

Making a Difference

FALL 2004

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The New Faces of Disability Policy in Georgia

Georgia's New
DHR Commissioner
Beverly "B.J." Walker

Georgia's New
MHDDAD Director
Gwen Skinner

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Crisis**

**Communities
Fill the Gap**

**First Call
For Help**

**Community vs.
Congregated Living**

Real Homes. Real Jobs. Real Education. Real Choice.

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A quarterly magazine of the
Governor's Council on
Developmental Disabilities.

The Governor's 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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To Georgia's Disability Community,

My vision as Governor is to change the culture of Georgia's government, where people are more important than politics. Developing an administration that is principle-centered and people-focused is the first and foremost way to accomplish this feat.

One of the most important administrative appointments I've made this year that affects the disability community is the commissioner of the Department of Human Resources (DHR). A new director of the Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) has also been hired and will be assisting the commissioner of DHR to make a difference in the disability community.

I conducted an extensive, nationwide search for the commissioner to find a leader of high caliber, someone who inspires confidence, a manager who demands the best of her staff and is experienced with change. Equally important in this search was finding someone who would bring an energetic passion to Georgia's DHR. Georgia needed this proven leadership.

This edition of *Making a Difference* will introduce you to two remarkable women – DHR Commissioner Beverly "B.J." Walker and Gwen Skinner, the director of the Division of MHDDAD.

After a number of interviews with various candidates, it was crystal clear that B.J. Walker would be an invaluable addition to Georgia. Since, she has shown herself to be a hands-on leader and passionate about getting the right tools to the people who do the work, including the best technology.

Not only is she an inspiring professional to work with, she's an inspiring person. She demonstrates compassion on the job as well as in her personal life. She is nationally recognized for her professional work in human relations. Walker has also been a foster parent herself.

Walker recently hired Gwen Skinner as director of the Division of MHDDAD. Skinner brings with her many years of public service and is more than qualified to face the many challenges in the disability community. The expertise she brings to Georgia is accompanied with compassion. There is no doubt that she has already made tremendous efforts toward strengthening Georgia's system of services for people with disabilities.

A people-focused culture change is essential in the great state of Georgia, and with these leaders on board, it's inevitable. I ask you to join me in supporting them in their new roles as servants to Georgia and to the disability community.



Sonny Perdue

Sonny Perdue
Governor



Georgia Has Opportunity to Change for the Better

Charlotte's Web author E.B. White wrote, "I wake up every morning determined to both change the world and have one hell of a good time." For many it's hard enough just trying to change our small piece of the world. People with developmental disabilities and their families battle every day hoping that the personal attendant arrives, worrying about having a ride to work or getting respite so they can fight another day. A change in their world means accessing quality supports, having teachers prepared and willing to teach to all children and acquiring services that are not a barrier to having a job or getting health care.



It often seems to me that we are in a constant battle with policymakers and the bureaucracies that determine the available funds and services that people can access. Every couple of years, we "look up" and find someone new appointed commissioner of a department or director of a division. We always hope that this is the person who will bring the leadership necessary to create positive change, and that we can work together to make that change. Most of the time we are disappointed; the person stays for a year or two, or their voice is lost among the bureaucrats.

We have that opportunity once again. In this edition of *Making a Difference*, you will meet Commissioner B.J. Walker from the Department of Human Resources and Gwen Skinner, director of the Division of Mental Health, Developmental Disabilities and Addictive Diseases. Both women bring a fresh perspective and renewed hope that we can work together to make significant changes in the service system for people with developmental disabilities and their families. Already, they have taken a positive step by recommending to the Department of Human Resources board that its budget include 1,100 new mental retardation waivers and a six percent provider rate increase.

Already, they have taken a positive step by recommending to the Department of Human Resources board that its budget include 1,100 new mental retardation waivers and a six percent provider rate increase.

Commissioner Walker and Ms. Skinner's work should begin with a vision that starts with Community First and holds that individuals have access to real homes, real jobs, real education and real choice in their lives. They should make sure that the system reflects and promotes the values of dignity, independence, individual responsibility, choice and self-direction. The focus of funding and service planning should be on the individual and not on the services or providers.

They should consider the following recommendations that would significantly improve the system and people's lives:

- Enable active participation by consulting and encouraging people with disabilities and their family members to be a part of any reform effort.
- Make sure that services for people with disabilities are person-centered and consumer directed.
- Revise the quality assurance system to effectively and appropriately assess risk and strive to enhance safety, health and quality of life for all people.
- Develop opportunities in each community for all sources of services and supports, public and private funding, businesses and civic as well as other community resources to meet and find ways to leverage nontraditional resources.
- Develop and support the provider market so that individuals and families have more choices in who provides services.
- Develop the direct support profession by helping providers offer a fair wage, and requiring training beyond the minimum of 30 hours.
- Find ways to encourage best practice, especially in the area of employment where we pay more for day habilitation than we do for supported employment.
- Support legislation that would allow money to follow the individual from institutions to the community.

We look forward to working with Commissioner Walker and Ms. Skinner to implement these recommendations. We could then meet Mr. White's charge, and our reward would be communities that welcome and value all members. I invite your comments, please reach me at eejacobson@dhr.state.ga.us or 1-888-275-4233.

Eric E. Jacobson
Executive Director, GCDD



Letters to the Editor

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

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It is the policy of *Making a Difference* to publish readers' comments. Contents do not necessarily reflect the opinions of GCDD, the editors or state government.

Terrific Resource for Students

I got my issue of *Making a Difference* and I was just tickled to death!! You did a wonderful job!! I actually called and ordered 100 copies!! I'm going to write a cover letter and send it to parents and teachers here in Rockdale County. Hopefully they will want to get this terrific resource on a regular basis themselves!

Thank you so much for doing such a terrific job!

Denise Oravec, *Rockdale County School System Transition Coordinator*

Jobs and Training Edition a Powerful One

I just received my copy of *Making a Difference* . . . it is a remarkable edition!!! I hope all DD Councils get this, it is such a powerful edition!!

Thanks so much for including us and the remarkable work Doug Crandell and Nancy Brooks Lane and their team continue to do! And Eric, thanks for your obvious leadership in making (customized employment) a reality!!!

Cary Griffin, *Griffin-Hammis Associates, Florence, MT*

Increased Awareness

I thought *Making a Difference* looked wonderful. The colors and the attention to details have come a long way!!!!

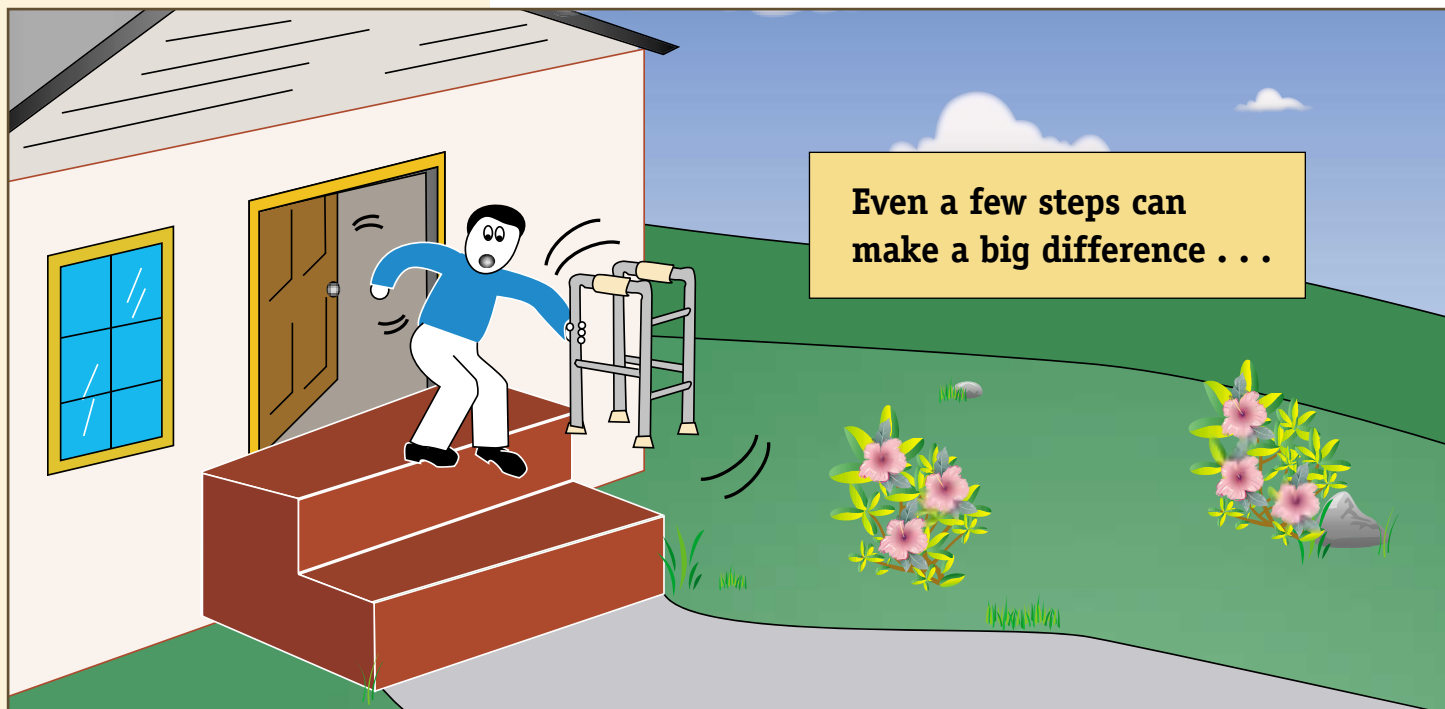
Keep up the GREAT work!

Sharon O'Prey, *GCDD*



Correction:

In the Summer 2004 article "Georgia Woman Advocates for Independence", the photographs were misidentified. The caption should have read: "Annette Dotson surrounded by her family (top), her friends George and Linda Pogue (middle), and Normalee Asheber (bottom). *Making a Difference* regrets the error.



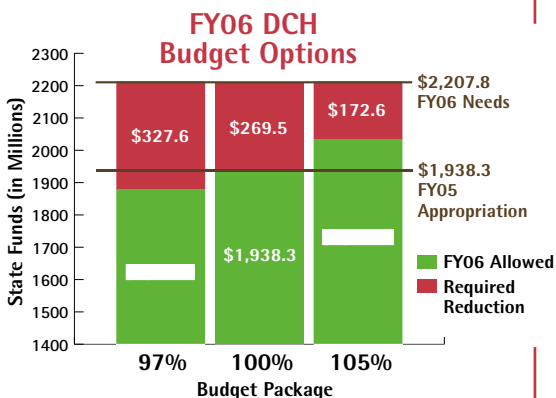
Expect Changes in 2006 DCH, MHDDAD Budgets

Georgia's Department of Community Health (DCH) and the Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) recently announced their proposed budget plans for fiscal year 2006.

Per Governor Sonny Perdue's instructions, DCH and MHDDAD prepared three potential budgets: one assuming the divisions would receive 105% of their Fiscal Year 2005 budget, one assuming they would receive the same budget, and one assuming they would receive 97% of their respective Fiscal Year 2005 budgets

DCH Budget Cuts May Affect People with Disabilities

As more people are enrolled in Medicaid and other state and federally-funded programs due to a lagging economy, even if DCH receives 105% of its budget, it will need to make changes and cuts to its programs due to the sheer number of people enrolled.



Changes and cuts proposed that would directly affect people with disabilities:

- Implementing disease and case management for people with disabilities, visual impairment and the aged
- Eliminate optional adult orthotics and prosthetics
- Transfer funding for the Marcus Institute to the Dept. of Human Resources
- Implement a fixed expenditure cap for home and community-based services provided in mental retardation waivers

- and Independent Care Waiver Program
- Eliminate all adult transportation services
- Charge premiums to families of Katie Beckett children on a sliding fee scale
- Reduce coverage for people with disabilities, visual impairments and the aged with incomes greater than 2X SSI

MHDDAD Considers Changing Budget Focus

The preliminary MHDDAD budget affects several Unlock the Waiting Lists items. The proposed Mental Retardation and Developmental Disability Waiver slots have dramatic increases at the 100% and 105% budget levels.

Changes and cuts proposed that would directly affect people with disabilities:

- Increase Mental Retardation and Developmental Disability Waiver slots (1,124 slots at 105%, 925 slots at 100%, 30 slots at 97%)
- Increase MR/DD provider rates for select services that are currently reimbursed at a rate below southeastern average
- Fund a 6% provider rate increase in MR/DD services (105% budget level)
- Discontinue room and board payments to align payments for services with other states
- Downsize adult services at East Central Regional Hospital in Augusta and develop more appropriate community-based services
 - Reduce outpatient dental services by 50% - remaining outpatient dental services will prioritize serving consumers with severe behavioral problems or physical complications

These budget recommendations are very early in the process. If you are concerned with any of the above proposed changes or cuts, there is time to contact your legislators, the DCH, or the MHDDAD and the governor's office to let them know how these cuts would affect your life.

For more info, visit the Department of Community Health's web site at www.communityhealth.state.ga.us or visit www.dhr.state.ga.us and click on Divisions > Mental Health, Developmental Disabilities and Addictive Diseases.

California Found in Violation of Olmstead

The Justice Department announced the results of its investigation into the State of California's role in the unnecessary institutionalization of residents at Laguna Honda Hospital and Rehabilitation Center ("Laguna Honda"), in San Francisco August 3. The Department found evidence that the state is contributing to the unnecessary segregation of individuals with disabilities residing at the 1,200 bed nursing home.

"The Supreme Court has made clear that unnecessary isolation of individuals with disabilities in institutions, including nursing homes, is discrimination that diminishes individuals' ability to lead full and independent lives," said R. Alexander Acosta, Assistant Attorney General for Civil Rights. "The law requires that people with disabilities, like all Americans, have equal access and opportunity to participate in community life."

The announcement is part of the Department's long-standing investigation into whether residents of Laguna Honda are being served in the most integrated setting appropriate to their needs, as required by the Americans with Disabilities Act of 1990 (ADA).

The Department found the state routinely authorizes placements without requiring adequate assessments evaluating the appropriateness of home and community-based care. As a result, individuals are not informed of community options available in California and remain at Laguna Honda long after they become eligible for community programs and services.

This investigation is part of the Department's efforts to enforce the Supreme Court's 1999 decision, *Olmstead v. L.C.*, in which the Court held that, pursuant to the ADA, states must provide services to residents with disabilities in the most integrated setting appropriate.

The Department's focus in this area targets unnecessary institutionalization of individuals with disabilities.

For more info about the Special Litigation Section of the Justice Department's Civil Rights Division, visit [http:// www.usdoj.gov/crt/split/index.html](http://www.usdoj.gov/crt/split/index.html).

Advocate Anil Lewis Receives ABA Award

The American Bar Association Commission on Mental and Physical Disability Law presented the 2004 Paul G. Hearne Award to Anil Lewis, chair of board of directors of the Disability Law and Policy Center of Georgia. ABA President Dennis W. Archer presented the award to Lewis during a ceremony August 9. The award is presented in conjunction with the National Organization on Disability.

Lewis' vision, effective communication and persistence resulted in Georgia being the first state to make voting machines accessible to people with disabilities in every polling precinct for the 2002 elections. In 2004 Lewis was instrumental in securing the unanimous passage in the Georgia House of Representatives of legislation creating NewsLine, an audio service that allows people with disabilities to access newspapers via telephone.

The Disability Law and Policy Center of Georgia uses a variety of methods to influence and enforce disability policy. In 2003 the center prevailed in an Americans With Disabilities Act lawsuit against Atlanta's rapid transit system, a nationally significant case that requires transit systems to make their web sites accessible to people with disabilities.

Lewis was born in 1964 in Atlanta. He is the third of four children; both his older brother and sister became legally blind at an early age due to retinitis pigmentosa. Early in his life Lewis was labeled "educable mentally retarded," but as the first member of his family to attend a four-year college, he excelled academically and received many awards.

Although he was diagnosed with retinitis pigmentosa as a child, his vision was reasonably unaffected until he was 25. The Paul G. Hearne award is presented each year to an individual or organization that has performed exemplary service in furthering the rights, dignity and access to justice for some 54 million Americans with disabilities.

Candidates Respond to DD Issues at Forum in North Fulton County

On Tuesday, September 21 the Atlanta Alliance for Developmental Disabilities (AADD) held a candidate forum in North Fulton county. Six candidates attended and shared their stances on four issues.

The candidates in attendance were: House Rep. Jan Jones, R-Alpharetta; Democrat Jan Hackney running against Rep. Harry Geisinger, R-Sandy Springs; Rep. Wendell Willard, R-East Roswell; Cobb democratic candidate for Senate, Akhtar Sadiq; and Senator Dan Moody, R-Roswell.

The first issue attacked in the forum was how to move 5,000 people from hospitals to community residences. Hackney vied for assisted living homes. Jones and Sadiq agreed that living at home with support is more financially efficient than a hospitalized setting.



Disability advocates Heidi Moore, Peggy Ferris, and Mark Johnson discuss the issues during the forum in North Fulton County.



Rep. Jan Jones, R-Alpharetta, answers questions from a forum participant.

Sadiq insisted that budget waste must be cut in other areas and Moody emphasized that "one size does not fit all." He recommended cash and counseling programs to get people into the community. Willard's solution was a community foster care program for people with disabilities that would cost less than institutionalization.

The issue of high turnover in personal assistants for people with disabilities brought an onslaught of generic responses. Nearly all candidates decided that workers should be paid more but didn't specify where the money would come from. Hackney suggested it would come from a decrease in hospitalization costs when people were moved into the community. Sadiq wanted the workers to be paid comparably to school teachers and suggested budget cuts could be made elsewhere to fund this. Willard said he would persuade the government to increase the budget.

Most of the candidates responded passionately to the Katie Beckett (Deeming) Waiver cuts. They thanked AADD for informing them of the issue. Geisinger assured the crowd that after the coalition's response, the government wouldn't suggest cutting the budget again.

Most of the candidates at the forum insisted that budget cuts could be made in other areas that were wasteful to help to fund Unlock the Waiting List. Hackney insisted that early intervention is the key. She claimed that every dollar spent for a child will save 10 as an adult. ●

Disability Advocates Honored by GCDD



Tonya McConnell (l) with Heidi Moore (r) and their sons at the Save Our Special Kids rally at the Capitol last year.

Through a year that saw drastic budget cuts and a proposed premium on the Katie Beckett Waiver, many Georgians stood up and advocated against reduced services for people with disabilities. Georgia's Governor's Council on Developmental Disabilities (GCDD) honored several of these individuals during an awards banquet July 15.

"This awards banquet is a chance for GCDD and advocates to express our thanks and gratitude to those who have helped to improve the lives of people with disabilities and their families during the past year," explained GCDD chairperson Lynnette Bragg.



2004 Advocacy Leadership Awardees (l to r) Mary Beth Morris; Dawn Shepherd; Jon Burton; Heidi Fernandez, presenter and Council member; Philip Riley; Rachel Barron; Eric Jacobson, GCDD executive director; Gene Evans and children, and Lynnette Bragg, GCDD chairperson.

"When we work together with a sense of community, we are more likely to share a vision, to contribute and communicate freely, to seek and welcome feedback and direction and to be future-oriented and solution-minded, not prone to focus on the past or our problems," she continued.

GCDD honors outstanding advocates, media and legislators because, in the words of Executive Director Eric Jacobson, "It is important that we say thank you to those who have helped us along the way."

As a result of the work of the honorees, the proposed premium on the Katie Beckett Waiver was defeated; a resolution was passed requiring the Departments of Human Resources and Community Health to submit a multi-year plan to address the waiting list; and one advocate even managed to secure additional funds to support people coming off the waiting list.

"None of this would have happened without the support, enthusiasm and energy of the people we thanked during our awards banquet," Jacobson reiterated.

Advocates of the Year Award: Heidi Moore & Tonya McConnell

Heidi Moore and Tonya McConnell worked tirelessly over the past year to call attention to the needs of children with disabilities, organizing a Save Our Special Kids (SOS) event at the Capitol in October, attended by about 200 parents.

Because of their organization of the SOS rally, Moore and McConnell also helped find parents to testify at the Department of Community Health (DCH) meetings when the issue of putting a premium on the Katie Beckett Waiver was raised.

"Their efforts to tell their story to elected officials are a great example of grassroots advocacy. Heidi and Tonya helped organize these moms and dads to work together to get the word out and testify before the DCH board and legislative committees, present their stories to the media and made sure that they were represented on Disability Day," explained GCDD vice-chairperson Vallorie Butler.

Advocacy Leadership Award: Rachel Baron, Jon Burton, Gene Evans, Mary Beth Morris, Philip Riley, Dawn Shepherd

While Heidi Moore and Tonya McConnell were instrumental in organizing parents to testify regarding the Katie Beckett Waiver, the parents who took time out of their busy schedules to share their stories were also recognized.

"Without their efforts, we would not have been able to defeat the proposed premium," revealed Heidi Fernandez, chairperson of GCDD's Advocacy and Information Committee. "These families have shown that they are not afraid to voice their opinions. They are the future of advocacy for people with disabilities."

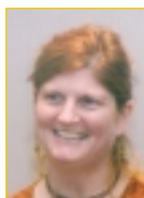
Media of the Year Award: Andy Miller and Patti Guthrie

Atlanta Journal Constitution staff writers Andy Miller and Patti Guthrie wrote a series of articles on the impact of the premiums to Katie Beckett Waiver and cuts to Medicaid. Some of their stories included:

- Legislators Champion Funds for Fragile Kids
- Medicaid Waiver Fees May Vanish
- Tough Break for Medically Fragile Kids: Families already stretched thin by the needs of their children beg state budget cutters to spare them
- Budget Cuts Bring Pain: Families Denounce Medicaid Plans



Andy Miller



Patti Guthrie



GCDD Board Member David Cowan explained why Miller and Guthrie were honored, "Both writers spent many hours during this past year learning the issues that are important to people with disabilities and helped us get our message out."

Legislative Leadership Awards: Sen. David Adelman, Sen. Jack Hill, Rep. Chuck Martin, Rep. Jay Shaw, Rep. Sally Harrell



2004 Legislative Leadership Awards were presented to Rep. Chuck Martin (photo above) and Sen. David Adelman (r) by Council member Tom Seegmueller (photo at right).

Five Georgia legislators distinguished themselves as friends of the disability community this year by providing leadership during discussions about adding a premium to the Katie Beckett Waiver.

GCDD Board Member Tom Seegmueller, explained, "This was a bipartisan issue because we recognized that this was about families who are doing everything they can



to support their families and even then may need a little help."

Sen. David Adelman, D-Decatur, was recognized for his leadership when he spoke at a press conference concerning the needs of families and children; helped his colleagues understand those needs; and met with Julie Beckett and parents to listen to their concerns regarding the proposed premium. He was also recognized by the Long Road Home for his support of efforts to implement the Olmstead decision.

Sen. Jack Hill, R-Reidsville, met with several parents regarding the proposed premium on the Katie Beckett Waiver during an Appropriations Subcommittee hearing. He told them that he would do everything he could to make sure the premiums were not part of the budget, and he kept his word.

Rep. Chuck Martin, R-Alpharetta, worked to determine what alternatives to the premium might exist and where the funds might come from if the premiums were removed from the budget. He met with advocates and then attended the press conference and met with parents to discuss alternatives.

As chairperson of the House Appropriations Subcommittee on Community Health, Rep. Jay Shaw, D-Lakeland, made sure



Enjoying the GCDD Awards Banquet were audience members (l to r) Natalie Tumlin, self-advocate; Beth Tumlin, parent advocate; and Geneice McCoy, GCDD Council member.

parents got their chance to speak during the budget hearings. One of the first to question the Department of Community Health about the process they were planning to implement, he assigned Rep. Sally Harrell to learn more about the issue and report back to him with recommendations.

Special Legislative Leadership Award: Sally Harrell

Rep. Sally Harrell, D-Atlanta, met with parents and Julie Beckett and made a recommendation to the House Appropriations Subcommittee on Community Health that the proposed premiums on the Katie Beckett Waiver be removed from the budget. Her recommendations were the key to ensuring the premiums were not implemented.



Rep. Sally Harrell (l), recipient of the 2004 Special Legislative Leadership Award, and daughter Salena met with Julie Beckett (r) and parents regarding the Katie Beckett Waiver premium.

C. Anthony Cunningham Council Member Leadership Award: Tom Seegmueller

This year, GCDD added an award that recognizes one of its members for outstanding contributions during the year. The award is named after Carl Cunningham who was the Council chairperson from 1998-99. "Carl really exhibited all the traits of leadership: he believed in continual learning; he radiated positive energy; he was proactive; he had vision; and, he sought to understand others point of view before he spoke. He recognized that we needed to continually build and support the future leaders of this movement," Bragg said.

GCDD's first recipient of the C. Anthony Cunningham Leadership Award was Tom Seegmueller. Seegmueller was

appointed to the Council in 2002 and is actively involved in all parts of GCDD, never afraid to voice his opinion or participate in a conversation. He currently serves as the chairperson of the Public Policy Committee and on the Public Policy Committee of the National Association of Councils on Developmental Disabilities. ●



Tom Seegmueller (r), recipient of the 2004 C. Anthony Cunningham Council Member Leadership Award, with Eric Jacobson, executive director of GCDD (photo at left).

The New Faces of Disability Policy

in Georgia

“Society needs to change,” Beverly “B.J.” Walker, commissioner of the Department of Human Resources (DHR) said with feeling. “We used to reach out and help our neighbors.”

Evidently, society isn't the only thing that will change. Living up to her past experience of reorganization and compassion will produce structural, programmatic and personnel changes at Georgia's DHR.

Walker was appointed by Governor Sonny Perdue as commissioner of the DHR May 17 and will oversee the DHR's mission, which is to assist Georgians in achieving healthy, independent and self-sufficient lives.

With a track record of success in similar tasks, Walker brings unmatched experience to DHR.

She served for four years as commissioner at the Illinois Department of Human Services, including two years as the director of Community Operations. Previously, she was Illinois Governor Jim Edgar's assistant for Human Services Reform and was responsible for managing a statewide reorganization of human services agencies.

“Commissioner Walker has shown great leadership and understanding of the needs of people with developmental disabilities through her budget and programmatic recommendations up to this point in time. She understands the problems that

exist and is willing to make the changes necessary to make sure people have quality services and support,” said Eric Jacobson, executive director of Georgia's Governor's Council on Developmental Disabilities (GCDD).

Among budgetary responsibilities, staffing challenges and child welfare system reform in Georgia, Walker appointed Gwen Skinner as director of the Division of Mental Health, Developmental

Disabilities and Addictive Diseases (MHDDAD) on June 16. The two have worked hard to find the right person to serve as director of Developmental Disabilities.

“Supervision is the heart and soul of any organization,” Walker said.

“We need accessible, accountable and well-managed services that respect the needs and wishes of consumers and their families.”

“We need accessible, accountable and well-managed services that respect the needs and wishes of consumers and their families.”

The primary involvement of DHR in the lives of people with disabilities is making sure that those who need services have access to those services within their communities, close to their homes and families.

“We have had a good day when a person with developmental disabilities moves into high quality community placement closer to family,” Walker said.

Another of Walker's immediate concerns was the Mental Retardation Waiver Program (MRWP). The program is a home and community-based waiver for people who have been diagnosed with mental retardation or other developmental disabilities requiring similar amounts of care. Her interest in the waiver lies in recipients' placement in quality homes.

Walker believes that governmental programs, although very necessary, should be a supplement, not a replacement, for community, family and faith-based support for people with disabilities – which she strongly encourages.

B.J. Walker hopes to bring new opportunities to people with disabilities in Georgia. She proclaimed that Georgia's DHR is becoming a place in which “Challenges are sometimes intimidating, but I always find them exciting.” ●



B.J. Walker: Molding Strong Communities



Gwen Skinner was named director of the Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) by DHR Commissioner B.J. Walker on June 16, and she's had her hands full ever since.

"I'm delighted to have her on board," smiled an enthusiastic Commissioner Walker.

As head of MHDDAD, Skinner oversees issues from developmental disabilities to substance abuse. She gets to know and work with very young children all the way up to senior citizens. However busy and however late into the night she works, she enjoys her new job. "I really like the variety here," she said.

Skinner has a deep-rooted background in serving the community. She has over 20 years of experience in Georgia's child welfare and juvenile justice system.

She has served as deputy commissioner of the Georgia Department of Juvenile Justice (DJJ) for the past five years and previously headed DJJ's Division of Community Programs.

Executive Director of GCDD Eric Jacobson, said, "Gwen comes to the table with the right values and uses them in her decisions about the direction she wants to take the division."

In her first few months, Skinner tackled two large issues: budgets and staff. Her most important staffing decision to make is choosing a director of the Office of Developmental Disabilities.

She emphasized that the new director must be industrious, committed, successful, research-driven and must bring new ideas to Georgia – and willing to work long hours! Skinner and Walker have involved advocates for the disability community in the interview process. Although no director had been chosen by press time, they were steps closer to making a final decision.

Secondly, Skinner served up an impressive budget. Of all the items to plan for on her plate, she asserted that she was dedicated to increasing the Medicaid Waiver Program, even if doing so might require a monetary shift later. Her proposal included 1,100 home and community-based waiver slots, a six percent provider rate increase and the relocation of 70 people out of institutions.

"That package is the best that we've seen, ever," revealed Jacobson.

The waiting list is perhaps the most serious issue for the disability community in Georgia with over 5,000 people waiting for help. Those on the waiting list have significant disabilities and need vital services to remain in their communities. Because these services have been poorly funded, more so in the State of Georgia than almost any other state, many people are segregated from their communities and placed in nursing homes and institutions. Skinner expressed a deep sense of urgency to improve this by encouraging policymakers to shift financing focus from institutions to community-based living.

"It's more than having them just exist in the community, we want them to thrive in the community," Skinner said. Besides improving existing programs, new programs will respond to these challenges. "We've got to offer a broader continuum that's flexible enough to meet differing needs, instead of offering a prescribed set of services," she explained.

Skinner also stressed that the use of technology will lead to a higher quality in training and assessment of professional caregivers.

However, Skinner hasn't planned the details of these visions quite yet. She feels it's important to wait until the new director is on board, giving him or her space to create solutions. ●

Gwen Skinner: Making Community Connections

The search for a new director of the Office of Developmental Disabilities is a top priority for Skinner and Walker.

"We've got to offer a broader continuum that's flexible enough to meet differing needs, instead of offering a prescribed set of services."

Support Starts *in the* Community

Finding services and support can be difficult for people with disabilities and their families. Often during the search, one of the biggest resources available is overlooked – the person’s community.

“People need to change their way of thinking. They should look to their community first. In addition to receiving the support they need, they will connect with their communities,” explained Connie Lyle O’Brien, who works all over the world advocating for people with disabilities.

“People with disabilities are whole people who need support. They don’t need to be treated or rehabilitated before they’re integrated into their community,” she said.

Across the state of Georgia, many different organizations are working to support people with disabilities while integrating them into the community to assure they live a full, satisfying life. Resources are available for all people with disabilities, from children through adulthood.

their lives, and we help connect them with community resources,” explained Inez Cannon, program manager for School Outreach for the council. “We have a ‘whatever it takes’ philosophy.”

The council has more than 60 in-home support coordinators who are trained in assessing needs and knowing what’s available in the community to help with discipline, clothes or what’s needed to accommodate the child to be successful at school and at home.

“They help develop resources for the families and can perform developmental assessments, which may lead to helping the families access the evaluation process for programs like Babies Can’t Wait or Success by Six,” Cannon said. “We want the child to get off to a good start.”

The council helps the whole family, not just the children. “We had a young mother, Angela Holcomb, who had been injured in a car accident and was quadriplegic. She took her child to school in her motorized wheelchair. DFCS (Department of Family and Children’s Services) told her she couldn’t do that anymore, or she could lose her child.

“We helped coordinate with a church in Dalton that purchased a wheelchair accessible van for her. She has a lot of obstacles, but she’s a good parent. It’s been great to offer her support.”

The Family Support Council also helps Holcomb in other ways. “I live on a low income because I can’t work,” Holcomb said. “The Family Support Council helps my daughter have a good Christmas.”

Another program supported by the council is Teens Unlimited, which is a group of teenagers, with and without disabilities, who perform service projects, such as ensuring all children are included in the council’s Celebrate the Family event.

“They ensured children with disabilities could

“Everyone needs support at certain times of their lives, and we help connect them with community resources.”



Angela Holcomb and daughters, Courtney (left) and Shannon at Westwood Elementary School in Dalton.

Community Support for Children

In North Georgia, the Family Support Council in Dalton was formed to help prevent child abuse by helping all families, including families who are caring for someone with a disability.

“Everyone needs support at certain times of



Lack of Funding Ties Up State-Funded Services

agencies. "The state is divided into seven regions, and each has a list of services they try to provide, which may include day and residential services, plus supported employment and mental retardation service centers," he said.

DHR funds a wide range of services for people with developmental disabilities, but the demand for services far outweighs the availability of them. "We have about 14,000 people being served, but 3,500 people are waiting for residential services," Hopkins said. In addition more than 4,900 people are waiting for other types of services, such as transportation or respite care.

Because of recent budget shortfalls, the state is unable to provide support for all the people with developmental disabilities who need services. "We have scarce resources and limited new resources," he said. "Georgia is behind most states in the percentage of tax dollars going to developmental disability support services. Additional funding is really important."

Another problem is supporting people who may never have received services before and suddenly need them desperately. For example, if a mother who has taken care of her child with a disability for his whole life suddenly becomes incapacitated or dies, her adult child has an immediate need for services.

When this happens, that person must take priority over others on what the state calls the "planning list," causing those who have been on the list for a while to wait even longer for services. "It's a crisis," Hopkins said. "If we could address problems earlier, we could prevent them from becoming crises tomorrow," he said.

People waiting for services on the planning list are divided into two categories – short-term and long-term. "People on the short-term lists have an immediate need that needs to be met within six months. We assign them a case manager who meets with them monthly.

"The case manager looks for natural supports and other services the individual can be linked with to help alleviate the need while waiting for state funding," he said.

DHR is working to offset budget shortfalls by helping people with disabilities integrate more into their communities.

"Employment services are less than some day services, and not only is the individual doing meaningful work, their lives are more positive, they feel better about themselves and a job offers them a degree of protection. If people with disabilities participate more in their communities, state-funded monitoring is not as necessary because their co-workers or neighbors are checking on them," Hopkins explained.

The state also supports a Natural Support Enhancement program designed to assist families. "This program acknowledges people have various supports in their community, through churches and family members. Through this program, we help, but don't supplant, these natural supports," he said. "We're working to get better at facilitating those supports.

"In areas where the paid support system is well connected with natural supports, the results have been very successful for providing help to people with disabilities."

Finally, the Director of DHR's Mental Health, Developmental Disabilities and Addictive Diseases Gwen Skinner has proposed a budget that includes funding for 1,100 people to receive waivers (see related article, page 11).

"Additional funding is really important," Hopkins said. But in the long-term, he feels integrating people with disabilities into the community is paramount. "People are less dependent on paid supports when they are part of our community, but it's also in our interests to support people with disabilities because they bring their gifts to the community and make our lives richer." ●

People who participate more fully in the community, such as Boy Scout Russell Johnson, generally require fewer state-funded services.

While many community support organizations are funded by private donations, many are funded by the state of Georgia, including the Family Connection Partnership.

Charles Hopkins of the Department of Human Resources' (DHR) Office of Developmental Disabilities explained, "All the services we support are community-based."

Many of the services funded by DHR are delivered via Community Service Boards, non-profit and for-profit service providers and other

participate in Celebrate the Family by providing adaptive toys," Cannon said. "They won the 2003 Youth Volunteer award from the Whitfield County United Way." A second Teens Unlimited group formed last March and will continue the good work.

Luke Morrison, a member of Teens Unlimited, has learned a lot about different disabilities. "It helps me know how kids with disabilities feel," Morrison, who has fetal alcohol syndrome, said.

"I like to help as much as I can in the community. I'd like to get a job helping kids with

disabilities in school," he commented.

One of the group's activities included learning what it's like to have a visual impairment at a shopping mall, and the group is planning to attend Disability Day at the Capitol. "They're a good group of marchers!" Cannon said.

While the Family Support Council in Dalton is a private organization, many counties have state-funded Family Connection county collaboratives, such as Dougherty County's Dougherty for Children in Albany.



Using an adaptive toy, Dennis Wilson participates in the Dalton Family Support Council's Celebrate the Family event in Eton, GA (above).

Teens Unlimited member Luke Morrison with one of the preschoolers at the International Inclusion Center (right).



"We want children to be healthy, ready for school and successful in school. We also want families to be self sufficient and to succeed," revealed Anne Stokes, executive director.

"It's hard to be a parent and not know where to go for information about your child's disability."

"Each Family Connection collaborative assesses their community and what they need to address. We are a resource that helps all the different agencies get together. We take a holistic approach," she said.

Dougherty for Children works with community agencies, as well as families. "We hold workshops to get our community's service providers together. Now they have a better understanding of what other agencies are doing and work together more efficiently."

In addition, Dougherty for Children works in county neighborhoods, assessing needs, then brings the families and the service providers together. "We determined how everyone could help each other – then it became very exciting," Stokes said.

"We determined how everyone could help each other – then it became very exciting."

A number of people involved with Dougherty for Children have children with disabilities, including Stokes. "We're really passionate about helping children with disabilities. It's hard to be a parent and not know where to go for information about your child's disability.

"Sometimes the needs are real basic – nutritional supplements or diapers," she said. Other times, the issues are more complex. For example, one mother had a child who was nonverbal and was about to be included in a regular classroom. "The mother wondered what would happen to her son because he didn't talk. We put her together with Exceptional Students representatives who answered her questions. Now her son is in speech therapy, and she has become an advocate for other families."

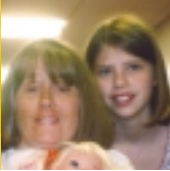
While people with disabilities may be referred to state-funded services for support, Dougherty for Children also regularly refers people to community groups and religious organizations.

"We're marketing the needs so people know our neighbors require help," Stokes said.

Community Support for Adults

Community support for adults with disabilities is just as vital as support for children. No one knows that as well as Tom Kohler, coordinator for Chatham-Savannah Citizen Advocacy, who has been putting people with disabilities together with members of the community for years.

"For many people with developmental



Neel Foster (l) and Loretta Washington were paired by the Chatham-Savannah Citizen Advocacy program which provides community support for adults with disabilities.

disabilities, everything happens to them through a system, and all bureaucratic structures depersonalize people," Kohler said. "Some people spend all day every day in a system and have few people that are unpaid in their lives."

Citizen Advocacy asks a person in the community to become an advocate for a person with a developmental disability. These

relationships can become lifelong friendships.

"The first step is to learn more about the person with a disability in an individual way . . . Where are they now? Where would they like to be?"

"The first step is to learn more about the person with a disability in an individual way. What role could someone play to help them become less vulnerable? Where are they now? Where would they like to be?" Kohler asked.

After learning about the person, Kohler has a better picture of what type of person they should be matched with. Knowing the person's experiences, background and personal preferences helps Kohler start thinking about specific people who would be appropriate citizen advocates for the individual.

The next step is to go to what Kohler calls his "Trust Networks." "We talk to people we know and trust to introduce us to people they know and trust," he said. "Our advocates need a backbone if they are to be a spokesperson."

People with disabilities benefit from the

relationship by having someone who will advocate on their behalf for a better life. In addition, friendships often grow and the person with a disability becomes more involved in the community as a result.

Advocates also benefit. "Part of the value of Citizen Advocacy is that more people learn about the social, political and cultural challenges of having a disability. They often realize they have made incorrect assumptions about people with disabilities.

"Citizen Advocacy helps the lives of people with disabilities become more visible and opens up more possibilities."

"Citizen Advocacy helps the lives of people with disabilities become more visible and opens up more possibilities," he concluded. ●

Best Practices in Community Support

- **Combining unpaid community support with paid services helps people with disabilities interact more with their communities and live a fuller life.**
- **Many community members would be willing to provide support but are simply unaware of the needs of people with disabilities. Communicating these needs is essential in developing a strong network of community supporters.**
- **When community agencies are brought together to learn about each other, they can offer improved support through cooperation and collaboration.**

Residents Choose to Live in Just People Village

By Becky Dowling

Just People, Inc., an organization that provides services to people with developmental disabilities and mental illnesses, is currently constructing an apartment complex in Roswell, and many of our clients are planning to live there.

The Just People staff doesn't understand the controversy the apartments are causing. "Freedom of Choice" should mean just that – the people who are members of Just People have chosen our program because it meets their needs. Of our 130 consumers, 90 have chosen to move



Becky Dowling

founded Just People in 1995, after many years of working with people with disabilities. The program's design came from listening to the needs of the consumers, concerns the families had about their futures and observing the problems people with disabilities need to resolve.

into the apartments. Those who choose not to move into the complex will still receive services from Just People.

Just People clients and their families wanted to live in a place that was safe, had access to transportation, was rent controlled and was located near their friends. Many expressed they were lonely in their current apartments. When you and I look for a place to call home, we look for a place that makes it convenient for us to work, play and socialize among people we're comfortable with, is affordable and safe.

The benefits of the Just People Village lifestyle are many:

- Case managers can offer more time to individuals because most of their clients will be in the same apartment complex.

- Cookouts or social gatherings can become more spontaneous.
- Residents with no family will develop a support system of both service providers and friends.
- Residents with mental illnesses need less hospitalizations when they have immediate access to staff or friends.
- Vans provide safe transportation from 6 AM to midnight. As a result, residents are not at the mercy of MARTA or others for rides to work or social activities, fostering more independence.
- Just People consumers who currently live near other consumers and/or staff have had fewer behavioral issues because they aren't as lonely.

Our consumers want to be more independent, and they want to do things with their friends without having to coordinate with their case manager and/or families whenever they get together.

Just People residents are not isolated from the community – they work in the community at companies such as Kroger, Publix, Wal-Mart, Emory, PetSmart, TJ Maxx, Target, Just Boxes, hotels and other places.

In addition, Just People consumers socialize in the community at places like Six Flags, movies, bowling, Rendezvous, parks and more, plus we have traveled to Alaska, Hawaii, Jamaica, Florida, Tennessee, North Carolina, Seattle, Las Vegas, Bahamas, Puerto Rico and the Virgin Islands. We are planning a trip to the Panama Canal next fall. All of these activities give our consumers daily opportunities to participate in their community.

Being accepted for who you are is hard enough on everyone. Try to imagine how hard it is for people with disabilities. Everyone in this industry is trying to make a difference in the lives of people with disabilities. We are not saying the Just People Village is absolutely the way to go for everyone – what we are trying to offer our consumers are options – a choice. ●

FOUNT





Congregated Living May Reduce Community Interaction

By Trish Farnham

Groups are not always a bad thing. When a number of people share a common history, trait or interest, groups often result. We gravitate to people who "get" us. We feel safer, freer to be ourselves and more relaxed in the common experience. In a world suspicious of difference, those of us who are "different" often find solidarity with each other.

Yet, as history reveals, people who are "different" often fall victim to stereotype, alienation and bigotry. Many people have had their individual choices and freedoms restricted because they were part of a socially devalued group. People with disabilities have long suffered this experience. Even in a time of self determination, people with cognitive disabilities are rarely given true choice in how they live their lives. They must often "choose" between unsatisfactory options: "Do you want to live in this group home or that institution?" "Do you want to work cleaning toilets or washing dishes?" As providers, we neatly document these "choices" and then hide behind them.

Georgia Options does not have "clustered living," sheltered workshops or other arrangements that group people. We put incredible effort and funding into individualized staffing, so that people can build an identity broader than disability. We want a person to be known by his neighbors as "John" and not as a resident of "that home for disabled folks." We have witnessed countless connections between a person and his neighbor, her coworker or his local grocery clerk because of this individualized support.

Yet, even with these individualized opportunities, people can be lonely and in need of friends. Within Georgia Options, many people we support have built friendships with each other after meeting by coincidence. These friends have spontaneously organized parties, trips and other events that result in a very obvious grouping of people with disabilities.

So how have we made peace with these groups? How have we maintained our commitment to support people in building individual relationships in their community? The critical question we now ask ourselves is "Who is doing the grouping?" Whether groups are good or counterproductive turns on the question of REAL choice. Did a person choose to be a part of this particular cluster of people? Does the person have true opportunity to build an identity outside the group? Outside this group, what other real friends does a person have? By asking these questions, we recognize the value of these



Trish Farnham

is the Executive Director of Georgia Options. Georgia Options is an Athens-based, locally organized nonprofit organization that supports people with disabilities to live in their own homes and have typical life experiences.

friendships but push ourselves to support people in building a larger, more diverse, community for themselves.

Whether clustered living is acceptable is also answered with questions of choice. Does a person choose to be there? What other options are available? If the provider discontinues services, must a person move out of his "private" apartment that is really provider-run?

Groups can serve a purpose for all of us and therefore cannot be summarily dismissed. Yet, to prevent further social alienation of people with disabilities, we must ask ourselves hard questions about who is doing the grouping and what other real choices are available. The acceptability of the group lies in honest answers to these questions. ●

Community Connections for Parents

By Gordon O'Neill

The concept is simple – connecting parents, caregivers and self-advocates with local support and local solutions to better support families of children with disabilities in their own community.

Today, there is a growing coalition of non-profit community service organizations and governmental agencies working together to provide better localized access to information and services for the disability community across Georgia. The network is leveraging existing community-based and state-wide programs to develop better ways to provide a specific child or family with the help they need.

Local community support begins with the **First Call for Help** to Parent to Parent of Georgia, an organization that immediately starts helping families find the resources, answers and solutions to the challenges they face in advocating and caring for their child with disabilities. Parents can

expect responsive services and support from the toll free information line at 800-229-2038 or the web site, www.parenttoparentofga.org, which offer parent match capabilities and a comprehensive database for information.

In reality, most of the infrastructure is already in place to help these families, but questions remain: Where to begin? How to provide community-based solutions? How to assure access to good information?

Today, the Georgia Parent Leadership Coalition, a group of 10 community service and governmental organizations, is answering these questions.

"We are leveraging the success of the Family Connections program here in Georgia and integrating the Atlanta Alliance for Developmental Disabilities' (AADD) Partners in Policymaking, Parent to Parent database and web site, and

resources from other coalition members to create a more accessible, comprehensive solution," Lori von Schmelting, a representative of Project Bridges and a member of the coalition, said. "We are working together to better support families of children with disabilities in Georgia."

"When you contact Parent to Parent, you will find coordinators who can speak English or Spanish, and most of the staff have children with disabilities and can relate to the problems you are facing," Esther Sherberger, executive director of Parent

to Parent, said. The organization also offers two satellite offices and, as she noted, "local people always know more than what's on the computer."

"While we encourage people to use our Special Needs database and Roadmap to Services, our coordinators have more contacts and information than the web site because we had to keep it simple," she explained. "While we may email back and forth, we really want to talk to parents . . . so we can help them sort out what they really need."

Counselors are available 8 AM to 5 PM Monday through Friday to respond to information and technical requests. To provide emotional or local support, 2,000 Supporting Parents have volunteered to help other parents of children with disabilities, especially newborns, with advice and support.

When parents call for a parent match, "We try to respond to crisis situations," Sherberger said. "We try to have a Supporting Parent call back within 24 hours, but it depends on the rarity of the disability and the volunteer's schedule."

Parent to Parent's web site features an easy to understand and easy to navigate Roadmap to Services that provides helpful tips and information about local, state and national resources. In

"While we may email back and forth, we really want to talk to parents . . . so we can help them sort out what they really need."

Parent to Parent
and the Coalition's

First Call For Help

www.parenttoparentofga.org
info@parenttoparentofga.org
800-229-2038 in Georgia
Fax: 770-458-4091



Graphic design and illustration services for the Roadmap volunteered by Richard Linden.

addition, the site offers general information in such areas as diagnosis and intervention, articles and information, public education, jobs, housing, advocacy and law, insurance and care plans, childcare, recreation and camps.

Navigators for Local Communities

To improve service in local communities, the coalition wants to create a statewide network of Navigators. The Navigator is one person or part of a team that serves as a local point of contact in communities across the state to steer people dealing with disability issues to the right resources and contacts. "They will know who to call on the local level – some communities in Georgia already have local support in place," said von Schmeling, a parent of a 10-year-old child with Down syndrome. "Navigators are communicators – they connect people to where they need to go on a local basis."

Family Connections, a statewide community-based support organization, already has a growing network of community "collaborators" that focus on local solutions to many of the same issues that families with children with disabilities face – childcare, education, legal challenges and more.

"While Family Connections is not focused on disability issues, they have a network that shares the same vision and values as the coalition," von

Schmeling said. "We continue working on how Navigators for the disability community interface with and leverage the strength of the Family Connections network to provide the best services possible in local communities for all families – inclusive of families of children with disabilities."

Whether recruiting new Navigators or integrating local disability expertise into the Family Connections network, the coalition hopes to realize its goal of local support in every community in the state over the next several years.

"Our Partners in Policymaking program is a leadership and advocacy training program with over 384 graduates in Georgia," Rita Young, education coordinator for AADD, said. "We need to identify graduates of the leadership program across the state who have the time and are willing to give back to their community."

Graduates of Partners in Policymaking already have the leadership training and the tools needed to become part of the Navigator teams, she explained. "Partners in Policymaking is about giving folks the tools and resources they need to help improve their lives . . . then to effect change on the federal and local level."

Whether Family Connections 'Collaborators,' graduates from Partners in Policymaking or new volunteers, the success of the Navigator teams depends on training that includes

Parent to Parent's web site features an easy to understand and easy to navigate Roadmap to Services that provides helpful tips and information about local, state and national resources.

"We hope to start piloting Navigator teams by early next year and have identified at least four locations around the state."

Parent Leadership Coalition

- *Babies Can't Wait/Project SCEIs Parent Educators*
- *Department of Education, Division for Exceptional Students*
- *Family Connections*
- *Georgia Advocacy Office*
- *Governor's Council on Developmental Disabilities (GCDD)*
- *Institute for Human Development and Disability*
- *Parent to Parent of Georgia*
- *Parents Educating Parents and Professionals for All Children*
- *Partners in Policymaking, Atlanta Alliance on Developmental Disabilities*
- *Project Bridges*

The Georgia Parent Leadership Coalition is currently made up of 10 nonprofit community service organizations and governmental agencies working together to provide better localized access to information and services for the disability community across the state.

community believe that access and choice should be based on parental expertise – and that requires access to accurate information and resources. The Parent to Parent web site, its database and parent match are all valuable resources that provide the knowledge and information a parent needs to help choose the best path for their family and child regarding education, support, medical attention, jobs and community living.

Public education plays a large role in the life of children. The Parent Mentor Partnership, a coordinated effort between the Division for Exceptional Students, Georgia Department of Education (DOE) and local school systems, is dedicated to helping parents develop positive partnerships with their local schools. Patti Solomon, parent liaison for the Georgia DOE, believes parents need a “clear understanding of the law to best advocate on behalf of their particular child to be equal partners in making choices in their schools or their community.”

For successful outcomes, the coalition believes children and young adults are more successful when families and professionals work together. Combined with family support in local, inclusive communities, the coalition and organizations that make up the coalition are better able to respond to the diverse needs of Georgia's families.

using the Parent to Parent Special Needs database and web site.

“The training must deal with confidentiality issues, accepting and respecting that every family is different – Parent to Parent does a good job training volunteers in remaining non-judgmental,” von Schmeling said. “We hope to start piloting Navigator teams by early next year and have identified at least four potential locations around the state, based on the success of Family Connections, to start them.”

Knowledge, Information, Contacts

The Parent Leadership Coalition and disability

“The bottom line for our children is that they grow up in the community and go to school where people know them and care about them – we build communities around our children.” von Schmeling explained. “Then, our local communities will best know how to support them and their families – then our children will be safe and valued members of their community.”

The Coalition

The emergence of the Parent Leadership Coalition demonstrates the power of a small group that is clearly focused on what is best for children and improving outcomes. Solomon, a mother of an 18-year-old high school student with autism, explained that as a group, the coalition is “very focused on communications on the local level. We want to make people aware – to know what services are available and how to find them.”

While recognizing the great strides being made by the coalition, Solomon looks back and notes, “We were all operating in a vacuum. A year and a half ago, we started talking to each other – we started with four or five organizations . . . working away, trying to get it done . . . and we asked what can we do? How can we work together? How can we share resources?”

As a group, they are focused on “making it all work together” – healthcare, education, government services and local nonprofit organizations. With Parent to Parent as the first point of contact and Navigators in communities across the state, they believe the system can work better – a lot better.

“As a group we are all working together and finally doing something that works,” Solomon said. “We want to become one organization supporting people and families inclusive of those families who have children with disabilities.”

Rita Young explained it this way, “It's all about collaboration. It's about people coming together, understanding how they can work together to solve their own challenges.”

While there is a great deal of excitement and a lot has been accomplished, Solomon concluded, “So much still has to happen.” ●

“It's all about collaboration. It's about people coming together, understanding how they can work together to solve their own challenges.”

Peer Support Fosters Independence

By Valerie Smith Buxton

After her accident, Cheryl Laurendeau was afraid to leave her home because she didn't feel comfortable with her wheelchair.

"I was scared when I first became disabled," she revealed.

But all that changed when she turned to a peer supporter. "My first peer supporter invited me to an Independent Living Center. I was afraid because I'd have to ride MARTA, but it was easy. Nobody could have told me that except someone who'd been through it," she said.

Since that first breakthrough, Laurendeau, a member of the Governor's Council on Developmental Disabilities (GCDD) has been dedicated to helping other people with disabilities become more independent, and is now a facilitator for a new program that helps train peer supporters, the Georgia Peer Support Project.

"Our goals for the project are to strengthen peer support; make it available to more people; and, help peer support be recognized as a skill that can be paid for by Medicaid," explained Linda Pogue, of disABILITY LINK, who provides administrative support and coordination to the project.

The two-pronged project, organized by the GCDD, was funded with the Department of Human Resource's Division of Mental Health, Developmental Disabilities and Addictive Disease's Real Choice Systems Change Grant received through the Centers for Medicare and

Medicaid Services. The first step was developing a formal curriculum. While the process was facilitated by Linda Kendall Fields, who had worked with Georgia's Department of Community Health developing aging and disability services and policies, the bulk of the training curriculum was developed by people with disabilities.

"There's not much published for peer support training," Kendall Fields said. "So the curriculum committee brought the experiences they had in peer supporting at their Independent Living Centers."

Kendall Fields organized the information, then the committee broke into pairs to review and edit it, and the curriculum was approved. "What's unique about our curriculum is that we worked hard to ensure the training and materials are available to everyone. We paid attention to how the manuals were physically put together.

For example, we used large print so there would be universal ease in using the materials," she said. "We also made sure the curriculum fit to various learning styles."

The training sessions are three days long, with the first day focused on providing background information on peer support and defining why it is important. Disability etiquette is covered so trainees learn about issues that affect people with different disabilities than their own.

"Nobody can teach a person with a disability



Garrick Scott (peer supporter) mentors Rann Akers.

“
**Nobody can
teach a person with
a disability how to
live life better than
another person with
a disability.**
”

Peer Support Skill Sets

The training focuses on seven skill sets, which include:

1

Listening / Communicating: “This is the most important skill to master. It’s hard for any person to be patient and do a good job listening,” Kendall Fields revealed. “You have to let the individual receiving support lead the way – you help them solve problems, you don’t do it for them.”

2

Understanding Self Directed Care: This skill set focuses on the consumer’s circle of support and self determination. Participants receive training on how to direct their own supports.

3

Helping People Find Community Services: Here, participants learn about all the resources that are available to assist people with disabilities. They also learn to network with each other to identify services they may not know about, in an effort to best serve the consumer.

4

Helping People with Employment Issues: Finding employment is a big issue for consumers, and peer supporters are trained to help them learn interview skills, find job resources, keep their benefits and more.

5

Developing Relationships: Peer supporters learn how to help people with disabilities meet new friends and learn the characteristics of forming relationships, including romantic relationships. “Sex is a big issue for people with disabilities, and it’s an issue that’s been previously ignored,” Kendall Fields said. “We need to have that intimacy like everyone else,” Laurendeau explained.

6

Creating Boundaries: During this part of the training, peer supporters learn what lines they need to draw, how to deal with inappropriate behavior and how to develop a trusting relationship with their client.

7

Knowing When to Refer or Dealing with a Crisis: The signs of abuse, depression and suicide are presented so supporters know when they need to seek additional help for their client.



Peer supporter Samuel Mitchell (r) shares the Martin Luther King, Jr. Center with fellow advocates.

how to live life better than another person with a disability,” Laurendeau said.

Informally, peer supporters learn other skills during the training. “They help each other handle the stress and know they can contact each other,” Kendall Fields said. Training sessions help participants build a network of other peer supporters with whom they can share information and experiences, as well.

Also, because participants represent a broad spectrum of disabilities, they are exposed to different disabilities they may not know much about.

According to Laurendeau, “There’s no support like the support you get from people who are going through the same thing. Someone has to show people with disabilities they can be independent, and that should be someone who is independent.

“Because of our own circumstances, we had to find more innovative ways to do things, and we can share that,” she said.

Pogue said the peer support relationship can be a critical step for people with disabilities.

“It might start out that someone needs help figuring out their SSI benefits. The peer supporter connects them with the right phone numbers. They are there to guide and support people, not do it for them. It helps the person with a disability live a fuller life and take risks.”

“Peer supporters are going to be an essential part of self determination. They have a background in finding resources and can help individuals do what they want to do.”

Laurendeau agreed. “Family and friends can be overprotective and make you into an invalid. We’re dedicated to helping people become as



Participants in the Atlanta peer support training class provided feedback to help shape the curriculum for future classes.

independent as they can," she said.

Because of the Supreme Court's Olmstead Decision that mandates people who are able and want to live on their own cannot be kept in nursing facilities, more Georgians are transitioning to their communities from nursing homes, and the need for trained peer support is growing.

Currently, peer support can be accessed through the majority of Georgia's Independent Living Centers, and most supporters are volunteers. Those who participate in the Peer Support Project are certified after the training, and project organizers hope this increased professionalism will lead to paid peer supporter positions, funded eventually by Medicaid.

The training is available to new and current peer supporters. "It's a good course for people starting out, and it's a good opportunity to go back over the basics for those who are already supporters," Laurendeau said.

Margo Waters, who took the seminar in Atlanta, agreed. "Everything was great about the training. I really liked the discussions and the role playing at the end of each session. I learned to listen more and the importance of building a circle of support so people with disabilities can accomplish their goals."

Waters, who has multiple sclerosis, feels the program will be positive for people with disabilities in Georgia. "I wish I'd had someone to point me in the right direction when I moved here," she said.

While Waters is not a formal peer supporter at this time, she uses what she's learned in the class almost daily in her job at disABILITY LINK. "It's a continuous thing - we support one another every day," she said.

Best Practices in Peer Support

- **Peer supporters should be trained with a curriculum developed by people with disabilities, and taught by people with disabilities who know what issues and resources are of importance to the disability community.**
- **Peer supporters should be compensated for their services.**
- **More peer supporters should be trained and available throughout Georgia to ensure everyone with a disability who wants support receives it.**
- **Building a peer supporter network allows supporters to share resources, information and experiences.**

Kendall Fields is proud of her involvement with the Peer Support Project. "It's very fulfilling to witness both what I see from training participants, as well as leadership with the facilitators rising to a new place of excellence by teaching," she said.

"Peer supporters are going to be an essential part of self determination. They have a background in finding resources and can help individuals do what they want to do," Laurendeau said.

For more information on receiving peer support, contact one of Georgia's Independent Living Centers. (See the resources section in this issue on page 28.) To participate in peer support training, contact Linda Pogue at disABILITY LINK at 404-687-8890, extension 114. ●

Georgia Peer Support Project facilitator Cheryl Laurendeau is dedicated to helping others become more independent.



Wide Open Spaces

By Christina Carlton

EasyLiving Home Standards

- **Easy Access** – a step-free entrance to the central living area of a home
- **Easy Passage** – broader doorways
- **Easy Use** – a bedroom, entertainment area, kitchen and a full bathroom with sufficient maneuvering space for a wheelchair on the main floor

EasyLiving Home™ (ELH) program encourages easy access to living spaces for everyone. The ELH program is built on the collaboration of leaders in the housing industry, nonprofit organizations, and disability advocacy groups.

Currently, the ELH program is getting such a positive response from builders and buyers that it is ready to begin replicating. "We've had several inquiries from other states," said Mettina van der Veen, the replication project director.

September 18-20, the organization held a Replication Summit in Atlanta for organizations exploring the possibility of an ELH program in their states. Attendees from Maryland, Delaware, New Hampshire, Colorado, Tennessee and California came to review the program's certification materials, organizational structures and completed projects.

Carol Stamatakis of the New Hampshire Developmental Disabilities Council (NHDDC) saw a short presentation on EasyLiving Homes in early June and thought it looked like a worthwhile project, so she brought a team to the summit, including NHDDC Council member Bob Elliott and architect Karl McKinster. "We think New Hampshire might be a suitable state for replication," she said.

McKinster was impressed by what he saw. "I

A Contrast to Compact Housing

Builder Roy Wendt and Mark Schlossberg of Maryland tour one of Wendt's EasyLiving Homes in Snellville.

Parallel parking – a funny sight to behold in the city. First the car goes in backward. Then pulls out and goes in forward. Then inches backward and forward a few more times. The driver, conquered, finally realizes the spot is too small and drives away in search of a larger, less gratifying spot.

Thankfully, this is a laughable matter. However, many people in wheelchairs can't fit into countless places – and it's not funny. Often, people with disabilities experience this frustration looking for their own homes, and encounter many houses that aren't user-friendly. Also, it's difficult to visit friends and neighbors due to hard-to-navigate steps, small door frames and inaccessible bathrooms.

About five years ago, a coalition of organizations poured the foundation to address these accessibility issues in Georgia. Today, the

Rhonda Buckley, Georgia's first EasyLiving Home purchaser, stands at her step-free entrance and welcomes summit participants to tour her home.





Wider doorways allow people who use wheelchairs to navigate the home more easily.

think what they're doing is great. Everyone should be building homes this way across the United States," he said. "Architects can easily design these principles into their plans."

Attendees visited Georgia's first EasyLiving Home, owned by Rhonda Buckley, who does not have a disability, but who appreciates the ELH features. "I didn't even notice the doors being wider, but I really appreciated them when I hurt my foot after I moved in and had to use crutches and wear a cast," Buckley said.

Roy Wendt of Wendt Builders, Inc., built Buckley's house and is working on a similar development in which each home is certified an ELH home. "People keep saying this makes so much sense because it allows people to age in place," he said.

"Everyone should be building homes this way across the United States. Architects can easily design these principles into their plans."

After touring the four ELH certified homes, Stamatakis said, "I wouldn't have noticed the wider door. It made me wonder why this isn't standard."

Susan Mack, an occupational therapist from California said, "This is good design for everyone. There's no downside. Ability is on a continuum, and the universal design accommodates diversity in human function and changes in life," she said.

Mack pointed out several features that would be generally helpful. "The ergonomic lever door handle makes your life so much easier – if you have a load of groceries, you can open the door with your elbow," she said.

While the EasyLiving Home standards do not cover specific modifications such as lower heating/air conditioning controls, these modifications are relatively easy and inexpensive to complete. Expensive structural changes such as widening

EasyLiving Homes Benefit Everyone

- Homes are accessible to visitors who have disabilities.
- People have diverse abilities throughout their lives and may benefit from wider doorways if they have an injury.
- The value of the home increases.
- Zero step entryways are easier for moms pushing baby strollers, not just someone using a wheelchair.

doorways or adding ramps are not necessary on homes that meet EasyLiving Homes criteria.

The homes on the tour ranged in price from \$189,000 - \$300,000, but van der Veen said less expensive homes are being certified, as well. "In Camilla, GA, we just certified eight Housing Authority homes that are selling for \$80,000," she said. She also noted that all new Habitat for Humanity homes in Valdosta are now being built to EasyLiving Home standards.

With the interest shown by summit attendees, van der Veen hopes the ELH program will expand to at least two other states next year and ultimately, the EasyLiving Home program will go national.

The key is to ensure disability advocates work with builders so each can educate the other on the issues. "That's the only way we can truly understand how to do this right – the builders understand why it is important to add certain features, and it's important for advocacy groups to understand why the building industry may have issues with certain designs that make houses accessible," reiterated van der Veen. ●

The key is to ensure disability advocates work with builders so each can educate the other on the issues.



Alicia Cone of Tennessee measures to make sure the area in front of the commode is at least 30" x 48" (above).



Melinda van der Veen and Schlossberg check out the space available in the bathroom (left).



China –

An Eye-Opening Experience!

By Pat Nobbie, D.P.A.

The Winter edition of *Making a Difference* described my opportunity to travel to China as a member of the steering committee for a joint Chinese-U.S. Conference on Educating Children with Special Needs. Visiting China was a more inspiring and rewarding experience than I had imagined.



Chinese and American attendees hope to learn from each other (top photo).

In China, children with disabilities are not segregated into separate classrooms (bottom photo).

Eighty-nine Americans departed from Los Angeles after an intensive orientation session that united the group and set our focus. Our first day, we visited a neighborhood elementary school, and spent time with the head mistress and her staff. We visited a

second grade class with 18 children, one of whom has disabilities who was fully included. Although we didn't understand a word, it was very engaging. The kids loved getting their pictures taken, and tried to speak to us with their few words of English.

We spent the next three days at Beijing Normal University, China's premier teaching college. Organizing any conference is a challenge, but imagine doing it in two languages! The conference contained several strands: law and policy, early childhood, teacher preparation and training, assistive technology and community integration. An American and a Chinese moderated each strand, and a set of translators, who were students at the university, assisted us. We alternated between American and Chinese papers, which were translated by paragraph.

The first day was exhausting, but by the second day, we had our rhythm down, and began some interesting cross-language discussions. I moderated the community integration strand, which included papers on international inclusion

research, theory of change evaluation, direct support staff training, community safety training for students with developmental disabilities, community-based classroom and parent programs for students with severe disabilities, Chinese braille system reform and the history of self determination, among others.

Our Chinese counterparts are struggling with many of the same ideas and challenges as we are – their task is much more daunting because of the sheer numbers of children with disabilities. By their last good count, in 1984, 60 million children had identified disabilities – but this is NOT including learning disabilities, autism or emotional behavioral disabilities, which are only beginning to be recognized as legitimate categories.

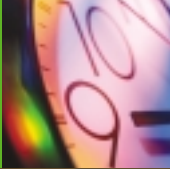
China really impressed me. Each site was more beautiful than the one before, and it amazed me how old everything was. The people were friendly and helpful. Traffic was unbelievably hair-raising, and the air pollution was dismaying and really gave me pause in a very global sense. We all have to take care of this problem, not just the Chinese, who are only beginning to enjoy the fruits of economic growth and development. Beijing was building to prepare for the Olympics, and vendors were even selling Beijing 2008 hats and T-shirts!

“Our Chinese counterparts are struggling with many of the same ideas and challenges as we are – their task is much more daunting because of the sheer numbers of children with disabilities.”

Western thought. I felt comfortable there, and I hope to keep up an international dialogue with my colleagues until I visit again. ●

“By their last good count, in 1984, 60 million (Chinese) children had identified disabilities – but this is NOT including learning disabilities, autism or emotional behavioral disabilities.”

In the architecture, painting, music and interactions with people, I really began to appreciate the differences between Eastern and



OCTOBER

October 21

**A Taste Of Inspiration:
A Wine Tasting Event
benefiting Special Olympics
of Georgia**

Atlanta, GA, 770-414-9390
www.specialolympicsga.org

October 25-28

**43rd Annual Meeting &
Exposition: Sponsored by the
American Assoc. of Homes
& Services for the Aging**

Nashville, TN, 202-508-9434
Email: faculty@aahsa.org
www.aahsa.org

October 27-29

**Touch the Future/Transition
Conference & Expo 2004**

Augusta, GA, 800-497-8665
TDD: 1-866-373-7778
www.gatfl.org

October 28

**State Interagency
Coordinating Council**

Athens, GA, 404-657-2726

NOVEMBER

November 3-6

**International Dyslexia
Assoc. Conference**

Philadelphia, PA, www.interdys.org

November 5

**13th Annual Consumer
Rights Litigation Conference**

National Consumer Law Center
Boston, MA, 202-898-2578
Email: cwellons@nasua.org

November 7

**Down Syndrome Association
of Atlanta Fall Festival &
Carnival**

Madison, GA
Shere Owens at 770-495-6396
www.down-syndrome-atlanta.org

November 9-12

**7th Annual Accessing
Higher Ground's "Assistive
Technology and Accessible
Media in Higher Education"**

Boulder, CO
www.colorado.edu/ATconference

November 12-14

**2004 Expo and Workshops
"Prime Time Living/
Living the Senior Life"**

Smyrna, GA
Melanie D. Jackson, 404-344-1425,
Melanie@livingtheseniorlife.com
Matthew Malok at 404-657-5348

November 14-17

**11th Annual Native
American Vocational
Rehabilitation Conference**

Seattle, WA, Tammi Olson or
John McClure at 888-377-0100
Email: tammi.olson@www.edu or
john.mcclure@www.edu

November 17-19

**NASDDDS 2004
Annual Meeting**

Alexandria, VA, 703-683-4202

November 17-20

TASH Conference

Reno, Nevada
www.tash.org/2004reno/

November 18

Aging for All Symposium

Atlanta, GA, Dave Blanchard at
404-881-9777 x215
Email: info@agingforall.com
www.agingforall.com

November 19

**Rosalynn Carter Institute
"Creating Caring Caregivers
Conference"**

Atlanta, GA, Terry Elder at 229-931-
2791, Email: telder@rci.gsw.edu
<http://rci.gsw.edu/home-pc.htm>

UPCOMING CONFERENCES

November 17-20

TASH Conference

Known for pioneering strategies and blazing trails towards inclusive lives for people with disabilities and their families, this international conference brings together several hundred presenters and features over 250 breakout sessions, exhibits, discussions and much more.

November 19

"Creating Caring Caregiving Networks"

The Rosalynn Carter Institute for Caregiving will host its first statewide conference at the Carter Presidential Center in Atlanta, featuring remarks from former First Lady Rosalynn Carter and Josefina G. Carbonell, assistant secretary for Aging, U.S. Administration on Aging.

November 19-23

**57th Annual GSA
Scientific Meeting**

Washington, DC
Email: geron@geron.org
www.geron.org

November 22

**Down Syndrome Association
of Atlanta Golf Tournament**

Country Club of the South
404-320-3233
Email: golf_tournament@down-syndrome-atlanta.org

December 5-12

Hartford Ski Spectacular

**Learn to Ski and Learn to Race for
anyone with a physical disability**
Breckenridge, CO, 301-217-9840
Email: events@dsusa.org
www.dsusa.org

December 15-17

**Southeast DBTAC's Annual
Regional Conference**

Atlanta, GA
www.sedbtac.org

DECEMBER

December 2-3

**Easter Seals Project
ACTION People On The
Move – Using All
Transportation Options
(ADA and Beyond ...)**

Charleston, SC, 800-659-6428
projectaction@easterseals.com
www.projectaction.org

JANUARY

January 13-14 (tentative)

GCDD Quarterly Meeting
Atlanta, GA, 404-657-2126
www.gcdd.org

January 19-22

**Assistive Technology
Industry Association
Conference and Exhibition**

Orlando, FL, 877-OUR-ATIA
www.ATIA.org

Send in your
organization's
events to val@oneillcommunications.com
to be added to the
calendar!



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

Governor's Council on Developmental Disabilities (GCDD)

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

State Government

General Information
www.georgia.gov

Georgia General Assembly
www.legis.state.ga.us/

Georgia House of Representatives
www.legis.state.ga.us/legis/2003_04/house/index.htm

Georgia Senate
www.legis.state.ga.us/legis/2003_04/senate/index.htm

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

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



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Accessible Homes

EasyLiving Home^{cm}
www.easylivinghome.org
770-270-1611

Concrete Change
www.ConcreteChange.org

Community Support

Chatham-Savannah Citizen Advocacy
912-236-5798

Dalton Family Support Council
706-272-7919

Dougherty For Children
www.dou4kids.org, 229-430-6327

Georgia's Family Connection Partnership
www.gafcp.org, 404-527-7394

Georgia Department of Human Resources (DHR) Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD)
www2.state.ga.us/departments/dhr/mhmrsa/
Community Service Boards

North Region: 800-646-7721
Metro Atlanta: 770-414-3093
West Central: 706-568-5281
Central Region: 478-274-7912
East Central: 706-667-4833
Southwest Region: 229-430-3017
Southeast Region: 912-651-0964



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Family Support

Parent to Parent of Georgia
www.parenttoparentofga.org
Central Office: 770-451-5484
or 800-229-2038
Middle Georgia: 478-934-3694
Southeast: 912-489-1904

Parent to Parent Advisors
Augusta: 706-721-5160
Valdosta: 229-599-0036

Spanish Statewide Project Coordinators
770-451-5484, x 230 or x 227

Spanish Parent Leaders
Clayton County: 678-596-6716
Cobb County: 770-509-1067
DeKalb County: 770-492-9974
Hall County: 678-887-7792
Whitfield County: 770-451-5484
or 800-229-2038



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New Faces of GA Disability Policy

Georgia Department of Human Resources (DHR)
www2.state.ga.us/Departments/DHR/, 404-651-5980

Division of Mental Health, Developmental Disabilities and Addictive Diseases
www2.state.ga.us/departments/dhr/mhmrsa/
404-657-2252



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Peer Support

Statewide Independent Living Council of Georgia
www.silcga.org
770-270-6860, TTY: 770-270-5671
Toll Free: 888-288-9780

Access Center for Independent Living
www.access4il.org
770-534-6626

BAIN (Bainbridge Advocacy Individual Network)
229-246-0150

Disability Connections
478-741-1425

disABILITY LINK
www.disabilitylink.org
404-687-8890

disABILITY LINK – Northwest
706-314-0008

LIFE (Living Independence for Everyone)
www.lifecil.com
912-920-2314 or 800-948-4824

Multiple Choices
www.multiplechoices.org
706-549-1020

Walton Options for Independent Living
www.waltonoptions.org
706-724-6262

Warrenton Satellite Office
706-465-1148



Understanding and Communicating Key to Quality Health Care for People with Disabilities

by Karen Green McGowan, RN, CDDN

Let's face it, nobody seems to be getting any younger these days, including people with disabilities. That makes access to competent health care a pretty big deal for all of us. The ability to communicate our symptoms to the physician is critical, even if we need an interpreter to speak for us. Most everyone knows how important early diagnosis is to the outcome of an illness.

Many people with complex disabilities have been aspirating (swallowing down the wrong tube) for years. While you and I might promptly seek medical attention for this uncomfortable symptom, persons who cannot speak might only cough, or refuse to eat offending substances to let us know that something is awry. The earlier that pattern is identified and fixed, the better the person's quality and quantity of life.

The ability to keep moving as we age is an important predictor of our life expectancy. Finding a way for those with significant physical problems to alter gravity's impact on their body parts is the biggest challenge in any service. Remember, gravity is the factor that causes all of our soft tissue to gradually slide to the floor as we age. For those who don't move on their own, it is the major contributor to all kinds of deformity that can then alter the function inside of the body.

Now that the majority of individuals with significant disabilities are living outside of state-operated congregate care settings, we all have to face the sometimes daunting task of finding competent health care in a community that may judge the person on the basis of how s/he looks:

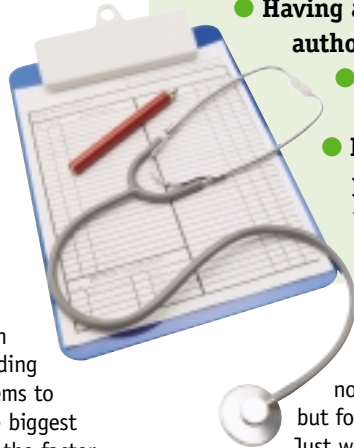
***"Mortality among people with severe cognitive impairments as well as allied medical conditions who move from institutions to the community has been the most recent issue facing states."* (Hayden, 1998)**

This has led to some fairly outrageous conclusions about where people ought to be living, namely, that institutions are somehow safer for persons with complex health care issues. Sometimes we forget that many congregate care settings were sued into doing the right thing, and that competent health care was often a direct

Effective Health Care Management

One study established that early identification of health destabilization was the major factor in reducing preventable deaths in persons with complex physical disabilities (Hodges, 1984). This study demonstrated that the following contributed significantly to effective health care management:

- Having a person with sufficient skill, opportunity and authority to implement effective health care management.
- Obtaining health care information sufficient to detect and act upon early patterns of health deterioration.
- Having adequate health care advocacy to provide to persons with any level of health risk the same care that would be provided to persons without disabilities.



result of class action litigation.

The question we need to ask, not just for people with disabilities, but for all of us, is a bit more complex.

Just what does it take to assure that all of us have access to health care that assures an adequate level of wellness and safety? Being old may determine how aggressively we are treated and so too, unfortunately, may a person's physical appearance affect these decisions. Having someone in our lives who isn't paid to care about us is another factor that can profoundly impact on decisions about health.

Most persons with profound physical and intellectual disabilities have no effective means of telling their caretakers when they do not feel well. Most community physicians and nurses have no formal training in how to assess individuals without verbal communication skills. Worse yet may be a widely held belief on the part of health care practitioners that these individuals may not have a life worth living. Withholding of treatment (widely practiced as Do Not Resuscitate) may be practiced more frequently than is appropriate.

Those persons who have learned to communicate creatively when they cannot speak can use self-injurious behavior, such as head banging or hands-in-mouth, to tell us when they have a stomach ache. What we hear is often something else. We may wind up giving these creative communicators drugs that slow down the GI tract, such as Mellaril or Thorazine because we perceive them as "behavior problems". When the person winds up with a bowel obstruction, diagnosis may be delayed because the unique form of communication is being treated rather than the root cause. ●

Karen Green McGowan, RN, CDDN

is a clinical nurse consultant who specializes in technical assistance to agencies serving persons with complex health needs. She has provided training and curriculum development to clinicians, administrators and direct care staff in identifying and removing or reducing health barriers to development for over 25 years. She has developed systems approaches to identifying health risk potential and assisted several states in the design and implementation of strategies to manage individuals in dispersed community systems.

Hayden, M.F. *Mortality Among People with Mental Retardation Living in the United States: Research Review and Policy Application*. Mental Retardation, Vol. 36, No. 5, October, 1998, p. 345.

Brehon Institute for Human Services, THE HODGES REPORT. Tallahassee, FL: January, 1984.

StraightTalk

A Sister Fights to Keep Her Brother at Home

By Jacquelyn G. Richards

My brother, Charles M. Green, age 49 (we call him Mike), and our mother have lived together for 14 years. Mike was born with developmental disabilities and was later diagnosed with schizophrenia. Our mother took care of everything for my brother, but in June 2003, everything changed. I took our mother, age 75, to the emergency room with a case of pneumonia. She was hospitalized. Based on these circumstances, my brother had to leave the comfort of his own home for the care he needed.

In anticipation of any catastrophic emergency, I had placed my brother's name on the list for respite care a year earlier. In hindsight, this saved me the most time. While working the phones to receive respite care, I had to make sure he had his medication and breakfast and was ready for the bus to attend his day program that lasted until 2:00 PM.

Each afternoon I had to prepare his lunch then give him more medication. Later, there was dinner, bath and nighttime medication. I had to do all these things to show that Mike could and should remain in his own home. I balanced this with my husband, a first grader and a three-year-old. Each day I also visited the hospital to check on my mother and speak with her doctors. After two weeks, my brother was accepted into respite care. Fortunately, the respite care providers were in our community.

Respite care was only a temporary solution. I soon found out my mother would no longer be able to care for my brother as she had in the past. This is



Charles M. Green

when the visits, phone calls and return calls started. I was told at the outset it would take a minimum of one year to get in-home support for Mike. It took about four months.

I called the regional board of the Division of Mental Health, Developmental Disabilities and Addictive Diseases, headed by Mr. Phil Harshaw. I found Mike needed a waiver to become eligible for in-home support. As we were waiting for the waiver's approval, illnesses at the regional board put decisions affecting waivers on hold for about a month. I left countless messages and talked to anyone who would listen.

Mike had been assigned a support coordinator. A support coordinator mediates between the family and the regional board. Unfortunately, support coordinators have a very heavy caseload, so I became Mike's support coordinator as well as his advocate. Mike soon received his waiver. The battle turned to Georgia Community Support Solutions, which after mounds of paperwork, located the personnel to successfully pair with my brother in his home. We could finally take a sigh of relief. Mike was allowed to remain in his own home. ●

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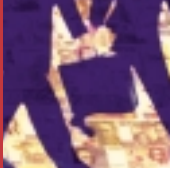
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www.ucpga.org



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- their families

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- the Children 1st Coordinator at your local health department at 800-822-2539
- Parent to Parent of Georgia at 800-229-2038 or in Atlanta at 770-451-5484

<http://health.state.ga.us/programs/specialneeds/>


 GEORGIA
 DEPARTMENT OF
 HUMAN RESOURCES
 DIVISION OF PUBLIC HEALTH
 FAMILY HEALTH BRANCH
 Office of Children with Special Needs

Babies Can't Wait Program

Who?

- Birth to age three
- With disability or developmental delay

What?

- Provides evaluation, assessment, and service coordination at no charge
- Offers early intervention services, based on an individualized Family Service Plan, using sliding fee scale

Children's Medical Services Program

Who?

- Birth to age 21
- With chronic medical condition and family income eligibility

What?

- Coordinates/provides specialty medical evaluations/treatment

High Risk Infant Follow-Up Program

Who?

- Birth to age one
- With medical conditions requiring intensive follow-up services from Public Health

What?

- Provides direct follow-up services (i.e., in-home nursing assessment and parent training)

Making a Difference

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Home Is Where the Support Is.

With a growing number of peer, family and community support initiatives, people with disabilities won't have to look as far for services. Peer supporters, pictured above, are available through Georgia's Independent Living Councils. Family Connection county collaboratives, such as Dougherty for Children in Albany, pictured at left, provide support for all families.



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