforLiving.org

The Center for Assistive Technology & Environmental Access

CATEA advances its mission through a variety of projects which focus on:

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- Information Dissemination - on disability, assistive technology, disability-related legislation and policies, and effective accommodations
- Training & Education - on assistive technology, accessible distance education, disability, and disability policy
- Design & Technology - on accessible environments and accessible electronic and information technology, with a particular focus on universal design

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Albany Advocacy Resource Center

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

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

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www.gcdd.org 31
For more details, or to register for Disability Day at the Capitol, see page 7.

Accessible voting is an important issue for people with disabilities. Join with hundreds of other self-advocates from across the state and let your legislator know how you feel on that issue and others that affect the lives of people with disabilities.