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MAKING a DIFFERENCE

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FIRST *Comes Love* THEN *Comes Marriage*

NEWS FOR YOU:

LOVE & MARRIAGE: Disabilities & Relationships

LEGISLATIVE UPDATE: Reflecting on the General Assembly

DISABILITY DAY: Annual Rally Reaches its 15th Milestone

GCDD
GEORGIA COUNCIL ON
DEVELOPMENTAL DISABILITIES

On the Cover:
Jamie and Michael Teal, a married couple of 17 years, featured in the "First Comes Love Then Comes Marriage" article, outside of their home in Athens, GA.

The Georgia Council on Developmental Disabilities, a federally funded state agency, works to bring about social and policy changes that promote opportunities for persons with developmental disabilities and their families to live, learn, work, play and worship in Georgia communities.

GCDD
GEORGIA COUNCIL ON
DEVELOPMENTAL DISABILITIES

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SPRING 2013

MAKING a DIFFERENCE

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VOLUME 13, ISSUE 4

FEATURES

DEPARTMENTS

ERIC E. JACOBSON

Look for GCDD to Reach Out to You

Spring is a time for rebirth and reflection. For many it means flowers and love is in the air. This edition of *Making a Difference* reflects on how people connect with each other through relationships and how some of those relationships lead to marriage.

We also reflect on the 2013 legislative session that just ended. This session was relatively quiet for issues important to people with developmental disabilities. The State budget continues to reflect a slow economy and most new money for people with developmental disabilities is targeted to those individuals leaving public institutions or those who are at risk of institutionalization. There was not support for increasing the funding beyond the requirements from the Department of Justice settlement. However, we hope to build this funding over the coming years.

Many of you were there on February 21 to help us rally at the 15th Annual Disability Day at the State Capitol, and you heard Governor Deal proclaim his support for expanding post-secondary options for students with intellectual disabilities. This support leads to new funds for the initiative at Kennesaw State University and will allow a new program to begin at a yet to be determined university.

Over 2,500 people attended Disability Day this year. The weather was perfect and speakers such as Governor Deal, Commissioner Frank Barry (DBHDD) and Greg Schmeig (GVRA), reinforced our beliefs and efforts that no person should live in an institution or nursing home and that we need to expand employment opportunities for people with disabilities. On that day, we stood as a community with our policy leaders and made a statement that every Georgian needs to have a Real Life. We even heard that some of the "old timers" thought this was the best rally ever.

Finally, our advocacy efforts were heard around the world as we pushed to keep Warren Hill from being put to death. Many of us stood on the Capitol steps and spoke about the injustice that would occur if Hill was executed. Now, we must fix Georgia's law so that "beyond a reasonable doubt" becomes a "preponderance of evidence" and aligns Georgia with other states so that no person with an intellectual disability is executed here.

While we had some good things happen, we cannot let our guard down. We must work to build a robust network of advocates around the State who are willing to tell our elected officials that we must expand these efforts. There must be new money in the budget to help the 7,500 people currently on waiting lists. This must happen while we move people out of institutions – we can't wait until 2015. GCDD will work to help make sure your voice is heard and will be expanding its grassroots advocacy efforts in partnership with others over the coming months. Look for us to reach out to you.

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

Eric E. Jacobson

Eric E. Jacobson
Executive Director, GCDD

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

Letters To The Editor.

GCDD **VIEWPOINT**

How to Reach Us

Letters to the Editor

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

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GOVERNOR'S
ARTICLE

The following is a transcript of Governor Deal's Disability Day speech from February 21, 2013.

Deal Reaffirms Commitment to Georgia's Disability Community

Welcome to everybody here at the State Capitol, and we are glad to have you. I want to thank the Georgia Council on Developmental Disabilities for hosting this event again this year and thanks to all of you for what you do to help and assist those who have disabilities.

> I think we are making great progress, and it is all together appropriate that whenever possible, we move individuals who are in nursing homes into private and community-based settings.

I know your theme is being connected and that is of course an appropriate theme. I think all of us would like to see those with disabilities connected to better living conditions, better educational and training opportunities and then of course better integration into society as a whole. We are working on that.

I want to thank all of you who are providing the kind of assistance in your local communities that is necessary to make programs and efforts of this type successful. I want to thank our Department of Behavioral Health and Developmental Disabilities for their leadership, especially Frank Barry for his leadership.

We are moving in a very positive direction to implementing what we have agreed upon in our settlement with the Department of Justice in regard to moving as many of those as we can from our hospital and institutional settings back into community-based settings.

It takes everybody working in the same direction to achieve that, and it requires that your local communities step up and work with state agencies and other agencies as we attempt to find the appropriate facilities for individuals with disabilities. It also requires those in the housing community in various parts of this great State to cooperate in that undertaking.

I think we are making great progress, and it is all together appropriate that whenever possible, we move individuals who are in nursing homes into private and community-based settings. Thank you for your efforts to do that.

But there is another important linkage in all of this, and that is employability. As much as possible, we should attempt to do everything we can to provide employment opportunities to those with disabilities. I want to commend Kennesaw State University for a program that they have initiated.

> "As much as possible, we should attempt to do everything we can to provide employment opportunities to those with disabilities."

They are allowing students with disabilities to participate in classes and in educational opportunities along with students who don't have disabilities. They are a forerunner of this in our higher educational institutions, and I believe it is a program that we can replicate throughout our entire university system. I commend them for taking that role.

As you know we have goals that we have classified as our Olmstead goals, and I have enumerated some of those here today, but I want to thank you for your support, for your efforts both here at the Capitol on this occasion and more importantly for your efforts every day back in the communities in which you work and live. Those with disabilities have great abilities and we need to capitalize on it. Thank you very much for letting me be with you.

IN THE NEWS

Georgia Winter Institute 2013

The Georgia Winter Institute, which brings together people from across Georgia and beyond to discover how to infuse values-based, person-centered philosophies into community-building efforts, was held January 6-9, 2013 in Columbus, GA at the Columbus Convention & Trade Center and Columbus Marriott.

Attendees had a chance to learn from well-known leaders in the community and explored strategies on sharing stories of successes and dreams of community members, to better understand how to share those stories in ways that both engage and excite the listener and to participate in various activities, including encouraging commitments to sponsor readings of *Waddie Welcome and the Beloved Community*. This is a story of friendships transcending divisions of disability, race and income to get Waddie Welcome out of a nursing facility and back home to Savannah.

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

"This is a great event because it facilitates open conversations on how to engage people with disabilities in all aspects of community life and lets others know we have made tremendous progress toward opportunities for people with disabilities to become an integral part of community life," said GCDD Executive Director Eric Jacobson.

GCDD Advocating for Hill's Stay of Execution

GCDD has been closely following the national controversy surrounding the Warren Hill case, a man with an undisputed intellectual disability, and his call for an unconstitutional execution in Georgia. Despite being diagnosed as having an intellectual disability, Georgia law requires that those on death row must prove "beyond a reasonable doubt" that they have an intellectual disability. Amidst national outcry on Hill's case, a press conference of disability advocates calling for clemency was held on February 19, 2013 at the Georgia State Capitol on the day Hill was set to be executed.

"People with intellectual disabilities deserve to live as full citizens of this country and State, protected by laws designed to recognize our diversity and uphold our basic rights, despite our differences," said GCDD Executive Director Eric Jacobson, who spoke at the press conference. "We in Georgia will continue to fight to bring our State into alignment with other states by working with policymakers to change the 'beyond a reasonable doubt' standard."

Although Hill was granted a stay of execution one hour before he was set to die, GCDD will continue to advocate for justice and a fair trial for Hill's case.

Schools Must Open Sports to Kids with Disabilities

For the first time, the US Department of Education's Office for Civil Rights declared that children with disabilities have the right to participate in their school's extracurricular activities under Section 504 of the Rehabilitation Act.

This guidance will allow students with intellectual, developmental, physical and other types of disabilities equal access to their school's sports and opportunities to join their school teams with modifications, aids and services as needed.

"Sports can provide invaluable lessons in discipline, selflessness, passion and courage, and this guidance will help schools ensure that students with disabilities have an equal opportunity to benefit from the life lessons they can learn on the playing field or on the court," said Education Secretary Arne Duncan.

For more information, visit www.disabilityscoop.com/2013/01/25/feds-schools-sports/17177/

Looking Forward to Making Georgia Connections with GCDD...

Things I've learned since arriving in Georgia two months ago: Disability Day is a heart-thumping and inspiring event. When getting directions, always remember there are many, many roads with "Peachtree" in the name. The Georgia advocacy community is diverse, passionate and committed. And that's a very good thing because we have lots of exciting and important work to do.

For those of you I haven't had a chance to meet, I'm D'Arcy Robb, the new public policy director for the Georgia Council on Developmental Disabilities (GCDD). Before coming to GCDD, I did public policy for the equivalent council in Kentucky. I have my master's in public administration from the University of Kentucky and my bachelor's from Williams College. In between those degrees, I worked first for a political campaign and then for the news media.

Putting professional experience aside, I tease my family that growing up with them was the perfect preparation for being GCDD's public policy director! A lot of that is thanks to my dad, who held elected office since before I was born until just a few years ago. A lot of it also goes to my mom, the most creative and hardworking Title I teacher I know. But most of all, it's thanks to my brother, an exceptionally kindhearted young man who is a voracious reader on subjects like the royal family of Saudi Arabia. Although it took several years and multiple misdiagnoses to figure it out, my brother is also a proud "Aspie" (an individual with Asperger Syndrome) on the diverse spectrum of autism. When I first started doing public policy for the DD Council in Kentucky, my brother immediately told me he was proud and that I should come to him "if you have any questions about us Aspies."

This goes to show how well my brother knows me – I am a question-asker. And one

> "The many individuals with disabilities and family members that I get to connect with, keep me grounded and coming back to the overall goal of moving the ball forward for people with disabilities and the communities we all live in."

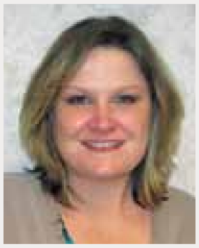
> I am so very excited to be here in Georgia and look forward to connecting and working with you on public policy.

of the things I love about this job is that I'm constantly learning and seeing how different perspectives fit into the ongoing puzzle of public policy. The many individuals with disabilities and family members that I get to connect with, keep me grounded and coming back to the overall goal of moving the ball forward for people with disabilities and the communities we all live in.

So, that's where I'm from and a few of the people I love the most. In mentioning the people I love, I would be highly remiss if I did not mention my husband, who never fails to make me laugh, helps bring me perspective on just about anything and was even coerced into dancing at a self-advocacy conference last spring. Having failed on previous occasions when I tried to get him to dance in public, I was not the person who convinced him to hit the dance floor, and I can only chalk it up as a small but telling example of the power of determined self-advocates.

I am so very excited to be here in Georgia and look forward to connecting and working with you on public policy.

GCDD Welcomes New Organizing Coordinator



The Georgia Council on Developmental Disabilities (GCDD) welcomes new staff member, Cheri Pace in the newly created position of organizing coordinator.

Pace, a former member of GCDD's Advisory Board has been active in the Real Communities Initiative and involved in broad coalition-building and community organizing advocacy for more than 10 years. She brings valuable experience in uniting individuals, organizations and communities together toward common goals and facilitating open dialogues and participatory workshops for both children and adults, as well as diverse groups of people. Throughout her career, Pace has directed a youth advocacy program in Detroit, MI, conducted workshops for consumers with disabilities at the Ann Arbor Center for Independent Living, served as a guest lecturer on disability and community, organized dialogues on race and ethnicity and built a multicultural coalition around immigration rights.

"I am excited for the opportunity to join the GCDD team," said Pace. "As a community organizer, social worker, friend and both a parent and daughter of a child and father with developmental disabilities, this is close to my heart. I am committed to identifying and developing avenues that lead to the full participation of all people in all aspects of community life."

In her new role as organizing coordinator, she will be working with GCDD Organizing Director Caitlin Childs, and other community builders throughout the State to support the expansion of the Real Communities Initiative.

GCDD's Real Communities Initiative

Launched in 2009, the Real Communities Initiative is GCDD's signature concept that has received national attention for its innovation and diversity. Real Communities provides cutting edge, intentionally inclusive activities throughout the State with a focus on projects that create opportunities for all people – with and without disabilities – to work together as full partners in the social life and the civic development of their communities.

The goal is to build inclusive communities throughout Georgia and connect people with developmental disabilities and their organizations to other citizens and their associations to act collectively on community issues. GCDD commissioned six videos to celebrate its Real Communities Initiative projects and share the stories of people with and without disabilities working together to achieve common goals that strengthen community life for everyone.

> "As a community organizer, social worker, friend and both a parent and daughter of a child and father with developmental disabilities, this is close to my heart.

Scan the QR code to visit GCDD's collection of Real Communities Initiatives' video projects.

First Comes Love
Then Comes Marriage

By Bill Lewis

Love, sexual relationships and marriage are common, everyday, ordinary life experiences that most look forward to and some may even take for granted, but when it comes to people with developmental disabilities, these matters have too often been viewed as taboo or considered off-limits. People with disabilities have been falling in love, enjoying relationships and getting married throughout time. However, it is happening now more than ever before, and a much needed dialogue is beginning to take place as fresh, new perspectives replace old attitudes.

“There is a trend that is slowly growing where people are more open to talking about these issues. The problem with sexuality generally and culturally is that we have a lot of silence around it, even more so around disabilities and relationships, but these are conversations that need to be had,” says Bethany Stevens, a faculty member at Georgia State in Public Health, a sexologist and a non-practicing attorney.

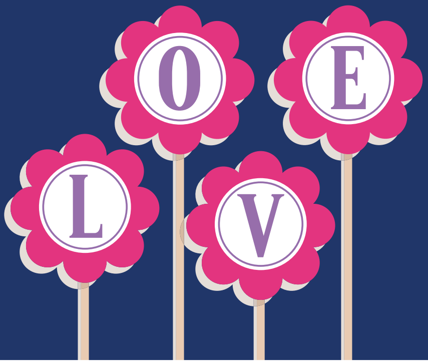
For example, a 2010-11 report by the National Core Indicators, an annual survey of people with developmental disabilities receiving services through the state system, revealed that “39% of Georgians feel lonely at least half of the time.” But, the same report showed that “84% of (Georgia) respondents reported that they could go on a date or can date with some restrictions if they want to.”

According to Stevens, there are still tremendous barriers, and one is that a lot of people think individuals with disabilities are de-sexual and may have no desire to be in a relationship. But, many sexual self-advocates are pushing to change this view.

“I think people are recognizing this as a right just like self-determination,” says Stevens. “We’re starting to understand it’s not just housing and employment that need to become a focus for people with disabilities to participate as full members of communities, but we need to be thinking about relationships and sexuality as well.”

Stevens, who married Sara Palmer in 2011 in Washington, DC, has firsthand experience with the cultural stigma of those with disabilities being classified as de-sexual. Stevens has disabilities and Palmer does not. “But too often Sara is viewed by some as my caregiver rather than my spouse,” Stevens says. However, she notes there is an overall shift starting to take place that is promoting inclusion for people with disabilities in all aspects of life that is making it easier for them to explore romantic and sexual relationships.

Stevens and Palmer are featured as a couple on the cover of the current issue of *New Mobility* magazine. You can find the magazine at www.newmobility.com/articleView.cfm?id=12296



> “Many universities are working on post-secondary education for people with developmental disabilities, bringing them into the typical college atmosphere where they are getting an education along with the social interaction that could *lead to dating.*

For instance, many universities are working on post-secondary education for people with developmental disabilities, bringing them into the typical college atmosphere where they are getting an education along with the social interaction that could lead to dating.

While most of society focuses on two people who both have a developmental disability being involved in a relationship, it's important to note that not all people with disabilities are ending up with others who have disabilities.

"I tell my students that the one universal around sexuality is that there is no universal, and that we all have different desires and attractions," says Stevens.

As customs change and inclusion for people with disabilities in all aspects of community life is becoming more of a priority, many of the cultural barriers are starting to break down. But, as Professor Stevens points out, it's not something that happens overnight nor without a lot of involvement by many.

"I think there really needs to be training on all levels of society, looking at faith-based organizations, people who are support care workers, parents, schools and particularly special education, where it is important to learn how to talk about this in a positive way."

"...the desire to find a partner and someone to share your life with is natural. It is time the taboo is broken in the disability community."

Whether it's distance, hesitancy by family members, money or typical marital spats, people with disabilities in relationships face the same problems as those without disabilities in relationships. Love and relationships are not easy. In fact those with disabilities may even face more challenges, but the desire to find a partner and someone to share your life with is natural. It is time the taboo is broken in the disability community.

Lori Berger and David Bryan

For many people, taking a trip to Israel can be a life-changing experience. Lori Berger and David Bryan would not disagree.

In the late 1990s, Lori, who has Down syndrome, and David, who has a developmental disability, both went to Israel through the Atlanta Jewish Community Center's developmental disabilities program.

The way Sheryl Arno, the director of the program at the time remembers it, "There was an empty seat next to Lori on the plane and she looked at David and said, 'Sit down.' They got off the plane holding hands. And they've been together ever since."

Lori's mother Robin, remembers they came home from the trip and Lori told her she had a boyfriend. That wasn't unusual. Lori always had boyfriends throughout her childhood and teenage years.

But she kept talking about David. "So I asked her to see if he wanted to go to dinner with us. He turned out to be quite a charmer," Robin said. "I felt like a third wheel at the dinner since my husband was out of town."

Lori and David dated about two years. Then, one night, David invited Lori to go to Bones for dinner. "We went to Bones and we ordered dinner. I had filet mignon," Lori says. "All of the sudden, the waitress came out with a plate of dessert and a box. The message on the plate said in chocolate, 'Will you marry me?' And the ring was in the box."

On September 14, 2003 in front of 350 people at the Westin Hotel, Lori and David got married. "It was lots of fun, with lots of dancing," says Lori.

Since then, the couple has lived in their own apartment in the Toco Hills area of Atlanta. They take care of their apartment, do their own laundry and cook. Each has support from consultants who work with them, but they split up the chores like typical married couples do.

"All of the sudden, the waitress came out with a plate of dessert and a box. The message on the plate said in chocolate, 'Will you marry me?' And the ring was in the box.

Lori Berger and David Bryan

"There was an empty seat next to Lori on the plane and she looked at David and said, 'Sit down.' They got off the plane holding hands. And they've been together ever since.

Lori does the grocery shopping from a list she and David make up together. She likes to make sure they eat healthy food and the consultant will go with her to the store to make sure she stays within her budget and buys the healthy food. In return, David's consultant helps him with banking and shopping once or twice a week.

For their second anniversary, they got a kitten, and it's their baby. "Her name is Sabrina Bryan and we just love her to death," says Lori.

"They complement each other and are so tolerant of each other," says Robin. "They don't always agree, but they get over it quickly."

Robin notes after a spat, Lori's usual response is, "Men. What are you gonna do about them?"

But the spats are few and far between. They've had a wonderful relationship and life for over 10 years now. Offering the simple reason how, Lori says, "Because I love him."

Jamie and Michael Teal

Jamie and Michael Teal

Bill Holley, executive director of the Athens Multiple Choices Center for Independent Living, has known Jamie and Michael Teal for a long time. "They don't know any strangers," he says in describing the couple. "Really friendly… the kind of people you're proud to be part of their lives."

They first laid eyes on each other in the lobby of the Roosevelt Rehabilitation Center in Warm Springs over 17 years ago.

"We were both living in the dorm there," says Michael. "I was helping as a sighted guide for people to get to the dining hall from the dorm. I saw Jamie in the lobby and I casually asked her where her cane was. We were just kind of passing."

Jamie, who has a traumatic brain injury and visual impairment, was there for an Independent Living Skills program. Michael, who has dyssemia, is cognitively impaired and was enrolled in a job-training program for the printing industry.

Michael admits he didn't really like Jamie right off the bat. But during the spring semester, "It's one of those things that kind of blossomed," he said. Jamie says, "We used to call each other 'our better half.' It was kind of a joke around the school."

> "It's one of those things that kind of blossomed. We used to call each other 'our better half.' It was kind of a joke around the school."

After graduation, Michael moved back to Marietta and Jamie to Athens. Once a month trips became once a week treks to see her. Eventually Jamie moved into a one-bedroom apartment to try things on her own. Michael would visit and stay on the couch.

Michael later moved to Athens and into the apartment. Things went pretty well, with the occasional hiccups. Both families approved, and they got married in 1996. Jamie says she brought organizing strength to the relationship, while Michael helps with everything visual, including their transportation needs.

Today, the Teals live in a condo that they own in Athens. They are very active in several organizations around the city and are instrumental in helping with marketing, advertising, fundraisers and social activities.

Jamie has an assistant that comes in five days a week to help take her to places like the doctor, to get a haircut or with other needs. Grocery shopping she and Michael do together. And who cooks? "Well, that depends on what we want," says Jamie. "Mostly we go to restaurants."

So what's the secret to their 17 years of success at marriage? "I haven't figured that out yet," says Jamie. Michael has a more spiritual answer, "At the end of the marriage

Getting Married?

How will this affect your Social Security (SS), Childhood Disability Benefits (CDB), Supplemental Security Income (SSI), Supplemental Security Disability Income (SSDI), Medicaid, Medicare or other government benefits?

- **Will married individuals lose CDB or Medicare?** Since Medicare and CDB are "means-tested" programs, the SS Administration won't look at assets or income to determine eligibility. Normally CDB ends if the person marries, but if a person with a disability marries another person who receives disability benefits, then he/she is still eligible for CDB.
- **Will you lose SSI or see reductions?** When they marry, both individuals' income and resources will be assessed in determining SSI eligibility. If both people receive SSI, they will remain eligible, but there is a "marriage penalty." Because their assets combine as a couple, their SSI could be reduced.
- **Will you lose Medicaid?** The federal Medicaid program combines a couple's income and resources, and if those income and assets exceed the Medicaid eligibility levels, the individual could lose his/her Medicaid and safety net.

We're getting married!

- **What about wedding gifts?** Gifts of money given directly to the couple will adversely affect government benefits. Although cash benefits won't affect Medicare or CDB, it's important the couple receive only household or gift cards that cannot be redeemed for cash or food items, without affecting SSI or SSDI benefits.

Getting married could affect the benefits you receive, but each person's situation is unique. For more information, visit http://www.specialneedsalliance.org/the-voice/4/9 or http://ssa-custhelp.ssa.gov/app/answers/detail/a_id/2310/~/effects-of-getting-married-on-social-security-benefits.

ceremony it says, 'What God has joined let not man put asunder.' Even though we have normal issues as well as issues with our disabilities, with God in our lives…well, I just don't go against God."

Carmine Vara and Amanda Lineberry

"Well, I can tell you this: I didn't think it would ever happen," says Nancy Vara, mother of 29-year-old Carmine Vara, whom she proudly shares is newly engaged to 26-year-old Amanda Lineberry.

"Carmine is handsome and friendly, works at Stone Mountain Park and lives in his own home," says his mom. He uses a motorized wheelchair and requires 24-hour personal care due to his cerebral palsy. Amanda lives with her family and has autism. "She's a real sweetheart and really cares about Carmine," says Vara.

The couple met through Amanda's sister who worked for Carmine's father. The sister knew Carmine through the office and she and Amanda were at the mall one day when Carmine was also there. They all started talking and Amanda gave Carmine her phone number. "It was love at first sight," says Carmine. "He came home awfully excited," his mom said.

And for three years, they've not only been dating, but burning up the phone lines. Vara remembers, "AT&T actually called me and wanted to know if I wanted unlimited calling for his line because otherwise it was going to cost $1,300."

The idea of Carmine having a girlfriend was exciting for Vara. Even though they live 30 miles apart, the families and support staff help Carmine and Amanda go to movies and dinner. And one of their favorite activities? "Swimming (in Lake Lanier)," says Carmine.

Amanda "looks good," says Carmine, "and she makes me feel loved." Not only that, "She's a very caring person," he adds.

> *"It was love at first sight.*

Carmine Vara and Amanda Lineberry

"When marriage came up though, I thought, 'Are you kidding me'?" says Vara. Dating was one thing, but "we're talking about Medicaid dollars, Social Security, the legalities of that, Carmine having 24/7 direct support staff and people in the home with him. And now with the possibility of having a wife in the picture who doesn't have support staff, and the support staff dealing with him personally …there are lots of issues."

Vara points out that even in a marriage between people without disabilities family dynamics can play a part. And that issue is substantially heightened in this situation. For both Carmine and Amanda, there has always been some form of adult supervision in their lives, whether it's parents or support staff.

Vara has "suggested" to Carmine that they be engaged for a couple of years. "There would need to be boundaries," she says. That includes family and support staff. And there are money issues as well. Carmine currently has a roommate who helps with expenses. Amanda receives Social Security, but there is a possibility that income would be reduced as a married couple. But, as Carmine says, he thinks one of the best things about being married would be, "Having Amanda cook for me."

"They are definitely in love, there's no doubt about that," says Vara. "But marriage is a whole can of worms with lots of things to think about."

A Recap on the 2013 Legislative Session

By D’Arcy Robb

This edition of *Making a Difference* goes to print as the cries of “Sine die!” are still echoing under the Gold Dome. The 2013 legislative session has been a quick one compared to previous years, ending before April Fool’s Day. Both the Fiscal Year 2013 amended budget and the Fiscal Year 2014 budget passed, along with a relatively small number of bills. However, since this was the first of a two-year session, bills that did not make it this year will still be alive for consideration in 2014. Below are highlights on what happened in the 2013 General Assembly and what Georgia’s disability advocates were working toward.

This year’s Unlock the Waiting Lists! campaign focused on advocating for small but key additions to the budget, restoring crucial cuts and supporting the Department of Justice settlement dollars.

FY 2014 Budget

A quick overview – for the second year in a row, Georgia’s economy has shown modest growth. This allowed for $578 million in state funds to be added into the budget for 2014, resulting in a total budget of $19.9 billion. Dollars went into areas including education, public safety, juvenile justice, funding the employee retirement system, water supply projects and transportation. Funds also went into supporting the Department of Justice settlement agreement and into expense growth for Medicaid and PeachCare. The Governor was able to keep Georgia’s AAA Bond Rating and add to the State’s “Rainy Day” fund. Much like the 2013 budget, the 2014 budget is essentially one of modest relief.

This year’s Unlock the Waiting Lists! campaign focused on advocating for small but key additions to the budget, restoring crucial cuts and supporting the Department of Justice settlement dollars. Unlock coordinators D’Arcy Robb and Dave Zilles want to give our sincerest thanks to the many advocates and legislators who gave us their partnership and support this year. We were successful at getting an additional 20 slots in the Independent Care Waiver Program for adults with physical disabilities, which means an additional 20 people can come off the waiting list and receive services. It was by all accounts a challenging budget year, and unfortunately, the other Unlock requests for additional funding did not make it into the final 2014 budget.

Unlock joined with many other advocates and provider groups advocating for the removal of the 0.74% rate cut proposed for home and community-based service providers, and our collective voices were heard and this proposed cut was removed. Additionally, Unlock worked with advocates for seniors in requesting the removal of two key cuts to aging services – the proposed elimination of 17 elder abuse investigator positions and funding for respite care. All of the funding for respite care was restored, along with half of the funding for the elder abuse investigator positions.

The Department of Justice settlement funding relating to developmental disabilities is supported in full in the 2014 budget. The funding for 2014 is as follows:

FY 2014

- Family Supports: $6,520,400
    - Includes $1,872,000 increase to serve 500 new families
- NOW/COMP Waivers: $31,812,512
    - Includes $11,966,160 increase for 250 new waivers
- Crisis Respite Homes (12) & Mobile Crisis Teams (6): $11,917,681
- Education of Judges and Law Enforcement: $250,000
- DD Total spending: $50,700,593
    - Includes $13,838,160 total increase

> Regarding Medicaid, the 2014 budget includes $7.2 million worth of state savings to be achieved by better enforcing the level of care that is required to qualify for long-term care and home and community-based services.

In another piece of exciting news, $100,000 was added to the budget to expand inclusive post-secondary education programs, which provide a college experience for students with intellectual disabilities with the goal of preparing them for employment. Many organizations and individuals, including Senator Butch Miller, worked hard to advocate for this funding. Currently, the Academy for Inclusive Learning and Social Growth (AILSG) at Kennesaw State University, which is supported by the Georgia Council on Developmental Disabilities (GCDD), is the only post-secondary program in Georgia. The additional funds will support expansion of the AILSG program and support the creation of a new program in south Georgia.

Also of note in the 2014 budget, funds were increased by $500,000 for the Marcus Autism Center, with state funds accounting for half the increase.

Regarding Medicaid, the 2014 budget includes $7.2 million worth of state savings to be achieved by better enforcing the level of care that is required to qualify for long-term care and home and community-based services. There is language in the budget regarding consumer choice in the elderly and disabled waiver, which says that eligible beneficiaries can choose from the SOURCE Care Management companies and the Community Care Services Program that are available in each county. The budget also includes $300,000 to create a SOURCE Quality Incentive Program based on client satisfaction measures.

The budget also includes language authorizing the Department of Community Health (DCH) to apply for an 1115 federal waiver. This is an important piece of the ongoing conversation about Medicaid redesign happening in Georgia. The 1115 waiver is a particular kind of Medicaid waiver that the DCH staff plans to use to create the new managed care system for children in foster care. Discussions are ongoing regarding a separate 1115 waiver for the Aged, Blind and Disabled Medicaid program. GCDD and several other advocacy groups are working together as the CARE-M coalition and continue to be very involved in discussions with DCH. The 1115 waiver approval process requires opportunity for public input and public comment, so stay tuned for more information to come.

For further details on the 2014 and 2013 amended budgets, please see *Moving Forward*, GCDD's newsletter that comes out weekly during the legislative session.

{ *Moving Forward is available at www.gcdd.org/public-policy/moving-forward.html* }

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AND LAW ENFORCEMENT:
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TOTAL INCREASE

If you aren't sure who your legislators are, you can check by going to

votesmart.org

and entering your zip code and looking for your State representative and State senator. Let them know about the issues that are important to individuals with disabilities and those who care about them.

Legislation

The Family Care Act - House Bill 290
This legislation, sponsored by Representative Katie Dempsey, would allow individuals whose jobs provide sick days the option of using that time to care for sick children or aging parents without penalty from their employers. The Family Care Act was reported favorably out of the House Human Relations and Aging committee, but did not make it out of House Rules committee. The bill will still be alive during next year's legislative session and advocates plan to continue working on this issue over the summer.

> Many disability advocates are passionate supporters of Ava's Law and the therapies it would cover, but there are some advocates who object to the bill, particularly its inclusion of Applied Behavior Analysis (ABA) therapy.

Ava's Law - House Bill 309/ Senate Bill 191/House Bill 559
This bill would require insurance plans to cover a range of therapies for individuals on the autism spectrum. The original House bill is sponsored by Representative Ben Harbin, the Senate bill is sponsored by Senator John Albers and an additional House bill is sponsored by Representative Chuck Sims. Ava's Law did not pass out of either chamber, but there was an informational hearing held in the Senate Insurance committee. The bill is currently under consideration by the non-legislative Health Insurance Mandates committee. Before the 2014 legislative session convenes, the Mandates committee will make a recommendation on Ava's Law. Over the next several months, the Mandates committee will study the potential cost, social ramifications and medical efficacy of Ava's Law. Many disability advocates are passionate supporters of Ava's Law and the therapies it would cover, but there are some advocates who object to the bill, particularly its inclusion of Applied Behavior Analysis (ABA) therapy.

Protection of Vulnerable Adults - House Bill 78
This bill, sponsored by Representative Wendell Willard, expands the definition of what is considered exploitation, abuse or neglect of adults with disabilities or elderly persons, and moves these offenses to the criminal section of the State code. It also expands the lists of people who are required to report suspected abuse, as well as provides for information sharing among agencies that receive reports. House Bill 78 passed both chambers and awaits the Governor's signature.

Medicaid Reform and Oversight - Various Bills
House Resolution 107: Sponsored by Representative Donna Sheldon, this bill creates a time-limited committee of legislators and other stakeholders who will study options for Medicaid reform. The resolution passed both chambers and awaits the Governor's signature.

Senate Bill 62: Sponsored by Senator Judson Hill, this bill creates a standing legislative committee to oversee state and federally funded healthcare programs, including Medicaid. The bill passed both chambers and awaits the Governor's signature.

Senate Bill 163: Sponsored by Senator William Ligon, this bill requires the Department of Community Health to study and identify options for Medicaid reform. The bill passed the Senate but not the House.

Hospital funding for Medicaid - Senate Bill 24/House Bill 51
This bill, with versions sponsored by Senator Charlie Bethel in the Senate and Representative Matt Hatchett in the House, was a big piece of the Governor's legislative agenda. It allows the Department of Community Health to collect a fee from hospitals that helps to fund Medicaid, which is needed as the hospital bed tax is expiring. The Senate bill passed both chambers early in the legislative session and has been signed by the Governor.

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GCDD MAILING & EMAIL LISTS:
Go to www.gcdd.org – scroll down and click "Stay Connected" on the right-hand side

UNLOCK THE WAITING LISTS!: Go to www.unlockthewaitinglists.com

Navigators for Health Benefits Exchanges - HB 198
This bill, sponsored by Representative Richard Smith, provides for the licensing of health insurance navigators who can help people understand their options under the health insurance exchange. Under the federal Affordable Care Act, a health insurance exchange is set to operate in every state by January 2014. This bill allows the Georgia Commissioner of Insurance to license and regulate those who wish to be navigators – in other words, to guide and advise individuals and companies about health insurance policies. The bill passed both chambers and awaits the Governor's signature.

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Nursing Facility Arbitration - SB 202
This bill, sponsored by Senator Renee Unterman, would formalize the process for signing arbitration agreements when a person enters a skilled nursing facility. Under the arbitration process, a person or family would go before third-party decision makers, known as arbitrators, instead of going to court if they wished to bring charges of wrongdoing against the facility. Advocates in the disability and aging communities have concerns that this process would put consumers and families at a disadvantage. The bill did not make it out of committee this year.

Juvenile Justice Reform - HB 242
This bill, sponsored by Representative Wendell Willard, reforms the juvenile code. This substantial bill has been several years in the making and is supported by the Governor. It emphasizes keeping youth who are charged with less serious offenses in community-based programs and out of detention facilities. The bill passed both chambers and awaits the Governor's signature.

Ethics Reform - HB 142
This is the high profile ethics and lobbying reform bill sponsored by House Speaker David Ralston. The final bill ultimately passed both chambers on Sine Die and contains various restrictions on lobbyist spending. Under the bill, persons who are volunteer advocates do not have to register as lobbyists unless they receive more than $250 in reimbursement for lobbying expenses. The bill awaits the Governor's signature.

While many issues moved along or gained momentum this session, there is much left to do. You are an advocate, or can be one! Get to know your legislators in the off-season and offer yourself as a resource of information.

If you aren't sure who your legislators are, you can check by going to votesmart.org and entering your zip code and looking for your State representative and State senator. Let them know about the issues that are important to individuals with disabilities and those who care about them.

One major and ongoing issue is the need for more community-based services for individuals with disabilities. Under the Department of Justice settlement, we are getting 100 new waivers per year for people in the community. But with 6,683 people on the waiting list, this only begins to scratch the surface of need. We also need increased opportunities and resources to support employment in the community. These are just a few of the issues that GCDD plans to work on with various partners in the months ahead. We urge you to stay connected, be a part of the conversation and stand up to advocate for yourself and your community!

PERSPECTIVES

Georgia's Beyond a Reasonable Doubt Standard for Proving Intellectual Disability Must Go

By Terrica Redfield Ganzy

TERRICA REDFIELD GANZY is a staff attorney at the Southern Center for Human Rights and a member of the Board of Directors of Georgians for Alternatives to the Death Penalty (GFADP).

Georgia is the only State in the nation that requires those with intellectual disabilities facing the death penalty to prove their disability beyond a reasonable doubt. Once a trailblazer as the first State to outlaw the execution of those with intellectual disabilities, this requirement makes Georgia the most regressive State in the nation on this issue.

The fact that limitations co-occur with strengths, particularly in those with mild intellectual disabilities, is not readily understood by most. Therefore, a capital defendant's abilities, no matter how rudimentary, inherently create reasonable doubt about whether the defendant has an intellectual disability. While Georgia was the first to offer a lifeline to capital defendants with intellectual disabilities, it turns out that the lifeline is just an illusion. A person's ability to prove an intellectual disability under the current law is virtually impossible.

Warren Hill, a man with an intellectual disability on Georgia's death row, is an example of this conundrum in practice. Hill has been determined by a preponderance of the evidence to have an intellectual disability by two separate courts, yet he faces execution because he hasn't been able to prove this beyond a reasonable doubt. Although the United States Court of Appeals for the Eleventh Circuit has granted a stay of execution to determine whether new evidence in Hill's case will be heard, the court is not reviewing the constitutionality of Georgia's statute. Thus, a change to the law is the only way to prevent those with intellectual disabilities facing the death penalty in Georgia from being executed.

The American Bar Association (ABA) has provided guidance to Georgia lawmakers on how to rectify O.C.G.A. § 17-7-131. In its 2006 report on Georgia's capital punishment system, the ABA study commission described Georgia's beyond a reasonable doubt burden of proof as inappropriate. They recommended that Georgia either "place the burden of disproving mental retardation on the prosecution when the defendant presents a substantial showing that he may have mental retardation" or "limit the burden of proof required by the defendant to a preponderance of the evidence." Now is the time to act on these recommendations.

The Georgia legislature should commission its own study, so mental health experts, social workers, parents and those with intellectual disabilities could educate lawmakers on what it means to have intellectual disabilities; why making the determination is not as easy as looking at a person; how a person with an intellectual disability could, for example, hold a job; why focusing on a person's strengths is the wrong way to assess a disability; why a beyond a reasonable doubt burden for proving an intellectual disability is unreasonable; why a preponderance of the evidence standard of proof would ensure the interests of justice; and the feasibility of other options to protect people with intellectual disabilities from execution, including the ABA's recommendation that a burden of disproving intellectual disability be placed on the State.

By taking action to ensure that those with intellectual disabilities facing the death penalty are in fact protected from execution, Georgia could reestablish itself as a leader in protecting some of society's most vulnerable members.

> "The Georgia legislature should commission its own study, so mental health experts, social workers, parents and those with intellectual disabilities could educate lawmakers on what it means to have intellectual disabilities; why making the determination is not as easy as looking at a person...

The Kennesaw State University Academy for Inclusive Learning and Social Growth

By Dr. Ibrahim Elsawy

This program also includes a focus on social integration, career exploration and wellness, and the graduates receive a Certificate of Social Growth and Development.

The faces of the college students that surround me are bright with concentration and hands shoot up in the air as I ask question after compelling question. I am surprised by the depth and thoughtfulness of their answers, proud of the hard work to prepare and see young minds expanding in the Global Issues class at Kennesaw State University (KSU).

The students are a mixed group: some are typical business, psychology or arts majors working as student mentors in Georgia's first fully inclusive two-year college experience for students with intellectual or developmental disabilities. The rest are students with developmental disabilities enrolled in the Academy for Inclusive Learning and Social Growth (AILSG).

With continued support from the Georgia Council on Developmental Disabilities (GCDD), the AILSG students, who would not otherwise meet the university requirements for degree-seeking entry, enroll in typical university courses as non-degree seeking audit students alongside their peers. This program also includes a focus on social integration, career exploration and wellness, and the graduates receive a Certificate of Social Growth and Development.

The Global Issues course gives AILSG students and their mentors an opportunity to hone their class participation skills and work together on assignments, building the skills that AILSG students will need as they audit their remaining classes with their typical peers. The professors of audited classes agree – from education and history to sports management, AILSG students are among the best prepared and most interactive. The Academy Coordinator, Jill Sloan, negotiates with departments campus-wide to assure that accommodations for the AILSG students support the integrity of the courses and that second-year students have individual preference.

Additionally, support from the student mentors is non-invasive but vital. These mentors help when asked and guide the AILSG students to class, through the paper-writing process or into relationship negotiations with a professor or a peer.

The fully inclusive aspect of the program means that like their typical peers, students have access to the entire campus, including applying for student housing, where several of them live and develop independence skills and increase their confidence.

Career development is also an important aspect of the program. The students receive support from an employment specialist, as well as in job shadowing, person-centered planning and job-readiness training. The AILSG students are held to high standards and subject to the requirements of any student intern and leave the program prepared to join the workforce.

Using person-centered planning unites the students with their circle of support and facilitates a graphic model of resources, goals and aspirations. This encourages students to develop steps to take power over their futures, and the results inform both the job-readiness training and selection of coursework during the students' pivotal second year.

Initially in 2009, there were only three students and now 2013 will open with 19. Our vision as we move into our fifth year is to light the way for other universities in Georgia to open similar programs.

In cooperation with the GCDD, the Georgia Inclusive Post-Secondary Consortia and All About Developmental Disabilities (AADD), we welcome opportunities to collaborate in that regard.

DR. IBRAHIM ELSAWY is executive director of the Academy for Inclusive Learning and Social Growth for the WellStar College of Health and Human Services, as well as director of Middle East Initiatives for the Institute for Global Initiatives at Kennesaw State University. An international advocate for Inclusion and Disability Rights, he organized the First Arab-American Dialogue on Disability held at KSU in 2009, as well as the Second Arab-American Dialogue on Disability in 2010, held in Tripoli, Libya.

For more information about the KSU AILSG program, visit www.kennesaw.edu/chhs/academy. To watch a video on the program, visit www.gcdd.org/news-a-media/videos/viewvideo/28/ksu-academy-for-inclusive-learning-and-social-growth.html

The Annual Disability Day Rally Promotes Community Connections and Reaches its 15th Milestone

By Becca Bauer

The Georgia Council on Developmental Disabilities' (GCDD) Annual Disability Day rally that started out 15 years ago in a small room in the State Capitol with about 25 people, has evolved into a movement that brings thousands of advocates across the State to promote access, opportunity and meaningful community living for Georgians with disabilities and their families. With nearly 2,500 attendees, the 15th Annual Disability Day rally on February 21, 2013 on the Capitol steps united a record number of supporters in their mission to have their voices heard in celebration of community, advocacy, friendship and achievement.

> "Being connected is about connecting with people in places where you live, where you work, where you play and where you worship.

Ranging from small groups to groups of more than 250, individuals from all over Georgia gathered at the nearby Georgia Railroad Freight Depot to don shirts, make signs for the rally and connect together as one before taking their message to elected officials at the State Capitol.

GCDD Executive Director Eric Jacobson energized the crowd at the start of the rally touching on this year's theme, "What's Your Connection?" borrowed from the US Department of Labor's Office of Disability Employment Policy's (ODEP) national campaign that emphasizes a disability as a universal link that each of us have in common and encourages inclusion in all aspects of life.

"Being connected is about connecting with people in places where you live, where you work, where you play and where you worship," Jacobson exclaimed. "It shows that we are truly connected from all over the State when we come to Disability Day at the Capitol. We can all point to this and say today is about us; it is about our community; it is about our State and it is about what we do to make our place a better place to live."

Introduced by Evan Nodvin, a 34-year-old self-advocate who was recently appointed to the GCDD Council, Governor Nathan Deal addressed the crowd for a second year in a row.

Presenting Governor Deal with an official 2013 Disability Day t-shirt, Nodvin, who serves as a prime example of being connected, independently living, working and participating in the community noted, "I was excited to introduce the Governor. He has always said that people with disabilities should not live in institutions or nursing homes and that people need to have real careers, real homes and real opportunities to be connected, especially in the community."

Governor Deal reaffirmed his support to Georgia's disability community and delivered a message of hope and commitment to work with them on issues including job opportunities and post-secondary education. *(A transcript of Deal's speech appears on page 4).*

Additionally, the Governor was not the only elected official to show his support and address the crowd. Senator John Albers (R-Dist 56), who was accompanied by his son Ryan and recently introduced the bill Ava's Law to support children with autism, rallied the crowd with his words, "someone earlier today came up to me and said, 'thank you for supporting those with disabilities.' I said, you're welcome, but let me correct one thing that is very important, you don't have disabilities, we do."

Representative Scott Holcomb (D-Dist 81) and Representative Alisha Thomas Morgan (D-Dist 39), also came to the rally and let the crowd know they hear them inside the Capitol and are working to move forward on legislation.

"I want each and every person here to know that your voice is powerful," said Thomas Morgan. "I need my colleagues inside to know you can speak for yourself, you can advertise for your own jobs and your own services and the things that you deserve as human beings."

> "someone earlier today came up to me and said, 'thank you for supporting those with disabilities.' I said, you're welcome, but let me correct one thing that is very important, you don't have disabilities, we do."

D'Arcy Robb, GCDD's new public policy director and co-coordinator of the Unlock the Waiting Lists! campaign delivered encouraging words on a positive start to the 2013 legislative activity. But, she cautioned there is much more work to be done to truly support real communities and good lives in those communities.

Among the many issues she is tackling this session include more funds to allow people to live in their own homes, support for young people with disabilities graduating from high school to find and maintain real jobs in the community through supportive employment and transportation services, more new independent care waivers and calling on policymakers to avoid making cuts to home and community-based providers. *(See page 12 for a full legislative update).*

GCDD is working with the Post-Secondary Inclusive Consortium to identify resources that would expand higher education through a program at the Academy for Inclusive Learning and Social Growth at Kennesaw State University (KSU), which is currently the only program in the State of Georgia that provides a two-year college experience for individuals with intellectual disabilities.

"The key to this program is that it prepares people for real jobs," said Robb. "We are so excited to hear the Governor support this program because this year we are partnering with other organizations and advocates to ask lawmakers for $350,000 that will allow programs like KSU's to be established at four other universities across Georgia. And, this a very exciting prospect."

In conclusion, prompting the crowd to get involved and advocate the best way each person sees fit, Robb noted, "when it comes to legislation, I urge you to get connected and stay connected."

After years of talking about closing state public institutions for people with developmental disabilities, by 2015 the doors will be closed forever.

"As we envision that day in 2015, where no person is locked away because they have a developmental disability, it is very appropriate that we stand here today and hear from our legislators, our Governor and other folks about what we are doing to make sure that is the reality," said Jacobson.

Over the past year, new leadership has emerged in the disability community that

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Albany Advocacy Resource Center • Another Chance Customize Services, Inc. • Autism Society of Georgia • Brain & Spinal Injury Trust Fund Commission • Delmarva Foundation – GA Quality Management System • Fulton County Equal Employment • GAAPSE • Georgia Advocacy Office (GAO) • Georgia Association of Community Care Providers • Georgia Association of Community Service Boards • Georgia Council for Exceptional Children • Georgia Financing & Investment Commission • Kaleidoscope • Shepherd Center • SILC of Georgia, Inc. • The Arc of Bleckley County • The Arc of Georgia • United Cerebral Palsy • View Point Health Developmental Disabilities Services

> We need to continue to make sure that no person with an intellectual disability is ever executed in the State of Georgia.

has been dedicated to moving forward and leading the way for positive change in the community.

Frank Barry, commissioner of the Department of Behavioral Health and Developmental Disabilities (DBHDD), joined the rally and updated the crowd on the progress made by his agency so far. "We have moved almost 900 people off the waiting list since July 1, and people who have been desperately needing services have received those services," said Barry.

However, with over 7,500 people still remaining on waiting lists, Barry noted, "But we will still do better. Your voices are being heard, but we need to do even more. We have never had a Governor and a legislature that have been more supportive of what we are trying to accomplish and we need to take advantage of this day."

Along with Commissioner Barry, Greg Schmieg, executive director of the newly formed Georgia Vocational Rehabilitation Agency established last year by Governor Deal, touched on his vision for Georgia and the need to improve the employment of people with disabilities.

According to Schmieg, the United States Senate conducted a study 22 years after the passing of the Americans with Disabilities Act (ADA), and the results were very discouraging. "Currently the unemployment rate among people with disabilities across our country is 70%," he said. "The earning potential of person with a disability who does get a job is two-thirds that of non-disabled worker. A person with a disability is three times more likely to end up in poverty. And do you know what my answer is? That is just not acceptable!"

Energizing the crowd, Schmieg made his message ring loud and clear leading the crowd in the chant, "everybody who wants a job should have a job."

Additionally, Jacobson spoke on the highly publicized case of Warren Hill, a man with an intellectual disability scheduled to be executed right here in Georgia the night before the rally. Although Hill was declared to have an intellectual disability, to take a person off the death penalty under current law in Georgia, that person must prove beyond a reasonable doubt that he/she has intellectual disabilities.

Proving the great power of public advocacy, Hill was granted a stay of execution at the last minute, but Jacobson noted there is still a vital need to work with partners in both the human rights and developmental disability community to get the State legislators to initiate the lower standard of proof that most other states operate under.

> "The earning potential of person with a disability who does get a job is two-thirds that of non-disabled worker. A person with a disability is three times more likely to end up in poverty. And do you know what my answer is? That is JUST NOT ACCEPTABLE!"

"The advocacy efforts for Warren Hill show that we are a powerful group and if we are willing to work together, if we are willing to have a common message and work as a team, there is nothing that can stop us," added Jacobson. "We need to continue to make sure that no person with an intellectual disability is ever executed in the State of Georgia.

The rally also offered an opportunity to recognize seven fallen soldiers, Georgia's disability advocates who passed away in 2012.

Rabbi Analia Bortz of the Congregation Or Hadash, who is at the forefront of ensuring social justice issues are part of the congregation's everyday efforts and that the Jewish community is working to make sure that synagogues are welcoming and accessible to anyone who wants to attend, led the crowd in honoring their memories.

"We would also like to remember those who have perished while in institutions and nursing homes though we do not know their names," said Bortz. "Today, we remember the ones who don't have a voice anymore to claim their rights."

"We all have disabilities in one way or another and we are also skilled in other areas," she added. "Special needs is about asking the entire society to listen to the needs of unique and special people. I am grateful to God for making me understand that I have to bring awareness to each one of us to make sure that we are all part of this society that embraces us from the ranks in institutions to the access to buses to schools, to healthcare, to jobs. That is why we are all here today."

After the rally concluded, those in attendance returned to the Freight Depot in a unity march to gather with other advocates, their families, friends and State Legislators including Senator Nan Orrock (D-Dist 36), Senator Vincent Fort (D-Dist 39) and Representative Tommy Benton (R-Dist 31), to share a catered lunch and reflect on the day.

There was also an awards ceremony held at the post-rally event to honor and celebrate the work of several of Georgia's self-advocates.

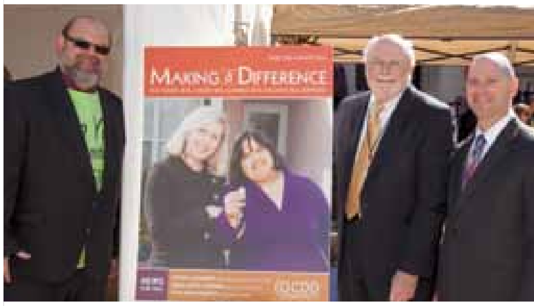
Georgia's Outstanding Self-Advocate of the Year Award was created in loving memory of Natalie Norwood Tumlin, who passed away in 2005. This award is presented annually at Disability Day by the Tumlin family, with assistance from GCDD, to recognize a self-advocate who demonstrates leadership qualities and brings self-determination to Georgia. This year Ken Mitchell, advocacy coordinator of DisABILITY Link and a strong believer in independent living, transportation advocacy and a mentor to numerous children since 1992, was recognized with this honor.

Accepting his award, Mitchell declared, "Thank you to the Tumlin family for even considering me for this award. We are all advocates. We are just everyday people living every day."

Additionally, the Samuel Mitchell Lifetime Achievement Award, created to honor the memory of Samuel Mitchell, an influential self-advocate who passed away in 2008, was awarded to Yvette Sangster, director of advocacy education at the Georgia Advocacy Office (GAO) and a nationally known disability advocate. Presented by Cheri Mitchell, wife of the late Samuel Mitchell, Mitchell brought Sangster to tears as she presented her with the award and said, "no one deserves this award more than Yvette. She has truly given her all."

> "I am grateful to God for making me understand that I have to bring awareness to each one of us to make sure that we are all part of this society that embraces us from the ranks in institutions to the access to buses to schools, to healthcare, to jobs. That is why we are all here today."

After 15 years, with both long-time attendees and first timers, the annual Disability Day rally continues to thrive and each year is filled with more progress and hope. "I come back each year because I want to help myself and I want to help others," declared Krishna Goel, a sixth time attendee. "I am proud of myself and I am proud to be a part of this community."



What's Your Connection?

Since the Georgia Council on Developmental Disabilities' (GCDD) Annual Disability Day hit a milestone this year, it seemed fitting to share its theme with the US Department of Labor's Office of Disability Employment Policy's (ODEP) national campaign, "What's Your Connection?" celebrating the 10th anniversary of Disability.gov.

There are 57 million individuals with disabilities in the United States, and they are all connected to the people around them in some way. The "What's Your Connection?" campaign emphasizes a disability as a universal link that each of us have in common and encourages inclusion in all aspects of life. From sons and daughters, sisters and brothers, parents and grandparents, coworkers, neighbors and friends, we are all connected to each other in some way whether you have a disability or not.

As part of the national campaign, ODEP launched the "What's Your Connection?" initiative on October 30, 2012 to invite people nationwide to submit a captioned photograph or video that answers the question, "What's your connection to disability?" spark conversations and build support for inclusion of people with disabilities in the workplace and in communities. The campaign will run until July 31, 2013. For more information or to submit a "What's Your Connection?" piece, visit www.disability.gov/home/newsroom/what's_your_connection.

At the 15th Annual Disability Day, Partnerships for Success (PFS), a high school-based program designed to promote relationships between young people with disabilities and their peers through leadership building, recreation and social activities, community service and other shared experiences that allow all students to make contributions to their school and community

> "We live in a diverse world where it is essential for all students to learn acceptance and tolerance. It is important for students with and without disabilities to connect with each other and see what they have in common so they can fully understand the meaning and importance of inclusion."

at large, set up a booth at the Georgia Freight Depot for the pre-rally to share how its clubs were staying connected and participating in the "What's Your Connection?" campaign.

Over 226 students, leaders and adults from PFS representing schools in various counties including Flowery Branch High, West Hall High, North Hall High, Chestatee High, East Hall High, CW Davis Middle, Project Success at the Lanier Career Academy, Apalachee High, Colquitt County High and Woodland High came to the pre-rally to interact with the crowd and discover how others were connecting in the community, as well as showcase works that they had already submitted to the national campaign. Although the students have until July to submit stories to the "What's Your Connection?" campaign, PFS received about 30 stories to feature at its booth for Disability Day.

"We live in a diverse world where it is essential for all students to learn acceptance and tolerance. It is important for students with and without disabilities to connect with each other and see what they have in common so they can fully understand the meaning and importance of inclusion," said Cindy Saylor, PFS program coordinator who promoted the "What's Your Connection?" theme at Disability Day. "The relationships we form are key to helping us connect with others in our community."

Dottie Adams, GCDD's individual and family supports director, worked with PFS to engage with attendees at Disability Day and created an interactive wallpaper board allowing people to share insight on questions including "What is your connection to disability?" "What is your connection with disability?" and "How are you connected in the community?"

From young kids to adults, attendees filled the wallpaper and contributed to exploring the Disability Day theme.

WHAT'S YOUR CONNECTION?

Embracing a Human Right – Sexual Health and Disabilities

Sexual health is a human right. This statement may sound strange to some, yet it is grounded in international human rights and the large governing bodies of public health. The problem with this frame of sexual health as a human right for people with disabilities is that we are often not thought of us as "human enough" for human rights. We face several significant barriers – including those driven by policy and social assumptions about what our sexuality entails, and consequently, what our likely prospects may be for romance, love and marriage.

For many with disabilities, we are either assumed to be de-sexual or hypersexual. Desexualization is a belief that a group is not sexual or asexual. This stereotype is most often affiliated with people with physical or sensory disabilities (disabilities that have visible markers of difference – a wheelchair, white cane, etc.). Hypersexuality is the belief that sexuality is out of one's control and is often associated with people with intellectual or mental health disabilities. Regardless of which assumption is imposed on us, we are culturally conceived to be sexually problematic and in need of control. There is a general fear of discussing sexuality in a healthy way in our culture, which is compounded by these dominant notions of disability and sexuality.

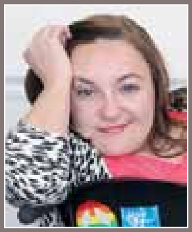
Sadly, stereotypical assumptions are not our only problem when it comes to sexual health. Many of us (about two million right now) are locked away in institutions or nursing homes where our sexuality is taken from us; in these spaces sexual activity is generally not permissible, and if it is, only heterosexual activity between married partners is considered acceptable. Additionally, sexual violence in institutions is a rampant health problem for people with disabilities that many activists and researchers are calling attention to.

It's also imperative to note the financial issues associated with sexual health as people with disabilities pursue their full rights of expression. Many people with disabilities receive SSI or SSDI benefits. Under these funding systems that include much needed health insurance, people with disabilities may lose their benefits if they marry because their partner's income will be judged as their own assets. This can mean that marrying someone living at or just above the poverty line can trigger loss of benefits – and loss of survivability. This puts some folks in a precarious situation because they want to marry – and not live in sin – but can't. It is really disturbing to think about all of the people who are denied sexual expression because of this discriminatory policy.

These are only a few of the salient burdens placed on people with disabilities regarding our sexuality that are difficult to navigate. When wading through these difficult social issues, I encourage you to remember people with disabilities are human; we do deserve the right to choose if we want to marry, reproduce and to say 'yes' just as much as we have the right to say 'no' to sexual activity. Please consider embracing sexuality and disability by having a conversation about this with your family members or friends. Communication about these problems is a remarkable tool to push against these troubling forces.

When wading through these difficult social issues, I encourage you to remember people with disabilities are human; we do deserve the right to choose if we want to marry, reproduce and to say 'yes' just as much as we have the right to say 'no' to sexual activity.

EXPERT **UPDATE**



Bethany Stevens is a faculty member and a policy analyst with the Center for Leadership in Disability within the Institute of the Public Health at Georgia State University. As a sexologist with a disability, for nearly a decade, Stevens has studied, taught and written about disability and sexuality including writing "Politicizing Sexual Pleasure, Oppression and Disability: Recognizing and Undoing the Impacts of Ableism on Sexual and Reproductive Health" in May 2012. Contact her for more information at @disaBethany or bstevens@gsu.edu.

It is really disturbing to think about all of the people who are denied sexual expression because of this discriminatory policy.

Life Goes On!

By Pat Nobbie, PhD, Mia's Mom

In the past six weeks, both Mia and I have learned a few things being this far away from each other. First, this is really a reminder and not a new realization, transportation is a huge pain in the neck. Most of the phone calls I have received from ANYONE who works for or with Mia, including Mia herself, has been on this topic.

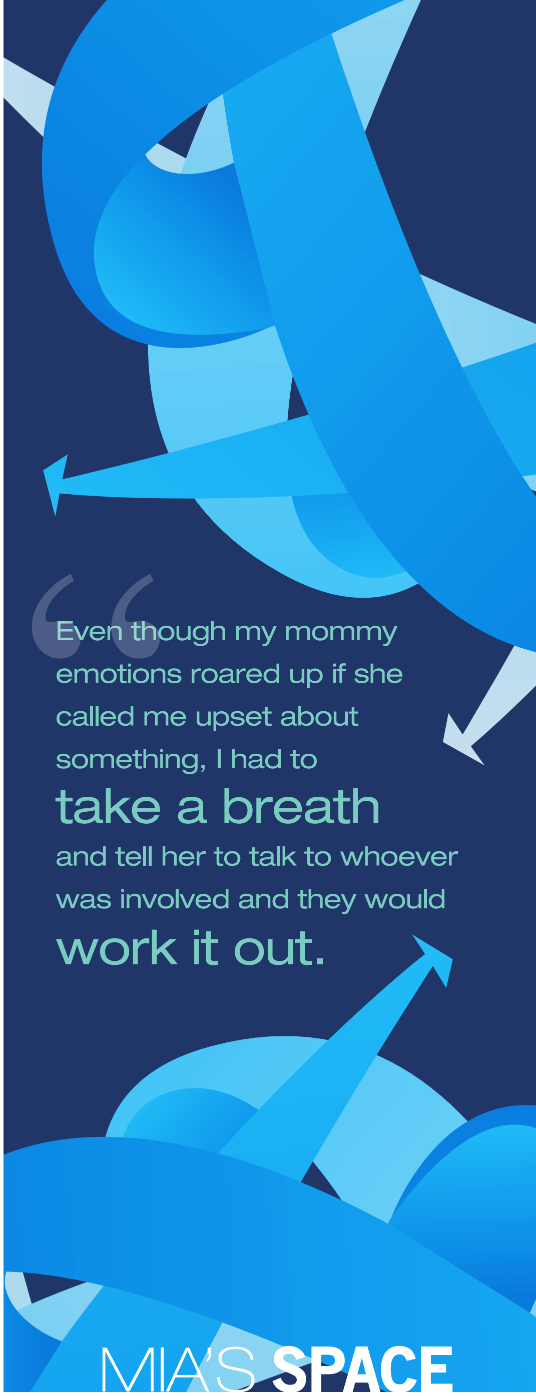
Even though she has lots of support and para-transits to work three days a week, things happen and rides need to be arranged, changed, cancelled or added. I'm the first person Mia would contact when any of the transportation snafus occurred. My usual modus operandi was to start the rounds of texts or phone calls, find out what happened and then try to fix it. Because I am the LEAST capable of fixing anything since I am in DC, this had to change. It was a big day when Mia called from the hospital where she works and told me the bus didn't come. The next time I heard from her, she had called her Dad and he took her home. Laura and I were cheering!

> "It was a big day when Mia called from the hospital where she works and told me the bus didn't come. The next time I heard from her, she had called her Dad and he took her home."

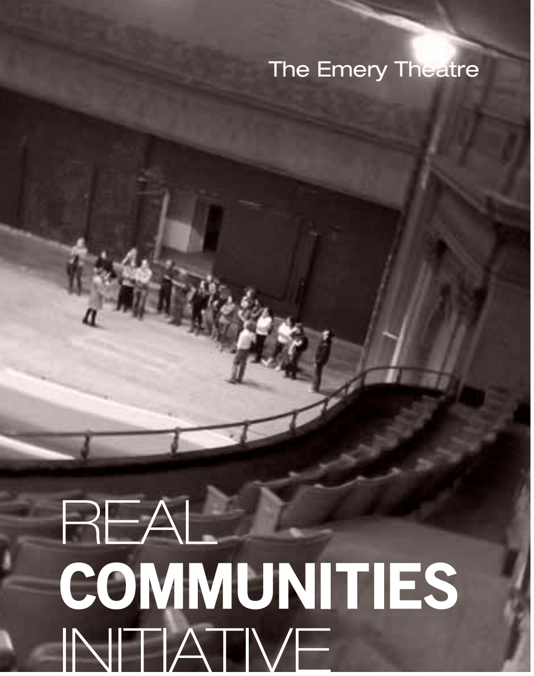
So, I learned I wasn't the center anymore. Even though my mommy emotions roared up if she called me upset about something, I had to take a breath and tell her to talk to whoever was involved and they would work it out. It reminds me of when I realized that the hair brained but "very scary plans" my other two kids would come up with when they were teenagers went away if I didn't react with panic. Instead, I'd take a breath and respond, "Really? Get back to me on that." And inevitably, the very scary plans would fall apart. Mia and her team are working it out. As Laura wrote me after one upset over a dessert, "It's family stuff, like any other family."

Otherwise, it's been pretty much as I wrote in the last issue – nothing in her life would change except that she wouldn't see me every week or so. She calls each night at 8:05 PM, and sometimes at lunchtime from the cafeteria at work. She got a cold, but got taken care of. Her phone got stolen, but Joe took her to get a new one. Her prescriptions are getting filled, she's getting to swimming, the University of Georgia, birthday parties, bowling and church. The AAAAAAAAA is sticking on her computer, but Fabersha will take her to Best Buy to get it cleaned and they'll figure it out from there.

On February 20, I blew into Athens, took her to her doctor's appointment, picked up her aunt and uncle at the airport and then drove to Montgomery to surprise grandpa for his 80th birthday. We hung out for a few days, took my dad out to dinner, replenished her sock supply and other little things. Then we went back to Hartsfield, I dropped everyone off and put Mia on Groome Transportation back to Athens where the Whitakers picked her up. She just said, "I'll miss you Mom," and "I'll call you tonight." I got on a plane and flew back to DC. Ooo blah dee Ooo blah da. Life is going on!



> "Even though my mommy emotions roared up if she called me upset about something, I had to take a breath and tell her to talk to whoever was involved and they would work it out.


The Emery Theatre


Road trip to Cincinnati


Meeting with the Starfire Council at the Red Tree

Guest article by April Doner

Learning Journeys Spark and Promote Connections

Learning journeys are a key piece of the purposeful learning process for Real Communities. The Georgia Council on Developmental Disabilities (GCDD) believes it is vital to create opportunities to support individuals to travel to other places, learn about different approaches and consider how we might apply that learning to our work in Georgia. We find that when we get people away from the day-to-day grind and take part in an immersive and experiential learning process, people are able to open themselves up and see new possibilities.

This past October, I had the privilege of taking part in an eight-day learning journey to the Midwest with colleagues and friends who are exploring inclusion and community-building in their local communities. My friend and partner in community-building, April Doner, a talented photojournalist, storyteller and a current fellow of the ABCD Institute, accompanied me on our learning journey. Over the course of our trip, April was constantly documenting our time with her camera and writing in her notebook. She has an incredible gift that she enjoys sharing, and I invited her to tell about our adventures, meeting some of the people who welcomed us into their homes and communities and share the entire story of that trip with all of you here in Georgia.

- Caitlin Childs, GCDD Organizing Director, Real Communities Initiative

……

This October, I was among a crew of people to undertake a weeklong "learning journey" throughout the Midwest, visiting people who were pioneering exciting grassroots, citizen-led change in their communities.

Accompanying me were Anna and Amara, artists and neighbors in the Village of the Arts neighborhood in Bradenton, FL, who are trying out ways to create a more connected, welcoming community. We were also joined by Caitlin Childs of the Georgia Council on Developmental Disabilities, Kirk Hinkleman (CA) with Lifeworks Supported Living, Anne Mitchell of Tesserae Learning and Sheldon Schwitek of the Center for Positive Living Support.

> "Hearing their stories made me realize the challenges that families, people labeled as "disabled" and communities face in creating a welcoming, respectful place for folks with this label in community life. I also realized the joy when those challenges are overcome."

My background is in neighborhood community-building in the tradition of Asset-Based Community Development (ABCD), and I have been practicing ABCD here for about six years. While "inclusion" is always a major focus of ABCD, Toronto marked my first in-depth exposure to the growing network of folks doing

Joseph, Tara and Tina connecting in a coffee shop

Lunch with Mike and Kirk

> It was fitting that we began with a simple social gathering, because as the journey continued, we all began to realize a core truth:
>
> ALL SIGNIFICANT CHANGE BEGINS AND ENDS WITH CONVERSATION, RELATIONSHIP, AND AUTHENTIC CARING BETWEEN PEOPLE.

amazing things around inclusion for people with disabilities. Hearing their stories made me realize the challenges that families, people labeled as "disabled" and communities face in creating a welcoming, respectful place for folks with this label in community life. I also realized the joy when those challenges are overcome. This journey opened my eyes even more.

My companions and I also learned about the core principles behind truly creative social innovation and impact. We learned that real, sustainable change starts with conversation and relationships, and in continuing those two things. It also lies in each of us developing some solid personal habits and orientations toward curiosity, regular reflection and an openness to adventure and encountering the unexpected, unpredictable and unknown.

The journey began at the beautiful home of Anne Mitchell and her husband Chuck. Anne was the host and behind-the-scenes coordinator of our learning journey. She is an incredible woman with a fierce, inquisitive and experimental spirit. At her home, we came to appreciate her love for her two dogs and her stellar talent for aesthetic gardening. Together with De'Amon Harges, Anne runs Tesserae Learning, a teaching and consulting company that empowers people to build community and influence their environment wherever they are.

It was fitting that we began with a simple social gathering, because as the journey continued, we all began to realize a core truth: all significant change begins and ends with conversation, relationship and authentic caring between people.

Stop #1: Cincinnati, Starfire Council

Our "Cincy" visit was hosted by the wonderful folks at Starfire Council, a person-centered organization focusing on building inclusive lives and communities. We started at the Red Tree Gallery, where we met the Starfire team and a young woman named Melissa.

> "My companions and I also learned about the core principles behind truly creative social innovation and impact. We learned that real, sustainable change starts with conversation and relationships and in continuing those two things."

I was impressed with Director Tim Vogt's description of how Starfire has evolved from a service orientation to a person-centered approach that focuses on building connections and relationships in which people with disabilities enjoy reciprocal, satisfying relationships in their community and can act on their passions. Starfire members, family and now anyone from the community are encouraged to take on a capstone project as a way to take action around something they love to do or care about.

Melissa told us about her project, which involved selling her baked goods. But, Tim told me later, her baking is just part of her capstone project. She is working on developing an after-party for the 5K that's held in her neighborhood of Saylor Park, and she and a group of other bakers are going to collaborate on the treats for it leading up to the party.

Starfire has also found innovative ways to encourage members, members' families and local citizens to begin expanding their web of relationships locally through learning conversations. Individuals are encouraged to have coffee or a meal and learn about each others' lives, talents and passions. Starfire then hosts gatherings for people to share what they have learned.

We then went to another coffee shop and met with Joseph, a Starfire member, and Tina Manchise and Tara Lindsey Gordon, founders of the Emery Theatre Requiem Project.

Through Starfire, Joseph made a connection earlier this year with Northside Slow Ride, a group of biking enthusiasts who meet every Thursday. From there, Joseph was inspired to create Streetfilms Fest, which Emery was happy to host.

Tina and Tara have partnered with Starfire on several great community events over the last year. The two groups have found a common passion for community and including people in the margins as leaders and artists to be celebrated.

After exploring Emery, we had lunch with Mike Holmes. Through Starfire, Mike has connected with his passion for sports and now coaches girl's basketball for the Cincy Swish.

To read April Doner's full learning journey blog and view her photographs, visit www.gcdd.org/blogs/gcdd-spotlight/2459-learning-journeys-spark-and-promote-connections-.html.

My Life and Dreams

By Evan Nodvin

Evan Nodvin works every day at the Weinstein Senior Adult Day Center at the Marcus Jewish Community of Atlanta. He was recently appointed to the Georgia Council on Developmental Disabilities board and introduced Governor Deal at the 15th Annual Disability Day. Nodvin is also currently practicing every evening for the Habima Theater performance of *Grease*.

I am Evan Nodvin and I just had my 34th birthday. I want to tell you about some of the things I have done and the things that are important to me. I graduated from Chamblee High School in the class of 2000. In high school, I was in the marching band. I got to play and march at all of the football games. A highlight was performing at the Outback Bowl in Florida.

I work as a kitchen assistant at the Weinstein Senior Adult Day Center. I have had this job for 12 years. I talk to the clients, help them when they go on outings, set up for meals and snack, prepare the meals and clean up afterward. It is hard work. I live in an apartment and have a roommate. I do all of the things a single man does like grocery shopping, cooking and cleaning the apartment, paying my bills and managing my checkbook. I have a girlfriend and enjoy going out with her.

I enjoy music (especially the Beatles), playing the drums, playing computer games, playing sports and hanging out with my friends. I am on a bowling team, take yoga, swim and exercise with a trainer. I belong to some social groups and enjoy going to activities and dances. I love power lifting and train very hard to compete every year in the Special Olympics. I enjoy acting and I perform in a special theatrical group called Habima Theater. When I can, I volunteer in the community. I especially like helping at a community garden.

I am proud that I am a graduate of a special self-advocacy program called Partners in Policymaking. I have been voted as Buddy of the Year for the Down Syndrome Association of Atlanta. I like to follow the news and vote in every election.

I have Down syndrome and I am proud of my abilities. I am able to be an independent man because I get help from my Medicaid Waiver. These funds provide me with needed transportation, a job coach and a personal consultant. I continue to learn new things that make me so proud. Because I have worked so long and have a disability, I receive SSDI (Social Security Disability Insurance). That along with my paycheck, I am able to be independent.

My parents, Janice and Joe Nodvin, are happy to see me living my dreams. They tell me that these are their dreams too. They have worked very hard to make things happen for me and others by volunteering, advocating and working for people with disabilities. I have three sisters, two brothers-in-law, one nephew and four nieces who call me Uncle "Ev."

As you can see, my life is very full. I work, live and play in the community. My dream is to continue this healthy and useful life.

> "I am able to be an independent man because I get help from my Medicaid Waiver. These funds provide me with needed transportation, a job coach and a personal consultant.

2013
CALENDAR

April

April 18-19

GCDD Quarterly Meeting
Atlanta, GA
404.657.2126

April 25-27

United Cerebral Palsy
2013 UCP Annual Conference
San Diego, CA
www.ucp.org

May

May 3-5

Abilities Expo
Edison, NJ
Free Admission
www.abilitiesexpo.com

May 6-9

YAI Network International Conference
Seeing Beyond Disability
New York, NY
212.273.6472
www.yai.org

May 7

3rd Annual Culbreth Cup
Golf Tournament
Benefit UCP of GA –
People With Out Limits
Roswell, GA
www.ucpga.org

May 13-15

2013 National Early Childhood
Inclusion Institute
University of North Carolina at Chapel Hill
Chapel Hill, NC
919.966.0888
www.inclusioninstitute.fpg.unc.edu

June

June 3-6

137th American Association on Intellectual
and Developmental Disabilities (AAIDD)
Annual Conference
Pittsburgh, PA
www.aaidd.org

June 6

2013 National Sibling Leadership
Network Conference
Pittsburgh, PA
www.siblingleadership.org

June 9-14

2013 UCEDD Leadership Development
Institute Association of University Centers
on Disabilities (AUCD)
Newark, DE
www.aucd.org

June 10-11

Evidence-based Practice in Disability
Disciplines Conference
Flagstaff, AZ
www.nau.edu

June 28-30

Abilities Expo
Chicago, IL
Free Admission
www.abilitiesexpo.com

July

July 8-10

2013 NACDD TA Institute
and Annual Conference
Washington, DC
www.ncdd.org
svega@nacdd.org

July 18-19

GCDD Quarterly Meeting
Atlanta, GA
404.657.2126

July 18

Annual Making a Difference
Appreciation Ceremony
Atlanta, GA
404.657.2126

Planning an upcoming event?

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

CALENDAR HIGHLIGHT:

GCDD commissioned six videos to celebrate its Real Communities Initiative projects and share the stories of people with and without disabilities working together to achieve common goals that strengthen community life for everyone.

RESOURCES

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

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

State Government

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

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

Department of Community Affairs
www.dca.ga.gov

Georgia Housing Search
www.georgiahousingsearch.org
877.428.8844

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

General Information
www.georgia.gov

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

News

Schools Open Sports to Kids with Disabilities
www.disabilityscoop.com/2013/01/25/feds-schools-sports/17177/

Around GCDD

Real Communities Initiative Video Projects
www.gcdd.org/news-a-media/videos/viewcategory/12/real-communities.html

Love & Marriage Feature

Athens Multiple Choices Center for Independent Living
http://multiplechoices.us/

Center for Leadership in Disability
http://publichealth.gsu.edu/678.html

National Core Indicators
www.nationalcoreindicators.org/

National Core Indicators
www.nationalcoreindicators.org/

Social Security Administration
http://ssa-custhelp.ssa.gov/app/answers/detail/a_id/2310/~/effects-of-getting-married-on-social-security-benefits

Special Needs Alliance
www.specialneedsalliance.org/the-voice/4/9

Legislative Feature

Moving Forward Newsletter
www.gcdd.org/public-policy/moving-forward.html

Unlock the Waiting Lists!
www.unlockthewaitinglists.com/

Perspectives

Georgians for Alternatives to the Death Penalty
www.gfadp.org/

Kennesaw State University Academy for Inclusive Learning and Social Growth (AILSG)
www.kennesaw.edu/chhs/ and
Video Project: www.gcdd.org/news-a-media/videos/viewvideo/28/ksu-academy-for-inclusive-learning-and-social-growth.html

Southern Center for Human Rights
www.schr.org/

Expert Update

Center for Leadership in Disability
http://publichealth.gsu.edu/678.html
Contact: bstevens@gsu.edu

Real Communities

April Doner's Learning Journey Blog
www.gcdd.org/blogs/gcdd-spotlight/2459-learning-journeys-spark-and-promote-connections-.html

Straight Talk

Marcus Jewish Community Center of Atlanta
www.atlantajcc.org/

Stay Connected with GCDD Online!

Share your thoughts, learn and interact with others in the disability community . . .

Visit our website @ GCDD.org to join our

GCDD Online Community

or

GCDD Forum

Like us on Facebook @

facebook.com/georgiaddcouncil

Follow us on Twitter @

twitter.com/georgiacouncil

We want to hear from you!

GCDD
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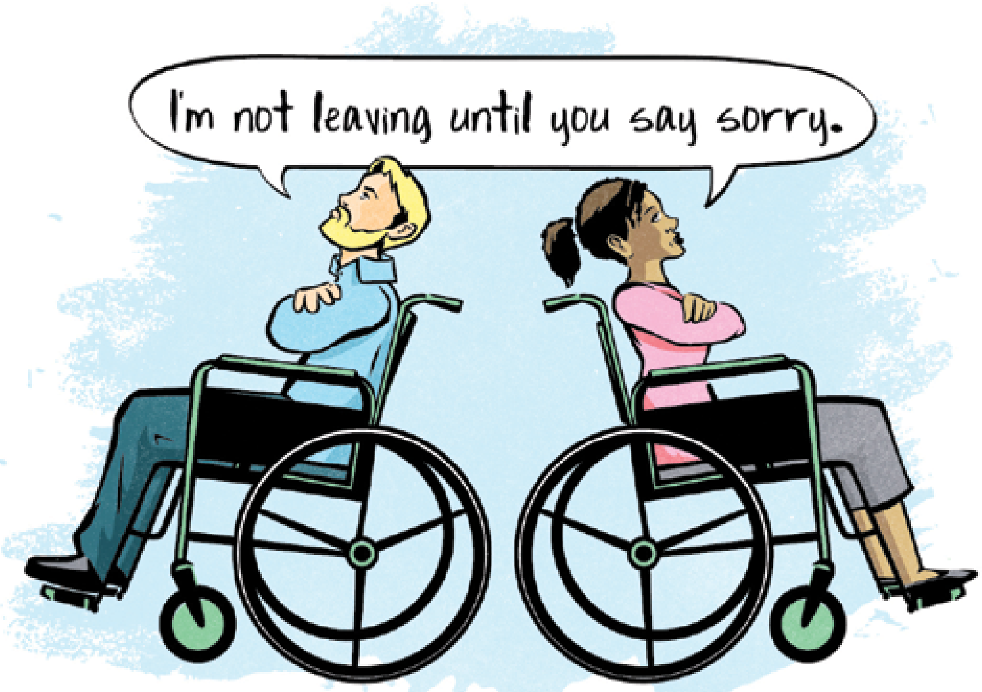
DEVELOPMENTAL DISABILITIES



How to make a relationship last.

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If you are interested in being a sponsor for *Making a Difference* magazine, please call Kim Shapland @ 678.384.7837.

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MAKING a DIFFERENCE

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VOLUME 13, ISSUE 4

SPRING 2013

Disability Day 2013
Turn to page 18 to
read the full article.