



# Breaking Ground

## Changing Labels Can Make A Difference

By Windy Smith

I am on the President's Committee on Mental Retardation (PCMR). We meet four times a year in Washington and report back to the President on the issues we are working on.

President George W. Bush has a Freedom Initiative Plan to help people who are mentally challenged to knock down barriers that keep them from having the best health care, jobs, and housing. His plan is really important to him and so are all of Americans with disabilities. He is helping us to make our lives better.

When I was first asked to serve on the PCMR I almost said no. I didn't like the name of it. I decided I wanted to serve my country and the President, but I wanted to change the name. My friends want it changed, too. My mom and dad told me that the change would probably never happen, but that I could tell other members how I felt when the committee met.

At our first meeting, in September 2002, we sat at big tables in a square, and took turns standing and telling a

little about ourselves. When it was my turn, I said I was there to help people like me. I said I wanted to change the words "mental retardation" in the committee's name to "mentally challenged," or any other word the members thought was good. People like me used to be called "mongoloid," and now the word is "Down syndrome." Changing that word has made a lot of difference in how people treat us. I think changing the word "mental retardation" will make a big, good change for a lot of people with intellectual disabilities.

I am doing my job for my friends and for people who can't speak about this like I can. ■

*Editor's note:* On May 12, the members of the PCMR voted to change the agency's name to the "President's Committee for People with Intellectual Disabilities."

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Windy Smith at her swearing in for PCMR, in Washington, D.C., with Tommy Thompson, Secretary of Health and Human Services.

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[www.breakingground.org](http://www.breakingground.org)

# Meeting the Unique Concerns of Brothers and Sisters of People with Special Needs

By Don Meyer

In the United States, over five million children have disabilities or special health concerns. Most have brothers and sisters. Throughout their lives, these brothers and sisters will share many—if not most—of the same concerns that parents of children with special needs experience. The concerns mentioned by authors, parents, and siblings themselves include:

- a lifelong and ever-changing need for information about the disability or illness;
- feelings of isolation when siblings are excluded from information available to other family members, ignored by service providers, or having no contact with peers who share their often ambivalent feelings about their siblings;
- feelings of guilt about having caused the illness or disability, or being spared having the condition;
- feelings of resentment when the child with special needs becomes the focus of the family's attention or when the child with special needs is indulged, or overprotected;
- a perceived pressure to achieve in academics, sports, or behavior;
- increased caregiving demands, especially for older sisters; and
- concerns about their role in their sibling's future.

Increasingly, opportunities experienced by these brothers and sisters are also being acknowledged. A short list of opportunities observed by parents and brothers and sisters could include:

- The insights a sibling will have on the human condition as a result of growing up with a

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Windy Smith

## Windy Smith

Windy Smith, 30, is the middle child and only daughter of David and Vicki Smith of Knoxville. She is a graduate of Farragut High School.

Ms. Smith is the winner of numerous awards, including the Knoxville News-Sentinel Citizens Award for Outstanding Students, 1996; a Special Arts contest for her self-portrait, "My Place in the World," 1996; a 100-hour pin for volunteer work at East Tennessee Children's Hospital; a silver medal in gymnastics at the International Special Olympics, 1987; and Poster Child for Citizens with Mental Retardation for the State of Tennessee, 1983.

Ms. Smith has made television spots with University of Tennessee football coach Phil Fulmer for United Way. Her picture was chosen to be in Times Square in New York City for the Down Syndrome Buddy Walk. She spoke at the Republican National Convention in August 2000 and read her letter to Governor George W. Bush on national television. She sat beside First Lady Laura Bush at the President's first State of the Union address. She published an article about her experiences in the Down Syndrome Congress magazine and urged others to vote in elections.

Ms. Smith was employed for six years at a corporate office for a retail clothing company. She is a member of a Sunday School class and at Wednesday night church group at the Baptist Church where she belongs. ■

brother or sister with special needs: Said one typically developing child of a sister: “She taught me how to love without reservation and without expectation of returned love.”

- The maturity many brothers or sisters develop as a result of successfully coping with a sibling's special needs: “I have a different outlook on life than many other people my age,” one child said. “With Jennifer, there are negatives, but there's so much more that is good.”
- The pride brothers and sisters report in their sibling's abilities: One youngster observed, “Jennifer has probably achieved more than I have. She's been through so much. She's fulfilling her potential. I'm not sure the rest of us are.”
- The loyalty brothers and sisters display toward their siblings and families: A typically developing sibling remarked, “I'm used to being kind to my brother and sister, so I'm kind to everybody else. But, I won't put up with anyone teasing Wade or Jolene.”
- The appreciation many brothers and sisters have for their good health and own families. “Living with Melissa's handicaps makes me so much more cognizant of my own blessings,” one sister said of another. “This encourages me to take advantage of my mental capacities and to take care of my healthy body.”

Within the family, siblings will likely spend more time with the child with special needs than any other person, with the exception of the child's mother. Sibling issues are lifespan issues: preschool-age siblings will grapple with issues not faced by their peers in the community and so will siblings who are senior citizens.

Below are suggestions for parents and service providers to minimize siblings' concerns and maximize their opportunities:

**1. Provide brothers and sisters with age-appropriate information.** Most brothers and sisters have a lifelong and ever-changing need for information. Parents and service providers have an obligation to provide siblings with helpful information.

**2. Provide siblings with opportunities to meet other siblings of children with special needs.**

For most parents, the thought of “going it alone,” without the benefit of knowing another parent in a similar situation, is unthinkable. Yet, this happens routinely to brothers and sisters. Sibshops and similar efforts offer siblings the same common-sense support that parents value. They let brothers and sisters know that they are not alone with their unique joys and concerns.

**3. Encourage good communication with typically developing children.**

While good communication between parent and child is important, it is especially important in families where there is a child with special needs. An evening course in active listening can help improve communication among all family members. Also, books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

**4. Encourage parents to set aside special time to spend with the typically developing children.**

Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with the typically developing child, it conveys a message that parents “are there” for them as well.

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*Meeting the Unique Concerns  
continued from page 3*

**5. Encourage parents and service providers to learn more about siblings' experiences.** Sibling panels, books, newsletters and videos are all excellent means of learning more about sibling issues. A bibliography is available from the Sibling Support Project.

**6. Encourage parents to reassure their typically developing children by planning for the future of the child with special needs.** Early in life, brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Parents should be encouraged to plan for the future and share these plans with their children. When brothers and sisters are "brought into the loop" and given the message that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. ■

**Tennessee Sibshops**  
Susie Thurman or Ginger Shirling  
Williamson County Board  
of Education  
1320 West Main Street, Suite 202  
Franklin, TN 37064-3700  
Phone: (615) 595-4708  
E-mail: [susiet1@wcs.edu](mailto:susiet1@wcs.edu) or  
[gingers@wcs.edu](mailto:gingers@wcs.edu)

Note: Our sibshop is sponsored by WCS, Franklin Special School District and The ARC. We plan to have a sibshop in August 2003

## Sibling

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and will expand to more frequent events next year. Our first groups met in December 2002 and March 2003 and were great successes! We have sibs from 6 to 18 years of age and will break out age groups as needed. We serve siblings of children with a variety of special needs.

**Sibshops at Tennessee School for the Deaf**  
Tina Prochaska  
2725 Island Home Blvd.  
Knoxville, TN 37920  
Phone/voice/TTY: (865) 579-2429  
E-mail: [tinap@tsd.k12.tn.us](mailto:tinap@tsd.k12.tn.us)

Note: We offer Sibshops for sibs ages 8-13 on a quarterly basis. We also offer Teen Sibshops for sibs ages 14 -18. All Sibshops are open to children whose siblings have any special needs. We offer a special Sibshop during TSD's Family Learning Weekend in June for youngsters with Deaf or Hard of Hearing siblings.

**Sibshops at John F. Kennedy Center for Research on Human Development**  
Vanderbilt University  
Elise McMillan  
Peabody Box 40  
230 Appleton Place  
Nashville, Tennessee 37203  
Phone: (615) 343-2540  
E-mail: [elise.mcmillan@vanderbilt.edu](mailto:elise.mcmillan@vanderbilt.edu)

Note: Our Sibshop has been a collaborative effort of several disability groups in the Nashville area. We plan to have Sibshops in fall 2003 and spring 2004. We include siblings from ages 8 to 12 and invite siblings of children with a wide variety of disabilities.

*Donald Meyer is director of The Sibling Support Project of The Arc of the US, Seattle, Washington. This article is adapted from Sibshops: Workshops for brothers and sisters of children with special needs, 1994, by Donald J. Meyer and Patricia F. Vadasy (Baltimore: Paul H. Brookes). All right reserved. A longer version which includes citations to the literature drawn on for the article is available at [www.thearc.org/siblingsupport/](http://www.thearc.org/siblingsupport/)*

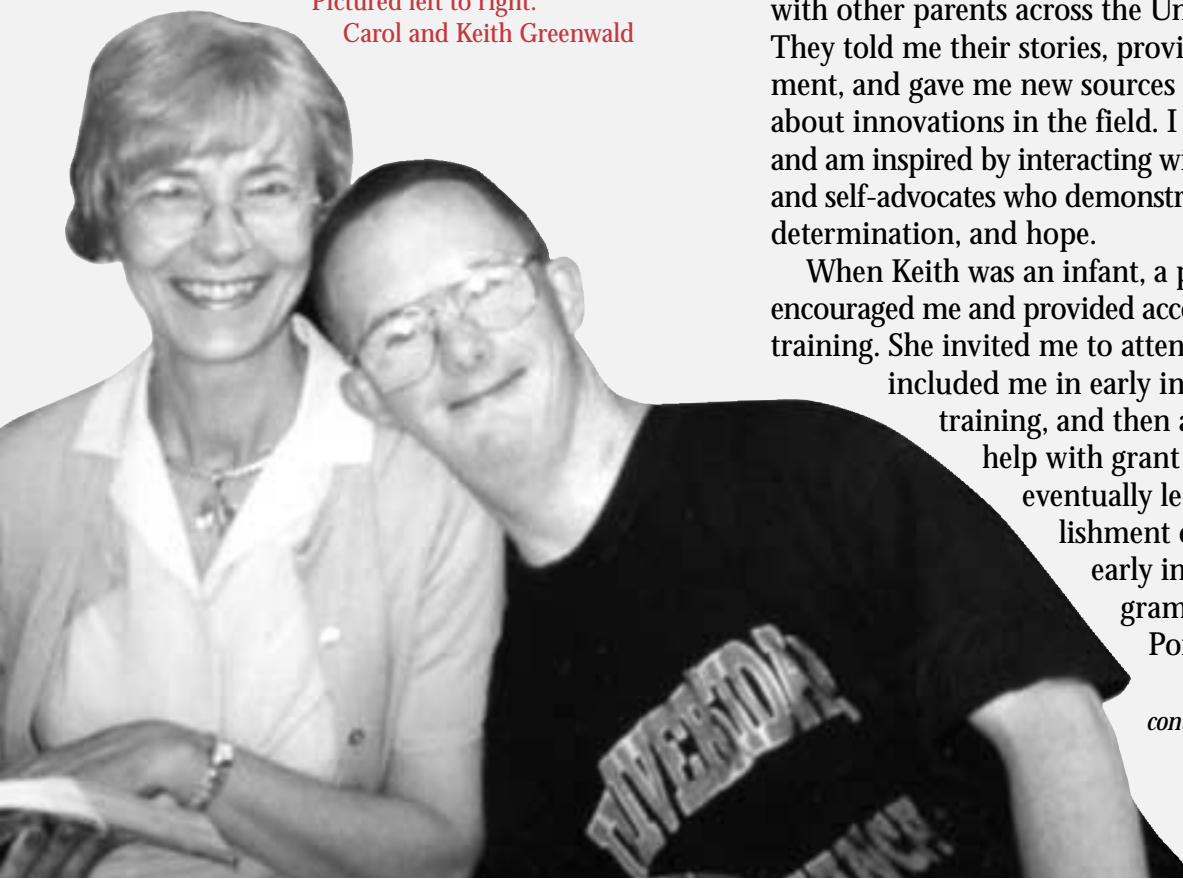
# An Interview with Carol Greenwald

By Ned Andrew Solomon

Recently, Carol Greenwald retired from her position at the Boling Center for Developmental Disabilities, where she was employed as an interdisciplinary training coordinator for seven years. In that role, Carol planned and coordinated graduate level training in neurodevelopmental disabilities for students in 11 disciplines, and participated in grant writing and grant management, program development and implementation, faculty development, and outreach training, among many other responsibilities. Throughout her long active career in the field of disabilities and disability advocacy, Carol has worn many hats, including professor, speech pathologist, and Arc chapter director. She is currently an Augmentative Communication Specialist at the Star Center in Jackson. Her *vita* lists numerous publications, grant activities, conference and in-service presentations, and memberships in professional organizations.

We decided to catch up with Carol and ask her a few questions as she embarks on the next phase of her life.

Pictured left to right:  
Carol and Keith Greenwald



**BG: Like many parents, did your career in the disability field begin when you became a parent of a child with a disability?**

**CG:** Yes, like so many people, I became interested in the disability field because of becoming the parent of a child with a disability. Being introduced to a career is one of the benefits that I have experienced from becoming Keith's mother. When Keith was born, I had never met any one to my knowledge with a disability, which also shows how much more inclusive our communities are now than they were in 1973.

**BG: When and how did you learn your advocacy skills, and was there a defining moment in this education?**

**CG:** I'm still learning! I have used and still use many resources to learn about advocacy. One of the most important resources has been other advocates, other parents, and people who have disabilities. The Down Syndrome Congress was established in Chicago just about the time Keith was born. Since my sister lived in Chicago, she was able to connect me with the parents who were members, and very soon I was connected with other parents across the United States. They told me their stories, provided encouragement, and gave me new sources of information about innovations in the field. I still learn from and am inspired by interacting with other parents and self-advocates who demonstrate persistence, determination, and hope.

When Keith was an infant, a professional encouraged me and provided access to wonderful training. She invited me to attend conferences, included me in early intervention staff training, and then asked me to help with grant writing, which eventually led to the establishment of a homebased early intervention program based on the Portage Project.

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*Carol Greenwald continued from page 5*

Much later, another defining moment for me was when I read an article in the National Arc newsletter about Partners in Policymaking™ and I decided to apply to the first class that was held in Arkansas in the late 1980s. I was the only person to attend from our section of the state, and the experience was a wonderful one.

**BG: What have been some of your biggest “fights” throughout the years?**

**CG:** The first fight was to establish an early intervention program in Northeast Arkansas. There were none at all, and I was determined that we would have access to programs that were beginning at that time in Wisconsin, Washington state, and a few other places. The first thing we had to do was to identify other families who would like to participate because all of us

were isolated from each other. A local TV station agreed to air public broadcasts of Keith and me asking for other parents who would be interested in early intervention to call. Within a few weeks we had more than a hundred names, which led to the first early intervention program in our area. It is still in

operation. The next year we added an inclusive center-based program for children under three years of age.

Another major fight occurred when Keith was in high school. During part of the day, Keith attended a regional vocational technical high school, and during the rest of the day he



had resource and typical high school classes, such as health and keyboarding. We requested that an aide assist Keith in the vocational program. The vocational school and the high school each claimed that the other program had the responsibility for funding the aide, and meanwhile Keith was in the middle. We resolved the issue eventually with several five-hour IEP meetings, an outside negotiator, and endless phone calls. An aide was hired, Keith graduated with awards from the VoTech program, and it was all worth it.

Now that Keith is an adult, “fights” are ongoing. It seems that no formal supports are made available without a struggle. Our biggest fights lie ahead of us: the waiting list, continuing access to health care, protection from harm, and maintaining access to choice and control.

**BG: What is your lifetime perspective on the ways attitudes, policies, and practices have evolved in the state, or in society, in terms of the meaningful inclusion of people with disabilities in their communities?**

**CG:** In 1973, when Keith was born, IDEA had not been passed. As a member of the Arc in our area, I visited school superintendents to tell them about the legislation when it was passed in 1975. Our Arc groups were typically met with hostility. Since I knew nothing about special education, I began to volunteer as a tutor in public school special education programs to find out what to expect for Keith. Of course, the only students in the classes were those with “mild” disabilities. There were certainly no children with Down syndrome in the classes. The children spent most of their days watching TV. I remember my dismay and concern. It was frightening, but it also provided great motivation to make changes! Even though IDEA has not brought a quality education to many, and even though the “least restrictive environment” is not a reality across school districts, special education has changed dramatically for the

We have made tremendous progress in making communities more inclusive. However, many of our laws, such as the Americans with Disabilities Act, have not been implemented, and attitudes about people with disabilities are still often negative.



better. The more recent reauthorizations of IDEA have been important in the strengthening of accountability by requiring alternative assessments. Keeping the law strong and continuing to press for full funding are extremely important for all of us. IDEA's protections are precious.

Our communities are much more accepting of people with disabilities than they were in 1973. People with any visible disabilities were rarely seen in public at that time. The rights to accommodations and access to public places were in their infancy. Institutions were considered among the best places to find services. Often they were the only place to find services. We have made tremendous progress in making communities more inclusive. However, many of our laws, such as the Americans with Disabilities Act, have not been implemented, and attitudes about people with disabilities are still often negative. We have an especially long way to go to dispel myths and low expectations related to people with cognitive disabilities. Accommodations for such "invisible" disabilities are even more frequently overlooked than those for physical disabilities.

**BG: What have been some of your greatest challenges—and your greatest successes?**

**CG:** One of my biggest challenges has been to keep a balance in my life. I enjoy working on projects, and there always seems to be a new opportunity presenting itself in our field. I need to remember to protect time for personal relationships and interests.

A different type of challenge is being Keith's parent now that he is an adult. I don't think I was very well prepared for what to expect. As my older son made the transition into adulthood, it was hard to become a "benevolent observer" of his life decisions, but I accepted my new role over time. As Keith has become an adult, he has also sought to become independent and frequently reminds me, "I'm an adult now." I often feel as if I am walking on very thin ice as I try to support Keith in expressing his preferences, making his own decisions, providing him with the information he needs to make decisions, and maintaining his safety and health.

When I think about successes, I have the most satisfaction from having been a part of bringing groups together. There was no family support group in Northeast Arkansas, and with just one other family, we were able to organize a group that grew to more than 75 families in just a few months. When we moved back to Tennessee in 1996, the Down Syndrome Association in Memphis was no longer meeting, but just a year later with a small group of parents we held the first Buddy Walk. Now the group is meeting monthly again, and more than 500 people attended the Buddy Walk last fall. With the help of the Tennessee Council on Developmental Disabilities, I was able to help establish Project DOCC at the Boling Center, a project that is bringing family members together to help train health care professionals.

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# A Whole New Way of Life

By Tim Wood

Life's challenges can be so rewarding, even in the midst of a life-or-death situation. There was a time, about two years ago, that my perspective on life was completely different from what it is today. At that time I was a 28-year-old man with a feeling of invincibility. I had recently graduated from Wichita State University with a major in Health Services Organization and Policy with a minor in Political Science. During my time at school, I served as supreme court justice of the Student Government Association, played baseball, and was part of many other school and community groups, all while working as a full-time lobbyist for the largest health care provider in Kansas. Upon graduation, I and Melanie, my wife of five years, moved back to Middle Tennessee. We had just purchased a home in Portland, and everything seemed to be falling into place.

Very soon thereafter came the devastating attack on September 11th. My wife works in the hospitality industry and was part of the major cutbacks. I was in the midst of finding a job. The job market was difficult before 9/11 and seemed almost nonexistent afterwards. We were both working interim jobs when our lives took another sudden turn. On November 4th we were blessed to learn that our family was going to have an addition in July. We were quite excited with the news but remained apprehensive due to our insurance issue. Being young and healthy we had decided to play insurance roulette. In our uncertain situation, paying for COBRA insurance quickly went to the bottom of the necessity list. My wife's insurance with her job was going to be effective in a matter of days.

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*Carol Greenwald  
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I also have to mention some of the successes Keith has had. Keith has a high school diploma, a real achievement! He has had jobs in the community since he was 15 and continues to be called the "most valuable employee." These are his successes, and I enjoy them with him. I don't think I'll feel that we have achieved real success, however, until he has reached his goal to have a place of his own. We're making progress, but it's a goal that will need the support of others.

**BG:** Even though you have retired from the Boling Center, do you have any advocacy activities planned for the future?

**CG:** One of the reasons that I left the Boling Center was to have more time for advocacy and time to support Keith in self-advocacy. Keith was 30 this year. He has been on a waiting list



*Keith and Carol Greenwald*

for community supports since he was a teenager. Somehow our elected officials and the communities in which we live have not yet placed a high enough value on making appropriate community supports available. We have got to get people's attention and share with them the incredible resources of the disability community. ■

## Things

I used to be able to do without a second thought—tie my shoes, button my shirt, smile—were for the time being impossible. I understood what it felt like to look at a part of your body willing it to move to no avail.

The very next day, November 5th, began normally, but what we did not know is that I would have a grand mal seizure, then be transported to the hospital to learn that I had a golf-ball size lesion on the right frontal lobe of my brain. Thankfully, my wife was home at the time and was able to call the ambulance. I needed surgery to save my life and that was the bottom line. Fortunately for the Wood family, TennCare had open enrollment, allowing me to receive the operation.

On November 20, I underwent a craniotomy. Because the tumor was cancerous and had infiltrated the eloquent brain tissue, the surgeon was forced to remove a very small amount of the the latter, which resulted in temporary left side paralysis. I suddenly became aware of a whole new way of life. Things I used to be able to do without a second thought—tie my shoes, button my shirt, smile—were for the time being impossible. I understood what it felt like to look at a part of your body willing it to move to no avail. I received extensive physical and occupational therapy and have regained use of most of my left side. As part of my rehabilitation, I went through a complete round of radiation therapy in addition to twelve months of chemotherapy.

During that time, my mother passed away at an early age of 51. She lost a five-year battle with pulmonary fibrosis. My parents lived just north of Seattle, Washington. The two of us, being restricted from travel, longed desperately to see each other as we both faced serious health concerns. I spoke with my mother a month before she passed away, not knowing the very next day she would be intubated and would never regain consciousness.

On July 3, 2002, my beautiful daughter Cheyenna Dawn Wood was born. When I held Cheyenna in my arms for the first time I knew how my mother must have felt the day I was

born. A very close friend of mine, who is not among the most sophisticated of my friends, offered simple yet touching words as he asked me, “Tim, do you know why your mother died?” I asked, “Why?” And my friend’s response was “So you could live and Cheyenna could have her very own guardian angel.”

The past year or so of my life has been challenging, but the rewards I have reaped lead me to believe that, if given the chance, I would not change anything that has occurred. I miss my mother on a daily basis, and that will never change. However, Melanie and I are blessed by our daughter, and I see glimpses of my mother in her every day. Though I have lost some of the dexterity in my left hand, I have gained an appreciation for the disability community. What I learned through my personal challenges, I have been able to apply to my responsibilities as consumer advocate for United Cerebral Palsy of Middle Tennessee. I also consider it a great honor to be involved with Partners in Policymaking™ Leadership Institute and Tennessee Youth Leadership Forum. I must say that each and every person that I have come into contact with in the disability community has had an impact on my recovery and survival. Thank you for allowing me to share my story, and thanks for all the love and support. God Bless! ■



Tim Wood

# Meet the 2003 Youth Leadership Forum Class

By Ned Andrew Solomon

I am pleased to report that the 2003 Youth Leadership Forum class has been selected. By the time you read this, 20 stellar high school student delegates with disabilities from across the State of Tennessee will have gathered in Nashville on Vanderbilt University's campus for four days of informative activities and fun.

This is the fourth year the Forum has been held in Tennessee. The busy agenda includes presentations by local and national speakers in the disability field, small and large group discussions on leadership and a variety of disability topics, a trip downtown to tour the Capitol and meet with a member of the legislature. On the fun side are eating lunch and sharing stories with adult mentors from the community, a photography workshop, a talent show, and much mingling with new friends.

As in the past, this is an impressive group of students who have overcome challenges and barriers to make their marks in their schools, places of worship, and communities. They are Boy and Girl Scouts, nursing home volunteers, fund raisers, musical instrumentalists and choir members, athletes, artists, student government officers, tutors, equestrians, dancers, puppeteers, babysitters, and employees—just like any other cross-section of outstanding students.

A little fanfare, please, for:

Sam Allen, *Memphis*

Jami Bennett, *Elizabethton*

April Cooper, *Somerville*

Megan Johnson, *Dyer*

Lea Carignan, *Oak Ridge*

Christopher Dennis, *Smyrna*

Joy Eichler, *Erwin*

Allison Eoff, *Nashville*

Eric Ewing, *Franklin*

John Farley, *Memphis*

Joshua Gibson, *Nashville*

Erin Kestner, *Blountville*

LaQuandra Leverett, *Chattanooga*

TaShauna Mathias, *South Fulton*

Jillian Shelton, *Hixson*

Amanda Smith, *Powell*

Cory Spradlen, *Powell*

Brittany Vogt, *Jonesborough*

Robert Wilson, *Antioch*

Lakeita Yates, *Somerville* ■

**If you would like more information about YLF, or would like a delegate or volunteer staff application for the 2004 class, please contact me at:**

**Ned Andrew Solomon**

**Director, Partners in Policymaking**

**Tennessee Council on Developmental Disabilities**

**Andrew Jackson Building**

**13th Floor, Suite 1310**

**Nashville, TN 37243-0228**

**Phone: (615) 532-6556**

**E-mail: [ned.solomon@state.tn.us](mailto:ned.solomon@state.tn.us)**

It has become a tradition at *Breaking Ground* to highlight a few of the selected students, by presenting excerpts from the essays submitted with their applications. Meet the next generation of leaders and self-advocates coming to rock the boat in a community near you.

## **BY SAM ALLEN**

Traveling to Europe was a positive experience for me. England was disabled-friendly. All London taxis were wheelchair accessible, and the drivers were courteous and helpful. Paris, by contrast, was not very handicapped accessible. However, our family got around using a wheelchair accessible van we rented in England.

Being in other countries during the matches for the World Cup of soccer was interesting. Europeans get very excited over the game.



Sam Allen



Lea Carignan



Christopher Dennis

Returning home from Chicago my family and I had a negative experience. We stopped in Haiti, Missouri, late at night for gas. The gas station's bathroom was not accessible, and my wheelchair got stuck inside. The clerks on duty were not helpful, and when they called the manager at home he said, "If you got your wheelchair in the bathroom, then you can get it out!" Finally, my father had to take the hinges off the door. It really made me mad and sad that this manager and his employees were not more understanding about the challenges of being disabled. ■

**BY LEA CARIGNAN**

There are several reasons why I look forward to attending the Tennessee Youth Leadership Forum. I think it would be a great learning experience. I would like to get to know other students with the same disability as me. I would like to have a better understanding of developmental disabilities and the impact they have on others. It would be very interesting to meet with legislators. I like new settings and enjoy meeting new people.

One person who has influenced my life greatly is my sister Jenna. She plans to attend college this summer. She has set a great example for me to follow. She is strong-willed, responsible, diligent, and loyal. She is one of my best friends. I know I can talk to her about anything and she accepts me as I am. She has showed me that even if you are small you can make a difference in the world. Jenna never leaves a job unfinished. She has given me encouragement and direction for the future.

The experience that I remember most, because it happened often, was in elementary school. The teacher would assign a silent reading for the class. Everyone else would finish it but me. I would get a sick feeling in my stomach, hoping the teacher would not call on me for answers, because I had not been able to finish the assignment or fully understand it. I did not know until the 6th grade that I had a reading disability, when testing confirmed this. It was a relief to understand the problem and to learn that there were measures to help overcome it. ■

**BY CHRISTOPHER DENNIS**

My dad positively influenced my life. He died about five years ago. My dad had ADHD (Attention Deficit Hyperactivity Disorder), and I have this, too. My dad made mistakes in his life, and I don't want to repeat those mistakes. The mistakes he made were partly due to ADHD. He did not find out he had ADHD until he was in his thirties and was going to college. He did not get a lot of treatment for it. My dad's younger brother, my uncle, was diagnosed with ADHD when he was in elementary school, and so got treatment at an early age. He went to resource classes and got tutoring and occupational therapy. He also received medication. I did these things, too, and I think this made a difference. There are a lot of famous, successful people who we think had ADHD and learning disabilities, including Albert Einstein, Bill Gates, Tom Arnold, and Ozzy Osborne. I feel I can be successful, too. ■

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Meet the 2003 YLF Class continued from page 11

**BY ALLISON EOFF**

As a senior in high school, I realize our actions in everything we do affects underclassmen. I am involved with an organization called Youth Alive and Free, which is a support service for teenagers facing peer pressure. If anyone needs to talk to someone in confidence, they know they can come to me. Training to be a peer leader was a great experience because we learned many skills, including public speaking and counseling.

I feel that I have been a leader since I was a young age. I have overcome peer pressure and kept my head in the books. I taught myself how to speak (I lost my hearing before I was able to talk). I have demonstrated my leadership abilities on the softball field. As one of the captains of the team, I am expected to lead it to a state tournament. I don't like to see people give up on their goals and dreams, so I strive to help people attain them. ■

**BY JILLIAN SHELTON**

I want to attend the Tennessee Youth Leadership Forum because I wish to become more independent in my community. At this point in my life, I will soon need things that I am not used to needing, notably transportation and a job. How am I going to find such things? I am hoping that this forum will help in these areas. In addition, I do not get away from my little town of Soddy-Daisy alone that much, and I need to learn how to become independent in new environments. I would also like to meet other teens like myself, to whom I can talk and relate.

In my own school I know that I have the respect of other students. In class when I am doing my work, I look up, aware that people are staring at me. Then I hear, "How does she do that?" These classmates are referring to the Braille books and Braille-lite that I use.



Allison Eoff



Jillian Shelton



Cory Spradlen

I have gotten used to answering questions about my disability, and the more questions I answer, the more comfortable people feel around me.

–Jillian Shelton

I taught myself how to speak (I lost my hearing before I was able to talk). I don't like to see people give up on their goals and dreams, so I strive to help people attain them.

–Allison Eoff

That does not bother me. I have gotten used to answering questions about my disability, and the more questions I answer, the more comfortable people feel around me. I also find that if I make fun of myself, people see that I'm fine with my disability. I know I cannot see, and people do not need to pretend that I can. So let's say if I am walking down the hall and I run into a trashcan, I just laugh along with everyone else. I am happy, and so are all my friends. ■

#### BY CORY SPRADLEN

I would like to be involved with YLF and help get the information it offers out to others with disabilities, because I think there are so many who could benefit. There is a lot of help available but unless you are lucky enough to have counselors that really care and who will share information with you, you will never know what kinds of help exist.

I believe I was very lucky. When I entered high school my counselor, Mrs. Northern, informed me of a new technology that has completely changed my outlook on the future. She introduced me to Dr. Michael Matvey who, like me, has a reading disability. He showed me how I could order most of my classes on tapes and taught me methods for retaining the information. Most of all, he helped me to see my problem as really not a disability—just

a difference. My freshman year I had a 4.0 the first semester and a 3.8 the second semester. This year I had a 3.8 for the first semester. ■

#### BY LAKEITA YATES

I feel this forum will help me accept the fact that I have a disability and strive to overcome it. I will also get the chance to meet others with like disabilities.

I am an outspoken person who will ask a lot of needed questions. Learning as much as I can I will share the information with peers. I will not only help myself but also my friends with disabilities and our teachers and parents in our county.

My mother has influenced me a great deal. She is a strong woman to whom everyone listens. She's a woman who always gets the job done. No matter who the person is, she treats them like they are somebody. She tells her children that no matter who you are and what you do, you are here for a reason. She's a leader to me because she makes me feel important and helps build my confidence that I am an achiever. With the example of my mother, I do all the things that I try to do. ■



Lakeita Yates

*Ned Andrew*

*Solomon is director of the Partners in Policymaking™ Leadership Institute at the Tennessee Council on Developmental Disabilities.*



## YLF Graduate Helps Students Stay on Track

*By Ned Andrew Solomon*

**W**hen we were reviewing applications for last year's Tennessee Youth Leadership Forum, it was obvious to us that Amanda Crowe from Johnson City had great credentials. She was extensively involved with school and community activities, including work with The Civinettes, Health Occupations Students of America, providing food to the homeless, and the Adopt-a-Grandparent program. It was apparent that her diagnosis of dyslexia was not a significant barrier to her activities, and if anything, provided a platform for her to inform and help others. This short excerpt from her YLF application essay was a clincher, given our expectation that the leaders we train at the Forum share their skills with their peers and society at large:

“We can succeed if we make the playing field level for our diverse learning styles. No one fits into a mold. We are all unique individuals and should be treated as such. A problem with any learning disability is poor self-esteem. I want to be able to say I am dyslexic and not be embarrassed. I want to make a difference to people who have a disability and I want to help others who aren't disabled learn about us.”

As good as Amanda looked on paper, nothing prepared us for the positive impact she would have on the Forum in person. Amanda was one of the earliest students to arrive, and ironically, considering what transpired later, one of the more hesitant to get out of the car and plunge into this totally new situation. That reserve faded fast though, and before we even

realized it, Amanda had taken on the role of welcoming committee, warmly approaching each new arrival in turn, and encouraging them to join her for an informal get-acquainted session in the courtyard in front of the dorm. Amanda made each and every student—regardless of gender, age, race, type of and severity of disability—feel like they had known her for years. This opening gesture greatly influenced the cohesiveness and camaraderie of this group of students throughout the four days, and made me hope that in subsequent YLF years the courtyard gathering would “spontaneously” appear!

Amanda’s sense of community continued to grow throughout the Forum. Although Amanda made fast friends with another female student from Chattanooga, she never let that partnership exclude any of the other students. Amanda would frequently seek out those who were sitting by themselves and gently coax them into joining the group, or find a way for an activity to expand its scope so more folks could participate.

Amanda’s compassion, team approach and leadership qualities are utilized to their fullest in her participation in The Homework Club, an after school homework assistance program in Johnson City for students who are homeless and or at-risk. The Federal government qualifies students for The Club if they lack a fixed, regular, or adequate nighttime residence, so it includes children who live in shelters, share a house with another family, or live in homes without electricity and water.

“Most of the students’ parents cannot help their children with their homework because they can’t read themselves or they have to work long hours,” explains Amanda. “Some of the children have low self-esteem, and have a lot of anger built

“I like working with the kids,” says Amanda. “They are all so different in personalities, abilities and each child has his or her own struggle. I just want to help and I don't get anything but joy!”

up inside. I don't blame them! They have a difficult life. And I thought I had it bad with a learning disability. That is nothing compared to what they go through. I know what it is like to be made fun of for not understanding how to do something in school. But, I have always had a place to live and my needs supplied.”

A file full of “thank you” letters from community program directors and the principal at Science Hill High School, and newspaper articles and awards for her service-giving initiatives are gratifying enough. But Amanda understands that the important part is what she gives to the kids, and what they in turn give to her. “I like working with the kids,” says Amanda. “They are all so different in personalities, abilities and each child has his or her own struggle. I heard some of the children talk that most of the helpers just come for a while and then never come back.

The reason why those helpers come is to get hours, credits, points for classes. I just want to help and I don't get anything but joy! I love it!” ■





## Tenth Partners Class Graduates with Flying Colors

*By Ned Andrew Solomon*

**A**rmed with enhanced advocacy skills and heads and heartfuls of information about a vast array of disability-related issues, 25 individuals from all corners of the State graduated on April 26 at the downtown Nashville Doubletree Hotel. Grabbing diplomas, the graduates set off to educate and enrich their local and larger communities. As tradition dictates, friends and family members, Council Executive Director Wanda Willis and Partners Director Ned Solomon congratulated them on their accomplishments, and bid them good fortune in their future endeavors.

The graduation weekend also included a tour of the Capitol, a visit with Representative Ben West, Jr., and a multi-talented talent show. There was also an inspirational Partners in Policymaking™ wrap up by Chicago Partner's Director Ginny Cooke.

There was a significant first for the program this year. During the March session, 02-03 Partners participated in the program's premiere Mock Testimony, geared toward preparing Partners for future appearances before legislators at the State or national level. Carol Westlake from the Tennessee Disability Coalition and Tim Wood from United Cerebral Palsy of Middle Tennessee spent three hours guiding Partners in preparing testimony for and against an actual bill.

After a working dinner, Partners gave their testimonies to a "mock" panel of legislators: Michael McDonald of the Metro Election Commission, Deana Claiborne of UCP of Middle Tennessee, Jim Whaley of the Commission on Aging and Disability and former Partners director Kevin Wright, of the Tennessee Technology Access Project. After an outstanding year,

# Bargain! 2001-2002 Disability Supports and Services Directory

Because a new statewide directory for disability supports and services will be published in 2004, you have a chance to obtain one of the few remaining copies of the 2001-2002 directory at a cost of \$5 to cover mailing.

Three volumes are available: East, Middle and West regions. Each directory includes information about State agencies and community agencies that provide disability services and social service programs, as well as articles on Americans with Disabilities Act (ADA), Tennessee Family Support Program, Housing Resources in Tennessee, Individuals with Disabilities Act (IDEA), and Social Security Disability.

Please make your check payable to Vanderbilt University, indicate which regional directory you want, and mail to the address below. Questions? Call Carole Moore-Slater at 800-640-INFO (4636).

Tennessee Disability Information & Referral Office  
Vanderbilt University  
Peabody Box 40  
230 Appleton Place  
Nashville, TN 37203-5701

The Tennessee Disability Information and Referral Office is a project of the Tennessee Council on Developmental Disabilities and Vanderbilt University's John F. Kennedy Center for Research on Human Development. This office

maintains Tennessee Family Pathfinder, an Internet disability source of State and national information at [www.familypathfinder.org](http://www.familypathfinder.org). See Pathfinder's "Search for Services" to search by county and type of service all the information in the Tennessee Disability Information and Referral Office database.



it should have come as no surprise that the Partners rose to the occasion and surpassed expectations. Due to the success of the event, the Mock Testimony will now be a regular feature of the Partners program.

I am extremely proud to present the names of the graduating Partners 2002-03 class:

- Cheryl Coleman, *Crossville*
- Laura Corby, *Cordova*
- Joanne Cunningham, *Cordova*
- Sarah Davis, *Oak Ridge*
- Darrin Decker, *Murfreesboro*
- Kathleen Donaldson, *Smyrna*
- Jerome Franklin, *Nashville*
- Keith Greenwald, *Memphis*
- Anthony Harrison, *Columbia*
- Kathryn Huffman, *Collierville*

- Beverly Carol Hart, *Cordova*
  - Pamela Huber, *Kingsport*
  - Molly King, *Antioch*
  - Sandi Klink, *Memphis*
  - Donna McGaha, *Sevierville*
  - Iva McGavock, *Nashville*
  - Katherine Peatross, *Memphis*
  - Pam Rader, *Lavergne*
  - John Shouse, *Franklin*
  - Thor Spencer, *Louisville*
  - Bobby Sumpter, *Knoxville*
  - Kenneth Tonahill, *Millington*
  - Robin Welsh, *Memphis*
  - Heather Wilson, *Loudon*
  - Marsha Wilson, *Antioch*
- Watch out world! ■

# New Council Members

By Ned Andrew Solomon



The Council on Developmental Disabilities is pleased to welcome several new members from across the State. *Breaking Ground* continues to present short biographies of each of these individuals.

## Coral Getino

Coral Getino is a native of Spain and has been a resident of Knoxville since 1990. She lives with her husband Bobby, and sons Jonathan (10) and Justin (8)—who has PDD-NOS and

“an array of other labels”. Coral is a doctor in chemistry by training, former scientist, and stay-at-home mom. She also teaches Spanish at UT or provides translation/interpretation services for a variety of individuals and organizations.

Her list of community activities is extensive. She is among many other things president of HOLA HOra LATina (a Hispanic non-profit organization), a ASA-ETC board member, a 2002 Partners in Policymaking™ graduate, a member of the Knox County Schools Parent Advisory Council, and a member of NAPPE, The Arc, NADD and LINK of Knox County. She was honored at last year’s FAST (Families and Schools Together) Conference with the 2002 Wayne Parker Parent-of-the-Year Award from STEP for her extensive efforts toward the inclusion of students with disabilities.

Ms. Getino says: “I strive to ‘break down barriers’ and ‘build community’ in two worlds, Hispanics and Disability. I am very interested in education, multicultural understanding and solidarity.



Tony and Becky Smith

The world is large and there is room for all! I believe strongly that NONE of us is better than ALL of us, and that knowledge is power. What I value the most in a person is integrity, a positive attitude and a bright smile! Something I say a lot is “Hoy por tí, mañana por mí” (today I help you, tomorrow you’ll help me) and “Life is short, make it count!”

## Rebecca “Becky” Smith

At the age of eight, Becky Smith was diagnosed with Juvenile Rheumatoid Arthritis (JRA). She lives in McMinnville, and has been married for eight years to “the sweetest man, Tony.” They met in July 1994 at Camp Easter Seals.

Becky is a member of the Statewide Independent Living Council (SILC) and Advocacy for the Disabled. She is also a Sunday School teacher for 5th & 6th graders, and an independent sales representative with AVON.

Ms. Smith told *Breaking Ground*:

“What I hope to accomplish as a Council member would be to help make changes for the betterment of everyone. I feel that the decisions this Council helps make will at one time or another affect everyone. I am very honored to be chosen to this council.”

## David Duncan

David Duncan was born on July 14, 1944, in Memphis, and grew up in Martin, Weakley County. He is married to the former Nancy Anderson, who is currently librarian with the Trenton Elementary School. He and Nancy

have four children and six grandchildren.

David has had a history of epilepsy of unknown etiology that has been arrested for some time, and has a granddaughter with spina bifida.

“What I hope to accomplish as a Council member would be to help make changes for the betterment of everyone.”  
—Becky Smith

## 2003 Summer Camps



**I**t is the time of year for summer activities for children and youth with and without disabilities.

There are many summer camp opportunities in communities across Tennessee for children with all abilities including Girl Scouts, Boy Scouts, YMCA Summer Programs, Boys & Girls Clubs, and church-sponsored camps. For families looking for camp programs that serve children, youth, and/or adults with disabilities, Tennessee Family Pathfinder at [www.familypathfinder.org](http://www.familypathfinder.org) has updated information. On Pathfinder's home page select "Recreation," where

you will find information on Tennessee summer camps. ■

**If you have questions or need individualized assistance contact:**  
**Carole Moore-Slater**  
*[carole.moore-slater@vanderbilt.edu](mailto:carole.moore-slater@vanderbilt.edu)*  
**Phone: 800-640-INFO (4636)**  
**TDD: 800-273-9595**  
**Nashville area: (615) 322-8529**  
**Español: (615) 322-7830**

Pathfinder and the Tennessee Disability Information and Referral Office are projects of the Tennessee Council on Developmental Disabilities and the John F. Kennedy Center for Research on Human Development at Vanderbilt University in Nashville.

Editor: Mr. Jim Summerville  
Contributing Editor: Dr. Jan Rosemergy  
Graphic Design: Ms. Kylie Beck

### About the Council:

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of systems change.

The editor will consider for publication original contributions, including news and feature stories, short fiction, poetry, artwork, and photographs but reserves the right to edit or decline publication. Brief letters to the editor are also welcome. Opinions expressed in any published matter are the author's and not necessarily those of the Tennessee Council on Developmental Disabilities or its staff.

This free publication is produced six times a year by the John F. Kennedy Center for Research on Human Development at Vanderbilt University. Subscription requests, change of address, and submissions for possible publication should be directed to the Editor, *Breaking Ground*, Vanderbilt University, Peabody Box 40, Nashville, Tennessee 37203. Telephone (615) 322-8473 or 1-800-288-0403; TDD (615) 343-3330 or 1-800-288-3311; FAX (615) 322-8236. E-mail: [Jim.Summerville@Vanderbilt.edu](mailto:Jim.Summerville@Vanderbilt.edu)

Tennessee Department of Mental Health and Developmental Disabilities, Tennessee Council on Developmental Disabilities Grant Number 1-03999-1-0. Authorization Number 339371, July 2001. 5,600 copies. This public document was promulgated at a cost of \$.46 per copy.



David Duncan

Employed with the Tennessee Department of Human Services since 1968, David is currently serving as Field Supervisor at the Dyer County office in Dyersburg. Other activities include being a member and deacon at the First Baptist Church,

Dyersburg, and a member of the Family Support Council, C.S. Patterson Center for Crockett and Dyer Counties, and the Domestic Violence Task Force.

Mr. Duncan says:  
"An individual should be judged in light of his/her integrity, character, and the presence of or potential for quality contributions to mankind—never in light of his or her mental and/or physical limitations." ■

Breaking Ground is now on the World Wide Web: [www.breakingground.org](http://www.breakingground.org)

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*in Policymaking Leadership Institute*

**William Edington**, *Legislative Analyst*

For more information about the Council, contact the Council office at the Andrew Jackson Building

500 Deaderick Street, 13th floor, Suite 1310, Nashville, TN 37243-0228

Telephone (615) 532-6615 • TTY (615) 741-4562 • Fax (615) 532-6964

E-mail [tnddc@state.tn.us](mailto:tnddc@state.tn.us) • Web site [www.state.tn.us/cdd](http://www.state.tn.us/cdd)

Vanderbilt University  
John F. Kennedy Center  
Peabody Box 40  
230 Appleton Place  
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