

SUMMER 2010

Making a Difference



Children's Freedom Initiative:

Coming Home Made Possible

Summer Fun for Everyone

*20th Anniversary of Americans
with Disabilities Act*

State Legislature Summary and Outlook

www.gcdd.org

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Mathew Harp was recently reunited with his family after living in a nursing facility.

(Front) Anniston Adcock, Mathew Harp, Alexis Adcock (Back) Lauren Harp, Cindy Adcock and Riley, Mindy Harp

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A quarterly magazine of the Georgia Council on Developmental Disabilities

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

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

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Summer in Georgia: Time to Reflect, Recharge, Refocus

Summer is often a quiet time when school is out, families take vacations, and the work pace mellows. Not so for the Georgia Council on Developmental Disabilities. Since the last edition of *Making a Difference*, the legislative session ended, the State Board of Education promulgated rules concerning the use of seclusion and restraints in schools, the Department of Behavioral Health and Developmental Disabilities continues to negotiate a settlement with the Department of Justice around moving people out of institutions and strengthening home and community based services, and election season is just around the corner. And, the GCDD is about to undertake a five year strategic planning process.

This edition of *Making a Difference* is focused on kids. Because let's face it, summer is for kids! We provide you with information about recreational opportunities where all kids, those with and without disabilities have the opportunity to play and learn from each other. Isn't that what camp is all about? However, for some kids, those still living in nursing homes and other facilities camp is not a reality. An exposure of what is happening to some children is provided as follow up to the Children's Freedom Initiative. While this Initiative has been successful at pressuring the systems to move children out of institutions, there still remain too many kids from Georgia living in nursing homes in Alabama and other states. We think that all of these children should be at home with loving families with the opportunity to attend summer camp.

This edition includes a continuation of our coverage of the 2010 legislative session, one of the longest in the history of Georgia. For people with disabilities and their families it will be hard to say things are better now than before the session began. Because of the economy there were few new dollars for services. While legislation such as changes to the nurse practice act may help some people, we need to recognize that without an improved economy people will continue to go without services and supports. Expect sharp decreases in available services next year when the federal stimulus dollars go away and the State struggles to make up over \$1 billion.

The good news is that the July (primaries) and November election seasons are upon us. Your job is to make the people who make decisions about how dollars are raised and spent, and the policies that drive services and supports listen and understand your story. Tell them about you or your child. Make them understand that you are doing everything possible to remain independent but need some additional supports. Tell them we want to close places where people with disabilities are segregated and isolated and instead need to put those resources into building an infrastructure of quality home and community-based services. Tell them this is what it will take to get your vote!

The summer primaries are just a warm up for the fall when we will elect a new governor, lieutenant governor and many other statewide and local officials. This is our opportunity as citizens of Georgia to decide the direction we want to go in during the next four years.

We hope you enjoy reading *Making a Difference* and we want to hear from you. Let us know what you like or don't like by writing to vmsuber@dhr.state.ga.us. ●



Eric E. Jacobson
 ERIC E. JACOBSON
 EXECUTIVE DIRECTOR, GCDD

Tom Seegmuller
 TOM SEEGMUELLER
 CHAIRPERSON, GCDD



Fostering Children with Disabilities is a Two-Way Street

By Twanda Black

Some years ago, as foster parents of four young boys (siblings), my husband and I were asked to be a respite for a 17 year old young man with physical and learning disabilities, just until another home was found for him. Well, one week turned into one year and Vernon was part of the family.

He had significant developmental delays, but I recognized that he was still a teen-aged boy who wanted to be accepted and treated the same as everybody else. I really think that at times Vernon felt no different from the other kids. My two sons were teens at the time and spent valuable recreational time with Vernon, playing basketball, going to the movies and the mall. Now this didn't always turn out well, but the boys learned a great degree of patience and how to explain things to Vernon on his level. My boys also learned that everyone is not born the same nor did they have the same upbringing or privileges – they simply learned to accept the differences. You see, fostering absolutely expanded our capacity to love outside of our own family!

He had significant developmental delays, but I recognized that he was still a teen-aged boy who wanted to be accepted and treated the same as everybody else.

We enrolled Vernon in the local high school where one of the administrators was overheard saying “Why are they bringing him to our school? He’s going to bring our test scores down.” I knew then that I was in for a fight. I may be short but I’ll fight for what’s right and Vernon had every right to be in that school! My husband and I spoke to the principal that day, and we didn’t have any

issues after that because we let him know that we would be involved parents. We wanted the best for all of our children and we wouldn’t settle for anything less!

Vernon was placed in the “special” class with children with various disabilities and his teachers were awesome and so very helpful. Vernon began to work hard to achieve his reading and math goals because although he was 17, his reading and math abilities were around

His integration into the mainstream classroom helped to develop his social skills and it allowed him to make new friends and even be invited to parties and events.

the 6th grade level. His teacher told him that if he worked hard enough they would place him in a regular 9th grade reading class and Vernon was truly excited. In the last semester of the year, Vernon was placed in a regular class with modifications, and it was a major boost to his self esteem! His teachers and classmates loved Vernon’s energy and simple honesty and “the guy from the special education” class was simply like everyone else – with a few accommodations of course! His integration into the mainstream classroom helped develop his social skills, and it allowed him to make new friends and even be invited to parties and events. Vernon became a social butterfly and excelled at many tasks because we all believed in him and accepted him just as he was!

My husband and I have been foster parents to thirty-four boys and five girls over the course of five years. Our children enriched our lives through the experience of loving and caring for them when they most needed a family and a home. Vernon was typical of our kids in this way. We all learned from each other, including the entire community. ●

Twanda Black is Public Affairs Director for KISS 104.1 FM in Atlanta where she hosts the talk show, “Business in the Black” and the music show, “Good News Gospel.” The Tampa native is mother to two young men, an avid reader, photographer, published writer, and is active in her community.

GaRRS Live Disability Day Radio Broadcast Wins International Award

The Georgia Radio Reading Service has been honored for its coverage of GCDD's 11th Annual Disability Day at the Capitol (2009) by the International Association of Audio Information Services (IAAIS). The live broadcast collaboration, a first for both GaRRS and GCDD, included the Disability Day Rally at the Capitol and a selection of interviews from among the nearly 2,000 advocates in attendance. Visit www.garrs.org for more information.

New Radio Show Focuses on Disabilities

A new radio talk show, "Handle With Care," on 91.7 FM-WUGA, interviews persons with disabilities, family members and community influencers on a wide range of disability related topics. The program, which premiered in June, airs every Tuesday at 4:30-5:00 PM from the University of Georgia in Athens. "Handle With Care offers resources, advice and life-serving tips that will assist listeners on how they can live a great life with disabilities," host Telmeko R. Smith said. For more information visit www.wuga.org.

"Handle With Care offers resources, advice and life-serving tips that will assist listeners on how they can live a great life with disabilities."

Grant Establishes Healthcare Program for Homeless Children

The Institute for the Study of Disadvantage and Disability (ISDD) was recently awarded a five-year, \$250,000 Healthy Tomorrows grant by the Maternal and Child Health Bureau of HRSA and the American Academy of Pediatrics. This is the first Healthy Tomorrows grant awarded to Georgia in 17 years. ISDD will establish *Healthcare Without Walls: A Medical Home for Homeless Children*, a collaborative and comprehensive community-based program to address the health care needs of vulnerable children. Contact Janice Nodvin at jnodvin@aol.com for more information.



Leslie Lipson, parent leadership support project director, GAO; Eric Jacobson, executive director, GCDD; as well as family members including Don and Tina King; Ed and Lisa Jenkins; Alicia Boyd; Deborah Quinn; and David Hawk.

Safe Schools Initiative Challenges State Board of Education

On June 9, five leading Georgia disabilities advocacy organizations gathered at the State Board of Education to implore its members to pass and strengthen a new rule to protect schoolchildren from restraint and seclusion. The Coalition behind the "Safe Schools Initiative" – the Georgia Advocacy Office (GAO), Georgia Council on Developmental Disabilities (GCDD), Center for Leadership in Disability at Georgia State University, Institute on Human Development and Disability at the University of Georgia and Parent to Parent of Georgia – declared at a public hearing its determination to free all children from the harmful practices of restraint and seclusion. They called for the 13-body board to go beyond passing the Rule 160-5-1-.35 as it is currently written but to also strengthen it by adding a safeguard that would require data collection and analysis. The board has 30 days to vote on and pass the Rule.

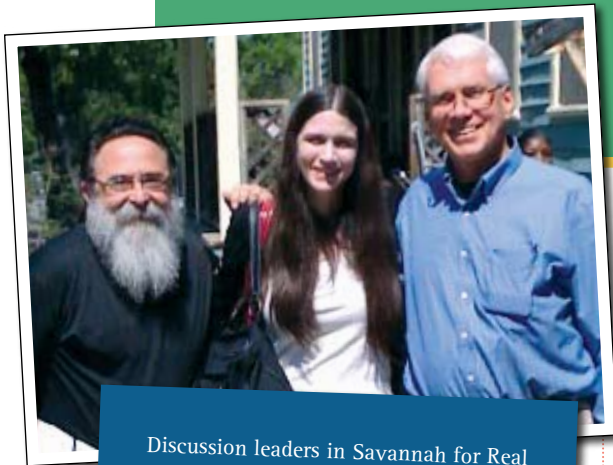
"We applaud the State Board of Education for its commitment to initiate a new rule to better protect our children," said Leslie Lipson, parent leadership support project director, Georgia Advocacy Office. "Data collection and analysis are pivotal in identifying schools that need additional support."

"This is not a rule about discipline; it is a rule about safety. This is not an issue relevant only to children with disabilities or behavioral issues. This issue impacts all of our children," said Eric E. Jacobson, executive director, Georgia Council on Developmental Disabilities. "We must shift the culture of Georgia public schools so that all students have the right to receive an education in a safe environment." ●

Real Communities Initiative Moving Ahead

Caitlin Childs, organizing director of GCDD's Real Communities Initiative, a program that encourages collective action, engaging in purposeful learning, and focusing on community assets to solve problems, has been busy meeting with potential member groups throughout Georgia.

"It's all about identifying and building a core group of organizations that are interested in the Asset Based Communities Development (ABCD) model and wanting to be a part of a greater learning community," said Childs.



Discussion leaders in Savannah for Real Communities Initiative meetings included Tom Kohler, executive director of the Chatham-Savannah Citizen Advocacy, Mike Green of Asset Based Community Development, and Caitlin Childs of GCDD.

"We're still exploring which community groups will be the best fit for the Real Communities Initiative model," added Childs. "We're excited that more groups have expressed interest in participating in Real Communities. A great example is the Korean Coalition that will be participating in our August learning community retreat along with the cities of Milton and Fitzgerald, and a parent group from Gwinnett County."

"We're excited that more groups have expressed interest in participating in Real Communities."

Childs just returned from Savannah where she met with community groups interested in the Real Communities Initiative. "I met with four different groups in "listen and learn" sessions that could be a great fit for GCDD," Childs explained. "Three of the groups were non-disability groups but are interested in exploring the connection between disability and poverty, and the need for more educational programs for the disability community."

Chester Speaks in Washington

GCDD council member Kim Chester spoke at the April National Making It Work Conference in Washington, DC. Kim and her daughter, Haley, provided personal testimony immediately following remarks from Secretary of Labor Hilda Solis. Kim and Haley were accompanied by her husband, Chris, and son, Payton, on visits to the offices of Congressman Dr. Phil Gingrey and Senator Johnny Isakson on Capitol Hill.

GCDD Announces Award Winners

The following individuals will be recognized for their commitment and contributions to the Georgia disability community at the Annual Making a Difference Appreciation Ceremony in Atlanta:

Legislative Leadership:

- Representative Jimmy Pruett (R-144th House District) is recognized for his able guidance of the Amendments to the Nurse Practice Act, HB 1040.
- Representative Sharon Cooper (R-41st House District) is also recognized for her work on the Amendments to the Nurse Practice Act, HB 1040.
- Senator Don "Doc" Thomas (R-54th Senate District) is being recognized upon his retirement from the Senate for his many years of service, particularly for his able chairmanship of the Senate Health and Human Services Committee.

Council Member of the Year:

- Kim Chester, GCDD council member, is being honored as the 2010 C. Anthony Cunningham Council Member of The Year in recognition of her work on discretionary sick leave legislation in collaboration with the Georgia Job/Family Collaborative.

The Advocate of The Year and the Media Professional of The Year award winners were not announced as of this publishing. ●



★ VOTE JULY 20TH ★

Your Vote Counts!

By Pat Nobbie, Ph.D., Deputy Director

Remember the theme from Disability Day at the Capitol? **Count me in, Count my Vote, Count my Community? Well, your opinion can't count unless you vote. Every race is up for grabs, and there is so much at stake. This election will take place in the midst of the worst recession in 70 years, and the recovery is slow in coming.**

Georgia's growth statistics are in the top ten: fastest growing state, fastest growing senior population, fastest growth in college enrollment. Yet, we have 91 counties classified as in persistent poverty. Seventy-one counties record poverty rates of over 20%. Four of those counties have poverty rates recorded at over 30%, one of which is Clarke County, home of the University of Georgia! Georgia ranks in the bottom 10% of states in most indicators for education, health care outcomes, transportation, and trauma care. For the community of people with disabilities, there are equally sobering statistics: a waiting list over 5,000, but no new community services funded in the FY 2011 budget, no new family support dollars, no ICWP waivers, some of the lowest Medicaid provider reimbursement rates in the country, a patchwork of qualified providers across the state, and an unsettled Department of Justice investigation. How can you let your incumbent legislators, and/or their competition know what you hope they can accomplish for your community in the upcoming two-year session?

FIND OUT WHO IS RUNNING:

The Secretary of State's website is full of useful voter information. Go to www.sos.georgia.gov. Click on Elections on the top banner, then on the link for qualified federal and state candidates for the July 20th primary. Then you

can click on House or Senate and see the candidates for each race. The incumbent (person already in office) is marked. Contact information for all the candidates is provided. Also on that page is a link for MVP, My Voter Page. Click on that, enter your first initial, last name, county and birthdate, and it will provide your current voter information, your registration status, your polling place, and names of your House and Senate legislators.

MEET OVER THE SUMMER: During the Conversations that Matter event held in Gwinnett last year, Senator Renee Unterman encouraged all who attended to meet with her

in her district during the summer, and this is good advice. Call the district offices and make an appointment to meet them at a local eatery. Watch for fliers and announcements about election events, and attend if you can, introduce yourself, and remind

the legislator or candidate about your family concerns. If your community hosts a candidate forum, be sure to attend so you can hear their responses to the questions posed. Some groups are hosting forums for the statewide races such as Labor Commissioner, or School Superintendent, and these are also good to attend.

READ ELECTION GUIDES: Many newspapers begin printing election guides, which include the candidate bios, their public service background, and their views on major issues. These are good to read. Healthcare Georgia Foundation published a gubernatorial candidate guide on Georgia's critical healthcare challenges. This is an extremely informative review of the Governor candidates' views on healthcare reform, covering the uninsured, and on the status of mental health services. Watch your local paper, or organization websites that promote these guides.

ASK QUESTIONS: WABE public radio will be posing questions to the candidates for Governor, and invite their listening audience to submit questions that will be asked of all the candidates. Go to www.wabe.org, click on Ask the Candidates, and you will be given a page to put your name, phone number, email address, and space to write your question. Questions will be posed during "Morning Edition" and "All Things Considered."

VOTE!: The primary is July 20th. The primary will whittle down the pool of candidates for the November election. If there is someone you want to make sure stays in the race for the November election, show your support in the primary!

Democracy only succeeds with an educated citizenry who participate in the process. This election, make your voice heard and counted! ●



After the Perfect Storm

The session wasn't finished when we went to press in April, so this is the legislative wrap-up! It was, by all accounts, an interesting year, but despite a weak budget scenario, an unpredictable legislative calendar, and new leadership, we did get a few things accomplished!

The final FY11 budget totals \$17.9 billion in state funds, a reduction of more than \$300 million since it was originally recommended to the legislature in January, and \$3.5 billion less than the original FY 2008 budget recommendation. The press release issued by the Governor when he signed the bill stated that he was assured the budget preserved essential services and the state's Triple A bond rating, which allows Georgia to borrow money at optimal interest rates. We fear that the implications of such a drastically reduced budget are yet to be realized in the human serving agencies, including education. For example, according to the Governor's statement, Georgia has 6,000 fewer state employees now than it did two years ago.

One of the few departments that was spared cuts and recommended for enhanced funding was the Department of Behavioral Health and Developmental Disabilities (DBHDD). The budget package that was described in previous editions was retained, except for a \$500,000 cut to administration. Most of the money (\$46,143,277) is in program categories to "enhance hospital operations and quality of care," which is the result of the state's intent to show the Department of Justice that it is trying to ameliorate the conditions in the state hospitals. Advocates are very interested in how DBHDD plans to spend some of this money to develop

and support the community infrastructure, because without this work, the default service for people whose families are no longer able to care for them is the hospital system or the emergency room. How DBHDD plans to deploy some of that funding to the community, and the settlement agreement between the state and the Department of Justice had not been resolved as of press time.

Developmental disabilities did receive funding for 150 COMP waiver services to transition individuals from the state hospitals to the community, and to annualize the funding for the waivers appropriated in the FY 2010 budget, \$5,567,066. In this budget, there are NO services funded for people IN the community who are on the waiting list. Funds for emergency services are also very scarce. As of May, the waiting list was up, again, to 5,009.

We fear that the implications of such a drastically reduced budget are yet to be realized in the human serving agencies...

In the Department of Community Health (DCH), there is no funding for new services in the Independent Care Waiver Program. In the Department of Human Services (DHS), Elder Community Living Services had \$1.7 million of their funding for community-based support services for Georgia's elders restored but will not have the resources to keep pace with their waiting list for elders wishing to remain in their homes. In the Department of Education, virtually no program was spared cuts. According to the Georgia Budget and Policy Institute, the state funding for K-12 will be \$950 million less than the QBE (Quality Basic Education) formula

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directs, even after including the federal American Recovery and Reinvestment Act (ARRA) funds. The University System of Georgia also suffered a 16% reduction to its programs, services, staff, and physical plant development, triggering a tuition increase. A balanced budget was possible due to

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the passage of the hospital bed tax legislation, increases to certain public fees and services, and the anticipated continuation of the enhanced federal match for Medicaid, which will expire in December 2010 unless Congress extends it. If not, Medicaid will experience another \$700 million shortfall.

Some hard questions are being asked as we go into another fiscal year with economic uncertainty.

Legislation

HB 1040 PASSED: Amendments to the Nurse Practice Act was signed into law on June 3. "This legislation will allow thousands of Georgians to be cared for at home that currently cannot afford home-care by a licensed nurse," said Governor Sonny Perdue. "As a result of HB 1040 healthcare will be more affordable and more accessible. It will allow more disabled Georgians to stay in their homes." The multi-stakeholder committee that worked on the bill has met three times since then to provide guidance to the agencies responsible

for writing the rules for implementation of HB 1040. Families should expect to get information about proxy caregivers being able to provide health maintenance activities for the people they support in the Fall if they are self-directing, and by January for people being served in licensed state facilities. The GCDD will send out information to families and individuals as it becomes available.

HR 1713 PASSED: This resolution expands the request to the Departments of BHDD, DCH and DHS to include strategic planning and funding projections for the NOW/COMP waivers, state-funded family support, community-based mental health services, ICWP waivers, funds necessary to support rates that will increase provider capacity, and to create a strategic plan for the next five years to incorporate the funds and develop community capacity. It is anticipated that the strategic plan will closely mirror the Olmstead Plan currently under development.

HB 1314, INDIVIDUAL DEVELOPMENT ACCOUNT LEGISLATION: Despite unanimous approval all the way through the process, a slight change to this bill after it left the House meant it had to be agreed on after the vote in the Senate. On the last day of the session, the agreement was not asked for and the bill died.

HB 277, THE GEORGIA 2020 TRANSPORTATION ACT: HB 1218 got new legs at the last minute in the form of the original transportation legislation, and SB 22, the Human Services Transportation bill was wrapped into it. The legislation creates 12 Regional Transportation Districts. Each district will be responsible for designing a regional transportation plan and holding a referendum for an additional 1% sales tax to support the plan. All

"As a result of HB 1040 healthcare will be more affordable and more accessible. It will allow more disabled Georgians to stay in their homes."



All citizens, but particularly people with disabilities, need to be involved in the planning process for their regions so transportation systems that get designed are truly accessible.

citizens, but particularly people with disabilities, need to be involved in the planning process for their regions so transportation systems that get designed are truly accessible. In the fall, we will be disseminating information and discussing with communities how to make their transportation needs and wishes known in Conversations that Matter sponsored by Unlock the Waiting Lists! Stay tuned for schedule and locations.

SB 367, REGARDING MEDICAL DECISION-MAKERS:

This piece of legislation also had a strange trip, having started out in the House as HB 742. Thanks to some quick work by Senator Balfour, Representative Mary Margaret Oliver’s bill to expand the list of relationships that can be legally authorized to stand for someone in making medical decisions was passed. This legislation is a great companion bill to HB 1040 because it will enable people with disabilities who no longer have family in their lives to designate an “adult friend” to help them make decisions about proxy caregiving for their health maintenance activities.

SR 324, RECOGNIZING THE UNINTENDED CONSEQUENCES OF THE USE OF THE TERM “MENTAL RETARDATION”:

This resolution is a precursor to a respectful language bill that will take some concerted effort but will clean the Georgia Code of words like “imbecile,” “moron,” “idiot,” etc., artifacts of a less-enlightened time.

This legislation is a great companion bill to HB 1040 because it will enable people with disabilities who no longer have family in their lives to designate an “adult friend” to help them make decisions about proxy caregiving for their health maintenance activities.

SB 391: This was the DBHDD’s bill, enabling the Department to assess and hold juveniles who have a disability and have been determined incompetent to stand trial in secure community residential facilities instead of state hospitals. This legislation was combined with HB 1324, the cleanup bill for

the DBHDD and passed as SB 244, which was the original Nurse Practice legislation left on the table in conference committee last session!

SB 206, TAX EXPENDITURES BILL: This bill requires the legislature to create tax expenditure reports as part of the budget report. The legislature must catalogue the tax incentives, credits, breaks or rebates it proposes each year so they, and citizens, can determine how much revenue may be lost through those tax breaks. HB 1405 enacted the 2010 Tax Reform Council to examine, and potentially adjust, Georgia’s antiquated tax structure through legislation in the 2011 General Assembly.

SB 161, STATEWIDE AUTISM TASK FORCE: This legislation did not make it out of House Rules and therefore failed. Members of the Autism research, advocacy and provider community will be working over the summer to determine next steps.

HB 1407, SINGLE ADMINISTRATOR FOR DENTAL SERVICES FAMILIES IN THE CMOS: This bill passed, but was vetoed by the Governor. The bill would have eliminated one of the administrative layers in the provision of dental services, which could have resulted in dentists in the CMO networks receiving better reimbursement rates for their services.

No Rest for the Weary!

With the end of the General Assembly, election campaign activities are ramped up. We are already meeting with potential leaders in several races. Unlock the Waiting Lists! is discussing strategy for next year. We anxiously await the resolution of the Department of Justice settlement. We urge our friends and advocates to meet with their legislators and candidates during the summer and ask the hard questions. See page 7 on election advocacy. Have a great summer! ●



Our Future is in the Balance

During a couple of public meetings or forums lately, I have actually heard people say, “We need more money in the budget.” This gives me an opportunity to start talking about what that means exactly. And fortunately, there is another organized effort to help citizens have this conversation about meeting the needs of our state.

The common goal is “to promote a balanced approach to budget and revenue solutions that meet the short and long-term needs of our state and its people.”

2020 Georgia is a new alliance of community leaders and organizations, which began meeting in the fall after the realization that we would not be able to sustain a state budget with the growing state revenue shortfall and the prospect of deeper spending cuts. The common goal is “to promote a balanced approach to budget and revenue solutions that meet the short and long-term needs of our state and its people.” Here are the principles of the new alliance.

Our Approach

Though Georgia faces unprecedented economic and budget challenges, these challenges also offer a unique opportunity to build an even better and more prosperous state. We now have the chance to take action that keeps Georgia

focused on the future, action that encourages and maintains the State’s long-term fiscal well-being. By investing in our families, in our resources, and in our existing assets, we create the potential for the renewed prosperity of our state.

In the past, Georgia has led the way through innovative investments, creating a healthy environment for economic growth. These strategies have included universal pre-K and college scholarships; internationally-renowned seaport and air transportation infrastructure; insurance for children through PeachCare for Kids; and 21st century post-secondary instruction and skills advancement through technical colleges, universities, and QuickStart. If we do not keep building on these successes, we risk falling behind.

We urge policymakers to use the following guiding principles as they build a state budget that creates a better Georgia for all citizens:

- **Take a balanced approach.**

A balanced approach to meeting Georgia’s current budget crisis will lead to faster, more sustainable recovery and prosperity. Innovative funding and revenue solutions must be considered along with cuts to public services, as available resources are falling far short of need.

- **Address the immediate crisis and plan for the future.**

Now more than ever is the time for long-term strategies and lasting solutions. Georgia must thoughtfully invest in education, public safety, health, the environment and our state’s natural and cultural resources to ensure that Georgia remains prosperous and competitive.

- **Craft revenue solutions that promote Georgia’s competitiveness.**

Georgia is facing the demands of a growing population while collecting the same amount of revenue in fiscal year 2010 as was collected in fiscal year 2005. We must reform our outdated revenue system in order to meet current needs and position our state for further growth.

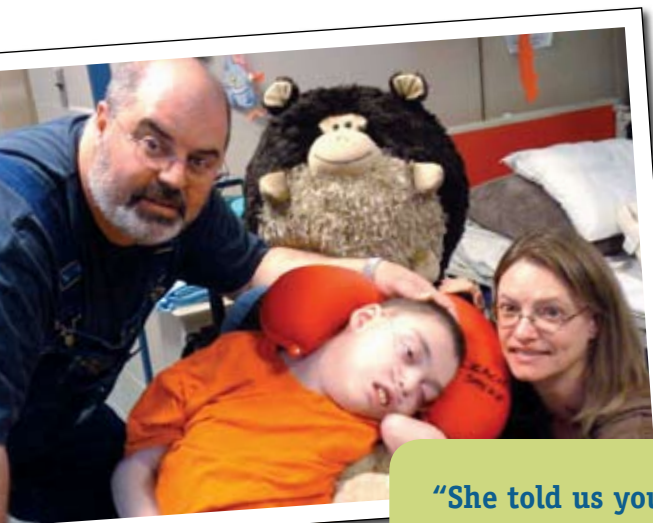
Over 40 organizations have joined, by signing on to these principles. Ashley Wilson is the project coordinator and can be reached at ashley@2020georgia.org. The website is www.2020georgia.org. Stay tuned for events, activities and conversations that will be held in the late summer and into the fall as we try to expand the conversation about the state budget beyond more cuts.

2020 georgia

Our future is in the balance.

Children's Freedom Initiative: Another Road Home

She was a single parent, with a 10-year old child who had been born with cerebral palsy, and was now suffering from severe reflux, weighing only 30 pounds. After doctors inserted a feeding tube to keep him from starving to death, the child's daycare facility said they could no longer provide care. She desperately searched for another option and could find no one who would help her care for her child. Out of choices, she placed him in a pediatric nursing facility hundreds of miles away, in another state.



Zach Sayne with parents Jeff and Nola Sayne.

That was thirteen years ago.

Zach Sayne is now 23 years old, and still lives in the Father Walters Memorial pediatric nursing facility in Montgomery, Alabama. And for the first time in thirteen years, Nola Sayne has a glimmer of hope that her child can finally come home.

"She told us you can bring kids home. It wasn't sinking in. I couldn't imagine how this would be possible."

It all started with a call from Katie Chandler, a licensed master social worker and advocate with the Georgia Advocacy Office (GAO). The staff there had uncovered information that several Georgia children were living in the Montgomery facility, and then had begun reaching out to the parents. "Katie found Zach and contacted us and we went to a meeting with other parents," explained Nola Sayne. "She told us you can bring kids home. It wasn't sinking in. I couldn't imagine how this would be possible."

The GAO had obtained a list of the guardians of nine Georgia children at the Alabama facility with the help of the Alabama Protection and Advocacy Agency. "We started reaching out to families," explained Chandler. "We set up a meeting for families with similar situations to come together to learn what their options might be."

"Representatives from GCDD and other partner agencies explained how Medicaid Waivers work and outlined transition plans for children leaving hospitals."

The event was held in November, followed by a study tour organized by the Georgia Council on Developmental Disabilities (GCDD), a lead partner with GAO. The study tour kicked off with a dinner presentation on April 30, followed by the tour on May 1.

"We told them about Children's Freedom Initiative," said Dottie Adams, family and individual supports director for GCDD. Representatives from GCDD and other partner agencies explained how Medicaid Waivers work and outlined transition plans for children leaving hospitals."

The Children's Freedom Initiative was formed in 2005, after disability advocates at the GAO discovered 141 children under the age of 22 were still living in state-run institutions and other nursing facilities. At that time some states had



Mathew Harp shares his testimony during the study tour kick-off dinner.



ended the institutionalization of children, and the GAO and GCDD determined that Georgia needed to be one of those states. The GCDD and GAO joined with its federal partner, the Institute on Human Development and Disability (IHDD), to successfully lobby for a resolution in the Georgia House of Representatives in the 2005 legislative session. The resulting Children’s Initiative Resolution (House Resolution 633) led to a plan to provide home and community-based supports to children under the age of 22 who are currently living in state-run facilities and to implement the plan within five years.

“For a lot of people, ‘seeing is believing’ and it takes having that experience before you can start imagining it for yourself or for a family member.”

Of the 141 children initially identified by the GAO, several have transitioned from facilities to home-based care. But, there are untold numbers of Georgia children still living in pediatric facilities in other states, because their parents don’t realize there are other options. So, the work of the Children’s Freedom Initiative has moved into a new phase of identifying those children in facilities in other states, and helping their families learn about the options that will bring their loved ones back home.

“We wanted to show families and people with disabilities what some of the options and possibilities are in living in the community,” said GCDD’s Adams. “For a lot of people, ‘seeing is believing’ and it takes having that experience before you can start imagining it for yourself or for a family member.”

“That night at the presentation, I told my husband, I don’t get this,” Sayne continued. “The kid who was there was functional, whereas Zach isn’t. My kid is bedridden. He can move his right hand and can blink. Otherwise he can’t move. I couldn’t imagine a host home...diaper changes...feeding tubes. But Katie said, ‘Believe me, this can work for you.’”

That evening, 22-year-old Mathew Harp gave a speech about his experience living in a geriatric nursing facility for a year. He had recently moved back home with his mother, and, using a communication device, explained how he had wanted to get out of the nursing facility, where he had to use paper to point to words in order to communicate. Now, back home, he could control everything he needs with an electronic communication device, and enjoys a better quality of life.

“I felt really alone and depressed at the nursing facility,” said Mathew Harp. “My goal was to get back home and be with my family. And now I’m home!”

“We had no idea that returning Mathew back home was even possible until we met with the GAO and GCDD people,” shared Cindy Adcock, Mathew’s mother. “They laid out a plan and showed me what supports were available for Mathew. Everything from that point fell into place, and Mathew is back home where he belongs.”

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Bylon Alexander with her advocate, Jessie Saladino.



“Through this tour, she was able to see for herself how others live and is now able to visualize moving out and living somewhere else, hopefully soon.”

“Mathew represents what is possible,” observed Joe Shapiro. Shapiro is a correspondent for National Public Radio, covering issues relating to disability, children and families. He had been conducting research on the anniversaries of the Americans with Disabilities Act and the Olmstead ruling, which had led him to learn of, and then cover, the tour event. “His family simply had not known about the possibilities when they placed him in the nursing facility.”

“You see how hard it is for families, the guilt,” Shapiro reflected. “In a system where there aren’t a lot of good choices or choices at all, it’s hard to make good decisions.”

Nola Sayne knows the guilt all too well. “The first year he (Zach) was there (nursing facility) he was very depressed, and so was I. He used to roll around on the floor and laugh and kick his feet, but all of that stopped. He quit laughing, smiling, got withdrawn.”

Mathew Harp at home with mother, Cindy Adcock.



“They laid out a plan and showed me what supports were available for Mathew. Everything from that point fell into place, and Mathew is back home where he belongs.”

The day following the dinner meeting, GAO and GCDD, along with other partner agencies, hosted a tour, starting with a group home. At that home, the mother of a 50-year-old resident explained they have three shifts of caregivers providing 24-hour support. The tour group next visited a home where the child lives with his biological family. They learned that in this situation, caregiver support can be provided from eight to twelve hours a day, depending on the parent’s marital status.

“If I was single mom I could get twelve hours of care a day. But since I’m married I can only get eight hours a day,” Sayne said. She is married to Zach’s stepfather, Jeff, who had since adopted him. The family has two other children, and both parents work full time.

“But then we went to a host home, and met an angel who lives here on Earth,” continued Sayne. “She has four girls, and has adopted three of them. She is an RN and loves these children like they’re her own. I was so impressed with her.”

Sayne immediately felt the host home was the answer for Zach and for her family.

The idea of a host home also appealed to Bylon Alexander, who has been on a Medicaid Waiver waiting list for almost a year. She attended the tour to see for herself what it would be like to move from a nursing facility, where she has been living for the past year, into home-based care.

When asked about getting out of the nursing home, Bylon said, “The quicker the better. I was ready to leave the first day I got here! I feel like no one cares about me and they want me to vanish. It makes me want to cry.”

“We saw how others with disabilities live and learned about possible living arrangements for Bylon in the future,” said Jessie Saladino, Bylon’s citizen advocate. “I have wanted Bylon to move out of the nursing facility and into home-based care since I met her last summer. Through this tour, she was able to see for herself how others live and is now able to visualize moving out and living somewhere else, hopefully soon.”

Bylon’s mother passed away early this year and her father lives outside the country. “I feel stuck since my mother died,” Bylon said passionately. “I would like to be out of here by my birthday, October 28th.”

Since the tour, Adams and Chandler have continued to help individuals and families with the steps involved in transitioning to home-based care. “As a follow-up to the study tour, Katie (Chandler) and I went over with Nola Sayne to meet her son Zach at the nursing home in Alabama,” Adams said. “Nola has picked a provider she would like to work with to move Zach back to Georgia.”



Adams and Chandler have also since met with other residents and their guardians from the Alabama facility who did not attend the tour, and are working on transitional plans with them as well.

Currently the Saynes are still filling out paperwork and waiting on federal funding in the form of a Medicaid Waiver that could come as early as October. But they've finally found the support they need through the Children's Freedom Initiative partner agencies, and they now know how to navigate the system, and can actually envision bringing Zach back to the Atlanta area.

"I could just drop by and see him instead of making treks. I could see him several times a week, have dinner, and hang out with him. It would allow Josh (Zach's brother) to see him more. He'll have more family, more visits, and have one person (host caregiver) who will care for him and love him."

"We advocate for children and young adults to remain in home settings (birth, adoptive, or foster) because children thrive where they receive one-on-one support and nurturing."

The Children's Freedom Initiative was established to help bring children who are living in institutions back into a home and community-based environment, but the program also helps parents understand the options available, and helps them deal with the paperwork. It also puts parents in touch with resources and agencies that can help them with the myriad of questions and needs along the way. One such agency is Childkind, an Atlanta-based support and placement service that believes children with complex medical or developmental disabilities should live with biological, adoptive or foster parents in real homes within supportive communities.

"We advocate for children and young adults to remain in home settings (birth, adoptive, or foster) because children thrive where they receive one-on-one support and nurturing," said Joe Sarra, director of family services at Childkind. "This approach results in the young adults going on to lead rewarding and dignified lives."

While there is no question that the Children's Freedom Initiative has been successful, it ends this year. What happens next is, in part, up to the agencies involved, and the amount of funding made available to these children and their families.

"No Waiver slots were directed toward the Children's Freedom Initiative this year," Adams explained. "There are some Waivers targeted for getting people out of institutions that we may be able to tap if or when people are ready to move. We may also try to see if 'Money Follows the Person' funds could help. The agreement with the Department of Justice may also make it so we have funding for future placements."

"The goal is to get the agencies to look at cross agency support," said Patricia Nobbie, Ph.D., GCDD deputy director. "Kids need to be supported in families to become productive adults."

"I think one thing we will do is to make our legislators aware that Georgia children are being placed out of state," Adams added.

"As far as legislative processes go, it's easy to get a resolution passed, but they're not putting any money behind it," Nobbie acknowledged, saying the resolution is more of a philosophical statement than a mandate. Nobbie was instrumental in getting the original resolution passed in the general assembly.

Eleven years ago, the Supreme Court rejected the state of Georgia's appeal to enforce institutionalization of individuals with disabilities, affirming the individuals' rights to live in their communities. The landmark Olmstead decision has forever marked the state of Georgia as the ground zero state for the rights of those with disabilities to choose to live in community and home-based settings. The Children's Freedom Initiative furthers that cause for Georgia's children.

"Georgia is the Olmstead state and yet, Georgia has a long way to go," said Shapiro. "But I think all states are struggling with this. In a period of tight budgets they are required to pay for nursing home care, forced to cut social services. That makes it hard to expand community-based care. What Georgia is facing is similar to pressures you'll find in any state right now."

The GAO and partner agency, IHDD, have since identified 150 facilities across the nation where Georgia children may be institutionalized. A plan is in progress to contact those facilities and then, to reach out to the families of Georgia children who may be living there. It will be a long process but even if it's one-by-one, those involved with the Children's Freedom Initiative are determined to make sure those families know there are alternatives for their loved ones; and to help them with supports and resources that will bring their children back home to Georgia. ●

Attitudes and Policies are Evolving. But More Needs to be Done.

By Sue Jamieson



*Sue Jamieson is the founder and director of the Mental Health and Disability Rights Project at Atlanta Legal Aid Society. In 1999, the United States Supreme Court, in *Olmstead v. L.C.*, ruled that the Americans with Disabilities Act requires public entities to place persons with disabilities who are in institutions in more integrated, community-based settings if their clinicians agree and this is their choice. The *Olmstead* case was brought by Sue and others on behalf of two women in a Georgia state institution.*

I decided in 1979 to focus my legal work on providing legal assistance to persons in state psychiatric institutions. At the time, I worked for a legal services office in Jacksonville, Florida, that served low-income people but had never served individuals in a state hospital that was within its service area. The office had served the poor for decades but never included the people with mental disabilities locked behind those closed doors. Their legal problems – confinement; forced medication; discharges to homeless shelters; repeated re-admissions; lack of, inadequate, or inappropriate treatment; dangerous conditions; absence of meaningful due process – struck me to be as significant as the rights typically served by a legal services poverty law practice. Of course, the program was willing to do the work – the institutionalized individuals had just never been noticed.

The passage of the Americans with Disabilities Act (ADA) in 1990 reflects our society's slowly evolving recognition of the inhumanity of segregating people with disabilities behind locked doors in large groups and the concurrent understanding that there are other ways to provide services safely and humanely in community settings.

The legal tools and remedies prior to the ADA were varied and often useful to assert a person's right to be discharged, but a major stumbling block was the absence of viable legal theory that imposed any duty on the state or other public entities to provide community services.

Speaking from my personal perspective, the imposition of a duty to provide disability services outside of institutions is the most significant accomplishment of the ADA for the individuals I have represented over the years. The ADA first provided a critical legal platform for the principle that confinement in institutions is discriminatory. The ADA then erected a framework upon that platform that supports a transforming second principle: services must be provided in the most integrated setting appropriate to the needs of the person with a disability.

Although the ADA stated unequivocally that institutionalization is a form of discrimination, I did not immediately see the ADA as a tool for liberating people from institutions. The *Helen L.* case, brought by Steve Gold in 1994, was the breakthrough that interpreted the ADA's "most integrated setting" regulation to require that public services be provided in the community rather than institutions. *Helen L.* inspired our office to file the case that became the *Olmstead* case, decided by the U.S. Supreme Court in 1999, holding that the ADA not only prohibited unnecessary institutionalization but also required public entities and programs to deliver disability services in community settings. To the extent that *Olmstead* was a conduit for inching toward appropriate community-based disability services for people who are or might be institutionalized in state institutions or nursing facilities, we can thank the brick wall that Lois Curtis and Elaine Wilson faced at Georgia Regional Hospital-Atlanta in 1995.

However, in the 20 years since the ADA and the 11 years since *Olmstead*, my observation is that the powerful civil right to freedom, integration, and full participation has not been the driving force behind the movement from institution to community. Instead, the same debates about funding, "downsizing," "consolidating," jobs, program eligibility, Medicaid details, and pilot programs continue. I know this is one part of transforming a system. But the other part should be a recognition that the changes are not discretionary or benevolent, but rather, are required by law. It feels, in other words, a bit like a "Jim Crow" era for disability rights, during which governments slowly adjust, neighborhoods continue to resist, discharge planners face countless obstacles, and individuals struggle against the cycle of institutional admissions, long waiting lists, and uncertain discharge planning. Hopefully, the energy of a civil rights movement will build until the demands for alternative, integrated services form a loud, articulate, and relentless chorus. ●

We've Come a Long Way with ADA

By Linda Priest

Just recently, the last of my uncles died. As a member of what they call the "Greatest Generation," it struck me that he had seen a tremendous number of changes take place in his lifetime. The idea of people flying was unique when he was young. Today, there are thousands of jet planes in the air every day.

I feel that same sense of progress as the Americans with Disabilities Act turns 20. We've certainly come a long way in a very short period of time in both physical access and attitudes about disability.

I've been fortunate to see the changes take place right before my eyes. At the age of two, I contracted polio and have been in a wheelchair for over 60 years. As a little girl growing up in South Georgia and the only one in town in a wheelchair, I basically didn't have access to anything or anywhere. The passage of the ADA has helped change all that dramatically.

I was the Georgia State ADA coordinator in the 1990s, and am proud to say I was able to have a hand in effecting changes that now make accessibility commonplace. That's not to say all the work is done by any means. But the difference between the past and the present is really mind-boggling. I can vividly remember being on trips, and there were no curb cuts or places I could use a bathroom. Access for people with mobility impairments was not on anyone's radar screen. It was a way of life and no one in a wheelchair had any expectations about finding something as simple as a hotel room that they could use.

The timing for the provisions of the ADA couldn't have been better for Georgia. Within a couple of years of passage, Atlanta was host to the Olympics and Paralympics, and a lot of things were done in a hurry to comply with the law, in part because we were having people come from all over the world to visit us.

One of the areas where we made great progress in a short time was in our state parks and roadside areas. Amicalola Falls, for example, has a beautifully accessible trail that takes you around and above the falls. Our state recreational facilities as a whole have led the

changes in accessibility that have made Georgia's gorgeous vistas and valleys open for everyone.

Still, there are places that aren't accessible. I was recently in a small North Georgia town. Knowing I was going to visit, I looked up local restaurants on the internet. Two came highly recommended. Unfortunately, neither one of them offered accessibility. For 2010, that's pretty amazing. Both of these establishments probably predate the law, but that doesn't give them a free ticket. There is no grandfathering clause in the ADA. They are still required to do what they are financially capable of doing. And in 20 years, they should at least be able to afford a ramp and an accessible parking space. There really is no excuse for that.

The law has also helped in other areas, for people with all kinds of disabilities. I now have a service dog. I'm not visually impaired, but Penny helps me with tasks like picking up things and opening doors and closing cabinets. The ADA gives me the right to have a service dog that can be with me virtually any time or anywhere.

In what's really a great irony, I think most people with disabilities today probably don't appreciate how far we've come with creating access and changing attitudes. It's almost like a birthright to them to expect access, and I guess it should be. Which definitely means we have indeed come quite a distance in a very short period of time. ●



Linda Priest is the CEO of ADA Consulting Services which provides a wide range of assistance to those with obligations and protections under the ADA. Previously, she was the State ADA Coordinator for the State of Georgia working under two Governors to assist with ADA compliance within the many departments and agencies of state government.

Americans with Disabilities Act: 20th Anniversary Marks Progress

Twenty years ago this July, President George H.W. Bush signed the Americans with Disabilities Act (ADA). As anyone who worked toward its passage can tell you, the law didn't come quickly and it didn't come easily.

The ADA had its birth in the Civil Rights Movement of the 1960s. The broadly based Civil Rights Act of 1964 prohibited discrimination on the basis of race, religion and national origin. It did not, however, protect people with disabilities.

Small victories were achieved during the 1970s, but it wasn't until the 1980s, under continual pushing and prodding from people like Justin Dart, the acknowledged "Father of the ADA," and groups like ADAPT (originally Americans Disabled for Accessible Public Transit) that real progress was made.

Mark Johnson, director of advocacy at the Shepherd Center in Atlanta, was part of ADAPT from the beginning. "That first campaign, from 1983-1990, was getting individual transit systems to change their purchase policy so when they bought a new bus it was accessible."

But progress was slow. Mike Galifianakis, Georgia Statewide ADA coordinator said, "Attempts at passage of the Act started in earnest in the 1980s during Reagan's Administration. A small group of supporters in the executive branch thought it would be important to create a comprehensive civil rights statute mirrored on the other civil rights acts for people with disabilities."

Even with momentum, it took action – literally. "In 1990, the ADA had stalled out in the House," recalled Mark Johnson. "So ADAPT helped organize a crawl up the House side of the Capitol in Washington, D.C. The rest of us gathered in the Capitol Rotunda and refused to leave."

Atlanta activist Eleanor Smith was among the throng. "We went in the Capital and filled up the

rotunda with hundreds of people," said Smith. "And we began shouting for certain Congressional members. Many people were arrested, one by one. It took forever for us to get in, and it took even longer to get us out. I believe that was a key part in moving ADA out of committee."

At its passage, the ADA gave "comprehensive civil rights protections to individuals with disabilities in the areas of employment, public accommodations, state and local government services and telecommunications," as the website of the Georgia ADA Coordinator's Office denotes.

"ADAPT helped organize a crawl up the House side of the Capitol in Washington, D.C. The rest of us gathered in the Capitol Rotunda and refused to leave."

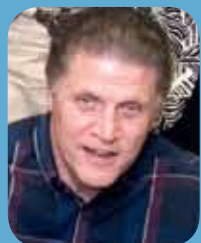
1990

To fully understand what the ADA means, though, you need only ask Nancy Duncan. "One of the proudest moments of my life is when I voted completely independently using the voting machine. And that's something that just happened that the ADA was responsible for," reflected Duncan.

Duncan is the executive director of the Disability Resource Group. She also just happens to be blind. Those two facts put her in a good position to comment on some of the positive changes brought about by the ADA.

Increased awareness is high on the list. "Restaurants, hotels, bowling alleys, law offices, banks...all those places, retail stores, anything where goods or service are offered to the public and it's privately owned...all those places probably never thought about disabilities unless the owner had a disability. Now, they've put in a ramp or have a sign that says, 'If you need assistance, let our associates know.' Those signs of accommodation make the general public aware that we are among them."

Mike Galifianakis added, "I think the areas in which ADA has had the greatest impact are in



Mark Johnson

"That first campaign, from 1983-1990, was getting individual transit systems to change their purchase policy so when they bought a new bus it was accessible."

1983-1990



Nancy Duncan

“One of the proudest moments of my life is when I voted completely independently using the voting machine. And that’s something that just happened that the ADA was responsible for.”

architectural and structural and telecommunications. ADA has had a major impact in the way we design and build. It’s not perfect, but you can really see the transformation.”

Galifianakis also says there is an economic issue involved. “More and more private businesses, larger business, are starting to develop disability-related services and products. The fact that you had a federal civil rights statute that requires federal and state governments to conform also creates awareness these are potential customers. And it makes good business sense.”

There’s still a long way to go however.

“There is not enough awareness of accommodations that are not quick fixes,” said Duncan. “You can build a ramp quickly, and the ramps are concrete with iron rails and they last forever, but accommodating a person who is visually impaired or hearing impaired in a workplace, you have to do something different from day to day.”

Employment is another huge issue. According to Galifianakis, “In general, people with disabilities are still employed at the about the same rate as they were prior to the enactment of the ADA.”

Part of what’s going to push things like the ADA are the Baby Boomers. Johnson said, “As Baby Boomers age, there will be more people identifying with ADA than in the past, and therefore it becomes much more ingrained in our culture. The law isn’t seen as impacting too many people. But it will.”

“The Olmstead decision (affirming the right of individuals with disabilities to live in their community) will truly be implemented,” he added. “But we’re still a long way away from complete Olmstead action.”

Education is another area where improvements can be made. Galifianakis predicted, “It seems there are pockets of school districts under the ADA and its parallel legislation, the IDEA (Individuals with Disabilities Education Act), but we need to do more to address the most appropriate education for children with all types of disabilities. It’s important for upward mobility and growing as a person.”

Jonathan Young, new chair of the National Council on Disabilities reported on the NCD website that, “We are not just thinking about housing in abstraction, or employment as a concept, or research in isolation. We are taking these issues and asking how do we undertake the process of developing livable communities that are fully accessible and become home to many people with disabilities? How do we take the idea of learning and all that’s encompassed within that from a traditional K-12 lens to consider the entire span of an individual’s lifelong learning process? How do we work on earning so that one of the goals of the ADA, economic self-sufficiency, is met? How do we think creatively about all of the pieces fitting together?”

Activist Justin Dart’s obituary said he “remained dedicated to his vision of a ‘revolution of empowerment.’” This would be, he said, “a revolution that confronts and eliminates obsolete thoughts and systems, that focuses the full power of science and free-enterprise democracy on the systematic empowerment of every person to live his or her God-given potential.” ●



So What’s Going to Happen in the Ensuing 20 Years?

Mark Johnson commented, “ADA will become a larger part of the everyday culture. More pieces of it will be implemented. You hope we will see employment get better, but a huge change needs to occur with regard to how we view employment.”

20 YEARS

ADA will become a larger part of the everyday culture.

Summer Fun for Everyone

By Bill Lewis

Have you ever heard of Camp Catch-a-Breath? How about Camp High Five, Camp Kudzu, Camp New Hope, Camp Strong Hearts, or Camp Sunshine? Then there's Camp ESP, Camp Hardgrove and Camp Wannaklot. Not to mention Camp Walk 'N Roll, Camp Spectrum, Camp TBI and Camp Wee-Kan-Eat-It. And that's just the beginning.

Summer camp is a rite of passage for kids. All kids. And here in Georgia, fortunately, there are all kinds of camps for all kinds of kids.

Every one of those camps mentioned above encourages kids with disabilities to join in the fun. Most of the facilities are geared to a specific kind of disability. Depending on the disability, barriers are removed, dietary needs are observed, activities are adapted and customized, and other changes are made to

the camps' curricula so that those who attend can enjoy themselves.

Like camps everywhere, those that offer programs for kids with disabilities, physical or illness or emotional, help campers gain self-esteem and awareness, not to mention offering them the opportunity to stretch their limits and do things they may never have thought possible.

There are also camps and organizations that design their activities for kids of all abilities. The Girl Scouts, Boy Scouts, Camp Fire USA, 4H, the YMCA and more all sponsor inclusive camp programs that encourage kids with disabilities to be involved.

One of the most inclusive camps is called Sparrowwood in Dahlonega. "The kids participate in everything," said Russell Davis, camp director. "There's creek hiking, a 50-foot high alpine tower with a giant swing on it. They do the alpine tower and the giant swing. They kayak, do crafts and lead worship. We have chapel services daily and the different living groups will sign up to take turns leading. They participate fully in the camp community."

In Northeast Georgia, Camp Rainey Mountain was one of the first Boy Scout camps in the nation to have a barrier-free campsite. Trip Selman, Scout Executive and CEO of the 26-county NE Georgia Council reported, "That particular campsite is now over 20 years old. It's fully accessible, with larger tents, and paths wide enough for wheelchairs."

"It's been put to good use," said Selman. "It's a regular Boy Scout camp and it's not uncommon to see boys with certain challenges. They are included in with the rest of the boys, which is a wonderful thing to see."

The Boy Scouts general axiom of inclusion is very evident in the person of First Class Scout Joshua Bacon. Thirteen-year-old Joshua is from

Boy Scout Joshua Bacon thrives in his Scouting activities.





Summer CAMP

Leesburg, Georgia, has spina bifida, and uses a wheelchair. But that hasn't made his summer scout camp experience any less exciting than any other camper's.

Joshua's mother, Amy, had seen the benefits of scouting when her older son was going through the program. Her husband wasn't sure Joshua could have the same positive experiences, so as Ms. Bacon said, "I took that as a challenge."

"I was nominated as Cub master," she says, "and I was going to make sure Joshua could do scouting. He started in Cub Scouts. I was afraid in the beginning that he would hold the other kids back. They would have to wait on him and do alternative activities because he couldn't do some of the things that they could do.

"I quickly found out that they embraced him, engulfed him and pushed him. There wasn't holding any of them back. They kind of took him on, and he flourished in front of my eyes."

The results speak for themselves. "He loves it," said Bacon. "Just truly loves it. He loves archery, he loves all the activities. This will be his third year of summer camp."

"Inclusion at summer camps also applies to our staff," said BlazeSports' director Mara Galic. BlazeSports is a GCDD 2010 Innovative Grant recipient. "We have camp counselors with and without disabilities. Just the role modeling, mentoring and leadership component of that of a young kid having a physical disability and being a camp leader is quite lovely."

One overarching theme that runs through all the camps that feature inclusion is the outpouring of support and willingness to help from kids without disabilities.

Amy Bacon, Joshua's Mom, has seen it first hand. "The other boys will help out, helping him get to different classes at camp. If he's headed in the wrong direction, an adult or another scout





is going to make sure he gets where he needs to be. The older scouts are the ones that teach the classes and they're always willing to help him get what he needs. They're always willing to help him during free time."

"All of the five 4H centers in Georgia are accessible," said Dr. Lori Bledsoe, 4H program development coordinator for the Northwest Georgia 4H District. "Everybody is treated the same regardless. Campers with disabilities stay in accessible cabins if that's what they need, but as far as all of their activities that they do and the schedule they keep, everything is the same as the other children."

At the Girls Scouts' summer camps, "We try and match up every girl and find something else if we can't meet their needs," said Jill Allison, outdoor program manager for the 42,000 girls that make up the Metro and Northwest Georgia Council, and inclusion is always encouraged.

"There are accessible buildings at each camp site. We even have platform tents that are accessible," said Allison.

This year, for the first time, the staffs of all the Girl Scout camps in Allison's domain were together for training. "One of our training issues is called Focus on Abilities. And it's all about including girls of different abilities and saying you can take any activity and adapt it. And so all the counselors go through that training."

The girls all live together and participate in activities together at camp. And, as Allison reported, the interaction is very interesting to observe. "The girls are really accepting. They ask a lot of questions once they're comfortable with each other, which is very educational for them. My experience is, as they get to know the girls who have different abilities then they do, they start to ask pretty candid questions, but because it's from a peer and the setting we're in, it's an educational conversation back and forth. Much more powerful than from an adult. It's so much more powerful when they can ask questions of each other."

Not all summer camps are overnight camps by any means. Often there is greater opportunity for inclusion in day camps.

Kristen Obaranec, communications director for Metro Atlanta YMCAs said, "The Y's philosophy on camp programs always has been to include as



many kids as we can. We want to work individually with the parents and the child to figure out the best fit for them.”

“We try to accommodate whatever the needs are so it’s a good experience for all campers,” said Obaranec.

Destination venues also offer summertime experiences for kids that include programs that are suited for everyone.

“We want to work individually with the parents and the child to figure out the best fit for them.”

The Chattahoochee Nature Center offers Camp Kingfisher. “Each week, the groups are subdivided into age-appropriate groupings,” said Lynn McIntyre, director of community relations.

“Counselors work with small groups so they have very one-on-one helpers. Each group has a name and they usually pick the names. Each session has a specific theme. They always have to have a funny name such as Fascinating Forest, Rollin’ on the River, Planet Protectors. Within those sessions, the counselors will pick a funny name like Barn Owls and the subgroups come to identify themselves and they can make up little jingles. They dress funny or wear costumes, and as Planet Protectors they get to be super heroes. And they learn something new every day.”

At Zoo Atlanta, “The train is accessible, the carousel is accessible, everything is accessible,” reported spokesperson Millie Powell. Kids learn

while they have fun in theme camps like “Frightful Birds, If I Ran the Zoo and others.”

The staff goes through training, especially for kids who sign. “We have an orangutan that uses sign language,” said Powell, a former member of GCDD who is also a mom of children with disabilities. “He was fascinated to see all these kids using their hands.”

Taken as a whole, from overnight camps to daily adventures, it means there’s a lot of summertime fun to be had throughout Georgia.

The key is finding the right fit for every child. There may not

be something for everyone within every camp program, but the plethora of camping options in Georgia comes close to accommodating all.

Parents are wise to spend time talking with program directors before choosing where to send their child. Planning activities, knowing when to push and when to pull back, and figuring out ways to say, “Yes, I can,” instead of “Well, I’m not sure that’s going to work,” can make each child’s summer experience exciting, happy and adventuresome.

With opportunities abounding, there’s no reason almost every kid shouldn’t have a great story to tell when the teacher asks in August, “What did you do on your summer vacation?” ●

My experience is, as they get to know the kids who have different abilities then they do, they start to ask pretty candid questions, but because it's from a peer and the setting we're in, it's a real educational conversation back and forth.

Destination venues also offer summertime experiences for kids that include programs available to and suited for everyone.



Success On The Court

By Bill Lewis

Grab a tennis ball with your left hand...face down. Flip the ball up, raise your racket with your right hand, position your body and hit an ace over the net. It's not an easy shot.

Now imagine doing that with cerebral palsy. Better yet, watch 12-year-old Gregory Sovie do it. The result is nothing short of remarkable.

Gregory was born with cerebral palsy. "It's mild, but it affected his whole left side," said his mother, Connie Sovie. "The balance...he couldn't hold a flip-flop on his foot until he was six. He couldn't ride a bike very well. Still to this day he has difficulty tying his shoes."

"He's ranked 25th in the South, in the Under-12 Division. He is playing in the best tournaments that all of the top 12 and Unders in the country are playing. And he's winning matches!"

But according to his coaches, Murphy and Aurandrea Payne, "He's ranked 25th in the South, in the Under-12 Division. He is playing in the best tournaments that all of the top 12 and Unders in the country are playing. And he's winning matches!"

"At first I didn't notice his disability," said his coach. "He has kind of a swagger to him that you don't really notice. But once you do, you realize his left side – his feet and his left leg – don't move as well."

Gregory himself said he needs to work on his serve more than anything else. "And my





PHOTO CREDIT: YOURGAMEFACE.COM

backhand,” he added. As for tossing the ball up during a serve, “Most kids open up their hand so their palm is facing the sky. My palm is facing down. So it’s like a flip when I throw the ball up.”

His conditioning routine has allowed him to build up considerable strength on his right side. But how does he run after the balls so well?

“I don’t know,” said his mom Connie. “It’s a God-given talent. A lot of people don’t even pick up on it.”

Gregory started playing tennis when he was about 7 years old. “He tried everything,” said Ms. Sovie. “Then one day he just picked up a racket and fell in love with the sport.”

Gregory is home-schooled and practices five or six hours a day. “We probably spend 25-30 hours a week on the court with Gregory,” reported Payne. “He is by far the hardest working player I coach. My wife and I have coached over 20 WTA Grand Slam players and right now we’re focused on working with juniors who are trying to reach the high Division I level or play professional. And Gregory is remarkable.”

The payoff is traveling and playing other top contenders. “It’s fun to go to the other places,” said Gregory. “Like Mobile, Alabama, or Del Ray Beach, Florida. And I like the competition.”

Gregory’s success on the court is even more amazing when compared to some of the day-to-day struggles he has. His coach knows that firsthand. “When I first went on the road with him (without his mother), we had to leave the hotel by 5:15 AM for a 5:30 practice. I came barging in the room. He’s the first one ready, but you see him trying to zip up his jacket and you realize, ‘Everything he does is a challenge.’”

At this level of tennis, though, no one gets any breaks in the routine. “He does all the physical conditioning,” said Coach Payne. “All of it.”

“He doesn’t cut me any slack,” said Gregory. He’ll tell you himself he needs to keep working on his game. “Especially my backhand,” he added. His best shot? “My forehand. I win a lot of points off my forehand.”

Gregory’s success on the court is even more amazing when compared to some of the day-to-day struggles he has.

Gregory is climbing the rankings as fast or faster than any kid in the whole Southern group going from #180 to #25 in the space of about nine months. And Coach Payne sees no end in sight. “Right now, the way he’s working and with this kind of passion, there are no limits to what he could do. He could make money on the tour playing tennis without a doubt.” Gregory’s goal at the moment, though, is to earn a Division I scholarship to play tennis in college.”

His inspiration even hits the coach’s home. “My wife says all the time, he’s the kid we want our daughter and our son to look up to. His athletic ability is super-gifted. People at tournaments are amazed.”

All of which means, Gregory Sovie could go very far in the world of tennis. ●

He’s the first one ready, but you see him trying to zip up his jacket and you realize, ‘EVERYTHING he does is a CHALLENGE.’



Maximizing Service to People Who Need it Most

By Don Cole



Don Cole is Vice-Chairman of the Georgia Board of Behavioral Health and Developmental Disabilities and the Chairman of the Committee on Developmental Disabilities. He was first appointed to the Board of Human Resources in 2003 by Governor Sonny Perdue. Don is President/CEO of RTT Associates, Inc., a management and technology consulting company. He resides in Cordele, GA.

Government agencies sometimes have the reputation of being out of touch with the people they are supposed to serve. Rules, protocols, and regulations from Washington or Atlanta seem to magically appear sometimes raising more questions than they answer. Dr. Frank Shelp, Commissioner of the Department of Behavioral Health and Developmental Disabilities decided to try another approach. He, along with Board Members, had been hearing issues and concerns raised by families, providers, and advocates over the implementation of the new DD Waivers. Commissioner Shelp asked Board Chair Mary Burns and myself as Vice-Chair, to help get other stakeholders more engaged in the policy development process to address some of these issues.

Special committees and task forces are not a new concept. Many times they are overloaded by membership requirements such as role or location. By the time all groups and regions are represented, the size is so large that nothing gets done. Another challenge is the question of who is on the committee, who is not, and why. If the Commissioner or someone on the staff selects the individuals on the committee, then almost invariably, there are rumors and whispers about the agency “stacking the deck” to get the result it wanted all along. The DD Committee took a different approach. We decided to keep the Advisory Work Group small with around eight members. The members of the Advisory Work Group had to have some involvement in the DD area and have a positive and solution-oriented mind-set. The Board members of the DD Committee

would recruit, review, and select the group. Our mission was simple and concise: Maximum Service to the Most People Using Available Resources. There would be no pay, no expense reimbursements, basically no cost to the state for the advisory group.

Based on recommendations from other Board members, the DD Committee asked Annette Bowling, Laurie Bradford, Ira Cavallo, Debbie Conway, Estelle Duncan, Karen Lynn, Beverly Parsley, and Nancy Vara to serve on the Advisory Work Group. The group has the perspective of parents, providers, Community Service Boards, and self-directed families and it also has a regional and rural/urban balance. The group represents decades of experience with Developmental Disabilities.

The members of the Advisory Work Group had to have some involvement in the DD area and have a positive and solution-oriented mind-set.

This group has met several times with Director Rollins and her staff. The meetings have been positive, solution-oriented, and innovative. The one thing that has impressed me most about the group is that time and time again they and others have expressed such appreciation to BHDD for calling on them for help and allowing them to

help. They have already made specific recommendations which will save the state money and provide a better service for consumers.

The DD community has always been innovative, steadfast, and persistent in meeting the needs of those who need it the most. They have to be. It is a permanent way of life. They have risen to meet the challenge. I am thankful to Commissioner Shelp, Director Rollins, and this Advisory Work Group working together to provide Maximum Service to the Most People Using Available Resources. ●

Our mission was simple and concise:
Maximum Service to the Most People Using Available Resources.

StraightTalk

Coming Home: Inspiration For All

By Mathew Harp

I am Mathew Harp and I am 22 years old. I am the oldest of six children. I have four sisters and one baby brother. We have a large family and live with my mother, Cynthia. I love to play Xbox and watch movies. I also love to go shopping, and I love the Georgia Bulldogs. Go Dawgs!

I have a muscle disorder that affects my whole body. I was born with this disease, and I've been in a wheelchair for about 12 years. I have a lot of special needs and when I was 21 years old I had to move into a nursing home because my mother and my sisters could not take care of me by themselves any longer. I did not like the nursing home. I did not like moving away from my family and school friends. I missed them very much because they could not visit me often enough.

I have a lot of special needs and when I was 21 years old I had to move into a nursing home because my mother and my sisters could not take care of me by themselves any longer.

I was the youngest person in the nursing home since most of the others were very old. I had only a few friends that would come and see me. I missed everyone very much and I wanted I wanted to live with my family so that I would not miss them so much. I am not the only young person in Georgia that had to be in a nursing home facility because of the need for assistance for themselves or their families. There are a lot of other people that have to live in the nursing

home because they do not have anyone to help take care of them at home, so a facility is the only thing they know to do.

I am very happy that I can live at home with my family and that I have a caregiver like Zenobia to take care of my needs. They take me shopping and to visit people. They do my

I want to thank everyone that had a part in helping me to move back home and be near my friends and all of my family.

laundry, feed me, make my bed, clean up my things; they bathe me, dress me, and make sure that I am comfortable. If it were not for the people at the Georgia Advocacy Office like Katie and Leyna, I would still be in the nursing home.

I want to thank everyone that had a part in helping me to move back home and be near my friends and all of my family. I love them very much and they are glad that I am back home, too.

I hope programs like Money Follows the Person and the special waivers can help many others like myself to be able to get out of the awful nursing homes and be able to live at home with their families, or on their own. ●



Mathew Harp, 22, shares a moment with his caregiver. Mathew lives with his family in Peachtree City, GA.



The Politics of Choice

By Patricia Nobbie, Ph.D., Mia's Mom

A young woman goes every Friday to the snack store. She buys a regular Coke in a bottle, a regular Coke in a can, a family size bag of Ruffles, a Milky Way and a sticky bun. She has her own spending money, and the clerks at the snack store know her. She is morbidly obese, by medical terms, and her support person waits for her in the car, knowing she can handle the transaction herself, and she won't win a debate with her. It's her choice.

A family decides the best residential option for their son with disabilities is an apartment complex where everyone has a disability. It is safe and comfortable, and there is professional help available round the clock. They are frustrated because they cannot get the Medicaid waiver to pay the residential expense because the complex is congregated living, and best practice and unofficial state policy says that individual homes and apartments in the community are the way to go. The parents question why a system that supposedly honors choice doesn't honor THEIR choice.

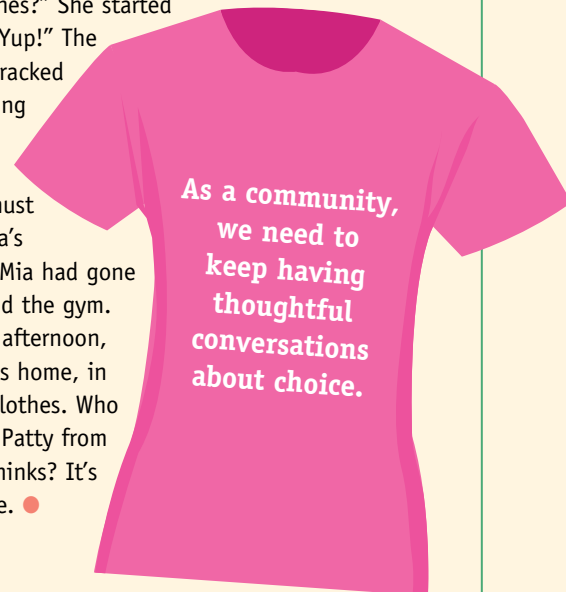
How do we honor choice for one individual if it is contrary to what society says is best for all individuals?

A group of providers at a conference discuss letting an older gentleman they serve smoke cigarettes. Does he, as an individual, have the choice to use public money to engage in a bad health practice that the state might eventually have to treat him for? As a person with a disability in a system that honors choice, shouldn't they let him have a smoke in the afternoon on his porch if that gives him pleasure?

If we are the "system," where are we in the choice continuum? If public dollars are involved, the system chooses? If we are the "parents," where are we in the choice continuum? We know best,

even for a 25 year old, a 40 year old or a 60 year old? What if the choice is life-threatening? Do we decide for people when we think they can't assume the risk of their decisions? How do we honor choice for people with limited capacity for understanding or communication? How do we honor choice without being parental or patronizing? How do we honor choice for one individual if it is contrary to what society says is best for all individuals?

That's heavy stuff. So let me share something funny. Mia has a T-shirt that has been lovingly worn for more than a decade. In her apartment, there is a picture of her wearing this shirt at a lake when she was 14. The shirt is practically threadbare, has a couple of huge holes, which, because those holes were strategically placed, Fabersha and I finally convinced her she needed to wear the shirt backwards. She calls it her "home" clothes. One day when I called, "Patty" from Delmarva was there, interviewing Mia on the quality of her life. Patty got on the phone with me, said Mia seemed to be in a good mood, and asked me if she was always like that. I said, "Yeah, pretty much, she is." When we finished talking, I asked her to put Fabersha on the phone. "Fabersha," I said. "Is Mia wearing her 'home' clothes?" She started laughing, "Yup!" The two of us cracked up, imagining what Patty from Delmarva must think of Mia's attire. But Mia had gone to work, and the gym. It was late afternoon, and she was home, in her home clothes. Who cares what Patty from Delmarva thinks? It's Mia's choice. ●



JULY

July 20-25

Association for Education and Rehabilitation of the Blind and Visually Impaired International Conference

Little Rock, AR
www.aerbvi.org

July 22

State Interagency Coordinating Council

SICC for Early Intervention Programs
Athens, GA
Ruth Cantor, 404-657-4395
rfcantor@dhr.state.ga.us

July 23

Intimacy, Love, and Relationships

Co-sponsored by People First of Georgia and the Center for Leadership in Disability
Manuel Maloof Center Auditorium, Decatur, GA
Jamie Blakenship, 404-413-1281 or
jblankenship3@gsu.edu

July 26

20th Anniversary of the Americans with Disabilities Act

AUGUST

August 8-10

Reinventing Quality 2010 Conference

Baltimore, MD
www.reinventingquality.org

August 19-20

Real Communities Retreat

Eatonton, GA

August 28

Down Syndrome Association of Atlanta Night at Turner Field

Atlanta, GA
www.atlantadsaa.org/get-involved/braves

SEPTEMBER

September 8-11

National Association for Rights Protection and Advocacy

Hilton Atlanta • Atlanta, GA
narpa@aol.com or www.narpa.org

September 9-11

The Down Syndrome Education Conference

Atlanta, GA
www.atlantadsaa.org

September 10-12

People First of Georgia Annual Conference

Calloway Gardens
Cheri Mitchell, 678-755-6015 or
cherimitchellg@gmail.com

September 14

Good to Great Meeting

A gathering of people interested in sustaining "Good to Great" work
Atlanta, GA
Dottie Adams, 404-657-2129
dxadams@dhr.state.ga.us

September 15-17

MAP & PATH Training: Person Centered Ways to Build Community

Toronto, Ontario
www.inclusion.com

September 18

Microboard Association Meeting

Atlanta, GA
Nancy Vara, 678-983-6217
gamicro1@gmail.com

September 23-26

2010 SABE National Self Advocacy Conference

Kansas City, Missouri
www.sabekc2010.org

September 24

Project Search Quarterly Meeting

Macon, GA
Dottie Adams, 404-657-2129
dxadams@dhr.state.ga.us

September 24-25

The ARC of Georgia Annual Meeting

Macon, GA
Dredla O'Brien, 678-904-1967
obrien@thearcofgeorgia.org

September 26-29

The 26th National Home & Community Based Services Conference

The Hilton Hotel
Atlanta, Georgia
Kimberly Fletcher, 202-898-2578 x131
www.nasua.org

September 27-28

National Association of Councils on Developmental Disabilities

2010 Annual Conference
Orlando, FL
202-506-5813 • www.nacdd.org

OCTOBER

October 14-15

GCDD Quarterly Meeting

Statesboro, GA
404-657-2126 • 888-275-4233 (ASK-GCDD)
www.gcdd.org

October 15-17

Abilities Expo

Cobb Galleria Centre • Atlanta, GA
www.abilitiesexpo.com

October 17

Down Syndrome Association of Atlanta's Buddy Walk

www.atlantadsaa.org/what-we-do/buddy-walk/

October 10 (session I)

October 24 (session II)

Jewish Family & Career Services The Caregiver Support Group

Atlanta, GA
770-677-9345 • revere@jfcs.atlanta.org

October 21-23

Closing the Gap 28th Annual Conference

Bloomington, MN
www.closingthegap.com/conference

NOVEMBER

November 7 (session III)

Jewish Family & Career Services The Caregiver Support Group

Atlanta, GA
770-677-9345 • revere@jfcs.atlanta.org



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

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

State Government

Georgia Senate & House of Representatives
www.legis.state.ga.us

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

Department of Community Affairs
www.dca.ga.gov

Georgia Housing Search
www.georgiahousingsearch.org
 877-428-8844

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

General Information
www.georgia.gov

Georgia Lieutenant Governor's Office
www.ltgov.georgia.gov
 404-656-5030

Children's Freedom Initiative

Georgia Council on Developmental Disabilities
 Dottie Adams
dxadams@thr.state.ga.us
 404-657-2129

Georgia Advocacy Office
 Katie B. Chandler, LMSW
www.thegao.org
 404-885-1234

Childkind, Inc.
 Joe Sarra, Director,
 Family Support Services
www.childkind.org
 404-248-1980

20th Anniversary of Americans with Disabilities Act

Shepherd Center
 Mark Johnson,
 Director of Advocacy
Mark_johnson@shepherd.org
www.shepherd.org
 404-352-2020 (main)

Georgia State Financing & Investment Commission

Mike Galifianakis,
 Statewide ADA Coordinator
www.gsfc.georgia.gov
 404-463-5600

Disability Resource Group
 Nancy Duncan,
 Executive Director
www.disabilityresourcegroup.org
 770-451-2340

Summer Fun

Georgia 4-H
 Dr. Lori Bledsoe, Program
 Development Coordinator
www.georgia4h.org
 770-233-5561

Camp Glisson & Sparrowwood
 Russell Davis, Camp Director
www.campglisson.org
 706-864-6181

Boy Scouts of America
 Trip Selman, Scout Executive/
 CEO, Northeast Georgia Council
www.nega-bsa.org
 800-699-8806

Girl Scouts of Greater Atlanta

Jill Allison,
 Outdoor Program Manager
www.gsgatl.org
 770-702-9151

Camp Fire USA Georgia Council

Elaine Brinkley,
 Executive Director
www.campfireusa.org
 706-886-2457

YMCA

Kristen Obaranec,
 Communications Director
www.ymcaatlanta.org
 404-267-5335

BlazeSports

Mara Galic, Director,
 Project Development
www.blazesports.org
 770-850-8199

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Letters to the Editor

Have something to say about one of the issues discussed in *Making a Difference*? Please send your "Letters to the Editor" to vmsuber@dhr.state.ga.us by September 1 for inclusion in the Fall 2010 issue of *Making a Difference*.

Developmental Disabilities Services Tools for Independence

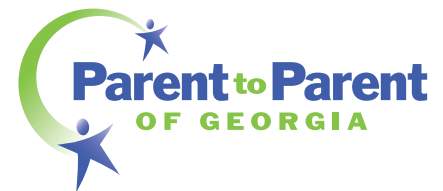
- Residential: Highly individualized community living supports with all ADL skills.
- Tools for Independence WORKS: Training and employing adults with developmental disabilities for meaningful community access or work. Also provides creative resources for businesses and the community. Includes LifeWORKS day program.
- Transition Supports: Life and prevocational skills development.

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Georgia's Family to Family Health Information Center (F2F)

The Babies Can't Wait Central Directory

Georgia's Family Voices



800.229.2038
www.parenttoparentofga.org



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404-657-2126, www.gcdd.org

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Making **a** Difference

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In addition to specialized camps throughout the state of Georgia, there are also camps and organizations that encourage inclusion with kids sharing facilities and activities.