

# BREAKING GROUND



## A FEW FEELINGS FROM A NEW GUIDE DOG USER



[ 4 ] 2010 YOUTH LEADERSHIP FORUM



[ 8 ] IN SUPPORT OF FAMILY SUPPORT



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Cover Photo by Lindsay Kababik

## CONTACT INFORMATION



This free publication is produced six times a year by the Vanderbilt Kennedy Center for Research on Human Development and Kent Communications Group. Subscription requests, change of address, and submissions for possible publication should be directed to: *Breaking Ground*, Council on Developmental Disabilities, 404 James Robertson Parkway, Suite 130, Nashville, TN 37243. phone: 615-532-6615.

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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.

# A FEW FEELINGS FROM A NEW GUIDE DOG USER

BY JAMES BROWN

With my guide dog dragging me around town into metaphorical rock star status, everyone seems to be interested in how it feels. For someone who has not owned a dog in almost 20 years, it is difficult to describe the attachment between me and my new pet.

So, how can I attempt to portray my experience over the past two weeks with my first guide dog? There are so many things to consider, but beyond all the really cool things he does, like finding doors, elevators, steps and leading me around faster than a speeding bullet, I have to say that the experience has been more therapeutic than I could have ever imagined. The Jewish concept of shalom, meaning peace, wholeness and completion, is the best way to describe it.

Sitting at my kitchen table a couple of weeks ago, Jason Stankoski, the instructor from Fidelco Guide Dog School, told me what the first days of training would look like. He said, "For the first five days, you are going to hold on to Jordan's leash and not let it go. Wherever he goes, you go, and, consequently, wherever you go he goes as well." And that is exactly what we did.

When I went to the bathroom, he was tagging along; when it was time for him to be relieved, I was there. We ate together, wrestled, played tug of war, went out for Mexican food and sang together at church. Well, I guess the last one was kind of more me, but anyway, there was a special relationship building between me and my pup. I was taking care of his every need. From food to grooming, he was my responsibility.

In return for my care of Jordan, he has become my eyes when we leave the security of home. I started realizing how much this would change my life as he led me around a puddle in the middle of the street. In the past, I would have no other option but to walk right through the puddle with my white cane. The next day, at one curb, he thought I was going to step out into the road into oncoming traffic, so he moved his body in front of me, shielding me from walking out into the dangerous intersection. On numerous occasions, he has scraped himself up against a wall or object so I could occupy a place of safety on the sidewalk.

Another way in which Jordan has changed my life has to do with pace. Interestingly enough, I find it too cool that I can now walk faster than almost any sighted person. Jordan will walk up behind a group of people walking at a slower pace on the sidewalk, gently nudge one of them to step aside, then hit the passing gear to zoom right by! He has become my eyes, fulfilling a physical aspect of shalom's peace and wholeness. However, Jordan has filled much more than a physical hole in my life.



Photo by Lindsay Kababik

My entire adult life I have struggled with the Christian principle of servanthood, and how to put servanthood into practice as someone with a disability. More often than not, I find myself the one being served and not the one serving. So, once every few months, I end up asking myself the same old question, how can I serve others, often finding an unsatisfactory explanation. Recently, I realized the real question I have been asking is how can I uncover the Jewish principle of shalom?

I believe I have answered at least part of that question with Jordan. My big German Shepherd puppy is totally dependent on me to take care of him. In serving him, I feel needed, which is perhaps one of humanity's most basic needs. It is a symbiotic relationship that has the potential for true oneness. Servanthood seems to be the cocoon in which the larva of shalom is transformed into a beautiful butterfly. Call it therapeutic or spiritual, but all I know is, it feels like love.

*James Brown just graduated from the Partners in Policymaking™ Leadership Institute. He lives with Jordan in Antioch.*

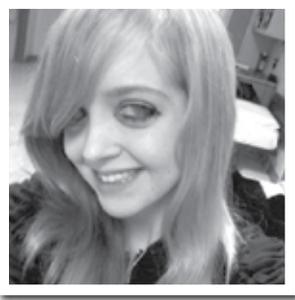
# 2010

## TENNESSEE YOUTH LEADERSHIP FORUM

### Student Delegates Speak for Themselves

In July, the **TENNESSEE YOUTH LEADERSHIP FORUM** (YLF) will again inhabit the Vanderbilt University campus. Tennessee high school students with disabilities will learn how to speak up for themselves and how to begin thinking about their plans after high school. To be accepted for the Forum, the students who applied had to complete essay questions related to their lives, disabilities and future dreams.

Please meet the 2010 YLF class, through their own words and experiences.



**SABRINA BLACK**, *Gleason*

"I feel that I am a good delegate because my disability has caused me, over the years, to shelter and hide myself from the world...From all the years of public school, I sheltered myself from the sighted world because I felt like no one really understood my disability and the help I needed in life. I feel that this would help me open up to the social aspect of life and feel accepted in any type of environment. I would love to learn about resources available and any college opportunities."



**MELISSA COSTELLO**, *Pulaski*

"I spoke at two disability conferences and talked about how far I have come with being both hearing and visually impaired. It was about Charge Syndrome, which is what I have.

"I go to Therapeutic Riding lessons and have learned how to ride on my own. I have gone to four shows for students with disabilities. I felt good because my older sister shows horses and I can do the same as her.

"People tell me I'm a natural leader. I love and enjoy people, helping out wherever I can, either with a smile or a hug."



**BLAKE-LYN GILES**, *Springfield*

"I was born deaf and did not know any sign language. It was very difficult for me at first that I didn't understand why I was not like other people. When I moved to America, there were so many opportunities out there that I was very lucky to receive an education from the deaf program. It was an amazing experience that I learned how to communicate with my hands and meet deaf people. I am proud to be deaf."

**DAVID FOLLETT**, *Huntingdon*

"I love art just as I love music. I even look at photography as art from my own

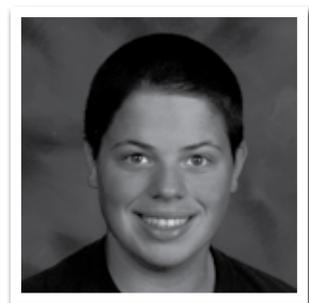
perspective. As they say, 'beauty is in the eye of the beholder'. If you think about it, art is everything around you. The shape of a computer, the design of a chair, even people you see everyday. Everything is art once you think of it that way, like God when He created us.

"After I graduate from Clarksburg I plan on joining the military as a member of the US Air Force...I haven't got a precise goal for a career, but a couple of things that I have in mind is a chiropractor or a massage therapist."

**CODI HEUER**, *Woodlawn*

"I do not view my visual impairment as a handicap, but as an opportunity to challenge myself. I have maintained passing grades while participating in extracurricular activities, most specifically cheerleading, since elementary school. I have been a cheerleader throughout my high school career, holding leadership positions as captain and co-captain. As the flier of my high school cheerleading squad, I have developed a strong trust in my team mates, because of and in spite of my visual impairment.

"As a student with visual impairments, I will bring a diverse point of view to the Tennessee Youth Leadership Forum. My interaction with the staff and students at YLF will challenge stereotypical thoughts associated with people who are visually impaired."



**DANNY JANISSE**, *Franklin*

"I am a good leader on my swim team. I like to talk to friends at school. My brother Joey, I look out for him...I have great computer skills, so I can help them get on the computer.

"I just want to be independent. I graduate Independence in 2012 with my diploma."



**HAILEY LAWSON**, *Smyrna*

"I was sitting at a lunch table with my friends, laughing and enjoying the 25 minutes we were allotted for lunch, when the conversation started to take a turn. I'm not sure how we had gotten to the topic of dating...I made an off-hand comment that I had never had a boyfriend and a friend of mine looked at me funny. 'I don't know why you have never had a boyfriend, after a while you don't notice the walker thing anymore'.

"This stumped me. Sure I didn't really notice that I had to walk with a walker or that I was short, but that was because I had grown so used to it that it was normal for me. However, I had never thought that others would stop noticing too. This revelation both shocked and warmed my heart. It felt good to know that the people didn't really notice how 'different' I was anymore. I was one of them, and I knew right then and there that I have the ability to be accepted for exactly who I was, and anyone that didn't accept me wasn't worth my time."



**HARDIN MANHEIN**, *Memphis*

"I don't like having this disability. I would rather be normal. I would like to go out

and do things with friends as much as my brother and sister do. I also care and worry about my family and friends a lot.

"I hope to go to college. I hope I can get into Vanderbilt. I hope to figure out what I want to be and get a job."



**SPENCER MAYHAN**, *Mt. Juliet*

"My experience as a person with a disability has been sad most of the time. People make fun of me and people do not understand me...I don't have a lot of friends, and most of the time I am quiet because I do not want people looking at me.

"Boy Scouts has been a huge part and impacted a majority of my life. I will have Eagle Scout less than five months from now. My scout master believed in me when I thought I was nothing, and could not perform the task at hand. He made me feel good about myself and I felt like I could do most things as long as I could talk to him."



**CHRISTOPHER MCKINNEY**, *Clinton*

"My dad has really influenced me to become a great student at my school. My dad tells me to keep trying and do my best, because there are no short cuts in life.

CONTINUED ON PAGE 6 →

"My disability is a syndrome classified as Asperger's. Asperger's is a social disorder that makes my brain different from a lot of other people...Though I am very intelligent, I lack what 'normal' people call 'common' sense...It would be very beneficial to me if you accepted me...because it might help me learn to function with people around me."



**TEVIN MURPHY**, *Jackson*

"I have some problems with my studies and working by myself but I think that the Tennessee Youth Leadership Forum can change that for me. I want to be a leader and I want to show my family that even though I have some weakness, that I'm not going to give up at all."

"I want to stay on top of things by going to college to become a teacher and coach. It's part of my dreams...Keeping kids' dreams alive is what I need."



**RYAN PITTMAN**, *Spring Hill*

"Chris Wheeler [taught me] about truth and trust, and no drugs. And be kind around the girls."

"I want to go shopping by myself, and go to the gym to exercise. Get an apartment and cook my own food. College in downtown Nashville at Vanderbilt."



**MARIA TATMAN**, *Medina*

"I was born with congenital hydrocephalus, which means water on the brain...I'm legally blind and wear glasses which help me see better...Even though I have this disability, I can still work hard to accomplish certain goals and achieve success."

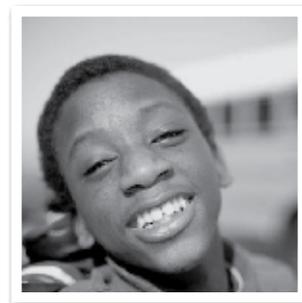
"I want to work in a nursing home where I can communicate with the elderly and read them stories. I'm also interested in putting books on tape or reading stories to younger children at the library."



**DYLAN TOOMBS**, *Murfreesboro*

"There have been many clubs at school that I would have liked to join but couldn't because of my disability. I recently took the test for the military (Navy)...and could not pass it because of my disability. It hurts my feelings to want some things and not be able to do them. I don't feel smart because of my disability."

"I would like to go [to the Forum] and be with kids like me, and to be able to [meet] new people and make new friends."



**ROBERT WELLS**, *Madison*

"My mother and I have gone to the Legislature and talked about disability issues, and I want to learn how to do this better. I like to help others and to share what I learn with others."

"I plan to go to college after I graduate from high school. After college I want to become a teacher for high school students. I want to be a role model for other students with disabilities, to show them their disability should not define them..."



For more information about the Tennessee Youth Leadership Forum, contact Ned Solomon at [ned.solomon@tn.gov](mailto:ned.solomon@tn.gov) or Parkway Towers, 404 James Robertson Parkway, Suite 130, Nashville, TN 37243-0228.

# PARTNERS 2009-10 CLASS GRADUATES

Photo by Mildred Sparkman



On Saturday, April 24<sup>th</sup>, 25 individuals graduated from the Partners in Policymaking™ Leadership Institute in a ceremony at the Sheraton Music City in Nashville. These Partners—individuals with disabilities and family members of persons with disabilities—successfully completed their seven-session Partners training, geared toward better advocating for themselves, their loved ones and others in their communities.

The Council is excited to welcome the following individuals into our ever-growing statewide Partners graduate network.

Photo by Lynette Swinford



Ned Solomon, Alyson Edwards, Wanda Willis

<b>SAM ALLEN</b> , Memphis	<b>MICHAEL MEVIS</b> , Fairview
<b>CONNIE BOWLAN</b> , Arlington	<b>JENNIFER NICHOLS</b> , Chattanooga
<b>JAMES BROWN</b> , Antioch	<b>DEBORAH PEARSON</b> , Memphis
<b>SAVANNAH DAVIS</b> , Elizabethton	<b>KIMBERLY RAINES</b> , Alamo
<b>ALYSON EDWARDS</b> , Germantown	<b>CHRISTI RICE</b> , Knoxville
<b>SHARON EDWARDS</b> , Murfreesboro	<b>MARAINA ROBERSON</b> , Memphis
<b>ALICIA FITTS</b> , Brentwood	<b>RICKY SKILLINGTON</b> , Lewisburg
<b>WINNIE FORRESTER</b> , Nashville	<b>JENNIFER THORPE</b> , Shelbyville
<b>STEVEN JOHNSON</b> , Clinton	<b>SHERYL VARNEDOE</b> , Oakland
<b>RICHARD LIKENS</b> , Smyrna	<b>TIM VOGUS</b> , Brentwood
<b>DONALD MARTIN</b> , Tullahoma	<b>PAMELA WESTON</b> , Sweetwater
<b>JANICE MARTIN</b> , Lascassas	<b>STEPHANIE YOUNG</b> , Gallatin
<b>CECILIA MELO-ROMIE</b> , Franklin	

*“Partners gave me the confidence to advocate, and know how to do it.”*

*“I believe I gained an overall view of disability that helps me see the entire picture. In other words, blindness is not the only disability, and ignoring other disabilities doesn't increase one's productivity.”*

*“The Partners program has expanded my view, knowledge and ability to advocate for positive change.”*

# IN SUPPORT OF FAMILY SUPPORT

## THE MULLINS FAMILY



Our family has been receiving family support for six or seven years now. I think it was TEIS [Tennessee Early Intervention System] that first introduced us to the program. From the first time we met Ruthelma Warf, we knew she was the person for her job. We have loved every moment with her over the years.

We are a family of six now. We have two teenage biological children, who are our main helpers, and two younger children with disabilities who we have adopted. Our third child, Mandi, has multiple disabilities and health issues, the main being spina bifida and paralysis. She was on a feeding tube, taking multiple medications and seeing several specialists for various other matters of health. It seemed as though we had appointments once a week for her for a long time. We were a bit overwhelmed and not sure of what all was there to help us out when we adopted her, but we knew she needed a family and we were the one for her.

Family Support has given us a connection to someone who cares and knows of many resources, relationships with other families going through similar issues, and some extra financial help to cover medical needs that insurance doesn't cover, like home modifications, gloves needed for certain procedures, gas to and from appointments, and educational/play supplements since Mandi cannot do many things that other children can do. Just knowing that we had something extra coming in to ease the financial part also helped to ease the mental part.

It also has helped that we could do it monthly or in one lump sum for major purchases. Home modifications require a large amount of money at one time, and being able to count on Family Support to be there for those has been a blessing to us and I know to many others as well.

Mandi has made quite a bit of progress over the past few years, but still has many things to deal with that most of the rest of us take for granted. These are things she is expected to have for the rest of her life.

We would like to thank everyone involved, from decision making, to paperwork and phone calls, etc., for making this available. Every bit of support has helped us to stay home and be Mandi's main care provider. This keeps all of her needs being met consistently, not having to expose her personal matters to complete strangers, and gives a security that she needs in her life. Family Support does make a difference in the lives of people who already have so many other struggles.

*Jason and Connie Mullins*  
Ashland City

# IN SUPPORT OF FAMILY SUPPORT

## SHIRLEY & PAM JOYCE



BY LESLIE HARTMAN

Life can throw us curve balls at a moment's notice. One minute life can be seemingly perfect; the next it seems as though the world is crashing down. This is the story of the Joyce Family.

At 16, Pam Joyce was an active teenager involved in sports and holding down a part-time job. Ms. Joyce was on her way to school when she was involved in a car wreck. The wreck resulted in a brain injury that has left Ms. Joyce immobile except for some use in her left arm and hand. She is now dependent on others to take care of her basic needs and to feed her through her a feeding tube.

Seventeen months after the wreck, her father had a stroke that left him paralyzed on his right side. After the stroke and some health problems that occurred later on, Mr. Joyce also needed some of the assistance his daughter now required. The matriarch of the family, Shirley Joyce, stayed at home to take care of her daughter and husband.

For 21 years, the Family Support Program has been providing financial support to the Joyce family. Family Support has transitioned with the family as their needs have changed. The help that Family Support gives the Joyce family allows Ms. Joyce—as well as Mr. Joyce until his death two years ago—to stay at home rather than in a nursing home, providing them with the financial assistance to have a sitter/ housekeeper to assist the family.

Without Family Support, the Joyce family would not be able to stay together in the home and the stress of taking care of both Ms. Joyce and Mr. Joyce would have been even more difficult. "I wouldn't have made it this long without the help, I know," said Shirley Joyce. "Family Support has been a great help to me."

*Leslie Hartman is a graduate of Lee University in Cleveland, Tennessee, and an intern with the Council on Developmental Disabilities.*

**TENNESSEE FAMILY SUPPORT ALLIANCE** is a grassroots organization comprised of citizens who care about the Tennessee Family Support Program, and who support it as a necessary component of Tennessee's service array for families who have loved ones with disabilities. We maintain a list of individuals who have volunteered to serve as representatives of various groups.

We applaud and thank Governor Bredesen for including continued funding for the Family Support Program in his budget for the next two fiscal years. We also thank all the families, individuals and legislators who have spoken and acted on behalf of this important program.

Membership in the Tennessee Family Support Alliance is open to everyone. The purpose is to voice endorsement of one of Tennessee's most valued and effective statewide programs serving persons of all ages with a variety of severe

disabilities, and providing essential support to their families and caregivers.

We actively solicit comments and discussion from the general public, as well as communications from individuals and families who use the program.

Visit [www.tnfamilysupport.org](http://www.tnfamilysupport.org) for more information or to contact the Alliance.

Photos by Susan Urmy



(Left to right) Curtis Peters, Leslie Price, Courtney Lanasa, Aaron Hiscutt, Alex Burke, Courtney Crussell and Brook Peters.

## SPEAKING FOR EACH OTHER

### A Youth Speakers Bureau for children with combined hearing and vision loss



BY CAROLE BARTOO

Aaron Hiscutt could easily have been left in isolation by his classmates in middle school. After all, he cannot see or hear them well, and communication is very, very difficult.

But instead, the energetic 12-year-old has many friends; he is responsible for a sign language club at school; and he is the inspiration and driving force behind a pilot of a new program guided by experts based in Vanderbilt's Division of Developmental Medicine.

Colonial Heights Middle School, in Kingsport, Tennessee, is home to the first pilot of a Youth Speakers Bureau for the Tennessee Project for Individuals with Combined Hearing and Vision

Loss, which goes by the name TREDIS. This winter, a group of Aaron's middle school classmates brought their program to the twice-annual meeting of the TREDIS Advisory Council, a group of representatives from various agencies and disciplines from across the state of Tennessee.

More on that presentation later—but first a little background on how the pilot came to be.

Aaron's family began working with the TREDIS program before he turned two. Despite near blindness, severe hearing loss and serious speech impairment, the Hiscutts wanted their son to become fully engaged in life and school. With all that love and support, Aaron had no problems all the way through elementary school. But once he turned 10, everyone recognized they would have to do something special to help Aaron navigate the perilous waters of middle school.

### LABOR OF LOVE

"Kids can be tough in middle school," said Aaron's mother, Susan Hiscutt. "TREDIS came up with a great idea, and suggested a Youth Speakers Bureau. They came up to Kingsport and helped select friends who already knew him and helped the students make this terrific video and Power Point presentation."

The presentation quickly became a labor of love for friends and initiating members of the Youth Speakers Bureau, Courtney Crussell and Leslie Price, both 11.

"We were trying to get the message that Aaron is a regular kid. He looks a little different, but he is the same as us," Leslie said.

"Aaron is so funny. He can make great funny faces, and sign language has been fun for us to learn," Courtney said.

With guidance and technical assistance from the Vanderbilt TREDIS team, Aaron and his friends completed the presentation in spring of 2009. Aaron, whose vision and hearing impairment are the result of a condition called CHARGE Syndrome, would rely on his classmates to bridge the communication gap for others who might not know how to approach Aaron.

### FIRST IMPRESSIONS OF AARON

"We worked on video interviews the students collected themselves, talking to their peers about Aaron. They each began by telling how they felt when they first met him. Even his elementary school teachers were interviewed on videotape. Each person talked about how at first they were scared and curious. Then they describe how they feel now and what advice they have for new students and teachers meeting Aaron," said Jennifer Miller, an educational consultant with TREDIS, who worked on the project.

After a few practices at churches and his elementary school, the TREDIS Youth Speakers Bureau presented the project to Aaron's new classmates—the whole middle school—right at the start of the school year.

It was a hit. The school's principal told Susan that she had rarely seen middle schoolers so attentive.

When the group was invited to present at Vanderbilt in December 2009, it was an opportunity to show what a peer youth speakers bureau can do to help Tennessee children who need transition support because of their combined vision and hearing challenges. The group Aaron and his friends presented to, the TREDIS Advisory Council, is the group that determines which programs should be promoted for funding in the future.

Aaron and about six of his classmates wore matching T-shirts and sat in front of a video screen. The video interviews played first, then, one-by-one, Aaron's classmates stood to read from cards.

***"Aaron, he is caring, cool, and a comedian."***

***"He has hearing aids and had a feeding tube until he was four."***

***"Because he has sensory issues he may need to talk around or make sounds."***

***"Aaron draws maps of his favorite places."***

***"He can find anything on Google."***

***"He is enthusiastic and giggles a lot."***

***"But he needs to know what is going on around him."***

The presentation wrapped up with Aaron waving to the crowd before a video was played about his life with CHARGE Syndrome.

The TREDIS Advisory Council was impressed. Thanks to Aaron and his remarkable friends, the TREDIS Youth Speakers Bureau will be included in the next writing of the grant, which will be up for renewal in 2012.

For more information about TREDIS-Tennessee Project for Individuals with Combined Hearing and Vision Loss visit [www.treds-deafblindproject.com](http://www.treds-deafblindproject.com).

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*Carole Bartoo, RN, is a senior information officer in News and Communication at Vanderbilt Medical Center.*

# DISABILITY, RELIGION AND SPIRITUALITY

## A SURVEY ON INCLUSION

BY LYDIA WINGO KANE

Just as full participation in school, work and community is a normal part of life, so too is participating in a faith community. Although research has focused on inclusion of people with disabilities in many of these areas, inclusion in religious communities has not been examined as fully.

To understand more about this issue, the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities conducted a survey of faith communities in Tennessee. The survey gathered the perspectives of people with disabilities and their families, members of faith communities and religious leaders.

The goal of the survey was to gain information about the experiences of people with disabilities in faith communities. Overall, we wanted to determine the different characteristics of inclusive faith communities based on the perspectives of people with disabilities and their families, religious leaders and congregants. The survey included questions about an individual's relationship with and participation in a religious community, the community's practices of including individuals with disabilities and the barriers that may prevent participation.

Over the past year, 165 respondents completed the survey. Of these, 13% were people with disabilities; 26% were faith leaders; 30% were family members of people with disabilities; and 30% were congregants. Most of the survey respondents were white (91%), Christian (90%), college-educated (86%) and female (71%).

Respondents overwhelmingly reported that most physical barriers have been eliminated at their places of worship. Entrances to buildings, gathering spaces, restrooms and classrooms are accessible. Unfortunately, a major physical barrier that remains is access to the chancel/bema/lectern/choir space/meditation space. The area in which most leadership in worship takes place is not accessible to people with physical disabilities.

Regarding another potential barrier to full inclusion, respondents reported that negative attitudes toward people with disabilities are not a problem in their faith communities. People with intellectual and physical disabilities are being welcomed and included in worship rituals and small groups. The presence of full inclusion also is reflected in the nearly 70% of people who said that their congregations do not have separate programs for people with disabilities.

When considering these findings, we noted that 60% of the respondents said that the issue of inclusion in faith communities is very important to them. This suggests that the survey respondents may belong to faith communities that they have sought out because the communities themselves are more inclusive. The importance of inclusion for the survey respondents is significant because the survey results would then be a report of this smaller subset of faith communities, rather than a random sampling representative of all faith communities.

Although physical and attitudinal barriers are being removed, people with disabilities are still being served by their congregations rather than serving with other members of their faith communities. Respondents reported that people with disabilities rarely serve in leadership roles, as ushers, choir members or worship leaders. People with disabilities are the recipients of service instead of being given the opportunity to serve as leaders. These and other practices are examples of ways in which people with disabilities are not fully included in faith communities.

Therefore, we were interested in understanding which characteristics differentiated inclusive faith communities from those that do not fully include people with disabilities. Based on survey results, we identified five characteristics that are related to inclusion of people with disabilities within faith communities. We found that more inclusive communities (1) had relationships with disability advocacy organizations; (2) portrayed people with disabilities positively; (3) were committed to social justice issues; (4) offered training related to the needs of congregants with disabilities; and (5) had leaders who supported inclusion. In contrast, the numbers of persons with disabilities within a faith community, by itself, did not translate into a religious community becoming more inclusive.

These findings will help us to develop trainings, service programs and educational materials to promote inclusion within faith communities. Results will be disseminated over disability and religion listservs. To sign up to receive the results, contact [courtney.taylor@vanderbilt.edu](mailto:courtney.taylor@vanderbilt.edu).

*Lydia Wingo Kane has a Master's of Theological Studies from Vanderbilt Divinity School and completed a Master's of Education in special education at Vanderbilt University in May.*



## WHY HAD I NEVER SEEN THINGS THIS WAY?

BY TERRELL SMITH, RN, MSN

I'm embarrassed to admit this because I was a

pediatric nurse for many years. I took care of a variety of children who had developmental delays, ranging from newborns with Down syndrome having cardiac surgery to children with closed head trauma from abuse. It never occurred to me that they could ever be considered for employment at a hospital.

Then I saw a presentation by a nurse manager at a conference. In my opinion, she was making some fairly unbelievable claims so I decided to go for a site visit. On tour at Cincinnati Children's Hospital, Erin Riehle showed me a job description for a position that recycled oxygen monitoring probes. One of the requirements was the ability to count, since the probes had to be bundled in groups of 40 to be returned to the manufacturer. Another was the use of both hands to manually feel for breaks in the probe line wires.

So who did she hire for this position? Someone with one arm who couldn't count! I thought she was kidding until she showed me the simple piece of adaptive equipment that made this all possible. It was a large wooden spool—the type that industrial cable comes on. On the top of the spool, they had placed 40 pegs (no more need to count!). The employee was able to hook the probes onto the pegs and pull his (one) hand along the probe to check the wires. So simple. Why had I never seen things this way?

Then she introduced me to an employee with Down syndrome. Her job was to assemble the instrument trays for a busy 16-room dental clinic. I was impressed. But I noted that some of these trays had over 60 instruments in them, so I asked who else was there to assist her. The answer was...no one! She packed all of the trays and ran three different sterilizers. How could this be? I was then shown the training manual, all done with digital photography. First picture: empty tray; second picture: tray with first instrument inside; third picture: tray with the next instrument; and so on. It was like someone had pulled back a magical curtain and there were multitudes of capable people who I had never noticed.

I returned to Vanderbilt with new eyes for jobs that were complex but predictable. Those also happen to be the jobs that have high turnover because many people get bored with doing the same

thing every day. So from an administrator's perspective, I had just found a good business case for hiring staff with developmental delays. I knew it was the right thing to do but I had no idea how to get started. Fortunately, I was introduced to two people who were invaluable mentors in setting up a program: Elise MacMillan and Wanda Willis. They guided me through agencies and grants that were, frankly, another world to me. We based our training program, Project Opportunity, on the model at Cincinnati and I hired a brilliant program coordinator, Sara Ezell, who happens to be a wheelchair user and knows everyone in the disability community. So off we went.

A cornerstone of the program's success is the assurance of a "follow-along" coach for as long as the graduate is employed. This is key for very busy managers who cannot afford to take extended time to retrain staff if a procedure changes. This coach also helps with orientation and annual required competencies. To date, Project Opportunity has served 29 student-interns with severe disabilities from Nashville and contiguous counties; 21 graduates of the program are currently working in full- or part-time positions at Vanderbilt. It should be noted that these positions are regular positions at Vanderbilt. They have not been created for these individuals.

The departments where they work are as varied as the interests of our students and include materials management, dietary, environmental services, grounds, peri-operative services and sterile processing. In addition to filling a business need, we have discovered some additional benefits of the program. The manuals created for our students are so clear and easy to follow that the departments have requested copies for their regular training programs.

We also didn't realize the enormous encouragement this program could have for parents whose children are currently being treated at the hospital. Imagine bringing your daughter with Down syndrome for surgery and seeing a Vanderbilt employee with Down syndrome stocking all of the bedside supplies for the busy recovery room. It's a win-win.

*Terrell Smith is director of Patient and Family Centered Care, Vanderbilt University Hospital and Clinics*

Photos by Andy Teili, Tennessee Register



## BLIND GOLFER SEES LIFE THROUGH ROSE-COLORED GLASSES

BY NED ANDREW SOLOMON

Christ the King parishioner, and championship golfer, David Meador, got his first taste of the green at eight years old, in his hometown of Salem, Illinois. He picked up the game and his appreciation of the sport from his dad. "I loved the ball," said Mr. Meador. "Just seeing it explode off the club in those early years was something deeper than just the beautiful golf course, and the camaraderie."

The young Mr. Meador's game steadily improved, but in 1966 at age 18, Mr. Meador was in a car wreck and lost his eyesight. Six weeks later he was, in his own words, "going nowhere, sitting on the couch, watching TV," and worrying about what his new world had in store. Then his father had an idea.

The two got in the car and drove to the golf course. The elder Meador set his son in place, described the distance to the hole, selected the right club for the shot, and let the boy swing. Mr. Meador was able to connect with the ball, and reconnect with the pastime he was convinced he'd left behind forever. "My father got me back into the game, in so many senses of the word," Mr. Meador said.

What his father did that day was pretty much what "coaches" do for Mr. Meador, and other blind players, today. Unbeknownst to Mr. Meador and his dad, coaching in this manner had already been in existence for about 15 years.

Golfing blind sounds nearly impossible to a sighted person, but having a stationary ball—unlike in most other sports—helps. As Mr. Meador explained it, "all I have to do is be responsible for my balance, tempo, and returning the club to where it started."

The Meador "team" practiced regularly, joined the United States Blind Golfers Association (USBGA) and went to their first official blind golf tournament in 1974. "It was an eye-opener to see all of these blind golfers, some of which were phenomenal," recalled Mr. Meador.

One in particular, Pat Browne, proved to be a real inspiration for the young Mr. Meador. One of the top three blind golfers of the time, Browne had lost his sight in a car accident the same year as Mr. Meador.

He was coached by his dad until 1976, when Mr. Meadors moved to Tennessee. There he found his second coach, a 16-year-old, Brentwood High student named Stuart Smith. That team trained

during the week and played against sighted golfers on the weekend. "Because it's kind of hard to get up a foursome of blind golfers," laughed Mr. Meador.

The following year they went together to their first USBGA national tournament and Mr. Meador won—beating Pat Browne in the playoff. Although Mr. Meador has won several other tournaments since then—including the national Guiding Eyes Classic tournament in 2005 and 2009 with his current coach, retired banker, Everett Davis—the 1977 win has proven to be his only USBGA national championship—so far. "We've finished second several times," said Mr. Meador. "That darn Pat Browne!"

But there's so much more to Mr. Meador's story than golf. It's one of perseverance, even in the darkest times, and continual adaptation. Mr. Meador learned Braille very quickly, and figured out how to navigate his universe with a white cane. "The white cane has literally, and figuratively, connected me with the world," said Mr. Meador. "Without it, you really know what blindness is. Thanks to the white cane I didn't have to sit on that couch the rest of my life."

In fact, he's done little sitting still at all. Mr. Meador went on to college and a business degree at Southern Illinois University, where he met his wife of 33 years, Connie. He received his graduate degree in personnel and industrial relations from Loyola University in Chicago. Mr. Meador worked in the insurance field in Chicago for several years, until the couple decided to move to a warmer climate, and chose Nashville for their new home.

Mr. Meador spent the next five years with Metro Government, working in the personnel department. The following 18 years he sold insurance for Northwestern Mutual Life. About 10 years ago, disillusionment with and changes in the industry pushed Mr. Meador into a new career, as a motivational speaker and writer.

Although Mr. Meador was convinced his accident and subsequent blindness was an automatic "exemption from other biggies", he has had to endure two other serious health challenges. At age 24, Mr. Meador contracted Hodgkin's disease—a form of cancer—and underwent an intensive chemotherapy program for four years. Although he survived that round, Mr. Meador was diagnosed with colon cancer a few years back. Thankfully, his chemotherapy only lasted 12 months this time, but the end result was the removal of part of his colon and a frustrating, daily drain on his energy.

Throughout all this, Mr. Meador has relied heavily on his strong faith. He and Connie have been actively involved with Christ the King Church since moving to Nashville, and they consider the parish "the anchor" in their lives. Their two daughters, now grown, were both raised with Catholic educations at St. Bernard's and St. Cecilia's. His two grandchildren currently attend Christ the King School.

Despite many life obstacles, Mr. Meador has kept a stubbornly positive outlook. Most times he views his blindness as an advantage, allowing him to disregard distractions that might have slipped him up, like the water traps on the golf course he never has to see, or get



anxious about. "It's totally a skewed view," said Mr. Meador. "My wife accuses me with good reason of looking at life through rose-colored glasses. I don't see the beer bottles on the side of the road—they're all just paved in gold."

*This article originally appeared in Tennessee Register, the newspaper of the Diocese of Nashville, and is reprinted by permission.*

*Ned Andrew Solomon is director of the Partners in Policymaking Leadership Institute of the Council on Developmental Disabilities.*

For many folks, Summer is the season of travel. Deciding where to travel can be fun; planning the safest, most affordable travel from Point A to Point B can be tedious. If you're a person with a disability, you may need to include additional considerations in your travel plans, such as accessible transportation or accommodations, accessible activities, appropriate weather and climate, dietary needs and equipment transport.

The Pathfinder "**DISABILITIES RESOURCES LIBRARY**" contains useful information about traveling with a disability or with someone who has a disability. To locate these resources, go to the Pathfinder Web site at [www.familypathfinder.org](http://www.familypathfinder.org), click on "Disability Resources Library," then scroll down until you see the heading "Transportation".

Click on "**Transportation**" and you will find the following resources.

Able To Travel at <http://www.abletotravel.org/>

Sponsored by the United Spinal Association, this organization specializes in travel arrangement for people with disabilities.

DisabilityInfo.gov at <http://www.disability.gov/>

DisabilityInfo.gov provides quick and easy access to comprehensive information about disability programs, services, laws and benefits. Also offers information on accessibility, assistive and adaptive technology, and laws and regulations related to technology.

DisabledTravelers.com at <http://www.disabledtravelers.com/>

Resource dedicated to accessible travel information. Includes information on businesses that specialize in travel for people with disabilities.

MossRehab ResourceNet's Accessible Travel at

<http://www.mossresourcenet.org/travel.htm>

Provides information for travelers with disabilities.

NICHCY's Travel Training for Youth with Disabilities at

<http://www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/ts9.pdf>

Provides information on using public transportation safely and independently.

Transportation Security Administration (TSA) Information for Travelers with Disabilities at

<http://www.tsa.gov/travelers/airtravel/specialneeds/index.shtm>

Provides information and guidance to travelers with disabilities, including tips for specific disabilities and medical conditions.

U.S. Department of Transportation (DOT) at

[http://www.dot.gov/citizen\\_services/disability/disability.html](http://www.dot.gov/citizen_services/disability/disability.html)

Provides links to DOT accessibility policy, resources for travelers with disabilities, disability laws and regulations and more.

Visit Pathfinder's "**DISABILITY RESOURCES LIBRARY**" to find a wealth of information on both state and national resources, including advocacy and law, arts and recreation, assistive technology, education (including transition), emergency preparedness, employment, health care, housing, Junior League Family Resource Center, mental health, religion and spirituality resources for congregations/faith communities, support for families, and Vanderbilt Kennedy Center Resources.

*Angela Bechtel, MSSW, is the information & referral services coordinator with Tennessee Disability Pathfinder.*

## SEVEN DAYS AT OAK VALLEY BY RUTHIE-MARIE BECKWITH

BOOK REVIEW BY LYNNETTE HENDERSON



Those who have no personal memories of institutional life for people with developmental disabilities can assimilate the emotional and sensory experiences vicariously through Ruthie-Marie Beckwith's mystery novel, *Seven Days at Oak Valley*. Oak Valley is the fictional East Tennessee institution and "home" to internees Tony, Joey and newcomer Angela. References to

the fiduciary, medical, ethical, safety and family issues that plagued state institutions for people with disabilities are woven into the story, making this historical novel a recommended read for those who want to understand the turbulent time of change in disability history that was the 1970s. Ms. Beckwith plans to follow this novel with two subsequent others set in institutions in Middle and West Tennessee.

The novel opens with a burial. No one but Tony is concerned about the frequency of deaths at Oak Valley until the medical director is



# THE *BREAKING GROUND* EMPLOYMENT SERIES WRAPS UP: WHAT DID WE LEARN?

BY WANDA WILLIS

We've just completed our series of articles about employment. What did we learn?

- Trends in supporting individuals with disabilities to receive services they want and need include greater opportunities for employment.
- Employers are receptive to hiring employees with disabilities and many companies have launched initiatives to increase their recruitment of employees with significant disabilities.
- Tennessee has several successful models for students transitioning from public school programs to employment.
- Thousands of Tennesseans with intellectual and other significant disabilities have expressed a desire for job training and a chance at employment.

As the Office of Disability Employment Policy (ODEP) points out, the greatest challenges to employment are not with employers or people with disabilities themselves. The biggest barrier to finding meaningful and productive employment lies with our public system of disability assistance—little coordination of benefits and services, and conflicting policies that make it difficult for an individual with disabilities to become self-sufficient. As stated by ODEP, individuals are “caught in a cycle of poverty by the laws, regulations and policies of the public and private programs providing their supports and services.”

Where do we go from here? Fortunately, new resources and approaches have emerged that demonstrate ways to remove barriers to employment and self-sufficiency for individuals with disabilities. Employment for individuals with significant, complex disabilities in

diverse work places, with competitive salaries and benefits, is well supported in theory and in practice.

The role of both state and federal funding agencies is key. In recent years, Centers for Medicare and Medicaid Services supported Medicaid Infrastructure Grants have encouraged states to explore employment strategies using Medicaid long term service dollars. Several states have found the customized employment approach so successful that they have adopted ‘employment first’ policies that require employment to be a prime consideration for Medicaid Waiver dollars that are used to support individuals who have high support needs.

The Council on Developmental Disabilities, along with our partners in the Tennessee Alliance for Disability Policy, supports an aggressive agenda to improve our responsiveness to Tennesseans with disabilities who want continuing education and job training that will lead to employment opportunities. We will be urging Tennessee to become an ‘Employment First’ state in policy and practice. Together with Tennessee colleges, universities and technology centers that are coming forward to develop new and innovative programs on their campuses for students with intellectual disabilities, the Council plans to support new opportunities for Tennesseans with significant and complex disabilities to find supports and services they need to pursue employment.

*Wanda Willis is executive director of the Council on Developmental Disabilities.*



found murdered. Tony, the unofficial sleuth in Ms. Beckwith’s story, offers his observations on the institutional system, as well as on the character and activities of the other occupants and staff of Oak Valley. Tony delivers the mail at Oak Valley, enjoys imitating Elvis, and both personifies and serves as a window into the egregious injustice of institutionalization. Tony’s ingenuity, deviousness and desire to exert his autonomy within a soul-less system remind the reader of characters in “The Great Escape”, “Stalag 17” and “Hogan’s Heroes”; inspiring examples of autonomy and team-work within a stifling institutional system.

Ms. Beckwith also gives us character sketches of staff members all along the continuum from caring to scary, clueless to ruthless, sympathetic to loathsome. Some archetypical outsider characters

include the folksy, smarter-than-he-seems local Sheriff and the controlling and slippery State Senator. Tony’s attempts to solve the murder mystery require help from several staff allies. As they discover Tony’s observational and deductive strengths, we thrill to see their view of Tony re-align with his reality. All these characters come together to move the mystery along to its climactic revelations. Though some readers may find the frequent copy-editing mistakes distracting, the power of the characters keeps one motivated to see what will become of Tony and his friends during their Seven Days at Oak Valley.

*Lynnette Henderson, PhD, is research participant coordinator at Vanderbilt Kennedy Center.*

# TENNESSEE SPOTLIGHT



Congratulations to **Jalyn Weston**, son of Partners 2009-10 Graduate, **Pam Weston**. His artwork, **The Enchanted Forest**, was one of 51 pieces selected from over 5,500 submissions nationwide. He will represent the State of Tennessee in the **VSA and CVS Caremark All Kids Can...CREATE!** exhibition **State of the Art**. The exhibition will debut at

Washington, DC's **Union Station** from May 24 – June 12, 2010 before beginning a two-year tour to children's museums across the country. In addition, the national VSA office will provide Jalyn and Pam an all expense paid trip to Washington, DC, for the ribbon cutting ceremony that will open this exhibit.



On May 12, the **National Federation of the Blind** (NFB) announced its **2010 Scholarship Program Winners**. The nation's oldest and largest organization of blind people awards 30 scholarships each year to recognize achievement by blind scholars. **Sheri Anderson**, a Partners 2006-07 Graduate and current member of the **Tennessee Council**

**on Developmental Disabilities** is one of the recipients for her work in the area of emergency management.

In July each winner will attend the NFB's 70th annual national convention in Dallas, Texas, where the committee will spend several days getting to know each student and deciding which scholarship—ranging in value from \$3,000 to \$12,000—to award each winner.



**Gordon Bonnyman**, executive director of the **Tennessee Justice Center**, recently received the **2010 TAP Lifetime Achievement Long Haul Award** from the Tennessee Alliance for Progress for making a significant contribution over a period of years to social change in Tennessee.



**Carol Westlake**, executive director of the **Tennessee Disability Coalition**, received the **2010 TAP Long Haul Award** for her outstanding work on issues of social, economic and environmental justice.

TAP is a think/act tank with a mission to create healthy families and communities in Tennessee. TAP held its annual Long Haul Awards on May 22, 2010, at **St. Ann's Episcopal Church** in Nashville.



The **Davidson County Mental Health Court** recently honored **Elisabeth M. Dykens, PhD**, for her work in developing a program for participants in the Mental Health Court who have mental health issues, developmental disabilities and substance abuse. Dr. Dykens is director of the **Vanderbilt Kennedy Center for Research on Human Development**.

In addition, Dr. Dykens was awarded a **Power of Inclusion Award** by **CABLE** on May 12th, "in recognition of exceptional leadership to promote diversity and inclusion in the community." CABLE presented Power of Inclusion Awards to **Goodwill Industries, Barefoot Republic Camp, Deloitte-Nashville**, and Elisabeth Dykens as "role models representing the highest standards of Diversity Best Practice in Nashville."

On Tuesday May 18th, **Paula Denslow** received the **2010 Vanderbilt Bill Wilkerson Center Communication Services Award** for helping link patients with traumatic brain injuries and other cognitive issues to supports in the community. Ms. Denslow has been the coordinator of the **Project BRAIN** program at the **Tennessee Disability Coalition** since 2003.

**VSA Tennessee** partnered with **The Arc of Tennessee** to present **VSA at the Ryman** on Monday, May 24. Performers for this event included the **Tennessee School for the Blind Choral and Jazz Ensembles, Amanda Stevens** from Whitehouse (VSA Tennessee's Young Soloist winner for 2010), **Brian Werner**, country vocalist from

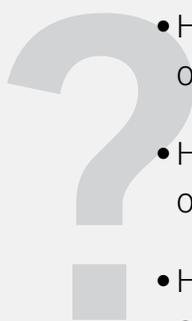
Crossville, **Nick Sharp**, guitarist and vocalist from Murfreesboro, the **VSA/Blair Dulcimer Choir**, and **Cages Bend**, a blues/pop band.

The evening concert also featured **Lake Rise Place**, a jazz/pop trio whose members are from Mt. Juliet, Gallatin and Hendersonville. Tennessee Spotlight readers may recall that Lake Rise Place was one of 28 acts in the world to be selected to perform at the prestigious **VSA International Festival** to be held in Washington, DC, in June.

In addition to musical performances, VSA at the Ryman showcased the works of several Tennessee artists. Special awards were presented to **Patty Daniels**, a special education teacher at **Beech High School** and **Jalyn Weston** (see page 18). VSA Tennessee would like to express gratitude to **CVS/Caremark** and **Lisa Hester** of the **Tennessee Arts Commission** for their assistance with the event and general support of the arts.

Half of the proceeds from ticket sales went to The Arc of Tennessee; the other half to VSA Tennessee to help defray travel expenses for sending Lake Rise Place to the International Festival.

## TENNESSEE SPOTLIGHT wants to hear great things about YOU!



- Have you or your family member been accepted into or successfully completed an educational program?
- Have you or your family member received a nomination or an award for your wonderful work in the community?
- Have you or your family member been hired for a new job or gotten a recent promotion?

Send your good news and pictures by e-mail to: **ned.solomon@tn.gov** and we'll make every attempt to get it in an upcoming issue of **Breaking Ground!**

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