

BREAKING GROUND



A Family's Journey

BY RUTH WISEMAN [3]



TEC PROJECT PROMOTES
COMMUNITY-BASED
EMPLOYMENT [6]



ACCESS NASHVILLE TRAINING
PREPARES VOLUNTEERS TO
SURVEY PUBLIC PLACES [12]



Q&A WITH
ROBERT WATSON [14]

TENNESSEE
COUNCIL



DEVELOPMENTAL
DISABILITIES

CONTENTS

- 3 An Exceptional Gift
- 5 West Tennessee Partners Help Parent Support Group FIRM Up
- 6 TEC Project Promotes Community-Based Employment for Persons with Disabilities
- 7 Exploring the Self-Employment Option for Persons with Disabilities
- 8 Access Nashville Training Prepares Volunteers to Survey Public Places
- 9 Over 300 Gather for Career Day in Cookeville
- 10 Building Relationships with State and Federal Legislators
- 11 "It's a Small, Small World!" Diversity and Disability Resources
- 14 Sex and Disability Q & A with Robert Watson
- 15 Book Review: Healthy Relationships and Safe Sex: Tips for Self Advocates
- 16 News from Pathfinder
- 17 Compass and Partners Train Law Enforcement
- 18 YLF Student Delegates Join Other Youth to Discuss Strategies for Empowerment and Community Change
- 19 Tennessee Spotlight

Cover photos by Ruth Wiseman

CORRECTION TO ISSUE 33 PAGE 9:

Seven of the photos were taken by Tina Marascia, 2006–07 Partners participant.

CONTACT INFORMATION



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AN EXCEPTIONAL GIFT

BY RUTH WISEMAN

PHOTOS BY RUTH WISEMAN

3

I grew up understanding that God does not make mistakes, particularly when it comes to people. We are here for a reason. Many of us are given opportunities which stretch and mold us beyond what we believed to be our capabilities. Others live with very complex challenges, which not only test them, but the people who love them. Jason braved such a challenge and, as his family, we were changed for the better and thankful for the gift of him.

It was evident close to the start that Jason was not a typically developing infant. He had a rough beginning and at four months old we dove into the world of genetic testing to begin to rule out the source of “facial abnormalities” and developmental concerns noted by our physician. The initial tests were negative, which was a relief. The fact that he was not progressing developmentally, however, was not comforting and before the end of his first year we were involved in the early intervention program.



At eight months old, Jason began to exhibit self-injurious behavior, or SIB. It began with him hitting his head on the crib with enough force to break the skin. My husband, Orin, and I padded up his world, which kept him safe from the furniture’s hard edges, but not from himself. Within weeks of the first episode, he began pummeling

himself with great force and damaging his delicate skin. These horrific, episodic acts of violence, which would continue throughout his life, were not only terribly sad to witness, but created a very stressful environment. Orin, our daughter Erica, and I experienced both sides of adrenaline; it fueled his body to do harm, but it also drove us to attend to his needs with the speed of an emergency medical team, no matter the time of day or night.

We did not shy away from seeking advice or asking for help. We networked with parents and staff at The Arc, United Cerebral Palsy, and Jason’s school. Many hours were spent researching at libraries and bookstores; there was no Internet. We also joined a support group soon after he received a diagnosis of autism.

Autism was only one piece of the puzzle, however. In addition, he was diagnosed with mental retardation and microcephaly and our physician suspected some form of Tourette’s Syndrome and Cerebral Palsy. Jason had multiple allergies too, as well as a growth problem—he never managed enough height or weight to be on the average growth chart. Our rounds with the specialists consumed time and involved painful tests, but the answer to the puzzle of his underlying condition was never found. After a year or two we

learned to anticipate that test results would be negative. Seemingly, science had not caught up with Jason.

The results of the developmental tests, which gave him an IQ of 32, did not match Jason’s level of interests, receptiveness or relationships. For example, when taking a break, his favorite movie was *That Thing You Do* starring Tom Hanks and his favorite magazine was *Architectural Digest*, both beyond his years. He enjoyed art with bold colors and chose music to fit his mood. When preparing to run errands, he understood the plan and anticipated the route. Jason also had a marvelous sense of humor, chiming in on family jokes with shouts of glee and giggling along with the rest of us; just one of the gang.

It was our good fortune to have teachers and classroom assistants who nurtured Jason’s interests instead of limiting his opportunities based on written results or physical limitations. With this respect and understanding came trust, and his trust in people was often reflected in the progress he made. In other seasons, we were challenged to help caregivers look past his SIB and test results. We found that circulating a communication notebook between all of the individuals responsible for him during the day was a key to understanding him, particularly as he was non-verbal and could not tell us the whole story.

Following his cues and allowing him the right to say “no” when he couldn’t handle demands was imperative. His nervous system was tied to his SIB, and with great anxiety came the possibility of severe, damaging abuse. It was in his best interest to give him control, and those who loved him and worked with him understood this best. This did not deter us from encouraging progress or setting goals, but we learned that his body gave him cues which we could not see.

Living with Jason and the intricacies of his condition was extremely demanding of everyone’s time. Yet we found it important to remember that he was one person in a family of four people. We were cognizant of the fact that we as a couple and Erica as our daughter required time outside of the demands associated with Jason’s needs. We did our best to balance our after-school, weekend, and vacation time between all of us. To help facilitate this, we were fortunate to be able to rely on family and respite care. With all of this help and a great deal of faith, we managed to build a strong, united family.



CONTINUED ON PAGE 4

WWW.BREAKINGGROUND.ORG

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The complexities of Jason's condition challenged us to not only have increasing patience and physical stamina, but to constantly look beyond his disability to the boy inside. Consciously separating the battle with SIB from the boy reminded us not only how frustrating it was for him, but how brave he was. He was the one stuck in the body that he could not control and he was aware of it. Yet he lived in the moment, enjoying the good times and dealing with the tough times as gracefully as he could. Jason never seemed to lay blame for his ordeal, but sought compassion and security. The example of his life taught those close to him the meaning of unconditional love.



Without any history of severe health problems, Jason collapsed unexpectedly and was hospitalized in February of 2001. For the first time since infancy, his body was free of self-injurious behavior, but lying in a semi-conscious state and experiencing seizures which he had not had before, was not an equitable trade. In spite of the attempts of experienced physicians, some 30 years in practice, Jason died five weeks later at the age of 13.

Learning to live without him has taken time. I think of him every day and his legacy continues to affect who we are. As his mother, I had to come to grips with the fact that much of my energy, creativity, and time were wrapped up in caring for him. Yes, I am so thankful that he is no longer struggling in that body and that I hold on to my faith that we will see him again. Yet, it has also been necessary to allow myself to transition to a new purpose.



I am fortunate to work for the Division of Special Education in Tennessee, which allows me to use my experiences in a professional arena toward the betterment of children and families. In my role as a consultant for the Office of Early Childhood, I provide

technical assistance related to Part C of IDEA (Individuals with Disabilities Education Act), which addresses families with children birth to three years old. My family's experiences with Jason and my background as a special educator and service coordinator help me to convey the importance of enhancing the ability of families to work with their children with disabilities, as I provide training and technical assistance to those within Tennessee's Early Intervention System (TEIS). As a FACT (Families as Classroom Teachers) participant, I also share my story with university students, who may in turn work with children with disabilities and their families. Through these avenues, it is my hope that people will know that families and communities can grow stronger through the challenge of a disability.

Tennessee Early Intervention System

TEIS is devoted to providing services to families of children with special needs in the most natural environments, close to home, and with children of all abilities.

TEIS is committed to finding and to helping children with special needs, birth to three years of age, and their families.

For information, contact TEIS at:

Box 5012
Tennessee Technological University
Cookeville, TN 38505
1-800-852-7157

Cindy Mayer at cmayer@tntech.edu

For information about [Tennessee's Family Support Program](#), contact:

Jan Coatney
Andrew Jackson Building, 15th Floor
500 Deaderick Street
Nashville, TN 37243
Telephone: 615-532-6552
Fax: 615-532-9940
Email: jan.coatney@state.tn.us

For information about Tennessee's Respite Programs, contact:

Tennessee Respite Coalition

Kelly Tipler, Executive Director
P.O. Box 90433
Nashville, TN 37209
Telephone: (615) 269-8687
Toll Free: 1-888-579-3754
Fax: 615-469-7791
Email: info@tnrespite.org
www.tnrespite.org

Tennessee Respite Network

Laura Fair, Respite Program Coordinator
1315 8th Avenue South
Nashville, TN 37203
Telephone: 615-269-7855
Toll Free: 1-888-269-7855
Email: TVC@TNVoices.org
www.tnvoices.org

WEST TENNESSEE PARTNERS HELP PARENT SUPPORT GROUP FIRM UP

BY NED ANDREW SOLOMON

Partners in Policymaking™ graduates Robin Stevens, Laurel Ryan and Jawanda Mast put together their energies and networking skills to create The FIRM, which stands for Family Information and Resource Meetings. Their idea was to start a regular family support group in the Mid-South that would augment, not be a substitute for, existing agencies that support families.

The group elected not to be disability specific, but rather open to all families who deal with the issue of disability, whether it be a diagnosed condition, an unspecified developmental disability or a chronic condition. The group also planned to offer programs that might be important to families across all age groups.

“...we gain inner strength and build community support through partnerships.”

An early organizational meeting included representatives from TIPS (Tennessee Infant Parent Services), Down Syndrome Association of the Mid-South (DSAM), UT Boling Center for Developmental Disabilities, Fetal Alcohol Syndrome Support Group, Agape and Collierville Parks, Recreation and Cultural Arts, with input from folks who could not attend. It was decided that the initiative would focus on research-based information, and that the informational meetings would work best on a quarterly basis. At that point, individuals representing different agencies volunteered to be the organizers for the quarterly meetings, which would take place in July, October, January and April.

With two well-attended meetings under its belt, it appears The FIRM has landed on solid ground. So far, attendees learned about

preparing for IEP (Individualized Education Program) meetings and disability-related resources and agencies in the community. Upcoming meetings will cover financial planning, guardianships and conservatorships.

The meetings are open to anyone who might benefit from the information being offered and there is no cost to attend the programming. “I believe it is a benefit to our families first and foremost because it provides needed resources and information,” says Jawanda Mast. “Second, it is another networking opportunity. I met a Hispanic family at the first FIRM that had a baby with Down syndrome. They weren’t aware of our organization (DSAM) and we were able to provide them with some resources in Spanish.”

The list of program partners has grown too, adding The Harwood Center, Special Mom’s, Memphis Fetal Alcohol Spectrum Disorders Support Network, Baptist Pediatric Rehab, Someone to Lean On Support Group, the Memphis Respite Voucher Program, Mid-South Arc, Special Kids and Families, Inc., United Cerebral Palsy of the Mid-South and (STEP) Support and Training for Exceptional Parents.

“I think you build strength in your community through positive partnerships,” said Ms. Mast. “While we must always advocate for issues specific to our disability, we gain inner strength and build community support through partnerships.”

For more information, please contact DSAM at 901-547-7588 or at dsaminfo@yahoo.com, or Laurel Ryan at the Boling Center at 901-448-3737.

Ned Andrew Solomon is the director of Partners in Policymaking™



<p>When? May 31 – June 2, 2007</p> <p>Where? Nashville Airport Marriott</p> <p>Why? Workshops and interactive sessions on a variety of disability-related topics presented by local and national speakers</p>	<p>How? For more information including registration forms please visit the conference Web site at:</p>
	<p>www.tndisabilitymegaconference.org</p> <ul style="list-style-type: none"> • EVENING ENTERTAINMENT • • NETWORKING OPPORTUNITIES • • INFORMATIVE EXHIBITS •

TEC PROJECT PROMOTES COMMUNITY-BASED EMPLOYMENT FOR PERSONS WITH DISABILITIES

BY ALICIA CONE

Through a challenge grant to the Tennessee Division of Mental Retardation Services (DMRS) from the Council, the Tennessee Employment Consortium (TEC) was established. The challenge to the DMRS in July, 2001, was to increase to 25% the number of people served who are in community-based employment.

One of the first tasks, and one of the absolutely hardest TEC undertook, was to develop a definition of employment for the purpose of this grant project. Our goal was to push the system to provide real jobs, for real wages in a person-centered manner. The definition developed is "Employment is paid work based on competitive wages and benefits commensurate to the job and responsibilities, occurring in an integrated community setting, and that encourages a person to work to their maximum choice and potential. The goal is minimum wage or higher, however, an individual may work and earn less, based on how their specific job is developed."

The definition further defined the components of employment as including some combination of the following:

- Paid work the person wants/chooses to do.
- Ongoing supports, both formal (employment provider, technology, etc.) and natural (co-workers, friends, family) based on the person's needs.
- Demonstrated respect for people's choices by assisting them to find and change jobs as their interests and skills change.
- Meeting the individual's level of satisfaction.
- Developing and implementing a skill or career plan and opportunity for professional development and advancement, if a person chooses.
- A job for everyone who wants one.

TEC has accomplished much. However, the two most important outcomes are the number of people who actually got jobs, and the number of people trained to better support people in their jobs.

The number of people over age 22 served by DMRS who were employed in real jobs in the community increased from 1,108 in

March, 2002, to 1,542 in December, 2005. This reflects an increase of 434 people in real jobs.

Training was implemented on several fronts:

1. 2,706 people went through the TEC developed, DMRS approved Job Coach Training.
2. 136 trainers were trained in the area of Job Coach Training.
3. 57 people went through Advanced Job Coach Training
4. 163 people participated in Project Income, a training for people with disabilities and family members about employment and the benefits of employment.



In June of 2006, TEC received some much deserved national recognition. The Institute on Community Inclusion (ICI) at Boston University—the Massachusetts University Center on Excellence in Developmental Disabilities—is a nationally recognized research center, especially in the area of employment. Based on the ICI analysis of Tennessee's integrated employment system, TEC was identified as a Promising Practice in Integrated Employment.

We leave you with some personal quotes from individuals who participated in the TEC project.

- "I really like having something to do now. I like my co-workers and everything I do at work. So far, there is nothing about my job I don't like. Getting a check is the best."
- "I love my job. I love my friends at work. I love my girlfriend. I get to take her out to dinner when I get paid."
- "It makes me feel good that I can make something of myself. I make money to buy things and go places."
- "It means I have more money to buy things I want. Maybe I can get an apartment some day."
- "The job coach helped me through the beginning of the job and found me the best job ever."
- "I like mowing and would like to have more yards to mow. Beverly (job developer/coach) did a great job."
- "I love my job. It's better than sitting up in the workshop all day."
- "I want to work two jobs!"
- "The best part about my job is just coming to work. I can't wait till I get up and get ready to spend the day with people I work with. They are all so nice to me in so many ways."
- "My job makes me happy because it allows me to be around my friends and co-workers and gives me opportunities to learn new jobs."
- "Working helps me stay active and gives me a place to go where there are people and I am not by myself; it keeps me motivated."

The following is an excerpt from a Cary Griffin and Dave Hammis book on self-employment that sheds some light on its importance as an employment option for people with significant disabilities:



Jessi Garner

"Self-employment for individuals with disabilities represents another Customized Employment option and has its roots in the Supported Employment processes of matching a person's dreams and talents to economic activity, earning wages commensurate with others, and designing support strategies that promote a successful tenure.... Self-employment is also a rehabilitative option under the Rehabilitation and the Workforce Investment Acts (WIA). Both systems can help a person with a disability purchase business equipment and/or assistive technology, training, and the supports necessary to run their business (e.g., legal, marketing, accounting). The Social Security Administration (SSA) is also actively promoting the use of business ownership to stimulate employment of individuals with disabilities, through the Plan for Achieving Self Support (PASS)."

The Council realized that self-employment was an underutilized option for people with significant disabilities, and after initial research, released a Call for Application focusing on self-employment in the Summer of 2003. The goal of the project was to develop self-employment expertise among employment service providers in order to increase the number of people with disabilities who were able to start their own businesses.

In order to accomplish this goal, three pilot sites were selected: in the West, The Star Center; in Middle, Community Options; in East, The East Tennessee Technology Access Center (ETTAC). Each pilot site was asked to support a minimum of two people per year in starting their own businesses, with the goal of 18 businesses up and running during the life of the three-year project. Each pilot site was expected to develop the expertise necessary to continue to help people with disabilities achieve self-employment long after the grant project ended. The grantees received training and technical assistance from Cary Griffin and Dave Hammis to develop this expertise, and were taught how to utilize tools such as person-centered planning, business community involvement/outreach, individual budgeting, fiscal intermediary services, Social Security work incentives, marketing, and microenterprise/small business development strategies.

The demonstration project concluded its third year June 30, 2006, and it seemed a good time to reflect and evaluate what was learned from the project. First, what did the project accomplish over the course of the three years? Most importantly, 11 businesses were started.

EXPLORING THE SELF-EMPLOYMENT OPTION FOR PERSONS WITH DISABILITIES

BY ALICIA CONE

These businesses included: a fitness center, wheelchair modification, vegetable and bedding plants, equipment sales, photography, computer repair, concession stand, shitake mushrooms, reflexology, art education, and travel bags.

For the record, two of the businesses have closed and four are still "getting off the ground". Still, this is a success, especially because nearly 80% of all new start-ups close in the first year of business.

We also are proud that four people who started down the self-employment road realized during the "Discovery" phase that supported employment was their preferred option. In total, 15 people are now employed through their chosen option as a result of this demonstration. Another 55 people were supported to explore self-employment as an option, and may choose this avenue in the future.

Each pilot site sponsored Griffin and Hammis trainings in their region on a variety of self-employment topics, such as marketing, pricing, Discovery, SSI/SSDI issues and self-employment, and business plan development. These trainings were open to the community, which allowed another 355 people to be trained in various aspects of self-employment over the course of the project. Lastly, 748 people were educated about the self-employment option through outreach efforts of the three pilot sites.

So what did we learn through this effort? Corporate culture can change and did change. Even if self-employment does not seem like a natural fit within an agency, it can become a natural fit over time, especially if there is support and direction from the top leadership down. Providers need to have a broad understanding of all available employment options and the skills to support any employment option that is sought. The good news is that those skills can be developed.

In the near future, the Council will continue its self-employment activities. Next steps include conducting meetings with key state agency stakeholders (e.g., Division of Rehabilitation Services, Division of Mental Retardation Services), exploring self-employment barriers and resource development with the Tennessee Employment Consortium (TEC), and developing strategies with our partners to get providers the technical assistance, training, and resources they need to support people they serve in developing their own businesses.

PHOTO BY DARYLL MCGUIRE

ACCESS NASHVILLE TRAINING PREPARES VOLUNTEERS TO SURVEY PUBLIC PLACES

BY JENNIFER LEGG &

CAROLE MOORE-SLATER

PHOTOS BY CAROLE MOORE-SLATER

THE ACCESS NASHVILLE TRAINING PROJECT BEGAN IN 2004

when a diverse group of individuals from the disability, business, government, and aging communities joined together and decided to train community volunteers to gather "accessibility-friendly" information about restaurants, hotels, and entertainment attractions in Nashville. This project is not intended to assess compliance with the accessibility requirements of the Americans with Disabilities Act (ADA). Simply, the group decided that information about establishments for persons who are blind, deaf, or use a wheelchair needed to be available so that all people could make appropriate and comfortable choices about where to eat, shop, and play in Nashville. Each facility is given an accessibility friendly rating of "Wow", "Good" or "Limited" and this information is placed on the Nashville Convention & Visitors Web site at www.nashvillecvb.com.

I am a student at Belmont University who attended the Access Nashville Training Event at the Adventure Science Center. The event began with a light breakfast of fruit and pastries, which served as a great start to the day!



Jennifer Legg



Volunteers check their surveys

After the introductions, there was a Power Point presentation about the importance of accessibility which included specific items that we would be evaluating when visiting a restaurant, attraction or hotel following the training event. This information was made more relevant when the volunteers participated individually in a disability awareness exhibit at the Adventure Science Center. One participant sat in a wheelchair for the first time, and saw two ramps ahead: one ADA compliant, and the other slightly more elevated. She stated there was not much visible difference when looking at both ramps, but rolling in the wheelchair was a different story! She got stuck halfway up the slightly elevated ramp and was glad there was a rail to grab and an Access Nashville trainer to push her the rest of the way. The exhibit demonstrated other wheelchair challenges, including the user friendliness of placement of wall telephones, counter tops, and the importance of space to maneuver in a facility.

We also had a discussion about "Disability Etiquette" and "People First Language", with an emphasis on personal attitudes about disabilities and the importance of language used in everyday life. For example, a speaker who uses a wheelchair explained that his wheelchair is a "tool", and that no one is ever "confined to a wheelchair".

Then the 35 volunteer participants divided into small groups and informally surveyed the Adventure Science Center. We checked the museum's exhibits to determine if they were wheelchair accessible. Then, we talked with the manager to see if there were tour guides

for people who are deaf or blind, and there were. The Adventure Science Center has a "WOW" rating from Access Nashville.

In closing, there was a discussion about how to approach a manager in an "accessibility-friendly" way. Then we were given yardsticks, surveys, an Access-Nashville t-shirt, a clipboard and a list of a few places to survey, and sent on our way. Even though I went to the event with some apprehensions, it turned out to be a wonderful experience!

Jennifer Legg attends Belmont University and is doing a field placement in the Tennessee Disability Pathfinder office. Carole Moore-Slater is the director of Disability Pathfinder.

Disability Pathfinder has a grant from the Tennessee Council on Developmental Disabilities to promote Access Nashville with plans to expand this program to other areas of the State. For further information about Access Nashville and how to replicate this project in your community, please visit www.accessnashvilleonline.org or contact Suzanne Ezell at 800-640-4636.



OVER 300 GATHER FOR CAREER DAY IN COOKEVILLE

The Upper Cumberland Career Center, Cookeville Noon Rotary Club and Upper Cumberland Human Resource Agency (UCHRA) hosted the 2nd Annual Career Day for persons with disabilities on Wednesday, October 25th at the Leslie Town Center in Cookeville. Representatives from businesses, employment agencies, schools, social service organizations, and disability-related State and advocacy agencies, including the Council on Developmental Disabilities, were present to provide information and resource materials. Professionals in the field of disability employment, training, rehabilitation and other programs offering assistance for persons with disabilities gave presentations throughout the event, while participants visited exhibit booths.

The annual event drew more than 300 people, including 200 high school students, 16 exhibitors, and representatives from 10 school systems. "We are discovering a growing awareness of the needs of persons with disabilities, and we are seeing an increase in job opportunities and assistive services for them," said Charles West, UCHRA Disability Navigator and coordinator of the event. For further information about this initiative, or to participate in next year's event, please contact Charles West or Danielle Cason at 931-520-8733.

BUILDING RELATIONSHIPS WITH STATE AND FEDERAL LEGISLATORS

BY WILLIAM EDINGTON
& ALICIA CONE

WE ENCOURAGE OUR READERS TO DEVELOP RELATIONSHIPS WITH THEIR STATE AND FEDERAL POLICYMAKERS, AND TO EDUCATE AND ADVOCATE WITH THOSE POLICYMAKERS FOR THE ISSUES THAT ARE IMPORTANT TO THEM. IT IS OUR HOPE THAT THESE “HOW-TO” POINTERS WILL FACILITATE THAT ACTIVITY.



Plan ahead.

Always make your appointment with your legislator well in advance. Explain your purpose and whom you're representing, if you are representing an organization.

Plan your presentation.

- Explain the extent of need for the service or intervention you're seeking.
- Know the facts about your issue.
- Familiarize yourself with any issue talking points.
- Be familiar with other legislators already supportive of the idea or a piece of legislation.
- Stay focused and avoid side stories.
- Know what you want to get out of the meeting and don't lose sight of that.
- State your position and how you would like the member to vote/act on an issue.
- Share personal stories.
- Be factual, not emotional.
- Keep your message brief, to the point, and simple.
- Use your own style, but always be courteous, realistic, and professional.
- Make your pitch short... three minutes or so.
- Practice your pitch!

Always be straightforward.

Policymakers won't think you're rude for stating what you want, and may think it odd if you don't. Part of their job is to be asked, and part of your job is to ask!

Always be honest.

Gaining trust is critical in building a relationship with your legislators and public policymakers. Honesty is an essential component of creating that trusting relationship.

If you don't know, say so.

If you're asked a question and don't know the answer, tell the legislator that you don't know the answer. But add that you would be happy to look into the issue and provide the answer as soon as possible.

Be polite when you're talking to legislators, policymakers, or their staff.

Sometimes, an issue may be so important to us that we're very passionate when discussing it. Don't cross the boundary of politeness by being too aggressive or not showing respect. Remember: legislators are people just like the rest of us. If you are unhappy with the policymaker's response to an issue, express disagreement but don't threaten.

Work on building a relationship with the legislators' staff.

Get to know your legislator's secretaries and other staff. When meeting with a legislator, be sure to thank the staff for their assistance and making the appointment possible. Show appreciation for the staff's helpfulness.

Do not underestimate the importance of staff.

At the Federal level it is not always possible to get an appointment with a legislator. If you can only get an appointment with a staff person, don't underestimate the importance of the person or meeting. Sometimes this type of meeting can be even more important because it is that person's job to make sure his or her boss has all the facts and gets back to you in a timely manner.

Be a good listener.

Don't interrupt when a legislator or policymaker is speaking. Pay attention to the information being shared—it may prove to be very valuable. Leave time for questions, if you're making a presentation. Find out if the policymaker has heard opposing views. If so, try to find out what the arguments are and what groups are involved.

Do not exaggerate to make your situation seem more critical than it is.

If you exaggerate in explaining a situation to a legislator or policymaker for the purpose of enlisting his or her support and later he or she learns the true circumstances, you will likely lose the legislator's trust and it may be impossible for you to regain a trusting relationship.

Do not put down, criticize, or poke fun of people who may have a different point of view than yours. Focus on the issues.

A positive presentation of your ideas is best. Keep the issue foremost and avoid badmouthing other people or groups.

Express appreciation to the legislator for taking the time to talk to you.

We are all busy people and our legislators and policymakers are particularly busy and have limited time. They will appreciate, as we all do, acknowledgement of their time and attention.

Write a follow-up letter.

Thank the legislator for the opportunity to visit and talk to him or her. If there were questions asked during your meeting that you were not able to answer, provide this information in your letter.

Acknowledgement: These pointers are taken from several resources. Many thanks to the Tennessee Respite Coalition for allowing us to borrow from their Meeting with Senators and Members of the House of Representatives flyer, and Dennis M. Byars, author of Seven Keys for Effective Legislative Advocacy.

William Edington is legislative and public policy coordinator for the Council. Alicia Cone is project research and development coordinator for the Council.

"IT'S A SMALL, SMALL WORLD!" DIVERSITY AND DISABILITY RESOURCES

BY TRACI FLEISCHMAN
& JAN ROSEMERGY

OUR NATION AND OUR STATE ARE BECOMING MORE DIVERSE THAN EVER. The disability community strives to create a service system that is person-centered and family-centered—and increasingly this includes understanding disability from various cultural perspectives, and being able to communicate in languages in addition to English. National resources are available to help us become "culturally and linguistically competent."

As the 16th most populous state, Tennessee shares our nation's diversity. U.S. Census Bureau Quick Facts on Tennessee indicate that our population includes nearly 17% African-American, 3% Hispanic or Latino, and in nearly 5% of our homes, a language other than English is spoken.

Here are some other stats: over 13% of our population is living below poverty. Tennessee has over 1.1 million persons with a disability age 5 years or older. Our population is almost equally split between rural areas and five large metropolitan areas.

Also Nashville is home to the second largest concentration of Kurdish immigrants nationally. Some areas of the State are experiencing "hypergrowth" in Hispanic or Latino immigrants. To truly be "community," we must acknowledge and respect this diversity.

According to the National Center for Cultural Competence, cultural competence requires that organizations "have a defined set of values and principles, and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally." Organizations must "have the capacity to value diversity, conduct self-assessment, manage the dynamics of difference, acquire and institutionalize cultural knowledge, and adapt to diversity and the cultural contexts of the communities they serve." Finally, organizations must "incorporate the above in all

aspects of policymaking, administration, practice, service delivery, and systematically involve consumers, key stakeholders, and communities." Becoming "culturally competent" is a developmental process that occurs over time.

Language or linguistic competence is "the capacity of an organization and its personnel to communicate effectively and to convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities."

The following resources focus on particular populations.

American Indian Disability Technical Assistance Center
aidtac.ruralinstitute.umn.edu

The mission of the American Indian Disability Technical Assistance Center (AIDTAC) is to build the capacity and to support the efforts of American Indian tribes and Alaskan Native villages to develop and implement culturally appropriate laws, policies, cross-cutting infrastructure and direct service programs that assist their members with disabilities to achieve their employment goals, and to live healthy, integrated lives within their communities.

AIDTAC operates five training and technical assistance components: information dissemination and outreach training, intensive training and technical assistance, technical assistance with resource development and program implementation, national and nontribal agency network, and American Indian disability leadership development. Their site includes a training calendar, resource directory, and a publications list, including publications on independent living.

CONTINUED ON PAGE 12

"IT'S A SMALL, SMALL WORLD!"

CONTINUED FROM PAGE 11

Beach Center on Disability

<http://www.beachcenter.org/>

The Beach Center on Disability includes a rehabilitation research and training center on policies and families. Their resources include material on Cultural and Linguistic Diversity, as well as a book *Cultural Diversity, Families, and the Special Education System: Communication and Empowerment*, by B. Harry, which can be purchased on www.amazon.com for \$22.95.

Center for Capacity Building on Minorities with Disabilities Research

www.uic.edu/orgs/empower/Center%20web%20page/ccbmdr.htm

The Center for Capacity Building on Minorities with Disabilities Research (CCBMDR) seeks to increase the capacity of State Vocational Rehabilitation Agencies and community-based organizations (e.g., Centers for Independent Living and/or other agencies serving minorities with disabilities) to document the impact of their programs and to develop culturally competent services. This effort is conducted in order to promote positive rehabilitation outcomes for minority individuals with disabilities. The Center is conducting participatory research and demonstration projects, engaging in active dissemination efforts, and providing state-of-the-art evaluation and cultural competence training and technical assistance to professionals and researchers in the field.

The "Capacity Builder," the CCBMDR newsletter, is published twice a year, April and September. For a print or electronic copy, contact Tina Taylor-Ritzler at tritzler@uic.edu or 312-413-4149.

Community Building Partners, Elizabeth M. Boggs Center

rwjms.umdj.edu/boggscenter/projects/comm_sup_1.htm

Community Building Partners encompasses various activities of the Elizabeth M. Boggs Center on Developmental Disabilities. The project assists professional staff, direct support professionals, families, and community advocates in their skills and identity as community builders with people with developmental disabilities. It is focused on responding to requests from community agencies and organizations to lead workshops and customized training events related to community inclusion of people with developmental disabilities and their families. Other priorities include congregational supports, building cultural competence, and a number of statewide initiatives to enhance and strengthen the direct support workforce.

In the area of cultural competence, The Boggs Center is now participating in the development of a New Jersey Statewide Network on Cultural Competence. Its mission is "to strengthen culturally competent services in the state of New Jersey for people with diverse needs, and to facilitate access by individuals, families, providers, and professionals to these services." The Boggs Center maintains an email listserv for the NJSNCC. If you are interested in participating, contact Bill Gaventa at bill.gaventa@umdnj.edu.

Knowkidding Project, University of Alabama

www.uab.edu/knowkidding

Knowkidding is a Web site focused on early intervention that is coordinated through resources from the University of Alabama-Birmingham in collaboration with Civitan International Research Center, the Sparks Clinics, and the Lister Hill Library of Medical Sciences. The site identifies and links the user to high-quality consumer health and early intervention resources. Topics include child development; developmental disabilities and delays; early intervention (including law and regulations, evaluation and assessment); families, cultures, and communities; and team development. The site serves early intervention providers, families, and others.

Family Village

www.familyvillage.wisc.edu

Family Village describes itself as a "global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them with services and support." It includes information resources on specific diagnoses, communication connections, adaptive products and technology, education, worship, health issues, disability-related media and literature and more. One of its topic areas is "Disability Culture." Its resources include:

African American Disability Resources

www.familyvillage.wisc.edu:8000/frc_afrc.htm

Native American Disability Resources

www.familyvillage.wisc.edu:8000/frc_natv.htm

Proyecto Visión

www.proyectovision.net/index.html

The Proyecto Visión Web site identifies itself as “a bilingual website for Latinos with disabilities” and “the first national technical assistance center for Latinos with disabilities in the U.S.” The site features information in Spanish and English about employment services and resources such as job banks, résumé writing, employment success stories, assistive technology, and worksite accommodation. It also has news about employment initiatives of government agencies and service providers, legislation, and articles about the transition from school to work. New information is added to the Web site bimonthly.

A bilingual bimonthly newsletter features current job, internship, and scholarship opportunities; updated resources on employment, Latinos, and disability; interesting news stories; and more. The newsletter discusses important topics, such as “The New Immigration Reform Bill: How Will It Impact Undocumented Residents With or Without Disabilities?” and “Culture and Its Impact on Disability: One Mother’s Perspective on Healing.”

Tennessee Disability Pathfinder

www.familypathfinder.org

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’s Hispanic Outreach Project assists individuals with disabilities and/or family members in understanding disability systems and obtaining disability and community services. It is also identifying and developing bilingual information and referral resources to link Hispanic individuals to resources, and is providing technical assistance and disability training in the community.

Pathfinder Hispanic Outreach has begun a Parent Support Group (no cost to participants), which is meeting in the evenings at the Disability Pathfinder Office at 1114 17th Avenue South, Suite 105, Nashville. For information contact Carolina Meyerson (615) 400-4422.

Two national resources focus on health and mental health care.

National Center for Cultural Competence, Georgetown University

www11.georgetown.edu/research/gucchd/nccc/

The mission of the National Center for Cultural Competence (NCCC) is to increase the capacity of health and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems. NCCC maintains many online resources and tools including a Consultant Pool, which includes researchers, evaluators, and providers of training, technical assistance, or consultation.

Promising Practices is a list of evidence-based promising policies, structures, and practices that exemplify cultural and linguistic competence in many health care and mental health programs. NCCC publications include policy briefs, checklists, guides, articles, tools, monographs, and multimedia products. The NCCC also has a searchable Resource Database of resources on cultural and linguistic competence.

Rural Assistance Center

www.raconline.org

The Rural Assistance Center (RAC) is a rural health and human services “information portal.” It helps rural communities and other rural stakeholders access the full range of available programs, funding, and research that will enable them to provide quality health and human services to rural residents. Its Web-based services include funding opportunities, information guides, news and events, experts and organizations, publications and maps, success stories, a searchable resource database, and The Rural Monitor, RAC’s quarterly publication.

RAC also provides free customized assistance. The topics of their wide range of information guides include child care, aging, cultural competence and limited English proficiency, emergency preparedness, job training and adult education, mental health, migrant health, minority health, people with disabilities, and tribal health and human services.

Jan Rosemergy and Traci Fleischman are responsible for information dissemination for the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities Education, Research and Service.

SEX & DISABILITY

Q & A WITH

ROBERT WATSON

Breaking Ground recently sat down with Robert to discuss the issue of disability and sexuality.

RW: Sexuality is an extremely complicated and involved issue in our society no matter who you are. When you add a disability into the equation, the few constants that you have seem to disappear or become diluted. As a person with Cerebral Palsy myself, I have gone through the typical isolation issues as a teen, and have been through many different relationship scenarios. I have also been married since 1992 to a woman with Cerebral Palsy. I believe that I have dealt with almost every sexuality issue surrounding people with disabilities.

BG: In other words, there are factors that come into play when one or both partners have a disability—beyond what folks without disabilities experience? Can you elaborate?

RW: Several hard questions surface for individuals with disabilities, and their family members—and there are no easy answers. Should individuals with disabilities, cognitive or physical, have sexual activity in their lives? If so, should they be monitored in any way? Should they be educated about the dangers or consequences of a sexual relationship? Should individuals have the right to use a third party person to assist in facilitating sexual encounters? Should we educate people about how to develop boundaries and when it's appropriate for sexual touch? Should individuals with disabilities have people who can help them with the way they dress or remind them about daily hygiene issues?

BG: Lots to think about for sure. Can we take a question at a time?

RW: Ok. Should individuals with a disability have sexual activity in their lives? Of course they should. I believe that sexuality and the ability to explore a sexual life style ranks right up there with food and water!

I also believe that touch in general is vital to individuals. Many people with disabilities, especially ones in wheelchairs, are deprived of normal, everyday touch, such as hugs or even pats on the back.

BG: What about the issue of monitoring peoples' sexual activity?

RW: Of course not! I think if my parents had monitored my sexual activity they would have had a fit! Not to mention my own feelings. Now, in cases involving possible abuse, monitoring may be an option.

Interestingly, we worked with a young lady who had a significant cognitive disability who loved sex so much she would get physically involved with anyone to fulfill her desires. Eventually, through our dating service, she found a person with a different kind of developmental disability who was very interested in her. He took care of her needs which kept her safe, and she helped with his isolation issues.



BG: Speaking of safety issues, what about providing education about the more dangerous aspects of sexual activity?

RW: I think everyone needs to be educated about pregnancy, sexually transmitted diseases and sexual predators. Sometimes individuals with disabilities aren't educated through the public school system, because the educators aren't sure how to educate them on these issues—or perhaps wrongly assume they won't be sexual beings! On the flip side, many parents are afraid to educate their adult children, for fear they may go out and practice their new knowledge. Most parents don't even accept that their sons or daughters have been practicing on themselves for years.

I had a situation where a young lady with a disability came to me for help in procuring a pregnancy test and a HIV test because she had had unprotected sex. Two weeks later her mom called me wondering if she should explain the facts of life to her daughter. I asked the mother why she didn't think her 28-year-old daughter already knew about sex. Her response was, "of course not—where would she get that information?"

BG: What about boundary issues?

RW: Unfortunately, television has made reality very boring and my job much harder. What are the expectations in today's society after watching a show like *Grey's Anatomy*? People believe they can approach a co-worker and, within seconds, engage in intercourse in a linen closet! As we know, boundaries are a part of our lives and appropriate sexual touch has to be taught and encouraged, just as inappropriate touch and behaviors have to be taught, and discouraged. I guess I'd have to say that it's up to all of us to model appropriate behavior and to reinforce the positive interactions among peers.

BG: I imagine there are some difficult issues, especially involving privacy and trust, when a couple requires a third party to help them facilitate a sexual encounter?

RW: Most of you reading this article may have tolerated my ideas up to now, but some readers may think just the idea of having a third party intervention is totally crazy! I believe individuals who need this service should utilize it. I know of many couples who use a third party to assist in their love making. Sometimes it takes months to develop a relationship with this third-party person to understand their role in the whole process.

The role of a third party needs to be viewed as a job, and nothing else.

BG: You've often spoken about the importance of individuals having a "mirror", which may relate to your dressing and hygiene question.

RW: Everyone should have a reflective person in their lives to assist them in appropriate clothing or to remind them about bad breath or body odor. I believe that most single men, disability or not, don't know what clothes match. I remember after I was first married I was dressing for church—remember it takes me a lot of energy and approximately 38 minutes to get fully dressed—and as I walked out of the bedroom my wife said, "are you really going to church like that?" I had to go back and change because I had no sense of fashion!

A reflective partner does not need to be a wife. It only needs to be someone who is able to convey constructive advice when needed. It is extremely important that a reflective partner also tells the individual when he or she looks good, and praise them when they observe improvements.

Self image is a key to a healthy sexual relationship. A large number of people with disabilities have problems with their self image. Being very different in many ways from mainstream society has a tendency

to destroy one's self image. Self image develops self reliance; self reliance in turn develops self motivation. A good self image also allows for a healthy selection of a suitable partner.

BG: Thanks for your time and thoughts on this difficult subject. Any closing comments?

RW: I have talked with hundreds of people on their views, wants and desires concerning sexuality, and everyone has a different outlook on the subject. It is extremely important that we remember that people with disabilities have the same needs and anxieties about sex and relationships as people without disabilities; we just may need a little more support and direction to fulfill those desires. And we should be afforded the same rights, the same respect, and even the same allowances for learning from mistakes, as anyone else.

Robert Watson is the executive director of DateAble, Inc., a non-profit dating service for people with and without disabilities. He is also president of United Cerebral Palsy of Montgomery and Prince Georges County in Maryland, president of Ms. Wheelchair Maryland and the former national project director of United Cerebral Palsy.

HEALTHY RELATIONSHIPS AND SAFE SEX: TIPS FOR SELF ADVOCATES

BOOK REVIEW BY SUZANNE COLSEY

Sex and disability is an interest topic for today's society, because of the way people with disabilities are seen by society as a whole. As long as I can remember, people with disabilities have been seen as non-sexual beings needing platonic relationships, because we don't or can't have "those" kind of feelings. In this day and age, there are still people who believe in sterilization to prevent reproducing more children with disabilities.

As a strong self-advocate myself, I come across this attitude in my daily life and in supporting other self-advocates. For example, I had an OB-GYN tell me that I needed to go on birth control because I didn't want to have a child like me. My parents still think to this date that my husband and I don't have sex—and we've been married for nine years!

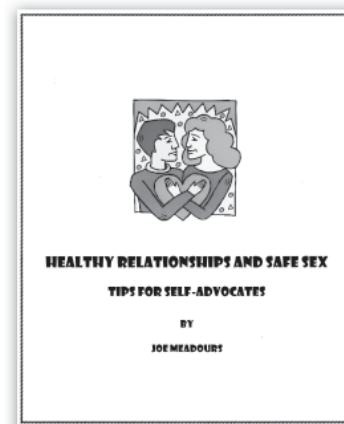
As for the self-advocates that I support, the major issue is trying to have a relationship when their house staff is always around. Many of the self-advocates enrolled in the Waiver system are required to have a house staff with them 24 hours a day. Maintaining a relationship is hard for anyone, and adding a fifth wheel makes it almost impossible! And the worst part is, a sexual relationship between two consenting adults is often considered taboo by providers and their staff.

I hope this review will get people to open their minds to sex and disability. Joe Meadours, a self-advocate, has written a wonderful guide to safe sex and the dating game. As a self-advocate, he presents what will really happen, because he's been in the same situations. I found it to be an easy read because there were no clinical words. The book is well laid out with all of the steps of a relationship. In my opinion, it's a great source to start discussions between self-advocates and their supporters.

Mr. Meadours' main focus is to take it slow, know yourself and have fun. It shows self-advocates that they can have relationships in spite of society's ideas of people with disabilities. There are great tips for what and what not to do in all of the different steps of the dating ritual. It gives some pointers on having relationships, including the things to look for when a relationship goes bad. It talks about deal makers that seal relationships, and deal breakers that end relationships. It describes the difference in types of relationships, like moving from friends to couples. A chapter on safe sex talks about sexually transmitted diseases and various types of birth control.

There are also memory exercises in each chapter to reinforce the steps of having a healthy relationship and safe sex, and a quiz in the back of the book to help readers see what they've learned. I would recommend this book to self-advocates and to those who support them.

Suzanne Colsey is the West Tennessee coordinator for People First of Tennessee, Inc., a non-profit advocacy organization for and run by people with disabilities. She is also a graduate of the Tennessee Partners in Policymaking™ Leadership Institute.





NEWS FROM PATHFINDER

BY MELISSA FORTSON

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 Research on Human Development.

PATHFINDER PREPARES FOR 2007 DIRECTORY

Pathfinder publishes the *Tennessee Disability Services & Supports Directory*, a statewide directory in three regional volumes (East, Middle & West Tennessee). We are currently preparing to publish a 2007 edition and want to make sure the resources we include are useful to people around the State. Please let us know if you are aware of a particular resource you think should be added to the directory. We will formally update these resources at least once a year, and, in addition to their inclusion in the print directory, they will also be maintained in the Pathfinder database, which is available free of charge on the Pathfinder Web site at www.familypathfinder.org. If you have disability-related resource information to share with Pathfinder, contact our Disability Resource Specialist at 615-936-5121.

RECENT ADDITIONS TO PATHFINDER

Pathfinder recently added a Disability Awareness & Etiquette section to its collection of local and national resources at www.familypathfinder.org. This section, found on the Advocacy, Law & Voting page, compiles general information about disability, etiquette and interaction tips, and People First language guidelines. We are especially pleased to offer the Tennessee Disability Coalition's excellent brochures, "Disability Etiquette: How to Interact with People Who Have Disabilities" and "Talking About Disability: A Guide to Using Appropriate Language."

Pathfinder also has expanded its offerings on Reproductive Health and Sexuality Education. Appropriate education gives people with disabilities the information they need to develop meaningful relationships and protect themselves from abuse. Pathfinder offers tools to help caregivers provide reproductive health and sexuality education that recognizes the needs of people with disabilities.

Web site users can also access the Pathfinder Database, which lists statewide disability resources, social service agencies, and other services. Agency information is organized by service area and keyword service category; there are over 50 categories of services

listed. A recently added service category, Dual Diagnosis, designates programs that serve individuals with both developmental disabilities and mental illness. Agencies listed under Dual Diagnosis may provide behavioral services, employment supports, residential or other services.

Pathfinder also continues to maintain the Pathfinder Disability Calendar, a list of disability-related trainings, meetings, and other events. Organizations post events to this calendar, Tennessee's most comprehensive listing of disability-related events. To add events to the calendar, contact Pathfinder.

SPANISH-LANGUAGE FAMILY SUPPORT GROUP

Tennessee Disability Pathfinder now sponsors a monthly support group for Spanish-speaking parents of children with disabilities. This group meets on a Monday from 6 to 7:30 pm at the Pathfinder office, and provides a forum for parents to feel supported and talk about their worries and concerns with other parents. Child care is provided. For more information about the group, please contact Carolina Meyerson at 615-400-4422 or eva.c.meyerson@vanderbilt.edu.



Ashley Coulter



Suzanne Ezell

NEW FACES AT PATHFINDER

Pathfinder continues to grow with the recent addition of two new staff members: Ashley Coulter, disability resource specialist, and Suzanne Ezell, Access Nashville coordinator. Ms. Ezell comes to Pathfinder having worked at Nashville area nonprofits for over 20 years. A disability-rights advocate for over 30 years, Ms. Ezell also has an adult daughter who uses a wheelchair. Immediately after joining the Pathfinder program, Ms. Ezell coordinated the fun and successful Access Nashville Day. Access Nashville, a volunteer effort to identify accessibility-friendly locations in downtown Nashville, is made up of

volunteers from the business and disability communities. Following a training session, volunteers survey restaurants, entertainment attractions, and hotels, and the results are posted online. Attracted to the project's positive philosophy, Ms. Ezell likes that Access Nashville is "positive and supportive in our advocate role, making friends with the folks we survey to foster a good and positive change."

NEW DISABILITY SERVICES AND SUPPORTS DIRECTORY AVAILABLE IN EARLY 2007

Tennessee Disability Pathfinder publishes the Tennessee Disability Services & Support Directory, a statewide directory in three regional volumes (East, West, and Middle Tennessee). A new edition of the directory will be available in early 2007. To receive notification when the directory is available, please send your name, e-mail address, and phone number to tnpathfinder@vanderbilt.edu or contact Pathfinder at 800-640-4636.

New disability resource specialist Ashley Coulter learned about Pathfinder during a public policy internship at the Tennessee Council on Developmental Disabilities. A graduate of Auburn University, Ms. Coulter holds a Bachelor's Degree in Education with a focus in Rehabilitation and Disability Studies. Ms. Coulter says that she has "always been interested in working with the disability community, especially in the advocacy realm. I have a brother with a disability and have seen the victories one can achieve with the right information and appropriate supports, and it is empowering to know that I can help someone achieve victories in his or her life." Among other duties, Ms. Coulter is responsible for the maintenance of Pathfinder's database and Web site, which contain information about local, State, and national resources. She will also coordinate the production and distribution of the *2007 Disability Services and Supports Directory*. Ms. Coulter welcomes the opportunity to provide "up-to-date information in regards to the disability community and assist persons with disabilities in becoming more independent."

Mss. Ezell and Coulter join program director Carole Moore-Slater, Hispanic Outreach Program coordinator Claudia Avila-Lopez,

information & referral specialist/program coordinator Melissa Fortson, and Hispanic Outreach Worker Carolina Meyerson.

STAY CONNECTED WITH PATHFINDER

Pathfinder publishes *The Pathfinder*, an e-newsletter containing information about program activities and other disability-related resources in Tennessee. Past issues of the publication are archived on the Pathfinder Web site (under Pathfinder Features, click on "*The Pathfinder: News from Tennessee Disability Pathfinder*"). To receive future news from Tennessee Disability Pathfinder via e-mail, please contact us at tnpathfinder@vanderbilt.edu.

FOR FURTHER INFORMATION:

Tennessee Disability Pathfinder
(615) 322-8529 (Nashville area)
(800) 640-4636 (toll-free, English & Español)
(800) 273-9595 (TTY)
www.familypathfinder.org
tnpathfinder@vanderbilt.edu

Melissa Fortson is information & referral specialist/program coordinator with Disability Pathfinder.

COMPASS AND PARTNERS TRAIN LAW ENFORCEMENT

BY PATTI TOSTI

In October, 2004, Compass Coordination, Inc, a private, non-profit organization, was awarded a two-year grant by the United States Department of Justice, Office on Violence Against Women. Compass, which was founded in 1996 by Randall Moore and LaWanna Edwards, partnered with the University of Memphis, Memphis-Shelby Crime Commission, and the YWCA of Greater Memphis to devise and deliver training to law enforcement officers on how to respond to individuals with disabilities and the elderly who are victims of sexual assault or domestic violence. The need for such training is based on research that suggests that persons with disabilities are at a higher risk of being victims of crime than the general population, and are often victimized multiple times.

A skills-based curriculum was developed utilizing national experts in the area of sexual assault and domestic violence affecting vulnerable populations, and the training was approved by Tennessee's POST (Peace Officers' Standards & Training) Commission. The concept was to teach about communicating effectively, collecting evidence, and legal and liability issues when responding to individuals with disabilities or the elderly. In addition, participants received continuing education credits at the University of Memphis.

"Didn't realize the impact that abuse of the elderly and people with disabilities was having on the law enforcement community and society in general."

Eight two-day trainings were conducted in the rural and urban areas of West Tennessee and North Mississippi. Over 200 law enforcement

officers and others were trained prior to the close of the grant in September of 2006. The training was highly recommended by the participants and received high marks on their evaluations.

The most informative and vital part of a training session was the Round Table discussion, which occurred at the end of the second day. The Round Table fostered communication and collaboration between the law enforcement officers and representatives from various agencies, such as Adult Protective Services, the Commission on Aging and Disability, the Division of Mental Retardation Services, the Alzheimer's Association, local Mental Health Agencies, Independent Living Centers, Domestic Violence Shelters, and Sexual Assault Resource Centers.

"Good source of information and will be able to work cases with this training."

As a follow-up to this successful project, Compass applied for and received a three-year grant to deliver training specifically designed for law enforcement, prosecutors, and judges. This training will extend Compass's partnership with others in Memphis and Shelby County, and provide an opportunity to improve the response and support to victims of sexual assault or domestic violence.

If you are interested in finding out more about the project, or how it may benefit your organization, please contact Patricia Tosti, project manager, in the Memphis office of Compass Coordination, Inc. at (901)682-0500 ext. 263, or via e-mail to patti.tosti@compasstn.org.

YLF STUDENT DELEGATES JOIN OTHER YOUTH TO DISCUSS STRATEGIES FOR EMPOWERMENT AND COMMUNITY CHANGE

OVER 120 MIDDLE TENNESSEE YOUTH ACTIVELY ENGAGED IN IMPROVING THEIR COMMUNITIES CONVENED AT VANDERBILT LAW SCHOOL OCTOBER 15TH TO SHARE THEIR EXPERIENCES AND DISCUSS STRATEGIES FOR EMPOWERING THEIR PEERS.

BY MELANIE MORAN

"We organized this event to bring together youth organizations from around the city to look at youth engagement models so that they can take these ideas back to their communities to effect change," said Michelle Crowley, co-coordinator of the Tennessee Youth Advisory Council, a group of current and former foster youth that advocates for children in the foster care system.



The forum was part of Family Reunion 12, an all-day conference focusing on education at the Vanderbilt Student Life Center. Participating groups included the Tennessee Youth Leadership Forum, Hands on Nashville Teen Volunteer Corps, University School of Nashville, USSAA, Rockettown, Tennessee Youth Advisory Council, the Mayor's Youth Council and Highly Intelligent Persons.

"We work to keep kids away from drugs, alcohol, violence and gangs, and work to break down barriers among different groups," said participant Amanda Womble of Students Taking a Right Stand (STARS). "We're here today to learn about other students' opinions."

Richard Lerner, Bergstrom Chair in Applied Developmental Science at Tufts University, opened the event and lauded Middle Tennessee youth for setting a national example for youth engagement. "Too often we define success with kids as the absence of 'bad,'" said Dr. Lerner. "That's incredibly dispiriting to youth, and it's also patently false. What we need to do in America is to look at youth not as problems to be managed but as resources to be developed. And where can we find examples of engaged, empowered youth? In Middle Tennessee. You and your colleagues are rich examples of empowered young people making a difference in their community."

The conference was organized around three topics, equity and justice, youth voice, and preparation for and transition to adulthood, which the participants addressed during panel and breakout discussions. The



Will McMillan

issues they discussed ranged from living with a disability, teaching young people how to voice their needs, financial challenges, education, discrimination, employment, mentoring and teamwork. A key component of the event was simply bringing all of the groups together in one room to share their experiences and learn from one another.

"They all have the same issues—they're all concerned with equity, they all have shared frustration with the lack of youth voice, and they're all going to transition to adulthood," said Andrew Shookhoff, event organizer and senior research associate at the Vanderbilt Institute of Public Policy. "There is so much opportunity for these youth to be a really positive lobbying force on these issues. What a powerful coalition that would be."



Kaitlyn Cherry

Tiara French, a former foster youth and member of the Tennessee Youth Advisory Council, said her experience in foster care motivated her to help other children. "It's my story that keeps me grounded in what I do," she said. "Not being able to forget where I came from, and not being able to forget that I'm not the last one that's going to have to go through that, unless I do something different to change it. Someone has to change the system. Why not me?"

"Change is a process, and it takes 24-7 shifts," said Sharon Shields, professor of the practice of health promotion and education. "No matter what it is that you do in the process, you are making change."

The event closed with a panel discussion by Dr. Shields and representatives and participants of Common Cents, a New York City elementary school engagement program founded in 1991 in which children have raised and distributed over \$4.5 million to community organizations, collected in annual "penny harvests" in their communities.

The youth forum was sponsored by the Vanderbilt Child and Family Policy Center and Tufts University Applied Developmental Sciences Institute, with support from Oasis Center, Peabody College of Education and Human Development, Tennessee Council on Developmental



Randy Oliver

Disabilities, Vanderbilt Center for Health Policy, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, Vanderbilt Law School and Vanderbilt News Service. Audio of portions of the event and a photo gallery are available on VUCast, www.vanderbilt.edu/news.

Melanie Moran is assistant director for Web Communication News Service at Vanderbilt University.

TENNESSEE SPOTLIGHT

Family Voices Adds Parent Consultants for Hearing Project

Family Voices of Tennessee at the Tennessee Disability Coalition has hired three part-time parent consultants to inform and support parents of children with hearing loss. The three are working exclusively with the Newborn Hearing Screening project funded by the Tennessee Department of Health through a federal grant.

The new consultants are Wonda Houston of Memphis, Teresa Turnbo from the greater Nashville area, and Camille Keck of Knoxville. Each has a child with a hearing loss and a strong desire to assist other families to manage the needs of their children with a hearing loss or related condition. Ms. Houston has an extensive work background in disability services as a technician and speech assistant and as a special education classroom assistant. For several years Ms. Turnbo has served as the family outreach coordinator at the Vanderbilt Kennedy Center, and is a graduate of Tennessee Partners in Policymaking™. Ms. Keck is the cofounder of FLASH, a support group for families of children with hearing loss.

John Farley Adds Community Theater to His Performance Resume

Youth Leadership Forum graduate John T. Farley (and son of Partners grad Brenda Farley), recently performed in the Harrell Theatre's production of *High School Musical*. The theater is located in Collierville, and is a cultural component of the area's Parks and Recreation programs. Mr. Farley is no stranger to the stage, as he is a longstanding member of the Company D dance troupe.

Tennessean Named to National Council on Disability

Last August, Lisa Mattheis of East Ridge was confirmed by the U.S. Senate as a member of The National Council on Disability (NCD). NCD is an independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate.

NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Ms. Mattheis is the parent of a child with a disability. She is a Parents Advisory Council member/volunteer at TC Thompson Children's Hospital in Chattanooga, founder and executive director of LifeLine Ministry of Hamilton Baptist Church, and a board member of STEP, Inc. (Support and Training for Exceptional Parents, Inc.)

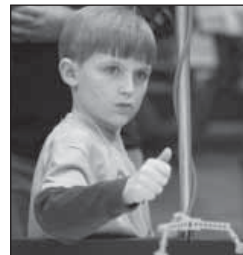


Bernie Lynette (left) with teammates

Bug Bytes Win Top Prize at State Lego League Competition

Forty-seven Lego League teams from around the State competed in a tournament on December 2nd in Cookeville. One of those teams was the Bug Bytes, and one member of that team was Bernie Lynette, son of Partners grad Gina Lynette.

The Bug Bytes took home 4th place in Robot Design, 1st Place in Robot Performance, and 1st Place Overall Champions. That win earned the team a spot at the April 2007 World Festival in Atlanta. At that event, 104 teams from around the world will compete in a two-day tournament, demonstrating each team's robotic and research accomplishments.



Bernie Lynette

"I was nervous, but that's okay, because people get nervous when they are working hard on something, or there's something important happening..."

The program is for kids aged 9–14. Mr. Lynette is 8, but got special permission to join the team because of his affinity for computers and building with LEGOs. The fact that he also has autism appears to not have been an issue. "I love building LEGO vehicles and saw a show on the LEGO League," says Mr. Lynette. "You get to build LEGO robots that do missions to win trophies. The trophies are even made out of LEGOs!"

And what was it like at the tournament? "It was pretty loud and exciting," recalls Mr. Lynette. "I was nervous, but that's okay, because people get nervous when they are working hard on something, or there's something important happening. We won a very important award."

Disability Coalition Receives Award

The Tennessee Disability Coalition recently received an award from the Tennessee Trial Lawyers Association "for its contributions in helping to protect and preserve our civil justice system."

PHOTOS BY LEA BOSSE



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