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To Georgia’s Disability Community,

This issue of Making A Difference comes on the eve of our legislative session. As parental, care-giver, and self-advocates for Georgians with disabilities, you will be heavily involved in the process. With your help more people with disabilities will live fuller lives by integrating into our local communities.

As Governor, I will continue to work hard to create a people-focused state government and a state budget that meets the needs of all Georgians. I remain committed to making investments in programs that achieve positive results.

The results I envision for people with disabilities are the same as I have for every Georgian. They should live as independently as possible, surrounded by people who love and care for them, in a safe community. This result can be accomplished through hard work, good ideas and creative actions. Over time, by making the best use of the state’s limited resources, positive results will be achieved.

A partnership with the Governor’s Council on Developmental Disabilities is essential to achieving this vision. So I welcome your best thinking and encourage your involvement with the Council.

On February 24th the Governor’s Council on Developmental Disabilities will be hosting Disability Day at the Capitol. I invite you to participate in this event as we work together to improve the lives of people with disabilities in the State of Georgia.

Sonny Perdue
Governor
Imagine waking up one March morning and reading the headlines of the newspaper:

It could happen. Maybe not this year, but it is not so hard to believe that Georgia could again become a leader in supporting people with developmental disabilities and their families. The real question is how to make it become a reality. I believe that it starts with advocacy – each individual and family member can be the agent necessary to move Georgia from 45th in the country to number one. By joining together we can become the force that demands the changes needed to make sure that the people who require services are receiving quality supports.

Many of you receiving this magazine are graduates of programs such as Partners in Policymaking. You have spent countless hours learning how to advocate for yourself and others; now is the time to use those tools to educate policymakers that it is time for a change.

By the time you receive this edition of Making a Difference, the 2005 legislative session will have begun. There is new leadership in the House of Representatives, which means we have an opportunity to create new relationships. You need to take the time and talk with the individuals you helped elect and tell them your story. Tell them the success story of an individual who once lived in a state hospital but now lives in the community and has a job. Introduce yourself or a family member who was once on the waiting list but now receives supports.

Last year, families receiving supports through the Deeming (Katie Beckett) Waiver launched a heroic and successful advocacy effort. Several legislators have used this effort as an example of how interaction between citizens and their elected representatives should work. Many families supported the leadership provided by Heidi Moore and Tonya McConnell across the state. Their focused message through the media and work with several key legislators resulted in the defeat of a proposal to place a premium on the waiver.

This year, the Department of Human Resources has recommended funding for 1,124 people who are currently on the waiting lists for home and community-based services. The department has also recommended a 6 percent provider rate increase. These requests were made because the department heard the same message from people across the state: “We must unlock the waiting lists!” This targeted message and advocacy resulted in the waiting lists becoming one of the department’s top priorities.

Now is the time to thank those legislators who have supported us in the past and educate new legislators about our issues. Take a copy of this magazine to your legislators and ask them to support the effort to reduce the waiting lists, increase provider rate reimbursements, and make polling places more accessible. Finally, invite them to the 7th annual Disability Day at the Capitol on February 24th.

You are the power that can make the headlines in your local newspaper a reality. I look forward to seeing each of you on February 24. I invite your comments; please reach me at eejacobson@dhr.state.ga.us or 1-888-275-4233.

Eric E. Jacobson
Executive Director, GCDD
Suber Joins GCDD as Public Information Director, Editor-In-Chief

For as long as she can remember, Valerie Meadows Suber, new public information director of the Governor’s Council on Developmental Disabilities and Making A Difference magazine editor-in-chief, wanted to communicate ideas to foster positive social change and improve conditions in people’s lives.

Media coverage of events during the civil rights movement sparked Suber’s early interest in public affairs. Its message of access and inclusion for all Americans captured her attention. As her appetite for news and information grew, she set her sights toward journalism that she studied at Boston University’s School of Public Communications.

“I personally share the vision of GCDD that supports and encourages inclusion, choice, achievement, potential, opportunity and advocacy for all persons, and I believe Making A Difference magazine is an important instrument for furthering public dialogue among all stakeholders within the developmental disabilities community,” Suber said.

Suber produced public affairs television programming in Philadelphia, where she crafted relevant shows on the day’s topics, including an Emmy-nominated documentary.

She served as a coordinator of community and media relations for Atlanta City Council, implementing community outreach and constituent services through district newsletters, community empowerment conferences and special projects.

As executive director of Kids Voting Atlanta, a nonprofit civics education organization, Suber managed a program for thousands of K-12 students that introduced the fundamentals of citizen participation in the democratic process, complete with a voting experience during election cycles at official polling precincts.

Suber provided spokespersons for community forums, media, news conferences and symposiums on a variety of social and economic development issues targeted by The Atlanta Project, a community outreach initiative of The Carter Center.

The sudden loss of nearly 80% of her eyesight did not deter Suber from pursuing work she loved. In fact, she became convinced that she had a lot more yet to offer. “I realized I would have to embrace the concept of interdependency. I knew I would have to commit to learning new ways of functioning in order to remain productive.”

Suber enrolled in classes at the Center for the Visually Impaired in Atlanta to acquire skills in the use of adaptive equipment and computer software. She became proficient in using magnification and speech screen reading devices. She was determined to continue to participate fully and effectively as a visually impaired person in a sighted world. Thanks to modern assistive technology, a system of family and community support and a lot of due diligence, she is doing exactly that.

Suber will assist GCDD Executive Director Eric Jacobson on a variety of special assignments and tasks.

“We are very excited to have Valerie join our team. She will help us educate the media and public about the needs of people with developmental disabilities and their families. She brings a new level of professionalism to our public relations efforts based on her knowledge and experience,” Jacobson said.

Suber will manage GCDD’s internal and external communications and publications. Greater emphasis on public awareness of developmental disabilities policy and programs will be among her top priorities.
DHR Names New DD Director

Stephen R. Hall, Ph.D., became director of the Office of Developmental Disabilities of the Georgia Department of Human Resources (DHR), January 1. Hall received his Ph.D. in disability policy from Virginia Commonwealth University and brings 14 years of executive leadership serving people with developmental disabilities. Hall leaves his position as executive director of the Resource Exchange, a community-centered board in Colorado responsible for disability service systems for children and adults where he managed a $24 million budget. Hall will work directly with Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) Director Gwen Skinner. “We believe that we have the best candidate for helping to move Georgia’s disability community to the next level,” Skinner said.

As DHR continues to expand and enhance community partnerships, advocates served an important role in the selection of the best person to support issues specific to Georgia’s disability community. Eric Jacobson, executive director for the Governor’s Council on Developmental Disabilities, participated in the selection process and stated, “We are excited about Dr. Hall’s appointment and look forward to working with him to create a new vision for Georgians with disabilities.”

With input from key stakeholders, Hall will be responsible for developing and implementing state policy for developmental disability services, in addition to setting standards for services and expected outcomes of those services.

Housing Champion Honored for Service

Eleanor Smith, founder of Concrete Change and co-founder of Georgia’s EasyLiving Home™ program, was recognized for her outstanding achievements in affordable housing by the Georgia Department of Community Affairs (DCA) during its Fourth Annual Housing Georgia Conference and Magnolia Awards Program November 10.

Smith received the Housing Champion Award in honor of her pioneering work in the “visitability” movement.

Visitability is the movement that focuses on designing housing in such a way that it can be lived in or visited by people with disabilities. According to Smith, “a house is considered visitable when it meets three basic requirements:"

- At least one zero-step entrance.
- Doors and hallways wide enough for a wheelchair to navigate through (minimum 32” clearance).
- A half bathroom on the main level large enough to be accessed by someone in a wheelchair.

Smith says her goal is to have visitability in every new home. DCA Commissioner Mike Beatty lauded Smith for “her efforts to make life easier for millions of people with disabilities and richer for millions of able-bodied people who will someday find their homes easier to live in and find it easier to welcome everyone into their homes.”

Smith’s determination has also helped to make the EasyLiving Home program a model certification program for other states. The program allows participating builders to certify that their homes are visitable and meet certain standards.

Among her other numerous achievements, Smith has received a Best Practices Award for Visitability from the Department of Housing and Urban Development in 1999 and the Vital Service Award from the Atlanta Alliance on Developmental Disabilities in 2002.

Transitioning Students Participate in Person-Centered Planning

The Georgia Department of Human Resources recently hosted a person-centered planning session, “Transition into Adulthood,” for people with disabilities in Duluth, as part of a three-year project funded by a grant from the Center for Medicare and Medicaid Resources.

During the two-day session, individuals with disabilities and their circles of support were taught to “think outside the box” and begin to develop plans to achieve key life goals.

Internationally renowned person-centered planning experts Connie Lyle O’Brien and Beth Mount are consulting with the Department of Human Resources Division of Mental Health, Developmental Disabilities and Addictive Diseases (DHR/
Volunteers with Disabilities Build Atlanta’s First ABILITY House

Volunteers with all ranges of disabilities, including paralysis, amputations, low vision, Down syndrome and more united at an Atlanta Habitat for Humanity home site in East Point to build an ABILITY House for Kawa Talabani, his wife Amina Shaheen, who has heart disease, and the couple’s four children, ages 13, 11, 4 and 10 months.

An ABILITY House is an affordable, accessible home built for a low-income family in which one or more members have disabilities. The ABILITY House program also uses volunteers with disabilities during construction and was recently honored by President Bush with a Presidential Community Volunteer Award.

“I always wanted to be a part of Habitat, but I thought my wheelchair might get in the way,” said Stephany Glassing, of Marietta, who worked several days on the project. Glassing helped cut siding and caulk chair rail on her visits to the home site. “I never felt like an outcast, and they gave me a lot of hands on work, which I thrive on. I really had a good time with it. I wish they’d build more houses like it in Atlanta,” she said.

“We have had tremendous response to the ABILITY House project and are pleased to be bringing it to Atlanta,” noted Chet Cooper, executive director of ABILITY Awareness, the organization that oversees the program. “It is also great to be working with the Atlanta Habitat affiliate, which is already dedicated to incorporating accessibility and visitability features into each home they build.”

Volunteers with disabilities worked alongside volunteers from BellSouth and BellSouth Telecom Pioneers to complete the home in only seven days of construction, over seven weekends. The Home Dedication Celebration was Saturday, Dec. 11, followed by an open house showcasing the home’s many universal design and visitability features.

Talabani and Shaheen are the first recipients of an ABILITY House in Atlanta. Shaheen, 35, had a life-threatening split in the wall of one of her major arteries in November 2003 and has since had coronary bypass surgery and has an implanted defibrillator, that shocks her heart if it stops beating for too long. The device causes weakness and discomfort in Shaheen’s left arm. She is frequently exhausted, and she has difficulty reaching, opening doors and performing routine household tasks.

Educators Honored for Transition Work

Pioneers in transitioning students with disabilities from school to work were honored October 29 during the Power Up For the Future (PUFF) Conference.

The Transition Honor Roll recipients prepared students to navigate the system of adult supports and services, while also preparing them for jobs.

The recipients, who were selected by representatives from the Department of Labor, Department of Education, Department of Technical and Adult Education and the Statewide Transition Steering Committee, include:

Debbie Mentzer, Beverly Blue, Jane Bruno, Paige Case, Carol Herb, Margo Greene, Denise Klesick, Mary Ford and Douglas Ann Smith of Savannah/Chatham County Schools began including a vocational endorsement seal on Special Education Diplomas to signify students completed a rigorous vocational curriculum. They also worked with a technical school to increase opportunities for students with disabilities.

Dr. Mike Blake and the Clarke County Schools Interagency Transition Planning Council in Athens are developing a regional Interagency Transition Planning Council to serve the rural areas of northeast Georgia. These councils bring various agencies together so students can access them more easily.

Teresa King, Lori Oliver, Lisa Rothschild and Cindy Saylor of Flowery Branch High School in Hall County received a grant from the Governor’s Council on Developmental Disabilities to help students develop self-determination skills, using a person-centered approach when developing transition plans. The staff also formed a “Partners Club” that pairs students with and without disabilities for school, community, civic and social activities.

Denise Oravec of Rockdale County Schools developed a proposal to attach a seal of endorsement for participation in a rigorous vocational preparation program on the Special Education Diploma.
Karen and Art De Chant have been waiting 13 years for a full Medicaid waiver for their son Brian, 31, who has Cockayne syndrome. Brian requires constant supervision and has a number of health issues related to his disability, including hearing loss, poor vision, extreme sensitivity to the sun and a frail body.

“We need a support system. Taking care of Brian is like having a three or five-year-old for a very long time. We can’t leave him alone, and you can’t get a babysitter for a 31-year-old man,” Karen De Chant said.

After Brian left school, De Chant had to cut back her work hours to part time to take care of him. While waiting for the waiver, the De Chants have been relying on respite care, the People Making Progress program and the YMCA’s HAPPY Program that pairs young adults with and without disabilities for social activities.

While these programs provide some support, caring for Brian has been difficult. “We don’t have a normal social life, and it’s impacted our income because I can’t work full time,” De Chant said. “One of our fears is that we will die before he does.” In addition, the De Chants pay extraordinary costs for dentistry and hearing aids that aren’t covered with insurance.

“When we call about the waiver, they always say we’re on the short-term list, but last year there were only 10 waiver slots,” she said.

Brian joins 5,516 other Georgians who are waiting for the state-funded supports and services they need to remain with their communities and families. Without these supports and services in place, many of these people may have to move into institutions, which cost taxpayers much more than community-based services.

“These are some of the most critical services for people that without these supports would be our state’s most vulnerable. These needs will not go away, and we have to begin facing them today,” said Dave Blanchard, of Atlanta Alliance on Developmental Disabilities.

People go on waiting lists when their area Regional Boards cannot serve them and/or meet all their needs due to lack of funding.

Some progress has been made. The new Director of the Division of Mental Health, Developmental Disabilities and Addictive Diseases Gwen Skinner included funding for more than 1,100 people to come off the waiting lists within the proposed Department of Human Resources (DHR) budget. But that still leaves more than 4,400 Georgians waiting for help. And, the slots will only be funded if Governor Sonny Perdue approves a DHR budget that is 105% of the current budget.

The problem is worsened by the fact that Georgia is facing a budget gap of $1.5 billion caused by an increase in need for state-funded services and a decrease in the revenue stream. Alan Essig, executive director of the Georgia Budget and Policy Institute, a nonprofit, nonpartisan organization, explained, “In the ’90s, when the economy was good, our revenues were good. Personal income and capital gains revenue was up. At the same time sales tax revenue went down due to exemptions for certain items, but revenues didn’t decline because the economy was strong.”
However, in the 2000s, Essig noted, “When the recession started, capital gains and income went back to normal levels, and the erosion in the sales tax was noticed. For two years in a row, 2001 and 2002, revenues decreased for the first time since the 1930s.”

While moderate revenue growth has returned at about a rate of 6 - 7%, expenditures are increasing at a higher rate than that, Essig said.

For example, the Department of Community Health (DCH) has projected it needs $2.35 billion to maintain its level of service because more people are enrolling in Medicaid every day. The governor has asked each department to prepare a budget that is 97%, 100% and 105% of last year’s budget. Even if DCH receives 105% of the current state budget and its expected federal funding, it will fall $170 million short of what it needs to deliver services, so cuts will need to be made.

“In the ’80s and ’90s, about 5.9 cents of every dollar we earned went to the state. Now it’s down to 5.3 cents. That causes a budget gap of $1.5 billion,” Essig said. “Our needs have increased due to growth, but we’re asking less of each person.”

While budget cuts can free some money, most state budgets have already been cut significantly in the past several years, and not many areas can afford more cutting.

“We need to maintain a culture of excellence, not fund the programs that don’t work and root out waste. There’s just not much waste. What we have to decide as the family of Georgia is the role of our state government and what we are willing to pay for and revise the tax structure to fit.

“It’s very difficult right now to receive additional funding or even continued funding for existing programs.”

Essig suggests advocating for new revenue sources might be a more effective way to fund services for people with disabilities who are on the waiting lists.

“I’m not suggesting we tax food or medicine, but we could tax services used by people in upper income brackets, such as lawn care, hair cuts, accountants or lawyers,” he said.

Essig also pointed out that Georgia loses between $300 - $400 million per year of potential revenue because it does not have a sales tax on items purchased over the Internet, and it loses about the same amount from corporations taking advantage of loopholes that should be closed.

“If we don’t do something about revenues, we can expect continued budget cuts for the next three to four years,” he concluded.

For Brian De Chant and the 5,516 other Georgians on the waiting lists, that is a long time to wait.
While Alan Essig suggests advocates consider a long-term fight for new sources of revenue to fund their needs, the Governor’s Council on Developmental Disabilities has identified several legislative items that require advocates’ immediate attention.

These agenda items are gathered by the staff and me, with input from other advocates, throughout the late summer and early fall as the agencies develop their budgets, and issues emerge. The GCDD’s agenda is divided into “Top Priority” and “Second Priority” levels, indicating the level of focus and advocacy that Council members wish the policy staff to place on the issues.

We recognize that the agenda is a moving target, and the policy staff needs to be able to shift gears or make changes as new issues emerge. When an issue arises during the session on which I believe the GCDD needs to take a position, I contact the Public Policy Committee, who recommend action, and this recommendation goes to GCDD for a vote.

For the 2005 session, most of the items on the legislative agenda concern the budget. Georgia will again experience budget cuts for the FY06 fiscal year. The governor asked the agencies to submit three budgets for his consideration; a 97% budget that effectively cuts all programs by 3%; a 100% budget that would keep agency allocations the same as last fiscal year; and a 105% budget that allows a 5% increase in funding over FY05.

However, for the Department of Community Health (DCH), Medicaid Services, the 105% budget still means a cut of 43 million dollars in state funding due to the growth in Medicaid enrollment and expenses. Advocates believe that the governor will select items, both cuts and additions, from among these three budget scenarios. Therefore, we will not really know where to focus advocacy efforts until we hear the governor’s budget address in January. The legislative agenda items that the GCDD voted on to support in the upcoming session are listed on the next page in order of priority.

Change in Legislative Session Schedule

The session begins the second Monday in January, and proceeds for 40 days. A “day” is counted when both houses are in session. In the past, lawmakers adjourned to conduct budget hearings the entire second week of the session. The joint house and senate appropriations hearings were always the opportunity for advocates to present their input on potential budget cuts or adds. This year, Capital Impact reports there will be no more early budget hearings. Instead, there will be “budget briefings” on Jan. 18 and 19, but at this time, we have no information on who would participate in those briefings. Senate President Pro-tem Eric Johnson and Speaker-elect Glenn Richardson have agreed that the General Assembly will convene as required on Jan. 10 and stay in session for three days. The legislature will be in recess from Jan. 13 through Jan. 23, and will reconvene for the fourth day of the session on Jan. 24 at 1 p.m.

“For the 2005 session, most of the items on the legislative agenda concern the budget.”

Advocates can stay tuned to Moving Forward, a legislative update issued weekly from January to the end of the session by the GCDD, for other changes in the legislative session procedures, and for current news on the budget and active legislation. Also, check the web site, www.gcdd.org, under the Public Policy heading for fact sheets related to budget and legislative items.
Top Priority Items

1. Oppose Cuts to Medicaid Services for People with Disabilities in the Department of Community Health budget. The targeted cuts are as follows:
   - Set fixed expenditure cap for the Independent Care Waiver Program (ICWP) at $50,000. This reduction will potentially affect 116 persons whose average annual expenditures currently exceed this cap. ($1.1 million*)
   - Cap eligibility for the Mental Retardation Waiver Program (MWRP) at two times SSI ($13,248 per year). Individuals on the waiver program who work and have incomes that exceed this amount annually will lose their Medicaid eligibility and therefore their waiver. ($24.6 million)
   - Provider Rate Cuts: There is a 3% provider rate cut included in the 100% and 105% budgets, and a 5% cut in the 97% budget. This cut comes on the heels of a 10% cut in the FY04 budget. Rates are protected for nursing homes, hospitals and pharmacy providers. ($41.8 million for 5% cut)
   - Elimination of emergency adult dental services. ($7,165,753)
   - Elimination of orthotics and prosthetics services. ($1,531,140)
   - Elimination of podiatry services. ($1,138,540)
   - Elimination of hospice care. ($10,328,171)
   - * figures are state dollars to be removed from the budget, and do not reflect the loss of federal Medicaid dollars

2. Support budget request for waiver slots in the Department of Human Resources budget. (Unlock the Waiting Lists! allocation)
   - The Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) proposes paying for 30 slots at $653,846 in the 97% budget, 924 slots at $3,451,129 budget, and 1,124 slots at $7,908,713 in the 105% budget.

3. Support increase in provider rates for services currently reimbursed below the Southeastern average. (4% at $4,604,295 in the 100% budget, and 6% at $9,208,590 in the 105% budget)

Second Priority Items

1. Oppose premiums for the Katie Beckett Waiver (access to Medicaid for families with medically fragile children) ($1.5 million)
   - This item is only in the 97% budget scenario. The premium proposal was successfully fought off last legislative session. In addition, as of December 1, the CMS regional office had not received an amendment to the current waiver that is required to begin charging premiums.

2. Medication Administration: Support amendments to the Nurse Practice Act that would enable direct support staff to administer certain routine medications to the consumers they support. Staff would be required to complete a Medication Administration Certification Program before being allowed to administer meds.

3. Support Amendments to the Election Code. The following changes to the election code have been discussed with the Secretary of State’s office, and we expect to have a bill drafted and prefilled before the session begins.
   - Remove term “physical” disability from election code and redefine disability consistent with the ADA.
   - Amend absentee voting language to enable those who provide attendant care to assist with absentee voting without penalty.
   - Amend oath requirement provision so voters with disabilities who need assistance are not treated differently from other voters who need assistance.
   - Allow poll workers to assist voters with disabilities in any election, not just federal elections.
   - Create provision that requires all election and voting information available to the public be made available in accessible formats.
   - Consider alternative voting procedures such as curbside voting.
Advocacy for many begins long before Georgia’s legislative session opens in January; it begins during the election process as the political parties approach their respective primaries.

For some, the political process begins even earlier with recruiting candidates that are sympathetic and, better yet, will champion disability and social services issues.

Heidi Fernandez is the chairperson of the Advocacy and Information Committee of the Governor’s Council on Developmental Disabilities (GCDD) and the mother of Andrew, a 10-year-old with autism. She attended the North Fulton forum and collaborated with a number of people to organize and sponsor a political forum in Cobb County.

“I think we were able to bring families and legislators together – and for some families, it was the first time they ever met a legislator,” Fernandez said. “For the families, it was the beginning of building relationships that will continue throughout the legislative session, and it was a great opportunity to educate legislators.”

Twelve candidates participated in the Cobb County forum, and two legislators who were running unopposed attended just to learn more about the issues surrounding the disability community. The forum focused strictly on disability issues and was held in the Cobb County Commission chambers. It was moderated by Carmen Burns of 11 Alive News and attracted over 100 people.

Fernandez was pleased with the turnout saying, “Any time we can get parents, care providers and legislators together, we are being successful. The key is really building those relationships with our legislators; that is the most important thing.

“Give yourself enough planning time,” she advises to those considering sponsoring a political forum. “Collaborate with other organizations and individuals in the community; work on getting the word out to as many organizations as you can.”

She took her own advice and worked with 13 organizations to sponsor the Cobb County forum. Sponsors included Georgia Community Support and Solutions, Cobb ARC, Atlanta Alliance for Developmental Disabilities (AADD), GCDD, Marietta Enrichment Center, Art & Food, Tommy Nobis Center, East Cobb Civitans, Marietta Civitans, Austell Civitans, Project Bridges, ARC of Georgia and the Rose Garden/ Davenport Neighborhood Association.

Generally the questions and topics focused on the need to move people from hospitals to community residences and the funds needed to unlock the more than 5,000 people on the waiting lists. Other topics included proposed premiums to the Katie Beckett (Deeming) Waiver and the importance of early intervention.

Generally, the debate is not whether a candidate will support programs that help people with disabilities, but where disability funding issues fall as a matter of budget priorities. To be effective, activists have to assure that their disability questions are well thought out, and that candidates are measured and considered on their commitment to the disability priorities.

Steve “Thunder” Tumlin, (R-Marietta) now represents House District 38 and participated in the Cobb forum which greatly affected him. “They sent
Candidates around the state attended a number of forums sponsored by AADD, Family Connections and other social services organizations. “The disability community appreciates the time that legislators and those running for public office will give us by attending these forums. They have the daunting task of needing to be aware of and knowledgeable about numerous issues. These forums are an opportunity for people with disabilities and their families to educate them about their issues of concern.”

The following state senators and state representatives were reported as participating in one or more forums.

**State Senate**
- Senator John Douglas
  (R-Covington) District 17
  404-375-1234
- Senator Steen Miles
  (D-Decatur) District 43
  Smiles2k@bellsouth.net
- Senator Dan Moody
  (R-Alpharetta) District 56
  404-463-8055
- Senator Chip Rogers
  (R-Woodstock) District 21
  404-656-0188
- Senator Steve Thompson
  (D-Marietta) District 33
  770-427-2600

**State House of Representatives**
- Representative Clay Cox
  (R-Lilburn) District 102
  Asc647@bellsouth.net
- Representative Matt Dollar
  (R-Marietta) District 45
  770-485-1946
- Representative Earl Ehrhart
  (R-Powder Springs) District 36
  770-437-7536
- Representative Harry Geisinger
  (R-Sandy Springs) District 48
  678-777-6010
- Representative Rich Golick
  (R-Smyrna) District 34
  770-319-7200

The Editor apologizes to any candidate who was elected and attended one of these forums and whose attendance was inadvertently not reported.
us four questions in advance, and you had to do your homework for the forum,” he said. “I was not aware of the waiting lists until I did some research, and without that meeting, I would probably never have brought myself up to date on these issues.”

Even with a close family member teaching special education, Tumlin admits, “My awareness quadrupled, and I was impressed that not only advocates were there but people with special needs were there, too.

“"My awareness quadrupled, and I was impressed that not only advocates were there but people with special needs were there, too.”

You can talk to all the legislators and see that everybody’s heart is there,” Tumlin said. “We need to give the needs for these special people a special place in the budget.”

Sen. Steen Miles (D-Decatur), who covered a number of disability issues when she was a reporter for 11 Alive News, participated in the DeKalb County forum. “The disability community is the only one any of us can belong to on any given day. It cuts across race, age, socio-economic status,” she said.

With the budget process already started for the next year, Miles has asked for funding for a number of projects for people with disabilities, including a respite center in Rockdale County and a foundation that provides scholarships for people with physical disabilities.

“We have to make certain we advocate, support and take care of people’s needs. It’s our responsibility to do so,” she said.

This past year, the disability community was quite active in creating and participating in candidate forums on the local level. Through its Partners in Policymaking leadership class and alumni, the AADD sponsored five different candidate forums and encouraged disability activists to participate in forums sponsored by other social services groups such as Family Connections. Dave Blanchard, public policy director of AADD, said, “When disability issues are connected to larger issues that the community cares about, there is a much better chance that we can be at the table with our issues.”

AADD even provided grants to help people organize political forums, and GCDD developed a 23-page “Guide to Hosting Forums” to help people put a successful forum together. The strategy paid off, allowing the disability community to connect with other organizations and legislators across the state.

Newly elected Rep. Gene Maddox (R-Bainbridge) of House District 172, attended a Family Connections forum in Bainbridge. He is enthused about representing his constituents in the state house and encourages people with disabilities to contact their legislators and get them involved in their issues.

“I’ve already been contacted by two young boys, one I met at the Bain Company and one I met at Family Connections (two separate forums), and I am already trying to help them,” he said. “At the forum, listening to people, I realized that people with disabilities need help, and I am for helping people who need help.”

His calendar is now full of meetings with other organizations and after listening to so many issues from so many people, he realizes that issue after issue concerns the budget. As the economy turns around, Maddox wants to be sure people with disabilities get their share of the new tax revenues. He concluded by saying, “My heart is sad for people who need help and we need to support them as much as we can.”

“The disability community is the only one any of us can belong to on any given day. It cuts across race, age, socio-economic status.”

Lea Goodman (left) shadowed State Sen. Dan Moody (R-Alpharetta) for a full day in the state legislature as part of her Partners in Policymaking course.
The political activity extended to Gwinnett County where Tiffany Fleming and Lori Von Schmeling were part of the team that organized a forum there. Disability-sponsored forums were also held in Henry and Barrow Counties.

“Through the Partners in Policymaking program, we encourage graduates to get involved,” Blanchard said. “The reason behind all of that is to help these parents get to know the legislators when we think they are listening the most.”

Lea Goodman, mother of a son with cerebral palsy, was a member of the Partners in Policymaking leadership training class and worked hard on both the North Fulton and DeKalb County forums. But she took her classwork to a whole new level in the political arena and “had an incredible experience.”

As part of the course, she was assigned to find out who her state representative and senator were, which led her to State Sen. Dan Moody (R-Alpharetta). She shadowed him throughout a full day in the state legislature, a day that included a meeting with Governor Sonny Perdue’s aides.

With this initial success, she shadowed as many politicians as possible as her major project for the course. This gave her a unique opportunity to educate legislators about the issues facing the disability community, most particularly the importance of keeping premiums out of the Deeming Waiver program. In addition to Moody, she developed close working relationships with State Sen. David Adelman (D-Decatur) and State Rep. Mark Burkhalter (R-Alpharetta). She said, “I believe it made a difference as part of a greater grass roots movement."

“I never really thought much about grass roots – it turned my world around,” she explained. “What I learned from the AADD course is there is power at the bottom, there is a lot of power at the bottom. We can do what we did last year, keep the programs we need to keep our kids at home and unlock the waiting lists for those in institutions and hospitals waiting to go home. “Our class’ advocacy at the capital kept the Deeming Waiver alive, and I thank him (her son Sammy) for what he did for 5,600 families,” she said, crediting her son with her own motivation.

“I just jumped in there and it worked. I constantly thank Sammy for what he has given our community.”

“What I learned from the AADD course is there is power at the bottom, there is a lot of power at the bottom.”

Writing letters to your elected officials is one way to advocate for change. Shelby Lindsey (left) expressed her frustration with transportation issues pertaining to her job in a petition to Councilman David Tolleson of the City of Roswell (right).

Contacting Georgia Legislators

Identify your legislator:
http://www.sos.state.ga.us/cgi-bin/locator.asp

Find your legislators’ contact information:
http://www.legis.state.ga.us/

Information about the House of Representatives:
404-656-5082, 800-282-5800
http://www.legis.state.ga.us/legis/2003_04/house/index.htm

Information about the Senate:
201 Legislative Office Building
Atlanta, Georgia 30334
404-656-0028
http://www.legis.state.ga.us/legis/2003_04/senate/index.htm
With the upcoming legislative session, each of us has a chance to make a difference in the lives of people with disabilities. Some may choose to take direct action such as a march, a sit-in or a protest; others choose to participate by getting involved in the legislative process. Both are valid approaches. Both are necessary because they combine to make a one-two punch.

As a former paid advocate, I cannot stress enough the importance of educating your local legislators. Remember, many are new in 2005. So how do we make the best of our chances to reach these newcomers as well as seasoned lawmakers? Follow up with a phone call to arrange an appointment. Because they get so much mail, it’s important to actually meet them. Make it brief – no more than 15 minutes. During that visit, let them know you will be available to help them with any issues that come up in the session regarding disability. Share your story, but don’t overwhelm them with long, drawn out details. The purpose is to begin a relationship that builds over time. Remember you are the expert on disability. If your legislator doesn’t have a family member or friend with a disability, he or she won’t have any first-hand experience. Legislators really need your insight and advice.

Secondly, participate, participate, participate. Here are three strategies that I consider most important for unpaid advocates. Roll up your sleeves and roll down the halls of the Capitol. Lobby for a budget item, piece of legislation or simply make your presence known. You don’t have to know everything about every issue. Part of the role of the paid advocate is to direct you to where you can make the most difference. In fact, it strengthens the ability of the paid advocate as well as the entire disability rights movement if unpaid advocates like you participate.

Write a letter, email or call your legislators when your advocacy organization asks you to speak out. By taking this action, you are letting legislators know that the message of the paid advocate is the message of the people at home.

Attend Disability Day at the Capitol. You’ll be strengthened and inspired by meeting people from all over the state who care about the same issues. Each of us could and should be a part of any one of these advocacy activities. The influence to affect policy that any paid advocate holds stems from the people he or she champions. For example, you are the power behind the Unlock the Waiting Lists! Campaign. We were able to influence appropriations and state law because we could depend on people from Waycross, Blue Ridge, Columbus, Gainesville, Waynesboro and Bainbridge to call their elected officials. I was a paid advocate; you don’t have to be. Just do your part.
“Confrontation is a thing of the past. This is 2004, a time for partnerships.” My experience tells me most advocates are willing to come to the table at any time and seriously discuss the issues, but I have not seen too many of our opponents come to the table willingly.

Partnerships are great as long as there is mutual respect. Frequently consumer groups usually have to fight to get that respect. In most of the productive partnerships I’ve helped form, we first had to get the attention of our opponents. Translated, that means they had to be confronted.

Few things cause as much controversy as confrontation. Yet Civil Disobedience (CD) is the main focus of nonviolent direct action movements around the world. Why do people participate in CD? For some, it’s for very personal reasons. For others, it’s out of rage, anger or lack of real progress with electoral politics or “normal” channels. But, the main reason people participate and stay committed to CD is that it works. From the Boston Tea Party, to Gandhi’s Salt Campaigns, to the ‘60s civil rights lunch counter sit-ins, to ADAPT’s blocking of buses and crawling up the steps of the U.S. Capitol, CD has continued to show its strength as a vehicle for change.

In the last 10 years, confrontation and direct action have become popular in the disability rights movement. Marches, rallies, sit-ins and other CD protests are moral acts. Through open disobedience, we take back some of the power we have lost to the institutions of society and use the power in a nonviolent way to get the opponents’ attention and bring about fundamental change. When real change finally occurs, it’s always been about an emotional change, not an intellectual persuasion. Direct action creates emotion.

Unfortunately many people still fear direct action. After all, it isn’t something you learn in school or that most parents teach. Some people want to believe research, being nice and normal channels are enough. Some people don’t want to be involved in the down-and-dirty, labor-intensive work of organizing. Lastly, some people are embarrassed by confrontation. Unfortunately for many of them, change becomes something they resist and fear. Denial and conformity become a way of life.

Personally I don’t think it’s about normal channels and being nice versus confrontational. A well thought out strategy must make use of multiple tactics. What becomes critical is making decisions about when to use what tactic, if at all.

My conclusion after 25 plus years of organizing is that confrontation and direct action still work and will be around as long as there are people who demand respect and want to create lasting change.

Mark Johnson, M.Ed.
is the Director of Advocacy at Shepherd Center in Atlanta. He has been advocating for people with disabilities for 25 years, and helped form ADAPT (American Disabled for Attendant Programs Today). He has served as past president of the Fund for Southern Communities that supports social change in NC, SC and GA, and has an extensive background in independent living.
P
eople across Georgia are fighting for the disability community. Whether motivation begins with increased funding or changing an existing bill about institutions, advocates are demanding change from policymakers – and they’re not doing it by standing by quietly.

“Everyone has the opportunity to be a leader and to step up when they’re needed,” said Stephanie Guilloud, development director for Project South: the Institute for the Elimination of Poverty and Genocide.

According to Appley and Randolph, advocacy can be achieved by anyone. “The first step is to clearly identify the issue,” Appley said. The issue she refers to is a matter of legality. Which bill would you like to see changed or how should funding be increased for a program? How many slots should be increased in the next year for the waiting lists for home and community services?

Once the issue has been identified, it’s important to know it well. Arguments for and against the issue, main talking points and the latest updates on the issue should all be researched.

Dawn Randolph, a fiscal policy consultant and analyst for several health and human service organizations agrees. “You have to be visible to get recognized,” she said. “Work toward communicating to the people that can make the change and tell them exactly what you want them to do and who’s behind it.”

It sounds easy coming from experts on disability advocacy but can people in the community really help make a difference?

How to Advocate for Legislative Change

1. Identify Your Issue
2. Know Your Issue
3. Network
4. Learn about Legislation
5. Build Relationships with Your Elected Officials
6. Establish and Maintain Visibility

Legislative Advocacy

“Building up relationships with legislators is the key,” said Elizabeth Appley, an attorney representing the Jewish Federation of Greater Atlanta on developmental disabilities at the Capitol. “The more you strengthen that relationship, the more they’ll want to help you in the future.”

Dawn Randolph, a fiscal policy consultant and analyst for several health and human service organizations agrees.
before talking to a legislator. “However, people shouldn’t feel intimidated not to advocate because they don’t have all the details,” Appley said.

When it comes to advocating though, it’s better to do it in a group. “It’s hard to be the lone voice in the wilderness,” Appley pointed out.

The next step after identifying the issue of importance is to get hooked into a network of people who are concerned with the same issue. “Contact organizations like GCDD (Governor’s Council on Developmental Disabilities), AADD (Atlanta Alliance for Developmental Disabilities), ARC of Georgia (an organization that focuses on a united advocacy for people with disabilities), DHR (Department of Human Resources), advocacy attorneys and other organizations – they’re the most powerful voices you can have speaking for you,” Appley emphasized. A few other organizations to check out are the Coalition United for Responsible Budget (CURB), Unlock the Waiting Lists!, disABILITY link, the Statewide Independent Living Council (SILC) and ADAPT.
Randolph agreed, "People need to come together to help elected officials understand the importance of services for people with disabilities."

The next step to effective advocacy is to work with your organization to find out about legislation. This is the type of information you'll communicate to your elected official like, "vote yes here," or "oppose this language." Most advocacy organizations will send out related email alerts about the issue at hand. Visitors to www.legis.state.ga.us can find out what legislation has been profiled for an upcoming session or what meetings are being held in advance.

The next step is where people actually make advocacy happen. Up to here, it's been a research project with occasional meetings. Build a relationship with your elected official or as Randolph puts it, "be visible." Once contact is made with your officials, it's important to stay in communication with them. "The more you strengthen that relationship, the more they'll want to help you in the future," Appley said. "It's not important to have all the details, just contacting your senator and letting him or her know what's on your mind is the first step."

But who do you contact?

You can find your elected representatives and senators by visiting www.vote-smart.org and entering your zip code. Appley reminded advocacy beginners that state legislators will change on January 10, 2005.

In addition, Appley suggested that it is important to form relationships with the governor and lieutenant governor, the leadership on both sides of the House and Senate (both Democrat and Republican) and members of committees that have responsibilities for the issue of concern. Of most significance to the disability community are the

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Sample Advocacy Letter

Dear (insert name of legislator):

I have developmental disabilities. I am eligible to receive state-funded services and supports, but because of lack of funding, I have been waiting for those services for (insert how many years on waiting list).

If I do not receive community-based services soon, I may have to move to a state institution, where it will cost the state more to support me than it would to provide services in my own community. I do not wish to move away from my community, as my family and friends are here.

Please support the Department of Human Resources budget request for waiver slots so people like me can remain in their own communities and have a better quality of life.

Sincerely,

(insert your name)

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When Should You Organize?

As emphasized by many advocacy experts, starting an organization isn't appropriate if one dealing with the issue at hand already exists. However, Dawn Randolph, a fiscal and policy consultant, recommends taking the following steps if there is no existing organization to join:

- Build a base of people who are interested in the issue
- Get informed about the issue
- Establish objectives and solutions for the next year
- Take action

So how do you take action anyway?

Find an identified target to take action against, look for a bill that needs to be changed or see what services need more funding. Then work toward communicating with the people that can make the change. "Tell them what you want them to do and who's behind it," Randolph said.

Stephanie Guilloud, development director for Project South, works in a capacity where she connects advocates to larger organizations with existing programs. She suggests checking out existing organizations rather than "reinventing the wheel." Then if no one else is dealing with an issue, an organization should be established.

Guilloud concluded that advocacy organizations for people with disabilities are stronger when people with disabilities are active within the group. She said, "There are quite a few organizations led by people in the disability community, and that's a very powerful position to effect change."
following committees: Appropriations (money), Health & Human Services, Insurance, Children & Youth and Education.

Randolph noted that talking with your elected officials is a big first step, but it may be time consuming and overwhelming to try to form additional relationships with committee members or the governor. “It would be amazing if every person just took the responsibility to talk to their elected officials,” she said. “You need to keep the visibility and communication year round – not just while legislators are in session.”

Advocacy Education

Another amazing tool for effective advocacy is education. Many organizations offer leadership and advocacy classes.

“I encourage people to come to advocacy training, to get hooked up to the developmental disabilities alert network, the state web site, the DHR web site and to call their legislator! It’s the only way to make a difference,” Appley said.

GCDD funds a variety of leadership programs, including Georgia Voices that Count, that it co-sponsors with disABILITY Link; AADD’s year-long program, Partners in Policymaking; and other educational opportunities offered by Project South.

“These programs together do a good job of building a strong base of educated leaders,” Guilloud said. “They also create a space for leaders and organizers to come together and discuss tensions and challenges they face. If there’s not a space to talk about what’s going on, then we won’t be able to continue effectively.”

(continued on page 22)

Stephanie Guilloud holds a strategic organizing workshop for grassroots leaders at Project South, which she explains is often a different route to get rights for people with disabilities than legal advocacy, although the two methods often overlap.

10 Tips on Talking to Legislators

1. Develop a relationship. The key to advocacy is developing long-term relationships with your legislators.

2. Be optimistic and upbeat.

3. Be specific. Keep it simple. Try to discuss one issue at a time.

4. “Personalize” the issue. For example, if talking about funding for community-based services, describe why the issue is important to YOU and your community. Use personal stories to inform the legislators – they will be remembered.

5. Don’t be argumentative. Don’t be defensive.

6. Remember there is strength in numbers. Work in collaboration with others whenever possible.

7. Provide good info. Give facts. Do not give a lot of materials. Fact sheets, brochures and personal letters are good.

8. It’s important that the legislators can match a face with the issue. A great idea is to wear a button with your child’s or family member’s picture. Also, include a picture at the top of any letters with your name and contact information.

9. Volunteer to be a resource contact. Legislators will always welcome a constituent who is knowledgeable on a specific issue and is willing to be a local resource contact.

10. Most importantly, always thank them and follow up with a thank you letter.

Submitted by Heidi Fernandez, GCDD Board Member
Guilloud pointed out that advocacy is just one door in a hall of many doorways to accomplishing goals in the disability community.

“There are a variety of strategies to change the system to get what we need – advocacy and organizing are two of them,” she said. “It’s important to distinguish between organizing and advocacy to be able to distinguish how to best go about getting what you want.”

What’s the difference?

“Advocacy is doing work to change a system or a service on behalf of a group of people that may or may not be part of the decision making,” Guilloud said.

According to Guilloud, one good example of advocacy at its best is Brown vs. Board of Education. In its decision, the Supreme Court ruled that racial segregation in schools (among other places) was unconstitutional. Legal advocacy landed this case in the Supreme Court.

According to Guilloud, while advocacy usually focuses on a single policy change or budgetary increase, organizing has the purpose of educating people on a longer term basis.

Her example of good organizing was the Montgomery Bus Boycott. A very well planned boycott, African Americans did not ride the buses for over a year, only giving up when they were awarded full racial integration on the buses. The party that had organized the boycott sent out communications to the community to bypass the public buses while putting alternative transportation in place to ensure an effective boycott.

Guilloud feels it is important to connect today’s struggles with historical struggles to find which strategies will best help the disability community find equality.

Since many organizations use a combination of strategies, it is important to “connect the education component to a specific action,” she said.

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**Organizing Basics**

- **Build Your Base**
  Identify who is most affected, communicate with the community, recruit members, build coalitions, create a membership structure, hold regular meetings and create a collective identity.

- **Educate Your Base**
  Use experience and interactive workshops to educate members about the issues and help members identify as a collective working for change.

- **Choose Your Goals**
  Identify the primary goals of the organization or group. Remember: goals are broad statements that describe what a group wants.

- **Build a Strategy**
  Create a strategy based on achieving your immediate goals and preparing a foundation for long-term goals. Strategy is the overall plan to get the person who has the power to give you what you want.

- **Implement Strategy**
  Develop an action plan that includes specific tactics. Each step should build on the last and toward the next to achieve your demands. Include a timeline that integrates fundraising, signing sponsors onto the campaign, media work, direct action, marches, education plans, etc.

- **Evaluate Your Work**
  Whether the group wins or loses its short-term demands, evaluate the goals, strategies and tactics to determine strengths and weaknesses. Use the evaluation process to create the next steps of action.

*This list was compiled by Project South.*

*For more information, please visit www.projectsouth.org.*
Those who live with developmental disabilities know well the story of the Olmstead Decision, and it is heartfelt. The story is a legend of two courageous women, Elaine Wilson and Lois Curtis, both diagnosed with developmental disabilities and mental illness, who pursued their hope and dream of returning to the community, and opened wide a door that would change the way thousands would live out their lives.

Elaine Wilson, 53, passed away December 5, at Grady Memorial Hospital in Atlanta. She lived five years free of institutional isolation in a community-based living environment made possible by the landmark U.S. Supreme court ruling known as the Olmstead Decision which she helped spearhead.

Wilson stepped into history when she and Curtis filed suit seeking release from a life sentence of institutionalized care. They wanted to return to a community setting. Their doctors agreed it would be healthier for them to do so. But the state of Georgia said it would be too costly.

June 22, 1999, the U.S. Supreme court sided with the two women. The Olmstead Decision recognized that unjustified isolation is properly regarded as discrimination based on disability and that confinement in an institution severely diminishes the every day life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural achievement.

Today thousands of Americans have benefited from the trail blazing contribution of Elaine Wilson and Lois Curtis. Still many wait.

A developmental disabilities advocate with People First of Georgia, Gail Bottoms wrote their story into poetry because, she said, “Elaine will be remembered for what she did for us.” GCDD honors the memory of Elaine Wilson; a pioneer in the nation’s disability rights movement.

~ To Elaine and Lois ~

There were two women, Elaine & Lois
In an institution that wasn’t their choice.
They wanted out so they used their voice.
To make a difference was their plan,
To help themselves and their fellow man.
They hired the lawyers who said “we can,”
and went to fight, their future to plan.
Elaine and Lois went through a big fight,
to set folks straight and put things right.
To tell institutions to go fly a kite,
To live in their community is a God-given right.
They convinced the judge
they could live on their own,
Make their own choices and have their own home.
Thanks, Lois, Thanks, Elaine.
Your action has made it even more plain.
Stand up for yourself, a self advocate be.
There is nothing to lose and everything to gain.
So tonight we honor you both
for what you have done.
You fought with the system
and thank God you won!

August 5, 1999
Gail Bottoms
Former President, People First of Georgia
Museums. Malls. Amusement parks. All come to mind when a tour bus is on the move. But what does equality have to do with it? On September 30, 2004, the Governor’s Council on Developmental Disabilities (GCDD) used a tour bus to educate the community about the current civil rights movement — disability rights. People with various backgrounds joined the tour by special invitation, and learned about the movement and how they could help make a difference in the disability community.

The Making a Difference Discovery Tour kicked off at the Martin Luther King, Jr. Historic Site in Atlanta with a speaker experienced in more than one civil rights movement. Kate Gainer of disABILITY LINK, the center for rights & resources, borrowed the original slogan of the 1960s civil rights movement, “People First,” and applied it to the disability rights movement. She called out for the community to notice that people with disabilities are in fact, considered unequal and they are demanding to be treated like every other member of society.

“Don’t treat people with disabilities like they’re special. . . . have expectations for us, we have expectations of you!”

“Don’t treat people with disabilities like they’re special. . . . have expectations for us, we have expectations of you!”

There’s a ’60s song that says something about a revolution going on and it isn’t being televised. There is a revolution and it’s not being televised!”

Gainer also discussed the Americans With Disabilities Act of 1990 to support her point. The act was established to provide a comprehensive understanding of the prohibition of discrimination of people with disabilities in critical areas such as employment, housing, education, transportation, health services, voting and access to public services.

“Congress gave the country a two-year grace period [to adjust] because Congress knew the country wasn’t ready. It was a novelty to see us on the street, driving cars, using public transportation. After the 14th anniversary of the Act, it’s still a novelty to see us working . . . to see us functioning in society.” She attributed that to the media and society sensationalizing people with disabilities actually working. “Don’t treat people with disabilities like they’re special. . . . have expectations for us, we have expectations of you!” she said.

Gainer ended her rally for support by saying, “I was raised to believe in the American dream — to be a productive member of society.”

Destination One:
Visitable Neighborhoods

Visitability. Is this a real word? Eleanor Smith, the matriarch of an organization called Concrete Change, explained that this tongue-twister, new enough to be unmentioned in the American dictionary, came out of the disability rights movement in England. It refers to homeowners without disabilities living in houses that people with disabilities can visit. Many people with disabilities have never been able to visit their neighbors or even relatives because their houses don’t have bathrooms on the main floor with enough space to fit a wheelchair into, and have entrances with steps and narrow doorways.

“All my life, I lived where I couldn’t go next door . . . until this community was built. It’s been wonderful going next door for the first time in my life,” Smith said.

Insisting that visitable housing is good not only for people with disabilities, but also for anybody, GCDD Executive Director Eric Jacobson told of a time when Senator-elect Johnny Isakson showed his home to a lineman in the NFL. When he walked through a door, he had to turn sideways.
Smith agreed that more typical families would benefit from houses built to be visitable. Parents with strollers appreciate the no-step entrance as well as wider doorways when carrying groceries. One homeowner in the community was pleased to have a visitable home when she hurt herself and was confined to a wheelchair for a few months. She could navigate comfortably into the front door, through the doorways, and have enough room to fit the chair in the bathroom. Also, if there is a bedroom on the main floor, these houses are more valuable as people can age in place.

Some people however, are voicing their concerns. Doesn’t it cost more money to build a visitable house? Smith claims it only costs a small amount of money; the built-in elements such as wider doors actually make the houses more attractive and raise the value of homes when owners are ready to resell. “For six dollars, a door can be made wider instead of $600 to widen it later,” she said.

After founding Concrete Change, Smith helped create a coalition that established the EasyLiving Home™ Program. Builders register with the organization and get a certificate when a home is built with basic access features. These homes aren’t just visitable – they accommodate people with disabilities who live there. “That’s the kind of housing we need to concentrate on,” said tour attendee, Nancey Green Leigh, a professor in the College of Architecture at Georgia Tech.

For more information on these programs, visit www.concretechange.org and www.easylivinghome.org.

Destination Two: Inclusive Religion

Many places of worship provide various support for people with disabilities during their services – but what about the rest of their programming? “Traditionally, people cannot physically get in,” said Jacobson. “Churches have not been programmatically accepting – they would provide assistance to get through the service, but were not inclusive.”

In a trip to the Central Congregational Church of Christ, the people on the tour learned about how churches or synagogues can be “Open and Affirming.” The Church’s focus is to include families and individuals of all backgrounds.

Senior Minister Budd Friend-Jones talked about the different cultures that congregate for worship. “There are people that hug . . . people that shake hands . . . and people that bow,” he said, stressing that the church is inclusive of everybody.

The church wasn’t always so accepting.

“Churches have not been programmatically accepting – they would provide assistance to get through the service, but were not inclusive.”

people with disabilities. When accessibility came up as an issue during the project, the church’s first response was that they didn’t need to worry about it because none of their members had disabilities. They quickly moved from avoidance to acceptance when they realized that some former members had stopped coming because of acquired disabilities and an inability to get into the church.

Ken Johnson, the architect for the renovation, helped make the Central Congregational Church of Christ building accessible. During the planning process, Johnson and others decided “the entrance for people with disabilities should not be separate from the main entrance,” an important however. Until about two years ago when a major renovation occurred, the church focused on acceptance, but hadn’t considered
consideration when working toward inclusion. The church’s renovations included an elevator, automatic openers for doors, bathrooms with a larger space for wheelchairs, improved fire escapes and perhaps the most significant part of the project took place in the parking lot. Originally, the parking lot had been equivalent to a roller coaster without brakes for people who use wheelchairs. The church leveled the parking lot to make entering church in a wheelchair a much safer experience.

Today, the church has many members with disabilities that are able to fully participate in all programs. However, Friend-Jones claims that they’re not finished yet. “We’re still aware of the barriers in this building and are working hard to improve them.”

Destination Three: Equal Employment & Education

Most people have a grocery store down the street with a bagger that has a disability. It’s the standard disability job. But what about people with disabilities who have abilities to do more? Dianne Prindle of Briggs & Associates employment agency helps people with disabilities find jobs that suit them, instead of placing them in a cookie cutter job for people with disabilities. “We work hard to find non-traditional work outlets,” she said.

One job candidate, Peter McKinnon, went to work for the Buckhead office of Marsh USA, the world’s leading risk and insurance services firm. During the job planning process, Julie Christensen, vice president, took an in-depth look at what he was capable of. “We didn’t want to just create tasks, we looked at the value he could provide,” she said. According to Christensen, McKinnon faithfully serves in his capacity of inventory control, never missing a day. He has his own cubicle and feels like part of a team. Since Peter was hired, Tom Flynn, VP at the time and the “Champion” of the company says, “They’re [people with disabilities] the best employees you’ll ever have.”

Another success story is an employment program called Project SEARCH. The hospital unit where the program was started has increased its employment of two people with disabilities to 56. Briggs & Associates worked with Barbara Sverdlil, director of nursing for Emory Healthcare, to bring the Ohio-based program to Emory Crawford Long Hospital in Georgia, which was just recently implemented. For more information on customized employment, see resources on page 28.

Where do people with disabilities start? How do they find out that they are part of the community – not an attachment? Hopefully schools help people do this at an early age. Sadly, many students don’t believe in themselves and dream about the future, leaving them unprepared for the commencement of the rest of their lives.

However, GCDD’s Project of National Significance Grant given to eight schools in the state of Georgia is enabling students with disabilities to plan for the future. Cindy Saylor, the project coordinator for the grant at Flowery Branch High School, said the project has already changed lives.

“Their’s taking tremendous steps simply by learning how to accept themselves,” she said.

The one-year-old program includes a self-determination class called Steps, individual Futures Planning sessions and an after-school Partners Club.

During the weekly Steps class, students with and without disabilities collaborate to discover how they can apply what they are good at to their future. As a team, they brainstorm ideas on how to make each other’s dreams become reality.

A team of family, friends and a teacher combine to form a Futures Planning team. They meet with the student who has a disability to brainstorm how to use abilities for future careers, volunteer work, and community involvement. Then, a plan of action is formed, implemented and evaluated.

The after-school Partners Club gives students with and without disabilities a place to interact with each other. Many friendships have evolved and the students with disabilities are especially enjoying their social expansion. “The kids with disabilities used to sit at a separate table in the cafeteria,” said Lori Oliver, a special education teacher at Flowery Branch. “Now they’re interspersed among other students.”
Self-Advocate Receives Waiver

When Susie Edwards was growing up, the Americans with Disabilities Act did not exist. She graduated from high school and attended college, then expected to find a job and get an apartment.

“I started asking for employment services at 24 that I should have been looking for when I was 15. I didn’t know to start earlier. VR didn’t know what to do with me,” Edwards said. As a result, she used all the service options she could with vocational rehabilitation and was determined to be unemployable. “At 43, I’m still looking for a job,” she said.

That experience led Edwards, who has cerebral palsy, to participate in the Partners in Policymaking class held by the Atlanta Alliance for Developmental Disabilities (AADD) in 2001/2002. “At Partners I learned how to write a letter to the governor and how to ask for services,” she said.

Through her Partners in Policymaking experience, Edwards learned more about the options available to her. Edwards, who lives with her parents, also started wondering what would happen to her when her parents died. “I don’t want to be a burden on my family. With the Independent Care Waiver Program (ICWP), I wouldn’t have to go from my parents’ dying to becoming my family’s burden,” she said.

In October 2002, Edwards decided to apply for the ICWP. In December of that year she was evaluated, then placed on the waiting list because there was no funding available for her waiver. While waiting for her waiver to come through, Edwards tried other avenues for support and services. “Respite hours were a disaster. My respite worker brought her boyfriend to the house,” she said. She also started advocating for herself and other people with disabilities by participating in several lawsuits, including one filed in early 2003 against the governor, the Department of Community Health and the Department of Human Resources. The suit challenges the state’s policies that keep people in nursing homes or on waiting lists, instead of receiving waivers that would allow them to receive services and supports at home in their communities.

While she can’t say for sure if her advocacy for herself and others helped her receive a waiver, in September of 2004, Edwards finally received her ICWP, after nearly two years on the waiting list.

And though she’s excited to have her first step toward independence, Edwards said she still has battles to fight; in fact, the first personal care assistant (PCA) she hired quit before her first day. Edwards lives in Alpharetta, and not many PCAs live there. Other issues have also arisen.

“Now that I have the waiver, I need to know what questions to ask when I interview PCAs, what the requirements are for the care givers and how many supplies of gloves I’ll need in the next six months,” she said. “The case managers expect you to know all this stuff. They need to provide guidelines.”

But Edwards won’t give up on her hard-fought waiver, and will probably end up helping those who receive waivers in the future. “I’d love to create a handbook of what you have to do after you get the waiver,” she said.

“At Partners I learned how to write a letter to the governor and how to ask for services.”
Below, please find further resources of information related to the articles in this edition of Making a Difference magazine.

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

**State Government**

**General Information**
www.georgia.gov

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

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

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

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

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

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

**Advisory Organizations**

**ADAPT**
www.adapt.org
303-733-9324

**ARC of Georgia**
www.arcgeorgia.org
404-634-5512

**Atlanta Alliance on Developmental Disabilities**
www.aadd.org
404-881-9777

**disABILITY LINK**
www.disabilitylink.org
404-687-9175

**Governor’s Council on Developmental Disabilities**
www.gcdd.org
404-657-2126

**Project South**
www.projectsouth.org
404-622-0602

**Statewide Independent Living Council of Georgia**
www.silcga.org, 770-270-6860
Toll Free 888-288-9780
TTY 770-270-5671

**Budget and GA’s Waiting Lists**

**Georgia Budget and Policy Institute**
www.gbpi.org

**Unlock the Waiting Lists!**
www.unlockthewaitinglists.org

**Emergency Support**

**United Way Atlanta**
www.unitedwayatlanta.org
Dial 211 for support

**Legislative Information**

**Project Vote Smart**
www.vote-smart.org
406-859-8683

**State Legislator Locator**
http://www.sos.state.ga.us/cgi-bin/locator.asp

**Making a Difference Discovery Tour**

**Briggs & Associates**
www.briggsassociates.org
404-290-6860

**Central Congregational United Church of Christ**
www.central-ucc.org
404-633-4505

**Cobb/Douglas Community Service Board**
www.cobbcsb.com,
770-429-5000

**Concrete Change**
www.concretechange.org

**EasyLiving Home**
www.easylivinghome.org
770-270-1611

**Georgia Department of Community Affairs Housing Initiatives**
www.dca.state.ga.us
(404) 679-4940

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Early Testing Helps Determine Best Course of Action  

by Alan G. Weintraub, MD

Development is an ongoing process from birth. Although we are born fully formed, there are many changes expected. As a developmentalist, I see patients if their developmental milestones are not following the “typical” path. To do so, we explore the five spheres of development including cognition, language/learning, fine-motor, gross motor, and personal social skills.

Two common issues that surface in the first year of life are delays in motor development and language skills. These are “red flags” that should be explored immediately.

Because development is a continuum, we monitor well-described “developmental milestones.” These are timeframes during which children are expected to gain certain skills.

If a child’s skills are not developing as scheduled, we need to investigate. A developmental disability is a deviation from the normal continuum within any of these five spheres.

I perform a comprehensive neurodevelopmental assessment on children. This includes a comprehensive history, physical, and neurological examination. We do a neurodevelopmental assessment to identify the child’s functional level to obtain a profile of strengths and weaknesses.

Tests may be global, such as the Bayley Scales of Infant Development. They may explore specific areas of development, such as language, with the Preschool Language Scale or the Peabody Picture Vocabulary Test. We examine nonverbal reasoning skills, with tools like the Columbia Mental Maturity Scale, or eye-hand coordination with the Beery Scales.

After these tests are performed, we have a comprehensive sense of a child’s skills. As necessary, we can do laboratory tests, including cranial studies, genetic, metabolic, and hormonal tests to clarify the diagnosis.

Frequently, children will have global cognitive impairment. Alternatively, they may demonstrate primarily language-based disorders, or more broad based deficits, that impact on social functioning as well, such as autism spectrum disorders. We may identify motor impairments, like cerebral palsy, or behavioral and attentional disorders.

Developmental disabilities are lifelong. The milder the disability the less likely it will impact significantly as your child matures, but the underlying process may still be there. Because of this, we must understand that there won’t be a “quick fix.” However, there are multiple appropriate therapies available.

My role in treatment is two-fold. I serve as a “case manager” to assist the family in finding and coordinating care so we can get the child “back on track.” The other is to prescribe, monitor, and direct the specific treatments to help the child overcome the disability.

For example, children with communication disorders require speech/language therapy. We will direct that therapy and monitor the child’s progress. A child with tonal abnormalities and motor impairment requires physical therapy. Occupational therapy is utilized for treatment of motor coordination deficits. This also includes sensory integration therapy, which addresses ways to integrate sensory inputs into a cohesive, coordinated motor output.

Psychological intervention to assist the child (and family) in coping with the emotional and behavioral ramifications of a particular disability is important. Adaptive equipment such as braces, walkers or wheelchairs may be needed, and pharmacotherapy may be necessary if there are behavioral or attentional issues that are not responding to traditional psychological techniques.

No one piece of this program will suffice. A well thought out program must incorporate a comprehensive multidisciplinary approach.

We are all unique. Even if two children have the same genetically determined diagnosis, with similar IQs, they are still different. My goal is to help your child reach his/her maximal level of functioning, by removing the physical and cognitive impediments that may stand in your child’s way.

A disability should not be a handicap. By striving to reach maximal levels of potential, we can assist our children in becoming the best they can be. That should be your goal as a parent, and that is my goal as a professional – to assist you in uncovering the complexity that is your child, and build skills for a lifetime of maximizing fulfillment.

By striving to reach maximal levels of potential, we can assist our children in becoming the best they can be.”

Dr. Alan G. Weintraub is a board-certified Developmental-Behavioral Pediatrician who has practiced in Metro Atlanta since 1988. He trained at the Albert Einstein College of Medicine for both his general pediatrics residency and his developmental disabilities fellowship. He sits on several developmental disabilities committees in the metro area. His practice covers a diverse population including children with genetic disorders, cerebral palsy, autism spectrum disorders and complex ADHD. In 2001, Dr. Weintraub won the Lewis E. Jones MD Award from the Atlanta Alliance on Developmental Disabilities for his commitment to the DD population in metro Atlanta.
FEBRUARY

February 2
Healthy Mothers, Healthy Babies Coalition of GA – 18th Annual Legislative Breakfast
Atlanta, GA, 770-451-0020
www.hmhbga.org

February 4-5
A New Kind of Autism Spectrum Conference
Duluth, GA, 770-451-0954
www.asaga.com

February 7
Substance Abuse Day at the Capitol
Atlanta, GA, 404-523-3440
www.gasubstanceabuse.org

February 9
Early & Periodic Screening Diagnosis and Testing: How to get what children need through existing & unused Medicaid
Atlanta, GA, www.marcus.org
RSVP: catherine.trapani@marcus.org

February 10
Inclusion of Students with Significant Disabilities
Kennesaw, GA, 770-423-6577

February 19
Dimensions of Dyslexia
Understanding and Promoting Reading Fluency, Atlanta, GA
404-256-1232, www.idaga.org

February 24
Disability Day at the Capitol
Atlanta, GA, 404-657-2126
www.gcdd.org

February 24-25
Health Care In Community Settings - Theory to Practice
Reducing Health Care Disparities for People with DD
Health care providers will learn the evolution, challenges and expectations of health care services for people with developmental disabilities in community settings; examples of successful programs; strategies of care for people with complex medical and behavioral issues; how to ensure health care resources are accessible for aging adults with DD; and more. Consumers and family members are encouraged to attend.

MARCH

March 5-8
Easter Seals Project Action: 2005 Mobility Planning Services Institute, Washington, DC
www.projectaction.easterseals.com and click on “Training & Conferences”

March 10
Oppositional Defiant & Conduct Disorder
Atlanta, GA, www.marcus.org
RSVP: catherine.trapani@marcus.org

March 11-13
COPAA 7th Nat’l Conference
Atlanta, GA, 404-607-1600

March 15 & 23
Teaching English Language Learners
Kennesaw, GA, 770-423-6577

March 24
2nd Annual “Under One Roof” Housing Conference
Fort Valley, GA, 478-825-6954
www.ag.fvsu.edu/mainpages/housing.asp

APRIL

April 4-6
AAHSA Future of Aging Services Conference
Washington, DC, 888-508-9441
www.aaahsa.org

April 12 & 26
Reading Strategies for Students with Disabilities
Kennesaw, GA, 770-423-6577

April 13
Vocational & Life Skills Planning for Young Adults with DD.

MAY

May 9-11
Nat’l Training Conference for Deaf and Hard of Hearing in Government
Washington, DC
www.dhhig.org/ntc

SOUTHERN COMPANY

Proudly Salutes

The 7th Annual Disability Day at the Capitol
February 24, 2005

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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

United Cerebral Palsy of Georgia

Supporting people with all developmental disabilities throughout Georgia

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

Estate Planning & Guardianship

For Families with special needs

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• their families

A child with special needs (from birth to age 21) can be referred to a Public Health Program that serves these children by calling:
• the Children 1st Coordinator at your local health department at 800-822-2539
• Parent to Parent of Georgia at 800-229-2038 or in Atlanta at 770-451-5484
http://health.state.ga.us/programs/specialneeds/
Advocates from all over Georgia will meet with their legislators February 24 during Disability Day in Atlanta. This year’s event, sponsored by the Governor’s Council on Developmental Disabilities (GCDD), will be a prime opportunity to educate new legislators about the issues that affect the disability community.

The day will start with a rally at the Capitol, featuring stories from advocates and legislators, followed by a march to the Georgia Freight Depot for lunch with legislators. GCDD is also planning to offer some training on successful advocacy strategies. (Events subject to change.)

Visit www.gcdd.org for more information on this important day for Georgia’s disability advocates.