

Making a Difference

SUMMER 2009

Advocates Look
Toward Future

The Olmstead
Decision Turns
10

Faith Communities
Welcome Diversity

New Department
Launched July 1

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

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

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DISABILITIES**

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**GEORGIA
COUNCIL ON
DEVELOPMENTAL
DISABILITIES**

To Georgia's Disability Community,

As we marked the 10th anniversary of the Supreme Court's Olmstead Decision decreeing that people with disabilities should be able to live in their communities, we can look back over the past decade and celebrate how we have worked together to achieve that goal here in Georgia.

In this extremely tough budget year, we were able to fund 150 additional new options and comprehensive support waivers (NOW and COMP) and 100 independent care waivers as part of our Olmstead Voluntary Compliance Agreement and the state's Money Follows the Person grant. Additionally, we included full-year funding in this budget (FY10) for 365 Mental Retardation Medicaid Waiver Program (MRWP) waivers that were partially-funded in last year's budget (FY09).

I remain committed, along with our legislators and state agencies, to improving the lives of our citizens with disabilities. In May, I signed into law a reorganization of the Department of Human Resources to better serve the needs of Georgians with disabilities.

One of the changes is the creation of a new Department of Behavioral Health and Developmental Disabilities (DBHDD). Advocates from around the state supported the creation of this new department that replaces DHR's Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD).

The new commissioner of this department will be Dr. Frank Shelp, who currently works as the clinical director at Georgia Regional Hospital in Savannah. To improve transparency and accountability, the new agency will report directly to my office, and I've appointed Dr. Bill McDonald, a professor and psychiatrist at Emory University, as my special adviser in this matter.

"I consider this reorganization a major milestone in the progress we are making in caring for Georgians with disabilities."

I want to again thank the Health and Human Services Task Force, which put forward recommendations for the reorganization. Legislative members of the task force included Sen. Renee Unterman (R-Buford), Sen. Jack Hill (R-Reidsville), Rep. Ben Harbin (R-Evans) and Rep. Mark Butler (R-Carrollton). Rep. Pat Gardner (D-Atlanta) and Sen. Johnny Grant (R-Milledgeville) have also helped in the reorganization effort.

I consider this reorganization a major milestone in the progress we are making in caring for Georgians with disabilities. As we mark the 10th anniversary of the Olmstead decision, I am hopeful that in 10 years we will celebrate the creation of this focused agency and the difference it has made in the lives of citizens across our great state. ●

Sonny Perdue
Sonny Perdue
Governor





Start Building a Beloved Community

Rev. Jim Lawson, often called the teacher of the civil rights movement, said, “The beloved community is a place where the barriers between people gradually come down and where citizens make a constant effort to address even the most difficult problems of ordinary people.”

The “beloved community” has become the focus of not only this issue of *Making a Difference* but the Georgia Council on Developmental Disabilities as we prepare to unveil the new Real Community Initiative. For many people, the “beloved community” starts at the place where they worship, whether that is a church, synagogue or mosque.

Some of our most intimate conversations take place in these buildings, amongst the members as they relate to their god. Recently GCDD Executive Director Eric Jacobson, who is Jewish, was at lunch with friends who are Methodist and Catholic. “Our conversation was not only about which of our places of worship were the most welcoming to people with disabilities, but which were the most welcoming place for all its members to worship. For many people with disabilities, organized religion has not been a welcoming place. Instead, they have been both physically and programmatically inaccessible.”

There are too many stories that describe sanctuaries that people cannot get around in and programs that are not inclusive or worse yet paternalistic. Organized religion is important to most Americans and we must work together to ensure that they are welcoming and inclusive.

On June 2-3, more than 70 individuals gathered to think about how we can create communities, including places of worship, that are welcoming and build bridges between all the people who make up a community. Those who attended “A How to Guide to Social Inclusion: An Asset Based Community Development Workshop” engaged in conversation about how communities discover what they care about and come together

to create the change they want. Mike Green, Bruce Anderson and Amanda Bell brought wisdom, expertise and humor and asked participants to begin by having conversations with neighbors and begin discovering those issues where there is a common interest. GCDD will be working over the next year to invest in the practices that build Real Communities by organizing community assets, promoting learning about how people with developmental disabilities and their allies can act as contributing citizens and increasing the capacity for community development. We want to develop deeper collaborations, build bridges between disabilities and communities and organize communities through an asset-based approach.

“We are still the same organization, with the same passions and mission to improve the lives of people with developmental disabilities – we just have a new name.”

Finally, as of July 1, GCDD will have a new name: Georgia Council on Developmental Disabilities. The reorganization of the Department of Human Resources resulted in this name change. We are still the same organization, with the same passions and mission to improve the lives of people with developmental disabilities – we just have a new name. We are also now attached to the Department of Behavioral Health and Developmental Disabilities. We look forward to working with the new Department and the reconstituted Department of Human Services and Department of Community Health.

We want to hear from you. Please feel free to contact *Making A Difference* Editor-In-Chief, Valerie Meadows Suber at 1.888.275.4233 or vmsuber@dhr.state.ga.us. ●



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Zeldin Leads Georgians for a Healthy Future

Health care advocate Cindy Zeldin joined Georgians for a Healthy Future June 1 as the organization's executive director.

"Cindy is passionate about health care advocacy and policy, and we believe she is the right person to assume professional leadership of Georgians for a Healthy Future as we work together to build a consumer-based health care advocacy organization to promote change in Georgia," board member Patricia Nobbie, Ph.D., who serves as deputy director of the Georgia Council on Developmental Disabilities, said.

Zeldin began her career working on health issues as an analyst in the health care section of Georgia's Department of Audits. She also has extensive experience with public policy organizations, working at New America Foundation and Demos, where she served as an analyst and advocate, organizing briefings for Congressional staff, speaking at meetings and events, co-authoring policy reports and building relationships with other policy and advocacy organizations.

A strong believer in the link between solid research and effective health reform, Zeldin is studying health policy research methods and tools at Emory University while pursuing a Ph.D.

Georgians for a Healthy Future's mission is to establish a consumer health advocacy organization and build support for policies that will lead to better health care for all Georgians and long-term supports and services for people with disabilities.

Asian Americans Experience Difficulty in Accessing Services

As one of the fastest growing racial and ethnic groups in Georgia, about 250,000 Asian Pacific Islanders (APIs) live in the Atlanta area, and of those, 6.5 percent have disabilities. The Center for Pan Asian Community Services (CPACS), with funding from the Georgia Council on Developmental Disabilities, recently conducted a study of this community that resulted in recommendations that:

- Policymakers promote comprehensive and culturally competent systems for people with developmental disabilities.
- Service providers should dispel culturally-specific myths about developmental disabilities.
- Caregivers should create support groups (Pan-Asian and/or ethnic specific).
- Communities should advocate for compliance with the ADA laws regarding employment, physical accessibility, transportation, education, etc.

Caregiver focus groups felt they were not being treated equally because of language barriers. Additionally, cultural, financial and systems barriers exist, even for proficient English speakers.

Many participants noted issues with insurance companies and Medicaid not approving therapies and other services and trouble communicating with the school system. The participants shared the desire for bilingual social workers who interpret with empathy; having information translated in a way that works with their mind set; and counseling and stress management.

Many participants noted issues with insurance companies and Medicaid not approving therapies and other services and trouble communicating with the school system.

Asian and non-Asian service providers reported less than 1 – 2 percent of their clients are APIs. Finding funding is a hindrance in serving the Asian American community. A key concern is the language barrier because interpretation is expensive. Additionally, service providers find reaching out difficult because of lack of understanding about cultural differences, limited number of bilingual staff and limited cooperation among service providers.

Often, providers try to use existing programs without adapting them to the target population. At the same time, some Asian Americans think they can overcome barriers once they have acquired language skills, while others who are proficient in English believe that language is not enough to reach equality. To address these issues, service providers and caregivers must learn to work together.

Columbus Mayor Hosts Disabilities Day

More than 100 people attended the Mayor's Committee for Persons with Disabilities 2nd Annual Disabilities Day and Mayors Awards in Columbus, GA.

"I am excited about the participation we had this year. I believe this event was successful for many reasons. Besides increasing awareness in the community and educating people about the resources available, it is bringing solidarity of purpose and action. Instead of lots of individual groups working for their specific disability or service, the concept of cross-disability is taking on. Together we make a larger splash!" explained Joy Norman, disability service coordinator at Columbus State University.

Columbus Mayor Jim Wetherington and former Mayors Bob Poydasheff and Bobby Peters presented MCPD Chairwoman, Mitzi Oxford, with the Dr. Jack Hughston Humanitarian Award. Other awards included Educator of the Year, Employer of the Year, Exceptional Service to the Disability Community and Youth Advocacy Leadership Award. ●





New Name Won't Affect Council Role

The Governor's Council on Developmental Disabilities officially changed its name to the Georgia Council on Developmental Disabilities on July 1, in accordance with the same legislation that ordered the reorganization of the Department of Human Resources (see related story on opposite page).

"Some of the legislators were having confusion with the name 'governor's council' – when we went to them with the policies we were advocating for, some would ask if the governor advocated the same policy. The governor's office asked us to change our name, and we agreed. We hope it will eliminate that confusion," explained GCDD Executive Director Eric Jacobson.

"I don't think many people will notice the difference," he said.

GCDD Announces Award Winners

The following individuals were recognized for their contributions to the Georgia disability community July 16 in Atlanta:

Legislative Leadership:

Sen. Johnny Grant (R-Milledgeville) and Rep. Pat Gardner (D-Atlanta)

Media: Frank Ski of V-103 FM and Rachel Brown of the *Dalton Daily Citizen Reporter*

Advocate of the Year: Dave Zilles

Darius Screening Brings Together High School, College Students

About 85 members of the community and high school students from Hall County's three Partners Clubs attended a screening of *Darius Goes West* May 14 sponsored by the Freedom Advocacy Character Education (F.A.C.E.) Club at Gainesville State College in

collaboration with Partnerships for Success.

The movie depicts the journey a young man with a disability takes across the country with his friends to get his wheel chair "pimped out" by MTV. Five of the film's crew members were on hand to answer questions after the film.

"It's a great movie to talk about accessibility and friendships. We want Partners members to realize how they wouldn't have forged the deep friendships they have if they hadn't spent the outside time together," revealed Cindy Saylor, program coordinator for Partnerships for Success.

Partners Clubs are high school organizations that help students with and without disabilities connect through fun activities. F.A.C.E. Club is a disability advocacy organization.



South Asian Disability Advocates Attend GCDD Meeting

Disability advocates from Afghanistan, Bhutan and India attended the April Georgia Council on Developmental Disabilities meeting to learn how Americans influence policy and raise awareness of disability issues.

"We were honored that these international visitors looked to us as a resource they can then take back to their own countries," GCDD Executive Director Eric Jacobson said.

In addition to meeting with GCDD, Mohammad Sadiq Mohibi, Tshongpen Wangdi and Rajiv Rajan also learned more about the Americans with Disabilities Act and private and government funding of services.

Partnerships for Success Trains Teachers

Seventy-five people from nine school districts gathered for training in self-determination and student-led Individual Education Plans (IEP) May 28-29 at the Gainesville Civic Center.

"We wanted to show teachers how to create a continuum of self-determination and IEP starting in elementary school through high school," said Cindy Saylor, program coordinator for Partnerships for Success, who conducted the training.

"Elementary school kids are starting to lead their IEP meetings. If they start in elementary school, they're better advocates for themselves as they get older," she said. ●



New Georgia Disability Agency Launched July 1

By Valerie L. Smith



Dr. Olivia J. Garland

The new Georgia Department of Behavioral Health and Developmental Disabilities was created July 1 as a result of House Bill 228 signed into law by Gov. Sonny Perdue (R) May 4 that reorganized the Department of Human Resources (DHR) and Department of Community Health.

“The purpose of restructuring from our vantage point was to provide more focus on mental health, developmental disabilities and addictive diseases (MHDDAD) instead of having them imbedded in a larger agency (DHR),” explained Gwen Skinner, former director of the DHR’s Division of MHDDAD.

DBHDD will report directly to the governor, increasing transparency.

“The legislation reorients our approach to health care by shifting the focus from inputs to results,” Perdue said.

Dr. Frank Shelp will serve as the new agency’s commissioner. Shelp was previously the clinical director at Georgia Regional Hospital in Savannah. Dr. William McDonald was appointed to serve as a special adviser to the governor on mental health. McDonald currently serves as professor of psychiatry at Emory University. He is the chair for late life depression and chief of the Division of Geriatric Psychiatry.

“One of the biggest problems is finding intensive residential treatment for people with mental health issues. Outside of

Atlanta, it’s harder to find providers and resources,” McDonald said.

He plans to form an advisory committee to sort through recommendations and see what works and what doesn’t. “We have a big focus on hospitals, but frankly, we should be focusing on the community. The two are connected, and there needs to be some real focus on developing resources in the community,” he said.

“We must continue to strive and make our public and mental health systems the best and most efficient in the nation.”

Dr. Olivia J. Garland has been tapped to serve as deputy commissioner of DBHDD. She has had extensive experience developing community-based services and supports for people with developmental disabilities in Virginia and managed two mental health facilities there. As a mother of a child who had severe disabilities, Garland has a special commitment to providing person-centered community services.

Georgia Council on Developmental Disabilities Executive Director Eric Jacobson said, “I think the department will be more focused on developmental disabilities and mental health, and we’ll see a more effective and efficient delivery system. I don’t think initially that people will notice the difference until the new department really begins to evaluate how it’s doing things. Hopefully we’ll have a greater leadership role and connection with policy makers than we have in the past as well,” he said. ●

New Commissioner Brings Quality Improvement Experience

Frank E. Shelp, M.D., M.P.H. became commissioner of Georgia’s Department of Behavioral Health and Developmental Disabilities July 1. He is responsible for all mental health, developmental disabilities and addictive disease programs for the state of Georgia.

Shelp brings a breadth of experience from public, private, academic and corporate sectors of health care.

Prior to this position, Shelp was vice president of medical affairs for First Health Services Corporation, a national quality improvement company serving state Medicaid agencies, managing pharmacy, behavioral health and medical/surgical services with contracts in 28 states.

He also served as corporate medical director for behavioral health for United

HealthCare of Minnesota and has been in private practice.



Dr. Frank E. Shelp

Most importantly, Shelp helped establish a partnership between John Umstead Hospital in Butner, N.C. and Duke University Medical Center Department of Psychiatry, for research, residency training and clinical care. ●

Long Road Home

Optimistically Looking Toward the Future

Blistering heat and sudden downpours of rain – for lesser people, either of those two extremes would have been enough to stay inside all day. But for those who attended the Georgia State Capitol celebration of the 10th anniversary of *Olmstead v. L.C. and E.W.* on June 22, enduring both weather conditions was just another day in advocacy.

“This year’s Long Road Home event is not only a celebration of the *Olmstead* decision and of everyone that has benefited and now lives with the help of community supports, but as a stark reminder that the fight for freedom is not over,” stated Jennifer Holland, the program director of the Georgia Advocacy Office.

Echoing her thoughts was Eric Jacobson, executive director of the Georgia Council on Developmental Disabilities, who attended the event. “GCDD has been supportive of the goals of Long Road Home since the annual *Olmstead* celebrations in Georgia began five years ago,” he stated. “While we look forward to celebrating these anniversaries, there’s still an awful lot of work to do to make it a reality in our state.”

Sen. Nan Orrock (D-Atlanta) clearly agreed, as she addressed the crowd in front of the capitol.

“The *Olmstead* decision is something that we can both be proud of, and also have remorse and regret,” she stated. “This is another example of how you get the rights you fight for – we must fight to expand the promise of the Constitution!”

Orrock has been a longtime advocate for the disability community, and she expressed

regrets on behalf of Rep. John Lewis (D-Ga.) who was not able to attend the celebration as expected. “As a warrior in the Civil Rights movement, John is all too aware of the fight for freedom that we as Americans have to go through,” Orrock stated.

Orrock also geared attendees up for next year’s election. “This fight doesn’t end under this administration,” she said. “We’ve got to stand up and be a voice in the next election!”

The June 22 event was just one of many celebrations held across the state in Bainbridge, Savannah, Columbus, Milledgeville and Decatur. Additionally, another Atlanta event was held at Georgia Regional Hospital on June 21. Joy Norman of the Columbus State University Office of Disability Services helped plan the Columbus celebration.

“People do much better knowing that they are not alone.”

“Marc D’Antonio, chief clerk of the Muscogee County Probate Court, was our keynote speaker,” Norman explained. “We also had a tribute to caregivers – these people give up so much so that their family members and loved ones can live a happy life. It was important to me to include them in our celebration.”

Norman also noted that people enjoyed the camaraderie with each other. “I think the biggest thing for all attendees was that they were excited to make connections with others going through what they were going through, or what they had been through,” she stated. “People do much better knowing that they are not alone.”

Kaytha Burton of the Georgia Mental Health Consumer Network helped plan the celebration in Milledgeville, at Central State Hospital. “It was a great event,” she said. “Wayne Basford from the Georgia Advocacy Office was our keynote speaker – his speech was on the new emancipation

“The *Olmstead* decision is something that we can both be proud of, and also have remorse and regret.”



Sen. Nan Orrock rallied the crowd in front of the Capitol on June 22.



proclamation.” Burton went on to say that the celebration included music and dancing.

“There were a lot of people from the hospital – much more than what I was expecting,” she said, estimating that approximately 100 people attended. “Lois Curtis also attended, though she did not speak.”

Those who attended many or all of the Long Road Home events have estimated that nearly 700 individuals joined the celebrations throughout the state – though many were disappointed with attendance at the June 22 event. Murmurs throughout the crowd echoed one sentiment: “This is a big day for Georgia. Where is everyone?”

Ellyn Yeager of Mental Health America spoke before the crowd. “Ask your government!” she stated. “Where is everyone? Lack of transportation, lack of community support – these are the things that prevent those wanting to be here from attending!” Later in the event, Yeager explained to the crowd who to go to for their voices to be heard.

“Sonny Perdue (R-Ga.), Lt. Gov. Casey Cagle (R-Ga.), and State Speaker of the House Glenn Richardson (R-Hiram) – those are the three people in power in this state,” she said. “They are who you need to speak with to make sure your voices get heard. Write letters, come to events like this one and be involved.”

Shelley Simmons, chair of the Statewide Independent Living Council of Georgia, was excited to be at the event. “This is an important day to the entire United States, much less Georgia!” she stated.

“...make sure your voices get heard. Write letters, come to events like this one and be involved.”

Simmons moved to Georgia from California in 2005. This was her first Long Road Home event. “California is very different than Georgia,” she explained. “There is no waiting list. The money in

California follows the person. As a state, Georgia has a long way to go.”

Several people took the opportunity to stand at the podium and share their stories with others. People like Martha Elkinson, Charles Willis and Sandra Wilcox.

“People who have disabilities have their own rights,” Wilcox told the crowd. “That is why we must be self-advocates.”

Cherie Mitchell, widow of the late self-advocate Sam Mitchell, also spoke before the crowd, emotionally sharing her story of how she wasn’t

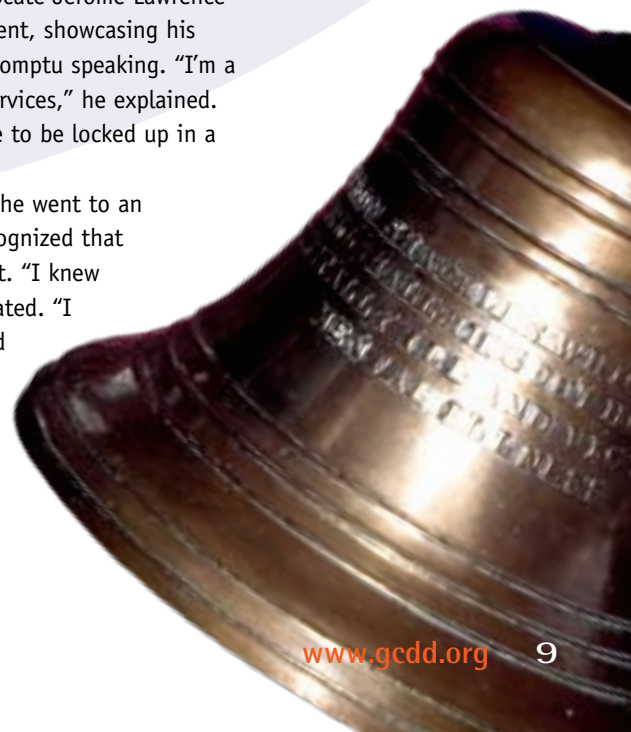


“Taking people in and locking them up without consent or even letting their families know – I have a problem with that! This is the land of the free!”

aware of issues surrounding the Olmstead decision until she experienced a disability in her own life. “Taking people in and locking them up without consent or even letting their families know – I have a problem with that! This is the land of the free!” she shouted over much cheering.

Local artist and self-advocate Jerome Lawrence also attended the June 22 event, showcasing his artwork and engaging in impromptu speaking. “I’m a consumer of mental health services,” he explained. “And I know what it feels like to be locked up in a hospital.”

Lawrence explained how he went to an emergency room when he recognized that something was not quite right. “I knew something was wrong,” he stated. “I needed help. The hospital had me sign some papers – I had no idea what I was signing, but I knew that I needed to sign if I wanted help, so I signed. They then took me down a hallway and locked me in a





Olmstead plaintiff Lois Curtis (seated) pauses to reflect the poignancy of the Mental Health Bell with Olmstead lawyer, Sue Jamieson

room.” Lawrence said that the hospital kept him for a little over one week until a doctor finally discharged him.

“I am now seeing a therapist and psychiatrist,” he said. “Luckily, I’ve had a lot of help and support. But if people are sick, they shouldn’t be treated like criminals.”

Those who shared their stories of being in institutions and then receiving community support were asked to ring the Mental Health Bell, which was cast from shackles that once bound people with mental illness living in asylums. Engraved on the bell was the following inscription:

From the shackles which bound them, this bell shall ring out hope for the mentally ill, and victory over mental illness.

The bell rang out loud, and could be heard from the back of the Capitol, signaling freedom to all who were listening, including Dr. Frank Shelp, the newly appointed commissioner of the Department of Behavioral Health and Developmental Disabilities and his deputy commissioner, Dr. Olivia Garland.

The *Atlanta Journal-Constitution* was recognized for the series headlined “Hidden Shame,” an in-depth view of the conditions of

continued on page 12

Can Georgia Finish What They Started?

By Carly Sharec

The landmark Supreme Court decision, *Olmstead v. L.C. and E.W.* was 10 years ago. While Americans with disabilities have felt the positive ripples of the court’s decision over the previous years, some are faring better than others, with states at various points of implementing the *Olmstead* decision.

The *Olmstead* decision was rendered when Lois Curtis and Elaine Wilson battled for their individual rights to live in a community of their choosing rather than being locked in an institution. In 1999, the United States Supreme Court ruled that keeping an individual in an institution if they were able to live in a community was a violation of the Americans with Disabilities Act.

Ironically, the court case originated in the state of Georgia, but many argue that Georgia is behind other states when it comes to decreasing the waiting list, providing plenty of help for a community-based support system and in closing institutions once and for all.

“As a state, we want to change our viewpoint from seeing the hospital as a community.”

“Every state is different,” said Abel Ortiz, Georgia’s *Olmstead* Coordinator. Ortiz is also chairman of Gov. Sonny Perdue’s (R) mental health commission. “Comparing Georgia to other states isn’t beneficial or useful. We need to focus our energy on what Georgia needs.” Ortiz continued to say that the state must develop its own timeline to ensure that Georgians have opportunities to move out of hospitals.

That answer isn’t good enough for many advocates within the disability community. “Look at other states,” said Shelley Simmons, chair of the Statewide Independent Living Council of Georgia. “Georgia is the state where this case originated, so to be considered at



Georgians shared their stories of residing in institutions, and then rang the Mental Health Bell, calling for freedom.





the bottom when it comes to providing services and implementing the Olmstead decision – well, it’s very disappointing.”

In fact, several other states are so far ahead of Georgia in implementing the Olmstead decision, many of them have closed their institutions for good. These states include Alaska, Hawaii, New Hampshire, Vermont, Maine, Washington, D.C., Rhode Island, New Mexico, West Virginia and Indiana. Virginia, Washington, Maryland and Massachusetts have plans to close down their major institutions during the 2009 – 2011 time period.

Steve Wiseman, executive director of the West Virginia Developmental Disabilities Council, explained how his state began closing its state institutions.

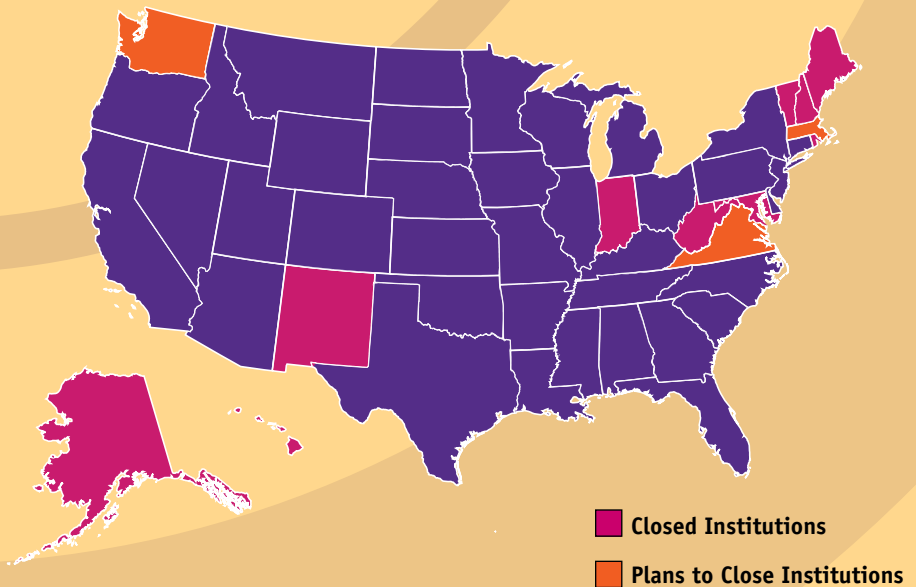
“We actually closed ours down in the 1990s,” he explained, which was before the Olmstead case made it to the Supreme Court in 1999. “There was a long history of collaboration between the developmental disabilities council and the division of developmental disabilities services – working together to provide support, we managed to close down the last institution in West Virginia by 1998.”

Michigan has successfully closed most of its institutions (a few do remain open) and has additionally established approximately 50 community mental health services programs across the state, as well as developing a self-determination initiative, funded by the Robert Wood Johnson Foundation, to allow people with developmental disabilities to have control over a fixed sum of money to determine and direct their own services. (Michigan is one of 18 states taking part of this national initiative.)

Meanwhile, Ortiz explained how a new plan is being constructed for Georgia. “A draft already went out in February, and we received public comment,” he stated. “We then have built up even more groups to review those comments, and to see where we needed to strengthen the plan.” This plan is a collection of guidelines on how to bring more of a focus on Georgians with developmental disabilities, mental health concerns, and addiction.

“Georgia is doing very well,” said Rie Kennedy-Lizotte, project manager for the National Association of State Directors of Developmental Disabilities Services. “If everything stays on track, and everything that is on paper is followed, Georgia will be among other states that have done incredibly well over the next five years.”

Kennedy-Lizotte pointed out that the United States has been working to decrease those living in institutions since the mid-1970s. “In 1977, we had approximately 160 million residents with intellectual or developmental disabilities living in large institutions of over 50 residents,” she said. “By 2007, that number was down to just over 36 million.”



Also, Ortiz iterated the idea of developing a mental health waiver. “There is currently not one in place,” he said. “We are beginning to focus more on this. Also, as a state, we want to change our viewpoint from seeing the hospital as a community.” Ortiz went on to explain that Georgians should view hospitals as a safety net and resource rather than a community, or permanent living arrangement.

“Georgia will be among other states that have done incredibly well over the next five years.”

Ortiz is optimistic about the future. “Overall, people are more accepting of individuals with disabilities being in communities. We are seeing that people with disabilities can be integrated, and lead full lives with community supports.” ●

Obama Announces New Initiatives for Americans with Disabilities

President Barack Obama celebrated the 10th anniversary of the landmark *Olmstead v. L.C.* Supreme Court decision by launching "The Year of Community Living," a new effort to assist Americans with disabilities.

Obama directed Health and Human Services Secretary Kathleen Sebelius and Housing and Urban Development Secretary Shaun Donovan to identify ways to improve access to housing, community supports and independent living arrangements. Sebelius and Donovan announced several new initiatives including increased numbers of Section 8 vouchers and enhanced interagency coordination to address this critical civil rights issue. The initiative also will include listening sessions conducted by HHS across the country to hear the voices and stories of Americans.

In addition, Sebelius announced HHS would be funding more Aging and Disability Resource Center programs to provide one-stop sources of information, counseling and access to programs and services to help people with disabilities and older Americans remain in their own homes and communities.

"If people have options, they will be able to find the most appropriate and often lower-cost health-related and social services..."

"If people have options, they will be able to find the most appropriate and often lower-cost health-related and social services that support individuals to allow them to lead meaningful lives in their homes and communities," Sebelius said.

"The *Olmstead* ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently," Obama said. "I am proud to launch this initiative to reaffirm my Administration's commitment to vigorous enforcement of civil rights for Americans with disabilities and to ensuring the fullest inclusion of all people in the life of our nation."

In the *Olmstead* case, the Court held that the unjustified institutional isolation of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act. Since that time, progress has been made. Many individuals have successfully transitioned to community settings, but waiting lists for community services have grown considerably and many individuals who would like to receive community services are not able to obtain them.

To help remedy that problem, the Obama Administration provided over \$140 million in the Recovery Act funding for independent living centers across the country. The Administration acknowledges that strides have been made, and knows and accepts that there is much work to do to maximize the choices and opportunities for individuals to receive long-term services and supports in institutional and community settings. ●



Local artist Jerome Lawrence showcased his artwork as well as his story of being in a hospital.

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Georgia's institutions. Sunday Editor Charles Gay and former reporter Andy Miller accepted awards.

Regarding *Olmstead*, Lawrence said, "I don't think there's a lot of information out there, so it seems like people may not know exactly how Georgia is faring when it comes to upholding the results of *Olmstead*," he said. "I know I'd like to see information more readily available."

The keynote speakers of the event were Sue Jamieson (of Atlanta Legal Aid Society) and Lois Curtis. Jamieson was the *Olmstead* plaintiffs' attorney. Curtis is well known throughout the United States for instigating the court case that eventually became a landmark decision. Joined by Elaine Wilson in the 1990s, Wilson and Curtis charged that they were being unfairly held in an institution for their individual developmental disabilities after having been cleared by their doctors that they were able to move into a community.

"Those of you who are here are speaking for thousands," Jamieson informed the crowd prior to introducing Curtis. "Elaine Wilson [co-plaintiff in the case] and Lois were in and out of personal care centers 47 times before they found freedom. Let's remember those who cannot be here today, and help their voices be heard!"

"Free our brothers! Free our sisters! Free our people NOW!"

Curtis then spoke to the crowd, leading them in a chant of "Free our brothers! Free our sisters! Free our people NOW!" as thunder rolled in the background.

"This is a good day for Georgia," Orrock stated. "We're starting the next leg of the journey on the Long Road Home!" ●



Lois Curtis: Advocate, Artist, and Well-Known Community Member

By Carly Sharec

A wide smile, a passion for art and a determination to be the best advocate she can be – both for herself and for others – are the three main things that people immediately notice about Lois Curtis. Curtis was a co-plaintiff in *Olmstead v. L.C. and E.W.*, and has been quite in demand recently as 2009 marks the 10th anniversary of the landmark United States Supreme Court decision, which declared that “unnecessary institutionalization amounts to segregation and is a violation of individual civil rights under the Americans with Disabilities Act.”

Playing a key role as co-plaintiff in the case that changed America has had a dramatic impact on Curtis, who now spends much of her time in her community.

“I like talking to people. I like a lot of things that I couldn’t do if I didn’t live in the community.”

When asked what some of her favorite activities were, Curtis confirmed that she is quite the artist. “I like playing with dogs,” she went on to explain. “I like talking to people. I like a lot of things that I couldn’t do if I didn’t live in the community.”

Along with being out and about in her neighborhood, Curtis also spends much time to focus on her calling as an artist.

“I like my art,” she said. “I want everyone I know to see my art.”

Elise Andrews, one of Curtis’ support system, couldn’t help but smile. “Lois is amazing,” she said fondly. “She doesn’t judge her artwork – she’s not critical. She just paints from her heart, and all of her pieces come out so beautifully.”

Harriet Harris of Circle of Support, the agency that provides Curtis’ community-based services, agrees. “She’s so friendly,” Harris stated. “The first

thing you notice about her is the big grin on her face.”

Another favorite pastime of Curtis’ is one that many people do not bother to do these days, and that is write letters. “She’ll offer to write anyone a letter,” Harris chuckled. “Lois just likes being around people, and sharing her thoughts and ideas with people.”

Charles Hopkins, a member of Curtis’ microboard, remarked on how extraordinary Curtis’ life has been. “This is a woman that had been in and out of institutions,” he said. “Instead of sitting back, she

“Instead of sitting back, she charged forward and changed how Americans with disabilities live forever.”

charged forward and changed how Americans with disabilities live forever.” Hopkins went on to say how she takes that same “take charge” attitude and applies it now to her own life, as she directs those around her as to how she would like to live in the community.

“I like to live my own life,” Curtis stated. “I like to do art and walk and other things.” While she didn’t comment on the actual *Olmstead* decision, it was clear that Curtis enjoys being on her own – outside of an institution.

“She’s just such a special person,” Andrews stated. “I enjoy all time spent with her, as does everyone around her.” ●

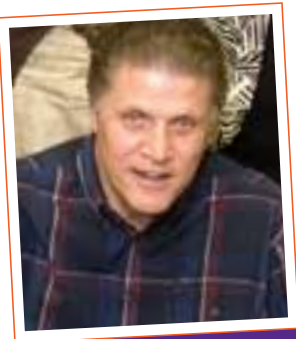


April in Washington D.C.: Tears, Cheers and Advocacy

Plenty of drama was on hand during a recent week in Washington D.C., courtesy of ADAPT and hundreds of disability advocates as they marched on the White House and Capitol from April 25 through 30.

"We were there to discuss health care reform, primarily," explained Mark Johnson, advocacy director at the Shepherd Center and member of ADAPT, Georgia. "Americans living with disabilities wanted to see what allowances were going to be placed in any health care changes that would help them – unfortunately, many of us were left discouraged."

So discouraged, in fact, that approximately 100 people ended up arrested as they chained themselves to the front gates of the White House. When police showed up to issue a warning, the crowd cheered. "We'd rather be arrested than die in an institution!" they chanted. Other attendees watched from across the street and cheered their fellow advocates on.



"Yes, we're angry!"

I feel like we did a lot to educate the president on the issues during his campaign, and once he was elected, we thought those promises would be kept."

"The arrests take away from the issues," Johnson continued to say. "It's not the point that there were arrests. It's that [President Barack] Obama made certain promises on the campaign trail, and Americans living with disabilities are now being pushed aside in favor of 'politics as usual.'"

The promise Obama made that Johnson is referring to is to uphold the Community Choice Act, which allows for community supports to be in place for Americans living in institutions who are able to and wish to move into the community. The current health care reform plan does not call for additional support systems to be put in place, a fact that angers many.

"Yes, we're angry," Johnson continued. "I feel like we did a lot to educate the president on the issues during his campaign, and once he was elected, we thought those promises would be kept. His Web site still contains a detailed plan for Americans with disabilities – but what's happened? We're pushed aside, yet again."

The week was not all about protesting, though. Selected as an event to celebrate the 10th anniversary of the Olmstead Decision, advocates still felt the need to rejoice. ADAPT sponsored a Fun Run and Walk at the beginning of the week, which Harriet Harris, director of Circle of Support, Inc., attended. The Circle of Support, founded in 1998, is a support system for people with disabilities in Georgia.

"It was a lot of fun," she enthused. "We did the Fun Walk, and it was just powerful to see so many passionate people there to fight for basic rights."

Harris was one of the few people from Georgia who attended, along with Lois Curtis, a co-plaintiff in the Olmstead v. LC case. Curtis appeared and was introduced at the Fun Run, and participated in the Fun Walk with Harris.

"A few of us drove up there in a van, enjoying the sights of the road trip along the way," revealed Harris. "We opted to leave D.C. on Monday so did not stay for the entire week, but we did manage to see many of the sights in Washington, including Arlington and the changing of the guards."

In addition to the Fun Run and Walk, Curtis participated in an art show held following the event. "She loves showing her pieces of art," Harris stated.



“About eight to 10 other artists participated in the show, which featured not only art but crafts projects as well. It was just a very laid back, fun activity that we all enjoyed participating in.

“There were several events going on that week,” Harris continued. “A real spirit of camaraderie permeated the atmosphere. It was just a lot of fun, and really poignant all at the same time.”

Eric Jacobson and Pat Nobbie from the Georgia Council on Developmental Disabilities were in Washington at the same time to visit Georgia legislators. Nobbie, the deputy director of GCDD, felt that the entire trip was very worthwhile.

“We met with several government officials,” she stated. “We had very successful meetings with Senators Saxby Chambliss (R-Ga.) and Johnny Isakson, (R-Ga.) along with various state senators. The following day, Eric met with Rep. John Lewis (D-Ga.).”

“...the conversation of long-term supports and services for people with disabilities needs to take place during the health care reform – not after.”

Jacobson explained how he hit three major issues in his conversations with the country’s leaders. “Health care was still not an entirely hot-button issue when we visited in late April,” he explained. “Many were taking a ‘wait-and-see’ approach until after the president’s administration laid out his plan. But I really wanted to serve as a reminder that the conversation of long-term supports and services for people with disabilities needs to take place during the health care reform – not after.” Jacobson explained how, if government officials wait until after health care gets entirely reformed, it could be years before Americans with disabilities see any changes.

Another issue, of course, was the budget. This was, and is, on top of all minds as the government crafts spending limits for the next fiscal year and beyond. “We wanted to make sure there were enough dollars in the budget for Medicaid and support systems,” explained Jacobson. “We also want funding for the reauthorization of the Developmental Disabilities Bill of Rights and Assistance Act.” This piece of legislation helps to create and fund disability councils.

The third and final issue was brought up between Jacobson and Lewis. “Congress needs to encourage this president to sign the U.N. Convention on the Rights of People with Disabilities. This is an international agreement that very few countries have NOT signed...sadly, the United States is one of them,” Jacobson said. It is an international document that states the rights of people with disabilities.

Jacobson stated that Lewis was quite enthusiastic about this issue. “A few weeks following our discussion, he sponsored a resolution to encourage the United States to sign,” he said. “That was quite encouraging – America may or may not sign, but at least we know we’ve been heard.”

When all was said and done, people had mixed feelings regarding the week, but were generally positive. “I think we have a lot to look forward to over the next few years,” Johnson said. Jacobson echoed those thoughts.

“The trip is always enlightening and encouraging,” he stated. “We spoke with President Obama’s counsel on disability issues, Kareem Dale, and got to hear what the new administration is thinking and what they would like to accomplish for Americans with disabilities. Many were encouraged, particularly after quite some time of feeling left out.” ●

The trip is always enlightening and encouraging.

Budget Crisis Makes Waiting List Even Longer

By Deirdre O'Brien, Executive Director, ARC of Georgia



Deirdre O'Brien is the executive director of the ARC of Georgia, where she promotes disability policy and supports best practices. O'Brien, whose daughter has intellectual and cognitive disabilities, believes only through inclusion and acceptance in all communities with strong formal and informal resources, will Georgians with disabilities lead robust lives.

Georgians have witnessed the failure of national and state economies. Our state budget has contracted and continues to shrink due to decreased revenues. The past legislative session was tense and stressful. Departments have cut their budgets, but revenues continue to decline. As a result of the economic crisis, U.S. President Barack Obama passed an unprecedented stimulus package – the American Recovery and Reinvestment Act (ARRA), one aspect of which increased the proportion of the Medicaid federal match to states for nine quarters, beginning in October 2008, and ending December, 2010. For Georgia, the increase in federal match in Medicaid will be worth over \$700,000,000.

Medicaid is the primary source of funding for supports and services for people with developmental disabilities. The state and US Department of Justice have signed a voluntary compliance agreement that directs implementation of the Olmstead Decision. The agreement reinforces that people with disabilities should be able to live in communities instead of being segregated in institutions and the care and safety of individuals with mental illness in state hospitals. The waiting list for community waivers for Georgians with developmental disabilities is greater than 7,200. Several hundred people with physical disabilities are waiting for waivers. Family support funds are exhausted in the first couple months of the fiscal year. Provider rate increases have been withdrawn.

I believed and hoped that some of the money from the enhanced Medicaid match would be used to build the community infrastructure and increase home and community-based services for those with developmental disabilities - in other words, I hoped Medicaid stimulus money would be used for Medicaid services. With nine quarters of enhanced Medicaid match, Georgia could have built a strong community support system.

Unfortunately, this is not what happened. Instead of keeping the savings generated by the enhanced Medicaid match within Georgia's Medicaid system to improve services, the money was used to plug holes in other areas of the state budget that resulted from the decline in revenue and a failure of will to seek alternative revenue sources. The 2009 budget was eventually balanced with \$630 million of ARRA funds replacing a loss of state funds. The fiscal year 2010 budget was balanced with \$1.3

“If even 3 percent of the state’s Medicaid savings were used for services, an additional 2,000 individuals could have come off the waiting lists...”

billion in ARRA funds, and in FY 2011, another \$1.1 billion of federal stimulus funds will be used to make up the projected revenue shortfall. If even 3 percent of the state's Medicaid savings were used for services, an additional 2,000 individuals could have come off the waiting lists and the providers could have kept their rate increases so they could stay in business. We might even have been able to fund some additional family support. Without additional resources, without needed assistance, families fall into crisis and their needs become even more intensive and expensive.

Georgia is still experiencing unprecedented decreases in revenue. There will not be the big check this year from the federal government to balance our state budget and our legislators refuse to consider an alternate revenue source. Most economists believe that states will recover slowly, without sharp increases in revenue. In January 2010, legislators will need to plan very carefully how they will replace the state funds or the system as we know it will collapse. ●

State uses Medicaid savings for other purposes.

Falling Off the Cliff: Georgia's Budget Crisis

By Alan Essig, Executive Director • Georgia Budget and Policy Institute

Georgia is in the midst of the worst fiscal crisis since the 1930s. Heading into it, Georgia was a very low tax-and-spend state. In fact, Georgia ranked 49th among the 50 states in spending per person. Due to the combination of tax cuts over the past 25 years, this recession and an outdated tax system, our tax base is not adequate to fund even the low level of services that Georgians have been receiving.

As a result, this coming year's state budget (fiscal year 2010 started July 1) came up more than \$3.1 billion short — 15.7 percent. Gov. Sonny Perdue (R) and the General Assembly closed this deficit through a combination of budget cuts, federal stimulus funds and reserve funds, raising very little revenue but giving away more preferential tax breaks.

Budget cuts to state agencies accounted for more than \$1.2 billion, and most state agency budgets suffered cuts between 5 and 20 percent. Without the use of federal stimulus funds, the legislature would have cut an additional \$1.4 billion from state agencies.

“Budget cuts to state agencies accounted for more than \$1.2 billion, and most state agency budgets suffered cuts between 5 and 20 percent.”

More than \$730 million of the stimulus funds came from the federal government matching state Medicaid dollars. Due to declining state revenues, these federal funds were used to replace state funds in the Medicaid program. Without these additional federal funds, the Medicaid budget could have been reduced by as much as \$700 million, with devastating consequences to the health care system in Georgia.

As job losses and lower consumer spending causes state revenues to continue to decline faster than originally projected, another shortfall of between \$600 million and \$800 million is expected at the close of the current fiscal year (FY 2009 ended June 30). The governor will most likely use most of the remaining reserve funds and a portion of the remaining stimulus funds to cover this gap. If revenues continue to decline as projected, Georgia will be staring the new budget year in the eye, with an additional \$1 billion shortfall.

The outlook for FY 2011 does not appear any better. Even as tax revenue begins to grow as the nation recovers from the recession, Georgia likely will face another \$1.5 billion deficit. Georgia would be facing this deficit without the availability of additional federal funds and with the state reserves empty. This truly is a structural problem that lawmakers have long ignored.

With billions of dollars in deficits expected over the next several years, Georgia policymakers have some very difficult choices to make. In that almost nine out of every 10 state tax dollars are spent on education, health care, criminal justice, the Department of Behavioral Health and Developmental Disabilities and the Department of Human Services, relying on budget cuts alone makes it impossible to balance the budget without drastic cuts to these vital services.

That being said, in crisis there is an opportunity. By making the choice to reform and modernize the state tax system, the state would be able to raise sufficient revenues in a fair manner, thereby providing high-quality public services that Georgians demand and deserve. The choice is clear, drastic cuts to the education, health care (including disability services) and public safety in Georgia, or an adequate and fair tax structure that funds high-quality government services in a modern and growing state. ●



Essig is the executive director of the Georgia Budget and Policy Institute. For more information about tax preferences, the state budget deficit and revenue solutions, please visit www.GBPI.org.

Faith Communities Welcome Diversity

By Valerie L. Smith

On the rare occasion he arrives at church at the last minute, Devin Strong feels awkward rolling his wheelchair all the way to the front of the church.

"All I want is to participate in as normal a way as possible – without being noticed or special treatment," he said. "It would be nice to have pew cut outs for wheelchairs somewhere in the middle."

Strong, a Lutheran pastor, has been both a leader and a participant in church, and as a person with cerebral palsy is attuned to how people with disabilities are welcomed into faith communities.

"I grew up in a church where I was able to use my gifts," he said. "I was very involved in church dramas, Sunday school, youth group and vacation bible school. I also read lessons and led a bible study. I never thought of myself as different from other kids in that regard."

Strong brought that same spirit of openness to his former church, Abundant Life Lutheran, which was in Braselton.

"You have to start with basic physical accessibility, which isn't always a given in Georgia. Then you have to treat people with disabilities as individuals – there's not one way to respond to people with disabilities. They need different things. Understanding what they need and what they can do to serve is key."

Because his former church was small, with only about 30 parishioners, everyone participated. "Everybody did everything – read lessons, took the offering, helped with music."

Faith communities of all religions have recently started becoming more interested in how they can better include people with disabilities, according to Bill Gaventa, director of community and congregational supports of the Elizabeth M. Boggs Center on Developmental Disabilities in New Jersey.

"Supporting people with disabilities is exploding in interest. If families have had bad experiences in the past, take heart and hope – there's a switch happening," Gaventa revealed.

Cathy Humphrey, director of church services for Developmental Disabilities Ministries, agreed. "We had our first statewide conference this year at Smoke Rise Baptist in Stone Mountain. We had more than 200 people attend. There's an awakening in churches to people with special needs."

Ginny Thornburgh, director of the Interfaith Initiative of the American Association of People with Disabilities, in Washington, DC, provides support to faith communities that are looking to become more welcoming. "Our program assists congregations, seminaries and religious communities to welcome and value children and adults with all types of disabilities. It offers resources and ideas to nudge religious communities forward and give families ideas how to approach their faith communities with their needs.

"Everyone has the right to be welcomed in the house of God of their choice."

"Everyone has the right to be welcomed in the house of God of their choice," she said.

Thornburgh's son, Peter, who is an adult with intellectual and physical disabilities, has run into issues in the past. "When he was growing up, our congregation didn't always know how to honor Peter or make him feel comfortable. They wouldn't do something hurtful, they just didn't know how to value people with disabilities," she explained.

But Thornburgh is glad to report times have changed, and her son is now more fully included in the life of his church. "Peter has been a greeter and one of the wise men in the Advent pageant. We had a moment on Palm Sunday where 23 people came over to Peter to say hello to him when we were

All I want is to participate in as normal a way as possible – without being noticed or special treatment.

“We have an old building that wasn’t up to code. No one ever came to me to tell me – they just stopped coming.”



Pastor Devin Strong made sure his congregation was welcoming to all people.



“If families have had bad experiences in the past, take heart and hope – there’s a switch happening.”

Bill Gaventa helps congregations as well as clergy become more welcoming to people with disabilities.

passing the peace. I can sense he brings out the best in other people,” she said.

Many times, physical barriers prevent people with disabilities from participating in their faith communities. Imam Furqan Muhammad of Masjid Al-Muminun has been working to overcome these barriers in his Muslim congregation.

“We have an old building that wasn’t up to code. No one ever came to me to tell me – they just stopped coming. They didn’t feel welcome or accommodated,” he said.

So Muhammad began making changes to the physical structure of his mosque, widening doorways and installing wheelchair ramps. But he didn’t stop there. He joined the Interfaith Disability Connection to get more ideas about how to include people with disabilities in his congregation.



“More people are coming since we’ve made our accommodations, and people with disabilities are now part of the staff and in leadership positions.”

“Faith leaders should plug into a disability organization. It brings about great awareness. Leadership should be involved because it represents so much consciousness. I hope all religious leaders really consider people with disabilities in their congregations. More people are coming since we’ve made our accommodations, and people with disabilities are now part of the staff and in leadership positions,” he revealed.

Rabbi Harvey J. Winokur of Temple Kehillat Chaim became interested in being more inclusive of people with disabilities when his adopted son was diagnosed with fetal alcohol syndrome spectrum.

“We renovated our facility and made it fully accessible,” he said. “We also offered opportunities for participation and leadership for those who desired,” Winokur, who is also a member of the Interfaith Disability Connection, said.

Denny Spear, a retired Baptist minister and member of the Georgia Council on Developmental Disabilities, and his wife Varion, have been making people with disabilities, including their daughter, Ann, welcome at Dunwoody Baptist Church for more than 30 years.

“When I was Director of Children’s Education, I got a call from the county saying it had a van full of young adults with disabilities who want to come to Sunday school and did I have a place for them?” Varion Spear said. “I told them, ‘No, but by the time you get here I will.’”

That was 30 years ago, and the class she started, which included her daughter, is still going strong, with some members now in their 50s.

“Faith leaders should plug into a disability organization. It brings about great awareness.”



Interfaith Disability Connection Summit: Pursuing Inclusion Beyond the Ramp

August 9

James H. "Sloppy" Floyd Building • Atlanta, Georgia

Clergy will discuss ways to accept and include people with disabilities into their congregations.

For more information, visit www.interfaithdisability.org or call 678.365.0073.

The class regularly participates in church activities. "They work with the babies, every Sunday we straighten out the hymn books, and we sing during the Wednesday night dinner," Varion Spear said.

In addition, the church recently launched "Palace Kids" – a program for young children and preschoolers with disabilities who are paired up one-on-one with a volunteer who helps them participate in Sunday school and church and can respond to the child's unique needs.

Denny Spear said the leader of a faith community plays an important role in how welcoming the congregation is to people with disabilities. "The minister sets the stage in the way he recognizes and speaks to people. He's a model," he said.

Georgia faith communities also reach out to children with special needs by including them in vacation bible school programs. Jean Davison, an occupational therapist in northeast Georgia started such a program at Royston Baptist Church.

"The minister sets the stage in the way he recognizes and speaks to people. He's a model."

"Parents fill out a questionnaire about their children's needs, then I hold a training session the week before with volunteers and give them the name of the child they'll be shepherding through vacation bible school," Davison explained. "We had



Rabbi Harvey Winokur and his family have made an effort to be more welcoming to people with disabilities in their synagogue.

"We also offered opportunities for participation and leadership for those who desired."

10 children last year and 10 this year. I hope that number continues to grow."

Davison said in addition to being fun for the children who participate, the vacation bible school program is educating the community.

"In rural areas, we don't see families with special needs in public, so we don't always know how to communicate with them. This program has opened up our congregation to know how to communicate and engage in conversation when they see these families and to learn what a blessing each of these families are," she explained. ●

Spear Wins Helping Hand Award



Developmental Disabilities Ministries (DDM) bestowed the Helping Hand Award on Georgia Council on Developmental Disabilities member Denny Spear during its conference in April.

"This award goes to people who have a heart for this ministry

and do a lot to be supportive," explained Cathy Humphrey, director of church services at DDM. "Denny has been outstanding in his support of this ministry. He has such a heart and has spent a long time helping us with fundraising and his wise advice."

Spear was touched by the award. "I respect DDM and the award had meaning coming from them. But it went to the wrong person. My wife (Varion Spear) should have gotten it," he said. ●



Beyond Faith: Community Outreach

By Valerie L. Smith

Devout Christian Ann Spear has performed in four plays sponsored by Jewish Family and Career Services. This is only one example of how faith communities reach out to people with disabilities beyond just those attending religious services.

Ann Spear's father, Denny Spear, is a retired Baptist minister and member of the Georgia Council on Developmental Disabilities. "When you develop caring on the part of the whole congregation, members then go out and deal with other people in the community with developmental disabilities. Some laypeople go beyond church and help to change laws!"

The Spears' church, Dunwoody Baptist, also hosts a community Boy Scouts troop. "The Explorer Scouts is a troop for boys with developmental disabilities that opens them to some of the activities scouting provides," Denny Spear said.

Bill Gaventa, director of community and congregational supports of the Elizabeth M. Boggs Center on Developmental Disabilities in New Jersey encourages congregations to create a welcoming

community in addition to a warm environment in their own mosques, synagogues and churches.

"Clergy and congregation members can help people with disabilities advocate for the supports they need in the community," Gaventa said. "Churches also provide recreational opportunities and help people become involved in service projects."

Rabbi Harvey J. Winokur of Temple Kehillat Chaim said his congregation supports members on a case-by-case basis. "We help one family go over

their child's IEP (individualized education plan) with a fine tooth comb," he said.

In rural areas of Georgia, where services and supports might not be readily available, faith communities can help fill that gap. Jean Davison, a pediatric occupational therapist in northeast Georgia started a program called Connections for Special Parents (CSP), that is based at her place of worship, Royston Baptist Church.

"CSP serves rural Georgia families from Franklin, Hart, Elbert, Madison and Stephens counties," she explained. "It provides fellowship and support to families who are facing similar issues."

While the 50 CSP families gather at Royston Baptist Church for support meetings, the group is interdenominational, though many of the volunteers who support the program come from the Royston Baptist family.

In addition to the support group, CSP hosts a variety of events throughout the year to provide

recreation and/or respite for the families it serves. "Our 5th annual Family Fun Day is coming up in September," Davison said. Staffed by church members, the fun carnival event is open to the entire community to raise awareness of disability issues.

While CSP has helped the broader community, it has also been of benefit to the Royston Baptist Church. "Our church is more accessible as a result of this. We have a better wheelchair ramp now," she said.

The CSP program has been so popular, it has been replicated elsewhere. "We just opened a Walton county chapter of CSP. The needs were really high there for a support group for families of children with all disabilities," she said.

Gaventa said faith communities are a natural choice to support people with disabilities in the community, and many already are. "Respite, employment, advocacy – you name a need that a family of a person with a disability has, and there's a church somewhere helping them with that need." ●



"Our 5th annual Family Fun Day is coming up in September."

Teamwork, Not Competition

Vital to Community Organizing

Ninety people from across Georgia came to Atlanta June 2-3 to learn how to identify what people in their communities care about and work together to make changes take place.

Georgia Council on Developmental Disabilities Executive Director Eric Jacobson welcomed the group. "I am very excited about the next two days. GCDD has been working toward real communities for almost a year now," he said. "We've been conducting a purposeful learning process to determine how to promote collective action to make sure all people get what they need."

While disability advocates have typically worked at the state level competing with other groups for scarce funding for supports and services, this training session focused on how joining with other advocacy groups at the local level could help solve shared problems, such as access to transportation, housing, education, employment, recreation and other community issues.

The two-day training session was led by community organizing experts Bruce Anderson of Asset Based Community Development Institute; Bruce Anderson of Community Activators; and, Amanda Bell of Living Our Visions (LOV)-Dane.

Attendee Katherine Mancuso of Atlanta works for the Center for Assistive Technology and Environmental Access (CATEA) and GimpGirl.com. "I'm really excited. I'm looking forward to building my community organizing skills," she said.

Anderson kicked off the seminar by pointing out the three types of people in a community: general community

members; exiles; and social service agents.

"People with disabilities are not the only people in communities who don't feel included. You have to leave disability on the table, otherwise you are pitting your self interests against others with self interests. You need to lay aside for a moment your central interest and think about the bigger picture," he revealed.

Pam Cannon, a family intervention specialist for the Atlanta Alliance on Developmental Disabilities found Anderson's strategies helpful. "These principles are so applicable," she said. "I'm working to organize South Fulton special needs parents, and we think of ourselves as exiles."

"Organizing communities together with other groups takes longer and can be messier, but the results are sustaining."

Traditionally, community activists have taken more of an "us against them" approach, based on aggression and winning against competing groups, but asset-based community development (ABCD) entails joining forces with other groups that have similar needs.

"Organizing communities together with other groups takes longer and can be messier, but the results are sustaining," Anderson said.

To begin the process of organizing the community around certain issues, Anderson suggests three strategies:

1. Build relationships – use intentional questioning and listening to learn more about others and how to appeal to their interests
2. Become more welcoming – most people know how to be welcoming, but may have barriers to being welcoming; this process helps uncover those barriers
3. Identify gifts – gifts are what people are in the world to do, as opposed to skills/talents, which are areas in which people excel

GCDD Executive Director Eric Jacobson discusses the fundamentals of community organizing with Bruce Anderson.

Mike Green urged the crowd to look beneath the surface of their communities to locate needs and resources.



**“When people come together
by common interest,
magic happens.”**



The city of Milton is already working to be more welcoming, especially to people with disabilities. Sharon Lockwood, a resident on the Milton Disability Awareness Council and seminar attendee, said, “I wanted to come see what everybody else is doing.”

Milton City Councilwoman Tina Daversa also attended the training. “We want to be sure as we build that we’re ADA (Americans with Disabilities Act) compliant, and we want to be inclusive, not exclusive, to people with and without disabilities. We want to be an open armed, welcoming community to everyone,” she said.

Green suggests organizers should keep three ideas in mind:

1. What are good guiding principles?
2. What are good practices for engaging a community?
3. What questions will help you learn the most from conversations with communities?

“Think of yourself as a community builder.

How can you support other people to engage the community directly? You need to move from the “me” plan to the “we” plan,” Green said.

Bell, who successfully implemented many of the techniques Anderson and Green discussed in the Madison, Wis., area, encouraged participants to look at their communities’ assets instead of the deficits.

“List all the things in your community that can be assets and used to create connections. Think about it as a treasure hunt,” she urged.

“Where some saw a weak spot in the community, others saw a strength.”

While many communities have similar assets, some participants were surprised by what they found.

GCDD Chair Tom Seegmueller said, “Where some saw a weak spot in the community, others saw a strength.”

Bell said, “The important part about this exercise is that it re-frames your community so instead of

focusing all the energy on what’s not there and the needs, you start to see what you have to work with.”

Participant Nancy Brooks-Lane, director of developmental disabilities services for the Cobb-Douglas Community Services Board, agreed. “When people come together by common interest, magic happens. The energy increases, and information and processes come out that you didn’t have coming in.”

Seminar attendee and Clarkston City Councilwoman Rosemarie Nelson has been working with GCDD Organizing Institute graduate Betty Hasin-Amin to ensure people with disabilities in their community have access to the services they need through Project ACCESS (Achieving Community Commitment Empowerment Sensitivity Services).

“We’re in the foundation stages. We have unique challenges because we have all different nationalities, and not everyone speaks English. We’re working to identify ‘bridge leaders’ who speak the language to help us get into those communities,” she explained.

Nelson believes the training session will help her continue her work in Clarkston. “I learned that I’m not alone, and there’s so many dynamic resources available. It’s important to understand we provide a general road map, but we must be adaptable in our application of it. The speakers spoke about the past and the future as being a learning journey. In that journey, things that worked in the past might not work now, and we can’t be sensitive when we need to make a change,” she said.

Jacobson has high expectations for the participants of the seminar and expects to host similar seminars in the future. “I hope the participants will realize if we are going to change what’s taking place in Georgia, we have to start at the local level. We have to recognize we can’t do it by ourselves, we have to reach out to others with the same issues as people with disabilities and their families.

“If we come together with those communities, we have a greater likelihood of real change,” he said. ●



**List all
the things in your
community
that can be assets
and used to create
connections.**

Oh, The Places You'll Go

This isn't just a catchy Dr. Seuss title for pre-school students and high school graduates – technology is quickly adapting to fill the needs of people with disabilities, meaning one day physical limitations will be meaningless.

By Carly Sharec



A rapt audience sits in front of the test aquarium for CATEA's accessible aquarium project.



A fish tries to swim away, but he can't hide – CATEA's accessible aquarium project is being developed for people with vision impairment to be able to detect what is going on in a tank at any given moment.

Everyone knows the frustrations of wanting to be able to do something but being unable to fulfill wants and needs. But what once seemed impossible is now possible, thanks to new technologies being developed around the world.

Researchers at the Center for Assistive Technology and Environmental Access (CATEA), a multidisciplinary research center at the Georgia Institute of Technology, are devoted to enhancing the lives of people with all levels of ability.

"The primary project we are working on is the accessible aquarium project," said CATEA Director Jon Sanford.

"Currently, aquariums have audio descriptions of what is in the tank, but it's not relative to what is going on in the tank at that moment," Sanford continued. "This project is the equivalent of how a live docent might explain what's going on in the tank. Right now, this is being done with video technology. In the future, we may use tags on fish, especially since so many fish in aquariums are already tagged."

John Rempel of the Center for the Visually Impaired has been collaborating on this project for two years. "We meet several times a year. They present their material to us, and we provide information as to how visually impaired and blind people access museums, aquariums, zoos and other

"We got to talking about Twitter, and Adam basically mused out loud how great it would be to be able to tweet with your mind."



recreational facilities." Rempel helps determine what information is useful, what is too much and what is too basic.

"This is more of a real experience than in simply listening to an audio tour, or even a live docent,"

he explained. "This interactivity really appeals particularly to the young blind and visually impaired community, as they want to explore on their own without having to rely on others."

The project was unveiled June 15 to the Georgia Alliance for Accessible Technologies (GAAT), formed by G3ict and other Georgia organizations as a pilot project to promote accessible and assistive technologies in travel and tourism. Other case studies included advanced path finding and geo-positioning services and a cutting edge accessible reservation Web site from Intercontinental Hotels Group.

Another project includes "AwareComm" – a development for people with communication impairment, and a Context Aware Prompting System (CAPS), which will provide a specific list of tasks to employees with developmental disabilities. "There are many devices that provide a 'to-do' list, but this will actually list the order that tasks must be completed," explained Sanford. "An example would be baking a cake. It's basically like a computerized assistant."

Elsewhere in America, Adam Wilson and Professor Justin Williams of the University of Wisconsin-Madison developed the "Brain-Twitter Interface Project." Simplistically, the idea is to be able to "tweet" with one's mind. And to hear Williams tell the story, it really was as simple as that.

"We got to talking about Twitter, and Adam basically mused out loud how great it would be to be able to tweet with your mind," Williams explained. "And I looked at him and said that it would be possible." The next day, Williams and Wilson experimented with an electrode cap, which looks like a shower cap except it covers your head with electrodes to read activity in the brain. That day, Wilson posted two updates to Twitter – without touching a keyboard.

"There's a lot of hype," said Williams. "Right now, this is very experimental and new. I think we had initially thought these developments would be wonderful for those with 'locked-in' syndrome, or who are paralyzed, but of course I realize that this technology can go mainstream very quickly." ●

New Options Waivers: The Transition is Over... Was the Change Worth It?

The New Options Waivers have been in effect for nine months – the first sweeping change of the state waiver program since it was created. As more families adapt to the switch, and as any kinks get ironed out, families are finding that the change is a bit more refreshing than expected.

Jodie Key, featured in the last issue along with daughter Chloe, was just one Georgian frustrated with the changes. “We didn’t get help with diapers anymore. Sometimes our support coordinator finds someone who might be interested in coming out to relieve my husband and me at certain points throughout the week, but none of the suggestions pan out,” Key had said to *Making a Difference*.

Today, while things are not entirely different, they are looking up. “Beginning on June 1, services began,” Key explained. “And not a moment too soon! We bought three packs of diapers for Chloe on May 24, and only had one package to go from May 27 until I got paid on the 29th. Going six months without any help, particularly diaper support, has been rough.”

“Obviously, this is not going to be ideal for every family, but it seems like it’s going to be the best option for mine.”

In a follow-up e-mail, Key was ecstatic to report that someone had been out to provide support and help take care of her daughter for two days in a row. “We’re incredibly grateful,” she enthused, “and that about sums it up!”

One person who felt the growing pains is Sherry Richardson, director of Family to Family for Health Choices and also of Parent to Parent,

who has been featured throughout the entire New Options Waiver series of articles. “Currently, we have selected access to community living supports, community access and natural support training services for Micah [her son],” she explained. “This allows Micah to receive supports at home and in the community, as well as for parental training to improve Micah’s wellbeing.”

Cindy Vickery, chairperson of the South Georgia Community Service Board, is still waiting to transfer to the new waivers. “At the time when the transition came, it was just not a good time for our family,” she explained. “We are now looking to make the switch on our son’s, Michael’s, next birthday, which will be in May 2010.”

“Going six months without any help, particularly diaper support, has been rough.”



Vickery thinks that NOW is a step forward in the right direction. “I’ve been to a couple of the community forums that helped to explain the waiver,” she said. “Obviously, this is not going to be ideal for every family, but it seems like it’s going to be the best option for mine. I want what’s right for every individual.”

Repeated attempts to interview a representative from the Department of Human Resources’ Office of Developmental Disabilities went unanswered as the department is in the midst of being restructured. However, the families are finding the bumpy transition period starting to smooth out.

“We continue to look at the change as the glass being half-full,” Richardson stated. “Let’s hope the glass will be overflowing shortly!” ●

Congregations Offer Opportunity for People with Disabilities to Share Gifts

By Mark Crenshaw, Interfaith Disability Connection

“Our tradition tells us that we Jews are supposed to be Rachamim b’nei Rachamim, “compassionate individuals born of compassionate individuals,” heirs to a legacy of human compassion. How we dedicate ourselves to meet the needs of our fellow Jews with disabilities is a true and accurate measure of how well we are living up to our legacy of compassion.”

RABBI BRADLEY LEVENBERG, ASSISTANT RABBI, TEMPLE SINAI, SANDY SPRINGS



Mark Crenshaw is the Director of the Interfaith Disabilities Connection at the Bobby Dodd Institute that seeks to bridge the gap between people with disabilities and meaningful participation in faith communities. Crenshaw, who has a disability, speaks to local, state, regional and national audiences regarding the importance of seeing the gifts that people with disabilities bring to congregational life. He served as a faculty member at the Candler School of Theology at Emory University and he currently serves on the advisory committee for the school's Contextual Education Program.

Rabbi Levenberg's correlation of the very definition of Judaism with the act of creating accessible and welcoming communities makes the above statement absolute, timeless and undeniable. The correlation to compassion goes beyond Judaism. In fact, compassion is a central tenet in all of the world's religions. We all believe that we are called to do what we can to make our communities and our world a more compassionate place.

By mining the rich resources of our sacred texts we begin to understand that this is work that people of all faiths are called to do. When we hear this call how do we respond as people of faith? By building collaborations that create opportunity and possibility that allow us to make the most of our leadership and visions of inclusion. It is the mission of the Interfaith Disability Connection (IDC) to do just that.

Since 2000, IDC has offered classes, consultation and information concerning best practices, and a forum for people with disabilities and their families to share their gifts and stories. In addition IDC offers examples of the best ways to collaborate with community partners to make congregational programs the best that they can be.

...IDC offers examples of the best ways to collaborate with community partners to make congregational programs the best that they can be.

Case in point: Rabbi Levenberg and the people of Temple Sinai. As a member of IDC, Temple Sinai has made the inclusion of people with disabilities a priority in their congregation. The inclusionary accomplishments of Temple Sinai through their Hineini Committee (Hineini is defined

as “Here I Am” in Hebrew) through leadership and vision has made their congregation more welcoming of the members of their community.

The journey of inclusion at the Lutheran Church of the Resurrection in Marietta, another IDC member congregation, is a story of collaborating to share resources and ideas to make volunteerism accessible to people with disabilities. Jim and Barbara Kirk, the volunteer coordinators of LCR's Circle of Friends Program gave participants with disabilities a chance to give back to their communities.

Circle of Friends members with the assistance of more than 100 volunteers from the church collected and delivered gifts to people with disabilities who live in group homes sponsored by Right In The Community.

These are but a few examples of congregations who have successfully built collaborations and cultivated compassion. IDC is committed to helping congregations of every faith accomplish similar results. IDC's second annual summit, “Pursuing Inclusion Beyond The Ramp,” which will be held from 1-6 p.m. on August 9 at the Sloppy Floyd Building in Atlanta, is a wonderful opportunity for congregations who are interested in starting or improving their inclusion programs. Visit www.interfaithdisability.org to register. In addition, the coming year will bring new and innovative opportunities to bring congregations together to join one another on the road toward the full inclusion of people with disabilities in their congregations.

The work of building communities that are dedicated to embracing the gifts of people with disabilities is wonderful work. The work begins with commitment, vision and courage on the part of our congregational leaders and it is executed through collaboration and the sharing of resources. IDC can help your faith community make this vision a reality. ●

StraightTalk

Faith Communities Help Support Three Young Men

By Scott Heyman and Gail Heyman

I live with my two best friends thanks to support from a Methodist church, a Jewish service provider and our community.

I have Fragile X syndrome, and my two roommates, Russell Clark and Paul Partus, have Down syndrome. We would not be able to live on our own without support.

Russell, Paul and I met in first grade in a self-contained special education class at Sope Creek Elementary School. We've been friends ever since. Russell is Methodist, Paul is Episcopalian and I am Jewish. We participated in Special Olympics together, and we went to the Chalutzim program at Camp Barney Medintz in Cleveland, Ga. for four weeks every summer. We went to Christmas dances and Hanukkah parties together, and our families would celebrate birthday parties each year.

When Russell graduated, he lived in an independent living transition home run by Jewish Family & Career Services. He was looking for a permanent place to live. Russell's dad asked their family church,

Mt. Bethel Methodist, if they could help him find somewhere to live. Russell had been a member of the church since he was little, and Mt. Bethel decided to help support him in a home.

Paul and I moved in with him when we graduated. We all get personal support, job coaching and recreational services from Jewish Family and Career Services. We get to decide what we want to do and when. We're free to make our own choices. We wouldn't be free if we lived in a group home.

We all get personal support, job coaching and recreational services from Jewish Family and Career Services.

I like my job, and I like eating at Mt. Bethel on Wednesdays. Our families come over to see us and help us.

We've lived together for five years now. Sometimes people from Mt. Bethel help us in the yard and fix things in the house. Firemen and Boy Scouts have helped us too.

I'm glad Mt. Bethel and Jewish Family and Career Services helps us. If they didn't, we might not be able to live in our own house, near our friends and family and do what we want. ●

We're free to make our own choices. We wouldn't be free if we lived in a group home.



Gail Heyman, is the co-founder and president of the Fragile X Association of Georgia and a board member of the National Fragile X Foundation. Her son, Scott Heyman, is a graduate of Wheeler High School and has lived independently for five years. He works at Publix and enjoys being part of his community. He was diagnosed with Fragile X syndrome at age nine.



The three roommates enjoy participating in their community and the freedom living in their own home allows.



Leaps and Bounds of Faith

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

Mia has had varied and rich experiences with faith, and has always liked going to church. She was baptized by an Episcopal priest in the garden of our St. Croix home with about 40 friends standing among the ferns and bougainvillea. The priest wore a beautiful stole of butterflies, symbolizing new life. That gathering was Mia's first circle of support.

When we moved to Athens in 1996, I went "church shopping." My first and last stop was First Presbyterian Church. I had grown up in a Congregational Church that had merged with a Presbyterian Church, and their service, music and worship style were all familiar. The first Sunday that I attended with Mia, I was greeted by members all around me. Not two days later, I got a call from Tom, who also happened to be the music director, and he said that it had come to their attention that I had a child with special needs, and was there anything they could do to accommodate her? I replied, no, Mia pretty much did everything everybody else did, but I appreciated being asked. We felt welcome.

In the years since, Mia has sung in the choir, participated in Youth Group and was confirmed with her peers, having two women named Jane sponsor and mentor her. When Mia was in high school, she and I led the two-year-old class, and she has assisted in the Sunday School Program since then. Her first class of two-year-olds are now in middle school. She knows them all by name, and their parents all know her. When we were trying out employment skills, Mr.

Julius, the church custodian, got her setting up the tables for Wednesday night suppers, which she still does, and taught her how to vacuum a large room. She collects Change for Children for an orphanage in Africa, turning her coins into the office each week in a ziplock bag with a little piece of paper on which she has written "Mia." My Women's Bible Class has supported her camp fundraisers and Buddy Walks, and a couple of the women are in her circle of support.

The first thing Mia said to me when we began talking about moving into her own place and me moving to Atlanta was, "Who's going to take me to church?" It turns out Wanda, our class leader, has volunteered to bring her, unless I miss the Women's Bible class too much and come to Athens on Sunday morning.

"I didn't have to advocate at all for Mia to be "included" in her faith community."

I didn't have to advocate at all for Mia to be "included" in her faith community. They stepped up, and not by setting up "special Sunday School" or singling her out. She needs them and they need her also, and the way she is included shows me she has brought a great deal of joy into the life of the congregation. I know we will be able to count on our faith community as Mia takes the next step in her life. ●



The first thing Mia said to me when we began talking about moving into her own place and me moving to Atlanta was, "Who's going to take me to church?"



JULY

July 16 - 17

Georgia Council on Developmental Disabilities Quarterly Meeting and Annual Awards Ceremony

Atlanta, GA
404-657-2126
888-275-4233 (ASK-GCDD)
www.gcdd.org

July 26

National Celebration of Americans with Disabilities Act Anniversary

July 27-28

Shared Commitment - Shared Results Administration on Developmental Disabilities 2009 Technical Assistance Institute

Arlington, VA
202-506-5813
www.nacdd.org

AUGUST

August 9

Interfaith Disability Connection Summit: Pursuing Inclusion Beyond the Ramp

James H. "Sloppy" Floyd Building
Atlanta, GA
678-365-0073
www.interfaithdisability.org

August 18 - 20

Georgia Mental Health Consumer Network, Inc. Peer Supporting Peers: Head to Toe Wellness 18th Annual Summer Conference

St. Simon's Island, GA
800-297-6146

August 21 - 24

Brain Injury Association of Georgia

Camp Hardgrove
Winder, GA
404-712-5504
www.braininjurygeorgia.org

August 22

People First State Conference

OCTOBER

October 10 - 15

National ADAPT Action

Atlanta, GA
www.adapt.org
www.disabilitylink.org/docs/adapt

October 15 - 16

Georgia Council on Developmental Disabilities Quarterly Meeting

Macon, GA
404-657-2126
888-275-4233 (ASK-GCDD)
www.gcdd.org

October 23

Olmstead Symposium

Georgia State University
Atlanta, GA
olmsteadsymposium@gmail.com

October 28 - 30

Rising to the Challenge: National Association of Councils on Developmental Disabilities Annual Conference

Albuquerque, NM
202-506-5813
www.nacdd.org



No playtime for Georgia until it makes the grade on Olmstead.



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

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

State Government

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

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

Department of Community Affairs
www.dca.ga.gov

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

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

General Information
www.georgia.gov

Georgia Lieutenant Governor's Office
www.ltgov.georgia.gov/02/ltgovhome/0,2214,2199618,00.html
404-656-5030

Faith Communities

American Association of People with Disabilities
www.aapd.com

Interfaith Disability Connection
www.interfaithdisability.org

Developmental Disabilities Ministries
www.ddmga.org
770-623-4899
888-340-5820

Connections for Special Parents
www.cspofnortheastgeorgia.org
706-245-6095

Technology

Center for Assistive Technology and Environmental Access (CATEA)
www.catea.gatech.edu
404-894-4960

University of Wisconsin-Madison
www.bme.wisc.edu
608-263-4660

Center for the Visually Impaired
www.cviatlanta.org
404-875-9011

G3ict
www.g3ict.com

Advocacy

The Arc of the United States
www.thearc.org
202-783-2229

Shepherd Center
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