## **GEORGIA COUNCIL ON DEVELOPMENTAL DISABILITIES**

## Health Care 101: What You Need to Know on the Issues that Matter Most

Ma

The Recovery & Reinvestment Act: How it Affects the Housing Industry

**FALL 2009** 

www.gcdd.org

ence

Georgia Tourist Attractions & Accessibility

Real Homes. Real Careers. Real Learning. Real Influence. Real Supports.



## TABLE OF CONTENTS

## In Each Issue



**On the Cover** - Perla Rodriguez (standing), a graduate of Project Search, works at Northeast Georgia Medical Center in Gainesville.

## **Features** 8 Health Care Reform 101

Separate fact from fiction, and how the current discussions can affect your quality of care.

## 12 Annual Awards Ceremony

GCDD honors disability advocates for their efforts throughout the year.

## 14 Accessible Housing

How are the recent funds from the American Recovery & Reinvestment Act being used to provide housing supports for citizens with disabilities?

## 18 Employment Update

Various employment entities report their latest updates, as well as share success stories.

## 22 Discovery Day Preview

Major advocacy events take place in Georgia this fall.

## 24 Staycations in Georgia: Accessibility

Georgia is a huge draw for tourists. How do some of our more popular attractions measure up in accessibility?

## **Departments** 7

## 3

**GCDD Viewpoint** The debate over health care continues to spark

### 4

**Guest Article** Moving health reform forward.

controversy.

## 5

News Easy Living Home Program's closure brings frustration to Georgians.

#### **Around GCDD** The council introduces their newest organizing director.

## 16

**Perspectives** Representatives from AARP and Voices for Georgia's Children discuss what the health care debate means for their constituents.

## 26

**Expert Update** Deputy Commissioner for Developmental Disabilities, Dr. Olivia Garland, introduces her goals for the upcoming year.



#### 27 Straight Talk

A man leaves the nursing home and advocates for the Community Choice Act.

## 28

Mia's Space Mia moves into her own place.



Volume 10, Issue 2 Fall 2009

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.

## G E O R G I A COUNCIL ON DEVELOPMENTAL DISABILITIES

Tom Seegmueller Chairperson tom@southwestgeorgialiving.com

Eric E. Jacobson Executive Director eejacobson@dhr.state.ga.us

Valerie Meadows Suber Editor-in-Chief & Public Information Director vmsuber@dhr.state.ga.us

2 Peachtree Street NW, Suite 26-246 Atlanta, GA 30303-3142 Voice 404-657-2126 Fax 404-657-2132 Toll free 1-888-275-4233 TDD 404-657-2133 www.gcdd.org

O'Neill Communications, Inc.

Carly Sharec O'Neill Communications, Inc. carly@oneillcommunications.com

O'Neill Communications, Inc. Design & Layout

Brandon D Hunt • Cartoonist

## HOW TO REACH US



## Letters to the Editor

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

#### Contact Our Editor and Public Information Director:

Valerie Meadows Suber, vmsuber@dhr.state.ga.us, 404-657-2122 Fax 404-657-2132 or: 2 Peachtree Street, NW Suite 26-246

Atlanta, GA 30303-3142

#### Audio or Large Print Versions:

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

#### Subscriptions / Back Issues:

Visit us at our Web site: www.gcdd.org or call us: 404-657-2126.

It is our policy to publish readers' comments. Contents do not necessarily reflect the opinions of GCDD, the editors or state government.



#### Magazine Sponsorship:

For sponsorship opportunities contact: Kim Shapland at 770-578-9765 or kim@oneillcommunications.com.

## Health Care Debate Affects Georgians with Disabilities

This has been a very interesting summer. Once again there is an effort to reform the health care system in the United States. Supposedly there is little argument about the need to increase the number of people who have access to health care and to reduce the costs. The question is – how do we do this? From the bitter battles that have taken place across the country and in Georgia it is hard to tell if there is any common ground. Most of us have no idea what is fact and what is fiction.

There has been little said about how health care reform would include access to long term services and supports. Organizations such as the Disability Policy Collaboration and ADAPT have been working to make long term services and supports a part of this conversation. For many people with disabilities reliance on a government funded and operated Medicaid or Medicare system has been a way of life. These programs have been the only way for many individuals and families to get the services and supports they need. Private insurance companies have either refused to pay or had caps that both individuals and families have met very quickly. Is everybody satisfied with these government funded and operated programs? That was an unequivocal NO spoken by many of our readers. Are we satisfied with efforts to "privatize" Medicaid or Medicare through health maintenance organizations or third party administrators? That was probably an even louder NO. We hope that in this edition of *Making a Difference* manazine that we will answer many of the questions you might have abo





magazine that we will answer many of the questions you might have about how health care reform might impact your life.

We will also take a look at issues around housing and employment. Without safe, affordable housing and access to the job market, many individuals will be forced to live at home with their parents and others may remain "locked up" because they have no place else to go. Take a minute and read *Mia's Space* (page 28) to see what possibilities exist when we allow individuals to grow up, move into their own homes with supports and go to work to earn a living. We at GCDD are all very proud that Mia Nobbie now has the keys to her own place.

### Health care reform needs to be about citizens having quality, affordable health care, and long term services and supports coverage that can not be taken away.

Finally, we want to welcome Caitlin Childs as the GCDD Organizing Director and Dr. Olivia Garland as the Deputy Commissioner for the Department of Behavioral Health and Developmental Disabilities.

We hope that you will take this time to find out all the information you can about what is proposed in Washington and Georgia. Let us know what you think about health care reform by emailing "Letters To The Editor" at vmsuber@dhr.state.ga.us.

Eric E. Jacobson Executive Director, GCDD

Tom Seegmueller Chairperson, GCDD



**GUEST ARTICLE** 

## Disability Community Works to Move Health Reform Forward

By Barbara Kornblau, health policy advisor to the American Association of People with Disabilities (AAPD) and the Justice for All Action Network; and Andrew Imparato, president and CEO of AAPD

The health reform debate has proven a rallying cry for the disability community across the country. From a visible national presence at town hall meetings to high level negotiations with top White House and administration officials -including the president - the disability community has mobilized to assure that when it comes to health care, "nothing about us, without us."

A leadership meeting in Boston led to the formation of the Justice for all Action Network





(JFAAN), a working group of leaders in disability self-advocacy – many of whom are leaders of local, state and national disability advocacy groups. JFAAN members have initiated, coordinated and organized a serious of events to promote the health reform issues important to people with disabilities. The

various groups represented in JFAAN have served different roles and contributed different expertise. For

example, self-advocate members of the broad-based DC-group the Consortium for Citizens with Disabilities put up a Web site focusing on the Community Choice Act (CCA) and the Community Living Attendant Services and Supports (CLASS) Act. The Disability Rights Education and Defense Fund (DREDF) focused on health disparities. ADAPT focused its efforts on

Community Choice Act (CCA) and the newer provision that would make CCA a state option, which is called the Community First Choice option.

The CCA is a major issue for the disability community. It would end Medicaid's institutional bias by giving people with disabilities of all ages the choice to live in the community with in-home assistance instead of nursing homes. The disability community came together under the leadership of ADAPT and the National Council on Independent Living to advocate President Barack Obama's health reform director, Nancy-Ann DeParle, on August 27. Many in the disability community met with key staff members in both the House and the Senate to advocate

for the inclusion of the CCA in the health reform bills.

These efforts culminated in a productive meeting with

members in both the House and the Senate to advocate for inclusion of our issues in health reform including the CCA, anti-discrimination provisions, data collection of health information of people with disabilities to improve care, rehabilitation and habilitation services, durable

> medical equipment, prosthetics and orthotics, and standards for accessible medical equipment.

Several advocacy groups held "hill day" events that mobilized the grassroots to come to Washington. Protests and rallies have been held in cities and communities throughout the country to advocate for the CCA, to show our support for health reform, and to commemorate the anniversaries of the Olmstead v. L.C. decision and the

passage of the Americans with Disabilities Act.

As a community, through our many activities in Washington and across the country, we influenced the White House and the Hill to see the disability community as an important constituency. This resulted in many conference calls with White House health policy makers, and the White House's creation of a policy document "How Health Insurance Reform Helps People With Disabilities" which can be found at www.WhiteHouse.gov.

We encourage Georgians to use the time that is left in this session of Congress to reach out to your members of the House and Senate and make sure they know how health reform will affect you. Now is the time to make our voices heard.

The CCA is a major issue for the disability community. It would end Medicaid's institutional bias by giving people with disabilities of all ages the choice to live in the community with in-home assistance instead of nursing homes.

We encourage Georgians to use the time that is left in this session of Congress to reach out to your members of the House and Senate.

## AROUND GCDD

## Childs Announced as Organizing Director



The Georgia Council on Developmental

Disabilities welcomes their latest organizing director, Caitlin Childs. "Caitlin comes to us as an experienced disability advocate," stated Eric Jacobson, executive director of GCDD. "I look forward to the enhancements she will bring to our work, and expect to see great things from her in the future."

Childs has over 10 years of social justice community organizing experience in the Atlanta area, and was a member of GCDD's first Organizing Institute in 2007-'08. In her new role as organizing director, she will continue to build and implement the Real Communities Initiative.

"I believe very strongly in the power of community organizing," Childs stated. "I look forward to working with disability advocates around the state to utilize community organizing strategies in their work." Childs continued to emphasize her passion for coalition building, and in working across identity lines to build inclusive and welcoming communities.

"I look forward to working with disability advocates around the state to utilize community organizing strategies in their work."

"My experience with the Organizing Institute are among the most powerful in my years as an activist," she said. "I gained and strengthened many skills, and was able to become more connected to disability communities. I look forward to using those skills as a part of GCDD."

## GCDD Joins Advocates Urging Positive Behavior Supports in Schools

The Georgia Advocacy Office (GAO), in collaboration with The Georgia Council on Developmental Disabilities, the Center for Leadership in Disability at Georgia State University, and the Institute on Human Development and Disability urge the Georgia State Board of Education to promulgate a rule that protects all Georgia students from restraint and seclusion, and encourages the proactive use of Positive Behavior Supports in schools.

The GAO acknowledges the Department of Education for heeding the call of advocates to regulate the dangerous practice of restraint and seclusion by preparing for rule initiation either in the late fall or early spring.

For information about this collaboration, please contact jholland@thegao.org. GCDD's

quarterly meeting will include an opportunity for the community to learn more about this issue and give public comment on Thursday, October 15, 2009 at 5:30 P.M. at the Pilot International Foundation located at 102 Preston Ct. in Macon.

••••

## Make a Difference ... Become an Advisory Member!

GCDD is now accepting applications from individuals with development disabilities to serve as advisory members of the Council. Applications are being accepted through December 1, 2009.

After serving a two-year term as an advisory member, GCDD may recommend them to the Governor for appointing to the Council as openings become available. Advisory members participate in many of the same activities, including attending all Council and committee meetings.

For more information and to submit an application, visit www.GCDD.org or mail to 2 Peachtree Street NW, Atlanta, GA 30303.

**Correction** In the Summer 2009 issue of *Making a Difference*, Rie Kennedy-Lizotte of the National Association of State Directors of Developmental Disabilities Services was erroneously quoted in the article "Can Georgia Finish What They Started?" The quote read "In 1977, we had approximately 160 million residents with intellectual or developmental disabilities living in large institutions of over 50 residents. By 2007, that number was down to just over 36 million." The quote should have read 160 thousand and 36 thousand.

Additionally, Oregon was inadvertently left out as a state that has less than 25 people to move to community homes. We are pleased to report that Oregon is expecting that their last state institution should be closed in the near future.



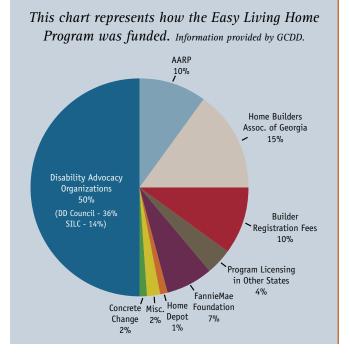
## Easy Living Home Program Has Closed

Effective October 1, the Georgia Easy Living Home program is no longer in existence. Eric Jacobson, one of the founding members of the program and executive director of the Georgia Council on Developmental Disabilities, explained. "A considerable amount of time and money has been spent recruiting and educating builders to design and build new homes with a few basic accessibility features," he said. Accessibility features include a zero-step entry, wide interior doorways and a complete living space on the first floor.

"Realtors says they are desperate for Easy Livingtype homes, but builders are saying that there is no market demand," said Pat Puckett, director of Georgia's Independent Living Council and head of the Statewide Independent Living Council. "I found it most confusing that these two business sectors had such different viewpoints."

Advocates for the program argue that accessible features have a negligible cost. What's more, they open up the market to people of all ages and abilities. "With the graying of America, it makes no sense to build homes with steps at every entry," Puckett argued.

Jacobson agreed. "It is saddening to have to close the program...but after a decade of effort, there are fewer than



one thousand certified homes in Georgia, in spite of the phenomenal building boom of the recent past."

Despite this disheartening news, there is some good to have come from this. The concept of the Easy Living Home program has spread to several other states in the nation, and it's been noted that this shift in thinking about the accessibility of homes will only benefit the future of America.

### "Realtors says they are desperate for Easy Living type homes, but builders are saying that there is no market demand."

"An article from the Journal of the American Planning Association demonstrated that 25 percent to 60 percent of all houses built in 2000 will have a resident with severe long term mobility impairment over the lifetime of the house," explained Eleanor Smith, a nationally recognized advocate on the issue of accessibility with new home construction. "That's simply astounding."

## The Long Road Home: Perspectives on Olmstead Ten Years Later

Marking the tenth anniversary of the United States Supreme Court's landmark decision in Olmstead v. L.C., local attorneys and Lois Curtis will participate in the Georgia State University College of Law's annual one-day symposium. Curtis is one of the original co-plaintiffs of the historic case, which originated in the heart of Atlanta. Topics will include the history of the Olmstead Initiative, the current state of the initiatives and what the future holds, as well as new applications outside of community-based services that the Olmstead Initiative could spur.

United States District Court Judge Marvin Shoob, who ruled on the original summary judgment motion, will speak at the luncheon. The line-up is full of guest speakers, including Susan Stefan, a staff attorney at the Center for Public Representation in Massachusetts; David Ferleger, a specialist in disability law; Steven J. Schwartz, the executive director of the Center for Public Representation; and Jessica Howell, assistant director of the Georgia State University Center for Leadership in Disability.



The symposium will be on October 23 from 8 AM to 5 PM at the law offices of Sutherland Asbill & Brennan at 999 Peachtree Street, NE. Attendance is \$30, including lunch. For more information, contact Toni Pastori with Atlanta Legal Aid at 404.377.0705.

Curtis is a quest speaker at the upcoming symposium.

## United Nations One Step Closer to Global Accessibility

Americans living with disabilities were excited to learn of President Barack Obama's recent signing of the Convention on the Rights of Persons with Disabilities, sponsored by the United Nations.

The Convention was to address the world's largest minority – according to the World Health Organization, 10 percent of the total world population experiences various forms of disabilities.

The purpose of the Convention is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." There's an optional protocol available for signatories and ratifications as well.

According to WhiteHouse.gov, Obama's signing – and the ratification of – the Convention is just one step in a series of four goals designed to promote equality for all Americans, including:

- Provide Americans with disabilities the educational opportunities needed for success
- End discrimination and promote equal opportunity
- Increase the employment rate of workers with disabilities
- Support independent, community-based living

To date, there are 142 signatures to the Convention including President Obama's – out of the 142, there have been 65 ratifications of the Convention.

"Once the country has signed, it is obligated to adjust its legislation on what the convention says – unless their legislation is even better than the convention," explained Alex Leblois. Leblois is the executive director of G3ict (Global Initiative for Inclusive ICTs.) "This is a universal ADA, if you will," Leblois further explained. "The treaty has had an incredible success – it's amazing to have so many signatures in just two years."

Lois Curtis (sitting) with Sue Jamieson, the plaintiff's attorney for the Olmstead decision.

According to Leblois, the convention now must go through the United States Senate, handled by the committee on foreign relations, which is chaired by John Kerry.

## Wii-hab: Video Games are Becoming the New Trend in Rehabilitation

Twenty-three years after the Nintendo Entertainment System first video game console premiered in the United States, Nintendo Wii has taken the video game industry as well as many American households by storm, and now at Albany Advocacy Resource Center (Albany ARC) the game system is starting to be used as a form of physical and occupational therapy to help improve movement and motor skills.

At Albany Advocacy Resource Center (Albany ARC) the game system is starting to be used as a form of physical and occupational therapy to help improve movement and motor skills.

Consumers at the Albany ARC Adult Day Program are finding recreation and therapeutic opportunities in Nintendo's Wii. The ease of use of the controllers and the interactivity of the games makes the Wii a unique and rewarding gaming experience for people of all ages and abilities. It benefits balancing, arm movement, eye-hand coordination, range of motion, and much more. It does not discriminate based on mobility and even people in wheelchairs can play some of the games.

Albany Advocacy Resource Center is the leading non-profit provider of services in southwest Georgia for individuals with developmental disabilities, physical disabilities and other special needs. For nearly 46 years, Albany ARC has offered help and hope to children and adults living with disabilities, and to the families who love them. Through therapy, training, education and support services, Albany ARC creates life-changing solutions to help people with disabilities live, learn, work and play. For more information, visit www.AlbanyARC.org.

## d long term services? What keys By Bill Lewis Don't Shy Away emport from the Health Care Debate

ention the words "health care reform" in a crowd and you'll probably get 100 different opinions on the subject. As health insurance becomes increasingly competitive, and more find themselves uninsured, reform by the year's end has become the goal for many.

Health care now takes center stage in a national debate that has many locked in heated arguments. Some advocate a single-payer system, while others think the system should be employer-based. Questions about funding surround each proposal made, and coverage for all is at the forefront of most discussions.

Health care reform takes on an added importance for people with disabilities. What will happen to existing programs? What about home and communitybased long term services? What kinds of changes would help strengthen Medicaid and Medicare? These and many other questions are all part of the ongoing debate.

"Health care reform has been an issue in our country for close to a century," said Shelby Butler, board chair of the Missouri Health Advocacy Alliance. "People need to have the support they need in order to stay healthy and independent." Butler explained how there are still barriers in place that prevent Americans with disabilities from attaining the services they need, including the practice of many current insurance companies of not electing to insure pre-existing conditions – a clause that disability advocates feel targets them.

Liz Savage of The Arc of the United States and United Cerebral Palsy explained that both the proposed bills from the House and the Senate include reforms for Medicaid by expanding income eligibility. "The proposed reform would include a new group of people for eligibility – non-elderly, non-pregnant childless adults," Savage explained. "This is an area that has frustrated people with disabilities in the past, but this new inclusion would expand Medicaid coverage." Coverage would also be expanded by the proposal to cover individuals with an income of up to 133 percent of the federal poverty levels, which is currently at \$14,404.

There is also the worry that, unless changed, the Medicare and Medicaid systems will simply get too large and become unable to support themselves. According to HealthReform.gov, Medicare expenditures in 2008 topped \$386 billion dollars, and

are currently expected to reach \$797 billion by 2018 if this system remains unchanged. Another alternative for Medicare

and Medicaid, Marty Ford of The Arc says, is the Community Living Assistance Services and Supports (CLASS) Act. "The CLASS Act involves establishing a long term insurance program. It would be a federal program with a trust fund that people would pay into voluntarily through their payroll."

The CLASS Act was introduced into both houses of Congress in March 2009. Its stated purpose is "to help individuals with functional impairments and their families pay for services and supports that they need to maximize their functionality and independence and have choices about community participation, education, employment and for other purposes."

As originally presented, the CLASS Act would create a national voluntary disability insurance program (CLASS program) under which: (1) all employees are automatically enrolled, but are allowed to waive enrollment; (2) payroll deductions pay monthly premiums; and (3) two-tiered benefits

People end up in Medicaid once they've used up their own assets...Medicaid requires you be in poverty. are provided, based on the level of disability, to purchase non-medical services and supports that the beneficiary needs to maintain independence.

Ford pointed out that the CLASS Act is designed to meet people's needs at home rather than a nursing facility with a cash benefit. "We hope people could supplement that through the private market as well," she said.

While the CLASS Act was in committee, Sen. Johnny Isakson (R-GA) offered an amendment that would allow those who participate to use the funds for additional purposes including but not limited to counseling on advanced directives, living wills and powers of attorney. Committee members accepted the amendment unanimously.

According to Savage, the act is in the Senate's version of the bill. Once the finance committee's bill is edited down, the two bills are expected to merge and become one bill in which the CLASS Act should be included.

Additionally in early 2009, the Community Choice Act was introduced to the House of Representatives. It's sponsored by Rep. Danny Davis (D-III.) and cosponsored by 116 other representatives and including Sanford Bishop (D-GA2), Henry Johnson (D-GA4), and John Lewis (D-GA5). The CCA was designed to amend Title XIX of the Social Security Act to provide individuals with disabilities and older Americans with equal access to communitybased attendant services and supports through state Medicaid coverage.

As of March 23, 2009, the bill has been referred to the House Committee on Energy and Commerce.

Savage, acting as spokesperson for the Disability Policy Collaboration (DPC), said her group has put together six key answers to the question: What do people with intellectual and developmental disabilities most need in health care reform?

- **1. No Pre-existing Conditions Exclusions**
- 2. No Annual or Lifetime Caps on Coverage
- 3. Coverage for Durable Medical Equipment, Prosthetics and Orthotics
- 4. Increased Medicaid Reimbursement Rates for Primary Care Physicians
- 5. Improved Home and Community Based Services
- 6. Reduced Demand for Medicaid Long Term Services and Supports

Medicaid will be strengthened when a national voluntary long-term care insurance program (from the CLASS Act) is implemented and people can receive support without having to use Medicaid.

While advocacy groups are making their voices heard for reform, Savage also points out, "It's



important for people to get in touch with legislators to let them know their constituents support health care reform."

That's the message from Isakson's office as well. A spokesperson for Isakson said that while Georgians with disabilities can and should contact any and all members of Congress who are dealing with the programs to be included in a health care bill, it's vitally important to provide information and suggestions to Georgia's senators and congresspersons specifically.

There are more than the DPC issues, as well. The American Association of People with Disabilities (AAPD) adds to the list:

- Address health disparities and accessibility issues that often prevent people with disabilities from receiving quality care in their communities;
- Provide access to health care based on individual health needs and not on income or employment status;
- Limit the burden of out-of-pocket expenses and cost-sharing requirements for participants on a sliding scale based on income, with a commitment to affordability and no work disincentives; and
- Engage people with disabilities as partners in the effort to make our health care system work better.

The AAPD has put its suggestions in the form of a "Petition for Health Care Reform that Meets the Needs of Individuals with Disabilities and Chronic Health Conditions and their Families."

And there are other pieces of legislation before Congress that could have an impact on people with disabilities in other ways. The act essentially allows people to work and still qualify for Medicaid.

Savage points out other items under discussion. "One thing in the House bill is the issue of quality. The difficulty people with disabilities have accessing quality medical care is that Medicaid "It's important for people to get in touch with legislators to let them know their constituents support health care reform."

> The difficulty people with disabilities have ACCESSING quality medical care is that Medicaid reimbursement is pretty low.

The ultimate outcome of supports and services should be a "good everyday life" in the community.

reimbursement is pretty low. This bill increases Medicaid reimbursement to Medicare levels, which are higher.

"The first four years are paid for by the federal government with full funding, with 90 percent paid thereafter. That would significantly improve quality," Savage continued.

Savage also talked about provisions for accessibility. "The other issue in both the House Bill and Health, Education, Labor and Pensions Bill in the Senate is a provision that the U.S. Access Board develop guidelines for technical requirements regarding how medical and diagnostic equipment is used in hospitals and doctors' offices and how those should be

accessible. There are no current guidelines for accessibility."

The recently released Senate Finance committee health reform proposal does not explicitly include those provisions, along with explicit provisions for rehabilitation. "We're working hard to make it explicit in the bill," said Savage. "The final, signed bill must include those provisions in order to improve the quality of life of those living with disabilities. There should be no question as to what's covered and what isn't."

The National Association of State Directors of Developmental Disabilities Services is one of the groups at the forefront of trumpeting the message that people with developmental disabilities have the capacity to contribute to the social and economic wellbeing of their communities and the nation. NASDDDS has put together a list of important factors they feel are vital to include in any reforms being considered.

• The ultimate outcome of supports and services should be a "good everyday life" in the community. This end differs from the goal of simply reducing the need for institutional care. Health care reform efforts must presume that people with disabilities will live in their communities. This aim can best be accomplished by offering a broad range of flexible, high quality and personalized supports that honor individual choice and promote involvement in the community.

- People with developmental disabilities must have control over their lives. Service systems must honor individual preferences and offer services designed to achieve personal goals as determined by the person. Valuing each person's right to self-determination in the design and delivery of services will lead to greater competencies, independence and, consequently, less costly services.
- Employment is a central feature of independence and life in the community.

The majority of adults with developmental disabilities are of working age. Employment not only enhances an individual's sense of self-worth and improves his or her economic well-being, but also frequently reduces service needs and costs – sometimes dramatically. Health care reform must eliminate barriers to employment; i.e., both providing the support services needed to maintain employment and removing the risk of losing eligibility to the very services needed to remain employed.

• Families play a central role in supporting both adults and children with disabilities. Most people with developmental disabilities live with their families well into adulthood, many for their entire lives. Family members provide individuals with developmental disabilities with both a home and support that are critical to leading a full life in the community. To successfully provide support, family members need direct assistance such as information, counseling, training, and someone to coordinate services.

Paying family members/relatives to provide care in certain situations should be an element in any reform effort. Family members who provide support, particularly family members who are aging, may themselves have a disability and need their own support services. Policies should allow caregiving agencies to support more than one person with a disability in a household as a sensible and cost-effective strategy to avoid the need for out-of-home care.

• Waiting lists must be addressed. The existence of waiting lists for services is generally considered an anomaly in Medicaid, but is indeed a reality for those who need Medicaid-funded home and community-based services. As health care reform will surely seek to address the broader issue of covering the uninsured, it should also seek to ensure that individuals

currently on waiting lists for services and receiving little to no publicly funded support can access the array of services they need.

- Services must be coordinated and managed. A coordinated and cost-effective system would provide assistance to explore and identify the types of supports that would be most helpful to the person and their family, to help them access generic services and supports in the community as well as specialized services, to assist the person through transitions in life, and to coordinate with other systems.
- Disability-specific expertise must be retained as part of the service system. While long-term supports can be conceptualized as a generic set of services, the needs of people who rely on those supports are not generic.
- Quality of services and supports are an essential feature of a service system. Assuring health and safety are key features of quality, but quality must go beyond protecting health and safety. It must measure the effectiveness of services in achieving personal outcomes. Quality improvement mechanisms must be designed to ensure that supports and services maximize the achievement of desired outcomes in participants' lives based on their personal experiences as well as measured results.
- Information technology is an essential element to both delivering services and managing quality. Technology applications can streamline labor-intensive activities of assessing need and risks, service planning and monitoring. Individuals and families could better direct their own services, enabling public managers to monitor utilization and cost. Collection of

data on utilization, satisfaction, and personal outcomes would inform policy development and service design.

According to HealthReform.gov, here in Georgia alone 18 percent of citizens are uninsured. Additionally, the number of Georgians with employerbased coverage has dropped from 65 percent to 60 percent from 2000 to 2007. The same Web site also points out that two insurance providers account for 69 percent of those who are insured in the state, with both providers including clauses against insuring pre-existing conditions.

"Americans with disabilities are more likely to be predisposed to certain conditions," explained Barbara Kornblau, Health Committee Chair of the Justice For All Network. "If you have a disability, you are more likely to not receive the primary care needed due to both lack of accessibility, lack of health coverage and lack of knowledge on the part of the medical community. People with disabilities are likelier to be obese and to have the diseases associated with excess weight including diabetes and high blood pressure. They are also prone to not getting the screenings they need such as mammograms or colorectal screenings. By expanding coverage, these problems are not necessarily going to be entirely eliminated right away, but we're going to start getting close."

While debate over health care remains ongoing and far ranging, the issues that affect people with disabilities are being talked about by government officials. Advocacy groups play a vital role in presenting the facts and pushing for reform. As always, however, it's up to individuals to truly make a difference. Regardless of the outcome of this year's reforms, the debate won't end there. Legislators value the input of their constituents. By expanding coverage, these problems are not necessarily going to be entirely eliminated right away, but we're going to start getting close.

## You Have an Opinion – Make Sure People are Listening!

The often verbalized thought among disability advocates is that once health care reform is complete and signed, Americans will be "stuck" for quite a number of years. That's why advocates are ensuring that their thoughts are considered by contacting their congressmen.

Georgia's senators are Sen. Saxby Chambliss (R) and Sen. Johnny Isakson (R), both of whom have expressed concern in moving forward with health care reform as the current proposals stand. "We need meaningful reform, not reform for reform's sake!" Chambliss stated on his Web site.

In July, Isakson expressed his desire to decrease the financial burden of health care, but also stated that he felt the current proposals would only drive up the cost of insurance, as well as decrease patient choice.

## **Contact Your Senators:**

#### Sen. Saxby Chambliss

416 Russell Senate Office Building • Washington, D.C. 20510 202.224.3521 • chambliss.senate.gov

#### Sen. Johnny Isakson

120 Russell Senate Office Building • Washington, D.C. 20510 202.224.3643 • isakson.senate.gov

To find your district representative, visit www.house.gov and type in your zip code. Your local library will also have your representative's contact information.

## Appreciation Ceremony Awards Advocacy Efforts

he 2009 Annual Making a Difference Appreciation Ceremony, held July 16, highlighted the best of the best in advocacy work over the year. Promoted by the Georgia Council on Developmental Disabilities, a wide variety of people were recognized with enthusiastic supporters in the audience.

"I want to be an advocate in my community," said council member Lenora Maynard. "I live in Macon, and the issues I care about the most are housing and transportation."

Indeed, the spirit in the room was of overwhelming relief that another year had passed and that so many strides had been made - and resilience in the face of what still needs to be done in the work of ensuring equality for all.

"Our goals are to create a society based on justice and equality," stated Eric Jacobson, executive director of GCDD. Jacobson then commended all advocates for their work in ensuring Georgia citizens live in a society like that - and in decreasing the number of people on waiting lists as well as creating community-based support systems. "The worst thing you can do is nothing," he said.

After recapping events of the year, Jacobson and Tom Seegmueller, chairperson of GCDD,

> honored outgoing advisory members. "The council has had some incredible members over the years!"

Seegmueller stated. Outgoing members this year are Riley Buckmaster, Nicholas Harris and Madeline Ponder.

"The council members have been so warm and kind," Buckmaster said to the crowd. "I'm going to miss everyone, and will continue to be supportive.

Pat Nobbie, deputy director of GCDD, then listed legislative accomplishments achieved throughout the year - most notably the restructuring of the Georgia Department of Human Resources. "It's been a very large and difficult job of 'unbundling' the department of human resources," she said. "The reorganization effort - as outlined by House Bill 228 - was not just about moving boxes around on a chart."

## "I'm proud to be in the position I'm in, where I can encourage all voices to be heard by the government."

Recognized for his advocacy, Sen. Johnny Grant (R-Milledgeville) was a driving force behind the reorganization of DHR. "Legislative work is not rocket science," he joked with the crowd. "I'm proud to be in the position I'm in, where I can encourage all voices to be heard by the government."

Also presented with an award was Rep. Pat Gardner (D-Atlanta), who played a pivotal role in both the reorganization of DHR and the proposed expansion of PeachCare for Kids<sup>™</sup>. "I do thank you for this distinctive honor ... but I mostly want to thank you for your advocacy," Gardner said to ceremony attendees.

"The PeachCare for Kids legislation is an effort to allow more families access to health care through the expansion of Medicaid, PeachCare and a third option that would allow families to buy in to PeachCare if they so choose," Gardner explained. "As private health insurance plans began limiting services for children with disabilities, I had hoped that the

Sen. Johnny Grant was honored for his work on the reorganization of Georgia Department of Human Resources.

"Our goals are to create a society based on justice and equality."





more comprehensive Medicaid and PeachCare model would help."

Following the presentation to the two state legislators, Valerie Suber, public information director for GCDD and organizer of the July event, introduced a video presentation of the 11th annual Disability Day at the Capitol, which was a huge success in early 2009 - both in attendance and in press coverage. "Not enough can be said about the value of earned media and the power of our collaboration between GCDD and the Georgia Radio Reading Service (GaRRS)," Suber emphasized. For the first time, Disability Day was simulcast live to more than 20,000 GaRRS radio and internet listeners.

She also commended the enthusiastic show of support of Disability Day emcee, Frank Ski, v-103 FM radio personality, during his radio show the following morning.

"Frank Ski has been doing a lot for the Atlanta community," Tameeka Hunter, vice-chairperson of GCDD commented. "He encourages [the radio] audience to become aware."

"The only regret I have is that it took me so long to get involved in this wonderful organization," Ski said when accepting his award.

The Dalton Daily Citizen of Dalton, GA was also recognized for Outstanding Media Professionalism. Accepting the award was Rachel Brown, on behalf of the newspaper's executive editor,

Jimmy Espy and Victor Miller, city editor. staff writer and author of the article 'People with disabilities stress need for aid.' "This was one of my first articles after I started at the paper," Brown said. "I was so pleased to get out in the community and meet such wonderful people."

Dave Zilles, treasurer of the State Independent Living Council of Georgia, Inc., was applauded for his work in advocacy. "Dave is the best treasurer," Pat Puckett, executive director of SILC, stated. "He is always an enthusiastic participant."

Zilles' history with advocacy began when his son, now 30, was diagnosed with Friedreich's Ataxia at the age of 11. "When Jonathon began looking for his own place, I realized how important independence is for young adults with disabilities," Zilles explained. This is when he learned of the State Independent Living Council.

"I'm so grateful for this honor," Zilles said to the audience. Zilles has been instrumental in introducing Senate Bill 244 which would modify the Georgia Nurse Practice Act so that certified nursing assistants

could complete health maintenance activities normally done by licensed nurses. "The bill passed in the Senate, but not the House," he explained. "We've been working hard since April to develop new legislation for next year."

The evening culminated in recognizing Jill Alexander as the recipient of the C. Anthony Cunningham Council Member of the Year. "My life has been touched by the people who have the fortitude to overcome obstacles in front of them," she said, obviously moved to tears. Alexander leads the Ben Hill-Irwin Navigator Team, serves on Ben Hill County's Project Search team and is a parent trainer for Parent to Parent of Georgia. "It's about changing the way

things are to the way they're supposed to be," Alexander continued, discussing the importance and role of advocacy work.

Those who attended the ceremony also enjoyed the atmosphere of Renaissance Atlanta Downtown Hotel, as well as a silent auction featuring gifts from local shops as well as larger chains. Proceeds from the auction went to benefit People First of Georgia and the Long Road Home planning committee.



"My life has been touched by the people who have the fortitude to overcome obstacles in front of them."

#### Photos:

Top Left – Dave Zilles was honored with Advocacy Appreciation.

Top Middle – Jill Alexander, recipient of the C. Anthony Cunningham Council Member of the Year, is congratulated by Tom Seegmueller.

Top Right – Reporter Rachel Brown accepts an Outstanding Media Professionalism award on behalf of the Dalton Daily Citizen.

Middle – Frank Ski of radio station V103 thanks Tameeka Hunter for his Outstanding Media Professionalism award.



"The only regret I have is that it took me so long to get involved in this wonderful organization."

## **Deinstitutionalization** Major Issue as Funding Tightens Up

s more studies become available about people with disabilities leaving large congregate settings and developing more person-centered, individualized and community-based lives, the same stories keep emerging. With increases in independence being a continual theme.

Those, at least, are the summarized findings of David Mank in an August 2009 article written for the ArcLink. Mank is the Director of the Indiana Institute on Disability and Community and Professor at Indiana University.

The trend toward deinstitutionalization is spreading nationwide. "Over 20 state institutions for people with developmental disabilities have closed since 1995...at least four other states have fewer than 300 people with mental disabilities in state institutions," Mank reported.

Shelly Simmons, chair of Georgia's Statewide Independent Living Council, concurs. "We are really trying to push for the Community Choice Act which will allow for the money to follow the person," she explained. "That's just a small slice of the CCA. Unfortunately, we still have a waiting list that doesn't allow enough people to come

> out of nursing homes or institutions. Seventy-six percent of Medicaid dollars are going toward nursing homes and institutions. If we could get to 50 percent, that would be a plus."

The Community Choice Act is federal legislation that is for the development of a community-based alternative to nursing homes and institutions. This bill would also plan for the money to follow the person (rather than remain in one certain program and/or in a certain state), and allow people to choose how they receive services.

Robert Stack, president and CEO of Community Options, Inc. has put hard numbers to that equation on a national level. "If they took 50 percent of the people residing in the institutions the average cost savings would be over a billion dollars. And an equal amount would be saved by the states." Community Options, Inc. is a national organization based in Maryland that embraces the philosophy of selfdetermination and provides housing, support services and advocacy assistance to empower thousands of people with disabilities.

Andre Cooper of Lilburn is a man who knows first-hand that the system needs changing. Cooper is 40 years old, and was paralyzed in an accident in 2005. He has no family nearby that can help, and currently lives in a nursing home. But, as he points out, there's no need for him to be there. "I'm capable of staying in a hotel or a house or an apartment. I'm able to do pretty much everything [for myself]."

## "It just seems to me that the less you're able to take care of yourself, the more they are willing to help."

He knows it costs a great deal of money for him to remain in the nursing home, and he's also well aware it would cost less for him to be out on his own. "If Medicaid is willing to help me in a nursing home, why can't they help with an apartment or with some housekeeping?" he asks.

With a dearth of programs in Georgia, it's difficult for Cooper to find help. "It just seems to me that the less you're able to take care of yourself, the more they are willing to help," he says. "If I tell people I can take care of myself, they think I don't need any programs."

Refusing to give up, Cooper – along with many others - echoes Simmons' call to have the money follow the person. The state of Georgia currently

76% of Medicaid dollars are going toward nursing homes and institutions.

## Stimulus Money to go to Public Housing Agencies

### By Carly Sharec

Curious as to what the stimulus money from the American Recovery and Reinvestment Act means to you? You're not the only one.

"It's broken down into Section 8 Housing Choice and Mainstream vouchers, money for capital improvements and then gets into tenant-based rental assistance and HOME funds," Barbara Chandler explained. Chandler is the fair housing manager of Metropolitan Boston Housing Partnership in Massachusetts.

- "New" Section 8 These aren't technically new. This program has been around for some time, but \$30 million is now available for voucher assistance. This will allow for 4,000 vouchers – 3,000 for 'Housing Choice' and 1,000 for 'Mainstream.' "The Housing Choice vouchers are for anyone," Chandler said. "Mainstream vouchers are specifically for taking people out of institutions."
- **Public Housing Authorities** \$3 billion in stimulus money is specifically for capital improvements (repair work.) "Some of the housing stock owned by PHAs are 50 to 60 years old," Chandler stated. "This both creates jobs for construction workers, and enables older buildings to be brought up to code and be made more accessible."

• Tenant-Based Rental Assistance and HOME Funds – "These are used for a

wide variety of purposes

 from affordable single-family homes to creating portable rental properties."
Additionally, communities seeking these funds must have a consolidated plan detailing what they will be using funding for.

## "This is why disability advocates must be involved, to ensure that funds go to the proper places."

 Low Income Housing Tax Credits Previously, nonprofits could sell their \$1 million in a tax credit to a for-profit as a win-win situation for all involved however, that system has tanked in the past three years due to the downturn in the housing market. "It's been proposed that the department of housing and urban development now buy those credits for 85 cents to the dollar," Chandler said. "As the government is now involved, this is a significant win for disability advocates." Chandler explained that, as the government now directly purchases the credits, contractors must now adhere to Uniformed Federal Accessibility Standards.

As of August 2009, the state of Georgia has received approximately \$150 million dollars in stimulus funding for housing projects. "Around \$130 million is going to help produce affordable rental housing in our state," explained Don Watt, director of the Office of Special Housing Initiatives at the Georgia Department of Community Affairs. Watt continued to say that the left over approximate \$20 million is for the Homeless Prevention and Rapid Re-Housing Program, which helps to provide short-term assistance to households facing homelessness.

"What can really help people with disabilities is our Neighborhood Stabilization Program," Watt said. "This program can help people who are homeless or in an institution due to a disability afford long term permanent housing support." This program is expected to be available within one year.

"A lot of this is still floating out there – communities are just now in the beginning stages of getting together their applications for funding," Chandler said. Chandler said that advocates should show up at various meetings, including at state housing offices, public housing authorities, city halls and planning departments.

"Let officials know how they should be using the money based on the demographics of the area, including the number of people stuck in institutions and the composition of the waiting lists," Chandler said. "By going to public meetings, your thoughts go into the public record. This helps hold those in power accountable."

has a grant of over \$54 million in federal funds for the Money Follows the Person Initiative (MFP), which is helping to shift Medicaid Long-Term Care from its emphasis on institutional care to home and community-based services. The program began on September 1, 2008 and will run through 2011.

Through August 31 (for the 2009 fiscal year), 91 people with developmental disabilities have transitioned into the communities according to Alice Hogan of the department of community health. "An additional 63 people who are either senior adults or have a physical disability or brain injury have transitioned as well," Hogan confirmed. She continued to explain that they have benchmarks set for each year.

## "By going to public meetings, your thoughts go into the public record. This helps hold those in power accountable."

As far as a more permanent solution that lasts beyond 2011, disability advocates remain hopeful. "We're trying to get a lot of our senators and representatives on board to hopefully make a change. Georgia was the state where the Olmstead Act was enacted, but Georgia's at the bottom of the list when it comes to actually allowing people to live in a community. We should be leading and in the forefront and we're actually behind. So we have a lot of catching up to do," Simmons emphasized.

# PERSPECTIVES

## AARP Fighting For Health Care Reform, Says Premiums Will Climb Higher Without

By Kathy Floyd



Kathy Floyd is the associate state director for advocacy for AARP Georgia. She currently coordinates AARP's campaigns in Georgia on issues including health and long term care, economic issues and consumer protection issues. Floyd holds a masters degree in business with a concentration in finance from Georgia State University. The woman placed her hand on my arm and asked with fear in her voice, "Will this health care bill really keep my doctor from treating me?" She was an AARP member who attended AARP's town hall meeting with Congressman David Scott on August 28 in Atlanta. I assured her that the AARP staff have read every word and nothing in the proposals would prevent her from choosing the best possible care.

Unfortunately, her concern is not uncommon or accidental. Opponents of health care reform have targeted seniors with ads and viral email campaigns. Seniors take it very much to heart because they interact a lot with the health care system and they want to make sure that their Medicare works for them.

AARP is in this fight for health care reform to guarantee Americans a choice of dependable, affordable health insurance – along with a doctor who will work to make the best possible treatment choices. AARP pledges to help you find the facts about what health care reform means for you and your family.

Health care reform will preserve the employerbased health care system, meaning an estimated 175 million Americans will continue to get their coverage through their employers.

"If we do nothing, the cost of the average employer-sponsored health insurance plan for a family will reach an estimated \$24,000 by 2016."

AARP has not yet endorsed one of the health reform bills, but AARP has worked hard to ensure that both the House and Senate health reform bills include provisions to close the Medicare Part D "doughnut hole" over time, eliminate Medicare co-payments and deductibles for preventive care like cancer screenings and increase doctors' reimbursements.

AARP also supports provisions that would stop insurers from denying coverage based on preexisting conditions, ban lifetime insurance benefit caps, and eliminate other discriminatory practices that allow the private insurance market to ration the health care of Americans today.

If these scare tactics win and Congress does not pass comprehensive reform then premiums will only climb higher and higher, benefits will have to be cut, choices will be taken away and the numbers of the uninsured will grow by millions – with those ages 50 to 64 taking the greatest hits.

If we do nothing, the cost of the average employer-sponsored health insurance plan for families will reach an estimated \$24,000 by 2016. That's only seven years from now. At that cost, how many businesses do you think will continue coverage for their employees? And, at that cost, if families had to pay for coverage on their own, at least half of all households would need almost half of their incomes to buy health insurance. How many families do you think will be able to afford it? Could you?

Failing to address the problems in our health system will, over time, become the largest threat to your doctor and your health plan. In fact, the surest way to get rationed and "assembly line" health care in America that nobody wants is if we don't pass health care reform and keep on our present course.

Older Georgians need health reform now and AARP is working to make sure they get it.

# How does the health care debate affect our elderly and young?

## Georgia's Children Affected by Health Care Changes

By Joann Yoon

There are no do-overs for childhood. So, what does this mean in terms of health reform? It means we have to take a critical look at our flawed system and implement changes that will work for all of us, especially kids. Within the majority of conversations about health reform, there is little mention of how children will be impacted. Accordingly, as a statewide non-profit, non-partisan policy and advocacy organization that cares deeply about kids, Voices for Georgia's Children has made it a priority to speak out on behalf of children. We want to bring to light the dire reality of many

children in our state and to ensure that children are considered and valued as decisions are made about health reform.

Because health reform is currently a moving target, VGC has adopted a core set of principles we want to see incorporated within health reform. The four principles are:

- Do no harm to children
- Insure all children
- Cover children from head to toe
- Invest in child health quality improvement initiatives

While all four principles address health needs and concerns of children, two particularly are relevant for children with a developmental disability – insuring all children and covering children from head to toe.

Currently about nine million children in the United States are uninsured, 307,000 of whom live right here in Georgia. In a 2008 report published by Families USA, Georgia ranked fifth in the nation for the greatest number of uninsured children. This is particularly alarming since research shows that children who are uninsured are ten times less likely than insured children to receive the care they need, including developmental screenings and preventative health care. Without these screenings and regular visits to the doctor, children are less likely to receive an appropriate diagnosis and needed treatment.

In terms of covering children from head to toe, we must acknowledge that children are not just "little adults," but that they are unique in their health needs as they develop and grow. Physical development and cognitive, socialemotional development are linked during childhood,

"Currently about nine million children in the United States are uninsured, 307,000 of whom live right here in Georgia." making attention to all aspects of a child's health crucial for overall healthy development. For children with developmental disabilities, timely screenings are essential and interventions must be specifically tailored. Health reform efforts therefore must ensure comprehensive coverage to meet the unique health needs of children.

To predict what the future of Georgia will look like, the best indicator is to look at our children. If we want to maximize the overall physical, emotional, and economic health of our state tomorrow, we need to invest in the health of our children today. As our government examines changes to our health care delivery system, we must insist that our legislators specifically consider how children will be impacted.

Since we lack the "luxury" of do-overs for childhood, we have only one chance to ensure that our children grow up to be healthy and productive adults.

(For more in-depth information on the principles and for advocacy tools, visit our web site at www.georgiavoices.org).



As Child Policy Specialist for Voices for Georgia's Children, Joann Yoon focuses on analysis, outreach and advocacy specific to the issue of children's health. In addition, she supports the health aspects of VGC's early childhood and juvenile justice agendas. Yoon has represented VGC by providing testimony before state legislators, and also advocates for the health policy agenda in public forums and discussions before various audiences.



## Outlook for Employment Opportunities Looks Brighter

Perla Rodriguez is one of the lucky few who have found employment during this recession. "I love my job," she said. "I feel very lucky."

Rodriguez is a successful product of Project Search, a program that seeks to place citizens living with disabilities in job positions that use the person's unique talents and skills.

A self-described "people person," Rodriguez has found a home in the emergency room at Northeast Georgia Medical Center in Gainesville. "I'm responsible for stocking the rooms and taking vital signs of patients." In fact, Rodriguez often takes the temperature and blood pressure of those who visit the ER, and then logs the information into a computer for her fellow health care professionals to refer to during treatment and diagnosis.

June Fletcher is Rodriguez's mentor in her field. "Perla has been an

asset to our

department," she said. "She takes pride in her job, and is willing to learn."

Rodriguez is also trained in placing and taking out IV lines for patients. "My favorite part of my job, though, is transporting the patients," she says. "I love talking to them, and helping reassure them."

As for the future, Rodriguez isn't exactly sure what's in store. "I've seen how the nurses are able to work closely with the patients, and I think I would like to do that." As it is, Rodriguez has been at this particular job for a few months, and looks forward to continuing for some time to come. "I love learning new things, and I like coming in every day."

"She is caring and compassionate, and will be successful in the medical field," Fletcher summed up. "I fully do expect her to accomplish all of her goals - she's a very driven young woman!"

It is tough to find a job in this current economy – but people living with disabilities know all too well the difficulties that lay in finding and keeping a job. Programs like Project Search, Employment For All and Star Choices have been primarily successful in their missions to find employment for those with disabilities who are perfectly willing and able to work. But even as organizations such as the U.S. Department of Labor's Office of Disability Employment Policy (ODEP) and the more local Project Search continue to make significant headway in ensuring accessible and discrimination-free workplaces, many disability advocates believe there is still much work to do.

"I wouldn't say much has changed over the past few years," said Wade Stooksbury of Star Choices, a non-profit organization based in Macon that provides community-based support for people with disabilities. Consisting of three teams, Star Choices hosts the "New Horizons" team which works to match employee skills with employer needs.

"There is still a lot of initial pushback," Stooksbury continued. "The good news is that once relationships are built with employers, they truly see the benefits of including people with disabilities in their workforce."

Perla (right) with one of her "ER Angels" – June Fletcher, her mentor in the emergency room at Northeast Georgia Medical Center.



In August 2009, ODEP reported that the labor force was made up of only 22.2 percent of people with disabilities (down from 23 percent in July), with an unemployment rate of 16.9 percent among Americans with disabilities (as opposed to 9.3 percent for persons without disabilities.) Both numbers are startling high. "The current economy has shown signs of strengthening, but it is still very weak," said Norciva Shumpert of Employment For All. "EFA was developed by a small group of colleagues to assist persons with disabilities and prospective employers to develop what is needed for consistent employment," Shumpert explained.

"The good news is that once relationships are built with employers, they truly see the benefits of including people with disabilities in their workforce."

Dennis Puckett of Macon can confirm the difficulty that comes from job hunting - he has held several jobs in the past, but never had much luck in maintaining employment. "Finding a job wasn't really the problem. I needed more hours," he explained. "[Some employers] did not have the hours, while some just did not want to give me the hours." Luckily, Puckett found employment as a dishwasher via Aramark, a food service program, at Mercer University, where he has been employed for a little over a year.

"I love my job," he said enthusiastically. But while Puckett is confident in his skills now, it isn't easy to forget the difficulties in finding an employer that could accommodate both his needs and his desire to work longer hours. "It wasn't easy, but I feel very lucky now."

"We're hoping Dennis will be able to retire from this position," Stooksbury said. "His supervisors, Erin Tudzin and Mandy Gendron, have been fabulous with him, and he gets along very well with his coworkers." "Disability advocates should be both consistent in getting across their message that people with disabilities are just as willing and able to be valued members of the workforce as their non-disabled counterparts," Shumpert continued. "However, we need to also remember that the workforce is weak in general now. This is a great time for those seeking employment to build their skills and develop key relationships."

Shumpert, along with several other resources, offer the following advice when seeking employment:

#### Further Your Education.

If you're currently unemployed or are only employed part-time, this is a good time to go back to school – whether you opt to get a degree or simply take a few classes. "Several schools offer financial aid," explained Shumpert. "Additionally, low-interest loans are available through certain programs." Shumpert also pointed out that free or inexpensive classes and lectures that local libraries and museums may host from time to time also count. Above: Darrell McGhee is best known for being the "face" of Intercontinental Hotels Group as the company's receptionist. "They're very conscious of possible problems I might have, but fortunately I don't have that many," McGhee said about his accessibility needs.

Darrell was featured in the Fall 2008 issue of Making a Difference.

Disability advocates should be both consistent in getting across their message that people with disabilities are just as willing and able to be valued members of the workforce as their non-disabled counterparts.

#### Volunteer.

"This is something that is recommended to everyone! Not only is volunteering great for your community, but you can also build skills that appeal to employers." For example, an animal lover might want to become involved with the local animal shelter. Shumpert also advised that volunteering can help establish a routine and provide an easier transition into the workforce for some people.



## FEATURE

#### Network.

Asking around at your school, in your family, among your circle of friends and in your place of worship can all lead to a job offer. "It never hurts to ask," Stooksbury said. "And seriously, by letting people know that you are actively seeking employment, as well as to what needs you have that must be accommodated along with your expectations of the workforce can help place you in a position that satisfies both you and your employer."

Employees with disabilities seeking work are also encouraged to work on their interviewing skills and techniques. "The interview is a key process for not just the potential employee – this is the chance the employer has to ask questions and help determine how to make his or her office as accessible as possible," Shumpert said.

"We must remember that in good economic times and bad, people with disabilities have fewer opportunities than those without disabilities – a reality that stands in stark contrast to America's ideals," states Kathleen Martinez, assistant secretary of ODEP.

However, opportunities are growing. There are several resources available to people with disabilities seeking employment, with several provided by ODEP, including the Job Accommodation Network (JAN). JAN is a free consulting service which provides individualized workplace solutions for accomodations, as well as education on how and when self-employment can be a better option.

We must remember that in good economic times and bad, people with disabilities have fewer opportunities than those without disabilities – a reality that stands in stark contrast to America's ideals.

> While several of ODEP's programs address the needs of both employee and employer, EARN Works specifically assists employers in their recruitment efforts of workers with disabilities.

The real challenges still must be faced, including how disability advocates must change the opinions of several employers. "We're making



Perla Rodriguez loves her job in the emergency room at Northeast Georgia Medical Center.

headway," said Colleen Pirkle of Project Search. "As part of Project Search we set up potential employees with mentors who provide the proper training to transition into the workplace. There has definitely been a shift in the attitudes of several employers, especially when it comes to the thoughts of accommodations."

"It is no longer considered unusual that people with disabilities are in the workplace," said Stooksbury. "I do think attitudes have changed over the years – now we're placing more of an emphasis on accessibility issues as well as financial aid to both employers and employees. Making certain accommodations can be an expense."

Martinez agrees. "We need to move away from thinking that we're accommodating 'special needs,' and begin to think that we're accommodating people," she began. "Inclusive work environments have been shown to lead to higher productivity and more satisifed workers. Once employers begin looking at these numbers and realizing that it is very cost-effective to bring in accommodations, I think that is when we will notice the unemployment numbers for people with disabilities dropping."

To that effect, employers have access to certain incentives when beginning the hiring process or a person (or persons) with a disability, including tax incentives such as the Small Business Tax Credit, the Work Opportunity Tax Credit and the Architectural/ Transportation Tax Deduction. For example, a small business with a revenue of under \$1 million and at or under 30 employees can receive a tax deduction to expand architecture, while a business of any size can receive up to a \$15 thousand tax deduction (down from a previous \$35 thousand tax deduction in the 1990s) for the removal of any constructional barriers.

There are also tax credits for employees, including the Earned Income Tax Credit (EITC) which is for people who earn a very limited income (ranging from \$13,440 to \$48,279 in 2009 – maximum income is dependent on marital status and whether or not the filer has children.) The recent American Recovery & Reinvestment Act of 2009 (ARRA) provides a temporary increase in the credit for filers with three or more qualifying children, with the maximum credit now being \$5,657.

In tax year 2007, nearly 4.5 million tax returns were filed in the state of Georgia – with close to one million receiving the EITC. According to the IRS Web site, an estimated 20 to 25 percent of Americans qualify for the credit but do not apply.

"We need to move away from thinking that we're accommodating 'special needs,' and begin to think that we're accommodating people."

Hiring people with disabilities is both financially savvy – and also affects the bottom lines of businesses in positive ways. Those who work to place people in satisfying employment situations are confident that the situation will improve – as are those who are currently in successful jobs.

"I have always felt very welcomed," said Rodriguez when asked about her position at the hospital. "June [Fletcher, Rodriguez's mentor] has always been helpful."

"I could not have asked for a better job," said Brooks. "I really love the college atmosphere and am please to be in a place where I can work when I want and for how long I want."

## Martinez Named Head of ODEP



The United States Senate recently confirmed Kathleen Martinez as the Assistant Secretary for Disability Employment Policy (ODEP) on June 25, 2009. Martinez succeeds Neil Romano as the third person to fill this role since it was created in 2001.

Her goal for her position is to "create good jobs for everybody...as people with disabilities continue to enter the workforce, people will see us as a 'normal or average' part of the workday," Martinez stated. "As that fear of the unknown is reduced, attitudes are changed and people become more aware of accommodations."

Martinez is a well-known name among the international disability community, having been appointed executive director of the World Institute on Disability in 2005, where she was responsible for leading Proyecto Visión (designed to increase the employment opportunities for Latinos with disabilities in the U.S.), Access to Assets (an asset-building project to help reduce poverty among people with disabilities) and the team that produced the acclaimed webzine *DisabilityWorld*.

"As a Latina person, I feel welcome when I go into a place where the information is also offered in Spanish," Martinez said. "As someone who is blind, I feel welcome when I go to a place that offers their information in Braille. When people see themselves reflected, they feel welcome." Martinez explained that her goal in making the world an accessible place is simply to make the world accessible to everyone.

#### Her goal for her position is to "create good jobs for everybody...as people with disabilities continue to enter the workforce, people will see us as a 'normal or average' part of the workday."

"Look at ramps!" she continued. "Everyone uses ramps now – families with small children, movers, delivery men – ramps are now an accepted part of our reality. It's the same as big-button phones. They once could only be found at specialty stores, but now can be found very easily."

Martinez is also a member of the board of the U.S. Institute of Peace, a Congressionally created agency dedicated to research and projects in conflict management. She was also appointed by former President George W. Bush as one of 15 members of the National Council on Disability, an independent federal agency advising the president and congress on disability policy.

In her position with ODEP, Martinez advises the secretary of labor and works with all department of labor agencies to lead a comprehensive and coordinated national policy regarding the employment of people with disabilities.

"ODEP has done a lot to establish the baseline with policy," Martinez said. "We've developed quite a few strategies and support mechanisms. There's a lot of good information available. We always want to continue raising the bar, but I'm proud to be a part of ODEF now, and look forward to the work that will be accomplished."

## Fall Line-up Stacked with Advocacy Events

A Difference Discovery Day has, in recent years, been about opportunities and accommodations in the workplace with a focus on educating businesses about reliable, qualified job seekers living with disabilities in Georgia. This year's 9th annual Discovery Day, planned for early December, will take a different, yet equally important, track to advance the mission of building partnerships and collaborations to positively impact community life for people with disabilities and their families.

"The theme this year is on accessible travel and tourism," explained Valerie Meadows Suber, public information director and Discovery Day project coordinator for the Georgia Council on Developmental Disabilities.

Major collaborators for Discovery Day 2009 with the Georgia Council on Developmental Disabilities are G3ict (the global initiative for inclusive communications technologies) and Hartsfield-Jackson Atlanta International Airport. "We are very excited about new relationships we have been able to form around the recognition that people with disabilities want to travel for pleasure and business," Suber said.

As home to the busiest airport in the United States and a bustling convention business, Atlanta is the perfect backdrop for such a conversation. Axel Leblois, president of G3ict, which is in collaboration with GCDD for this year's Discovery Day, expressed his enthusiasm for the upcoming event.

"G3ict is all about improving the lives of people with disabilities by making technology accessible," explained Leblois. "We've always looked at Atlanta as a city that has great potential with its resources and positive attributes."

By Carly Sharec

But why tourism? Why travel? "Americans with disabilities spend on average \$14 billion a year!" Leblois stated. "That's a huge chunk of the industry. In Georgia, tourism is the second largest industry. Visitors spend an estimated \$25 billion annually!"

### "Georgia really has an opportunity to be a leader in disability advocacy in travel and tourism."

The half-day executive, invitation-only seminar will focus not only on the tourism industry, but also on government officials and disability organizations. "We want to reach many," Leblois said. "The more people who are aware, the better." Program committee members include Hartsfield-Jackson Atlanta International Airport, InterContinental Hotels Group and MARTA. "These are groups that make up the Georgia Alliance for Accessible Technologies that G3ict has set up," Leblois continued. GAAT is an innovative regional collaborative effort of multi-stakeholders, including local government, private and public sectors, disabled persons organizations, and academic and research institutions that are dedicated to exploring the field of accessible travel and tourism.

GCDD executive director, Eric Jacobson, expects a positive outcome. "Georgia really has an opportunity to be a leader in disability advocacy in travel and tourism," he stated. "We want to ensure that all destinations are available to anyone, regardless of ability. Discovery Day will be a great way to bring everyone together in a

In Georgia, TOURISM is the second largest industry. Visitors spend an estimated \$25 BILLION ANNUALLY!



"Disability advocates have more than football to look forward to this season."

Above: Georgia's Chief Operating Officer, Jim Lientz (second from right) appeared at 2009's Discovery Day on behalf of Governor Sonny Perdue. Above Right:Neil Romano, former assistant secretary of the Office of Disability Employment Policy, was the keynote speaker of Discovery Day '08.

spirit of camaraderie, and to emphasize our commitments in making the world an accessible place."

For more information on Discovery Day, interested parties are asked to visit www.gcdd.org, or to contact Suber at vmsuber@dhr.state.ga.us.

Another major event taking place in Atlanta from October 10 through 15 is the ADAPT National Action Week. Linda Pogue of disABILITY Link explained how the major goal of ADAPT is to raise awareness of the Community Choice Act. "There will be a march and a rally focusing on two or three key issues, but the main issue is the Community Choice Act." The CCA is a bill that plans for community-based alternatives to nursing homes and institutions. The hope is that the CCA will be a part of the current health care reform discussion, and will be a part of the final bill if passed and signed into effect.

"The event is basically a great way for people to figure out what can help enrich their lives without them having to make a commitment."

"ADAPT fights for access to services along with housing that is both affordable and decent," Pogue continued. A report of the ADAPT National Action Week will be included in the Winter 2010 issue of *Making a Difference* magazine. Rounding out the major events taking place in Atlanta before 2010 is the Abilities Expo, taking place from November 6 through 8 at the Cobb Galleria Convention Center in Atlanta.

"For nearly 30 years, Abilities Expo has worked to improve the lives of American with disabilities, along with their families and caregivers," explained Kevaleen Lara, public relations coordinator for Abilities Expo.

A variety of seminars along with a vast exhibition hall will help keep disability advocates informed as to what is available for accessibility issues. Topics planned to be covered range from how to make your computer as accessible as possible to figuring out what the best mobility device is for you. "The event is basically a great way for people to figure out what can help enrich their lives without them having to make a commitment," said Lara.

The Atlanta ambassadors for the Abilities Expo are Marquetta Bell Johnson, an artist, and Mark

Johnson, M.Ed., the director of advocacy at the Shepherd Center. "Marquetta and Mark are the ones that will help represent the Expo to the Atlanta community," Lara said. "They're very strong advocates, and we couldn't be more pleased that they're our representatives for Atlanta."

Admission is free, and the conference is expected to attract thousands. The Expo has also taken place in New York, Los Angeles and Chicago, with great success.

The line up of these three advocacy events are expected to keep Atlanta hopping this autumn. "Disability advocates have more than football to look forward to this season," Suber said.



Discovery Day Date TBA Atlanta, GA

### ADAPT National Action Week October 10 - 15 Atlanta

Abilities Expo November 6 - 8

Cobb Galleria Convention Center Atlanta



A panel of disability advocates and recognized experts present to the crowd at Discovery Day '08.

## Accessible Georgia: Plan a 'Staycation' With Some Helpful Advice

Fishing is a favorite pastime of several visitors to James H. "Sloppy" Floyd State Park. (right)

The Tallulah Gorge State Park's suspension bridge is accessible to all, but not for the faint of heart! (below) decided to explore a local park or simply go see a movie. Once you've imagined your ideal vacation spot, imagine that you can't get to it. That's the reality

magine: Just a few feet away is

your ideal vacation location. Is it

L a beach, with waves rippling onto

the shore and the sun gently beating

with scenic hikes? Or you may have

down? Or is it a mountain setting,

that up to one million Georgians face when planning a vacation in state. "Georgia is both a popular destination spot for tourists, and also

allows residents to be able to stay close to home and explore," explained Peggy Smith from the state's tourism department. "This is why it's important for popular locations

throughout the state to be sure that they are serving the needs of all visitors."

The Georgia State Parks and Historic Sites system works diligently to make parks and the state's historic locations accessible to all. "All state lodges have accessible rooms, meeting facilities and restaurants," said Kim Hatcher of the Georgia Department of Natural Resources. "The majority of parks with these areas also have accessible campgrounds, picnic areas and trails.

> "We are encouraging of people calling ahead to discuss any requirements they may need accommodated," Hatcher continued. All parks with campgrounds and cottages have at least one that is ADA-compliant. "Accessible campgrounds are close to a restroom, and offer flat, wheelchair-friendly trails leading up to the site," Hatcher explained.

She also said that all parks with cottages or hotels have ADA-compliant rooms available. "Of course, all new facilities are accessible and ADA-compliant," she said. "But with some of our older locations, it can be a struggle sometimes."

Hatcher is referring to the many historic buildings in Georgia that the DNR is responsible for in addition to the parks. "There's only so much you can do with historic buildings," she explained. "We are always working to maintain the structural integrity of the building to preserve it for future generations, but in some locations not everyone can view the entire site."

David Burke, a wheelchair user and interpretive ranger at Roosevelt's Little White House in Warm Springs, agrees. "I've never been up into our guest quarters and servant quarters because they're upstairs!" he chuckled. "You can't just put an elevator in a historic building. But we have several films and photos to share which greatly enhance the experience." Burke also explained that the recently built museum was designed with accessibility in mind, beginning in the parking lot and lasting all the way through the exhibits and into the gift shop.

"The funny thing is that at the president's cottage, it was built with President Franklin D. Roosevelt's wheelchair use in mind," Burke said. "His house was ADA-compliant years before the act went into effect!"

#### "Whether you're planning a vacation or a simple day trip, traveling is always much more fun when you plan ahead."

Other major attractions throughout Georgia are committed to not only accessibility, but enhancing the experience of all guests. One such place is the Georgia Aquarium in Atlanta. "We're always looking for ways to make the aquarium a better experience for everyone who comes through," said Elizabeth Williams of the aquarium's public relations department. For example, the large touch pool at the entrance of the



Photos courtesy of the Georgia Department of Natural Resources.



Photos courtesy of the Georgia Aquarium.

Cold Water Quest gallery has a ramp leading up to it for guests in wheelchairs.

"As we particularly have a lot of school groups coming The Georgia Aquarium is working to serve as a model for accessibility. A popular diving and snorkeling program at the Aquarium is available to all guests – just watch out for the whale sharks1

through, we offer a picture book via our Web site for parents and teachers to download," Williams said. "This helps prepare children with autism for a visit." Williams explained that adults with autism may find it helpful as well.

The aquarium is also home to the famous "dive" program, where guests have the opportunity to scuba dive (if certified) or snorkel with the whale sharks, a popular attraction. The aquarium's Web site states that the entire Dive Immersion Team is certified by the Handicapped Scuba Association.

"The funny thing is that at the president's cottage, it was built with President Franklin D. Roosevelt's wheelchair use in mind...his house was ADA-compliant years before the act went into effect!"

For other travel options in the state of Georgia, the Georgia Travel Guide offers a list of locations that are accessible and ADA-compliant. The guide can be viewed online, ordered for free from the Web site or found at any of the several tourist welcome centers throughout the state.

The main point to remember for any trip is to plan ahead. "Whether you're planning a vacation or a simple day trip, traveling is always much more fun when you plan ahead," Smith pointed out. "Calling ahead and looking at their Web site is going to provide an ease of mind for both you and the staff at the location as you both can plan together how to make your trip a success."

## Top Georgia Attractions

by Carly Sharec • (provided by Yahoo!® Travel)

Needing to stay close to home, but wanting to get out of the house? Check out some of the top-rated tourist attractions as voted upon by Yahoo!<sup>®</sup> users. How do they report their levels of accessibility?

**BONAVENTURE CEMETERY** - Located in Savannah, this cemetery was made famous in the 1994 novel and 1997 movie, *Midnight in the Garden of Good & Evil*. With few steps and flat surfaces, the cemetery is surprisingly accessible – though often crowded with tourists.

MARTIN LUTHER KING, JR. NATIONAL HISTORIC SITE (www.nps.gov/malu) - As part of the National Park Service, visitors who need special accommodations are encouraged to call beforehand to discuss how to have an enjoyable trip.

**CENTENNIAL OLYMPIC PARK** (www.CentennialPark.com) -The 'All Children's Playground' is designed for children of all capabilities.

ATLANTA BOTANICAL GARDENS (www.AtlantaBotanicalGarden. org) - With nearly all areas accessible, Atlanta Botanical Gardens offers wheelchairs on a first-come, first-serve basis. Electric mobility scooters are also available for rent.

STONE MOUNTAIN STATE PARK (www.StoneMountainPark.com) - There is limited accessibility to certain buildings (including the Antebellum Plantation and Farmyard), but guests can enter the Confederate Hall Historical Environmental & Education Center with ease. Several dining and lodging options are available as well.

**PIEDMONT PARK** (www.PiedmontPark.org) - Beginning in May 2009, visitors with disabilities now have access to the park's Aquatic Center, which features ramps and wheelchair lifts.

**ZOO ATLANTA** (www.ZooAtlanta.org) - Wheelchairs are available for a modest rental fee. However, a recent report in the Atlanta Journal-Constitution cited the parking at Zoo Atlanta and the Cyclorama & Civil War Museum as non-ADA compliant.

**GEORGIA STATE CAPITOL** (www.sos.georgia.gov) - The building itself is basically accessible - parking is available on Mitchell Street, and most legislative committee rooms are accessible. Guests with sight or hearing impairments can schedule tours by contacting the Capitol Guide Service at 404.656.2844.

JULIETTE GORDON LOW BIRTHPLACE - The home of Juliette Gordon Low, the founder of the Girl Scouts of the USA program, offers elevator accessibility. Special tours can be planned for guests with sight or hearing impairments. As an interesting side note, Gordon Low had a significant hearing impairment for much of her life, and welcomed all young girls with disabilities into the fledgling Girl Scout program at a time when exclusion was the norm.

**TYBEE ISLAND LIGHTHOUSE** (www.TybeeLighthouse.org) - Renovations completed in the late 1990s and early 2000s have helped make this historical site open to all - due to the nature of the buildings, not all areas are convenient for guests in wheelchairs.



Dr. Garland is the deputy commissioner for developmental disabilities for the Department of Behavioral Health and Developmental Disabilities.

## Much Has Been Done, Much Left To Do

By Dr. Olivia Garland, Deputy Commissioner for Developmental Disabilities

'm excited to be in Georgia with such a dedicated and accomplished community of advocates, providers and policy makers. You have been steadily turning the state's system of care from one that lags into one that leads by implementing the Supports Intensity Scale, transitioning people to communities through the Olmstead and Money Follows the Person Initiatives, becoming a system that supports self-determination, and implementing a statewide Quality Assurance Initiative.

As a mother of a child who is severely and profoundly disabled, I am particularly appreciative of the many families who have consistently spoken out for change on behalf of their loved ...all who set policy ones. Before my daughter was born, and provide services must I only understood developmental be held accountable. disabilities at an intellectual level, but my daughter's situation This accountability must helped me understand the needs, be seen in words, deeds, gaps in services and the need data and results. for advocacy at a personal level. This experience has given me a deep personal connection that broadens my perspective about advocacy and the treatment of individuals - not populations. My goal as deputy commissioner is to manage the agency to make it more results-oriented, to insist on excellent services,

to be responsive and also to connect our staff more with the community – with individuals, providers, families and hospitals. Our job is to make sure that all Georgians with developmental disabilities who look to us for services are able to have a satisfying life.

There is still much to be done in Georgia. The new Comprehensive and New Options Waivers moves

the system forward by providing the opportunity for individualized, flexible, community-based services. Of immediate concern, however, are any barriers that are delaying immediate access to services. I've also observed that more training is needed to fully realize the potential of self-direction. I'm acutely aware of the need to resolve issues related to payment of employees who are hired by families to support individuals with disabilities.

Our long-term focus will be eliminating the waiting list for Medicaid waivers. We will restore and expand the number of individuals who can choose to live in the community, in their own homes,

with their families or with others who support their independence and self-determination. Although some people with developmental disabilities may need the care afforded by hospitals, we must continue to move people back into communities with the appropriate supports.

Finally, we must be able to validate our philosophy and our support programs with real data – not anecdotes and emotions. This means

all who set policy and provide services must be held accountable. This accountability must be seen in words, deeds, data and results. What we do is necessary, valuable and impressive. Since this is so, we must capture in tangible ways all that each of us contributes to the success of our complex system.

I am grateful to be in charge of a division where, with few exceptions, the staff I have inherited are capable and dedicated people who share a common commitment to quality service.

## "Our job is to make sure that all Georgians with developmental disabilities who look to us for services are able to have a satisfying life."

# StraightTalk

## Get Rid of the Institutional Bias

By Bob Habas

was paralyzed from the neck down 30 years ago in a diving accident. From that point on, I ended up relying on others for assistance in my daily life. After time at both St. Joseph's Hospital and the Shepherd Spinal Center, I went home where I was taken care of by my mom. I spent the next few years in and out of hospitals, but I was always able to go back home. In 1984, my mom died.

In hindsight, my dad seemed more concerned about my safety than about my quality of life and, eventually, he decided to put me in a nursing home. I was able to block this event only for about one month. I was allowed to pick which nursing home to enter.

"I immediately realized that I had to get out of that place, or I would die. Nursing homes are frustrating places. The staff wasn't necessarily unkind, but they knew absolutely nothing about MY needs."

I immediately realized that I had to get out of that place, or I would die. Nursing homes are frustrating places. The staff knew absolutely nothing about my needs. If I had not previously gone through the Shepherd Center to learn about my bodily needs, they could have killed me with their incompetence.

I spent eight years in that nursing home, and over time I developed into a strong self-advocate. I constantly wrote letters and made phone calls to my legislators expressing my desire to live in a community. In 1992, the Independent Care Waiver Program was established and I was able to move into my apartment. I was scared at first, and really worried about whether or not my help would show up. Luckily, everything went as expected.

The way I see things is that we are all going to face something similar in the future, whether it's through an accident like mine or simply going through the aging process. I firmly believe that everybody should have a choice where they live.

This is why it's important to include the Community Choice Act in any health care reform plan. This would be a national program that could make a huge difference. Community supports have made a huge difference in the way I am able to live my life. I got an education from Savannah State College. After various jobs, I've finally found a place of employment that I love at LIFE Inc. as nursing home transition leader.

What sense does it make to keep someone locked up in a nursing home? First and foremost, it costs more. Living there is a depravation of life. At best you are surviving. I will continue to advocate for many changes, but most importantly, I will advocate to eliminate the institutional bias for those with disabilities.

#### "What sense does it make to keep someone locked up in a nursing home?"

Tell everyone you know about the Community Choice Act, and your thoughts on the health care reform. Tell your friends, people you go to church with, your coworkers and family members. Contact your representatives. If health care reform is pushed through, this could be our last chance in a while to have our voices heard. Make sure your voice is part of the discussion.



Bob Habas resides in Savannah and is a coordinator for Living Independence for Everyone, Inc.

Tell everyone you know about the Community Choice Act, and your thoughts on the health care reform.



## MIA'S SPACE

## Mia Moves Out!

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

n August 5, several friends and siblings helped Mia move into big, bright sunny rooms in a house with Laura and Joe Whitaker and their toddler, Owen.

I had to look back over the various *Mia* columns that I have written to revisit how we got here. At one DD Council meeting, where housing experts shared the options available to people with disabilities, Mia raised her hand and said she wanted her own apartment, with her own refrigerator and food, her own bed and desk, computer and TV, and – this she said with great emphasis and determination – "my own keys." Then followed a couple of years of jobs and no jobs, sleep apnea and weight gain,

and frustration on my part at not having the stamina or time to interrupt her cycles in any concerted way. I also feared that with continuing years of waiting for enough funding to support her independently and a minimal work schedule, she would become entrenched in habits impossible to break. I always felt that she would rise to the occasion if we changed her environment, like she has so many

changed her environment, like she has so many times before, and develop some more maturity and ownership of her life. I was encouraged in my gut feelings by other moms I have met along the way, who, despite significant trepidation and doubt, moved adult children with DD out into new lives, and told me without hesitation to just do it! "It's the best thing we ever did!" I was told.

We got a circle of support around her consisting of friends from Athens and colleagues from Atlanta who know how to get stuff done and who know Mia



personally. But the gift of her new life was realized by just asking. I knew the Whitakers were looking for a new place to live, and they have known Mia for many years. I just asked if they would consider having her live with them. And they said yes! Following a few weeks of logistics, SIS, budget and training to get the details worked out, we were good to go.

Mia has everything she mentioned in her statement at the DD Council meeting in the home she shares with Joe, Laura and Owen. She goes to bed every night by 11 PM and wears the CPAP machine, thanks to an incentive and positive reinforcement program Laura has set up. She prepares some of her meals, and

e prepares some of her meats, and



eats some family-style with them. She joined the YMCA and swims 20 laps twice a week, and still bowls and works in a Sunday school class. She goes to a gym with Fabersha, her direct support professional, and walks in the neighborhood with Laura and Owen, who adore her. She's still working at the AMAC. She sees a nutritionist at Athens Regional once a month and goes to Weight Watchers.

She's lost 15 pounds in the last three weeks. Her brother got her hooked up to Skype, and she can talk to him and her sister online, and she also uses email. She calls twice a day just full of news.

She finally has her own keys, but they are not exactly like she expected. She has her own garage door opener, which gives her access to her entryway. On the doorknob hangs a sign that says, "Mia's Space."

Following a few weeks of logistics, SIS, budget and training to get the details worked out, we were good to go.

CALENDAR



## **OCTOBER**

October 10 - 15 ADAPT National Action Week Atlanta, GA

October 15 - 16 GCDD Quarterly Meeting Macon, GA

#### October 23

Georgia State Law School Olmstead Symposium Atlanta, GA *law.gsu.edu/lawreview/index/ symposium* 

#### October 24 Learning Disabilities Association of Georgia Conference 2009 Atlanta, GA www.ldag.org

### October 25

Spin For Kids Rutledge, GA 770.234.9111 www.focus-ga.org

October 28 - 30 Rising to the Challenge! NACDD Annual Conference Albuquerque, NM 202.506.5813 www.nacdd.org

October 29 2009 Deaf Extreme Transition Conference Athens, GA www.PEPNet.org

## NOVEMBER

November 6 - 8 Abilities Expo Atlanta, GA 310.450.8831, ext 130 www.AbilitiesExpo.com

November 14 Association of Late-Deafened Adults 10th Anniversary Celebration ryvang@mymailstation.com

November 19 Faith, Family and Mental Health at Peachtree Presbyterian Church Atlanta, GA 404.842.5800

## DECEMBER

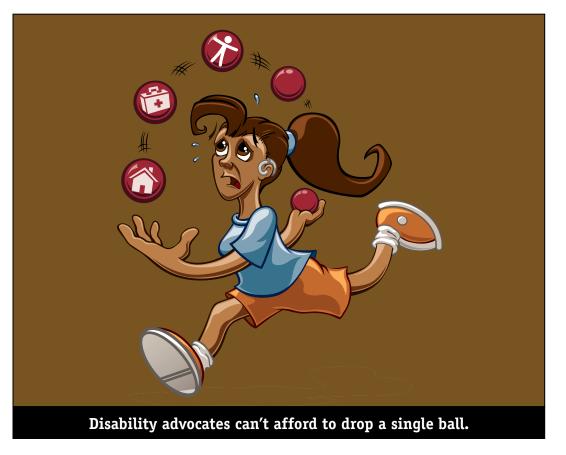
December 5 Special Time with Santa (for children with autism) Suwanee, GA 770.904.4474 www.asaqa.com

#### Date TBA

**Discovery Day** 

**Atlanta, GA** 404.657.2122 *www.GCDD.org* 

December 9 - 11 Perspectives on Employment of Persons with Disabilities Conference Bethesda, MD 202.314.4701 www.dol.gov/odep



## 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 November 30, 2009 for inclusion in the Winter 2010 issue of *Making a Difference*.



## RESOURCES



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/02/ ltgovhome/0,2214,2199618,00. html 404-656-5030

pg. 12

## Deinstitutionalization

Georgia Stimulus Accountability stimulusaccountability.ga.gov

Arc Link www.TheArcLink.org 812.323.0626

Statewide Independent Living Council of Georgia 770.807.8654

Community Options, Inc. www.ComOp.org 609.951.9900

Metropolitan Boston Housing Partnership www.mbhp.org 617.859.0400



## Health Care 101

Missouri Health Advocacy Alliance www.mohealthalliance.org 573.634.9800

The Arc of the United States www.thearc.org 202.783.2229

American Association of People with Disabilities www.AAPD.com 202.457.0046 800.840.8844

National Association of State Directors of Developmental Disabilities Services www.nasdds.org 706.683.4202

Health Insurance Reform www.HealthReform.gov



## Accessible Georgia

Georgia Tourism and Travel www.ExploreGeorgia.org 1.800.VISIT.GA (1.800.847.4842)

Georgia State Parks & Historic Sites www.gastateparks.org 1.800.864.7275

Georgia Aquarium www.GeorgiaAquarium.org

## **Discovery** Day

G3ICT – The Global Initiative for Inclusive ICTs www.g3ict.com

Abilities Expo www.AbilitiesExpo.com

disABILITY Link www.disabilitylink.org 404.687.8890 (Decatur) 706.314.0009 (Rome)

#### ADAPT

www.adapt.org 303.733.9324 (Denver) 512.442.0252 (Texas)





# Thanks to OUR SPONSORS for their Support.

If you are interested in being a sponsor for Making a Difference magazine, please call Kim Shapland @ 770.578.9765.

### Developmental Disabilities Services Tools for Independence

- Residential: Highly individualized community support 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.
- Transition Program: Life skills development.

770.677.9345 TFI@jfcs-atlanta.org www.YourToolsForIndependence.org JF&CS is a proud partner of the Jewish Federation of Greater Atlanta and the United Way of Metropolitan Atlanta.







Georgia's Parent Training and Information Center (PTI)

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

> The Babies Can't Wait Central Directory

Georgia's Family Voices



thanks thanks thanks than than thanks thanks



Georgia Council on Developmental Disabilities 2 Peachtree Street, NW, Suite 26-246 Atlanta, GA 30303-3142 404-657-2126, www.gcdd.org

Address Service Requested



The quarterly magazine of the Georgia Council on Developmental Disabilities

Volume 10, Issue 2 • Fall 2009

## Time Saved is Time Earned.



As a caregiver, you have to master the art of saving time. So, why run all over town to find the right size and brand of items like diapers, pull ups and wipes? Call ProMed. We can typically deliver the personal care products you need right to your door, the very next day.

Call us toll-free for a catalog and free samples. **877.516.4582** 



ProMed Professional Medical Fulfillment • www.ProMedPersonalCare.com