

FALL 2010

Making a Difference



2010 Awards Ceremony Recap

Aging & Disability: Securing Long-term Care for Aging Persons with Developmental Disabilities

November Elections: Who Has Your Vote?

www.gcdd.org

A quarterly magazine of the Georgia Council on Developmental Disabilities

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

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



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Citizen vs. Consumer. Which One Are You?

In their new book, *The Abundant Community*, Peter Block and John McKnight discuss the shift in our culture from citizen to consumer. "A citizen is one who is a participant in a democracy. They are those who choose to create the life, the neighborhood, the world from their own gifts and the gifts of others." On the other hand, a "consumer is one who has surrendered to others the power to provide what is essential for a full and satisfied life." The GCDD Real Communities Initiative is utilizing this philosophy of "citizenship" in several communities to create places where everyone can share those gifts and live in welcoming neighborhoods and towns. As citizens, it is important that each of us participate in our communities. Only as consumers do we give up our responsibility and let others create the places where we live, work, play and worship.

It is also important as citizens that we participate in the upcoming elections. Candidates for every major state and local office will be decided on November 2nd. In a democracy, you have an obligation to ask candidates where they stand on an issue and to vote based on the candidate's position as it relates to your own goals, beliefs and needs. We know the economy is bad, and candidates will tell you they can't do anything because there is no money. It might be a good time to find out where the candidates stand on looking for additional revenue sources, such as expanding the tax base. Before voting, ask each candidate what they will do to address the waiting list for home and community-based services. Ask them about ending the practice of segregating people with disabilities in public institutions and workplaces. Remember it is your civic duty as a citizen to vote on November 2nd.

It used to be that families and neighborhoods came together to provide support to those who might have needs. Now we rely less on our communities and more on large bureaucratic systems funded through even larger systems such as Medicaid. As Block and McKnight suggest, "consumerism is not about shopping, but about the transformation of citizens into consumers." It means we have surrendered the right to control our own lives and let others make decisions for us. In other words, entities such as the Department of Behavioral Health and Developmental Disabilities, Department of Community Health and other providers have told us what we need and put requirements on how we can or cannot spend funds. We are not suggesting getting rid of the publicly funded system of services and supports, but we do think it is time to take back our responsibilities of citizenship and find ways to bring communities together again. Maybe it means being a good neighbor and when we go to the grocery store asking others if they need something. What about recruiting church, synagogue or mosque members to outfit an older home so that someone who uses a wheelchair can get in and out? We heard someone recently talk about getting a job, not through a job coach, but by networking with members of his homeowner's association. These are the kinds of actions that make us citizens instead of consumers thereby improving our own quality of life and that of others in our communities.

This edition of *Making a Difference* will talk about all of these issues. You will also read about GCDD's new image and messaging, reflecting a new name (Georgia Council on Developmental Disabilities) and new initiatives. We hope you will like this new look. Let us know what you think by emailing us at vmsuber@dhr.state.ga.us. ●



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ADRCs help consumers, health professionals and caregivers learn about the availability of public and private services and also assist in streamlining access to care.

ADRCs Streamline Access to Care

By Jay Bulot, Director of Aging Services, GA Dept. of Human Services

As a new resident of Georgia, I have been impressed by some of the initiatives and innovative approaches that have been developed to maintain the independence and well-being of individuals with disabilities in this state. The similarity of needs faced by individuals, regardless of whether they are a result of age, developmental disability or both, is striking. Extended life expectancy is a common denominator that overlaps both the aging and disability populations. In the future, more attention will be paid to creating consumer directed systems of care that offer individuals a true choice of services and are oriented to allowing supports to individuals to maintain community living.

A harbinger of that trend is Georgia's Aging and Disability Resource Connection (ADRC) network. We are working to make ADRCs trusted, visible places in the community that provide information about a full range of long-term support options. In effect, they will be a one-stop-shop for consumers who are searching for help but are often frustrated and confused by the fragmentation of the existing healthcare delivery system.

Currently, ADRCs help consumers, health professionals and caregivers learn about the availability of public and private services and also assist in streamlining access to care. ADRCs provide information, referrals, screening, assessment, options and benefits counseling, crisis intervention and assistance in allowing consumers to make informed decisions about how to best meet their health needs.

Most importantly, ADRCs represent a mechanism for diverting individuals from institutions and keeping them in the most integrated community setting. Consider the following instances where the ADRCs were able to source and streamline care:

An open-heart surgery patient was frantic because her doctor would not immediately discharge her to care for an adult son at home with Duchene's Muscular Dystrophy. Her physician thought the physical burden of caring for her son would be too much for her. The mother began filling out applications from her hospital bed to get her son

on a waiting list for services. ADRC intervened and found temporary in-home care for the mother during her recovery, and arranged for a combination of Medicaid waiver services for personal supports and grant funds for emergency respite while the Medicaid services were being approved. Now, both mother and son are at home receiving services under the Community Care Services Program.

A 60-year-old grandmother and her teenage grandson with a developmental disability were moving to Georgia from New York and didn't know where to begin to find a school, medical assistance and other community-related resources. Through the ADRC, the grandmother not only learned what assistance was available to her, but she was also connected to a support group for grandparents raising grandchildren with developmental disabilities.

Since 2004, ADRCs in Georgia have grown from two pilot sites serving two regions of the state to 12 ADRCs that serve all 159 counties. In State Fiscal Year '09, the ADRCs served 106,279 individuals looking for a variety of home and community-based services. These numbers included clients over 60 years of age and younger individuals with disabilities. During that same period, a little more than 74,403 ADRC contacts were made by individuals and caregivers representing those with developmental disabilities, mental illness and physical disabilities seeking information about long-term care options.

The key to success for ADRCs is collaboration. Coalitions, advisory groups, educational programs, and partnerships help facilitate the flow of information between public, private and community organizations. Current federal demonstration grants and the Affordable Care Act assure that ADRCs will play a much more visible role in transitioning individuals from institutions into the community in the future. They will continue to benefit consumers by linking acute and primary care with long-term care and by serving as a gatekeeper to reduce costly medical expenses, as well as promote the well-being of Georgia's families and individuals dealing with chronic health conditions. ●

Dr. James Bulot, a 2004 graduate of the UMB Gerontology program, recently joined the Department of Human Services in the position of Director of Aging Services for the state of Georgia. Previously, Dr. Bulot had been appointed by Governor Bobby Jindal as Executive Director for the Louisiana Office of Elder Affairs. Before that, Dr. Bulot was an Associate Professor of Gerontology and head of the Department of Gerontology, Sociology, and Political Science; he was also the Endowed Professor of Gerontology at the University of Louisiana at Monroe.



Direct Support Professionals Are Recognized for Hard Work

To honor the direct support workforce, on September 15, 2010, Georgia Governor Sonny Perdue issued a proclamation designating the week of September 12, 2010 as Direct Support Professional Recognition Week. This honor, bestowed upon direct support professionals (DSPs), recognizes them for their work with Georgians living with disabilities.

The proclamation was adopted in many states and is now recognized nationally. In a press release issued by the National Advocacy Campaign for the American Network of Community Options and Resources (ANCOR):

"In a show of bipartisan support, and for the third consecutive year, the U.S. Senate unanimously approved a resolution designating the week beginning September 12th as "National Direct Support Professional Recognition Week." Sponsored by Senator Ben Nelson (D-NE), Senate Resolution 558 recognizes Direct Support Professionals (DSPs) for their commitment to supporting individuals and promoting community-inclusion for individuals with disabilities of all ages. Senator Nelson was joined by Senators Kerry (D-MA), Brownback (R-KS), Dodd (D-CT), Bingaman (D-NM), Johanns (R-NE), Collins (R-ME), Bunning (R-KY), Carper (D-DE), Brown (D-OH) and Udall (D-CO) as co-sponsors of the bill.

"In a show of bipartisan support, and for the third consecutive year, the U.S. Senate unanimously approved a resolution designating the week beginning September 12th as "National Direct Support Professional Recognition Week."

DSPs work tirelessly to ensure that people with disabilities live more independently and in community settings. However, low wages coupled with difficult work often leads to high turnover of DSPs. The Bureau of Labor Statistics projects that one million new DSPs will be needed by 2016. Of those, 38 percent (388,538) will be for personal and home care aide positions, which is the category where DSP positions are most often needed.

In 2004, GCDD developed the Direct Support Professional Certificate Program that imparts practical knowledge, but also teaches DSPs how to be advocates for their focus person. As caregivers and advocates, DSPs can help make dreams attainable for individuals with developmental disabilities. GCDD joins the nation in celebrating the undervalued work that DSPs do every day!

Hall County Project SEARCH Graduate Rescues Two-Year-Old from Near Drowning

Perla Rodriguez, a 2009 Project SEARCH graduate, recently performed CPR on a two-year-old little girl after she had been submerged for almost two minutes. Rodriguez not only saved the toddler, but she survived the incident with no injuries.

Perla and her family were enjoying an afternoon at a park near their home, when Perla's 16-year-old brother, Emmanuel, started calling her. Emmanuel happened upon the family of the little girl, whom they had just retrieved from the lake. When Perla reached the child, her face was blue and she was unresponsive. Her mother was clutching her tightly, apparently in shock.

Perla was able to convince the mother to release the child so that she could perform CPR. After performing CPR, the girl revived, expelling water into Perla's face.

According to Colleen Pirkle, Hall County Project SEARCH instructor, "The child's family was so grateful to Perla, and we are so proud of her heroic effort!"

Perla was featured in the Fall 2009 issue of *Making a Difference* for her graduation from Project SEARCH and subsequent hire at the Northeast Georgia Medical Center in Gainesville, GA, where she is responsible for taking the vital signs of new patients in the emergency room. As a prerequisite for her job, she took a CPR class. It turns out that CPR skills aren't just for the emergency room. ●



Perla Rodriguez



Disability Day at the Braves Game September 13, 2010

**Honorary Team Captain:
Reed King** (Shown center with his brother, Tate, and sister, Callie.)

Community Builders Provide Localized Support By Leigh Jones

In August, GCDD began work on three new initiatives designed to build bridges between people with disabilities and the communities where they live.

The outreach efforts in metro Atlanta, Fitzgerald and Milton are part of the Real Communities Initiative, which aims to make Georgia's cities and counties more inclusive and welcoming of all people, including those with disabilities. Each program, led by a trained community builder, was formed to meet the unique needs of the area it serves.

Fitzgerald Transportation Improves

In Fitzgerald, a rural city in south-central Georgia, the lack of public transportation makes it hard for individuals with disabilities, the elderly and anyone without a car to live independently, Caitlin Childs, GCDD's organizing director for the Real Communities Initiative said. Like other growing communities, many of Fitzgerald's grocery stores and schools are on the outskirts of the city, making them dangerous to get to on foot or in a wheelchair.

Last year, a car driving through town after dark struck and killed a man in a powered wheelchair. That accident, and others like it, helped convince area residents something had to be done about the city's lack of transportation, said Jill Alexander, GCDD's community builder in Fitzgerald.



Jill Alexander

"Transportation here is not just about getting people to the doctor but about helping them to live their lives."

"Transportation here is not just about getting people to the doctor but about helping them to live their lives," Alexander said.

Fitzgerald voters passed a special sales tax earlier this year that allocates

about \$250,000 to address transportation issues. Alexander is organizing neighborhood meetings to talk to residents about what kind of transportation network would serve them best.

Milton Funds Neighborhood Projects

In north Fulton County, the City of Milton is using seed money provided by GCDD to create a mini-grant program to encourage small groups of residents to invest in their community by creating and taking part in small neighborhood projects. Under the leadership of Ann Coggins, the committee will establish an application process and oversee the administration of the \$500 grants.



Ann Coggins

In other cities, similar successful grant programs provided funds for community gardens, public murals and block parties, all with the goal of making residents more connected to their communities, Childs said.

Atlanta Empowers Korean Community

The third Real Communities program will strengthen relationships between families dealing with disabilities in metro Atlanta's Korean community and help the group start thinking about ways to engage the larger community.

Many of the families are first generation immigrants who need help

figuring out the state's complicated social service programs, especially for children transitioning out of the public school system.

As the group gets started, the first goal is to change the typical Korean model that gravitates to top-down leadership and decision-making. Chung and other facilitators are focusing on building the families' confidence and setting goals they can successfully reach.



Sharon Chung

"We really want to empower parents to see that they do have the ability to make decisions for themselves," Chung said.

"We really want to empower parents to see that they do have the ability to make decisions for themselves."

While the first three community builders begin their work, Childs and Mike Green, the Real Communities consultant, are in talks with other groups who want to join the initiative.

The Community Action Pioneers of Gwinnett, a group of parents of children with disabilities, is exploring the possibility of creating a cooperative living space, where those with disabilities and those without could live in an integrated community.

Centenary United Methodist Church in Macon, which already has successful community outreach programs, is interested in partnering with GCDD to find ways to connect with the developmental disability community in its neighborhood.

And two groups in Savannah are starting to talk about ways they could participate in the Real Communities Initiative. All future programs are in the early stages, but the widespread interest in the program is promising.

For more information about the Real Communities Initiative, visit www.gcdd.org.

Aging & Disability: Addressing the Needs of a Growing Population



Jessie Simpkins

At four AM, Jessie Simpkins' alarm sounds, waking her out of a deep sleep. In a fog, she makes her way to her grandson's room, for whom she is the primary caregiver. She changes his clothes and feeds him. Out of the ordinary? Maybe not. Many grandmothers take part in the care of their grandchildren. What isn't ordinary is that Simpkins is 69 years old and her grandson, Kaimel Simpkins, is 25 years old. Ms. Simpkins has been providing Kaimel, KK to friends and family, with round-the-clock care since he was injured in a car accident at 18 months old. He has severe physical disabilities and needs help to breath and eat.

While Simpkins' day begins at 4 AM when she gets up to change and feed KK, she also has to administer medication and suction his breathing airway. At 8 AM, the process is repeated. At 10 AM, when Certified Nursing Assistants (CNAs) arrive, Simpkins does her best to get some much needed rest while the CNAs help with the physical part of KK's care, such as moving and bathing him. While the CNAs provide much needed assistance, their time in the home is not "time off" for Simpkins. Because the CNAs are only certified to administer CPR, Simpkins is required to be present throughout the duration of their visit. She must be there to suction his tracheotomy and manage his meals through a feeding tube. When the CNAs leave at 8 PM, Simpkins talks to KK and says a prayer with him before heading off to bed. At midnight, she gets up again for a feeding. At 4 AM, the routine begins again.

At nearly 70 years old, Ms. Simpkins deals with her own health issues in addition to KK's. Among the most pressing are arthritis, glaucoma, diabetes, aneurysm and respiratory problems. She has also assumed full-time care for KK's mother, who suffers from a mental illness. All three receive Medicaid and Disability. As the primary caregiver, Simpkins struggles to balance the medical needs of everyone in the household. When asked how she manages to get it all done, she says, "I'm tired, but I won't complain because [KK] can't do anything for himself and never complains."

Simpkins and her family represent a rapidly increasing segment of the population, those aging individuals who care for family members with physical and developmental disabilities whom are also aging. Consider the following statistics:

"Life expectancy for persons with developmental disabilities has increased from 19 years in the 1930s to 66 years in 1993."¹

"Sixty-six percent of all persons age 60+ with Down syndrome have been diagnosed with dementia/Alzheimer's disease, while 25% of persons with developmental disabilities age 40+ and without Down syndrome have been diagnosed with dementia/Alzheimer's disease."¹

"Twenty-six percent of all caregivers of persons with developmental disabilities are 60+, with an additional 35% who live in households of middle-aged caregivers for whom transition issues are near-term considerations."¹

In Georgia alone, there are 17,118 known adults with developmental disabilities living with a 60+ caregiver.



Jessie Simpkins with her grandson KK.

Who will care for aging persons with disabilities, a growing population, in the event of their caregiver's debilitating illness or death?

What are the resources available to them and how do they find them?

In short, persons with physical and developmental disabilities are living longer and often aging faster than their peers. And as both individuals with developmental disabilities and their caregivers age, their need for services increases. In Georgia alone, there are 17,118 known adults with developmental disabilities living with a 60+ caregiver. Furthermore, it is likely that there are even more who are currently not receiving publicly funded services but will most likely need them as they age.

Again, Ms. Simpkins is a case in point. While Medicaid provides 10 hours of CNA care for KK every day, Simpkins is finding it more and more difficult to manage the rigorous schedule of care that is required. KK's Medicaid services are maximized and without anyone to help share the responsibility, Simpkins has serious concerns about the future of her family.

Further complicating the reality that Simpkin's deteriorating health will one day prevent her from maintaining the current level of care she provides KK is the probability that there will be no one to care for him once she is gone. Simpkins has no relatives that are in a position to help, and while KK can retain ownership of the house when his mother passes, whomever cares for him must also live in the house, according to Habitat guidelines. The thought that her family might be left without a home and a caregiver is a sobering one.

Simpkins' situation, and the thousands of others like hers, beg the questions: Who will care for aging persons with disabilities, a growing population, in the event of their caregiver's debilitating illness

or death? What are the resources available to them and how do they find them? We approached the Aging & Developmental Disabilities Coalition for answers and found that they have been building their available resources over the past several years in anticipation of the rapidly growing needs of this segment of the population.

Seeking a Solution

In 2004, the Aging & Developmental Disabilities Coalition was established and held an "Aging for All Symposium," which sought to "help build customized strategies to increase community living options and decrease the need for institutional care."¹ Ultimately, the coalition sought to mitigate a potential crisis as more aging persons caring for aging persons with disabilities began to overwhelm the system.

The overall objective was to service the needs of the aging, developmental disability and physical disability communities. The symposium identified the following obstacles within the aging and disability communities:

- **Prioritization of Financial Resources** – The coalition felt that funding needed to be streamlined in order to enhance services for these families given that their numbers were on the rise, and that they were more likely to thrive in their communities as opposed to institutions.
- **Access to Information** – Given the number of organizations providing resources and information to the aging and developmental disabilities populations, the coalition felt that families needed more than one access point to comprehensive information. This paved the way for a No Wrong Door policy, which means that regardless of which organization families go to for help, they will be able to obtain the appropriate information for their needs.
- **Caregiver Supports** – Caregivers needed more financial and service supports in order to care for their loved ones in the home.
- **Planning Across the Life Span** – Families should be proactive in planning for long-term care in order to maximize publicly funded supports and supplement gaps in those supports so that the adult child with developmental disabilities is fully provided for.
- **Aging in Place** – Seventy-five percent of persons with disabilities live in their communities and are cared for by a family member.¹ The coalition



identified inconsistencies in the availability of care between cities and rural areas. In order to support families in their homes and communities, the reach of resources needed to be expanded.

- **Healthcare Issues** – Healthcare providers who understand health problems inherent to developmental disabilities are often ill-equipped to address the complications added by rapid aging, such as dementia and lethargy. This disconnect often forms a barrier between potential resources and aging persons with developmental disabilities.
- **End of Life Care** – Planning for an adult child with a developmental disability after the demise of his or her caregiver can require extensive research, proactive planning and expert guidance. Caregivers should have access to the appropriate guidance for planning for their futures and the futures of their adult children with developmental disabilities.

Not surprisingly, each of these obstacles is one that Jessie Simpkins is facing. As an aging caregiver, Simpkins has immediate needs, like additional help inside the home and better transportation options for getting KK to and from his doctors' appointments. She also has several long-term care concerns, like ensuring that KK and his mother have the financial and legal means to continue to be taken care of in their home. Most importantly, Simpkins said she wasn't sure where to go for answers to her questions and doesn't have the time or the resources to do much research. Her computer skills are limited at best, and she has little time outside of her current schedule to research her options.

A Streamlined Approach: Aging and Disability Resource Connection (ADRC)

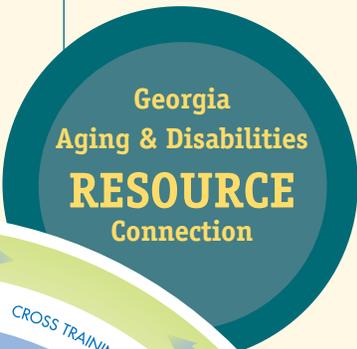
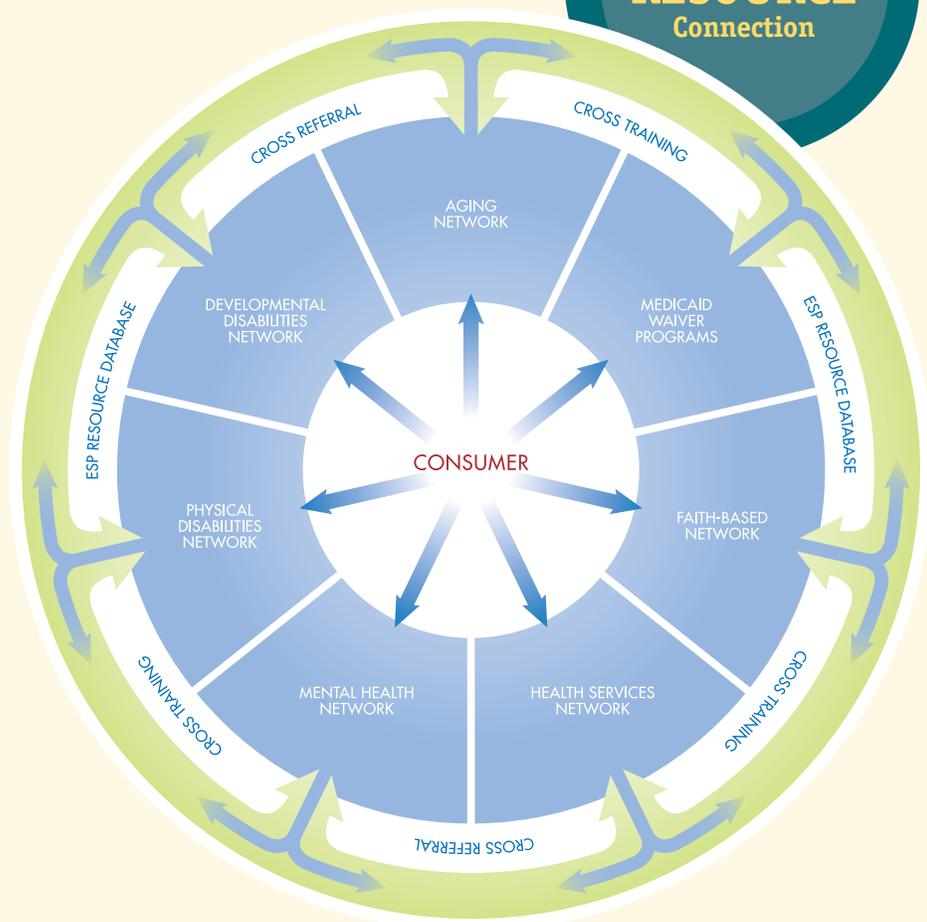
In order to better respond to complex cases like Simpkins', Georgia's Division of Aging Services applied for and received grant funding from the Administration on Aging (AoA) in 2004 to begin two pilot areas serving as Aging and Disability Resource Connections (ADRCs). In 2007, state funding was used to develop a partnership between the Division of Aging Services and the Department of Behavioral Health and Developmental Disabilities and to expand ADRC services. ADRCs serve as the main point of entry, or Gateway, for aging individuals, individuals with disabilities and aging individuals with

disabilities. This entity specializes in cataloguing and connecting those in need with all available resources. Utilizing the Enhanced Services Program (ESP) database system that originated within the Division of Aging, the ADRC began the task of adding resources that would be beneficial to individuals with disabilities.

According to Cheryl Harris, Gateway/ADRC program coordinator, "There is a great deal of overlap in the services for those aging and those with disabilities. With the combined issue of aging caregivers of adult children with disabilities and aging individuals with disabilities, we felt that offering a unified resource was the next logical step in meeting the growing needs of the developmental disabilities population."

Another reason to combine efforts with the Division of Aging was their well-established infrastructure and resource database. Sue Burgess, information services coordinator, said, "The aging services network was already experiencing success with the ESP system, so we devised a plan to add developmental disabilities resource information to the existing database."

Individuals enter the system in the center and are referred to other entities based on their needs. The two outermost rings demonstrate the flow of information within and between resources via cross training, cross referral, cross reference and the ESP database.





The resource database was expanded to include resources for persons with disabilities, a tedious process involving thousands of resources. Since then, the ADRCs have amassed a database of 22,000 resources statewide that are managed by the 12 ADRC regions in Georgia. To keep the information up-to-date, each of the 12 ADRCs has a dedicated resource specialist who is charged with making sure that the information in the database is accurate and current.

In addition to maintaining access to critical information, the ADRCs emphasize the role of communication and relationship building between field experts and the networks of state and local organizations that provide support. Burgess explains, "In order for the concept of No Wrong Door to be effective, we must ensure that the flow of information is reciprocal among local, regional and state entities."

ADRCs go about information exchange in a variety of ways. The ADRC state funding pays for three staff within the Department of Behavioral Health and Developmental Disabilities (DBHDD) to serve as ADRC

specialists and to partner with the Area Agencies on Aging. This includes opportunities to attend educational seminars and training about issues that pertain to individuals with developmental disabilities; cross-training staff in both aging and disabilities; quarterly meetings to facilitate the exchange of information between the 12 Georgia regional ADRCs; advisory boards that consist of healthcare providers, field experts and consumers; and of course, the ESP database helps disseminate information.

"In order for the concept of No Wrong Door to be effective, we must ensure that the flow of information is reciprocal among local, regional and state entities."

When asked if the ADRC was a comprehensive resource for individuals with developmental disabilities, the response from the developmental disability community ranged from accolades to skepticism. According to Nancy Thaler, executive director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS), while the ADRCs are able to provide assistance to aging developmental disability individuals, many individuals with developmental disabilities will enter the system through another entry point. She stated, "Because individuals with developmental disabilities have been enrolled in public schools since 1976, their families are likely to have knowledge about the developmental disability system and access services directly." She added that most of those who enter the system through the ADRC are individuals on the waiting list or have very mild disabilities and have not qualified for services in the past but may as an aging person with developmental disabilities.

Pat Puckett, executive director of the Statewide Independent Living Councils, was unsure about the capabilities of the ADRCs. "For those living with developmental disabilities who need public assistance, I don't know that the ADRCs can help, except to help them get on a waiting list. Also, I think homogenizing the needs of the different communities is inefficient. An elderly person that needs help with household tasks and transportation is vastly different than a person with cerebral palsy who is trying to live his or her life like everyone else."

Robyn Berger, director of the DeKalb Developmental Disabilities Council, called the ADRCs a "wonderful resource," adding that the depth and breadth of the ESP system is unparalleled in the

- Northwest Georgia
- Georgia Mountains
- Atlanta Region
- Northeast Georgia
- Southern Crescent
- Middle Georgia
- River Valley
- Central Savannah River
- Heart of Georgia
- Coastal Georgia
- Southern Georgia
- Southwest Georgia

Georgia ADRC Regional Map

To contact your regional office, visit georgiaadrc.com



What Happens When I Call My Local ADRC?

So what happens when a caregiver of an individual with developmental disabilities contacts his/her a regional ADRC.

1. The person calling will talk with a counselor to discuss their particular situation and identify areas of need.
2. The counselor will then present possible options to meet those needs with the caller, including the various pros and cons of those options, thereby helping the caller make informed decisions.
3. The counselor will use the ESP database to research all possible resources and supports and will provide this information to the caller.
4. The counselor may also consult with or refer the individual to one of the state's developmental disabilities specialists for additional assistance, or may consult with other specialists depending on the individual's needs.

developmental disability community. She noted, "The ADRC doesn't waste people's time by referring them to the wrong entities. Because of the ESP system, the collaboration and training that takes place within and between the ADRCs and local and state organizations, they are a viable source of information."

Dave Blanchard, executive director of All About Developmental Disabilities (AADD), commented, "For AADD, the ADRC represents a meaningful partnership between developmental disability and aging networks. For families and individuals experiencing the stress of both of these issues, it is one step closer to creating multiple entry points, or a No Wrong Door approach, that offer consistent information about the supports that they oftentimes desperately need."

For some, the ADRC is not really about aging anymore. Craig Young, executive director at the Brain and Spinal Injury Trust Fund Commission, feels that the ADRCs are more about identifying community supports for all adults with physical, developmental and psychological disabilities, which includes disabilities caused by aging. As a representative for the physical disability community, Young provides training to the ADRC teams that allows them to not only identify support, but also to help identify undiagnosed brain injuries. "Recently, we provided training to two ADRCs. We made them aware of all available supports, and we included a screening component that would make them aware of the symptoms and behavior that may indicate a brain injury. We develop our trainings to be applicable to everyone, not just to individuals with physical disabilities."

"We really want this system of resources and information to be a dynamic, community-owned service so that the public has integrated access to all long-term services and supports."

Pat Nobbie, deputy director at GCDD wondered if, ultimately, the goal would be to make the ADRC the main point of contact for individuals with developmental disabilities. "I'd like to actually call a few and see what information I am provided with for particular scenarios. I'm particularly interested in whether the staff at the various sites know the full array of developmental disability services in each community, which may consist of small providers."

When asked if a single point of entry was part of the plan for ADRCs, Burgess said, "We are working towards that end. We really want this system of resources and information to be a dynamic, community-

owned service so that the public has integrated access to all long-term services and supports."

After a lot of discussion about the role of ADRCs and their capabilities within the developmental disability community, the most obvious question was whether the ADRCs would be of any help to Jessie Simpkins. From the developmental disability community perspective, Nobbie explained that "It is unlikely that Jessie would call an ADRC because she already has a waiver. Her best option is to try to work with DCH (Department of Community Health) in order to add more hours to her waiver."

However, Sue Burgess, of the ADRC commented that they may be able to help Simpkins. "We encourage individuals to call us when they might need additional services, as Pat suggests. These calls are often extensive and move into the Options Counseling service that we offer. We occasionally get calls from families and help them address issues with services by referring them back to the appropriate agencies, waiver programs or case managers. With the help of our contributing partners at AADD, we also assist families with long-term care planning beyond their current services needs."

We can't help but wonder what might happen if Simpkins did contact the ADRC for additional services. If the No Wrong Door policy is effective, Simpkins would receive the same information regardless of the entity through which she entered the system. ●

¹ *Aging and Developmental Disability Coalition (2004, November). Aging for All Final Report. Retrieved August 18, 2010 • www.aadd.org/files/coalition.html*

Have you or someone you know used the ADRC for help with services and support?

If so, we would love to hear about it. Email us at vmsuber@dhr.state.ga.us. For more information about the ADRC or to connect with your region about services, visit www.georgiaadrc.com.

Appreciation Program Recognizes Outstanding Advocacy Efforts

Held at the Renaissance Atlanta Downtown Hotel, the Georgia Council on Developmental Disabilities (GCDD) *Making a Difference* Appreciation Program was about more than just handing out awards. After a warm welcome from Tom Seegmueller, GCDD chair, GCDD's Executive Director Eric Jacobson summed up a year of advocacy by saying, "GCDD is really about 'thinking outside the box.' Our healthy mistrust of the rules is what makes us effective at changing policies and the public's perception of people with developmental disabilities." Jacobson underscored this statement by explaining that the GCDD's mission is continue to do what it takes to achieve real careers, homes, learning, influence and supports for individuals and families who are living with developmental disabilities.

The 2010 Appreciation Program honored a year's worth of superlative advocacy work for people with developmental disabilities. As Pat Nobbie, Ph.D., GCDD deputy director, opened the ceremony, she acknowledged that a "bad budget scenario" was a daunting obstacle to overcome but that the legislators being honored never wavered in their commitment to their causes. As a result, positive change was affected in spite of budget limitations.

The first award recipient went to Rep. Jimmy Pruett (R-Eastman), who championed amendments to the Nurse Practice Act. The legislation allows thousands of Georgians who currently cannot afford home care by a licensed nurse to be cared for at home. Pruett shared that this bill meant more to him than any he had worked on in his four years as a Representative. With conviction he added, "People should be responsible for their own decisions without the government getting involved, regardless of the consequences. I want to make my own decisions, and I would think that most people feel the same."

"People should be responsible for their own decisions without the government getting involved, regardless of the consequences. I want to make my own decisions, and I would think that most people feel the same."

Rep. Sharon Cooper (R-Marietta), a former nurse and caretaker to her mother, was also recognized for her work on the Nurse Practice Act. Expressing frustration with the process of getting the bill passed, Cooper commented that the families and individuals who came to testify before the committee were key to its success, providing committee members with an intimate look into the experiences of the affected individuals. Cooper concluded her acceptance of the award with sincere thanks, remarking that children, people with disabilities and the elderly "hold a special place in [her] heart." She also expressed her hope that reelection would allow

Our healthy mistrust of the rules is what makes us effective at changing policies and the PUBLIC'S PERCEPTION of people with developmental disabilities.



1

Please continue to think outside the box. We appreciate all of your hard work and wish you all the best of luck.



2

1. Chairman Tom Seegmueller and Eric Jacobson with award recipient Rep. Sharon Cooper.
2. Rep. Jimmy Pruett thanks GCDD for honoring him.
3. Narcel Reedus talks about his documentary.
4. Kim Chester and family.
5. Ricardo Ayala introduces the first song.



3



4



5

AWARDS

Legislative Leadership Award:
 Rep. Jimmy Pruett
 Rep. Sharon Cooper
 Sen. Don Thomas

C. Anthony Cunningham Council Member of the Year Award:
 Kim Chester

her to continue her work to help all people with special needs to be more independent.

Sen. Don Thomas (R-Dalton) was given the final recognition for advocacy of the Nurse Practice Act. Thomas was unable to attend the Appreciation Ceremony but his efforts were acknowledged nonetheless.

Kim Chester of Cartersville, GA was given the prestigious C. Anthony Cunningham Council Member of the Year award. Presented by Tom

for school improvement. The text was a joint publication by Corwin Press and the Council for Exceptional Children. She serves as a parent mentor in Bartow County Schools, assisting families of children with disabilities.

The Appreciation Program also featured a sneak preview of the documentary entitled, *Not Home*, by Narcel Reedus, which examines the fate of children who are displaced from their homes because families lack the support needed to care for them. This topic is the subject of the Children's Freedom Initiative, which aims to bring children living in nursing homes back to reside with their families so that they may live as many other children do, with the love and support of their families.

Reedus expressed heartfelt thanks for all of GCDD's assistance in making the documentary. With regard to his inspiration, he said, "I was inspired to make *Not Home*, a documentary about kids living in nursing facilities, after speaking with Gillian Grable who works for the Georgia Advocacy Office and is part of the Children's Freedom Initiative. I was compelled by the decision parents make when they send their child away feeling they have no other choice. I wanted to somehow understand and share that painful decision."



From left: Cindia Cameron (Organizing Director, 9to5 National Association of Working Women and Chair of the GA Job/Family Collaborative); Valerie Meadows Suber (GCDD Public Information Director), Kim Chester (GCDD 2010 Council Member of the Year), and Claudia Lewis (Atlanta 9to5 Board Chair)

Seegmueller and Jill Alexander, Chester was honored for her work with the Georgia Job/Family Collaborative, which has been working on discretionary sick leave legislation for several years. In April, Kim traveled with the Georgia 9to5 Delegation to speak at the National Making it Work Conference in Washington, DC. She and her family visited our Senate delegation, and she and daughter Haley got to speak before Hilda Solis, U.S. Secretary of Labor. She was appointed to GCDD in 2007 by Governor Sonny Perdue.

Chester has also been recognized for her outstanding work as an educator dedicated to developing teaching methods, such as co-teaching and differentiating instruction, in order to accommodate the diverse needs of individuals with developmental disabilities. In 2009, she co-authored a best-selling educational text

"I was compelled by the decision parents make when they send their child away feeling they have no other choice. I wanted to somehow understand and share that painful decision."

Eric Jacobson concluded the evening's festivities with well wishes for the legislators in the imminent political season, saying, "Please continue to think outside the box. We appreciate all of your hard work and wish you all the best of luck." ●

Music Bonds Father and Son

By Claire Barth

As the clink of silverware and china begins to fade, the Appreciation Program attendees settle into a comfortable position in anticipation of the evening's entertainment. From the left corner of the room, two men, slight in stature, climb the stage with their guitars and pause in silence. The younger of the two men steps forward and in a Spanish accent says, "I am Ricardo C. Coloma Ayala. This is my father Cesar Coloma. He is my music teacher." As an afterthought he adds, "I play guitar and that's it."

Ricardo is a 24 year-old individual with Down syndrome, and as he explains, his mission is to "let people know they can do it when supported." He plays the Puerto Rican "cuatro," or four stringed guitar, accompanied by his father, Cesar. Ricardo attends the Interamerican University of Puerto Rico where he studies music. He will earn his degree in 2011.

As a supplement to their moving performance, Cesar tells Ricardo's story of discovering music; he relates how Ricardo's teachers doubted his ability to learn music initially, but understanding how strong Ricardo's desire to learn was, Cesar was determined to find a way. Using the fundamentals of the Suzuki method, Cesar taught Ricardo musical notes with colors. Ricardo learned music rapidly through this method, and he even began to memorize songs. His music teachers were amazed and learned how they, too, could modify their methods in order to continue to teach Ricardo. Today, Ricardo is a skilled cuatro player and plays all of his songs from memory.

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Ricardo recorded his CD "Solo" in order to save money to build a house for himself and his friends. One day, he would like to live on his own.

Ricardo and Cesar played a beautiful set of classical songs, along with a couple of Puerto Rican ballads. Both men thanked the audience for the opportunity to share their joy with the audience. Cesar concluded by saying, "My son is the greatest pleasure of my life. Thank you!"

After their performance, Ricardo sold a number of his CDs and greeted a line of admirers long after the program had ended. GCDD hopes the sales he made will help him get closer to building his home. ●



Make Georgia Work

By Roy Barnes, Democratic Nominee



Roy Barnes was born and raised in Mableton, GA. He earned his undergraduate and law degrees from the University of Georgia.

He served as a prosecutor in the Cobb County District Attorney's Office and then eight terms in the state Senate and three terms in the state House of Representatives before being elected governor in 1998.

After serving as governor from 1999 to 2003, Barnes devoted six months to Atlanta Legal Aid before returning to the private practice of law, which he has done through the establishment of The Barnes Law Group with his daughter.

He and his wife, Marie, live close to their three children and six grandchildren. The family attends the First United Methodist Church of Marietta.

I consider myself fortunate for having worked in both the public and private sector. After serving over 20 years in the state legislature and being in the governor's office for four years, I started a family law practice and spent every free minute I could with my six grandchildren. But during my time in private life, I began to watch Georgia fall behind. I saw our teachers being furloughed, our unemployment numbers jump and our property taxes hiked. I couldn't sit idly by – I decided to run for governor because I know we can make Georgia work again. We must restore the Georgia values and strong leadership that brought our state growth, opportunity and far-reaching prosperity.

We must restore the Georgia values and strong leadership that brought our state growth, opportunity and far-reaching prosperity.

Families like yours – families working hard to juggle daily life during tough economic times with a loved one with disabilities – deserve a governor who doesn't need on-the-job training. You deserve a governor who understands the difficulties and hardships you face, and who has the experience to create opportunities and level the playing field for Georgians living with mental and physical disabilities.

When I was first elected governor, over 12,000 Georgia adults were on waiting lists for community-based social services. Some suffered with severe

developmental disabilities. Others suffered brain injuries. Many were elderly and needed assistance to stay out of nursing homes. At the time, Georgia was serving fewer people in community-based programs per resident than any other state – and I was determined to unlock the waiting list for our citizens with disabilities. So, I appointed a 15-member commission to work on ways to reduce the waiting lists and pledged additional state money.

Before I reached the governor's office, I had assisted thousands of Georgians with disabilities during my time in the state legislature. For example, I sponsored a bill that imposed minimum sentences for crimes against individuals with disabilities. I'm also proud of my work to make Georgia's public buildings and facilities more accessible for everyone – six years before the American Disabilities Act mandated such standards. I even supported the bill that created your very organization – the Governor's Council on Developmental Disabilities.

I know every individual with a disability and their families face unique challenges. That's why as governor, I'll lead with all Georgians in mind – especially our citizens with developmental and physical disabilities. Together, I know we can rebuild a solid foundation in Georgia – one that will support a better life, stronger communities, and a brighter future for our families. ●

For more information about Roy Barnes and his strategy for governing Georgia, visit roy2010.com

Get the Real Deal

By Nathan Deal, Republican Nominee

As a young man, my father was seriously injured in an accident involving farm machinery. It was many months before he would walk again and he would never fully regain use of his leg and foot.

It was because of an early program for people with disabilities that he was given the resources to get an education to prepare him for a career as a vocational agriculture teacher.

I know first-hand the value of programs that stress ability and not disability to Georgians who earnestly seek a more independent lifestyle.

I know first-hand the value of programs that stress ability and not disability to Georgians who earnestly seek a more independent lifestyle.

Earlier this year, I visited the Bobby Dodd Institute in Atlanta. This wonderful organization has helped persons with disabilities find job training in programs that include data entry, switchboard and mailroom operations and packaging and order fulfillment. Providers such as this throughout Georgia have given opportunities and a great deal of confidence and satisfaction to those who might not otherwise find work. This is just one example of how Georgia has responded to those with disabilities.

Two years ago, the General Assembly separated the services for the disabled by forming the Department of Behavioral Health and Developmental Disabilities. This dismantled the giant Department of Human Resources into a smaller agency that is

more focused on the vital needs of people with disabilities and those with behavioral healthcare needs.

We continue to offer rehabilitation services through the Georgia Department of Labor to help train and equip people with disabilities and wish to seek a more independent way of life through successful employment.

As your next governor, I will continue my efforts to provide greater opportunities for the disability community. While in Congress, I had the privilege of serving as the chairman and ranking Republican member of the Energy and Commerce Committee's Subcommittee on Health. Here, I worked with my colleagues and advocates in the disability community to provide enhanced support services in their own homes through improved home and community-based services in the Medicaid program. Not only has greater independence and opportunity developed as a result, but healthcare costs have been reduced while quality continues to improve.

As we all look toward November and this critical election that will take place, members of the disability community can rest assured that they will have an advocate in the governor's office with Nathan Deal. I will be a leader who will continue the progress our state has made and will continue to seek new and innovative ways to better support initiatives that promote independence, employment and the health and well being of the great people of our state. ●

For more information about Nathan Deal and his vision for Georgia, visit nathandeal.org



Nathan Deal was born in Millen and grew up in Sandersville, GA. He earned his undergraduate and law degrees from Mercer University in Macon as he began preparing for full-time service in the United States Army.

He spent 23 years practicing law in Gainesville where he served as a criminal prosecutor, juvenile court judge, and in the state Senate for 12 years where served as president pro tem, the state Senate's highest-ranking position.

In 1992, he was elected to the first of nine terms in Congress, where he served as chairman and ranking member of the Subcommittee on Health.

During college, Deal met Sandra Dunagan of Gainesville to whom he has been married for 44 years. Their family now includes four children and six grandchildren.

Community Helps Redefine GCDD

If asked, could you explain just what GCDD does? And could you name the major issues that individuals with developmental disabilities face? If the answer is no or you're unsure, you're not alone.

Leading up to the Americans with Disabilities Act (ADA) 20th anniversary in July, the results of a study commissioned by GCDD about the public's level of disability awareness were released.

The survey sample was comprised of two groups: a random sample of the general public and individuals with disabilities and their families. There were a total of 379 respondents, and the questions posed to them were intended to evaluate the following:

- Awareness of and issues related to developmental disabilities
- Perceptions about employment, educational settings and living environments for persons with developmental disabilities
- Awareness of the Georgia Council on Developmental Disabilities (GCDD) and other organizations that provide services
- Awareness of the ADA
- Support for increasing taxes in order to support persons with developmental disabilities in their communities

The overall objective of the study was to explore the perceptions, attitudes and awareness of developmental disability issues among the general public and contrast them to the opinions of those living with and impacted by the challenges on a daily basis.

Awareness of Issues Related to Developmental Disabilities

The good news was that 55% of the general public and 78% of the disability community participants agreed that adults with disabilities should be able to live on their own with supports and services and not in institutions. In addition, 84% of respondents were likely to consider mental, cognitive or learning disabilities as developmental disabilities, although visual and hearing impairments were least likely to be mentioned.

55% of the general public and 78% of the disabilities community participants agreed that adults with disabilities should be able to live on their own with supports and services and not in institutions.

good news

While these results seemed to indicate that people are becoming more aware of the needs and desires of the disability community, the survey also revealed that there is more to be done to further educate the public.

For instance, only one-quarter of the general public and 28% of participants from the disability community believed it was very likely for persons with developmental disabilities to have careers with opportunities for advancement. In addition, more than half (52.8%) of the general public said that children with developmental disabilities would benefit most from being in separate classrooms or special schools versus learning in general classrooms with all students.





The survey revealed that only one-third of Georgia's general public comes across or interacts with persons with developmental disabilities in their everyday life, even if they or a family member has a disability.

The survey revealed that only one-third of Georgia's general public comes across or interacts with persons with developmental disabilities in their everyday life, even if they or a family member has a disability. Not surprisingly, 38% of respondents said that when they encounter a person with a disability that they sympathize with the difficulties that he or she faces. The general public cited difficulties such as prejudice, discrimination, fear and stigma, but overlooked practical issues, such as accessibility, independent living, employment and financial planning.

Awareness of the ADA

Among the general public, 79.5% had heard of the ADA, and within the developmental disability community, almost all (97.2%) were aware of it. Of the issues that the ADA addresses, respondents from both groups were most familiar with regulations related to the accessibility of public places and telecommunication services.

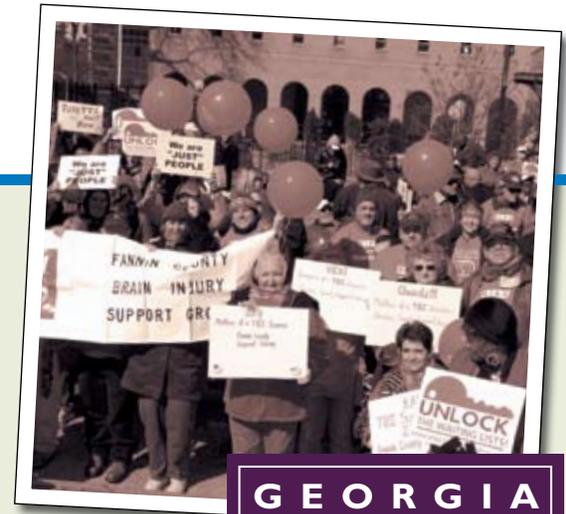
Awareness of GCDD and Other Organizations that Serve the Developmental Disability Community

Not surprisingly, the vast majority of respondents within the developmental disability community (86.5%) were familiar with GCDD before taking the survey. However, only 26.5% of the general public respondents had heard of GCDD. When asked to name organizations that serve the developmental disability community, GCDD was mentioned most often among the developmental disabilities sample; the general public named the United Way the most frequently.

Support for Increased Funding to Assist Persons with Developmental Disabilities

The majority of the total survey sample (87.0%) advocated increasing state government funding to support people with developmental disabilities in their communities. At the same time, neither of the two proposed revenue sources (special purpose sales tax, sin tax) was strongly supported by a majority of respondents outside the developmental disability community. However, survey responses indicated that members of the general public do not understand the variety of issues and funding needs faced by persons with developmental disabilities.

GCDD Executive Director Eric Jacobson commented on the findings by saying, "Persons with developmental disabilities and their issues are still somewhat invisible to everyday society."



GEORGIA COUNCIL ON DEVELOPMENTAL DISABILITIES

"It has been over 15 years since we have changed our logo."

"Although we have made progress as a result of the ADA, there is still a lot of education to be done among the general public, and the best way to do that is to create a society that better integrates persons with disabilities in our schools, workforce and community."

He added, "Although we have made progress as a result of the ADA, there is still a lot of education to be done among the general public, and the best way to do that is to create a society that better integrates persons with disabilities in our schools, workforce and community. Understanding comes through exposure and awareness. GCDD is



FEATURE

New homepage



committed to achieving this goal through public policy, advocacy programs and public information.”

According to Valerie Meadows Suber, GCDD public information director, “The results of the survey are further evidence of the importance of GCDD’s commitment and work to create opportunities for people with developmental disabilities to be more engaged in community life. The general public’s lack of regular interaction with individuals with developmental disabilities, may partially explain the lack of awareness,” she said. “This compounds the extent to which persons with developmental disabilities may go unnoticed and experience social isolation.”

The survey outcomes helped inform GCDD’s new public relations initiative, which is being spearheaded by Suber. “We felt that we really needed to get a better sense of public attitudes in order to devise a successful plan to raise awareness and improve perceptions. This led us to reevaluate our approach and make adjustments to our outreach strategy.”

Interior page



“The results of the survey are further evidence of the importance of GCDD’s commitment and work to create opportunities for people with developmental disabilities to be more engaged in community life.”

In April, GCDD conducted focus groups in which participants were asked to respond to GCDD’s current identity and messaging and answer questions about their knowledge of disability issues. The focus groups were comprised of GCDD’s target audiences: individuals with developmental disabilities and their families, representatives of disability organizations, community leaders and the general public. “The focus groups made it apparent that we need to develop messaging that is easier to understand; clarify exactly what GCDD does; and broaden the awareness of our programs,” Suber said.

Though GCDD’s objectives are the same, its messaging has been revised to be more comprehensive and transparent. Its new positioning statement is as follows, “The Georgia Council on Developmental Disabilities (GCDD) is a leading catalyst for systems change for individuals

and families living with developmental disabilities. Through public policy initiatives, advocacy programs and community building, GCDD promotes and creates opportunities to enable persons with disabilities to live, work, play and worship as an integral part of society.”

Accompanying the new messaging, GCDD has an entirely new look that speaks to its value and presence in the community. The focus groups felt that GCDD should have a bold, unique look and feel that would differentiate it from similar organizations with similar names.



Jacobson welcomed the feedback, saying, “It has been over 15 years since we have changed our logo. Last year we had a name change and became part of the newly created Department of Behavioral Health and Developmental Disabilities. This year we undertake a strategic planning process that will guide our activities for a five year span. It seemed like the right time to think about how we are perceived by the public.”

Once new logo designs were completed, the focus groups convened again to respond to several logo options. Their final choice was representative of their desire for a design that was bold, simple, memorable and straightforward. The logo design was officially adopted by Council vote at GCDD’s quarterly meeting in July.

The new logo and positioning will be incorporated into all media, including the redesign of the GCDD website, which is scheduled to launch in early November. The new website will contain a wealth of new interactive features, including a blog, community resources, the latest news and legislative updates, intuitive site structure and integration with social media outlets so that users can engage with one another and express their reactions to issues affecting the developmental disability community.

“We envision GCDD’s new web-site as a virtual gathering place for advocates, their supporters, as

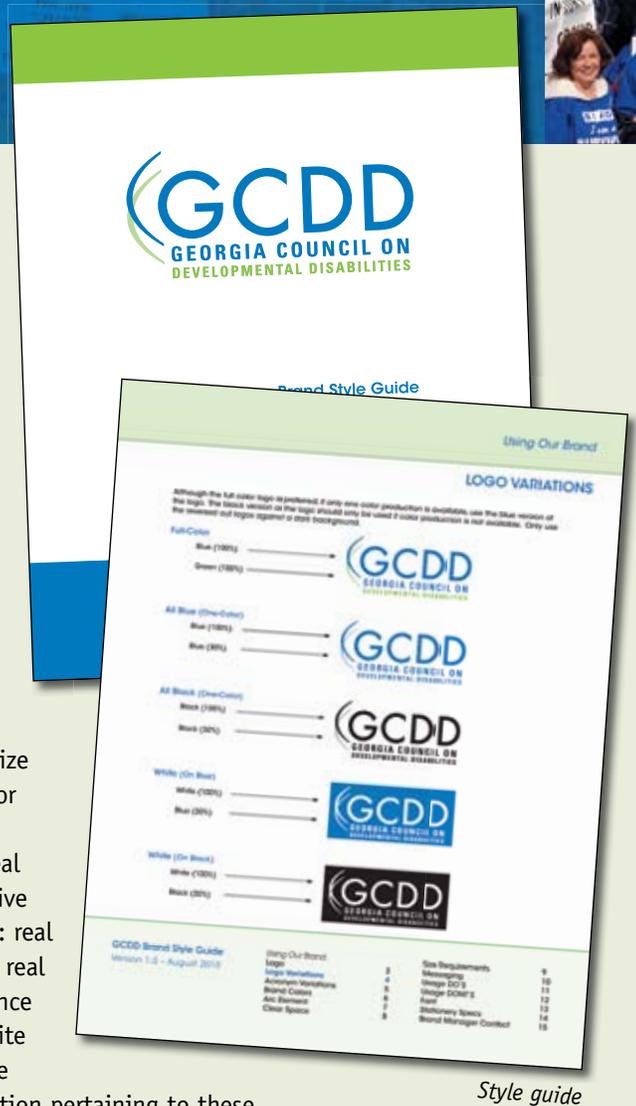
well as the general public, to find resources, share information and exchange ideas,” Suber said. “We expect this public relations initiative to enable GCDD to strengthen community ties and reach more people than ever before.”

The new website will emphasize GCDD’s philosophy for Real Communities, which covers The Real Communities Initiative and five focus areas: real homes, real careers, real learning, real influence and real supports. Site visitors will easily be able to find information pertaining to these categories by searching and browsing within them.

Making a Difference magazine will also undergo aesthetic revisions, so expect a new look for the Winter 2010 issue. The new logo, colors and messaging will form the basis for the magazine’s new look and feel.

“Last year we had a name change and became part of the newly created Department of Behavioral Health and Developmental Disabilities. This year we undertake a strategic planning process that will guide our activities for a five year span. It seemed like the right time to think about how we are perceived by the public.”

Until then, be sure to check out the new and improved GCDD website (www.gcdd.org) around Election Day. Thoughts about the new look and website? We welcome your feedback. Email comments to Valerie Meadows Suber, GCDD public information director at vmsuber@dhr.state.ga.us. Also, the complete survey results are available on the GCDD website. ●



Style guide

“SEARCH”ing (And Finding) The Right Fit.

The Georgia Council on Developmental Disabilities has long advocated the inclusion of individuals with disabilities into workplaces within our communities. Perhaps nowhere is that more evident than GCDD’s partnership with Project SEARCH. Project SEARCH is a one-year high school transition program that seeks to place citizens living with disabilities in job positions that use the person’s unique talents and skills. The program provides job training, interviewing and educational skills while giving students the opportunity to practice their employability skills during three-to-four 10-week internships in community businesses.

The cornerstone of Project SEARCH is total immersion in a business. Often, the internships lead to part-time or full-time positions in the normal workforce. These are six stories about Project SEARCH graduates, the jobs they are performing, and the enjoyment they are getting out of being very productive members of their communities.

Jared Caruso

No matter what kind of job you can think of, there’s always somebody who does it better than anyone else. In the field of preparing surgical trays for dermatologists at the Georgia Skin and Cancer Clinic in Savannah, that person is Jared Caruso. As one of Jared’s duties, he sterilizes surgical instruments and supplies, wraps them in special paper and puts them in a specific order so the physicians know exactly where everything is at any given time during their procedures on patients.



Jared Caruso

“There’s an art form to it,” says Kandie Spence, director of patient services at the clinic, “And he’s very good at it.”

Jared got his training through Project SEARCH, but not at the clinic. Cindy Burns, community employment supervisor for Coastal Center for Developmental Services, provides placements and long-term support. She was actually a patient at the clinic when, “I was able to identify a need the business had and placed Jared.”

Spence agreed. “After meeting Jared, we fell in love with him. Jared brings the heart back to our clinic. All our other employees have good and bad days. But Jared is always excited to be here. He really gets to know the staff and is interested in us. My six-year-old son calls him Uncle Jared. Jared loves root beer and usually brings one for me to take home to my son about once a week.”

“Due to the Project SEARCH partnership, we’ve been able to work together for these individuals to get jobs they wouldn’t ordinarily be able to get,” says Burns. “We’ve been able to get to know them and teach them aspects of a job, and that makes my job easier because they are much more marketable.”

Jared himself says what he likes best about his job is, “cleaning the instruments and working with the people.” Last year, he got to join in the fun of Halloween. The whole staff wore costumes and Jared showed up as a monk.

When he’s not at the clinic, he enjoys “playing computer games on the Internet and going grocery shopping with [his] parents.” High on the grocery

“After meeting Jared, we FELL IN LOVE with him. Jared brings the heart back to our clinic.”

Project SEARCH is a one-year high school transition program that seeks to place citizens living with disabilities in job positions that use the person's unique talents and skills.

list? "Popcorn and cheese puffs," which probably explains the need for the root beer.

It's at the clinic, though, where he really shines. "Jared does an exceptional job for us," says Spence. And that not only means with the surgical instruments, but in other ways as well. "He's expanded our happiness." Which really is an art form unto itself as well.

Jessica Sell

Every once in awhile, a person and an organization are just made for each other. The Children's House at St. Joseph in Candler and Jessica Sell fit that description perfectly. Jessica did a Project SEARCH internship at the daycare center, and it was love at first sight.

"I knew from the beginning she was going to be great," says Nancy Perkins, co-director of the center. "Her natural warmth with children and how she cared for them came through immediately."

Hired full-time in December 2009, Jessica has continued to take care of the young infants the same way she always did. "I change diapers, I play with the babies, feed them." And one of her favorite things to do is make them smile. "I sing to them, read to them, and I even dance with them sometimes. All of them smile, and they're very happy." One time, though, it was a baby making Jessica laugh. "She was scooting around on her butt," she says, with a slight giggle still in her voice at the memory.

Seeing Jessica interact with the children is what caught the staff's attention. "A child will always

respond positively to someone showing them love," says Perkins. "And Jessica has a natural ability to convey a lot of love to our children." In addition, "She's very quiet, efficient and dependable, a reliable and conscientious worker."

Jessica even takes her skills home with her. "I like to play with my four-year-old nephew. I see him every day. We watch movies. (He likes *Thomas the Train*; she likes *The Secret Garden*.) She also enjoys the laptop computer she bought with her own money. "I like to play Farmville on Facebook," she says.

Perkins also reports that Jessica works with older people as well as the younger ones. "She just gets along well with others. She has a nice sense of humor, and that's especially needed with children." It was that innate talent to get along with everyone that really caught the attention of those who now work with Jessica. She was given very high recommendations during her internship and while she volunteered and that was really what caused the center to hire her.

The kids who stop by the infant room all call her "Miss Jessica." And as Perkins says, the staff just calls her, "a blessing and an asset."

Marty Cromartie

At Coffee Regional Medical Center, each of the pizzas has exactly 36 pepperonis on them. Well, that's if Khiry "Marty" Cromartie makes the pizza. Thomas Maslowski, Marty's supervisor in the Food and Nutrition Department, said Marty asked him the first time he made a pizza how many pepperonis it should have on it. "I told him about 36 or so," says Maslowski. "And from that time on, every pizza has consistently had exactly 36."

Maslowski says that's really a perfect example of how Marty handles all of the jobs given to him. "He keeps a journal and is very meticulous with it. That helps him when he's stocking the doctors' and nurses' lounges with over 60 different items."

"I knew from the beginning she was going to be great. Her natural warmth with children and how she cared for them came through immediately."

Marty Cromartie



Jessica Sell with Co-Director Nancy Perkins



“He’s come out of his shell. Everybody likes him; his WORK ETHIC is excellent; and he’s never missed a day of work.”

Marty himself says he likes making the pizzas best. “That’s been my favorite job.” And while he likes his own pepperoni pizza, “The meat lovers pizza is the one most people like best.”

Away from work, Marty likes to make CDs. “I did some for the people I work with,” he said. And what music does he like to listen to? “I like rap. I like to listen to Bone Thugs-n-Harmony. They’re cool.”

In talking with Marty, you can feel his self-confidence and pride in his work. His mother says that’s really a result of Project SEARCH. “Before, he was very shy and introverted,” says Gloria Cromartie. “It seemed like there were limitations put on him at school. But at Project SEARCH, he was told ‘if you can believe it you can do it.’ Now, he’s making friends; he’s an usher at church; he’s driving his own car and becoming more conscious of who he is and less conscious of what people dictate to him.”

Even his nickname came from Project SEARCH. “There were two boys in the program,” says Cromartie, “one named Kiera and one Khiry. So to avoid confusion, they started calling Khiry ‘Marty.’ It stuck and now everybody at work calls him ‘Marty.’ Even I’m starting to call him that,” she says laughing.

Maslowski concurs with Cromartie that Marty has developed his self-confidence. “He’s come out of his shell. Everybody likes him; his work ethic is excellent; and he’s never missed a day of work.”

And he’s never made a pizza without 36 pepperonis on it.

Joanna Abundes

You know how it is around 3:00 or 3:30 every afternoon when you start to drag a little and it seems like all your energy is zapped? Well, if you need a pick-me-up, you might try spending that time of day with Joanna Abundes. She gets the giggles around then. And her supervisor, Stephanie Causbey, says it’s contagious. “We all know it’s that time again after Joanna has had her piece of candy for a snack.”

Joanna works in the Health Information Management department at the Atlanta Medical Center. Jennifer Buzbee from Briggs and Associates says Joanna’s Project SEARCH internship was actually done at Emory. But, unlike most participants in the program, she was hired for a part-time post at AMC that became full-time last February.

Joanna says that full-time position has now allowed her to get her own apartment. And

how does she like it? “I love it,” she says. Having overcome many obstacles in her life, she

now says, “Just the opportunity to be myself in my own apartment is one of the best parts. I like to organize and decorate places and make them look nice.” And, as she reports, “Everybody says my apartment looks nice.”

Her main job at the medical center is to prep discharge charts for patients. “I make sure the information matches with the patients I’m working with. Lots of detail things. Then it goes over to the

“She just has a wonderful personality. She relates well with the patients and staff, always smiling, always trying to help.”

scanners so they can put them in the system.”

In addition, “Joanna interviews moms on the weekend,” says Causbey. She’s bilingual and helps with the Hispanic population. She talks to the new mothers about the baby’s name, their marriage status, the father, all the information that goes on the work sheet to complete the baby’s birth certificate.” And she’s well suited to that work because, “She just has a wonderful personality. She relates well with the patients and staff, always smiling, always trying to help.”

Sounds like Joanna really doesn’t need that candy every afternoon to make her enjoyable to be around. But it is probably fun to see her get the giggles.

Bradley Schipper

“Bradley is an awesome person, always willing to go above and beyond, and he’s definitely a part of the team.” That’s the thumbnail assessment of Bradley Schipper by Clanfort Robinson, assistant director of Environmental Services at the Northeast Georgia Health System, and Bradley’s supervisor.

“He’s been with us full-time now for about six months or so,” say Robinson, “and I wish we had more like him. He leads by example, he has a can-do attitude, and he’s a model co-worker.”

Bradley works in many different areas of the department...patient care and non-patient care, cleaning the room and discharge. He makes sure the break rooms, lobbies, the first impression areas look good. And he helps remove medical waste from the facility.



Joanna Abundes



Bradley Schipper

To hear Bradley describe it, "I am a housekeeper. (When the patients are discharged) I go around and clean the floors, clean the rooms, clean the restrooms, get all the germs out of there. It takes about 30 minutes per room."

"I have a great job here," Bradley says. "We all like each other very much and our priority is to make sure we get our patients in and out and make them feel better."

Bradley actually had another job before this one. He worked at Chick-fil-A. And he's still loyal. When he's not working, he likes to hang out with his church buddies and says, "We always go to Chick-fil-A to eat."

That previous experience served him well because just after his first Project SEARCH rotation at the Health Center, he was hired. At that time, he was in the Sterile Processing department. "We would sterilize the instruments before they went up to the surgery room," Bradley says. "We had to make sure they were all cleaned and processed." Environmental Services liked what they saw of his work there and asked him to transfer into their department.

"Bradley is an awesome person, always willing to go above and beyond, and he's definitely a part of the team."

And that great work ethic continues today. As Robinson says, "Bradley has the aptitude and willingness to do any job put before him. As I said, he is an awesome person, definitely part of the team."

Wendy Cruz

Hopefully, you won't ever need the services of the Northeast Georgia Medical Center's emergency room. But, if you do, there are at least two things you can count on...outstanding care and the smiling face of Wendy Cruz.

As a patient care tech, Wendy is often one of the first caregivers patients see in the ER. June Fletcher, Wendy's supervisor and mentor, says Wendy's job includes, "transporting patients, assisting the

nurses with tasks, and getting vital signs." She's also responsible for making sure her area in the ER is always stocked with the necessary supplies.

After completing her rotations through Project SEARCH, Wendy was offered a full-time job in July. "I like working with the patients, and making them feel like they are being treated very well," she says. "But what I like best is meeting new people every day. There's always new faces and (she says with a smile in her voice) new drama."

She really enjoys taking care of the patients, especially when she's transporting them and gets a chance to talk. She says one of her favorite memories of being on the job was a patient she had just helped saying to her, "Wendy, don't change."

"I like working with the patients, and making them feel like they are being treated very well."

Her ability to speak Spanish has already come in handy too. She says she uses her second language "almost every day. When people have a concern, I try and answer it." Fletcher adds that her bilingual skill will be used even more once she completes a certification process.

As with most hospital schedules, Wendy sometimes works long days and nights. She says her hours are "crazy," but she likes it that way. "I'm not really a day person, so I like being here at night." But no matter when she works, as Fletcher points out, "There's always a smile on her face. She's very courteous, always friendly, very caring with the patients and definitely very much a team player."

And if you've ever been in an emergency room, you know that's exactly the kind of person you want taking care of you. ●

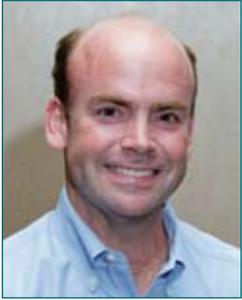


Wendy Cruz

For more information about how you can get involved with Project SEARCH, visit projectsearch.info. For more information about GCDD's Real Communities Initiative, visit www.gcdd.org.

Long-Term Care: Securing a Bright Future for Adult Children with Disabilities

By David Glass



David Glass is the father and son of family members with disabilities. He is the board president of Parent to Parent of Georgia and an advisory member on the Georgia Council on Developmental Disabilities. David is a member of the Atlanta Estate Planning Council. He also holds the Certified Financial Planner®(CFP) designation, and is principal of the LifePlan Advisory Group, Inc. He resides in Sandy Springs, GA and can be reached at: 404.847.1894 dglass@lifeplansolution.com

Every family is different, and planning for a child with a disability requires forethought and a coordinated decision-making effort.

As a parent of a child with a developmental disability, I am continually interested in creative ideas and strategies that can enhance quality of life for current and future generations of people with disabilities. These ideas and strategies focus on positive outcomes for people with disabilities in the form of bigger opportunities, meaningful experiences and lasting relationships within their community. Striving for these outcomes requires time, effort and personal planning on the part of families that have children with disabilities. A primary focus is to maintain and maximize public benefits, while also utilizing private resources as efficiently and effectively as possible.

Unfortunately, many people rely on public benefits, services and supports as the sole long-term solution for an aging population of people with disabilities. The problem with this as a strategy is that the future funding sources for these programs remains uncertain, and the funding amounts are trending downward. Compounding the funding problem is the increasing population of people with disabilities, life spans of people with disabilities, the cost of care and support and the demand for services. Public benefits really only fill the basic support needs anyway, and do not address “quality of life” issues.

In light of this sobering trend within the disability community, the question becomes: What areas can families plan for, focus on and take a proactive approach in providing a more secure future for their family member? The three primary areas of planning that require a coordinated effort are A) financial, B) legal or estate, and C) communication with others regarding intentions and desires.

With regard to financial needs, the parents of children who have disabilities are often faced with the proposition of providing financial support for two generations simultaneously (themselves and their child with a disability). In most situations, the only way to effectively accomplish this is to utilize creative strategies within extended families that can access resources when needed at specific points in time. There is also a heightened need among the parents for a degree of certainty and stability when it comes to providing this financial support. The risks that need to be addressed are A) longevity risk (i.e., living too long and running out of money), B) purchasing power risk (i.e., keeping up with the cost of living), and C) volatility risk (i.e., being susceptible to the highs and lows of investing money in the market). The

initial step is to determine how much money it really takes to support a child with a disability on an annual basis. Once determined, then it is essential to find a professional with the expertise and experience needed to evaluate strategies and customize solutions.

Parents also have important decisions to make with regard to estate planning. One approach is simply to disinherit the child with a disability. This is usually not in the child’s best interest. Another approach can be to give the inheritance for the child to another family member or sibling. This can have unintended consequences and risks (i.e., bankruptcy, divorce, death, etc. of the family member). Thirdly, the inheritance can go directly to the child with a disability. This, however, can negatively impact access to any public benefit programs. A fourth approach can involve the parents leaving any inheritance to a trust or sub-account that will maintain eligibility for benefits as well as providing for supplemental needs. In addition, parents will need to carefully consider who will be making the caregiving (i.e., guardian) and/or financial (i.e., trustee) decisions.

Communication among friends and family members is vitally important when it comes to planning for a child with a disability. Drafting a “Letter of Intent” is generally viewed as the ideal way to facilitate communication. It allows parents to communicate desires to future caregivers in detail, and should be revised on a regular basis (i.e., annually) as changes arise. The best way to begin creating this document is to start small and expand on the information annually or semi-annually.

This document should be distributed to guardians and/or trustees on a periodic basis. It should be kept with other estate planning documentation.

Every family is different, and planning for a child with a disability requires forethought and a coordinated decision-making effort. As the saying goes, “people don’t plan to fail, they fail to plan.” It is crucial to consider as many ideas and strategies as possible so that as a parent, you know that you have done everything to create the best future for your child.

Resources are scattered on this subject, but I am pretty familiar with Parent to Parent of Georgia as a resource to support families throughout Georgia, which includes a host of resources for this type of planning. As I mentioned, I have taken an interest in filling this need to help families on this topic and have experience as a resource as well. ●

StraightTalk

Hurry Up and Wait

By Danielle Coholich, a Project REACH graduate

My name is Danielle Coholich. I had a birthday this year; I am 22 years old. I can't go to school anymore. I have to wait. My mom says there is a list, so I don't have anywhere to go.

I want to learn to do stuff by myself. I write songs. I have friends. My mom drives me places and picks me up. I have a telephone to call my friends but I do not have a job because I do not have someone to show me what to do. I sit in my room and write songs or watch TV. I wait for my grandpa or my mom to come home from work and take me to see my friends, go to the gym to work out or go to McDonalds. I want to learn to do something. I do not want to wait and wait and wait.

I like to help people, but sometimes people are not nice. They don't talk nice. They laugh and can be mean. My mom says that we have to pray for those people that are not nice and wait for good things to happen. I want to work and help people; I want to make my own money to spend; I want to do stuff by myself. But I have to wait...every day wait, wait, wait.

I love everybody and just want to do things myself. I want to make money so I can buy things for myself.

I do not spell everything right, but I can do better when somebody helps me or shows me what to do. I love everybody and just want to do things myself. I want to make money so I can

buy things for myself. Can somebody help me so I don't have to wait and wait?

My mom works really hard but she can't make people hurry to help me. She tries but I don't want to wait anymore. I cry a lot. In school I enjoyed going to job sites. I was the best, too. Project REACH taught me to clean up after myself. I would like to work.

Maybe we can vote for somebody who would help us get money to teach us to work. I can't vote. I know I would be a good voter.

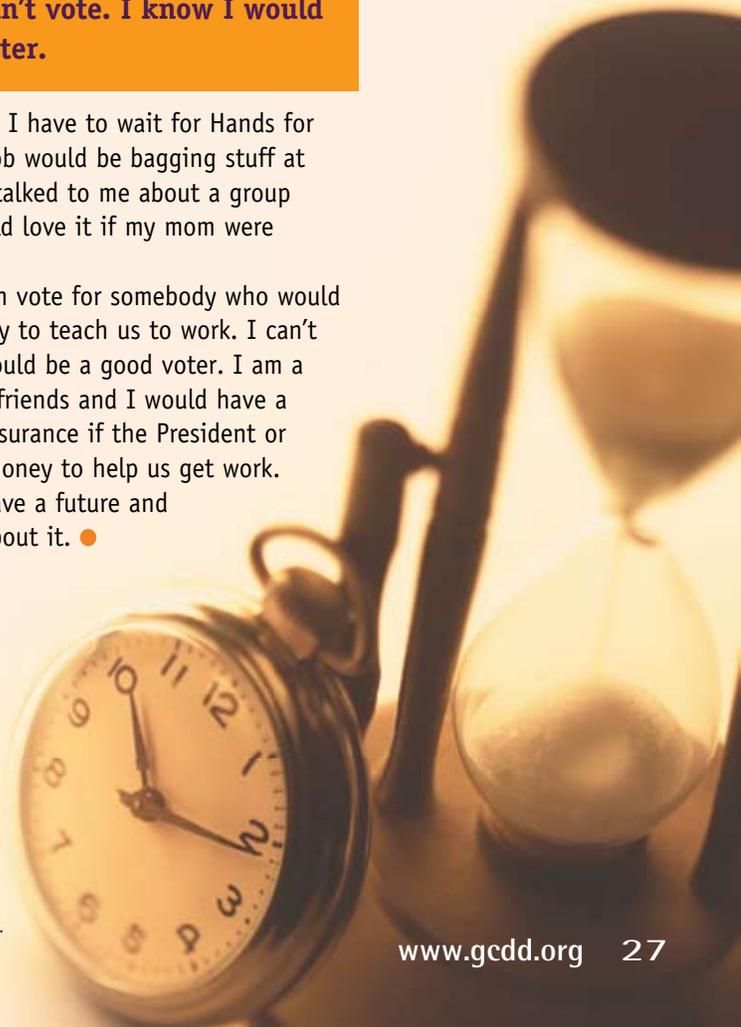
My mom says I have to wait for Hands for Hire. My dream job would be bagging stuff at Kroger. My mom talked to me about a group home, and I would love it if my mom were close by.

Maybe we can vote for somebody who would help us get money to teach us to work. I can't vote. I know I would be a good voter. I am a good worker. My friends and I would have a job and health insurance if the President or somebody gave money to help us get work.

I want to have a future and not just dream about it. ●



Danielle Coholich is a 2009 graduate of Fayette County High School where she participated in the Project REACH employment readiness program. She lives in Peachtree City with her mother, Rose Tucker.



Editor's Note: This is a policy issue that the Statewide Transition Steering Committee is working on. There are about 700 special education students who graduate each year. Plans should be made on how to support these students after graduation. There have been no new Medicaid Waivers for people in the community in the past two years. There are many young people waiting. Dr. Pat Nobbie, GCDD Deputy Director chairs the Statewide Transition Steering Committee.



After Your Birth

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

Mia is going to be 26 in October. When she tells people about her upcoming birthday, she always says, "I'm too old to be 26." To which I reply, "I'm too old for you to be 26!" Both statements make you go hmmm. What does that mean? But we know. She's recognizing she's older. And so am I.

This morning, I dug out the journal I wrote after she was born. I've always kept a journal, but for about 5 months after her birth, I didn't write anything. Then in February 1985, I began again. It's full of grief and joy and surprises.

"She was my first child and I was new at mothering, so the fact she was born with Down syndrome was almost secondary to all the other stuff I had to figure out about babies."

She was my first child and I was new at mothering, so the fact she was born with Down syndrome was almost secondary to all the other stuff I had to figure out about babies. We were living in the Virgin Islands, so scattered throughout the four years it took to finish this particular journal, I also recorded hurricane stories. And I wrote some poetry, probably because it took less time and could be fit between Mia's naps. Here's the poem I wrote after she was born:



*After the ocean of euphoria
they told me you had something
of one name or another
a "condition" a "developmental disability"
or, a "handicap" or yes, a "syndrome"*

*And after the swell of grief
and the questionings
and yes, even then
the fierce, protective love*

*After that
I was glad
that you had a lot of hair
and clear brown eyes
that all your parts worked
and you didn't forget
to breathe in your sleep*

*After all this
the something you have
of one name or another
seems a small price to pay
for your smiles*

*Smile girl!
Happy Birthday!*



OCTOBER

October 21-23
Closing the Gap
28th Annual Conference
 Bloomington, MN
www.closingthegap.com/conference

October 23
Eunice Kennedy Shriver Challenge
 Washington Monument, Washington, DC
www.kintera.org/faf/home/default.asp?ievent=420123

October 24 (Session II)
Jewish Family & Career Services
The Caregiver Support Group
 Atlanta, GA
 770-677-9345
revere@jfcs.atlanta.org

October 26
Albany Advocacy Resource Center
32nd Annual Awards Banquet
 229-888-6852 ext. 362
mjohnson@albanygaarc.org

NOVEMBER

November 5-7
Camp Caglewood
Camping trip to Brasstown Bald
 678-405-9000
info@caglewood.org
www.caglewood.org/contact.aspx

November 7 (Session III)
Jewish Family & Career Services
The Caregiver Support Group
 Atlanta, GA
 770-677-9345
revere@jfcs.atlanta.org

November 13
Workshop on Special Need Wills/
Guardianship & Waivers
 Rome, GA
 Karen Cook at 706-853-0144
Sandra@p2pga.org

November 13
Autism Society – Greater Georgia
A Purpose Filled Life
Seminar and Resource Fair
 Hilton Atlanta Northeast
 770-904-4474
www.asaga.com

November 15 - 19
13th Annual Accessing Higher
Ground – Accessible Media, Web
and Technology Conference
 Boulder, Colorado
 Howard Kramer
 303-492-8672
hkramer@colorado.edu
www.colorado.edu/ATconference/

November 17-19
NASDDDS 2010
Annual Conference
www.nasdds.org/Meetings/2010_Annual_Conference/index.shtml

DECEMBER

December 3-6
Camp Caglewood
Trip to Disney World
 678-405-9000
info@caglewood.org
www.caglewood.org/contact.aspx

December 8-11
TASH: Equity, Opportunity &
Inclusion for People with Disabilities
35th Annual Conference
 Denver, CO
www.tash.org

JANUARY

January 9-11
Winter Institute
sramirez@gsu.edu

January 17
Waddie Welcome Reading
tomkobler@bellsouth.net

January 20
State Interagency Coordinating
Council SICC for Early
Intervention Programs
 Atlanta, GA
 Ruth Cantor
 404-657-4395
rfcantor@dhr.state.ga.us

January 20-21
GCDD Quarterly Meeting
 Atlanta, GA
 404-657-2126 / 888-275-4233 (ASK-GCDD)
www.gcdd.org

January 26 - 29
Assistive Technology
Industry Association –
ATIA 2011 Conference
 Orlando, Florida
 312-321-5172 • info@atia.org
www.atia.org/i4a/pages/index.cfm?pageid=3733

Planning an Upcoming Event?

Send your information to Kim Shapland
 at kim@oneillcommunications.com
 to be included in the Winter calendar.





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

Georgia Council on Developmental Disabilities (GCDD)

www.gcdd.org
404-657-2126 or
888-275-4233 (ASK-GCDD)

State Government

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

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

Department of Community Affairs
www.dca.ga.gov

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

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

General Information
www.georgia.gov

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

Aging & Disability

Georgia's Aging and Disability Resource Connection (ADRC)
www.georgiaadrc.com



Adult Down Syndrome Program

www.isdd-home.org
Janice Nodvin
jnodvin@aol.com • 678-595-4854

Project GRANDD

Services for Grandparents Raising Grandchildren with Developmental Disabilities
Janice Nodvin
jnodvin@aol.com • 678-595-4854

All About Developmental Disabilities
www.aadd.org

Department of Community Health (DCH)
www.dch.georgia.gov

Department of Human Services
www.dhr.georgia.gov

Division of Aging Services (DAS)
aging.dhr.georgia.gov/portal/site

Division of Family and Children Services (DFCS)
www.dfcs.dhr.georgia.gov/portal/site/DHR-DFCS/menuitem

Department of Behavioral Health and Developmental Disabilities (DBHDD)



mhddad.dhr.georgia.gov/portal/site/DHR-MHDDAD/

Alzheimer's Association – Georgia Chapter
www.alz.org/georgia

American Association on Intellectual and Developmental Disabilities
www.aaid.org

Atlanta Alliance on Developmental Disabilities
www.aadd.org

Behavioral Health Link
www.mygcal.com

Benefits Check-up
www.benefitscheckup.org/

Brain Injury Resource Foundation
www.birf.info

Center for Positive Aging
www.centerforpositiveaging.org

GABIS (GA Benefit Information System)
www.workworld.org/wwwwebhelp/welcome_to_gabis.htm



Grandparents Raising Grandchildren
www.dhr.georgia.gov/grg

Online Disability Resources Directory for Georgia
www.disabilityresources.org/GEORGIA.html

Parent to Parent of Georgia
www.p2pga.org

David Glass
www.lifeplansolution.com
davidglass@lifeplansolution.com
404-847-1894

Employment

Project SEARCH
Dottie Adams
dxadams@dhr.state.ga.us

Race for Governor
Nathan Deal
www.nathandeal.org

Roy Barnes
www.roy2010.com

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www.GeorgiaHousingSearch.org





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Letters to the Editor

Have something to say about one of the issues discussed in *Making a Difference*? Please send your "Letters to the Editor" to vmsuber@dhr.state.ga.us by November 10 for inclusion in the Winter 2011 issue of *Making a Difference*.



Georgia's Parent Training and Information Center (PTI)
Georgia's Family to Family Health Information Center (F2F)
The Babies Can't Wait Central Directory
Georgia's Family Voices



800.229.2038
www.parenttoparentofga.org

Developmental Disabilities Services Tools for Independence

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

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SAVE THE DATE

DISABILITY DAY

Thursday, February 24th, 2011 • State Capitol