

BREAKING GROUND



THE SWAN



[4] INTERVIEW WITH
COMMISSIONER JIM HENRY



[12] A MOTHER WHO GOT
SO MUCH MORE



[18] TENNESSEE SPOTLIGHT

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Cover photo: Sharon Hazard

Photo by Jeff Hazard

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Photo by Jeff Hazard

Sharon Hazard

THE SWAN

BY NANCY VANDERLAN

When I first met Ms. Sharon Hazard in the Emory Valley Center parking lot, she did a swan dive from the driver's seat of her van into her wheelchair. This must have been in 2003, when we were having all types of problems, the least of which was the promptness of Family Support payments to families. I remember clearly how Ms. Hazard informed me that maintaining a Personal Assistant, who you know and trust, and paying them in a timely manner was high on the list of important issues. While she waited on our promptness to kick in, she talked with me about her trials and daily challenges of living with a physical disability, which were many.

It was soon after that day that I asked Ms. Hazard to join our Family Support Local Council. We needed someone who understood what individuals with physical disabilities face, who was a strong advocate and who worked hard to move forward in life to the best of their ability. We needed a voice for those who could not speak out for themselves. That was Sharon Hazard.

As Ms. Hazard became comfortable in her role as a Local Council member, I saw her teach and educate other Council members what it was like for some people like herself, who had no other support available. She was one of those who "fell through the cracks" since her husband had an income that kept them from being eligible for other programs. She told us what it was like to have to have assistance with

typical tasks, such as going to the grocery store. Through all this, she wanted to know what she could do for us.

Ms. Hazard started a business called "Imagine It Embroidery" and one of the first things she embroidered was the Tennessee Family Support logo! She developed a Web site, www.imagineitembroiderytn.com, that shows the many things that she can embroider. She gave me a tote bag with the Tennessee Family Support logo and that bag is in my office and close to my heart. What a remarkable person this Sharon Hazard is!

Ms. Hazard's old van recently met its final days while her husband went through a period of unemployment, and the family could not afford to have it replaced. Ms. Hazard, with her wonderful and caring personality, struck the chords in the heart of Gregory Fuller, a man who knew her from her daughter's skating rink. He noticed how remarkable Ms. Hazard is and bought her a customized van so she could be mobile once more. Mr. Fuller wanted to do something for her that would make a difference and give Ms. Hazard back the mobility and independence she so desperately desired. Vocational Rehabilitation helped fund the costly customized drive adaptations.

Ms. Hazard has named the van "Blue Angel". It sports a license plate with a flying wheelchair with wings, just like that swan I saw on that first day that I met her in the parking lot of Emory Valley Center. Ms. Hazard is free and flying through life!

Nancy Vanderlan is the Family Support Program coordinator at the Emory Valley Center in Oak Ridge.

INTERVIEW WITH COMMISSIONER JIM HENRY

(Department of Intellectual and Developmental Disabilities)

BY WILLIAM LOVELL WITH PHILIP GARNER

Hello
Breaking

Ground readers! I was asked to interview Commissioner Henry and I was very nervous at first, but Rosey Depriest and Phil Garner from Buffalo River Services assured me that they would help me read the questions. We came to Nashville to Commissioner Henry's office. The Commissioner's staff were very helpful. We did not have to wait very long until the Commissioner came and got us himself. That really impressed me.

Commissioner Henry made us feel very welcome and we did not feel rushed at any time. His phones were beeping and ringing and he went over and cut them on silent for the duration of the meeting and even though at times they buzzed, he ignored them. I noticed he had two phones and he explained that he had one for work and one for his family, in case his son needed assistance during the day.

I liked that Commissioner Henry took time to explain things and really couldn't believe that he let me take up so much of his time. I felt that Commissioner Henry was honest and friendly and that he seemed to be really interested and involved in making things better for the community. I also was impressed that Commissioner Henry talked about his son and that he was so involved in his care and that he knew about the things that others are going through with their disabilities. Commissioner Henry also asked me about my job and the things I am involved in and seemed to be really interested in what I was saying.

Here is the interview with Commissioner Henry's responses.

Q. WHAT DOES A COMMISSIONER DO?

A. The commissioner is responsible for over \$900 million worth of services for the people of Tennessee. He has to set priorities on how these funds will be used to benefit in the best possible way.

Q. WHAT IS THE BEST THING ABOUT BEING A COMMISSIONER?

A. I am still trying to figure this out. I feel fortunate to be able to do this work, coming from a background in the community. The buck stops here with me and I hope to effect change and [make] things better for the people we serve.

Q. WHAT HAS SURPRISED YOU ABOUT THE JOB?

A. The number of good people in State government. I always knew there were good people but [am] surprised by the really huge numbers.

Photo courtesy of the State of Tennessee



Commissioner Jim Henry



William Lovell

Photo by Kelly Ray

Q. TELL US ABOUT YOUR SON

A. My son John is 34 years old. He is an amazing person and is the 100% reason why I am here as commissioner. He has a diagnosis of spastic cerebral palsy, autism and problems with curvature of the spine. Also combined with a colostomy and a feeding tube. He has his good days and bad days just like anyone else. His world is always changing and has to deal with staff changes just like anyone else. [As Commissioner Henry is speaking about his son, his eyes light up and you can see how much he means to him.]

Q. HOW WILL PEOPLE WITH DISABILITIES, THEIR FAMILY MEMBERS, ADVOCATES, PROVIDERS AND OTHER STAKEHOLDERS BE INVOLVED IN INFLUENCING THE FUTURE DIRECTION OF OUR NEW DEPARTMENT?

A. We are having several focus meetings with stakeholders. This will be held in different locations over a period of time. We are doing more to communicate on a regular basis, including the Open Line updates. This is a document that I send out as important items develop that people need to know. We want to listen more to people who have ideas about how to improve things. Remember that no one has all the answers. So we want to be open and accessible. We want to communicate and to hear ideas of ways to do things better.

It seemed like a good idea to do job shadowing with provider agencies to allow DIDD [Department of Intellectual and Developmental Disabilities] employees the opportunity to have some first-hand experiences of what a person's day is like. I personally did this. I shadowed at Waves, Inc., a

provider in Franklin. We took care of three ladies for an afternoon. We spent time with them that evening. As they had dinner, I got to know them and I talked at length with the direct care staff. An interesting side to this is that one of the DSPs [Direct Support Professionals] was to open the show that same weekend for Carrie Underwood. It seems that this is one of the things [DSP] people are doing to make ends meet. This person obviously was creative.

I hear a million excuses of why things can't be done but we need to find ways. This idea of shadowing is one example of what can be achieved and I said if everyone is going, then I'm first.

The job shadowing is probably more important for our Central Office staff, even more so than the Regional Office. This is just another example of how we are trying to listen and learn.

Q. WHAT DO YOU WANT TO SEE HAPPEN FOR PEOPLE WITH DISABILITIES IN TENNESSEE?

A. I want to see people live life normally as much as possible.

Q. WHENEVER YOU MIGHT LEAVE THIS JOB AS COMMISSIONER, WHAT DO YOU PERSONALLY HOPE TO SEE AS ACCOMPLISHMENTS FOR THE DEPARTMENT?

A. When I leave the Department, I hope to say we have done something for the developmental disability side. One of the reasons we hired a person with the qualifications of Dr. Scott Modell was because of his expertise in autism. There are huge numbers of people with autism in our State and that is the big elephant in the room for the Department.

We at DIDD are going to do the best we can to convince the powers that be to do something to help with the developmentally disabled. I think this would be a great accomplishment.

Q. WHY DO YOU THINK THE EMPLOYMENT RATE IS SO LOW FOR PEOPLE WITH DISABILITIES—EVEN THOUGH THIS IS SOMETHING THE DEPARTMENT HAS BEEN WORKING ON FOR A LONG TIME?

A. I am told that it [low employment] is affected by current issues with our economy but I think it is more than that. I don't think we ever got the program right from the beginning. Julie Huber [director of Day Services] is doing a cooperative program with Vanderbilt [University] in an effort to build a more efficient response to the problem. There are some provider programs that are doing a good amount of placement. I believe that people should be able to work if they choose to. I have heard this saying, "Life worth living is a job worth doing." My son told us that he didn't want to work. I respect his opinion to not work

Q. WHAT WILL THE DEPARTMENT DO TO REMOVE BARRIERS SO THAT PEOPLE WITH DISABILITIES WHO WANT TO WORK CAN FIND JOBS IN THE COMMUNITY?

A. I guess that we have to identify those barriers that stand in the way of people being employed. Right now we are not even sure what all the barriers are. The more we can teach and tell people with influence and authority what the situations for people are truly like, the more changes we can make. I would like to ask the Governor to spend the

day in a wheelchair. I think it would help him better understand about the problems people face and deal with.

I think the more that we talk about what I can do, rather than what I can't do, the better off we will be. Traditional thinking is one. I don't give in to the idea that the economy is the biggest problem, but it has something to do with it.

Q. WHEN WILL TENNESSEE BE ABLE TO PROVIDE EMPLOYMENT SERVICES TO STUDENTS WITH DEVELOPMENTAL DISABILITIES WHEN THEY LEAVE PUBLIC SCHOOL SERVICES?

A. I don't know really what can be done. The expansion of services is very difficult. This is a priority here but when things will change, I don't know. When I stepped into the position, I expected to see an array of improvements, yet it seems we are spending a great deal of time trying to reduce cost and eliminate jobs.

Q. THE TENNESSEE FAMILY SUPPORT PROGRAM IS A LIFELINE FOR FAMILIES WHO HAVE NOWHERE ELSE TO TURN FOR ASSISTANCE IN TENNESSEE. HOW CAN WE ENSURE THAT THIS PROGRAM CONTINUES TO RECEIVE THE FUNDING IT NEEDS TO KEEP SERVING FAMILIES THAT NEED HELP?

A. I don't think anyone can guarantee that any type of services will be received right now. With Family Support there is a dual problem. In Tennessee, the State attempts to maximize all its funds. We have \$20 billion from the federal government that is matching to State funds. However, Family Support funding cannot be used to match federal dollars. That means that \$7 million is spent that could be matched with federal dollars, if it were redirected through the Waiver. It remains a difficult issue. The average person only gets about an average of \$1,300.00 a year [from Family Support]. When there are people that it costs around \$400,000 per year in the Waiver to serve as one individual, the discrepancies are great. With so many on the waiting list, it seems terrible that none of these people receive any help. We are well aware of the needs of Family Support recipients, however, we will be fortunate if we can hold the programs we have right now. If the worse scenario happens, we may have to cut and I don't know how we will manage to maintain some programs.

Q. THERE ARE MANY TENNESSEE CHILDREN AND ADULTS WITH DEVELOPMENTAL DISABILITIES, LIKE CEREBRAL PALSY, AUTISM AND SPINA BIFIDA. THESE ARE DEVELOPMENTAL DISABILITIES THAT ARE NOT CLASSIFIED AS INTELLECTUAL DISABILITIES. THESE PEOPLE ARE IN NEED OF SIGNIFICANT ASSISTANCE, AND THEY MEET CRITERIA SIMILAR TO MEDICAID QUALIFICATIONS FOR HOME-BASED SERVICES AND SUPPORTS LIKE THE ID [INTELLECTUAL DISABILITIES] WAIVER. WHEN WILL THEY BE ABLE TO ACCESS THESE SERVICES IN TENNESSEE?

A. I don't really know a good answer for that question. Once again, funding is the problem that we always come up against. We hired Dr. Modell to bring in vital knowledge and experience to DIDD in the area of developmental disabilities.

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There are several problems looming with the new federal health care program. We are assuming that there is going to be a huge scramble to use any new funding that may become available.

Q. WHAT ARE THE LARGEST BARRIERS THAT YOU ARE EXPERIENCING IN MAKING PROGRESS TOWARD INCORPORATION OF THE “DEVELOPMENTAL DISABILITY” ASPECT OF DIDD SERVICES?

A. In regards to the Governor’s reaction to the potential federal funding, we were asked to work out three budget scenarios. One was to be based on a potential 5% cut, one on 15% and one a 30% cut. It seems sadly comical when you are hoping to face cutting only 5%. The biggest barrier is the funding. Here at the DIDD, the will is here to help people with developmental and intellectual disabilities but the looming barrier is still available funds.

Q. WHY DO WE HAVE WAITING LISTS? IS THERE ANY OTHER DEPARTMENT IN TENNESSEE THAT HAS A WAITING LIST AS LONG AS WE DO?

A. I don’t know other than maybe in health care. However, the reason is almost the same answer as I have said in other questions. It is because we don’t have funding to take people from the waiting list. In Tennessee, serving people with developmental disabilities is not mandatory. It is a service that each state has different levels of funding to provide. In Tennessee, we are probably in the top 10 in the U.S. in total money spent for people with ID, but we are so centered on some specific people with crisis that more is spent on those individuals than on the average.

Q. WHAT WILL THE DEPARTMENT DO TO GET SERVICES FOR THE PEOPLE ON THE WAITING LISTS?

A. We limited personal assistance and nursing services to certain number of hours now, but if we had been much more conservative in the start, when these programs began, that would have been better. Once people get set with their services they expect continuation regardless of how many are on the waiting list with no services. We have to be very careful of how we make future decisions because many of [the] decisions at DIDD in the past have been made out of direct response to lawsuits. We over-did it. We hope we learned from our mistakes and we did make mistakes that led to those lawsuits. In the past, some things were going on in the institutions that should not have ever been allowed.

Still, finding ways to spend equitably is a big issue. If I had the “crystal ball” and we received any new money, it would be directed to a new community waiver, a low cost and more self-directed waiver. I might change, but right now those are my thoughts.

Q. WHAT CAN WE DO TO HELP YOU WITH YOUR JOB?

A. The main thing is be sure you have good legislative representation. Everyone needs to ensure that their Tennessee lawmakers understand all the challenges that we face. Progress really depends on how

legislative officials are motivated to provide necessary resources to the programs we need, especially since there is no mandate to provide services to people with disabilities. Stakeholders need to make the legislators their “best friend”, make them familiar with good and bad, the discrepancies in funding and other important facts. The more knowledgeable they are the more help you will likely get.

If you can spend an hour with your legislator, it is better than me spending two full days with him. You are his real community and not just another faceless bureaucrat trying to influence him as he walks down the halls.

Q. WHAT ARE YOUR EXPECTATIONS REGARDING THE CONTINUED USE OF THE PERSON CENTERED PRACTICE MODEL?

A. They have convinced me here, if I really needed to be convinced, that everything we do should be person centered. Laura Doutré [deputy director of Policy and Innovation] has spent a lot of time with me. She is nationally recognized and has convinced me that this is the path that we should take. She is a bright star here.

Q. IS THE DEPARTMENT TALKING ABOUT CREDENTIALING AND BETTER PAY FOR DIRECT SUPPORT PROFESSIONALS?

A. The worst thing you can do in an economic recession is to be out of work. The provider agencies are not getting any more money from DIDD right now and we can’t promise any more money right now or in the future. Here at DIDD we are asking people to take more responsibility and to work through the tough times together. It is difficult to say at this point how we can improve wages when we are adjusting to the issues with the economy. We have a lot of providers in Tennessee and could possibly do with fewer. Accreditation should make good providers better. Providers need to experience some growth in order to remain viable. With no foreseeable rate increases, providers must spread overhead and generalize programs. Providers, like any other business, have a difficult time cutting salaries in order to save money. But they likely can’t give increases in salaries either. It is a very difficult position to be in. So the idea is having a job [with] pay at all is better than no job.

The DIDD is unlike other situations in State government. This is the first time this Department has ever really cut anything. We have eliminated positions to assist in the cutting of expenses.

The DIDD has gained national recognition for Person Centered Practice work [and] Protection From Harm, and we are working on the idea of “health promotion” as contrasted to “prevention”. Perhaps the next area of national recognition will be that DIDD will be the first State department to be accredited. We are looking at potentially trying accreditation for the Department. If accreditation is a path we take, it is possible that the certification of Direct Support Professionals might play a part in that.

William Lovell is a self-advocate and 2010-11 Partners graduate who lives in Waynesboro. Philip Garner is executive director of Buffalo River Services, Inc.

MONEY FOLLOWS THE PERSON

BY MICHELLE MORSE JERNIGAN

Money Follows the Person (MFP) is a federal

demonstration grant that was established under the Deficit Reduction Act of 2005. The primary purpose of the grant program is to assist participating states to:

- Provide individuals living in Nursing Facilities and Intermediate Care Facilities (ICF/MRs) opportunities to transition to home and community settings with services and supports in place to remain in the community; and
- Help states rebalance Long Term Care (LTC) expenditures by spending Medicaid dollars on home and community based services (HCBS) rather than on institutional care.

Tennessee was awarded the MFP grant in March, 2011. The grant period is five years, with the option to extend the grant one year at a time up to an additional four years, potentially lasting until 2020. Tennessee is one of 43 states plus the District of Columbia participating in the MFP demonstration.

Currently in Tennessee, individuals with intellectual disabilities, adults with physical disabilities and individuals who are elderly (age 65 or over), live in a nursing facility and receive TennCare benefits are enrolled in the State's CHOICES program. CHOICES is a program that allows people a choice in the type and place of services they receive, including institutional care or HCBS. TennCare contracts with Managed Care Organizations (MCOs) to coordinate members' care and requires that the MCOs assist members in nursing facilities to transition to HCBS when appropriate. Individuals with intellectual disabilities who live in an ICF/MR also may transition to HCBS in one of the Medicaid Waiver programs offered by the Tennessee Department of Intellectual and Developmental Disabilities (DIDD). DIDD's transition team assists with this transition. The cost of these Medicaid services is shared by the State and the federal government's Centers for Medicare and Medicaid Services (CMS). The State of Tennessee pays 33.64% of the costs and CMS pays 66.36% of the costs; this is called a federal match.

The practice of transitioning individuals will continue as it does today in both the CHOICES and DIDD programs, however, if a person who wishes to transition home also is eligible for enrollment in MFP, the MCO or DIDD will discuss the MFP program with the person and obtain informed consent for participation. In order to be eligible for participation in MFP, you must reside in a licensed, Medicaid-certified institution for a minimum of 90 consecutive days. These days cannot include Medicare reimbursed rehabilitation days. You must also, upon the day of transition, be eligible for Medicaid HCBS. A person enrolling in MFP must move into what CMS considers a "qualified residence". Among other criteria, this means the person must have solitary or equal domain over living, sleeping, bathing and cooking spaces and the home must have a lockable entrance and exit. MFP enrollees must agree to participate in three Quality of Life surveys over a period of two years to help the State and CMS understand individual preference and community transition success.

For CHOICES members, MFP neither adds nor takes away any services.

All services are the same as the person would have received in CHOICES without MFP. For DIDD Waiver enrollees, there is one added benefit of a \$2,500 transition allowance to assist eligible enrollees with the expense of moving into the community. (This benefit already exists in the CHOICES program.)

The MFP participation period is 365 days. Each person enrolled in MFP will be in the demonstration for 365 days. At the end of the 365-day participation period, the person will continue to receive all their current HCBS without any changes or interruption in those services. The end of the MFP participation period will be invisible to the enrollee in regard to their services. (The DIDD MFP transition allowance is available only during the MFP participation period.)

Tennessee has proposed to assist 2,175 people transition from nursing facilities and 50 people from ICF/MRs to HCBS for a total of 2,225 people over the five-year grant period. The grant amount is up to \$119,624,597 over five years. This includes the money Tennessee would have received regardless of MFP for providing services to CHOICES and DIDD Waiver enrollees. The difference is that Tennessee will receive an enhanced federal match for each person enrolled in the MFP program for the 365-day participation period. Rather than TennCare paying 33.64% of the service amount, for MFP enrollees TennCare will pay an average of 16% for HCBS. This average 17% savings will be placed in Tennessee's Long-Term Care Rebalancing Fund to be used for helping the State meet proposed benchmarks and build direct support workforce and housing capacity.

Tennessee's MFP Proposed Benchmarks:

- Assist projected number of eligible individuals in successfully transitioning from an institution to a qualified community residence;
- Increase the amount and percentage of Medicaid spending for qualified HCBS;
- Increase the number and percentage of the Elderly/Disabled population receiving Medicaid LTC services in an HCBS (vs. institutional) setting;
- Increase the number of licensed Community Based Residential Alternatives contracted with TennCare MCOs to provide HCBS; and
- Increase the number of persons receiving Medicaid-reimbursed HCBS participating in Consumer Direction.

While individuals who agree to participate in MFP may not receive additional service benefits, they will all be a part of assisting Tennessee in developing a statewide community that is better prepared to serve those who wish to receive their long term care services in their own home. Someone who is able to transition today and enroll in MFP, allowing the State to receive enhanced federal match on their services, will be helping to pave the way for someone else in that institution who may not have the necessary housing resource to transition today.

TennCare is excited about this program and the future it will help build for our valued citizens who deserve the quality of life they desire for themselves.

Michelle Morse Jernigan is deputy of Long Term Care Quality and Administration with the Bureau of TennCare

DISCOVERING THE INTERSECTION OF ART AND DISABILITY: A PROFILE OF VSA TENNESSEE'S LORI KISSINGER

BY NED ANDREW SOLOMON

When Lori Kissinger was six years old in Evansville, Indiana, she had Scarlet Fever. The doctors were certain she wasn't going to make it and no outsiders were allowed in the house, nor were her parents allowed in her room. "They'd have to go outside and put food into the window," said Ms. Kissinger. "And if they came in, they had to put suits on."

Unfortunately, the fevers continued and gradually got higher. She overheard the doctor talking to her mother outside her door, saying, "She won't make it through the season." They brought in a little television set to distract Ms. Kissinger from fever-induced delusional thoughts. Ms. Kissinger watched a show called *The Littlest Angel*, about a boy who dies too soon, goes to heaven and discovers all the angels had harps except him.

"When my parents brought in my food, I told them I had heard what the doctors said," recalled Ms. Kissinger, "and that if I was going to heaven, they better get me harp lessons!" Luckily, Ms. Kissinger survived, and the harp lessons were put on hold.

Back in school, younger than many of her peers because of a late birthday, Ms. Kissinger was always a little "out of step". Her school also put great emphasis on athletic skill, which was not one of Ms. Kissinger's best attributes. Perhaps because of her prolonged fevers, her hand-eye coordination was poor. So, she would hide in church and began writing songs.

In high school, she joined the choir, and the director encouraged her to keep writing songs, which fell into the folk or country category. However, when she got on stage, she suffered terribly from stage fright. Her mom suggested she pack in that career and move on. "My one strength and weakness is I am persistent to a fault," Ms. Kissinger said. "So I kept trying."

The choir director suggested Ms. Kissinger put down the guitar and pick up a bigger instrument, like a piano, that she could hide behind when she played. Toward that end, Ms. Kissinger went to the Continuing Education Music Department at the University of Evansville, with the hope of learning the piano. Instead, Kissinger saw a harp and fell in love with it. In fact, she became the "house harpist" at the local country club for over 15 years, playing for Sunday brunch, weddings and other functions.

A few years later, in college at the University of Southern Indiana, Ms. Kissinger took a communications class from a holdover from the 60s, who exposed her to the music of legendary folk music artists like The Weavers and Peter, Paul & Mary. He also told her about a woman he knew in Kentucky who would tell stories while demonstrating a large variety of acoustic instruments. Ms. Kissinger contacted her and was able to trade giving this woman harp lessons in exchange for learning about folk music and other instruments.

Ms. Kissinger worked up her own story and music program and performed in every elementary and middle school in Southwest Indiana, at different community festivals and on Evansville's public radio and television stations. She became fairly well known in Kentucky, Illinois and even Dollywood.

After college, Ms. Kissinger became the director of a regional arts council, helping to coordinate a huge annual arts festival. That job would ultimately lead her to VSA (Very Special Arts), and her work with artists with disabilities. "One of the participants in that festival was a man who was blind," said Ms. Kissinger. "He wanted to do something at the festival for people with visual disabilities."

Unfortunately, Ms. Kissinger's budget was set for the year, but a colleague suggested asking the state VSA chapter for funds. Ms. Kissinger approached the woman in charge



Photo courtesy of Middle Tennessee State University

Lori Kissinger

and asked for a grant. The woman, in turn, asked Ms. Kissinger—whom she'd heard about—if she would be a VSA musician for the state, performing her show for young people with disabilities. "I said, 'I have never worked with people with disabilities,'" recalled Ms. Kissinger. "'I don't even know what to do!'"

The woman explained that artists and musicians, with and without disabilities, set up at a particular location and kids from the state's special education classes rotate through. Ms. Kissinger was insistent she couldn't do it, but the woman said in response, "Well, how much do you want that grant?"

"So, I set up, and I was scared to death," Ms. Kissinger said. "Then the kids came in, and I just fell in love with them. And VSA asked me to do it more and more."

But Ms. Kissinger was working full-time and had to squeeze these appearances in when she wasn't on the clock. Then her son, Christian, was born. "The only thing I wanted

to be in life was a wife and mother,” said Ms. Kissinger. “My goal was to NOT go out and work, and here I was working two jobs!” Ms. Kissinger ultimately quit her full-time job with the Arts Council, taught a couple of classes a week at the university and continued working with VSA, visiting special education classrooms. “My main focus was working with kids who had severe and profound disabilities, and autism,” said Ms. Kissinger. “And I would use the harp.”

As fate would have it, Ms. Kissinger moved to Nashville for her husband Eddie’s job, leaving behind an environment where she knew everyone (and was related to quite a few) for one where she knew nobody. By now, her son was six years old, and she was teaching communication as an adjunct professor at Middle Tennessee State University (MTSU), Belmont University and Volunteer State Community College. Her desire was to teach part time and continue to work with VSA. “And I thought Tennessee, of all places—with its music and crafts—they’re going to have a huge VSA,” Ms. Kissinger said.

To her surprise, a VSA Tennessee chapter didn’t exist. Then Ms. Kissinger got a call from the national VSA office, begging her to start one.

Ms. Kissinger didn’t want to, first because she hated fundraising, second because she had run a non-profit and it “nearly killed her”, working 24/7, and that was with a full staff, an active board and connections all over the place, having grown up in that community. “I said, ‘Now, I don’t even know my next door neighbor!’” said Ms. Kissinger. “‘I’m not from here, I’m already working and I’ve got a small child.’”

After some negotiations, Ms. Kissinger agreed to help write by-laws, create a mission statement and assemble a board. “I had a hodgepodge of people, most who had never been on any board, that had no clue what VSA was, no clue about disability, no clue about anything,” laughed Ms. Kissinger. “When we got together at the Black Eyed Pea in Hendersonville, it was the first time any of us had ever seen each other. I said, ‘Guys, here’s the deal: I’m starting this organization and then walking away.’”

Ms. Kissinger was convinced the organization would last, at most, three or four years. Other

Tennessee entities had tried to start a major arts and disability initiative that never got off the ground. A previous attempt to start a VSA Tennessee chapter made it about a year, though there are two arts festivals that still exist from that time. Additionally, the economic times weren’t the most conducive to funding a non-profit like this.

Going into VSA’s fourth year, the chapter was exactly where Ms. Kissinger expected it would be: ready to close its doors. At the same time, Ms. Kissinger became aware of an arts grant through the National Endowment for the Arts (NEA). She had had one crazy dream for VSA for some time, to put on a show at The Ryman Auditorium. All odds were against VSA Tennessee getting the grant, but she submitted it and promptly put it out of her mind.

The organization’s financial picture continued to get worse. Finally, driving home from teaching at MTSU, Ms. Kissinger decided to break the bad news at the board meeting that evening, that VSA Tennessee was history.

Instead, she walked in her door and discovered a letter from NEA telling her that VSA Tennessee had been awarded the grant to put on a show at the Ryman. In the grant application, Ms. Kissinger had proposed to bring students in special education programs to the Ryman throughout the day and have a public performance at night. “So instead of going to the board meeting to tell them we’re shutting down, I told them, ‘Guess what? We’re now doing a big event at the Ryman!’” said Ms. Kissinger. “That was the turning point for us.”

Awareness about VSA Tennessee spread exponentially with that event. The Department of Education came on board, giving VSA funding and providing a representative on the board.

Still, Ms. Kissinger was trying to pull off the Ryman show practically by herself. Luckily, MTSU asked her to teach a course on Organizational Communication—specifically on event planning—and Ms. Kissinger decided to enlist her 25 students. “I said, ‘You want to learn how to plan an event? That’s what you’re gonna get to do,’” Ms. Kissinger said. “So there was my volunteer group.”

The morning of the big day, over 600

kids in special education, primarily from Comprehensive Development Classrooms, came to the Ryman. The teachers told Ms. Kissinger that there were never field trips just for their kids, and that they never got to go on activities like this. “The kids were just enthralled by being there,” recalled Ms. Kissinger. “And, of course, the people on stage also had disabilities, and many of them were also kids. There was a great connection and, afterwards, the kids in the audience wanted autographs from the kids on stage. The whole thing was just amazing.”

The evening public performance was a huge hit too and drew a large, enthusiastic crowd. The Ryman asked VSA Tennessee to come back again, which they did a couple of years later with support from the Tennessee Council on Developmental Disabilities, The Arc Tennessee and others. “After that, we were able to take that success and really build,” said Ms. Kissinger.

That’s just the music part of VSA Tennessee. During its ten year run in Tennessee, the organization has exposed young people and adults with disabilities to a variety of opportunities in art, theater, dance and even costuming workshops. At the same time, it has brought to the State’s attention, and even national attention in some cases, incredibly talented artists, musicians, dancers and actors, who were “out there” but who may not have had the confidence, because of their disabilities or public perceptions, to step to the front of the stage.

“I love when I hear a parent say, ‘I never knew my child could do this’ or ‘they can’t do this’, and then they do,” said Ms. Kissinger. “VSA is constantly The Little Engine that Could. It really shouldn’t exist. The Ryman never should have happened. We could just go down the list of it shouldn’t, it shouldn’t, it shouldn’t. And it matches so much of what these kids see all the time. Nothing we do should ever have happened, and it does. Everybody tells these kids they can’t do things, and they do.”

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



Can't You Be Still? (1992; 28 pages), *Nobody Knows!* (1994; 24 pages), *Here's What I Mean to Say...* (1997; 24 pages)
Written by Sarah Yates; Illustrated by Darlene "Toots" Toews. Gemma B. Publishing, Winnipeg, Manitoba

CHILDREN'S BOOK SERIES TELLS WHAT LIFE'S LIKE FOR GIRL WITH CEREBRAL PALSY

BY NED ANDREW SOLOMON

Inspired by her own daughter's journey with cerebral palsy (CP), Sarah Yates set out to write a book—a children's picture book—about a young girl's trials and tribulations with her disability. That first one, *Can't You Be Still?*, which revealed the main character, Ann, at age four, turned into a series of three books, giving readers a glimpse of Ann at ages six and nine too. She's still struggling against obstacles, but making her way with her distinctive flair, imaginative spirit and the loving support of her mom, dad and best friend, Jay.

Each book presents a handful of unique challenges which Ann must overcome, though there are a few "givens" that follow Ann from book to book. Her CP makes it difficult for her to speak and articulate clearly, which often makes it hard for her to be understood, especially by people who haven't heard her talk before.

There's her "wild right", which is what she and her mom call her right

arm, which seems to have a life of its own. Ann's natural spasticity, and her brain's inability to always get the signals correctly to her limbs, causes her right arm to jut out unexpectedly, sometimes with mortifying, sometimes hysterical consequences.

And there's the inimitable Jay, who's a bit quirky himself, and who—unlike most of the children and adults that Ann encounters—appears to be "blind" to her disability. Best friends "from first sight", he's her companion, partner in crime, co-conspirator, fellow adventure seeker, confidant and buffer between her and a sometimes unfeeling, unaware and un-understanding world.

But it's those "unique" situations that make each of the books in the trilogy fun and poignant. In *Can't You Be Still?*, Ann is going to her first day at preschool, with her Andy Bear stuffed animal and her mom, or Mum, for transitional support. Ann is a bit anxious because, in her short lifetime of experiences, she's either been at events where all the kids have disabilities or where she's the only one. The classroom

seems to be more the latter type, though the boy with the spikey black hair—Jay—greeted her and wanted to know all about, and even have a turn with, Ann's reverse walker. Without asking, he jumps on and takes Ann for an impromptu spin, which sends the other classmates running for cover.

To Ann's chagrin, her "wild right" knocks off another kid's eyeglasses and then spills a bucket of paint at the art center. This causes another girl to remark, "Can't you be still, ever?" Her new, sensitive teacher (ah, if only all of them were like this!) comes to the rescue with a terrific explanation: when you sneeze, you can't help it either. That's similar to the way parts of Ann's body work.

Despite the things that Ann can't do as well as the others, she discovers there's one thing she can do better. On a field trip to a pool, Ann jumps in fearlessly with her floaties and swims weightlessly, gracefully around the pool, while the other kids stand hesitantly on the edge, afraid to test the water.

In *Nobody Knows!*, age six Ann grapples with not being understood—literally—because she can't verbally communicate what she needs to. Her Mum gives her juice instead of the milk she desires; she wants to play with a favorite toy schoolbus, but Dad hands her some blocks instead. Fortunately, her ally Jay shows up, and they proceed to have an afternoon of outdoor adventures. Jay "understands" Ann, even when words aren't exchanged and often serves as her interpreter to the rest of the world.

The story ends on a positive note. During a horseback riding lesson, Ann finally is able to give a verbal command to her horse, Josie. She says, "www...walk on." And Josie does exactly that.

In *Here's What I Mean To Say...*, Ann, now nine, discovers the liberating power of assistive technology. Her father brings home a computer, which Ann slowly learns to manipulate with a foot pedal, as her fine motor skills make typical keyboarding difficult. Unexpectedly, she hits a key and the computer "speaks" the words she has typed on the screen, which leads to an entire child-like misunderstanding. Ann thinks there's

an angel in her computer; in fact, it must be her "gardening angel", which is around to look after her. No matter, angel or just Bill Gates, the computer opens up all kinds of possibilities for being understood by the people around her.

In all three stories, there are great touches that get to "the heart" of CP. Ann takes a ride in a toy car with her feet propelling it, laughing because "it feels like speed and free". She knows she has "words inside her head, but people don't seem to hear them like she does." She imagines living life as a turtle, who nobody ever expects to talk; or as an alligator, which would cause people to just run away, avoiding the discomfort of not being able to interact successfully.

We hear her thought processes, and they are often quite funny. She confronts a stranger who asks, "Cat got your tongue?" Ann thinks, "No cat had my tongue. What kind of silliness was that? My cat stole my lunch once off the dining room table but he's never stolen my tongue. My cat has his own tongue and my dad says it's icky."

The illustrations by Darlene Toews also "grow" with Ann, becoming more sophisticated as the series continues. Even when they're rudimentary, there's lots of detail that kids will enjoy discovering as the stories progress.

These books are not new, but they are timeless. In a simple, heartfelt way, they introduce readers to the world of cerebral palsy as seen through the eyes of an otherwise ordinary kid.

For more information about these books, please visit www.gemmag.ca. Ms. Yates' books are also available on Amazon, in hard copy and digital formats. Ms. Yates also has a more recent Young Adult novel, called *Lucky Lou Gets Game*, about a 17-year-old female with cerebral palsy, who learns to play baseball in the midst of navigating her life as a teenager with a disability.

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

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Nashville Airport Radisson Hotel

A MOTHER WHO GOT SO MUCH MORE

BY MARY JANE GEORGE My husband and I were expecting our second child in July of 2009. We had not done an ultrasound to see what we were having, so when we got close to delivery the doctor asked me what I wanted 'it' to be—I just smiled and gave the universal answer ...

"It doesn't matter whether it's a girl or a boy, I just want it to be healthy and to have 10 fingers and 10 toes."

Of course, that's what I would have said. That's what any mother would have said. Mothers lie.

Truth be told, every mother wants a whole lot more. Every mother wants a perfectly healthy baby with a round head, red lips, button nose, beautiful eyes and satin skin. Every mother wants a baby so gorgeous that people will pity the Gerber baby for being so ugly.

Every mother wants a baby that will roll over, sit up and take those first steps right on schedule (according to the baby development chart).

Every mother wants a baby that can see, hear, run and jump. She wants a child that can smack the ball out of the park and run so fast that the other kids are left in the dust.

Some mothers get babies with something more...

Some mothers get babies with conditions they can't pronounce, a spine that didn't fuse, behaviors they can't explain, an extra chromosome or a palette that didn't close.

Most of those mothers can remember the time, the place, the shoes they were wearing and the color of the walls in the small, suffocating room where the doctor uttered the words that took their breath away...In some ways, it was a relief to have a name to put with the pain, but at the same time you knew that your world was about to completely change.

Some mothers leave the hospital with a healthy bundle, then, months, even years later take him in for a routine visit, or schedule him for a well check, and crash head first into a brick wall as they bear the brunt of devastating news. It can't be possible! That doesn't run in our family. Can this really be happening to us?

I am someone who watches the Olympics for the sheer thrill of seeing finely sculpted bodies. It's not a lust thing; it's a wondrous thing. The athletes appear as specimens without flaw—rippling muscles without an ounce of flab or fat, a powerhouse of strength with lungs and limbs working in perfect harmony. Then the athlete walks over to a tote bag, rustles through it and pulls out an inhaler.

In that moment, I'm beginning to learn—there's no such thing as a perfect body.

Everybody will bear something at some time or another. Maybe the

affliction will be apparent to curious eyes, or maybe it will be unseen, quietly treated with trips to the doctor, medication or surgery.

I used to watch with keen interest and great admiration the mothers of children with serious disabilities and wonder how they did it. Frankly, those mothers used to scare me.

How do they lift that child in and out of a wheelchair 20 times a day?

How do they not cry for their child when it struggles or is in pain?

How do they monitor tests, track medications, regulate diet, prepare for their child's surgery, and serve as the gatekeeper to a hundred specialists and insurance companies hammering in their ear?

I wondered how they endured the clichés like "He's a Gift from God" or "God has made him Special for a reason". I even wondered how they endure the praises—saluting them, painting them as a hero and a saint—when they know they are just ordinary mothers just like you. They snap, they bark, they bite.

Those mothers didn't volunteer for that. They didn't jump up and down in the motherhood line yelling, "Choose me, God! Choose me! I've got what it takes."

Well, I never imagined in a million years that I would be one of those mothers I just spoke about.

I will never forget the day my second child was born. The look on my husband's face is forever implanted in my mind...when the doctor held up our new baby and said, "Dad, tell her what the sex is." Bobby's face told me two things...first, that I had just given birth to a precious baby boy and, second, that there was something wrong. In that silence, a million thoughts ran through my mind. I kept asking Bobby what was wrong...and received no answer...I just saw the tears forming in his eyes...then, after what seemed like hours, he mumbled, "He has a short leg but he is ok."

The day after Owen was born we had x-rays taken and met with a pediatric orthopedic surgeon, who told us that his condition was called Proximal Femur Focal Deficiency, PFFD for short. The statistics are that 1 in 50,000 births have some type of limb (arm or leg) discrepancy. Basically, Owens's right femur was only one-third formed and probably stopped growing around two to four weeks of me being pregnant. This was never detected on my ultrasounds; since we were not finding out the sex of the baby, my doctor really stayed away from that area.

After traveling to Baltimore to see a specialist when Owen was three months old, we learned that his right leg would only grow from the knee down and if we did nothing to correct his condition he would have over a foot difference in his legs. When he was born he had a two-and-a-half-inch discrepancy and now, at 21 months, we have a five-inch difference in his legs.

At our visit back to Baltimore, when Owen was 16 months old, we decided that a prosthetic leg would be the least amount of surgeries and the fastest way to get Owen on the right track.

One of my biggest fears throughout all of this is—did we make the right choice for Owen? But I have to have faith and stand behind our choice and know that God is there with us every step of the way.

We will have a surgery next Summer at age three to get him fitted for his first prosthetic. This prosthetic is not the typical one most people are probably familiar with. Owen's leg will be turned around backwards so that we can use his ankle as a knee then fit him with a below-the-knee prosthetic for more mobility. In the mean time, he wears a shoe lift and we go to therapy three times a week in hopes that he will be walking by age two. That is only three months from now. I am ready for the day when Owen takes my hand and says, "Come here Mommy."

After my husband and I finally came to grasp Owen's short leg, we began to enjoy the little things in life and treasure our blessing that we did in fact give birth to a healthy baby boy who will see, hear, run and jump just liked we hoped for before he was born. Owen will just do things in his own time and in his own way.

Owen is not his disabilities; he is a beautiful child who does not know any differently.

What I was not prepared for, as a mother of a child with a disability, was the learning delays that Owen has faced thus far. Probably the lowest part of this whole journey so far was when Owen was nine months old and we went for his well check-up.

His doctor was going through all the typical age appropriate questions of what your child should be doing by nine months: can he sit up unassisted/is he crawling or pulling up to cruise/does he understand the word no/can he use his thumb and index finger to pick up food/does he reach to be picked up/does he wave hi or bye/does he point at objects/can he...? I had to stop her as tears filled my eyes...I could not answer YES to any of her questions. In that moment, I realized we were not just dealing with a short leg, that this journey would be a lot harder than I ever imagined.

Now, I realize that not all kids master the milestones at the correct time and that all children are different. But I will say that was the day my outlook on life changed forever. I wanted to question God and ask Him "Why Owen?" Instead I had to put my faith totally in Him and learn to be patient. I know that Owen will accomplish anything and everything in life but it must be at his own time and pace.

Owen has had and will continue to have several learning delays—he did not sit up until almost 10 months, he didn't crawl until 16 months, he is not walking or talking at 21 months, his vocabulary is only about four words, and he has just started pulling up to stand at 20 months.

The whole learning process for a child is so amazing. Every milestone is a stepping-stone for something else. Most children won't crawl before they sit up...they won't walk before they crawl...their speech won't develop until they are cruising or walking. I have learned a lot about development from Owen's therapists. Once children start sitting



Photo by Courtney Helton Photography, Nashville

Owen George

up and crawling, they develop the muscle tone and flexibility to do certain tasks. The reason Owen could not self-feed, reach to be picked up, wave or point all related back to him not crawling. His speech delay is because he is not walking.

I never realized this with my first son. I always seemed to push him to the next level once he completed a task. I never stopped to appreciate what he had just accomplished. I think we all can relate to that. We push and push our child to crawl then to walk. Then, before we know it, they are running and we just wish they were still sitting still.

What I learned through all of this is to cherish the little things in life and that EVERY milestone is precious.

Children teach us so many things if we open our eyes and let them. Even those lessons we may not want to learn. I would not be as thoughtful or considerate if it were not for Owen. I never would have learned acceptance, respect and understanding. I choose to learn what I can from Owen and strongly believe that my life has changed for the better all because of him.

I thank God every day for Owen. He is such a blessing in my life and has made me a more patient and loving mother, wife and friend. I also thank God for the wonderful support group that we have! My family, my church families, Owen's doctors and therapists, the many friends of children with disabilities that I have met. I could not be as strong as I am today without their support, prayers and love.

I'm a mother who wanted a healthy baby with 10 fingers and 10 toes, and I am a mother who got so much more.

Mary Jane George writes about her son on her blog at <http://owensfootsteps.blogspot.com/>. The George family uses the Family Support Program to help with the cost of traveling for Owen's medical treatment.

AN EXPLANATION OF DUAL CREDIT AND DUAL ENROLLMENT

COMPILED BY GAYLE FELTNER

Career and Technical high school students may receive

postsecondary (technology center, college or university) credit for courses that they take during their high school years. This opportunity, which is already in place for many programs and schools across Tennessee, was established under the federal Career and Technical Education (CTE) Perkins IV legislation, which requires school systems to facilitate the transition of CTE students into baccalaureate degree programs. The opportunities also are required by Tennessee State law, passed in 2007.

This credit may be received through dual credit or dual enrollment. Dual credit and dual enrollment are different, and frequently confused. Dual credit is a postsecondary course or a high school course aligned to a postsecondary course that is taught at the high school by high school faculty for high school credit. Students are able to receive postsecondary credit by successfully completing the course, plus passing the assessment developed or recognized by the granting postsecondary institution. The institution will grant the credit upon enrollment of the student.

Dual enrollment is a postsecondary course taught, either at the postsecondary institution or at the high school, by the postsecondary faculty (may be credentialed adjunct faculty), which, upon successful completion of the course, allows students to earn postsecondary and secondary credit concurrently. The student must meet dual enrollment eligibility under the Tennessee Board of Regents and University of Tennessee policies.

Articulation agreement is another term which often has been used to describe cooperative written agreements between high schools and postsecondary schools, in which students may be eligible to receive postsecondary credit while in high school. Articulation agreements within Tennessee are usually between individual postsecondary schools and secondary schools or school systems. Their provisions vary with the individual agreements. For additional information, contact a career and technical education director for the school system, a school counselor or a related teacher at the high school.

A special note for parents and students: Many courses meeting dual credit, dual enrollment or other articulation criteria are available through Tennessee secondary and postsecondary schools. The courses may be offered as part of a program of studies. Check with the resident high

school to determine eligibility for courses, availability of courses, course or credit requirements, and cost, if any.

The Tennessee Dual Enrollment Grant pays for one class at \$300 each semester, \$600 per year (Fall-Summer). Juniors and seniors are eligible. The following definitions were approved by the P – 16 Council of Tennessee on June 2008.

DUAL CREDIT

- **College Credit**
High school student receives high school credit and can receive postsecondary credit by successfully passing the course and passing a final assessment. The institution grants the credit upon enrollment of the student.
- **Credit Transfer**
Postsecondary credit can only be used at the issuing institution. Tennessee Technology Center (TTC) credit can transfer statewide to any other TTC institution offering the same program.
- **Instruction and Instructor**
Course is a high school class.
Instructor is a high school teacher.
Course content and assessment are approved by college.

DUAL ENROLLMENT

- **College Credit**
Student can earn both high school and postsecondary credit upon successful completion of the course.
- **Credit Transfer**
College credit can be transferred to other institutions.
- **Instruction and Instructor**
Course is a postsecondary course that may be taught at either the high school or the postsecondary institution.
Teacher must be a postsecondary instructor (may be credentialed adjunct faculty).
Course content and assessment are managed by instructor.

For more information, visit <http://www.tn.gov/education/cte/ad/clupos/cludulcrd.shtml>.

Gayle Feltner is transition consultant with the Department of Education, Division of Special Education.

TENNESSEE DISABILITY
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SAVE THE DATE

**The 2012 Tennessee
Disability MegaConference**

will take place **May 31st**
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MICROBOARDS AS A SUPPORT MODEL

BY JAN ROSEMERGY

Microboards are functioning well in Tennessee. That is the conclusion of a study by Vanderbilt Kennedy Center University Center of Excellence in Developmental Disabilities (VKC UCEDD) researchers that was initiated and funded by the Tennessee Council on Developmental Disabilities. Study authors were Marisa H. Fisher, Ashley Terrell-Rea, Allison Summer and Robert M. Hodapp, PhD, professor of Special Education and VKC UCEDD director of research.

In the U.S., Tennessee has been at the forefront of implementing microboards as an alternative to traditional service models. The concept, which originated in Canada in the mid-1980s, is a way to form a tiny, nonprofit organization and receive agency-level funding to provide supports for the focus individual.

The focus individual and others close to that person (for example, family members and close friends) comprise a board of directors who work together to make decisions. The members are a natural circle of support carrying out a person-centered planning process. The individual and microboard have the freedom to make life decisions, and the authority to receive and spend public funds and recruit, supervise, and terminate paid support staff.

The study combined information from in-depth interviews with four microboards, identified by the Tennessee Association of Microboards and Cooperatives, Inc., and from a Web-based questionnaire completed by many of the State's 30+ microboards that provide home and community based services. The four microboards were located across the State, were organized and operated differently, existed for differing amounts of time and served individuals with different needs.

Board members, direct support professionals and focus individuals themselves all saw microboards as a welcome addition to the service

delivery system. For focus individuals, microboards allowed them greater degrees of choice, independence and self-determination. Board members and direct support staff also reported that the focus individuals they worked with made behavioral gains.

Board members reported that microboards were an important, successful part of their lives. It allowed them to serve their loved ones in concrete, effective ways. By selecting, hiring and supervising their own direct support professionals, microboards were able to create another "family", a word that microboard members and their direct support professionals used often. For direct support professionals, microboards proved a more fulfilling way to work.

Challenges are several. Forming a microboard is difficult and time-consuming, and serving as a microboard member is a long term commitment. Anxiety was expressed about potential State funding cuts. The study cautioned that, as with any service model, not all microboards may be successful.

Future directions are to determine which internal and external factors help or hinder effective microboard performance, to use those factors in developing and evaluating microboards, and to scale up what seems to be an effective service-delivery option for many individuals with disabilities.

For information on microboards, contact the Tennessee Association of Microboards and Cooperatives, Inc. at tmicroboards.org. For a copy of the report, contact errol.elshtain@tn.gov, or call 615-532-6615.

Jan Rosemergy is director of Communications and Dissemination, and deputy director of the Vanderbilt Kennedy Center.

This article first appeared in Vanderbilt Kennedy Center's Discovery magazine, Summer 2011, and is reprinted with permission.

BREAKING GROUND

Tell us what you think – all year long!

In the past, we've included a hard-copy survey in one of our *Breaking Ground* Spring issues, asking you to send us your comments about what you like the best, and the least, about our publication. Although we appreciate the few comments we receive each year, and try to implement those suggestions, we would love to have more than a "few" readers' responses!

We want our readership to know that you can tell us what's wrong, what's right, what we should do more of, what we should do less of, or just your opinion of a particular story or feature. Anytime you want to. All year long.

So, please speak your mind by contacting us at
breakingground@vanderbilt.edu

or by taking the on-line survey at
www.breakingground.org

Thanks for reading!

It's all about connection. Thanks to a connection between Alexander Santana, coordinator of the Multicultural Program for Tennessee Disability Pathfinder, and the Sports 4 All Foundation, nine families from three countries as far-flung as Bhutan, Iran and Mexico are coming together once a week for an exercise class at the Coleman Community Center on Thompson Lane in Nashville. The class is part of Sports 4 All's Project HEALTH (Helping Every American Learn to be Healthy), an adaptive exercise and nutrition program for all abilities. When Mr. Santana learned about the project, he saw an opportunity for the refugee and immigrant families he assists through Pathfinder to connect with each other and with English-speaking families of individuals with disabilities.

Pathfinder's expanded Multicultural Program is dedicated to serving all of Tennessee's refugees and immigrants in need of disability information and community resources. Mr. Santana said that in their native cultures, movement would have been part of everyday life for these families. The individual with a disability would naturally have been taken care of within the safety of the community. Here, however, the families are largely isolated in the unfamiliar environs of an apartment complex. Seven of these families spent time in refugee camps before being resettled in Nashville. While they are safe here from the oppression they fled at home, they no longer have the community support they once knew. Individuals with disabilities, particularly those beyond school age, are apt to be stuck in an apartment all day. They are far less likely to get exercise or socialization. Furthermore, because a family member who could be working and bringing in income usually has to stay home from work to care for the individual, the entire family is affected.

The classes at the Coleman Center help keep everybody healthy, physically and emotionally. "At the beginning," Mr. Santana said, "We had the concern that some families wouldn't like the classes for some cultural

Photo by Sports 4 All Staff



issue." He worried about the stigma in some cultures surrounding disability, not to mention the language barriers. Happily, what he discovered was that the families loved the classes. The participants "were laughing, they were having fun, and they liked it. And the family members noticed that."

Mr. Santana pointed out that "These people have just come to this country. It's a good experience for them to be part of something that is not only American but is related to disability." The inclusive environment makes them more comfortable with having a family member with a disability because they are with other families who are in the same situation. In this atmosphere, cultural differences and language barriers fade, enabling families to connect at deeper places on common ground.

The vision of Sports 4 All is to help individuals live healthy lifestyles, whatever their level of ability. The program primarily serves adults, although children are welcome. Participants in the multicultural class range in age from 21 to 70. Generally speaking, there is a woeful absence of adult day services for those who have aged out of school, and most of what is

available is only for those on the Department of Intellectual and Developmental Disabilities Medicaid Waiver. But the classes through Sports 4 All are free.

In addition to the Coleman Center, there are classes at McCabe Park in West Nashville, Hartman Community Center in north Nashville and at Sports*Com in Murfreesboro. The exercise might be strength training, yoga, dance, or relay races. All are designed to teach fitness skills that participants can take home and integrate into daily life. Sports 4 All staff and volunteers are on hand at a ratio of 1:5, assistant-to-participant, to insure the safety of all. The organization is in the process of acquiring workout clothes for Mr. Santana's group through their Equipment Endowment Program. While transportation has been difficult, Mr. Santana is in the process of signing everyone up for AccessRide, Nashville's para-transit program.

Once a week at the Coleman Center, families from different backgrounds and vastly different regions of the world drop their differences just to have fun together. That's connection at its best.

Tennessee Disability Pathfinder has phone, Web and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers and advocates. Pathfinder is a joint project of the **TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES** and the **VANDERBILT KENNEDY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES**.

The class meets from 10 - 11 am on Wednesdays at the Coleman Community Center at 384 Thompson Lane. For more information, or to participate, please contact wellness coordinator Megan Miller at 615-354-6454 or miller@s4af.org. For more about Sports 4 All, please see their Web site at www.s4af.org. The events page is updated regularly.

For more information on Arts and Recreation programs throughout the State, please see the Pathfinder Web site at www.familypathfinder.org.

Nancy W. Muse is information & referral services coordinator with Tennessee Disability Pathfinder.

FOR FURTHER INFORMATION
Tennessee Disability Pathfinder
 English & Español
 (615) 322-8529
 (800) 640-4636

TTY/TDD users:
 please dial 711 for free relay service

www.familypathfinder.org
tnpathfinder@vanderbilt.edu

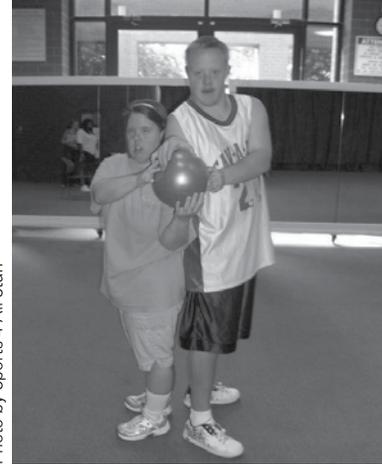


Photo by Sports 4 All Staff

SHARMANE PEARSON: HEALTH INTERN



Photo by Sports 4 All Staff

BY MEGAN GRAF

"I would like the turkey

burger and water. Please hold the fries—they have too much salt and fat," said Sharmane Pearson at a lunch stop on the way back from the 2011 Tennessee Recreation and Park Association Conference, where she was a speaker on behalf of the Sports 4 All Foundation (S4AF), just one of the many duties she encompasses as an intern. It is good health decisions like these that

impressed the Sports 4 All staff so much that they promoted Ms. Pearson from a Project HEALTH participant to her current S4AF Intern position.

Ms. Pearson's first involvement with S4AF was through Project HEALTH in 2009, a program that provides adaptive fitness and nutrition information to people with disabilities. Like many other adults, Ms. Pearson was overweight and looking to improve her lifestyle. As a participant of Project HEALTH, she took an immediate interest in losing weight and living a healthier lifestyle. She emerged as a leader in fitness classes and pushed her peers to embrace a healthy lifestyle as well.

After about one year of being a participant in Project HEALTH, a volunteer position opened in the S4AF office. Right away, Ms. Pearson expressed an interest in this opportunity. Having witnessed her work ethic and go-getter attitude in exercise class, S4AF staff knew Ms. Pearson would be a great fit! With more interaction with the staff, Ms. Pearson began keeping a food journal and became very serious about her workout routines. Due to her dedication to health and wellness, she lost over 10 pounds!

Ms. Pearson's first job with Sports 4 All as a volunteer was to help with Corks 4 Charity, a fund-raising program created by S4AF. It takes in donated wine, champagne and synthetic corks and sells them to raise funds for the organization's programs. Ms. Pearson helps with this process by separating and counting the corks so that they can be shipped. Ms. Pearson also is learning to use a personal computer and enters donors' e-mail addresses into the S4AF system so that we can keep our records up to date.

In the Summer of 2011, Ms. Pearson was promoted to an intern position. In addition to her cork and typing duties, she took on cleaning the office, tying ribbons to thank you messages, creating "Thank You" cards and, her favorite, assisting in leading Project HEALTH classes. Every week during the Summer, Ms. Pearson traveled to Murfreesboro with the S4AF staff to Camp Ability, a program for children with disabilities. Ms. Pearson led healthy activities for children ages 5-21. When asked what her favorite part of her work with Sports 4 All is, Ms. Pearson giggled and said, "Chasing the kids around."

It's not every day that you meet someone who is so dedicated to their job. Ms. Pearson takes extreme pride in her work and won't settle for anything but the best. She doesn't like taking breaks and always wants to complete tasks. She has a strong desire to work and to be productive, which makes her a great asset to the Sports 4 All staff.

The Ms. Pearson I know is greatly different from the diagnosis she received from the doctors when she was born. In 1978, the doctors told her mother, "She will probably never be able to walk or talk. No use in taking her home, just send her to an institution." Ms. Pearson has far surpassed that early judgment. Ms. Pearson is a beautiful, motivated, healthy woman with many accomplishments under her belt. Sports 4 All is pleased to have her as an intern and role model for its organization!

Megan Graf is Wellness and Volunteer coordinator for the Sports 4 All Foundation.

GraceArt goes to Soho. On October 27, 2011, the art work of **Grace Goad**, who lives in Nashville, began a three-week show at the **Soho Digital Art Gallery**. She is one of several artists with autism featured in the exhibit, "THE ART OF AUTISM, An Art Show Featuring Artists on the Spectrum".

Photo by Darren Leow



Left to right: Carl Gershman, Frank Fukuyama, Jean Bethke Elshtain and Martin Palous.



The National Endowment for Democracy (NED) presented its **Democracy Service Medal** to **Dr. Jean Bethke Elshtain** on October 13th in Chicago, Illinois. The Board of Directors of the NED created its

Democracy Service Medal to recognize individuals who have made significant contributions to the progress of democracy around the world. Dr. Elshtain is a polio survivor and lives in Nashville.

Partners 2004-05 graduate **Kelly Sanders**, a traumatic brain injury survivor and licensed massage therapist, graduated from Advanced Nurse Assistant Training, LLC, on October 24th. This training will allow Ms. Sanders to test to become a Certified Nurse Assistant.

Congratulations to **VSA Tennessee Young Soloist** winners **Lake Rise Place** for recently being selected by the Nashville's Mayor's Advisory Committee for People with Disabilities to be the recipient of "Artist of the Year". The award was presented on October 17th.

Photo by Kathy McGee



Jonathan McGee, an Eagle Scout from Maryville, was among the participants at a recent Buddy Walk at World's Fair Park in Knoxville, a fundraiser for the **Down Syndrome Awareness Group of East Tennessee**. Mr. McGee also traveled with his family to New York City in October.

"We went to New York City because Jonathan's photograph was selected out of some that were submitted for the Times Square video for the National Down Syndrome Society," explained his mother, Partners 2000-01 graduate Kathy McGee. The video with Mr. McGee's picture was shown on the giant Jumbotron in Times Square.

Christy Wells-Reece, Partners 2000-01 graduate, was selected for the **Community Advisory Committee** for the **Boling Center for Developmental Disabilities**. Ms. Wells-Reece has started back to school and was appointed Senator At Large at Cleveland State Community College. She recently addressed the full Senate about accessibility issues on the campus.



Paul Bullock, Michael Weininger and Jill Summers.

Students from the Norris Academy, located in Norris near Knoxville, a residential program that provides services for children and youth with Autism Spectrum Disorder and co-occurring mental health diagnosis and behavioral issues, created superheroes for an autism awareness art show. This was the 2nd annual art show to be featured at DaVinci's Pizzeria in Knoxville. Families of children with autism attended, making new friends and sharing an interest of autism awareness, superheroes and pizza!

Carol Westlake, executive director of the **Tennessee Disability Coalition**, announced that the Coalition received a State Implementation Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder. This is a two-year grant that began September 1st. An initial task will be to call together a **Tennessee Autism Planning Council** to provide core leadership to accomplish proposal objectives. The Coalition expects to form workgroups to assist in reviewing existing needs assessments and other data and to undertake community resource mapping.

Photo by Linda Raiteri



Anthony Sledge

Partners 2008-09 graduate **Anthony Sledge**, housing coordinator and home modifications specialist at the Memphis Center for Independent Living, is working to raise awareness about the **Visible Housing Initiative of Memphis**, which, when enacted, will provide simple, inexpensive solutions to housing barriers faced by the elderly and people with disabilities.

PHOTO IDENTIFICATION REQUIRED FOR VOTING

The Tennessee Department of State has launched a campaign to educate citizens about the new photo identification (ID) requirement that will go into effect for elections held in the State after January 1, 2012. "It is very important to us that people understand this new requirement so they are not surprised when they get to the polls next year," Coordinator Mark Goins said.

The new law requires people who wish to vote during early voting or on election day to present valid photo IDs when they arrive at the polls. The law allows people who forget to bring photo IDs to the polls to cast provisional ballots and provide their county election officials with proof of identity within two business days after an election.

People who do not have valid photo identification may get a State-issued ID, free of charge, at driver license offices around the State. People who vote absentee by mail are not required to show photo IDs nor are people who have religious objections to being photographed or are indigent and cannot obtain a State-issued ID without paying a fee. Those voters may sign oaths acknowledging their identities.

To help educate voters with disabilities about the voting process and the new law, the included handout explains what IDs are acceptable, what IDs are not acceptable and who is exempt from showing an ID. The handout also provides other useful information for voters with disabilities.

For additional information about the law, contact our office at 1-877-850-4959 and speak to Cara Harr, our disability coordinator. Groups also can invite their county administrators of elections to come to meetings to explain how the new law will work.



Beginning January 1, 2012, in order to vote during the early voting period or on Election Day, voters must present a state or federal ID containing the voter's name and photograph.

What Photo IDs are acceptable?

- Tennessee driver license with your photo - even if expired;
- United States Passport - even if expired;
- Tennessee Department of Safety Photo ID - even if expired;
- Photo ID issued by the federal or a state government - even if expired;
- United States Military Photo ID, including a Veteran Identification Card - even if expired;
- State-issued handgun carry permit card with your photo - even if expired.

What Photo IDs are NOT acceptable?

- A college student photo ID;
- A photo ID not issued by the federal or state government, such as your discount club or bank card with your photo.

What if I have a Photo ID but I forget to bring my photo ID to vote?

- You will be allowed to vote a provisional ballot, which is a paper ballot, at your polling location and
- Within two (2) business days after the election, you must take your valid photo ID to your local county election commission office for the election officials to make a copy of the ID.

Who does not have to show a Photo ID?

- Voters who qualify to vote absentee by mail;
- Voters who live in licensed nursing homes or assisted living centers and vote at the facilities;
- Voters who are hospitalized;
- Voters who have a religious objection to being photographed;
- Voters who are indigent and unable to obtain photo IDs without paying a fee.

Need Additional Information, Assistance or Have Suggestions?

Disability Law & Advocacy Center of TN at 800-342-1660

Tennessee Disability Coalition at 888-643-7811

Division of Elections

Tennessee Secretary of State Tre Hargett

How can a person with a disability who does not have an acceptable Photo ID obtain one?

- Any person with a physical or mental disability that substantially limits one or more life activities, who does not have a Tennessee driver license, may obtain a free photo ID.
- To obtain this free photo ID, you must take a letter from a Tennessee physician verifying your disability and a document that verifies your identity to one of the Department of Safety Driver License Testing Centers.
- For questions regarding what documents are acceptable to verify one's identity, call the Department of Safety Call Center at 1-866-849-3548.

What if I am indigent and cannot get a Photo ID without paying a fee?

- When asked for your photo ID at your polling place, tell the election worker that you were unable to afford a photo ID, for example, you can't pay for a birth certificate for proof of citizenship.
- You will complete and sign an affidavit, under the penalty of perjury, stating you were unable to afford a photo ID.
- You will then be allowed to vote.

What if my polling place is not accessible?

- You can vote during the early voting period at the county election commission office (Photo ID required); or
- You can file an affidavit with the county election commission office stating that your polling location is not accessible and you wish to vote at the county election commission office on Election Day. The affidavit must be filed at least ten (10) days before Election Day (Photo ID required); or
- You may request an absentee ballot (No Photo ID required).

What if I need assistance when voting?

You have a right to have anyone of your choice, except a candidate or poll watcher, assist you during the voting process. If you need assistance, ask any election official during the voting process and assistance will be given in a bipartisan manner.

EVERY VOTE COUNTS



Division of Elections
1-877-850-4959
tennessee.elections@tn.gov
www.GoVoteTN.com

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