

MAKING **a** DIFFERENCE

REAL HOMES. REAL CAREERS. REAL LEARNING. REAL INFLUENCE. REAL SUPPORTS.



**NEWS
FOR YOU:**

DISABILITY DAY: Over 2,000 rally on the Capitol Steps

LEGISLATIVE UPDATE: 2012 General Assembly

MANAGED CARE: What is it and what could it mean for you?

On the Cover:

Leading advocates join At Disability Day: (L-R) Marian Jackson, People First of Georgia President; Margo Waters, disABILITY LINK Independent Living Coordinator; Lois Curtis, Folk Artist, Olmstead Plaintiff.

MAKING a DIFFERENCE

A quarterly magazine of the Georgia Council on Developmental Disabilities **VOLUME 12, ISSUE 4**

The mission of the Georgia Council on Developmental Disabilities is to collaborate with Georgia citizens, public and private advocacy organizations and policymakers to positively influence public policies that enhance the quality of life for people with developmental disabilities and their families. GCDD provides collaboration through information and advocacy activities, program implementation and funding and public policy analysis and research.



Tom Seegmueller
Chairperson

tmseegmueller@gmail.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

Becca Bauer

becca@oneillcommunications.com

Chantelle Catania
Design & Layout

Disability Day

2,000 advocates unite as one community at the 14th Annual Disability Day 8

Legislative Update

A reflection on the progress made in the 2012 General Assembly 12

Managed Care in Georgia

A breakdown of the options, concerns and direction of managed care 18

FEATURES DEPARTMENTS

GCDD Viewpoint

Finding where the real power is 3

Guest Article

Governor Deal's speech at Disability Day 4

News

An update on events in the disability community and voter registration 5

Around GCDD

GCDD Council members attend the Georgia Winter Institute and GCDD sponsors Disability Day 6

Perspectives

2012 Disability Day award winners 16

Expert Update

Interview with the Department of Community Health commissioner 23

Mia's Space

A Mother-Daughter Road Trip 25

Real Communities Initiative

GCDD's Real Communities Initiatives continue to expand and develop 26

Straight Talk

Disability Day Through Our Eyes 28

Calendar 29

Resources 30

Cartoon & Sponsors 31

Correction: In the winter 2012 issue of *Making a Difference*, we regretfully misspelled our Expert Update author's name. Her name is Elizabeth Labbe-Webb.



ERIC E. JACOBSON



TOM SEEGMUELLER

Let's Find Where the Real Power Is

We have made it through another legislative session and our hard work continues. With each session, we celebrate people with disabilities, their family members, providers, supporters and advocates at Disability Day at the Capitol. This year, 2,000 people stood in the rain chanting, yelling and yes, there were even a few boos. The point is we stood as a community, representing every part of Georgia and making our presence known to legislators, policymakers and the media. We let them know it's important that every Georgian needs to have a Real Life.

The legislative session started out full of promise. We believed it was possible to pass legislation creating Individual Development Accounts (IDAs) and basic access in new homes. Additionally, we hoped to get new funds to increase the number of people receiving services and supports, but it did not quite turn out the way we hoped or expected. The expansion of home and community-based services received a few new dollars and a lot of discussion on the insufficient rates providers receive, but there was no legislation for the IDAs and basic access in new homes. However, there was legislation passed supporting the expansion of accessible taxi cabs throughout Georgia. The General Assembly also supported making Vocational Rehabilitation services a standalone agency attached to the Department of Human Services and included the principles of Employment First in the discussion. Finally, there was no legislation focused on redesigning Medicaid to support a managed care structure, but many people were involved in providing public comments and working with the Department of Community Health to examine possibilities that meet everyone's needs.

Now we turn our attention to election season! On July 31, Georgians will vote on the Transportation Investment Act (TIA), a 1% transportation sales tax in 12 separate regions throughout the State. We believe supporting the sales tax works toward creating opportunities to make transportation accessible to every Georgian. In November, we will go to the polls to vote on local, state and national issues. We encourage you to register to vote and then go VOTE! Throughout the elections, make sure you ask the candidates and their supporters, "What are we doing as a community, state and nation to make sure people with disabilities have the same opportunities for a Real Life as others?" Make that just as much a priority as other issues we hear about on television or the radio.

Finally, isn't it time we have the really tough discussions about whether Medicaid and other state and federal programs will ever be robust enough to support everyone with the services and supports they need? The greatest resources are in our local communities among the people, associations and businesses where we live, work, play and worship. We need to have coffee with our neighbors, co-workers and family members to talk about what is really great in our community and how we can make it even better for everyone including people with disabilities and others who have found themselves marginalized. We think this is where the real power is.

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

Eric E. Jacobson
Eric E. Jacobson
Executive Director, GCDD

Tom Seegmueller
Tom Seegmueller
Chairperson, GCDD

Tell us your thoughts about the magazine or what topics you would like to see addressed by emailing us at vmsuber@dhr.state.ga.us, subject line:

Letters To The Editor.

GCDD VIEWPOINT

How to Reach Us

Letters to the Editor

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

Contact Our Editor and Public Information Director:

Valerie Meadows Suber
vmsuber@dhr.state.ga.us
P: 404.657.2122
F: 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 gcdd.org.

Subscriptions / Back Issues:

Visit us at our website: 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.

Deal Takes Action in the Disability Community

The following is an excerpt of Governor Deal's Disability Day speech from February 16, 2012.

GUEST ARTICLE

I am proud to be with you here today on the 14th Annual Disability Day at the Capitol. For all of those of you who are supporting the communities across our State, I know that your work carries with it great rewards, and I want to thank you. Your service, advocacy and hard work help ensure that more Georgians with disabilities have the opportunity to live independent, healthy and productive lives.

I believe we share a common mission, and we are in the process of making major changes to improve developmental disabilities care in Georgia. Our Department of Behavioral Health and Developmental Disabilities is currently transitioning from an institutional care model to active community-based treatment. With a new department focused solely on behavioral health and developmental disabilities, we are putting in place strategies and tools that empower these individuals to become integrated in our communities and live safe, active lives.

Our team is hard at work expanding resources including waivers to move individuals with developmental disabilities out of our hospitals; waivers to care for those currently living in the community and to increase family support. We are strengthening our networks of crisis care with mobile crisis teams and crisis respite homes, while focusing on providing immediate, high quality and person-centered care.

After hearing from many of you and our Federal partners, we are taking decisive action and are proposing legislation that will make Vocational Rehabilitation attached

to the Department of Human Services, but act as an independent program. This will give new priority to our work and help ensure we are using funds efficiently and taking advantage of all outside assistance. Even more than budgeting prioritization and efficiency, this action will help better serve Georgia's disability community.

Our Department of Behavioral Health and Developmental Disabilities is currently transitioning from an institutional care model to active community-based treatment.

We have a broad-based plan to improve care for Georgians, and going forward, we will need your sustained support and ask for your continued partnership. Thank you for your input and together we have the opportunity for success in our State.

Nathan Deal, *Governor of Georgia*



“We are strengthening our networks of crisis care with mobile crisis teams and crisis respite homes, while focusing on providing immediate, high quality and person-centered care.”

Abilities Expo 2012

IN THE NEWS

The Abilities Expo was held February 17-19, 2012 at the Georgia World Congress Center in Atlanta, GA and the Georgia Council on Developmental Disabilities (GCDD) was one of many sponsors.

For more than three decades, Abilities Expo has improved the lives of Americans with disabilities, their families, caregivers and healthcare professionals. This unique forum has become one of the leading events for the community of people with disabilities. The three-day event featured the latest cutting-edge technologies, products and services and compelling workshops led by prominent figures in the community who addressed a wide range of pressing issues affecting the disability community. Topics included everything from finance and fitness to dating. There were also fun events for children, adults and seniors such as adaptive sports, dance performances, crafts, assistance dog demos and more.

Georgia Winter Institute 2012

The Georgia Winter Institute, where person-centered planning meets community building, was held January 8-11, 2012 at the Forrest Hills Mountain Resort & Conference Center in Dahlonega, GA. The event brought together people from across Georgia and beyond to discover how to infuse value-based, person-centered philosophies into community-building efforts. Attendees heard from leaders in the community such as John O'Brien, Connie Lyle O'Brien, Bruce Anderson, Tom Kohler, De'amon Harges, Mark Crenshaw, Jessie Coleman, Charles Hopkins and many more.

The Georgia Winter Institute also explored strategies for sharing stories of successes and dreams from community members, as well as encouraged commitments to sponsor community readings of *Waddie Welcome and the Beloved Community*. This is a story of friendships transcended divisions of disability, race and income to get Waddie Welcome out of a nursing facility and bring him back home to Savannah.

This four-day annual event was sponsored by the Center for Leadership in Disability, the Georgia Council on Developmental Disabilities, the Georgia Advocacy Office and the Arc of Georgia.



Register to vote by July 2, 2012

in order to vote on the Transportation Investment Act (TIA), which will on the ballot on July 31, 2012. The TIA will allow for a 1% regional sales tax that will increase transportation options for all Georgians. The Georgia Council on Developmental Disabilities (GCDD) and other organizations have worked statewide on this effort to ensure that people with disabilities have more transportation options, better access to those transportation options and information on how to access them. For more information on voter registration, visit <http://sos.georgia.gov/elections/vrinfo.htm> and for more information on the TIA, visit <http://connectgeorgia2012.com/>.

GCDD Council Members Attend the 2012 Georgia Winter Institute

The annual Georgia Winter Institute was held January 8-11, 2012 in Dahlonega, GA. This four-day event brought together people from across the State and beyond to learn, share, grow and work toward advancing the lives of people with disabilities through person-centered planning and community building. This year several of GCDD's Council members attended the event and share about their positive experiences.

Jamie Cahill My overall impression of the conference was positive and grateful. I was thankful to have the opportunity to meet and attend with many diverse people from all over the State and country who gathered together here to study, brainstorm and collaborate on how we can improve the lives of individuals with disabilities. I arrived with my aide, Patricia, from Jamaica. She had no clue what a "Conference Retreat" was. Everyone was so friendly to her, and neither of us felt awkward or uncomfortable about sitting at different tables with new people at each session, lunch, dinner or other activities. My favorite activity was the night featuring a hayride, a blue-grass band, wine tasting and the Alabama/LSU Championship football game. I wanted to watch the game and Patricia wanted to participate in the other activities (with people who had been total strangers 48 hours earlier), so we split up. After the game, I went to get Patricia and it was so heart-warming to see people of ALL ages, shapes, sizes, backgrounds, colors and disabilities up on the stage laughing and dancing together while the band was blaring "Sweet Home Alabama."

When we were getting ready to leave, a beautiful young Korean woman introduced herself to me as the pastor of a Korean church in Atlanta and asked if I would come talk to her congregation about how God loves people with disabilities and how special they are to Him and the world. I told her it would be my pleasure.



Dorothy Harris This was my first time attending the Georgia Winter Institute. I think this event was encouraging, inspiring and interesting. The educational information was great, and it was a good opportunity to meet new people and learn new things.



"...it was so heart-warming to see people of ALL ages, shapes, sizes, backgrounds, colors and disabilities up on the stage laughing and dancing together while the band was blaring "Sweet Home Alabama."





14th Annual Disability Day at the Capitol *My Life is FOR REAL*

Disability Day is an annual rally sponsored by the Georgia Council on Developmental Disabilities (GCDD) on the steps of the State Capitol to promote access, opportunity and meaningful community living for Georgians with disabilities and their families.

My Life is FOR REAL, the theme for this year’s rally, means that people with disabilities should have the same opportunities as others to have a meaningful life and contribute to the communities where they live, learn, work, play and worship. It also means that individuals who need support should have access to quality home and community-based services.

Despite rainy weather on February 16, advocates from across the State arrived to kick off the event at the nearby Georgia Freight Depot, where Disability Day supporters enjoyed breakfast, collected their t-shirts, added their names to the 2012 Disability Day signature banner and created signs to make their voices heard and seen during the rally.

The pre-rally event also featured voter registration, information on the Transportation Investment Act (a 1% sales tax on the ballot in July), signing of the Children’s Freedom Initiative declaration to move children out of nursing facilities and a look into the many sponsors who contributed to the success of Disability Day including a preview of the Abilities Expo.

GCDD also showed screenings of their public awareness video series, “Voices Beyond the Mirror,” which was created to commemorate the 40th anniversary of the Developmental Disabilities Bill of Rights Act and offers a thoughtful look into the everyday realities of people living with different types of disabilities.

After rallying at the Capitol, supporters returned to the Freight Depot to gather with other advocates, their families, friends and State legislators to share a catered lunch by Subway and reflect on the day.

For more information on the 14th Annual Disability Day, please read the full article on page 8.





14th Annual Disability Day at the Capitol

By Carmel Garvin Hearn



“I want these kids to have a great life and be in their loving homes with their families more than anything.”



The Georgia Council on Developmental Disabilities (GCDD) Annual Disability Day has been held at the Georgia Capitol on a day in February for the past 13 years. In recent times, the event has fallen on a beautiful day with fair weather and clear blue skies. This was not one of those days.

As February 16, 2012 dawned, a steady drizzle blanketed the Atlanta area. But the weather seemed to have little effect on the 2,000 advocates at this 14th Annual Disability Day. In spite of the weather, they came together and were strong in their mission to have their voices heard by legislators meeting under the Gold Dome.

Disability Day supporters made their way from across town and across the State. Several travelled solo, while others arrived in groups, accompanied by caregivers and advocates.

They first massed at the Georgia Railroad Freight Depot (a restored 1870s building on the Capitol Hill Complex) to make signs to display at the rally and sign the Children’s Freedom Initiative, a declaration affirming a child’s right to live in a permanent, loving home.

“I want these kids to have a great life and be in their loving homes with their families more than anything,” said Lyndzi Vaughn, co-president of the Partnerships for Success student club at Hall County’s Flowery Branch High School. “They should not be in nursing homes at all. That’s wrong and not a way to treat your loved ones.”

Vaughn, along with Co-President Joseph Martinez and another member of the club, Nick Dyson, would later introduce Disability Day’s keynote speaker, also from Hall County, Governor Nathan Deal.

“It’s an amazing relationship,” said Martinez of his fellow group members including some with and others without disabilities. “We all love one another and help each other out in different ways. If they’re in need of something, then we’re there for them always.”

“It’s fun to be with my friends,” affirmed Haley Hickman, another member of the club. “We usually play games. On Thursday we sell ice cream.”

The advocates made their way from the Depot shortly before 11 AM, marching, rolling walkers, steering wheelchairs or maneuvering canes through puddles and a light rain to the Capitol building. As the rally began, chants rang from the crowd in unity.



Making the World A Better Place

Georgia’s disability community has become a powerful voice. But, according to Mark Perriello, guest speaker for the 14th Annual Disability Day, Georgia’s disability advocates can become even more powerful.

“We can’t be satisfied with the status quo,” explained Perriello. “The time has come for more of us to run for and win elected office. The time has come for us to make sure we have a seat at the policymaking table whether it’s here in Georgia or in state capitols across the country.”

Perriello, who is president and CEO of the American Association of People with Disabilities (AAPD) in Washington, DC says that running for elected office as a person with a disability is the same as running for office like anyone else.

“Ultimately we’re all qualified for these jobs,” he remarked. “We know the issues and we know what it takes to make America succeed. It’s about taking that leap of faith.”

Perriello suggested the best way to get started is to volunteer on a campaign. “You can see what it takes to raise the money, knock on doors, make phone calls and turn people out on Election Day. It’s a great place for people to learn and work in general. Those fortunate to have their candidate win office often end up in the decision-making seats. Being part of a campaign is an important avenue into the corridors of power.”

Citing AAPD as the nation’s largest cross disability membership organization, fighting every day in Washington, DC to make the world a better place through good policy for people with disabilities, Perrillo encouraged those who may be interested in running for office or joining a campaign to contact the organization. For more information, please visit www.aapd.com.

“Real choice, real communities.”

“Unlock the waiting lists!”

“My life is for real.”

“Nothing about us without us.”

“For 14 years, Georgia’s Disability Movement has gained momentum, thanks to the families, advocates and people with disabilities who care enough to come from across the State and join together as one united voice on Disability Day,” said GCDD Executive Director Eric E. Jacobson opening the rally.

Jacobson was pleased to announce that Georgia’s governor and the top executive for the American Association of People with Disabilities (AAPD) in Washington, DC were among the dignitaries who addressed the large crowd assembled there to ensure that disability should be on everyone’s agenda.

“For 14 years, Georgia’s Disability Movement has gained momentum, thanks to the families, advocates and people with disabilities who care enough to come from across the State and join together as one united voice on Disability Day.”

“Real choice, real communities. That is what it is all about,” said Mark Perriello, president and CEO of the AAPD, as he addressed the assembly. “That is why we’re here today. It is about equality; it is about freedom and it is about the choices we all have as Americans to live our lives how we see fit and where we see fit. We are here today telling our elected officials that our voices need to be heard and that together we are stronger and more powerful as a community. It is so amazing to see all of you here today making sure that message is heard.”



Perriello pointed out that there are more than 50 million people with disabilities in the US, making Georgia's disability advocates part of a potentially powerful national voice.

The power of taking action and engaging lawmakers was not lost on this crowd. Several lawmakers addressed the group including Governor Nathan Deal himself.

"Our team is hard at work expanding resources including waivers to move individuals with developmental disabilities out of our hospitals; waivers to care for those currently living in the community and to increase family support," said Deal. "We are strengthening our networks of crisis care with mobile crisis teams and crisis respite homes, while focusing on providing immediate, high quality and person-centered care."

The rally is the one of the largest opportunities for the disability community to communicate important issues and needs to legislators. Other policymakers in attendance included Rep. Carl Rogers (R-Dist 26), Sen. John Albers (R-Dist 56) and Rep. Sharon Beasley-Teague (D-Dist 65).

"We need to support our communities, and the disability community is one I have supported in my 20 years in the General Assembly," said Beasley-Teague. "We need to do more and help those with disabilities so they can have a whole life and get around in their communities."

"When you don't come and share your needs and represent yourself, you will be forgotten," said Rogers in a nod to the huge turnout at the rally. "I tell folks, if you think somebody is representing you at the State or US Capitol but you haven't been involved, you are probably wrong. You have to show your presence and be engaged."

The rally was also a chance to acknowledge fallen heroes, as well as present outstanding advocacy leaders with awards for their hard work. Dr. Gerald Durley, recognized civil rights leader and pastor of the historic Providence Missionary Baptist Church of Atlanta, honored advocates who had recently passed away by reading the names of 48 of those he called "fallen soldiers" in the battle for disability rights.

Additionally, Margo Waters, disABILITY LINK independent living coordinator, was honored with the Georgia Outstanding Self-Advocate of the Year Award – In Loving Memory of Natalie Norwood Tumlin; and Joseph D. Frazier, Metro Fair Housing Services, Inc. president, was recognized with the Samuel Mitchell Lifetime Achievement Award.

"I tell folks, if you think somebody is representing you at the State or US Capitol but you haven't been involved, you are probably wrong. You have to show your presence and be engaged."

Jacobson and GCDD Chair Tom Seegmueller led the rally program, which provided an update on the status of legislation (*see article on pg. 12*) and addresses a number of public policy priorities, including:

- The Unlock The Waiting Lists! Campaign calling for funding of community-based services for over 6,000 persons on waiting lists for vital supports
- Transportation Investment Act (TIA) Referendum
- Children's Freedom Initiative
- Proposals to help people receive the supports they need to live and thrive in the community.

"I think today's activities were amazing. Even with the rain, the street was packed. People were engaged," Jacobson reflected as he made his way back to the Freight Depot with the crowd following the rally. "The message for Disability Day is that you can't forget the people with disabilities and many of us need supports in order to live life like everybody else. That message was clear from the chants and the speakers. That message went right into the halls of the legislature."

"We need to do more and help those with disabilities so they can have a whole life and get around in their communities."



“It was great to have the Governor here giving his message in person,” Seegmueller added. “The Governor has been listening to what people have to say and there are going to be some changes coming that should work well for Georgians with disabilities, particularly as we look for ways to provide services as efficiently as possible and ensure those services get where they’re needed.”

GCDD’s Disability Day at the Capitol was made possible by a host of partnering organizations and volunteers from the disability community, but also drew the attention of those advocating for other issues that could affect not only the disability community but also all Georgians. To see a complete list of the 2012 Disability Day sponsors, visit <http://www.gcdd.org/calendar/month.calendar/2012/04/05/- .html>

“We’re here advocating for the Family Care Act,” said Harriet Bradley of Atlanta, enjoying her first Disability Day. Bradley represents 9to5, the National Association of Working Women. “We are here to advocate

for anyone who has existing paid sick days to use them to take care of immediate family members that could include a child or parent.”

“This day means a lot for everyone who has a disability, not just me,” said Kelsey Ustrud, attending her first Disability Day with a group from the Disability Resource Center in Gainesville. “I’m excited to be a part of it.”

After the rally, you could feel a sense of elation and hope from the crowd. The rain had stopped and clouds were beginning to lift, but the energy was based on something greater than the improving weather. For most, it was a short walk back. For many, it would be a long ride home, but for all, the journey forward would continue to be difficult, yet full of possibilities.



“We are here to advocate for anyone who has existing paid sick days to use them to take care of immediate family members that could include a child or parent.”

“THE MESSAGE FOR DISABILITY DAY

is that you can’t forget the people with disabilities and many of us need supports in order to live life like everybody else.”

Children’s Freedom Initiative

The Children’s Freedom Initiative (CFI) is a collaborative effort to ensure that children who live in facilities are given the chance to live with permanent, loving families. At the 14th Annual Disability Day, hundreds of attendees signed the CFI’s “Declaration of a Child’s Right to Live in a Permanent, Loving Home” petition, which states:

We, the undersigned, believe that all children have the right to grow up in permanent, loving homes. We believe that all children can thrive in the community with the appropriate supports and encouragement. Additionally, children have a right to be treated with dignity and respect. We

believe that no child should be subjected to segregation and congregation under the guise of treatment services. Children should not grow up in institutions or nursing facilities.

Therefore: *To safeguard the right that all children have to grow up in their communities, all Georgia children should be free from institutionalization and shall be afforded the supports to grow up in permanent, loving homes.*

The CFI involves a coalition of advocates dedicated to creating a Georgia in which no child resides in a facility and plans to reach this goal through legislation, litigation,

coalition-building, telling children’s stories, elevating the issue and requesting resource allocation in the budgets of various departments. The group is supported by the Georgia Developmental Disabilities Network, which receives funding from the Administration on Developmental Disabilities, and includes the Georgia Council on Developmental Disabilities (GCDD), the Institute on Human Development and Disability at the University of Georgia (IHDD), the Georgia Advocacy Office (GAO), and the Center for Leadership in Disability at Georgia State University (CLD). To sign the CFI, please visit www.gcdd.org/cfi-declaration/petitions/declarations/cfi-declaration.html



Reflecting on the 2012 General Assembly

By Pat Nobbie, Ph.D.

As predicted, the legislative session was quick compared to previous years, ending before April Fool's Day. *Sine Die* is tomorrow. The FY 2013 budget has been agreed upon, but a few controversial legislative items remain to be settled.

A Little Bit of Improvement

An improved economy gave the chairs of appropriations an additional \$900 million to spend, which resulted in a total budget of \$19,224,524,133. As a result, funds were added back to bolster several areas including education, public health, residency slots for physicians to keep new doctors in Georgia, criminal justice reforms and accountability courts, the DOJ settlement, more pre-k days and cancer research funding at the new Georgia Health Sciences University. On another positive note, the Governor was able to keep the AAA Bond Rating, and add to the "Rainy Day" fund. Compared to what we have faced in past years, this is a small measure of relief.

The Unlock the Waiting Lists! campaign had an ambitious agenda that went beyond the requirements of the settlement agreement, and we were only successful in getting an additional 50 slots in the Independent Care Waiver Program for adults with physical disabilities. However, we may achieve more of our requests in the amended FY 2013 budget as a result of the Balancing Incentive Payment Program funds (BIPP). The BIPP is a federal initiative that authorizes grants to states that have spent less than 50% of

their long-term services in the home and community as opposed to in facility-based services. States wanting to make adjustments to that balance are eligible for an extra 2% federal match for Medicaid funding provided by the BIPP to help transform their long-term care systems. The BIPP application requires states to implement three structural guidelines including:

- No wrong door/single point of entry system, which enables individuals to gain access to all long-term services through a single point where they will receive information and financial and functional assessment for eligibility
- "Conflict-free" case management to develop individual service plans and arrange for and conduct ongoing monitoring of services
- A core standardized assessment instrument to be used to determine eligibility and appropriate services

The program makes \$3 billion available to states over three years. The Georgia Department of Community Health (DCH) submitted an application in early March, and the BIPP will give Georgia an additional \$19,086,355 each year for the next three years. These funds must be used specifically



The Unlock the Waiting Lists! campaign had an ambitious agenda that went beyond the requirements of the settlement agreement, and we were only successful in getting an additional 50 slots in the Independent Care Waiver Program for adults with physical disabilities.

for home and community-based services. The proposal also lists enhanced funding for all waivers, the Georgia Pediatric Program (GAPP), mental health community-based services and training and enhancements for the Aging and Disability Resource Connection (ADRC), so they can function effectively as the single point of entry.

The following items are listed within the adult developmental disabilities services budget in the FY 2013 budget:

Provide funding for developmental disabilities consumers' community settings to comply with the DOJ settlement agreement:

Total: \$4,216,000

This includes

Family Support \$1,466,000

9 crisis respite homes,

6 mobile crisis teams \$2,300,000

The \$1,466,000 figure reflects the average, actual costs of family supports delivered in the past fiscal year to 500 families.

Provide for additional 150 COMP waivers and annualize the cost of 100 NOW and COMP waivers from FY 2012 (community waiver): .. \$5,290,181

Use the Balancing Incentive Payment Program for an additional 100 NOW and COMP waivers in the community: YES

Use the Balancing Incentive Payment Program to annualize the cost of 150 FY 2012 COMP waivers: YES

Use the Balancing Incentive Payment Program to annualize the cost of NOW and COMP waivers for youth aging out of the Division of Family and Children Services (DFCS), Department of Human Services: YES

Increase funds for the Emory Autism Center: \$100,000

Increase funds for the Matthew Reardon Center for Autism: \$100,000

In DCH budget, provide funds for 50 Independent Care Waiver Program (ICWP) waiver slots:

State: \$810,101

Federal: \$2,362,499

In addition, language was added to the FY 2012 amended budget and the FY 2013 budget stating, "The Department will evaluate criteria for establishing a viable waiting list and report to the General Assembly by June 30th, 2012 with recommendations for maintaining such lists."

Legislative Agenda

Before the 2012 General Assembly got underway, GCDD identified several legislative, budget or public policy issues it would address, support with other groups or watch during the legislative session. The following is an update on the progress made.

Even though it is a small government solution that encourages economic self-sufficiency and doesn't use tax dollars, the IDA account legislation was halted early on in the session.

Individual Development Accounts (IDA):

This legislation enables eligible individuals to save money for assistive technology, accessible vehicles or home modifications that would support them to stay in their homes and work in the community. Individuals save their earned income in a custodial account in a partner bank, and it is matched by nonprofit or foundation funds. Even though it is a small government solution that encourages economic self-sufficiency and doesn't use tax dollars, the IDA account legislation was halted early on in the session. Representative Donna Sheldon has committed sponsorship to the legislation,





so we will work with her and the Governor's office on the IDA accounts before the 2013 General Assembly.

The Family Care Act: This legislation would allow individuals whose jobs provide sick leave to use it to care for sick children or aging parents without penalty from their employers. The passage of this act doesn't require additional sick leave or any other benefits, but it would give individuals with sick leave more flexibility to meet the caregiving needs of their families. Although this legislation was favorably reported out of the House Industrial Relations committee, it did not make it out of House Rules. Therefore, we will continue working on it again over the summer.

Advocates are hopeful we will be able to make progress over the summer building support for this legislation.

New Home Access Legislation: Early in the session, our majority party sponsor had to withdraw support on this legislation, and we were unable to get another sponsor to commit. Currently, there is a lot of momentum centered around the issue of accessible, affordable homes supported by the DOJ settlement needs, the progress being made in the Department of Community Affairs, the Department of Housing and Urban Development and the landmark housing study, "Shut Out, Priced Out, Segregated" (SOPOS) report. Advocates are hopeful we will be able to make progress over the summer building support for this legislation.

Medicaid Appeals Reform: This legislation was pulled from the committee calendar the day it was scheduled to be heard. The Department of Community Health (DCH) had addressed a number of issues in the application, eligibility and appeals process for Medicaid clients, particularly in the Katie

Beckett program. But the concern with this legislation was focused on a particular aspect of the appeals process that gives the Commissioner of DCH the power to overturn the Administrative Law Judge's decision.

Our Watch List: Legislation (HB 386) from the Special Council on Tax Reform and Fairness was released in the second week of March. Special rules on the legislation meant it could be brought back up in committee and sent directly to the House for a vote after day 30 without going through Rules. This was passed in both the House and Senate by day 36. The main components of the bill include:

- Repeal of the marriage penalty in the income tax exemptions
- Exemptions for energy resources used in manufacturing and agricultural exemptions, as well as fuel exemptions to all airlines operating in the State
- Cuts or caps to credits and exclusions for film productions
- New revenues through taxing of e-commerce purchases for businesses that have a physical presence in Georgia
- Revamping taxes collected on automobiles, moving from the "birthday tax" to a 7% tax at point of sale to be shared between the State and local governments
- Capping the tax break for wealthy seniors at \$65,000
- Streamlining tax breaks to maximize effectiveness
- Reinstatement of two sales tax holidays

According to the Special Council, the proposal is budget neutral. However, the Georgia Budget and Policy Institute estimates a loss of \$49 million in the first year. Fortunately, the legislation did not recommend a tax on groceries, while unfortunately, it did not recommend a dollar increase on cigarettes, which could generate \$340 million a year and significantly deter teen smoking. Many still believe that the tax

Fortunately, the legislation did not recommend a tax on groceries, while unfortunately, it did not recommend a dollar increase on cigarettes, which could generate \$340 million a year and significantly deter teen smoking.

This legislation restores child-only policies to the insurance marketplace, so that parents whose children are not eligible for PeachCare or who do not have coverage under their own employers can buy insurance for their children.

code needs comprehensive reform to meet the needs of a growing State.

Vocational Rehabilitation Agency (HB 1146): This bill transfers the services housed under the Department of Labor to a new agency and attaches the Georgia Vocational Rehabilitation Agency to the Department of Human Services for administrative purposes. This change authorizes the transfer of funds and establishes a new governing board. The programs to be transferred include Warm Springs Rehabilitation Hospital, Blind Enterprises program, Georgia Industries for the Blind, Disability Adjudication Unit and Vocational Rehabilitation. Advocates are now focused on ensuring that the new agency establishes an Employment First Policy for the State, which means that employment will be the first option for day services for people with disabilities and that option will be supported through funding streams, policies and program design. There will be a national search for a new Vocational Rehabilitation director.

Juvenile Justice Reform (HB 641): This legislation makes several long-awaited changes to the Juvenile Justice code and was in Senate Rules as of day 38. A large number of stakeholders worked on this legislation for several years, but nothing came of it this session. Advocates will start again with this legislation next year.

Accessible Taxi Cab Legislation (SB 373): This legislation did not get out of the House Rules for a vote on the floor by Sine Die, so it has died and we will have to work on it again over the summer. The accessible taxi legislation amends the Medallion restrictions for taxi cabs. It allows for a cab that is wheelchair accessible to take a fare outside its jurisdiction of origin, pick up a fare

there and return to avoid “dead head” trips. This legislation will encourage current cab operators to include accessible vehicles in their fleets because they can make the service pay.

Child-Only Insurance (HB 1166): When the Affordable Care Act passed, insurers were prohibited from denying coverage to children due to pre-existing conditions and Georgia insurance companies stopped writing policies for children-only. This legislation restores child-only policies to the insurance marketplace, so that parents whose children are not eligible for PeachCare or who do not have coverage under their own employers can buy insurance for their children. This bill was voted on in the Senate on Monday, March 26 and passed.

Although it was short, it was a busy legislative session. While many issues were moved along or gained momentum, there are still several issues that we need to continue promoting and working toward. We urge our advocates and partners to attend their legislators’ election events and impress upon them the need for more community-based services for people with disabilities. This is the second year with only 100 waivers available for youth graduating from high school or middle school-aged individuals with disabilities living with aging caregivers, or anyone else in the community at risk of crisis or institutionalization. We cannot sustain people adequately with so few resources. All legislators need to know the individuals in their communities who are “waiting” for assistance. Remember to SHOW UP, STAND UP and SPEAK UP!

2012 GENERAL ASSEMBLY



The accessible taxi legislation amends the Medallion restrictions for taxi cabs. It allows for a cab that is wheelchair accessible to take a fare outside its jurisdiction of origin, pick up a fare there and return to avoid “dead head” trips.

“The most common way people give up their power is by thinking they don’t have any.”

- Alice Walker

PERSPECTIVES



MARGO
WATERS

Georgia’s Outstanding Self-Advocate of the Year Award

The Georgia Outstanding Self-Advocate of the Year Award was created in loving memory of Natalie Norwood Tumlin, who passed away on October 1, 2005, just shy of 30-years-old. Natalie, who was born with Cerebral palsy and severe speech and physical disabilities, left her mark on the disability community and was a tireless self-advocate throughout her life. She was a strong supporter of People First of Georgia, Georgia Voices That Count and was the inspiration for the creation of the Unlock the Waiting List! Campaign in 1998. To honor her memory, the Tumlin family has created this award to recognize self-advocates who demonstrate leadership qualities and bring self-determination to Georgia. This award is presented annually by the Tumlin family, with assistance from the Georgia Council on Developmental Disabilities and the Unlock the Waiting List! campaign, at Disability Day.

Advocacy is What I Believe In

By Margo Waters

In 1998 my life changed. I was diagnosed with Multiple Sclerosis (MS) and was unable to continue in my job and was without health insurance. Seeking healthcare began my first experience with advocacy. I found an opportunity to participate in a research study, and I felt that I would at least be under doctor’s care. Later after graduating from the advocacy training program at Georgia Voices That Count, funded by the Georgia Council on Developmental Disabilities (GCDD), I officially started my career and became a disability rights advocate in 2004.

Over the past 10 years, I have been very active in advocacy, speaking up for independence and community inclusion issues such as transportation, accessible housing and all other barriers that affect the lives of people with disabilities.

As an Independent Living Coordinator at disABILITY Link, the Center for Independent Living serving the metro Atlanta area, I help people with disabilities embrace independent living through peer support, encouragement and training in skills needed to live independently in the community. I believe I’m a natural advocate at my job, on the bus and even in the grocery store.

Some of my proudest advocacy achievements include fighting against the Medicaid bias so that people with disabilities can live in their own homes and not in institutions or nursing facilities, as well as being active in Georgia ADAPT, a re-formed group of grassroots activists whose goal is to increase membership and advocacy across the State of Georgia.

I want to thank the Tumlin family and those who nominated and selected me for this great honor. I love advocacy work – it is always wonderful to be recognized, but recognition and awards are not the reason I do this work. Independent living is my life and **ADVOCACY** is something I believe in.

I believe I’m a natural advocate at my job, on the bus and even in the grocery store.

Positive, Persistent and Patient

By Joseph D. Frazier

When I was told that I was receiving an award named after Sam Mitchell, I was first shocked. I cannot hold a candle to the ground plowed by the Sam Mitchells of our community, and I feel humbled for having even been considered for this award in his name.

I became a quadriplegic in 1984 due to a 17-foot fall from a ladder onto a concrete patio. I started my disability advocacy before I left my 120-day inpatient stay at Shepherd Center. We patients bonded by our common individual struggles and later by our collective efforts to address the stereotypes, bureaucratic roadblocks and detrimental societal norms that ignore and discount the progress and contributions that people with disabilities have made and can make.

I have spent a total of 28 years attacking isolation and exclusion. The largest problem I see facing the disability community is the negative stereotypes and norms imposed upon us, as well as the unfortunate belief by some of us that perhaps we do not have what it takes to break free and emerge into the new mainstream that we can create.

Probably the biggest hurdle that is a drop-dead deal breaker for empowerment is housing. As a person ages out of their parents' home or other childhood arrangement, they and their advocates must have housing in which to create a home. As president of Metro Fair Housing Services, Inc., and as someone who was forced to live in a one-room hotel room for a year at one point in my life, I am proud to say that I recommended funding to be added to a Fair

Housing law suit settlement to develop what came to be known as the "Shut Out, Priced Out and Segregated" (SOPOS) report.

The report and resulting coalition is a call-to-action organization based on identifying the fundamental need for basic access to housing for all. Out of the same funding, I also produced a video chronicling the impact of accessible housing on two grantees of retrofit money so we captured the essence of "home" and family.

There comes a time when downright anger channeled into reasoned civil disobedience becomes necessary, and I believe the most critical qualities that an advocate (with a disability or within a circle of support) needs include a fearlessness and dogged determination to say no to naysayers and not become a de facto naysayer themselves. My mantra has always been "Positive, Persistent and Patient." Of course balancing these traits or tactics becomes an exercise in timing, self-control and focus – the traits that were embodied in Sam Mitchell, a true advocate.

To view the video produced by Frazier, visit www.youtube.com/watch?v=3tNt9Xqapaw. For more information on the SOPOS report, visit www.metrofairhousing.com/sopos_coalition.htm.

"I have spent a total of 28 years attacking isolation and exclusion."

PERSPECTIVES



JOSEPH
D. FRAZIER

The Samuel Mitchell Lifetime Achievement Award

The Samuel Mitchell Lifetime Achievement Award was created to honor the memory of Samuel Mitchell, an influential self-advocate who passed away August 18, 2008, just before his 58th birthday. As a leader in organizations such as ADAPT, People First of Georgia and Long Road Home, Mitchell continually fought for the rights of all people with disabilities. In order to recognize his memory as a firm and passionate equal and disabilities rights fighter, this award is presented annually at Disability Day by the State Independent Living Center (SILC) with assistance from the Georgia Council on Developmental Disabilities (GCDD).

Managed Care in Georgia Options, Concerns, Direction

By Bill Lewis

Right now, there is a lot of discussion surrounding the issue of managed care. But what actually is it? Managed care is a system of healthcare which organizes doctors, hospitals, insurance companies and other providers into groups with the aim of enhancing the quality and cost-effectiveness of healthcare. The cost of treatment is monitored by a managing company, and the patient relies on a primary care physician to serve as a gatekeeper for them to receive other health services such as specialty medical care, surgery or physical therapy.

Generally, there are three types of managed healthcare plans: PPOs (Preferred Provider Organizations), HMOs (Health Maintenance Organizations) and POS (Point of Service) organizations. You may very well be enrolled in one of these healthcare plans now.

Managed healthcare was at the core of the debate in Congress recently when the Affordable Healthcare for America Act was being discussed. Supporters of the measure believe some form of managed healthcare should be available to everyone, with the government as the fallback guarantor of payment. Its critics argue that this will be a step toward the government being a single-payer source, which they feel is not the best course for American medicine to pursue, fearing among other things, that it may lead to rationed care.

Healthcare vs Social Services

The entire Affordable Healthcare for America Act has yet to be implemented and much

remains to be seen as to how it will affect managed medical care. There is another component to managed care, though, that seldom gets as much attention as healthcare: social services. That includes services needed by the disability community such as finding housing or jobs, creating recreational activities, providing personal care services and others that are not usually part of healthcare and are not typically addressed since they are not needed by the population as a whole as much as general healthcare, which tends to be universal. Generally, managed healthcare organizations don't even have much experience in providing those social services.

Who then provides these vital social services for individuals with disabilities? According to the Georgia Council on Developmental Disabilities' (GCDD) Executive Director Eric Jacobson, "Those kinds of issues have really emerged as a system of service that is provided by Medicaid and other state government services at this point."

Many advocacy groups around the State are weighing in on the situation. As a whole, it's probably safe to say they would all only agree on the idea that while managed care may have some good attributes, any overall proposal must include safeguards for a variety of potential users.

Costs for all managed care continue to rise. And it's primarily because of that reason that the State of Georgia has "decided that they want to look at putting everybody who is categorized as aged, blind or with disabilities into managed care," adds Jacobson. "This also includes children with disabilities."

Reform Initiative by DCH

The Georgia Department of Community Health (DCH) has recently undertaken a reform initiative to investigate the possibility of creating a broad-based managed care program. Some states have put partial managed care programs into place, but Georgia would be the first to bring every service and every eligible person (aged, blind or those with disabilities – adults and children) under a more broad-based, state-planned system.

As you might imagine, there are a lot of emotional and practical considerations involved. Last August, DCH engaged an outside company to investigate current programs in other areas of the country, as well as assess Georgia's existing plans. Now, the Department is in phase two, which is to digest the report and gather input from many other sources. (See page 23 for more information on DCH.)

Broad-based Support Needed

Many advocacy groups around the State are weighing in on the situation. As a whole, it's probably safe to say they would all only agree on the idea that while managed care may have some good attributes, any overall proposal must include safeguards for a variety of potential users.

Jacobson believes there are some good things that can come out of this. But, there are some cautions that need to be out there as

well. "If you look at what other states have at least thought about through a managed care system, the major advantage is that there would not be a waiting list for services. Anybody who is eligible for Medicaid would be required to get the services," he points out.

"Essentially, there would be no waivers. It would all become state-planned services instead of a waiver, and the waiting list would potentially be eliminated for home and community-based services. That's a good thing, as long as there are enough providers who can offer those services," he adds. "In theory, you would be able to increase access and quality to services by eliminating or increasing the number of local providers across the State. But in reality, can that really happen?"

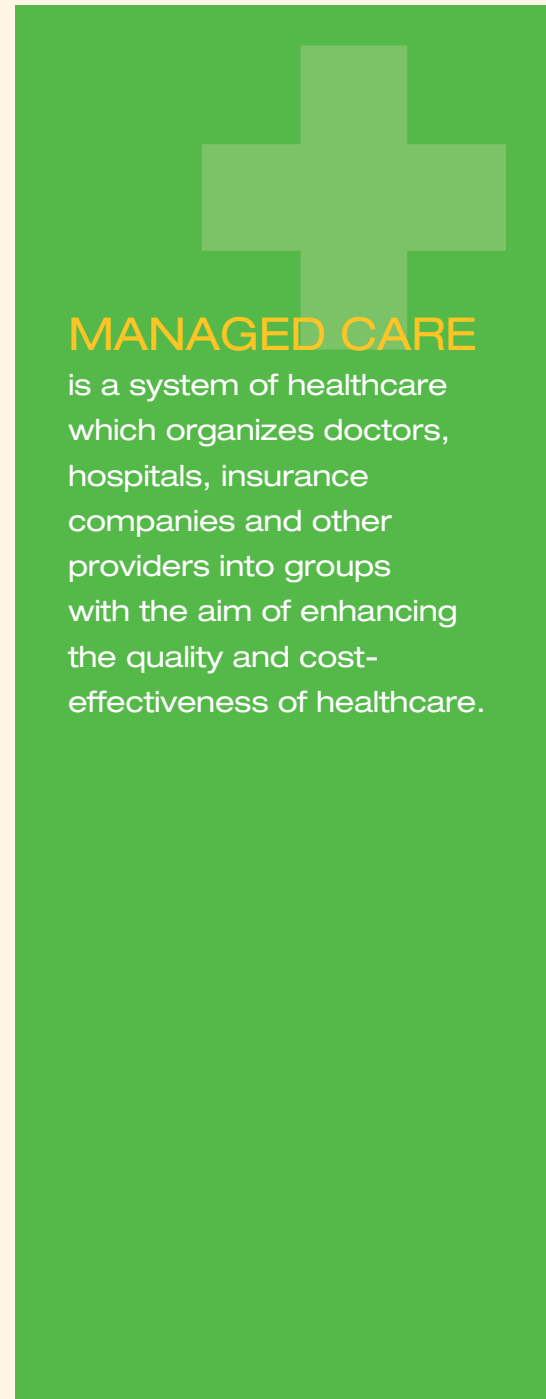
Children's Issues

Children with disabilities represent another group whose advocates are very vocal in making sure any managed care program includes individualized possibilities.

"My concern is for children with chronic health issues and developmental disabilities. Our goal is to keep them in their homes and thriving with their families and there is a certain level of support that will be needed to do that, often well into adulthood," says Karl Lehman, CEO and president of Childkind. "So a concern with managed care is that if the medical model says the individual will get better and services will taper off, there could quite possibly be a collision of philosophies down the line. There could be a model that says these people should have gotten better and be off the roles by a certain time. The program cannot be a one size fits all. It has to be based on individual needs."

Jeff Cornett, director of training, research and advocacy for Hemophilia of Georgia, says that for children with hemophilia, there

"So a concern with managed care is that if the medical model says the individual will get better and services will taper off, there could quite possibly be a collision of philosophies down the line."



is already an effective comprehensive care system that has been in place for almost 40 years. Funded originally by the federal government, the clinics are now mainly supported by Hemophilia of Georgia.

“Over the years, research has shown that patients who go to one of the comprehensive hemophiliac centers live longer than those who don’t. So most people go there,” says Cornett.

Hemophilia is very expensive to treat. “Depending on weight, it can cost \$30,000 to \$300,000 a year just for medications,” Cornett adds. Putting those children in a capitated (a defined limited dollar amount) managed care plan “becomes very scary.”

“Our concern with managed care is that the focus has been on managing costs, not care,” says Cornett. “We have found that Care Management Organizations (CMOs) seek to reduce costs by reducing care. It’s been a constant struggle for our patients in existing managed care programs. I really worry about the other children that have developmental disabilities and other complex chronic problems. If you have a child who deviates from the normal care for anything, that’s a trigger that you’re going to have problems.”

“Managed care right now is not set up to handle people with mental illness. For those who want to live in recovery, it’s more than healthcare.”

Mental Illness

Ellyn Jaeger, director of public policy for Mental Health America of Georgia, has expressed concern about the impact managed care would have on those with mental illness.

“Managed care right now is not set up to handle people with mental illness. For those who want to live in recovery, it’s more than healthcare. It’s jobs, transportation and housing,” she notes. “I think certain populations are at a disadvantage in the

managed care system. People with mental health illness and developmental disabilities would be at a disadvantage. Also the aging population.”

What does she see happening on the managed care front? “I don’t know. But, we are being asked our opinion by DCH and I appreciate that. In writing a contract though, to be effective, it would have to include a social model and not just a medical model. It all comes down to the contract. If it’s not in there, it doesn’t have to happen.”

Managed Care Elsewhere

Some managed long-term care programs have been tried in other states. In Wisconsin, one component is the Family Care Initiative that is being phased in as a replacement for state/county long-term care programs. “Family Care is designed as a capitated, managed long-term support and health care management program to serve adults with developmental disabilities, adults with physical disabilities and frail elders,” says spokesperson Dennis Harkins. “The goal is to focus on the individual. When and where it works as it is intended, it allows each person to be a full partner with the Managed Care Organization (MCO) in deciding where and with whom to live, to make decisions regarding supports and services, how to spend each day doing things they believe are important and in essence supporting people to live fulfilling lives in their communities.”

Wisconsin’s Family Care has been in effect since it began as a pilot in 2000. “The state reports that members are satisfied in meeting their desired outcomes,” says Harkins. “Overall, per person Medicaid costs (long-term care and acute) are decreasing compared to the previous system and nursing home usage is decreasing.”

However, Harkins comments that the program has not been without growing pains. “The rapid expansion has led to concerns over a growing segregation and congregation of services, provider rate-cutting and service reduction. Too often, care managers’ ideas of

“We have found that Care Management Organizations (CMOs) seek to reduce costs by reducing care. It’s been a constant struggle for our patients in existing managed care programs.”

what is best for a person hold more weight than the person's desired outcomes, despite our rhetoric to the contrary. That is definitely something that most of the Family Care programs are working on."

Harkins suggests that key elements to making this work are being clear up front about the values that guide the funding; having an Independent Ombudsman (oversight structure) that people can contact; requiring all MCOs to give people the option of using the principles of self-determination to develop their own plan for supports and services; and requiring the MCO to include, and if necessary, develop providers of highly individualized services.

"It's a very complex system and needs continual oversight and engagement by those who rely upon it," says Harkins. "If done well, it can support people in having fulfilling lives; if done poorly it can maintain or even increase the segregation and devaluation of the people it is designed to support."

Georgia's Version

The question though, is would managed care work in Georgia? Government Affairs Consultant Tom Bauer works with several advocacy groups, and he has a concern shared by many others that under a managed care system children and adults with disabilities, the blind and aged populations will have a much more difficult time getting the care they need.

"The managed care system basically uses a payment approach in which the managed care provider receives the same amount of money regardless of the amount of services provided," Bauer shares. "Therefore there is a built-in incentive to save money, and there may be some evidence that an approach like that might work for healthy people, but it leaves a lot to be desired for those with disabilities because they probably need more individualized care."

Bauer also adds, "Managed care frequently uses commercial standards to determine how much care to give someone. Customary therapy, for example, might be set at

twice a month. But a doctor or therapist might decide that a child with disabilities needs therapy once a week. Managed care companies have an incentive to rely on the commercial standards to minimize the amount or frequency of care. Their approach is to approve treatment as long as a child makes progress, but some children with disabilities may only be able to maintain their condition."

"If done well, it can support people in having fulfilling lives; if done poorly it can maintain or even increase the segregation and devaluation of the people it is designed to support."

"What we're saying is, before you take people out of their current healthcare plans, before you change a system that still takes individual cases into account, you have to make sure managed care will take care of them."

Nevertheless, some think managed care has come a long way. According to Kay Nelson, an occupational therapist who represents the Georgia Occupational Therapy Association, "When they first started, there were a lot of problems. There are still issues to work through, but we've seen some improvements."

"I think the biggest problem we run into is delays in services. If a child needs therapy or medical services, you have to apply to the managed care organization and sometimes there's a delay in getting that organization to respond," she says.

What safeguards should a managed care system going forward have? Nelson says, "An oversight structure to make sure service is timely is very important. Another thing is that currently only one of the CMOs is electronic-based. The others are paper-based and that creates delays. In a new system, everything needs to be electronic-based."

"I think the biggest problem we run into is delays in services. If a child needs therapy or medical services, you have to apply to the managed care organization and sometimes there's a delay in getting that organization to respond."

“In designing a service, the most important aspects are what services are available to the enrollee, how easily accessible are those services, and are they high quality services that are meeting their needs and helping them get the right care.”

DCH Task Forces

In February of this year, DCH convened two advisory task forces: a Provider Task Force and an Aged, Blind and Disabled (ABD) Task Force. These task forces will provide input into the Medicaid and CHIP Redesign Initiative, and a third task force will discuss Children and Family Services.

GCDD Deputy Director Pat Nobbie, Ph.D., says there is a group of advocates about 45 people strong including dental and pediatric representatives, meeting fairly regularly. “Well informed people are out there watching this very closely,” she says. They have created a 10-point guide for the new program that has been forwarded to DCH. (See listing of guidelines in sidebar.)

“People with disabilities and their families need to have access to comprehensive health and long-term support services and those services need to be provided on the basis of need, preference and choice,” says Nobbie. “In our language, that means things like making sure self-directed services are still an option for people so they can make the choice of what services they are getting and what providers they are using. That means things like person-centered planning, and access to the system recognizes individual issues.”

As with every program, money becomes a big issue. “Providers need to be reimbursed at an adequate level,” says Nobbie. “A huge issue right now is that rates are too low already. If you add a middleman, essentially, that will impact rates even more and then could there be an issue around quality of care.”

The Big Issue: Quality of Care

For virtually everyone involved with the managed care debate, what trumps the money issue though, is the quality of care.

Director of Health Policy at the Georgia Budget and Policy Institute, Tim Sweeney voiced what many think about managed care as a concept, “I generally don’t feel that it is inherently good or bad. It’s the way you organize the program. I don’t think budgetary savings should be a driving factor as the State moves toward re-designing the managed care program.”

Sweeney adds, “Every program can’t be designed to fix everything. It’s a perfect comparison to think about medical vs social populations; however, there are some populations we’re providing medical services for, but we don’t want to miss the boat on social services. Case management becomes even more important to other audiences.”

“In designing a service, the most important aspects are what services are available to the enrollee, how easily accessible are those services and if they are high quality services that are meeting their needs and helping them get the right care.”

DCH Timing

The current schedule for recommendations from DCH is to have a managed care proposal finalized this summer. At that time, managed care companies will have the opportunity to bid on requests for proposals. Those then will be reviewed with selected providers and are due by January 2013. With the providers in place, the new programs would then begin in January 2014.

Right now, probably the only thing that is certain is that managed care in Georgia would bring a change in the way healthcare and social services would be available to all citizens, especially people with disabilities. The most important thing an individual can do is to become informed and stay informed. Knowing what is coming can help make any change easier to comprehend and deal with as it occurs.

Guidelines for DCH Task Forces

1. Re-order the priorities.
2. Establish a values base.
3. Slow down and create a meaningful planning process.
4. Establish quality measures.
5. Adopt standards of care consistent with the mandates of the Medicaid Act and the Americans with Disabilities Act.
6. Engage stakeholders.
7. Establish independent review.
8. Keep the big picture in the forefront.
9. Do more of what works, less of what doesn’t.
10. Pilot services for new populations.

Medicaid Redesign: Charting Improvements in Medicaid and PeachCare for Kids®

An interview with Georgia Department of Community Health (DCH)
Commissioner David A. Cook.



David A. Cook

EXPERT UPDATE

The goals of a multi-year redesign initiative undertaken by the Georgia Department of Community Health (DCH) are to bring improvements to healthcare outcomes for members, enhance appropriate use of services by members and long-term financial sustainability. As the nation prepares to implement the Affordable Care Act, DCH Commissioner David A. Cook answered the following questions about the redesign of its Medicaid and Children’s Health Insurance Program (CHIP/PeachCare for Kids).

Why did DCH see a need to move to managed care?

In 2006, state leaders took action to address what was considered “unsustainable growth” in the Medicaid program in which 60% of all new state revenue would be consumed by growth in the program. DCH moved to a managed care model for the majority of its Medicaid populations as a way to address utilization that accounted for more than one third of total growth year over year.

Our focus is to improve access to quality care while maintaining a Medicaid program that is fiscally responsible and sustainable, particularly in light of the dramatic expansion of eligibility called for under the Affordable Care Act.

What were the goals of the redesign initiative and how did they ensure continuity throughout the process?

Early in the process, DCH identified three weighted goals and six weighted strategies to be used to evaluate the research and recommendations. These are:

These goals and strategies will be used throughout the evaluation phase of the redesign to guide our decision-making about the best healthcare delivery model for Medicaid and CHIP program members and their families.

Goals for Medicaid and PeachCare for Kids® Redesign		Weighting
1	Enhance appropriate use of services by members	33%
2	Achieve long-term sustainable savings in services	33%
3	Improve healthcare outcomes for members	34%
Goals - Weighted Total:		100%
Strategies for Medicaid and PeachCare for Kids® Redesign		Weighting
1	Gain administrative efficiencies to become a more attractive payer for providers	20%
2	Ensure timely and appropriate access to care for members within a reasonable geographic area	20%
3	Ensure operational feasibility from a fiscal and administrative oversight perspective	20%
4	Align reimbursement with patient outcomes and quality vs volume of services delivered	18%
5	Encourage members to be accountable for their own health and healthcare with a focus on prevention and wellness	18%
6	Develop a scalable solution to accommodate potential changes in member populations as well as potential changes in legislative and regulatory policies	4%
Strategies - Weighted Total:		100%

Here's some background about the redesign initiative:

In February 2011, the Department released a Request for Proposals (RFP) for a consulting firm to manage this process. Navigant Consulting Inc. was awarded the contract in the summer of 2011.

Navigant began the assessment phase in August 2011 with:

- 30 statewide focus groups that included providers, physicians, Medicaid members and caregivers, advocacy groups, legislators and others
- More than 400 online surveys completed by a wide range of stakeholders using category-specific questionnaires
- A national environmental scan of various states' Medicaid programs – DCH requested that Navigant examine 12 states
- A Georgia environmental scan to determine what is working and what can be improved in Georgia's existing system

In January 2012, Navigant presented its Redesign Strategy Report, a 400-page document that outlined the results of the research and presented nine recommended options for delivery systems, ranging from full risk-based managed care to free market health insurance. Since the release of the report, DCH has welcomed feedback through an online feedback tool, special email box, detailed written comments and both large and small meetings. Additionally, task forces representing three groups – the Aged, Blind, Disabled (ABD); Providers and Children and Family populations – are underway. These groups serve as advisers to DCH in building out certain aspects of the design plan and implementation.

What role has the Governor's office played?

Governor Deal asked DCH to review the current Medicaid and CHIP programs in Georgia when he first came into office in January 2011. The Governor's office has been involved throughout the process, which began in February of last year.

DCH has created the three task forces – Aged, Blind and Disabled; Providers; and Children and Families. These groups are meeting regularly to discuss the details of the various plan options presented in the report and to provide input to the agency.

Perspective of the Navigant report?

The report was well done and includes extensive research and information as outlined. Additionally, the report includes a variety of possible plan models – from full risk-based coverage to commercial style, free-market, fee-for-service plans. (See www.dch.georgia.gov to read the executive summaries and the entire report.)

In addition to an evaluation of the nine general option models, Navigant narrowed those options to four to consider specifically for Georgia's implementation, again measuring those options against the three weighted goals and six strategies listed in the chart on page 23.

Currently, DCH is analyzing and reviewing the report, meeting with scores of stakeholders and advocacy groups to garner their feedback and comments and weighing the feasibility of the best plan models.

What else is DCH doing to get input?

DCH created a feedback tool through its website. It was available for the first six weeks (mid-January to the end of February) after the report was released. Comments are still being accepted through MyOpinion@dch.ga.gov, which is monitored regularly by staff.

Additionally, DCH has created the three task forces – Aged, Blind and Disabled; Providers; and Children and Families. These groups are meeting regularly to discuss the details of the various plan options presented in the report and to provide input to the agency.

Who (groups, people) will be deciding on the best course of action?

The Department will make a decision on the path forward after consultation with the Governor and appropriate stakeholders.

When will that happen?

Timing for introducing the new plan models is early 2014. Several factors are in play: the implementation of the Affordable Care Act, the end of current contracts with our three Care Management Organizations (CMOs), who are providing services at this time and the results of review and evaluation of the possible delivery strategies.

We are currently in the Recommendation Phase, with many decisions to be made before DCH moves forward to the Procurement Phase. We anticipate that the Request(s) for Proposals will be issued during the last half of 2012.

Are there programs from other states that you will be taking pieces from?

All options are on the table. We are indeed looking at programs from other states, but beyond that, we cannot speculate about what our program will look like.

What does DCH see happening (with regards to a health and social aspect) to the final product?

It's too early in the process to speculate about the final outcome. Right now, we are examining all options, weighing them against our three goals and six strategies.

We continue to welcome comments through MyOpinion@dch.ga.gov and we encourage people to visit our website to read the executive summary and the report at

www.dch.georgia.gov.



A Mother-Daughter Road Trip

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

Every once in awhile, you just have to take off for a girls-only road trip. Mia and I decided to extend our vacation after Christmas at grandma and grandpa's by driving down to Ft. Myers, FL to see Barb, Mia's godmother and my long-time friend from St. Croix. My two other children had driven separately, so a couple days after Christmas they headed back to Atlanta and Mia and I hit the road to Florida.

Mia loves road trips. She likes the fast food breaks and the radio. I hate searching for stations in each new geographic area, so occasionally I'd sneak a CD or the iPod in there and pretend it was the radio. I love to sing. Mia hates it and always shouts, "Mom, Mom, MOM!" as I sing louder and more out of tune. When I stop, she starts singing. She knows the names of the songs, artists and most of the lyrics, while I can't remember a thing except maybe the Rolling Stones and the Beach Boys. Mia can sing entire songs from memory, and she also knows a considerable amount of the B52's, which is great music. When she was in middle school, her sister made her an entire 60-minute CD of "Love Shack," which she played over and over. That's one of my favorites to sing to as well, but as soon as I start, she goes, "Mom, Mom, MOM!"

Barb and I were both teachers, and we shared a closet between our classrooms where we would occasionally retreat to share stories of our kids or commiserate on the ridiculous requirements of our jobs, which we felt interfered with our students' needs. Over the years, Mia hosted many birthday parties at the bed and breakfast Barb and her husband ran in Christiansted, St. Croix and we holed up there for more than one hurricane, since it was a historic building and had thick walls.

In the 90s, Barb moved to Florida to be near her parents, brother and sister who all relocated there. Barb's house in Ft. Myers is a colorful collection of mementos from every trip she has ever taken and gifts from friends and visitors from around the US and world. Together, we spent lots of time catching up. We went to Ft. Myers beach and ate hamburgers at the beach bar, as well as went to Sanibel beach to collect shells and bags of powdery white sand. We also visited the Edison Plantation and stopped at Barnes and Noble to restock on Word Search books, Mia's favorite road trip activity. At Barb's parents' house, we looked through photo albums and Mia got to see pictures of herself as a baby. We took Barb out to dinner at Mama Mia's Italian Restaurant and had plates of spaghetti with enormous meatballs.

On New Years Eve, we went to the Rock and Roll street party in downtown Ft. Myers with Barb's brother and his family and hung out on the street with hundreds of other people to watch the ball drop and greet 2012. The next day, we drove back to Athens. It was a relaxing week. No policy. No philosophy. Just fun, sun, meatballs at Mama Mia's and singing out of tune to the radio. It was a perfect mother-daughter road trip.

"It was a relaxing week. No policy. No philosophy. Just fun, sun, meatballs at Mama Mia's and singing out of tune to the radio."

MIA'S SPACE



Real Communities Continue to Expand

The Global Growers Network has teamed up with the Georgia Council on Developmental Disabilities (GCDD) as a new Real Communities Initiative to encourage international refugees and people with and without disabilities to come together and unite as an inclusive, welcoming community. Located in the City of Clarkston, GA which is known for its diversity with refugees and immigrants from nearly 60 different countries across the world, the main goal of the new project will be to create two small gardens for all community members to get involved with and call their own.

The project will be led by Basmat Ahmed, who started as the community builder in late November 2011. As a native from Sudan and with a sibling with disabilities, this project is close to her heart. “My goal is to combine international families and people with and without disabilities to make them feel like the gardens are a common base where they can feel comfortable, interact with each other and see they can make an impact on the entire community,” said Ahmed.

Although the project has not broken ground yet, there will be a community garden located in Forty Oaks Park, owned by the county, and one in the Southern Place apartment complex. There are already people from 10 different countries interested in participating, and each person or family involved will have a small portion of land to grow his or her own vegetables, flowers, herbs and more.

In order to get people in Clarkston active in the project, Ahmed has been making house visits to let them know they will be welcomed. She wants to make people feel

that if they are from a different country or have a disability, they do not have to remain isolated in the community. The gardens are an opportunity to create independence, connect with others and change the mentality of stigmas as a whole in the community.

In order to get people in Clarkston active in the project, Ahmed has been making house visits to let them know they will be welcomed.

As the Real Communities Initiative continues to develop, GCDD will provide financial support, continued community growth through learning journeys and opportunities for Ahmed to collaborate and gain insight from other community builders and projects.

“It’s important to make everyone who feels they need a network in the community feel connected through the gardens,” added Ahmed.



With over 300 TimeBanks across the US and world, this will be the first TimeBank in metro Atlanta and the second in the State of Georgia.

To learn more about TimeBanks, please visit www.timebanks.org.

First TimeBank is Launched in Metro Atlanta

One of the Georgia Council on Developmental Disabilities' (GCDD) seven Real Communities, the Gwinnett Gives TimeBank, recently launched the first TimeBank in metro Atlanta. TimeBanks are an international movement that promote equality and build caring community economies through the inclusive and reciprocal exchange of time and talent. With over 300 TimeBanks across the US and world, this will be the first TimeBank in metro Atlanta and the second in the State of Georgia.

Detrice Gilbert, a parent of a child with disabilities and the community builder for Gwinnett Gives, advocated to develop a TimeBank project in this area as a way to create a network for an integrated and welcoming community. "The idea is about taking care of each other and giving back," said Gilbert.

TimeBanks provide people typically marginalized in society such as those with disabilities, the elderly or stay-at-home

moms, whose work is not usually valued from an economic standpoint, with the opportunity to contribute. The basis of the project is a time exchange of services. Regardless of the type of service provided, whether it is child care, handiwork, transportation, complimentary therapies or tech help, for every hour each member donates, they can receive the same amount of time for help with any service offered at the TimeBank.

The Gwinnett Gives TimeBank was officially launched in January 2012 and has been assisted by GCDD throughout the process. GCDD previously sponsored a learning journey opportunity for the group to visit a TimeBank in Madison, WI to help the group learn how to initiate their own TimeBank model in the community. Additionally, GCDD will also fund new software for the group, so they can track people's hours automatically.

"We are just getting started, but my goal is to make people feel like this is our project," shared Gilbert. "It is important everyone has a sense of responsibility and ownership in this project because it is about making the community better for all."



Regardless of the type of service provided, whether it is child care, handiwork, transportation, complimentary therapies or tech help, for every hour each member donates, they can receive the same amount of time for help with any service offered at the TimeBank.

"It is important everyone has a sense of responsibility and ownership in this project because it is about making the community better for all."

Students with GCDD's Partnership for Success Club at New Manchester High School in Douglasville, GA were asked to submit essays on Disability Day at the Capitol. The top essays submitted were written by Roscoe Mann and Jeremy Price, followed by excerpts from runner up essays in the top three. All three essays will be available on

www.gcdd.org

STRAIGHT TALK



"As fun as Disability Day was, it was also very eye opening. We realized that the general public does not treat people with disabilities fairly or like they are important. We feel that all people with disabilities should be treated just like people who do not have disabilities. All of our lives are important, and people with disabilities have a lot of talents and skills to offer. They are some of the hardest working people in the world. We just need some accommodations to be successful."

By Kasan Suggs and Kevon Cox



"I had so much fun. I got to meet many new people. That day, my disability did not matter. I was just a person. I got to meet

many people with disabilities that are successful. I hope that I can be as successful one day just like them."

By Breona Gibbs with assistance from her teacher Mrs. Waldrop

Disability Day Through Our Eyes

By Roscoe Manns and Jeremy Price

Our names are Jeremy and Roscoe. We attend New Manchester High School in Douglasville, GA. We attended Disability Day for the first time this year with our Partnerships for Success Club at our school.

Our experience at Disability Day at the Capitol was a great experience because we got to see that everyone is important no matter the disability or ability. Everyone was encouraging and passionate about helping those with disabilities. It was awesome to see everyone come together and advocate for those with disabilities. We hope that because of Disability Day the lawmakers of Georgia would open their eyes to the needs and abilities of those with disabilities.

Our experience at Disability Day 2012 prompted me, Roscoe Manns, to write the poem below. Attending Disability Day and being a part of Partnerships for Success Club at my school has shown me that just because you have a disability does not mean that you can't be successful or that you don't have dreams. I hope that this poem opens many eyes and makes them think about how they treat those who have a disability.

Just Because I Learn Slow

By Roscoe Manns

*Just because I learn slow
doesn't mean I'm retarded,*

*Just because I learn slow doesn't
mean that I am slow,*

*Just because I learn slow doesn't
mean you can talk about me,*

Just because I LEARN SLOW.

*Just because I learn slow doesn't
mean I can't get "IT."*

*Just because I learn slow doesn't
mean you can't be my friend.*

*Just because I learn slow doesn't mean I
Can't Help you out with your problems,*

Just because I LEARN SLOW.

*Just because I learn slow doesn't mean I Can't
Go To College and make my mom proud.*

*That Her Son Was The First To Go To College
And Finish It.*

*SO While you're Making Fun Of Me For Learning
Slow, And Thinking You're Better Than Me*

You're Not.

IT just shows how ignorant you are.

*YEAH I Learn slow But It doesn't mean
I can't fulfill my dreams to be the best
person that I can be For My Family.*

We appreciated the opportunity to attend Disability Day 2012. This experience has truly impacted our lives and way of thinking.

We hope that it will impact the decisions and rulings that our lawmakers will make during this session. We hope that they will remember that our lives are for real too!



Roscoe Manns and Jeremy Price

April

April 11

GCDD Media Roundtable
Savannah, GA
404.657.2126

April 12-13

GCDD Quarterly Meeting
Savannah, GA
404.657.2126

April 12

GCDD Public Forum
Savannah, GA
404.657.2126

April 13-14

Developmental Disability
Ministries Conference
Life Skills Center of Wesley
Glen Ministries Church
478.471.3711

April 23-25

2012 Disability Policy Seminar
Washington, DC
www.disabilityseminar.org

April 30 – May 3

33rd Annual International
Conference on Developmental
and Learning Disabilities
Hilton New York
New York City, NY
Tina Sobel
tina.sobel@yai.org
[http://yai.org/resources/conferences/
yai-conference/](http://yai.org/resources/conferences/yai-conference/)

May

May 10-11

Self-Advocacy Summit
Envisioning the Future:
Allies in Self-Advocacy
Seattle, WA
301.588.8252
www.aucd.org

June

June 19-20

Technical Assistance Institute
www.nacdd.org

July

July 7-12

Toronto Summer Institute 2012
Toronto, Canada
416.658.5067
inclusionpress@inclusion.com

July 19-20

GCDD Quarterly Meeting
Atlanta, GA
404.657.2126

July 19

Annual *Making a Difference*
Appreciation Ceremony
Atlanta, GA
404.657.2126

2012 CALENDAR

Planning an upcoming event?

Send your information to Dee Spearman, GCDD Public Information Assistant at dyspearman@dhr.state.ga.us; Subject line: "Community Calendar" by June 1 to be included in the summer calendar. For a full list of events, visit: gcdd.org/events-calendar



CALENDAR HIGHLIGHT:

The Georgia Council on Developmental Disabilities (GCDD) presents a Real Communities Initiative video featuring the Korean Coalition project and the stories of Korean families who have family members living with developmental disabilities.

RESOURCES

For additional information about the articles and issues in this edition of *Making a Difference* magazine, consult the following resources.

Georgia Council on Developmental Disabilities (GCDD)
www.gcdd.org
404.657.2126 or
888.275.4233 (ASK.GCDD)

State Government

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

Georgia Governor's Office
www.gov.state.ga.us
404.656.1776

Department of Community Affairs
www.dca.ga.gov

Georgia Housing Search
www.georgiahousingsearch.org
877.428.8844

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

General Information
www.georgia.gov

Georgia Lieutenant Governor's Office
www.ltgov.georgia.gov
404.656.5030

News

Abilities Expo
www.abilitiesexpo.com/atlanta/

Georgia Winter Institute
www.facebook.com/pages/Georgia-Winter-Institute/128370440557993
Stacey Ramirez, sramirez@gsu.edu
or Dottie Adams,
dxadams@dhr.state.ga.us

Voter Registration
http://sos.georgia.gov/elections/vrinfo.htm

Disability Day Feature

American Association of People with Disabilities (AAPD)
Mark Periello, mperriello@aapd.com
www.aapd.com

Children's Freedom Initiative
http://gcdd.org/site/real-support.html

Partnerships for Success
www.partnershipsforsuccess.com

9to5, National Association of Working Women
www.9to5.org/

disABILITY LINK
http://disabilitylink.org/

Metro Fair Housing Services
www.metrofairhousing.com/

Perspectives

disABILITY LINK
Margo Waters, Independent Living Coordinator
http://disabilitylink.org/

Georgia ADAPT
www.adapt.org/

Metro Fair Housing Services
Joseph D. Frazier, President
www.metrofairhousing.com/

Managed Care

Childkind
www.childkind.org/

Family Care Initiative in Wisconsin
Dennis Harkins
DWHarks@aol.com

Georgia Department of Community Health (DCH)
http://dch.georgia.gov

Georgia Occupational Therapy Association
www.gaota.com/

Georgia Budget and Policy Institute
http://gbpi.org/

Government Affairs Consultant, Tom Bauer
Tbauer23@aol.com

Hemophilia of Georgia
www.hog.org/

Mental Health America of Georgia
http://ciclt.net/sn/adm/editpage.aspx?ClientCode=nmhag&FileName=default2

Expert Update

Georgia Department of Community Health
David Cook, Commissioner
http://dch.georgia.gov

Real Communities

Global Growers Network, City of Clarkston
Basmat Ahmed, Community Builder
community@globalgrowers.net
770.865.1048

Gwinnett Gives TimeBank
Detrice Gilbert, Community Builder
GwinnettGives@gmail.com
http://timebanks.org/

Straight Talk

Partnership for Success, New Manchester High School in Douglasville, GA
Cindy Saylor, Program Coordinator
cidsaylor@bellsouth.net
www.partnershipsforsuccess.com



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

770.677.9345 | TFI@jfcs-atlanta.org

YourToolsforLiving.org

JF&CS is a proud partner of the Jewish Federation of Greater Atlanta and the United Way of Metropolitan Atlanta.

Jewish Family & Career Services
JF&CS
Your Tools for Living



Too bad there isn't a sign pointing to managed care 101.



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

MAKING a DIFFERENCE

A quarterly magazine of the Georgia Council on Developmental Disabilities VOLUME 12, ISSUE 4

SPRING 2012



On February 16, 2012, over 2,000 advocates came together for the 14th Annual Disability Day to have their voices heard by legislators meeting under the Gold Dome.