GCDD.ORG SUMMER 2011

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



**NEWS** FOR YOU:

TRANSPORTATION What does the future hold for Georgia? **SIBLING BONDS** The impact developmental disabilities have **GEORGIA'S DD NETWORK** Celebrating 40 years



On the Cover: Georgians utilizing one of the only five wheelchair accessible taxis in Georgia.

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.



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#### GCDD VIEWPOINT





## Rebuilding: Transportation in Georgia

Since the end of the Civil War, transportation has helped rebuild Atlanta and the rest of Georgia. The railroads came through Atlanta and many communities saw their economic livelihoods built and diminished based on where roads and interstates were constructed. Hartsfield Jackson International Airport became the busiest airport in the world, and we all have heard the joke that if you want to go to heaven, you have to change planes in Atlanta. Many people around the country were envious of the transportation infrastructure that made Georgia the capital of the South and a rising economic and political powerhouse.

For over 20 years, the Georgia Council on Developmental Disabilities (GCDD) has been hosting public forums around the State. During these forums we ask individuals to discuss the most pressing issues in their communities. Almost unanimously, the number one issue is transportation. Whether in rural South Georgia, urban Atlanta, the mountains of North Georgia or the coastal areas, transportation is one of the most vital needs of communities throughout our great State. It has been a difficult issue to work on due to the scope of the problem and because transportation affects everyone – not just people with disabilities.

Today, we have an opportunity to support the rebuilding of a crumbling transportation infrastructure and change what transportation looks like in every part of our state. Next July we will all be voting on a sales tax specifically for transportation where we live. But now is the time to voice our opinion on how those funds will be spent. Communities throughout Georgia are discussing their transportation needs and how the Transportation Special Purpose Local Option Sales Tax (T-SPLOST) will be used if passed by the voters next year. YOU MUST MAKE YOUR VOICES HEARD.

Statewide organizations including GCDD have been working with transportation advocates and local communities to identify potential projects, but it is up to you. Get involved in your community – identify potential projects and work to make sure that the funding is available to support projects so that people with disabilities can go to work, visit the doctor or participate in community events. We want to encourage you to be active and stay knowledgeable about what is happening. We will assist you with information on our website gcdd.org

Also, on the GCDD website will be our new five year strategic plan. Over the next five years GCDD will be (1) working to expand our efforts to create communities that welcome all people including those with disabilities; (2) increasing our outreach to the media and helping to tell the stories of people with disabilities and their families; (3) supporting initiatives that result in expanded opportunities for children with disabilities to transition from school; (4) continuing to support self-advocacy efforts; and (5) strengthening our public policy work by adopting a consolidated policy agenda that will focus on real careers, real homes, real learning and real supports. We hope that you will join us as we work to create a better Georgia for all of us.

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

Eric E. Jacobson Executive Director, GCDD



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.

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## Real Opportunities in Jobs and Education Require Transportation

By Nathan Deal, Governor

## GUEST ARTICLE



This is a critical economic development issue for the disability community because, through transportation, you have broader access to real homes, real careers and real learning experiences that assure you a better quality of life in the future."

#### To Georgia's Disability Community,

On Disability Day at The Capitol, I was inspired by the large crowd of enthusiastic advocates and people with disabilities who spoke with a strong, united voice. It was an honor to speak at such a successful event, and I want to thank the entire disability community for inviting me to join you.

Disability Day was certainly the highlight of a very successful legislative session that saw our legislators vote to support our efforts to implement Georgia's agreement to move all people with developmental disabilities out of state institutions by 2015. Disability advocates and legislators worked with my office to successfully expand Georgia's family support system by adding 450 families and 250 new NOW and Comp waivers to the state programs that will allow people to be a part of real communities instead of segregated institutions. This effort also includes providing a community-based crisis response system with six mobile crisis teams and respite care.

The success of real communities and economic prosperity for all lies in the future, and it may very well depend on transportation. In 2012, Georgians will have an important opportunity to help shape the future of transportation in their local communities through 12 separate regional transportation "project lists" that will be funded by an additional 1% sales tax, if passed, within each region. It is very important that all Georgians be involved in this process, including the disability community, to ensure strategic improvements in all areas of transportation including, improving the accessibility of transportation networks in major metropolitan areas, smaller cities and towns and the state's rural areas. What actually happens depends on the outcome of next year's regional votes.

This is a critical economic development issue for the disability community because, through transportation, you have broader access to real homes, real careers and real learning experiences that assure you a better quality of life. This is your chance to participate in the process and advocate for a transportation system that serves your community as well as the disability community.

Together, we must continue to seek new and innovative ways that make sure all Georgians enjoy the most full and productive lives that are available to them. The transportation issue is important to bringing this vision to reality.

I look forward to working with those of you who are active in the advocacy community on transportation and other issues facing our state. It's going to take your continuing support and cooperation to improve the quality of life for all Georgians in the disability community.

Nathan Deal, Governor of Georgia

#### **NEWS**

## 12th Anniversary of Olmstead Decision



Each year, People First of Georgia organizes a series of Long Road Home events across Georgia to honor Lois Curtis and the late Elaine Wilson, who led the way to the landmark Supreme Court Olmstead Decision.



To celebrate this year, 12 years after her original journey to the Supreme Court, Lois Curtis traveled once again to Washington DC. Only this time it was to meet President Obama where she presented him with a gift of one of her original paintings in the Oval Office. Lois also presented her art at local Long Road Home celebrations such as the June 15 kick-off in Decatur and closing presentations at the State Capitol on the June 22 Olmstead anniversary.

#### Unexpected News: Setback for IDA Legislation

For the past two years, GCDD and The Center for Financial Independence and Innovation have worked on legislation to establish a state Individual Development Account program. IDAs are asset-building mechanisms for people of low socio-economic status (defined in the bill as household income below 300% of poverty) to save money in an account that will be matched by a nonprofit organization or private foundation towards a specific purpose. Federal IDA programs help low-income families save for a first home, higher education or financing a small business. The proposed state IDA program added assistive technology as a category to encourage people with disabilities to participate in asset-building programs towards the purchase of home and vehicle modifications, communication devices and other technological supports that enable them to stay in the community, in school or employed.

The IDA legislation, HB 226, passed both House and Senate. However, the legislative session isn't over until the bill is signed. Governor Nathan Deal vetoed the IDA legislation because he expressed several concerns including, the oversight and monitoring mechanisms, how the target population that would benefit from the opportunity for establishing an individual development account was defined and how money generated from accounts could be spent. Conversations have begun to resolve these issues with the policy staff at the Governor's Office, the sponsor, Rep. Donna Sheldon and various partners who worked on the legislative support this past session. If these issues can be resolved to the satisfaction of the Governor's Office, they have promised their legislative support for the 2012 session. Rep. Sheldon also indicated that she will work on this legislation again next year.

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On the web



Advocacy Director of the Shepherd Center at gcdd.org. Click on the link to Spotlight on Advocacy.

## IN THE NEWS

Atlanta to host October Film Fest: "Changing the Scene from Disabilities to Capabilities"

The first annual REELABILITIES Atlanta Disabilities Film Fest slated for October 1-6, 2011, is dedicated to promoting awareness and appreciation of the lives, stories and artistic expressions of people with different disabilities.

The week-long festival, produced by Georgia Community Support and Solutions, and co-chaired by Lynne M. & Howard I. Halpern, will present winning films and Sundance Film Festival favorites in various locations throughout the Atlanta area, as well as hold discussions and other engaging programs, which bring together the community to explore, discuss and celebrate the diversity of our shared human experience.

For more information, go to reelabilitiesatl.org or contact Judy Marx at reelabilities@gacommunity. org or 404.634.4222 ext 267.



## AROUND GCDD

Average Number of Grants Awarded Each Year:

Partnership Funds:

**Innovative Grants:** 



Conference Support:

Disability the Ca

## Funding Opportunities With GCDD

Have you ever dreamed of attending a national conference? Or leading the way for change in your community? Or helping people overcome obstacles using never done before ideas? GCDD offers grants that encourage reforms supporting the rights of people with developmental disabilities. The purpose of the GCDD grants is to support continued growth and change within the system. GCDD awards grants to individuals and organizations that form ongoing partnerships designed to expand on best practices and affect change.

All funds and projects authorized by GCDD are dependent upon receipt of federal funds. Additionally, there is a match system in place for each grant awarded. For any grant exceeding \$1000, the recipient must match 25%, and any grant under \$1000 must be matched by 10%.

GCDD acts as a leader in linking the disability community and organizations with resources that support an all-inclusive community system that best addresses the needs of people with developmental disabilities and their families. The following are the three types of grants GCDD has available:

#### Partnership Fund

The Partnership Fund is a program that awards individuals with disabilities and their family members small grants to help them attend one-time learning events, advocacy events and conferences related to developmental disabilities. These events are great tools in learning how to improve lives with a disability. However, conferences are often located outside of Georgia and make it a challenge for families to afford the travel expenses needed to attend the event. GCDD grants reimburse recipients up to \$2500 to provide families with transportation, hotel and other additional costs. Applications for a Partnership Fund grant are accepted year-round and must be completed at least 30 days before the event.

#### **Innovative Grants**

Innovative Grants are small grants awarded for unique projects intended to help people with developmental disabilities in overcoming obstacles and providing access to a life involving homes, careers, learning, support and influence. Through these grants, GCDD provides financial support to organizations that promote new, out-of-the-box programs intended to advance public policies and system changes and have the capacity to impact the quality of life for Georgians with disabilities. Grants are typically awarded twice a year in April and October and those that show success and a potential for further advancement can request a renewal after one year.

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#### July Honors

Each July, GCDD recognizes individuals who have helped advance the message of community and inclusion in Georgia at its Annual Appreciation Ceremony. 2011 honorees are State Representative Donna Sheldon (R - District 105) for legislative leadership on passage of a strategic plan for a statewide transportation system and supporting IDA (Individual Development Accounts) legislation; Joe Shapiro of National Public Radio (NPR) for media excellence on coverage of the Children's Freedom Initiative; and six Partnership For Success (PFS) high school students who will be announced as GCDD's advocates of the year. The GCDD council member who has demonstrated exemplary leadership and service will also be named C. Anthony Cunningham council member of the year at the July 21 ceremony in Atlanta.

#### PFS GCDD Advocates of the Year:

Sara Cole, Apalachee H.S. Kristin Womack, Apalachee H.S. Lindzi Vaughn, Flowery Branch H.S. Nick Dyson, Flowery Branch H.S. Travis Baker, Colquitt County H.S. Katherine Walker, Colquitt County H.S.

## LOOK FOR THE FALL *MAKING A DIFFERENCE* THAT WILL HAVE A FULL WRITE-UP ON THE JULY 21 AWARDS CEREMONY.

#### Conference Support

The focus of conference support grants is on support of local, state and national advocacy organizations that hold events in Georgia. Conference Support grants are awarded through a sponsorship program that helps in the process of planning, developing and implementing a conference or event for developmental disability programs. This grant opportunity offers a budget of up to \$2000 for each conference, which must be applied specifically for the event. Typically grants can cover the cost of out-of-town speakers, luncheons, banners, ads and other sponsorship needs. Conference Support grants are available for a wide range of developmental disability events, from a medical center hosting a health fair to an informational meeting or reception held by a state agency. The number of Conference Support grants awarded each year varies depending on the fiscal budget.

To take advantage of these grant opportunities or for more information and applications, visit gcdd.org or contact Drelda Mackey at drmackey@dhr.state.ga.us.



#### Transportation: A Two-Way Street By Bill Lewis



#### Georgia is on the brink of a historical moment for transportation – everyone must seize this moment and help shape the future of transportation across the State.

Transportation is a necessity for a better quality of life for you, whether you have a disability or not, live in a rural area or simply don't have a car. The lack of transportation hampers your freedom to earn a living and achieve a quality of life. That is why the disability community needs to become involved in this issue – now.

Together we can identify and design the accessible transportation options we want and need to achieve independence and inclusion in the community. Participate in roundtable meetings which are being organized statewide. Spread the word. Immerse yourself in this issue because it affects not only the future of Georgia, but your future as well.

"For the first time in recent history, Georgia has developed a business plan for transportation investment, and that plan clearly gives reasoning behind additional investment in transportation," says Todd Long, director of planning for the Georgia Department of Transportation (GDOT).

The plan is found in legislation called the Transportation Investment Act (TIA), also known as HB277, a bill that was passed by the 2010 Georgia General Assembly. It creates the opportunity to make transportation more available and accessible to every Georgian.

#### A little background.

TIA authorizes a 1% transportation sales tax to be voted on by twelve separate regions of the State in the summer of 2012. In other words, the 1% additional tax will be decided within individual regions. It's entirely possible that one or more regions will vote in favor of the initiative, while others vote "no."

Only regions voting "yes" will pay the extra penny, but only those regions passing the initiative will benefit from the additional transportation money. And no money raised in one region will be spent in another region. The life of the tax is ten years, and the amount that could possibly be raised varies by region. Only regions voting "yes" will pay the extra penny, but only those regions passing the initiative will benefit from the additional transportation money.

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#### How To Stay Informed and Make Your Opinions Known.

- Find where your county is located in the system of 12 Regional Commissions throughout Georgia at: http://garc.ga.gov/main. php?Regional-Commissions-2
- 2. Review the "Unconstrained Projects" list for your region: www.it3.ga.gov/Pages/ Roundtable.aspx
- Before August 15, contact the Executive Committee and Regional Roundtable members under each region (See the link in #2 above, under "Membership and Executive Committee List.")
- Attend the meetings of the Executive Committees and Regional Roundtables. (See link #2 above.)
- 5. Make yourself and your issues known.

#### Why was TIA passed?

In a recent interview, Tad Leithead, chairman of the Atlanta Regional Commission (ARC), explained how TIA will apply to the Atlanta region: "ARC projects that over the next 30 years our transportation funding needs will be in the neighborhood of \$110 billion. We have identified federal resources over that same period of time for about half that. That means we have a shortfall of about \$65 billion that we would need to build all of the transportation improvements in this region. The referendum is a fantastic first step towards addressing that shortfall...and prioritizing projects in the region."

## What could the TIA mean to you?

As Pat Nobbie, deputy director of the Georgia Council on Developmental Disabilities (GCDD) points out, "Transit means having transportation choices in addition to the cars that some residents can't use or afford. It means greater mobility so that the disability community and others can get to their jobs or medical care and just plain live their lives."

You have the opportunity to voice your own transportation concerns and regional officials want input from every citizen. If you have trouble getting from Point A to Point B or Points C, D, E, F, etc., now is the time to speak up. Patricia Puckett, who is the executive director for the State Independent Living Council (SILC) and has a disability, says, "I think the opportunities to improve public transportation are enormous and getting involved in the Regional Roundtable meetings is essential for our community."

#### Getting the word out.

"Many feel that this is the most significant transportation legislation ever passed by the Georgia General Assembly. It is essential that everyone be knowledgeable about the bill," advises GDOT's Long. "For people who use wheelchairs or people who cannot drive for a variety of reasons, accessible routes to accessible public transportation mean the difference between going out or staying home; it's the difference between surviving on disability benefits or getting a job."

"We live in rural Georgia. My granddaughter goes to the Children's Medical Center at the Medical College of Georgia almost weekly; it used to be more. A trip up and back is close to 180 miles, a four hour drive for a ten minute appointment. When she was going to therapy, it was an hour one way to one therapist, 45 minutes to the other.

The problem is there is no public transportation in this part of the state. Gas prices are still in the \$3.65-\$3.95 range. I realize that there is state-provided transportation available, which in an emergency would be nice, but a bit confining. I have learned to combine trips when we go to Augusta."

- RURAL GEORGIA FAMILY

Education is a key factor in the TIA issue. The Act opens up additional funding sources for transportation, but more importantly, specifies the transportation sales tax can be used for *any type of transportation project*. For many that means:

- · Roads and bridges
- Transit capital and operating needs
- · Safety and traffic operations
- Freight and logistics
- Sidewalks, pedestrian and bicycling
- Aviation
- Other transportation alternatives

Other transportation alternatives may very well have the most meaning for older citizens and persons with disabilities.

Most of the billions of dollars the tax would generate would go toward specific projects within the region. However, extra flexibility is provided by setting aside: 1) 25% of total available funds for use within each county (and cities in them) outside the Atlanta Regional Commission area, and 2) 15% of total available funds for use within each county (and cities within them) inside the Atlanta Regional Commission area. These funds may be used for any transportation purpose.

Accessible transportation is needed not only for people with developmental disabilities, but for all Georgians, especially those in rural areas. Passage of TIA created the Governor's Development Council of Rural and Human Services Transportation Committee, which brings together and coordinates various state agencies involved in providing transportation for Georgians. These agencies include the Department of Human Services, the Department of Behavioral Health and Developmental Disabilities and the Department of Community Health.

In the future, this committee is expected to make transportation easier for Georgians, as well as more efficient and cost-effective.

## Thinking outside the box.

The Transportation Investment Act enables Georgians at grass roots levels to design transportation projects in their communities and offers greater flexibility to residents than ever before. The kicker is, *that has to happen now*.

Under the TIA legislation, all projects to be funded by the new tax must be approved prior to the vote. Nothing can be added afterwards – if it's not on the list, it doesn't get done. Advocates have been criss-crossing the State spreading the word and listening to ideas. Public transportation options headed most lists, but many tangential ideas were discussed as well, including:

• Accessible Taxi Cabs: There are now only five wheelchair accessible cabs in the State of Georgia. Four are in Atlanta, one in Savannah.

#### • Mobility Management Call Centers:

This is an idea being developed under the Governor's Development Council of Rural and Human Services Transportation Committee that would help map out a transportation need with one call. For example, if somebody lives in Alpharetta and wants to go to Conyers, instead of having to call a taxi company, call for a MARTA schedule, check on a bus schedule and arrange taxis at the destination, you would make one call and the Call Center would handle all the arrangements. It's still convoluted, but it's only one call instead of several.

- **Regional Sidewalks and Bus Shelters:** Just getting basic safety issues like sidewalks and shelters at bus stops on a region-wide basis are issues that need to be brought to the forefront.
- **Transit Systems in Rural Areas:** Some in the coastal region thought there should be a mandated amount of their region's money devoted to transit systems that would serve non-metropolitan areas.

Puckett echoed these sentiments: "These features help everyone – the delivery person, the business person with a roller board suitcase or the parent with a stroller. But for people who use wheelchairs or people who cannot drive for a variety of reasons, accessible routes to accessible public transportation mean the difference between going out or staying home; it's the difference between surviving on disability benefits or getting a job."

#### The Nitty-Gritty.

There are two lists involved in the process of getting TIA to the voters. One is the "Criteria" list and the other is "Non-Criteria." Projects that appear on the Criteria list have to meet certain guidelines as put forth in the legislation and include roads, bridges and sidewalks, etc.

The Non-Criteria list, while smaller, is also the most flexible and allows for greater innovative ideas. Any type of project can be approved by the regional commission on individual merit alone and not subject to mandated criteria.

## Who is involved in making up the lists?

The Transportation Investment Act requires each region to have a roundtable of elected officials to develop a project list that will be available to voters before they go to the polls. The roundtables include the chairperson of each county commission in the region and one mayor from each county in the region and are to select projects they feel would best benefit the citizens in their region. Once those projects are finalized, they will be the exact ones voters will be deciding on next summer. No new projects can be added to the list once the referendum is passed.

"The roundtables can amend, adopt and approve the projects. The bill clearly places the final authority of project selection in the hands of local leadership," says Long.

It is essential for Georgians to voice their opinions to the roundtables in their region during the process of making up the lists. It is the roundtables that have the power to address the communities' transportation needs.

## The time to act is NOW.

"One interesting component of this to me is the common focus from diverse groups," says Nobbie. "The transportation concerns of the elderly are very much in line with the concerns of people with disabilities. And that extends to really anyone without a car or the ability to drive one like teenagers trying to get to a job or school."

Nobbie suggests everyone ask themselves two basic questions: "Do you use public transportation now?" and "Do you foresee needing some form of it in the future?"

Nobbie says that if the answer to either of those questions is "Yes," you need to be involved in the transportation dialogue. "Go to a meeting," she says. "Get your voice heard and put your ideas on the table. Don't just think about big busses and trains. Think smaller and think specific." individuals who qualify for paratransit service in Muscogee County are outside the service area of Metra. There are parents and caregivers who are unable to work because they have to transport their loved ones. Additionally, where is the collaboration between neighboring counties? There are Harris County parents who want to use services in Muscogee (like the park district) and can't. Lastly, I would love for my own son to be able to utilize the service providers in other neighboring counties but again, because of the limited service area for Metra Paratransit Dial-A-Ride, he misses the opportunity to fully participate in the community."

"I hear too many times that

- MUSCOGEE COUNTY RESIDENT



The way the Transportation Investment Act (TIA) works is that all projects to be funded by the new tax must be approved PRIOR to the vote. Nothing can be added afterwards.



## DO YOU USE PUBLIC TRANSPORTATION NOW?

## DO YOU FORESEE NEEDING SOME FORM OF IT IN THE FUTURE?

If the answer to either of those questions is "Yes," you need to be involved in the transportation dialogue.

#### "Our son is just graduating from high school and will have two more years of job training in the school district. But one thing we would love to see is for him to learn to ride public transportation. Then, when he does begin working, he could get to work and home on his own. (We do not feel that he is capable of driving.) We do have a bus now in Gwinnett, but it only goes to certain places and there are no places to catch the bus close to where we live."

- GWINNETT COUNTY FAMILY

"This bill allows us to tell people and businesses that are looking to move or relocate their company to Georgia that we have a plan to fix transportation and that we are serious about addressing these issues."

## Keeping your voice heard statewide.

Brunswick resident Alice Ritchhart, who is blind, is state chair of the Georgia Coalition for the Blind, as well as a member of the board of the Statewide Independent Living Council (where she chairs the transportation committee). She agrees with Nobbie, "Everyone concerned should get involved, go to roundtable meetings in your regions, contact your representatives and make sure your projects are kept on the list that will be presented to voters next summer."

Ritchhart says when the roundtables were first being formed, "We encouraged all residents of Independent Living Centers to attend meetings. And we had three major issues that were important for all regions in the State:

- Make sure the dollars used for public transportation are earmarked for operating and maintenance expense and not just capital expenditures.
- 2. Make sure somebody in each transit area was hired specifically to educate people on how to use the public transit system, both those with disabilities and those without disabilities.
- 3. Make sure people have access: curb cuts, uniform bus signage, lifts on busses, audible announcements and accessible sidewalks."

Ritchhart reports that some regions fared better than others in including ideas on roundtable lists. In Region 12, for example, "We were lucky," she says, "because most of the elected officials 'get it' already down here." Projects in other regions didn't make the cut.

In 2010, the City of Fitzgerald and Ben Hill County showed how it can work with passage of a Special Purpose Local Optional Sales Tax (SPLOST), which included \$250,000 for community-based transportation models.

Athens Transit Director Butch McDuffie says one of their priorities is to "enhance the frequency of our service. We only have about 15 or 16 routes that run hourly and we'd like to operate them every 30 minutes. Being a smaller county, that's a big step in the right direction for us."

"We have to invest now in transportation alternatives that will boost the region's economic competitiveness, help attract good jobs and improve quality of life," says Ray Christman, executive director of the Liveable Communities Coalition. "It's time to make the investments that will give residents more transportation choices, more ways to unlock gridlock."

## Many issues make for an interesting vote.

In each of the 12 TIA regions, several counties are involved in the vote. The *total vote* in each region decides the issue. So if the initiative is defeated in one county but passes easily in another, it's conceivable some residents of the region will still have to pay the additional 1% even though their particular local county voted against it. Why would people vote against it? It's a complicated answer and one full of ironies. For example, as the *Atlanta Journal Constitution* (AJC) reported, one metro Atlanta county sees eight out of every ten residents drive out of the county everyday to their jobs. As the paper points out, that might be reason enough to want extra money for wider highways or more bridges, or even some form of mass transit.

But, other factors are involved as well. As the *AJC* indicates, "A confluence of a bad economy, the county's conservative politics and voter fatigue from self-imposed taxes ensures that the vote on the transportation SPLOST will be a tough sell in (this) county."

On the other side of the economic picture, a statewide commitment to fixing transportation issues is seen as a big plus for business and job growth in Georgia. When the bill was signed into law, Lt. Governor Casey Cagle said, "This bill allows us to tell people and businesses that are looking to move or relocate their company to Georgia that we have a plan to fix transportation and that we are serious about addressing these issues."

Dave Stockert, president and CEO of Post Properties and chair of the Metro Atlanta Chamber's transportation policy committee said, "The business community is ready to support the transportation referendum in every way possible as we move into the next phase of this process."

"Investing in Georgia's transportation infrastructure is critical to our long-term economic health," added Phil Jacobs, chair of the Georgia Chamber of Commerce's transportation committee. "We are pleased that this legislation will allow every region of our State to have a voice in what those investments will be and that it will provide a mechanism to improve upon our State's many transportation assets."

## Being informed is the key.

To say the least, TIA is a complicated issue. But it's one that will potentially affect every citizen of Georgia. Gathering as much information as possible and participating in the dialogue is essential to making sure individual voices are heard. The key element right now is to stay involved. Make your concerns known. Decision makers are listening.

And your voice doesn't have to cease if your region passes the tax. A five-member council will be set up to monitor approved expenditures in each region. It's important for people with disabilities to be represented on that council. And the best way to make sure that happens is to get voices heard and names known now. Attend meetings whenever possible. Be adamant in your support for issues that affect you most.

"This is a critical time for citizens who care what the shape of the transportation list looks like," says Christman.

And as Pat Nobbie says, "You won't get another chance like this." It is imperative to keep the wheels on the transportation issue turning. Right now, you and all Georgians have a chance to make significant alterations to the fate of the State's future in transportation. Make your needs heard loudly and clearly.

> "It's time to make the investments that will give residents more transportation choices, more ways to unlock gridlock."

"We live in Walton County where no public transportation is available. My adult son does not drive, so he is land-locked unless I take him. His opportunity for employment through Voc Rehab has been minimized in part because of the lack of transportation. This has been an issue brought to our county commissioner on more than one occasion, with no progress."

- WALTON COUNTY FAMILY

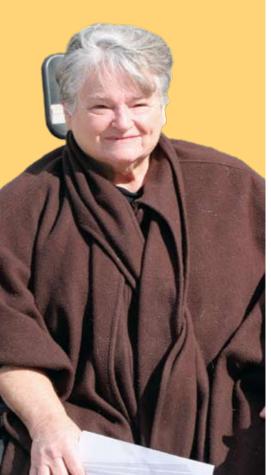


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## Celebrating 40 Years of Making A Difference

By Carmel Garvin Hearn

"It's about people having a decent home, relationships that matter to them, a way to make a contribution and being seen for who they are."



2011 marks the 40th anniversary of the Developmental Disabilities Bill of Rights and Assistance Act of 1971 (DD Act), which under the US Department of Health and Human Services, gave rise to the Georgia Council on Developmental Disabilities (GCDD) and its federal partners in the State's Developmental Disability (DD) Network. State leaders offer their views of the missions and goals of Georgia's DD Network, reflect on the accomplishments of the past four decades and take a glimpse into the future.

#### It's all about homes and friends and jobs.

"I was on the job for about three days when Eric Jacobson [GCDD executive director] called me up and said, 'OK, so here's the thing. It's all about homes and friends and jobs. I thought, *we're going to get along fine. I've been saying this for 25 years.* That's how we see the world – it's about people having a decent home, relationships that matter to them, a way to make a contribution and being seen for who they are." *Ruby Moore, Georgia Advocacy Organization (GAO) Executive Director* 

#### The Georgia DD Network - Who We Are

Georgia's DD Network works with self-advocates, parents, advocates, government and community support agencies to make a real difference for thousands of Georgians every day. There are four agencies in Georgia's DD Network that collaborate with each other and the media to inform the public about the lives and issues of people with developmental disabilities and their families.

These DD Network agencies work with each other (and other groups) in a dedicated effort to foster the rights, freedoms and empowerment of persons with developmental disabilities. Those agencies are:

- The DD Council: Georgia Council on Developmental Disabilities (GCDD) (www.gcdd.org)
- Protection and Advocacy for People with Developmental Disabilities (PADD): Georgia Advocacy Office (GAO) (www.thegao.org)
- University Centers of Excellence in Developmental Disabilities (UCEDDs): **The Institute** on Human Development and Disability (IHDD) at the University of Georgia (UGA) (*www.ihdd.uga.edu*) and the Center for Leadership and Disability (CLD) at Georgia State University (GSU) (*http://chhs.gsu.edu/cld/about.asp*)

Each agency of the DD Network has a particular strength that it brings to the table. GCDD is the lead agency for legislative advocacy, public policy and funding project demonstrations, the GAO focuses on individual rights and protection issues, the Network relies on the UCEDDs at UGA and GSU for research and educational resources.

"Here in Georgia there is great collaboration," said Eric Jacobson, GCDD executive director. "Our DD Network works the way the federal legislation intended. There is nothing in any federal program or network that looks like what we have. Our DD Network has two university programs, a federal component and a nonprofit agency. It is unique in that sense."

All states and territories have some form of the three-pronged DD Network envisioned by Congress. Some larger, growing states (as in the case in Georgia) have more than three agencies, but Georgia leads the way with a truly progressive collaboration.

"Georgia has a very good disability network," affirmed Tom Seegmueller, GCDD chairperson. "Those in the developmental disability community in Georgia tend to work closely with each other and that is fortunate for us. Georgia citizens with developmental disabilities greatly benefit from all the partners involved."

The agencies work in close partnership with each other, particularly through each group's advisory council, consisting of self-advocates, family members and professionals who identify goals and achieve outcomes that increase the quality of life for all people with disabilities.

"Georgia's DD Network is successful and growing," Jacobson confirmed. "The leadership of the four agencies recognizes that we need to work together. We respect the roles and strengths of each agency in that process."

"The strength of our DD network in Georgia is that we are very clear about the goal, and that is for people with disabilities to have good lives," added Moore.

She explained that the basic objectives of Georgia's DD Network, in conjunction

#### The Agencies of the Georgia DD Network

- Georgia Council on Developmental Disabilities (GCDD) This is Georgia's DD Council. It is a federally funded independent state agency promoting and creating opportunities to enable persons with disabilities to live, work, play and worship as an integral part of society. The agency collaborates 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. *(www.gcddd.org)*
- Georgia Advocacy Office (GAO) This is Georgia's Protection and Advocacy for People with Developmental Disabilities (PADD). The GAO is a private nonprofit corporation. Its mission is to work with and for oppressed and vulnerable individuals in Georgia who are labeled as disabled or mentally ill to secure their protection and advocacy. GAO's work is mandated by Congress, and GAO has been designated by Georgia as the agency to implement protection and advocacy within the State. (*www.thegao.org*)
- Institute on Human Development and Disability (IHDD) This was the first UCEDD established in Georgia (1965), and is now one of two in the State. Ranked as one of the University of Georgia's (UGA) oldest continuously funded federal programs, the IHDD works with people who have disabilities and others to ensure that all people can achieve their highest capacity and quality of life. IHDD applies the vast resources, research and scholarships of UGA on behalf of people with disabilities. All of the programs at IHDD are funded solely through grant funds and donations from private entities and friends. (www.ihdd.uga.edu)
- Center for Leadership and Disability (CLD) This was the second UCEDD established for Georgia and has been located at Georgia State University (GSU) since August 2008. CLD is one of 67 programs in the country funded by the Administration on Developmental Disabilities, US Department of Health and Human Services. Activities include community education and technical assistance to people with developmental disabilities as well as their family members, service providers, educators and professionals on a range of topics such as positive behavior support, person-centered planning, autism, individual services and supports and the SafeCare\* training model. (*http://chhs.gsu.edu/cld/about.asp*)

with the principles of the DD Act, is to work together towards the goals that people with developmental disabilities should be independent, economically self-sufficient, included and integrated in communities and self-determined in their lives. By working together, the DD Network is working to provide people with disabilities with:

- **Real Homes** People need to have a real home that is a true sanctuary and reflects who they really are.
- **Real Careers** People need to make a contribution to the community, and that is usually employment. Georgia's DD Network places a major emphasis on people getting good jobs that have a future.

- **Real Supports** People need relationships that are the same as those enjoyed by their peers. Real supports help keep people safe from harm as they are built with those who know, care and understand the individual.
- Real Communities The purpose is to connect people with developmental disabilities and their organizations to other citizens and their associations so all can act collectively on community issues and create positive changes that improve life in the community for all.

In addition to the basic objectives, one tool all of the agencies in Georgia's DD Network have in common is advocacy and leadership training. "It's hard to find somebody who's not impacted directly or indirectly by a family member with a developmental disability. We're not a minority."

## History of the DD Network

Originally authorized in 1963, passed in 1971 and last reauthorized in 2000, the Developmental Disabilities Assistance and Bill of Rights Act (DD Act, P.L. 106-402) addresses the changing needs and expectations of the estimated more than 4.7 million individuals with developmental disabilities (DD).

Congress set out to establish a set of programs to improve the lives of people with DD; to protect their civil and human rights; and to promote their maximum potential through increased independence, productivity and integration into the community.

This eventually turned into a three-pronged network of agencies for every US state and territory, with each network partner having a distinct role:

- State and Territorial Councils on Developmental Disabilities (DD Councils) advocate for and educate policymakers on, laws, regulations and policies to enhance community living.
- Protection and Advocacy for People with Developmental Disabilities (PADD) programs uses advocacy skills and legal avenues to enforce the laws.
- University Centers of Excellence in Developmental Disabilities (UCEDDs) provide research to identify successful community-based alternatives and train practitioners and leaders.

"As the protection and advocacy system, GAO's highest priority is preventing abuse and neglect including death," Moore added. "We start by supporting self-advocacy and help people hold on to their own power. We also use skillful tools for advocating on their own behalf."

> Working with people and ensuring their individual rights is one way the DD Network supports advocacy in the areas of legislation and public policy, as well as research and education. It also encourages the community and its citizens to become advocates themselves.

While each agency plays a part, Georgia's DD Council continues to serve as an advocacy leader within the developmental disability community by creating systems change for people with developmental disabilities through public policy research and analysis, reform, education and training and project demonstration.

The two UCEDDs in Georgia's DD Network, which focus their efforts on advocacy training, facilitate the flow of disability-related information and tap into the vast array of university research tools in that process. The centers also provide training programs for people with disabilities and members of their families. The UCEDDs offer training and technical assistance, including research and information sharing to state and local government agencies and community providers in projects that provide training, technical assistance, service, research and information sharing.

"We work through agencies, school districts and community organizations to try to support them in work with families and individuals," stated Daniel Crimmins, PhD, director of the CLD at Georgia State University (GSU). "We do some direct work with parent organizations, particularly with workshops and training programs for parents. Our core functions at CLD are to provide community services and supports."

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One of those programs, the SafeCare<sup>®</sup> Model, is an evidence-based, parent-training curriculum for parents who are at-risk or have been reported for child maltreatment. Through SafeCare, trained professionals work with at-risk families in their home environments to improve parents' skills in several domains. Parents are taught, for example, how to plan and implement activities with their children, respond appropriately to child behaviors, improve home safety and address health and safety issues.

"IHDD works with others to create opportunities that will improve the quality of life for people with disabilities and their families," remarked Zolinda Stoneman, PhD, director of the IHDD at the University of Georgia (UGA). "The work of the Institute advances the understanding of the ability of all people through education, research and public service."

One of the IHDD's recent efforts in conjunction with the Children's Freedom Initiative was to track every child in the State living in a nursing home. The IHDD helped connect parents with information and the support services they needed to move their children from institutional to home-based care.

#### Georgia's DD Network Initiatives

Here are just a few of the many, many successful and impactful initiatives that have sprung from Georgia's DD Network.

- Children's Freedom Initiative The Children's Freedom Initiative was directed by a legislative resolution that urged state departments to work together to get children out of state institutions and nursing homes. The goal is to ensure that children who live in facilities are given the chance to live with permanent, loving families and to create a Georgia in which no child resides in a facility. (www.georgiacfi.org)
- Unlock the Waiting Lists! Campaign Unlock the Waiting Lists! is an ongoing campaign to obtain more funding for home- and community-based waivers. It

has strong name recognition for legislators. It has pushed for NOW and COMP waivers, ICWP waivers and for more waivers under Money Follows the Person. It has pushed for a rate study to ensure adequate reimbursement for services and has asked for additional family support funds to keep families together. *(www.unlockthewaitinglists.com)* 

• The Olmstead Decision – This is a landmark US Supreme Court case that originated in Georgia. The case, Olmstead vs. L.C. and E.W., was decided on June 22, 1999. The Court found that people who were segregated in institutions were victims of disability discrimination and should be given the opportunity to live in community settings. This decision included people with developmental disabilities, people with mental illness and elderly people. Georgia's DD Network led a broad coalition of interested parties for years in an effort to enforce the decision, and in 2010, a settlement between the US Department of Justice (DOJ) and the State of Georgia was reached that outlines quantifiable steps toward providing essential services and support so the thousands of people with disabilities in Georgia can live in their community rather than in institutions. (www.gcdd.org)

**Safe Schools Initiative** – On May 13, 2010, the Georgia State Board of Education initiated Rule 160-5-1-.35 "Seclusion and Restraint for All Students," which bans seclusion and greatly limits the use of restraints for all students in Georgia public schools. This was the first Georgia School Board initiation of a rule aimed at curbing the dangerous practice of restraint and prohibiting the use of seclusion. Prior to the ruling, students in Georgia schools could be restrained and secluded in public schools for any reason, in any way, at any time without their parent's knowledge. This initiative was spearheaded by GAO in collaboration with the other agencies of the DD Network, along with the Department of Education and Parent to Parent of Georgia. (www.thegao.org/SafeSchools.htm)

#### What's on the Horizon?

The recent landmark settlement between the DOJ and State of Georgia to enforce the Olmstead Decision is both a victory and a challenge for the agencies of Georgia's DD Network. At the time of the settlement, the DOJ estimated that approximately 750 individuals were institutionalized in Georgia, each at an annual cost of at least \$174,000. This compares to \$47,000, which is the average cost of providing an individual with developmental disabilities services in their home.

"We must build relevant supports and services for people in their own communities so they don't have to be institutionalized," Moore summarized. "This is the call for real homes, real jobs, crisis prevention services and quality management systems."

Moore added that the task ahead also encourages agencies and the State to foster more collaboration and partnership opportunities that allow people with disabilities to have good lives.

"Our main focus is the Real Communities Initiative," added Seegmueller. "This relies on communities identifying their own strengths and weaknesses, as well as the partners within the collaborative coming to the table and saying 'we will make a positive change.' You have to go from community to community and allow those people to identify the issues most pressing to them as well as the resources they have on hand to address those issues."

Describing Georgia's DD Network as a strong collaborative effort, Seegmueller summed up the past 40 years with this observation: "Somebody made the statement once that if we spoke with one voice we'd have one of the largest majorities in the country. It's hard to find somebody who's not impacted directly or indirectly by a family member with a developmental disability. We're not a minority. I've seen a lot of change in that direction during my tenure at GCDD."

By supporting a collective effort, Georgia's DD Network continues to build strong partnerships that address the needs of people with developmental disabilities and provide access to a better quality of life.



#### CHILDREN'S FREEDOM INITIATIVE

The goal is to ensure that children who live in facilities are given the chance to live with permanent, loving families and to create a Georgia in which no child resides in a facility. (georgiacfi.org)



"Because we don't have public transportation already in place, we can start a clean slate and create what people want and need."

# Transportation Within Our Reach

By Jill R. Alexander

## PERSPECTIVES



Jill Alexander is a former graduate of Partners in Policymaking, an Advisory Member to the Georgia Council on

Developmental Disabilities and a 2009 C. Anthony Cunningham Award recipient. Currently she is a Community Builder in Fitzgerald for the GCDD, Program Coordinator for Communities In Schools of Fitzgerald-Ben Hill County, Inc. and she also serves on the CAC council and the Jessamine Place Advisory Board.



Fitzgerald is a quaint, small town. It has beautiful old houses, wild roaming chickens and even a few of the original brick streets remain. It's a place where everyone seems to know each other. With that being said, you tend to hear about the struggles people in town face. One such concern that is being repeatedly addressed is the issue of transportation.

Getting around the city and county has become increasingly important, since it is wrapped up in not only the essential needs of everyday life including going shopping, to the doctor and paying bills, but also involves enjoying the richness our community has to offer.

The Real Communities Initiative in Fitzgerald focuses on finding solutions to accessible, affordable transportation. This is a community issue, and the people who have gathered to work on the transportation project vary from everyday citizens to community organizations, the technical college, elected officials and the city/ county governments. Because we don't have public transportation already in place, we can start a clean slate and create what people want and need. A survey was developed and distributed in various methods around Fitzgerald so that we could get a better idea of our transportation needs. Shortly afterwards, a community forum was held to hear directly from the people and discuss ideas of what transportation in Fitzgerald might look like. It was obvious that transportation options were needed, desired and supported.

Last July, our community supported and passed a Splost tax (Special Purpose Local Option Sales Tax) that designated over \$200,000 toward transportation. This really seemed to give momentum to the transportation cause. The passage of the Georgia Transportation Act has

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allowed us another opportunity to maximize funding. This law will give the 12 regions of Georgia a one percent sales tax to fund transportation projects in their individual regions. Therefore, the work was begun to put together a proposal for funding with our city and county government. We remain hopeful that when the votes are cast for our region, the Ben Hill County Transit Project will be funded.

For now, we continue to work with small groups, while taking the Asset-Based Community Development approach to find community-based solutions that offer the people of Fitzgerald and Ben Hill County transportation options. It has been a wonderful discovery to see just how many assets our community has to offer that often go unnoticed. Physical resources are only one piece of the true treasure of our community. Our greatest resource yet are the people themselves. In Fitzgerald and Ben Hill County people have worked to help each other get where they are going. We hope that our work will build on these inherent assets and help bring support and new ideas to the table that will address the transportation needs for our community. We believe the answer lies in a combination of efforts from public transit to volunteer driver programs, carpools or maybe even a bike- sharing program. We look forward to deciding the future of transportation in Fitzgerald and Ben Hill County.

## Why Should the Disability Community Be Interested in Transportation?

By John Keys

I do not need to tell the disability community just how critical transportation is to living fulfilling, productive lives – they already know. At meetings and gatherings of the disability community (and seniors as well), transportation continues to be one of the first issues raised as a major impediment to independent living.

This issue is especially critical as the disability community is de-institutionalized and people are moved into communities and living environments in which they will need transportation. I believe that the whole state knows there is a lack of available transportation options for mobility not only in urban Georgia, but also in the rural areas. However, "nothing ever gets done" about it!

For the past four years, I have worked towards building coalitions to obtain passage of statelevel agency Transportation Coordination legislation, which ultimately became part of the Transportation Investment Act (TIA). With its passage in the 2010 Session, the TIA provides the disability community a golden opportunity to address ideas for improvements and accessibility, which we have advocated for many years.

As transportation project lists begin being developed for all the regions of the state as part of the TIA process, we are seeing good initial efforts to advance transportation options for all Georgians – including the disability community. Nevertheless, we're a long way from getting to the finish line and need to do a lot of work to make it happen!

What Is Needed? My company has partnered with GCDD and other organizations to navigate the process of implementing the TIA, as well as advising and recommending how to get projects benefiting the disability community onto all the project lists. Below is a partial list of thoughts, ideas and concerns continually voiced by the disability community compiled from Conversations That Matter. These thoughts have been continually communicated to officials charged under the TIA with putting transportation options in front of voters in July 2012.

Many of our community's ideas are identical with other groups, and we have sought to partner with them wherever possible. These partnerships and shared ideas make it that much more important for elected officials to see that these ideas encompass all of Georgia, not just one segment of our population – transportation is about everybody!

Widespread sidewalks, with ramps • Expand statewide transit availability • Transportation one-call center for information on all transportation modes • Curbless bus stops for transit access • More inter-county connections • More transportation options for rural areas • Encouragement of livable communities around transit • More transportation volunteer organization involvement • Encourage faith-based and nonprofit community transportation efforts • Expand public/ private transportation partnerships • Provide regional travel training • Accessible taxi availability and services for those who don't drive and taxis in rural areas • Driver training for people with special needs • School bus use during non-school hours for senior and disabled transportation • Vouchers' availability for all transportation options

"Many of our community's ideas are identical with other groups, and we have sought to partner with them wherever possible."

## PERSPECTIVES



John Keys is a transit professional who has worked for both GRTA and MARTA in the policy and advocacy areas.

Over the past four years he has built coalitions to obtain passage of state-level agency Transportation Coordination legislation, which ultimately became part of the Transportation Investment Act. He is president of JKeys Solutions, a government affairs and advocacy company, representing a number of public and private entities in the transportation area, including GCDD.

**So What Do We Need to Do?** Project Lists for projects in your community are being put together now! Get involved:

- Go to GCDD's website, Facebook, etc. to learn more.
- Use the website info above for more, including proposed projects in your area.
- Tell your local officials what you want and demand their attention!
- Contact the officials on your "Regional Roundtable" and let them know how important these projects are to you...and all Georgians!

Get to work, so we all can have a better Georgia, filled with vastly more transportation options than we have at present!

## Forever We Are Siblings

By Becca Bauer

"The sibling without a disability sometimes really worries about their brother or sister and they can take on a lot of the worry from their parents as well. They might feel more pressure not to add stress to their parents, but they often have the same feelings of expectations, uncertainty and worry." Siblings are our playmates, enemies, motivators, supporters, listeners, personal comedians and teachers of all the sneaky little tricks we learn like how to steal an extra cookie at dessert time. Brothers and sisters seem to master the art of pushing each other's buttons in ways like no one else, but through it all they are the ones who know your personal story from the beginning. It is no surprise that the unique and complex sibling bond can evolve into one of the longest lasting relationships of your life.

In the United States there are more than six million people with disabilities. Many have brothers or sisters. These siblings share the same relationships that typical brothers and sisters do. While a disability can alter the family dynamics and lead to greater pressure for all family members, the results are not necessarily negative. The relationship between siblings can be powerfully affected by a disability.

There is still a wide range of perspectives on how much a disability in the family impacts the lives of siblings. According to Cheryl A. Rhodes, M.S., co-author of *Brothers and Sisters: A Special Part of Exceptional Families*, Third Edition, and fellow of the Centers for Disease Control and Prevention(CDC) the children in the family without a disability often share similar experiences as their parents and face the same challenging issues.

"The sibling without a disability sometimes really worries about their brother or sister and they can take on a lot of the worry from their parents as well. They might feel more pressure not to add stress to their parents, but they often have the same feelings of expectations, uncertainty and worry," says Rhodes. She suggests one way to reduce this is for parents to simply give their typical developing child a chance to express their feelings and most of the time they will open up.

A family's time can become consumed by everything from numerous hours spent at the hospital, making adjustments to household needs or determining where you can or can't go as a family. There are a number of variables that can shape a sibling's bond, but it is very individualistic.

How a disability affects the relationship between brothers and sisters varies from person to person; nevertheless, there are some common issues they will address at some point in their



relationship. These may include siblings possibly having to deal with feeling excluded or not as important as their sibling, having to take on more responsibilities, teasing or bullying from peers, guilt and more. Despite these challenges, most siblings with a brother or sister who has a disability confront these tests head on and share an unbreakable bond.

There is a great mix of emotions that can arise growing up with a sibling who has a disability, from shame and resentment to understanding and inspiration. For this reason, it is not uncommon to see siblings gravitate towards the helping professions or specifically work with advocate groups applying their personal knowledge on developmental disabilities. "I think siblings have been instrumental in supporting advocacy efforts...they serve an important role because as they take on advocacy jobs to make sure their sibling can lead a dignified life, they are impacting the whole community," says Rhodes.

Because people in general are living longer lives, addressing the future is becoming an increasingly important subject. Adult siblings of people with developmental disabilities are the most likely people to be involved as parents age and can no longer provide support for their child with disabilities. Rhodes believes it is important to start making plans for the future early and include all of the family members. "Whether it is setting up a trust or making decisions about what is going to happen, it's on everybody's mind and the sooner they can make those plans and include the siblings the better, because one way or another it's going to affect them too."

It is up to each individual how they address the future and their relationship with their sibling, but it is not uncommon for them to share a different kind of closeness. A disability can influence life decisions for the whole family, and children who have siblings with a disability often become some of the most well-adjusted, compassionate and understanding people.

Twins Anna Watson and Ashley Freeman are sitting together watching a teeny-bopper film and flipping through magazines admiring the cute boys. They are at the height of sisterly bonding, indulging in some serious girl guilty pleasure. It would never cross your mind that Ashley has a developmental disability. After going into premature labor with Anna, unbeknownst to Claudia and Leigh Freeman and the doctors, two minutes later they welcomed Anna's twin sister, Ashley. Six months later Ashley was diagnosed with cerebral palsy. For Anna, it was scary having to watch her twin go through so many surgeries, but she says, "we were always chasing each other and even though she does not communicate verbally, we still share a normal sister relationship and healthy competition."



"We were always chasing each other and even though she does not communicate verbally, we still share a normal sister relationship and healthy competition."



## siblings



"When you are younger you don't realize. We did so many things that normal brothers and sisters do...I didn't know he had a disability and that he wasn't like all of us."



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Growing up, Ashley was known as more outgoing and Anna a little more introverted, and although they went to different schools, they were still very much involved in each other's life. Spending summers at the pool, anxiously waiting for Santa on Christmas and hanging out at the house with friends are just a few of their childhood and teen memories. It was not until middle school that Anna started having problems with people using unkind words about disabilities. She found it difficult when people would feel sorry for her because Ashley has a disability. "My philosophy is that it is something I'm better for. She is very happy and we are happy to

have her," she says. She understands that it is hard for people who aren't use to it, but it doesn't have to be awkward. Despite these feelings, Anna remembers her friends were all accepting and happy to include Ashley. Anna is especially grateful that one of her best friends became like a member of the family and treated Ashley like her own sister. She remains a great friend to both Anna and Ashley.

According to Claudia Freeman, "to this very day Anna is completely devoted to her. I think many of Ashley's successes result from having Anna as a sister." As an adult, Anna continues to be involved in Ashley's life and the developmental disability community. She spends time often with Ashley, is a committee board member at her sister's community center and works at GCDD as a planning and policy specialist. They are both there for each other in daily life and the big moments. Anna supported Ashley as she competed and won a gold medal in swimming at the Special Olympics, and Ashley was there by Anna's side at her wedding participating in all of the bridesmaid fun.

siblings

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Currently, Anna and the whole family are working towards getting Ashley more

active in the community and securing more supports for her. As for Anna, there is no doubt in her mind about the future. She and her husband would openly welcome sharing their home with Ashley if she ever needs to live with them one day. Ashley is Anna's sister and that's the way it is going to be.

Will and Claire Crain share a similar sibling bond. Passing the time playing in the family room, as any young girl without a sister would do, Claire has roped her brother into playing dress-up and becoming her personal "doll." Again, with this normal situation of a sister torturing her little brother you would never guess that Will, now a 15-year-old, has a developmental disability. Four days after being born Will was diagnosed with urea cycle, a genetic disorder, and underwent several traumas to his brain. Even for Claire, now 18, her brother's disability did not register until she was older. She says, "When I was in sixth grade that's when I really understood. When you are younger you don't realize. We did so many things that normal brothers and sisters do...I didn't know he had a disability and that he wasn't like all of us."

Claire is very involved and often helps her parents care for her brother. Will dresses and bathes himself and is in the process of learning independent living skills, but Claire

still helps with his homework and around the house. Sometimes when her parents are away she takes on a lot of responsibility and acts as a mini-mom, cooking, cleaning, doing laundry and getting everything in order. Although she takes on a lot, it doesn't mean that they don't share some of the household

responsibilities. Will has his own chores and takes out the trash, unloads the dishwasher and cleans his room.

Today the pair is still close and loves to play cards, spend time with the family, go to the movies and cheer each other on at sporting events. Claire is very active in tennis, and created a special needs tennis camp last year that Will plans to attend this summer. Additionally, Will does not let his disability hold him back from participating in team sports. On his kayaking and canoeing team, Will is the only member who has a disability. Recently the team participated in the Junior Olympics Canoe and Kayak Regatta in Will's hometown of Gainesville, GA, and they came away with the gold medal.

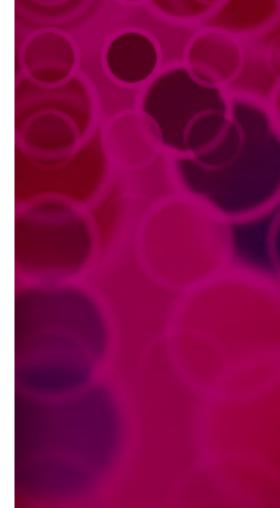
Sometimes it is a balancing act to make sure nobody in the family feels left out. When you have a child who has a disability their needs get pushed to the front of the table, and Scott Crain, Claire and Will's father, acknowledges that there have probably been times in Claire's life that she has experienced these feelings. He says, "we are parents and there have to be discussions. We have tried to confront these feelings with piano lessons, tennis and spending a lot of time with her and her activities."

The Crain's are confronting the uncharted future by setting up trust funds and starting to put things in place to maximize Will's independence as he grows older. It is a topic they consider to be a family decision. Not only do they plan to put Will's wants and

Not only do they plan to put Will's wants and needs first, but they make it clear that Claire understands that she doesn't need to take 100% responsibility of Will's future. It will be her choice if she wants to have Will live with her one day. It Will's wants and needs first, but they make it clear that Claire understands that she doesn't need to take 100% responsibility of Will's future. It will be her choice if she wants to have Will live with her one day.

Arjun and Angad Sahgal are joking and kicking around the soccer ball, like typical

brothers – getting dirty and playing outside. Arjun doesn't dwell on the fact that Angad has Down syndrome. Their mother, Aarti Sahgal, still remembers explaining what this meant to her oldest son Arjun, now 17. "We did not try and hide anything from him and "Sometimes it is a balancing act to make sure nobody in the family feels left out. When you have a child who has a disability their needs get pushed to the front of the table..."







"One of the ways Aarti acknowledges Angad's disability has really impacted Arjun's life, is that he is more responsible and focused than many young people his age." explained to Arjun that Angad had an extra chromosome and would be a little different from other kids." One day out of the blue, she remembers Arjun asking her about if that extra chromosome meant Angad was extra fast and extra special, and that is when she realized just how much he had thought about his brother's disability.

To this day, Arjun still thinks about the extra chromosome and all that it means. According to Aarti, growing up Arjun was "like a little surrogate parent in many ways. He knew he could set an example and Angad thought of him as a role model, always saying 'Arjun wouldn't do this and I should do what he does'." So to set an example, Arjun spends a lot of time playing soccer, basketball or video games with Angad. He even indulges his little brother and includes him in hanging out with his friends when they are at the house. Sometimes they even bring him along to the movies, something not many older siblings would relish doing.

One of the ways Aarti acknowledges Angad's disability has really impacted Arjun's life, is that he is more responsible and focused than many young people his age. She attributes this partly to her struggle to find a balance at giving equal attention to both boys, but also because Arjun reacted strongly to people who were mean to Angad or just didn't understand his disability.

As a way to confront his issues with bullying, he started a club at his high school focusing on inclusion. His aim was to make people who stand out feel comfortable and still be able to participate in school activities. Aarti describes his advocacy as "his way to come to terms with his brother's differences because in the past it made him angry."

Not only does Arjun help fight to change people's views in regards to differences, he also helps his parents around the house and cares for Angad. Arjun "is never ashamed or shy. He is very proud and realizes what Angad's strengths are," says Aarti.

The stories of Anna and Ashley, Will and Claire and Arjun and Angad can teach us a great deal and shed light on just a few ways that sibling relationships are impacted by a disability. Their stories are part education and part hope. At one time or another, all families experience challenges, whether it is the loss of a parent's job, a divorce or caring for a child with special needs. Yes, having a brother or sister with a disability can alter life for siblings, but it can also bring great gifts as well - helping siblings learn patience, kindness, empathy, the importance of speaking up for others like Arjun did, Claire's joy in seeing a loved one succeed on whatever level they can and sometimes even influence a choice in career like Anna.

For better or worse all siblings are tied together for life, but through its ups and downs, it is nice to always have someone there by you along for the ride.

#### EXPERT UPDATE

## Sibling Support: Understanding What's Out There For Siblings

By Don Meyer

I'm the lucky guy who gets to direct Sibling Support Project, a national effort dedicated to the lifelong concerns of brothers and sisters of people who have special health, developmental or mental health concerns.

At Sibling Support Project, we believe that disabilities, illnesses and mental health issues affect the lives of all family members. We seek to increase peer support and information opportunities for brothers and sisters of people with special needs, as well as to increase the understanding of sibling issues among parents and providers.

Throughout their lives, brothers and sisters often share many of the same joys and concerns that parents of children with special needs experience. Despite the important roles they will play in the lives of their siblings with special needs, even the most family-friendly agencies often overlook brothers and sisters.

While we have several sibling initiatives, we're probably best know for Sibshops, which provide young brothers and sisters with peer support within a lively, recreational context. Sibshops are pedal-to-the-metal events where brothers and sisters can meet other young peers experiencing similar circumstances and have fun, laugh and talk about the good and not-so-good parts of having a sibling with specials needs, play some great games and learn something about the services their brothers and sisters receive.

At Sibshops, kids have opportunities to talk about issues they sometime find themselves facing, such as defending your sibling from kids who make rude comments; explaining your sibling's disability to others who ask; what to do when you'd like a bit of your busy parent's time and attention; and what to do when your sib has a meltdown at the mall.

There are currently 320 Sibshops worldwide and four of them are in Georgia. Originally, Sibshops were developed for eight to 13-yearold brothers and sisters, but some Sibshops are for sibs as young as six and other are for teens.

We do many workshops for parents and service providers on sibling issues and frequently meet with adult siblings. For almost 15 years we have hosted SibNet, a listserv that provides validation and information for thousands of adult siblings from around the world. We also host the SibKids and SibParent listservs and have published six books on sibling-related topics.





Don Meyer is the director of Sibling Support Project and the senior author and editor of numerous articles and six books.

## EXPERT UPDATE

"Despite the important roles they will play in the lives of their siblings with special needs, even the most family-friendly agencies often overlook brothers and sisters."

> To learn more about the work of Sibling Support Project, please visit www.siblingsupport.org or call us at 206.297.6368.

# REAL COMMUNITIES



"I never thought to think about what my child wanted and I only focused on what I wanted as a parent."



Theresa An and her fellow group members enjoy their interactive learning journey in Wisconsin.



#### REAL COMMUNITIES INITIATIVE

## Real Communities Open Up Possibility to Real Change

Theresa An, a member of the Korean Coalition and mother of a son with autism, never could have believed the notion of two people with disabilities living together independently until she saw it firsthand. On a recent learning journey to Wisconsin, which are trips that offer the opportunity to travel and discover where innovative work is already in place and could be adapted to your community, An had an eye-opening epiphany on her perspective of disabilities.

In Wisconsin, An visited Living Our Visions (LOV-Dane), a grassroots organization of individuals with disabilities, families and community members building communitycentered lives for all individuals. Through LOV-Dane she had the chance to observe how others facing similar barriers embraced their disabilities and participated in the community. After having conversations with the young adults with disabilities and their parents, she gained a different outlook and realized that she could learn here and adapt several ideas to help her community grow as well.

For her it was interesting to talk with the young adults and parents separately and learn that what the people with disabilities wanted and what the parents wanted were different. "I never thought to think about what my child wanted and I only focused on what I wanted as a parent," she says. It shed light on the fact that it is important to remember to focus attention on the individuals

> with disabilities themselves because people's needs are different and cannot always be pushed together in one group.

An found that the people she met in Wisconsin did not dwell on the negative aspects, but rather came to terms and fully embraced their disabilities. She admits, "in the past I spent a lot of time focusing on what my son needed or what he lacked, but in Wisconsin they focused

what he lacked, but in Wisconsin they focused on their talents and skills and helping to grow those." It was an enlightening realization that it is important to not just concentrate on the deficits, and she wants to explore this concept with her community.

She realized that she has the ability to do more than wait and rely on resources from the government. Instead, she understands it is her role as a parent to help create a community that allows for social growth focusing on people with disabilities needs, wants and independence.

An has already put her goal in motion to be proactive and cultivate innovation, while experimenting with new approaches. Her first step was to meet with the other parents in the coalition to paint a picture of her new knowledge and how they can integrate these different outlooks into their community and become more comfortable reaching outward.

Other parents are supportive and open to An's new approach on disabilities. Already they are responding and trying to focus on the needs of the individual, making an effort to take into consideration the gifts and talents of each.

Traditionally the Korean community is closeknit and typically looks internally for support. Before the learning journey, An felt that their community was a little pond and only saw a little bit of the big idea, but after visiting Wisconsin she is determined to encourage others to take more steps toward the bigger community.

#### MIA'S SPACE



## Lessons for Living a Life

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

## Pay Attention. Be Astonished. Tell "about it."

These words for living a life were shared with 30 participants at GCDD's Real Communities retreat by the new director of the Frazier Center (he was quoting someone else) and I thought, "How nifty, easy to remember." The trouble is, you can be astonished by good and bad things. And you probably need to tell about both. So here are two contrasting things that I was astonished by in the past year that I need to tell about.

The day after the Real Communities retreat, I drove down to Warner Robbins to see Mia compete in the Special Olympics State Masters Bowling Tournament. Here's the astonishing part. Fifteen hundred athletes with cognitive disabilities, of all ages, were organized to compete in three games each, four athletes to a team (not the group they came with, but athletes from other parts of the state) and rotating bowling lanes between Friday night and Sunday morning in four hour shifts. Each group had an assigned volunteer and they were great supporters, just making sure things ran smoothly, but giving folks lots of space and autonomy in-between shifts, award ceremonies presented medals, ribbons, tears (from parents mostly) and laughter. It was loud and busy, but General Patton couldn't have organized it better. I haven't been surrounded by that much friendliness and support and joy in a long time. Athletes who had never met cheered for each other, high-fived, offered encouragement, congratulations and hugs. Their spirit was natural and genuine, and I felt like I needed to stock up on it, to build up a reserve.

Here's the contrast. After that experience, I heard this story of a woman, I'll call her Mary, caring for her sister with disabilities (whom I'll call Jane) who had come to live with her from another state. Jane needed medications to remain stable and if she got them, she was fine. Mary took Jane to a Community Service Board to try to get the prescription filled, and they ended up sending Jane to the nearby hospital emergency room for "medical clearance" and when she didn't emerge from the hospital intake area for a few hours, Mary anxiously inquired after her, and was told that she was being sent to a state institution quite a distance away. Mary wasn't allowed to see Jane or accompany her. She was literally just taken away and involuntarily committed to the same hospital system that we have an Olmstead Plan for transitioning people out of. I was astonished by this too.

I don't know all the details, but based on the story I heard about Mary and Jane, I cannot imagine that Jane had any more complex or significant disabilities going on than the 1500 athletes that took over Warner Robbins and played together for three days. Yet she ended up in an institution.

You have to wonder, just what are people paying attention to? Are we attending to the right things? Are we open to being astonished by the good things people bring to communities without trying to "treat" them? In the end, what kinds of stories are we going to be able to tell?

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"In the end, what kinds of stories are we going to be able to tell?"

## MIA'S **Space**





## Keeping Long Road Home Going

By Cheri Mitchell

Long Road Home, a campaign that supports enforcing and celebrating the famous Supreme Court decision Olmstead vs. L.C. and E.W., started in 2004 and was the brainchild of Kate Gainer, who brought the idea to People First of Atlanta and the rest is history! To this day we still hold celebrations that work towards transitioning individuals with disabilities out of institutions and into the community.

The first Long Road Home video starred my late husband, Samuel Mitchell, and was inducted into the Civil Rights Hall of Fame in Alabama. Long Road Home has a deep sentimental value to me because of Sam's involvement, and I am proud to chair Long Road Home this year. I dedicate my participation in memory of Sam, who spent two years in a nursing facility and never wanted to be there.

It is my hope to see Long Road Home celebrations happen all around the country next year. Is it possible? I do not know, but I am going to call friends and national organizations and put my best effort forward because Olmstead compliance is an important issue. I really feel this effort could make a difference, and I ask that everyone say a prayer for me that it happens. Because of Sam's personal experience and the fact that I know I am one health crisis away from being in a nursing facility myself, I, like every other person with a disability, live daily with this threat.

As a result, I focus my advocacy on helping people transition from nursing facilities into their own homes. I have done a lot of work with Money Follows the Person (MFP), which is an initiative that helps individuals in various institutions return to their communities, and I provided subject matter expertise for developing and editing of materials and training for the transition coordinators. Additionally, I have done housing trainings all around the state to help people with disabilities understand what they need to know and how to do a successful housing search.

I also want to bring the traveling exhibit, "The Lives They Left Behind: Suitcases from a State Hospital," to Georgia as part of the Long Road Home events. I need lots of support and help from the disability community to make this happen, but I believe it provides a glimpse into how it really was for people living in an institution.

As part of my advocacy work, I speak from my heart and share lots of my own and Sam's personal stories for people to relate to. One thing I hope to do more of in the future is share my story about why it is so important to do medical directives and person-centered planning in order to protect your wishes and improve the quality of your life. I am also excited about helping the Protection and Advocacy Agencies for Georgia (P&A Network) around the country, and I am thinking about how I can include self-advocacy into their work.

My motivation is to make a difference. I believe in equal rights and opportunities for everyone including people with disabilities – I really stress valuing all people. I am a disability civil rights activist, self-advocate, speaker, teacher, community organizer, role model and mentor for new self-advocates and people with disabilities. I act as a statewide leader in the disability community, and I am currently serving as a national chair for the National Disability Rights Networks Community Education and Selfadvocacy (CESA) committee.

I want to thank Ruby Moore, Julie Kigley and Jenny Puestow at the Georgia Advocacy Office for being great mentors, supporters and friends. I could not do half of what I do without them. I understand and live the independent living philosophy, and what I love most is to empower others to find their voice.



Cheri Mitchell

"I believe in equal rights and opportunities for everyone including people with disabilities – I really stress valuing all people."

## STRAIGHT TALK

"As part of my advocacy work, I speak from my heart and share lots of my own and Sam's personal stories for people to relate to."

Sam Mitchell

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## July

July 21-22 GCDD Quarterly Meeting Atlanta, GA 404.657.2126 / 888.275.4233 (ASK.GCDD)

July 21 GCDD Award Ceremony Open to Disability Organizations Atlanta, GA Contact: Dee Spearman 404 .657.2121

July 22-24 Camp Caglewood Nantahala River - White Water Rafting Bryson City, NC • www.caglewood.org

July 25-26 2011 Technical Assistance Inst. ITTAC (Information and Technical Assistance for Councils on Developmental Disabilities) The Liaison Hotel • Washington, DC www.itacchelp.org

## August

August 4-8

The Arc's National Conference of Executives (NCE) Summer Leadership Institute Hyatt Regency Inner Harbor, Baltimore MD Contact: Laurie Ertz at Ertz@thearc.org 202.534.3708 • www.thearc.org

#### August 5-11

The 39th Annual NDSC Convention National Down Syndrome Congress San Antonio, TX www.ndsccenter.org

## **CALENDAR** HIGHLIGHT:

August 26-28 Abilities Expo Houston, TX www.abilitiesexpo.com

## September

September 9-11 Camp Caglewood Amicalola Falls State Park Dawsonville, GA • www.caglewood.org

#### September 16-19

The Arc's National Convention The Sheraton Downtown Denver, CO Contact: Laurie Ertz Ertz@thearc.org • 202.534.3708 www.thearc.org

## October

October 1 Georgia Race for Autism and Fall Festival Gwinnett County Fairgrounds Lawrenceville, GA www.georgiaraceforautism.com

#### October 1-6

Reel Abilities Atlanta Disabilities Film Festival Atlanta, GA reelabilitiesatl@gacommunity.org www.reelabilitiesatl.org

#### October 3

GA APSE 2011 Statewide Conference Athens, GA Contact: Debbie Walker-Lass dswalker@clayton.k12.ga.us • 770.472.7675



October 9 1:00 – 5:00 PM Atlanta Buddy Walk Centennial Olympic Park Registration opens July 1 buddywalk@atlantadsaa.org www.atlantadsaa.org

#### October 11

11:00 AM Dads Appreciating Down Syndrome (DADS) of Atlanta Golf Tournament Bear's Best Atlanta Suwanee, GA www.atlantadsaa.org

#### October 21

GCDD Public Forum Gainesville, GA 404.657.2121

October 21-22 GCDD Quarterly Meeting Gainesville, GA 404.657.2126 / 888.275.4233 (ASK.GCDD)

## 2011 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 Sept. 1 to be included in the fall calendar. For a full list of events, visit: gcdd.org/events-calendar

The Festival will be a week long celebrating filled with first class films, artistic performances, and talkbacks in tribute to those living extraordinary lives with disability.

Please join us as we celebrate the lives of those who have: **REELABILITIES!** 

## **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

#### The DD Network

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

Georgia Advocacy Office (GAO) www.thegao.org

Institute on Human Development and Disability (IHDD) www.ihdd.org

Center for Leadership and Disability (CLD), GSU www.chhs.gsu.edu/cld/about.asp

#### **DD Network Initiatives**

Children's Freedom Initiative www.georgiacfi.org

Unlock the Waiting Lists! Campaign www.unlockthewaitinglists.com

#### Other

Rising Expectations: The Developmental Disability Act Revisited, National Council on Disabilities February 12, 2011 www.ncd.gov/publications/2011/ Feb142011#toc9

#### Transportation

Find the 12 Regional Commissions www.garc.ga.gov/main. php?Regional-Commissions-2

Atlanta Journal Constitution www.ajc.com

Ray Christman, Executive Director Liveable Communities Coailition www.livablecommunitiescoalition.org

Phil Jacobs, chair of Georgia Chamber of Commerce's transportation committee www.gachamber.com/ Butch McDuffie, Athens Transit Director www.athenstransit.com/

Pat Nobbie, PhD, GCDD Deputy Director pnobbie@dhr.state.ga.us www.gcdd.org

Patricia Puckett, Executive Director ppuckett@silcga.org

State Independent Living Council (SILC) www.silcga.org

Alice Ritchart Alice.ritchart@comcast.net Coalition for the Blind

Dave Stockert, President & CEO of Post Properties and chair of Metro Atlanta Chamber's transportation policy committee www.metroatlantachamber.com/

Tad Leithead, chairman Atlanta Regional Commission www.atlantaregional.com/

#### Expert Update

www.siblingsupport.com

#### News

REELABILITIES Atlanta Film Festival www.reelabilitiesatl.org Judy Marx reelabilities@gaccommunity.org

reelabilities@gacommunity.org 404.634.4222 ext 267





#### 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

YourToolsforLi**Y**ing.org

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



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Lois Curtis

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# A quarterly magazine of the Georgia Council on Developmental Disabilities VOLUME 12, ISSUE 1

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Curtis



**SUMMER 2011** 

## LONG ROAD HOME



