

BREAKING GROUND



SHIFTING LANDSCAPES

*Current Challenges and Opportunities
in Developmental Disabilities Policy*



[10] MULTISENSORY ENVIRONMENTS



[12] SIBCAMP



[14] SHELBY COUNTY RELATIVE CAREGIVER PROGRAM

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Cover Photo: Commissioner Sharon Lewis with Next Steps at Vanderbilt students.

Left to right

Front row: Jacquelyn West, Jeanne Gavigan, Elizabeth Story, Sharon Lewis, Hallie Bearden, Kelly Wendel

Back row: Steven Greiner, Andrew VanCleave, Sean Faulkner, Michael Heroux, Tammy Day

Photo by Susan Urmy/Vanderbilt University

ERRATA

Ryland LeGrand took the cover photo for *Breaking Ground* issue #59. The editors regret the omission of this credit.

William Benson, Jr., who wrote about his life with Asperger's Syndrome in *Breaking Ground* issue #59, lives in Memphis. The editors regret the omission of this biographical note.

CONTACT INFORMATION



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SHIFTING LANDSCAPES

Current Challenges and Opportunities in Developmental Disabilities Policy

REMARKS BY SHARON LEWIS — PART ONE

Sharon Lewis was appointed Commissioner of the Administration on Developmental Disabilities (ADD) in March 2010. ADD is the federal organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. She has over 10 years of experience as a disability policy advocate, including work on major disability-related federal legislation. She served as the Senior Disability Policy Advisor to the U.S. House Committee on Education & Labor and its Chairman George Miller on legislative strategy and disability-related policy in education, employment and health care. She is the parent of three daughters, including one with a disability. These are excerpts from her presentation at the Vanderbilt Kennedy Center as its 2011 Martin Luther King Jr. Commemorative Lecturer.

First and foremost, I'm a mom. This is passion work for me, as it is for so many other advocates. All that we're doing matters so much to so many. Thank you all for everything that you do.

I welcome the opportunity to reflect on the hopes and aspirations, expectations and needs of people with disabilities within the context of Dr. King's 1963 message when he dreamed of a day when we are all judged by the content of our character. Great strides have been made in establishing civil rights protections for people with disabilities. Dr. King's concept of living in Beloved Community with justice and dignity for all continues to be an unattained dream for many people with intellectual and developmental disabilities (ID/DD).

HISTORICAL CONTEXT. Vocational Rehabilitation (VR), which has helped to improve employment outcomes for people with disabilities, was established 90 years ago. The Education for All Handicapped Children Act, predecessor to IDEA [Individuals with Disabilities Education Act], became law 35 years ago, ensuring that children with disabilities would have access to a free, appropriate public education. Congress updated the Elementary and Secondary Education Act 10 years ago, with provisions to ensure that children with disabilities would be expected to access and achieve academic success. Last Summer, we celebrated the 20th anniversary of the Americans with Disabilities Act (ADA), our core civil rights law, which sets forth our goals for people with disabilities: equality of opportunity, full participation, independent living and economic self-sufficiency. Nearly 50 years ago, Congress passed the first version of what became the Developmental Disabilities Assistance Bill of Rights Act (DD Act).



Photos by Susan Urmy/Vanderbilt University

Above: Commissioner Sharon Lewis. Below: Audience response.



SOBERING STATISTICS. Even with all these efforts and cultural shifts in believing that people with disabilities can participate fully in our schools, communities, places of employment and economy, [current] statistics are sobering. People with disabilities are three times more likely than others to live at or below the poverty line. Half of all working-age adults who experience poverty each year have a disability. Families supporting individuals with intellectual or developmental disabilities across their lifespan experience far higher rates of economic hardships than other families. The percentage of students with disabilities who complete high school with a diploma hovers around 70% and in over a dozen states, including Tennessee, that statistic is closer to 50% or

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less. People with disabilities are less likely to attend college than people without disabilities. Less than 10% of people with disabilities own homes, compared to 70% without disabilities. Among individuals with disabilities, 50% do not have a bank account. The current workforce participation rate for people with disabilities is only 27%, compared to 73% of working-age adults without disabilities. These are devastating numbers.

EDUCATION. When Congress passed the Education for all Handicapped Children Act in 1975, our country finally said it was no longer acceptable for children with disabilities to be denied the opportunity to learn and to succeed in school. Eventually this law became IDEA, establishing the right for millions of children with disabilities to attend schools with their brothers and sisters, neighbors and friends, and guaranteeing these children free, appropriate public education in the least restrictive environment. In the last 35 years, students with intellectual and developmental disabilities have made major strides. Each year over 16,000 students with intellectual disabilities earn a regular high school diploma and thousands more earn other completion certificates. IDEA has made a tremendous difference for students with disabilities, like my high-school-age daughter. Yet so much more needs to be done.

Students with disabilities need to have the opportunity to be held to high expectations in our elementary and secondary schools. They should be able to access effective general education teachers who understand that to teach in today's schools means to teach all diverse learners, including individuals with intellectual and developmental disabilities. Students need access to special education supports and services that are designed to help them succeed in the general education curriculum, not separate tracks, not special curricula, and not segregated classrooms. They need access to differentiated and appropriate instruction and to grade-level content. Students with intellectual and developmental disabilities can be and should be held to these high standards and given the opportunity to achieve.

Students with disabilities need to build social capital and interdependent relationships in which they both receive and give support to others. They need to be full participants in our educational communities, on our sports teams, in our extracurricular clubs, volunteering in service learning and on the honor roll. We should be encouraging students with disabilities to become lifelong learners, pursuing their postsecondary education goals, finding gainful competitive integrated employment in jobs that they like, earning a living wage. Students with intellectual and developmental disabilities need to be supported so that the rights they are afforded under the ADA are not only protected but fully implemented—so that ADA's goals of equality of opportunity, independent living, full participation and economic self-sufficiency are fully realized for each person with a disability.

EMPLOYMENT. Education is about getting to employment. While the employment landscape for all workers is difficult now, it is bleak

for people with disabilities. Only 20% of people with disabilities are participating in the workforce. According to the most recent American Community Survey, 32% of working-age people with disabilities earned less than \$5,000, and 35% of the non-institutionalized population of people with disabilities live at or below 150% of the federal poverty level, as opposed to 19% of the general population. For people with intellectual and developmental disabilities, the challenges are even greater when we look to the need for supports.

States use Medicaid through Home and Community-Based Waivers to provide most of the employment support for people with intellectual or developmental disabilities. Only 22% of these individuals are receiving integrated employment services through Medicaid, while 74% are supported in sheltered employment, rehabilitation services or non-work community integration activities. Additionally, 8% of those in integrated employment are in group-supported employment models, including enclaves and segregated work crews. Despite nearly 50 years of the legacy of the DD Act, 35 years of IDEA and 20 years of ADA, cultural and attitudinal barriers still confront people with disabilities seeking employment. Low expectations remain the norm in our school systems, our training programs, our workplaces and sometimes even in our families. Parents are not to blame; often for years experts have told them to lower their expectations and modify their dreams.

According to the 2007-2008 National Core Indicators Data, people with intellectual and developmental disabilities working in facility-based work programs worked an average of 74 hours per month, earning an average wage of \$101, which equates to \$1.38 an hour. Individuals in competitive employment worked an average of 63 hours per month yet earned an average of \$422 per month, or \$6.70 an hour. We must do more to ensure that all people with intellectual and developmental disabilities can work and earn real wages.

Collaborative initiatives among VR, ID/DD agencies and the community are an important element in supporting employment outcomes. The most successful states have taken a comprehensive, collaborative approach. Employment-first policy in states like Washington can make measurable differences when the strategies, expectations and measured outcomes are built across systems: education, VR, home and community-based services and community employers themselves.

Individual and family factors are important. Work means more than money. Integrated employment provides expanded social relationships, heightened self-determination and more opportunities for different job roles. Research has shown that families want to consider community options for transitioning youth but have concerns about long-term placement and stability, safety, and the social environment. We must redouble our efforts to provide families and youth with information about success stories to foster this change.

Part Two will appear in the next issue of Breaking Ground.



BLIND MAN DRIVING

BY JAMES BROWN

A hundred years ago, it was incomprehensible to think that a person could walk on the moon. However, on July 21, 1969, Neil Armstrong took those amazing first steps that would change history forever. In 2011, there's a different kind of giant leap taking place for the disability community.

If you ask the average person on the street one thing that a blind person absolutely cannot do, most would say a blind person can't drive. But as I sit here on a sunny day at Daytona's Rolex 24, those perceptions are about to change. Over the past several years, the National Federation of the Blind (NFB) and student engineers at Virginia Polytechnic Institute and State University (Virginia Tech) have teamed up to design a car blind people can drive with non-visual technologies.

The non-visual interface basically consists of laser range-finding sensors that send information to a pair of driving gloves. Vibration strips run down the seat of the Ford Escape SUV to give the blind driver additional information about ideal driving speeds.

Mark Anthony Riccobono, a technology executive with the NFB, has been blind since early childhood. "I'm looking forward to getting behind the wheel and demonstrating to the world that being blind does not prevent

me from engaging in any activity I choose as long as I'm able to get the information I need," said Mr. Riccobono. "This will be a truly historic occasion for my blind brothers and sisters and for America, and I am humbled and proud to be part of it."

As he made his historic lap around one of the most famous racetracks in the world, a van pulled out in front of him and dropped boxes in his way. Mr. Riccobono was able to successfully navigate around the obstacles. Before completing the lap, Mr. Riccobono passed the van and made it around Daytona's horseshoe turn.

Marc Maurer, NFB president, said before the race, "The sight of a blind individual driving a vehicle without assistance from a sighted person will shake the foundation of public misconceptions about blindness and blind people by showing that even tasks that are thought to require vision are possible, if a blind person has access to information in a non-visual way. Vision is not a requirement for success. Capacity, imagination and determination are all that is needed, and blind people have all of these qualities."

Beyond breaking down stereotypical and psychological obstacles for the blind, the project also has potential in other areas. Going back to the man on the moon analogy, many

innovations of modern society came from NASA scientists who were trying to create adaptations for living in space and beyond. For example, the technology used to make the first moon boots was later adopted by some of the first tennis shoe companies. From Memory Foam beds, invisible braces, wireless long distance telephone calls, scratch-resistant lenses, cordless power tools, smoke detectors or water filters, we all have benefited from one man's walk on the moon and a group of people who believed they could get him there.

Is it possible that residual technologies from the blind car could continue to innovate adaptive and sighted technologies for years to come? Could these same technologies be placed into helmets or uniforms whereby blind people could play sports that have traditionally been inaccessible? As a person who is blind, is it possible that one day I could play a game of football or drive my sighted wife on a romantic date? The blind driver technology has tremendous potential to transform the lives of the blind. All that is left is for us to imagine what we want to achieve! In the words of the famous African American poet Langston Hughes, "Hold fast to dreams, For if dreams die, Life is a broken-winged bird, that cannot fly".

James Brown lives in Antioch and is a Partners in Policymaking™ Leadership Institute graduate (09-10).

Remembering

JOSEPH STOKELY RAINWATER

February 7, 1946 - November 12, 2010



Photo by Frank Wilhelm

BY EMILY JANE SMITH

Joseph Stokely Rainwater, known to many as "Uncle Joe", went home with Jesus on November 12, 2010. Joe's number one goal in his life was to do this very thing; death was just a stepping stone to a perfect life with Jesus and the loved ones who had gone on before.

When we were in PATH (Planning Alternative Tomorrows with Hope) training in Knoxville in 2003, Joe revealed his life's main goal and his PATH team worked to support him on this journey. Joe wasn't the only one who benefited from crafting his PATH. Before we left our three-day workshop, every person participating had had a spiritual experience, and had learned about God's love through Joe as they never had before.

Joe prayed for everyone he met. He would ask, "Are you a Christian?" and, whether they said yes or no, he promised to pray for them. And he did. I know because I was with him so many evenings, reading the Bible to him and listening to him praying for all those he knew, plus some. I asked him one time to name those on his prayer list and he talked for so long I asked him to finish telling me later. Joe wanted the people of the world to turn back to God and live in harmony.

Every woman Uncle Joe met received a hug and a kiss and was told, "You're pretty." Needless to say, he had a great number of women friends. As to men, he would shake hands or give a hug, if they initiated it. Often people would say to me, "Isn't he the sweetest person?" and all I could do was agree. Joe was always the same, except when he got aggravated with others for not understanding what he wanted or needed. Also Joe might have disapproved of someone's lifestyle, but he would never judge them; instead, he would invite them to his church.

For five years, Joe was a member of "The Cheerful Volunteers" at a nursing home in Newport, Tennessee. We helped with Monday Bingo and the refreshments served afterward. After this, we would walk around the halls and Joe would pray for those who said "yes" when asked if they needed prayer. Some residents would cry out before we could get to their rooms, "Joe, please come in and pray for me." We spent many happy hours there and residents who still live there ask about Uncle Joe every time I visit as an ETHRA (East Tennessee Human Resource Agency) volunteer ombudsman.

Joe loved traveling and attended many meetings, conferences and other events having to do with disabilities. He and I also graduated from the Partners in Policymaking Leadership Institute in 2005. We attended

several Partners Reunions in Nashville. Joe would always totally unpack and put his things in the hotel dresser drawers and closet. I always had to make sure we left nothing of his behind; he scattered things all over the room! When we visited Atlanta, Georgia, for a Self-Advocates Becoming Empowered (SABE) conference, Joe wanted to stay because people were so nice there, even on the street!

Joe lived in his mother's family home until he was 62. Then, he decided to transition to "supported living" under the care of Lakeway Achievement Center in Morristown, Tennessee, which is where he had worked for the past three years. My mother, Viva, had a hard time "letting go", but when Uncle Joe told my daughter, Sheila, "Honey, your grandmother is not able to take care of me and I'm not able to take care of her anymore," Viva knew that he was right. He had been with Viva for 60 years and every time I called him or went to visit without her, his first question was always, "How's your mother, dear?" or "How's my Vi?" He was brought home many weekends to visit. He still loved his church and wanted to attend there when he could.

Uncle Joe touched many lives. People everywhere I go ask about him and remember how he prayed for them. All of the people who worked with him at Lakeway still love him and honor him. He was very happy with them and I will always remember their love and service to my dear, sweet Uncle Joe.

To end, I am sharing a poem written by one of Joe's devoted workers and read by her at the balloon releasing ceremony at Lakeway Achievement Center the day after Joe's funeral.

A SOUL SET FREE

By: Jessica Kent

Everyone's uncle, ever ready to banish a tear,
Uncle Joe touched many lives while he was here.
He insisted on hugs and gave his "angels" a chase,
Running with arms open wide, a smile on this face.

If stockpiled hugs could stack up high,
And his smiles pave a path to the sky,
If we could climb to Heaven, there we would see,
A new angel, our sweetie pie, in wings of glory.

If we could ask Uncle Joe, I think he would agree,
Don't cry with heads hung low; celebrate a soul set free.
Know as we send up balloons and each one departs,
Joe rests in God's hands, but he lives in our hearts.

Goodbye for now, Uncle, We miss you.

Emily Jane Smith, called "Miss Emily" by Joe, is four years younger than Joe. She and her brother, Sam, grew up with Joe, being more like siblings than uncle and niece and nephew. She was also Joe's personal assistant, driver and companion in their adult lives until he left home at 62.

Remembering JOE MARSHALL

When I spoke to a long time colleague and advocate to let her know that Joe Marshall had died, she remarked about the disability community, “We have lost another lion.” She is right. Joe Marshall was not a lion who roared to exert his authority and leadership. He was a lion who used his strength, courage, and presence to provide leadership and to make a difference in the lives of people with disabilities. But he was so much more.

Joe was father to two daughters, Carolyn and JoAnn. JoAnn has autism and Carolyn is a special education teacher. When Joe began his journey as a disability advocate 40 years ago, he added that role to many other roles he had. Growing up in the Florida panhandle, Joe learned his skills as a sailor early. Like many men of his generation, Joe served as a soldier in the Army before going to college to become an engineer. That training really took. Joe’s daughter Carolyn says that he could “MacGyver” just about anything! When he married, he and his wife, Joyce, started their family in Knoxville. Joe was working for Tennessee Valley Authority (TVA). Together he and Joyce became involved in disability issues after JoAnn’s birth. Over the years, he helped parents and others organize to make a difference. He helped start the Autism Society of America (ASA) – East Tennessee Chapter and the ASA – Tennessee. Because of a particular interest in effective special education, he co-founded the Parents Association for the Rights of Educating Non-Traditional Students (PARENTS), an East Tennessee advocacy organization.

When disability leaders got together in 1984 to form an informal coalition for community services, Joe was there. He would regularly drive from Knoxville to participate. By 1988, Joe worked with leaders from the Developmental Disabilities Council and other statewide groups to formalize the Tennessee Disability Coalition. While others were paid staff based in Nashville, Joe was still traversing I-40 from Knoxville to Nashville, working as a volunteer. After his retirement from TVA in 1988, he devoted even more time to disability advocacy.

Joe believed in community. He believed in the power of people coming together for common purpose, each doing his part. And Joe frequently did more than his share. He remained a tireless leader and supporter of the Tennessee Disability Coalition. He was the last founder who was still serving on the board of directors. He served as treasurer, vice-chairman and chairman of the Board of Directors. For more than 10 years he served as chairman of the Special Education Task Force.

Joe believed in civic engagement. He participated in the political process and encouraged others to do the same. He believed in the power of government to be a force for good in the lives of people with disabilities and their families. Joe actively sought enabling state policies that promoted the independence, productivity and inclusion of people with disabilities. Over the years, he served as a volunteer on a variety of councils and commissions, including a law revision commission, and policy and planning councils.

Joe was thoughtful and committed. He could always be counted on to provide analysis and action on public policy issues related to individuals

Photo by Christy Wells-Reece



with disabilities. He read and reacted to proposals and legislation. He always built relationships with legislators and policymakers—and became the “go to” man for the Knoxville delegation. He never missed “Disability Days on the Hill”, and frequently contacted his legislators as they grappled with disability issues.

Joe inspired younger leaders. As a founding father of the Coalition, and through his more than 20 years of active participation, Joe served as an example and a mentor to many other family members and volunteer leaders. A younger generation of parents and advocates has learned from Joe and developed their own skills and abilities by working with him.

Another long time colleague of Joe’s recently said that a single-word description of Joe Marshall is steadfast. How very true. With quiet courage, imagination and unbeatable determination, Joe set about to change the world for people with disabilities—and he did.

Carol Westlake is executive director of the Tennessee Disability Coalition.

I knew Joe Marshall for many years. That is, I sat across the table from Joe at meetings of various councils and organizations. Or we greeted each other as he delivered his wife, Joyce, and daughter, JoAnn, to other meetings of other councils and organizations that I was attending also.

Joe was not the most talkative member around a table, but when he spoke, his comments were thoughtful and considered. He made his points succinctly and clearly. I came to appreciate these traits even more over the past two years.

Beginning in the Fall of 2008, Joe and I volunteered to review letters of interest and proposals as part of a Small Grants Committee. As discussions ensued, Joe often cut to the heart of the matter with a pithy comment to help the committee come to its decision. He also made sure that the numbers added up correctly and that the logic of a concept was sound. I did not know Joe’s background as a civil engineer, but based on his clear analysis of the issues and ideas, I was not surprised to learn it.

Joe Marshall has left a strong legacy of policies and ideas that benefit people with disabilities behind him. But we will miss his voice.

Errol L. Elshtain is director of development with the Council on Developmental Disabilities.

Remembering ANGELA MILLER



BY LORRI MABRY A few months

ago, the world lost a great person and self-advocate, and I lost my best friend and "sister", Angela May Miller. She passed away after a long fight with cancer. During most of that fight, she was determined to win for her kids, family and friends. I loved her spirit and her will to live.

She was not my sister by blood but in my heart. I met Angela when we were in first grade at Cavert Special Education School, now Harris-Hillman Special Education School. Our teacher asked her to help me do my exercises. Angela took her job seriously. She bent my legs like a pro! We hit it off instantly and we stayed close over the years. We did

fight like sisters but every few days we made up.

We were in the second group to be mainstreamed in Metro Nashville Public Schools. We had fun at Pennington Bend Elementary and were the focus of a front-page article in *The Tennessean*. We also joined the Deaf Girl Scout Troop, learned CPR and went on camping trips.

When I was down when my dad died, Angela always kidded me, and cheered me up. I helped her with math and she helped me with spelling. When I moved to another county, we loved our summers at camp, where we would catch up our lives in two weeks. We flirted with boys and loved to swim. We floated together and talked about the cute camp counselors. She graduated from Hillsboro High School and attended two years of college at Tennessee State University, majoring in social work. Angela won many swimming medals at the National Paralympics and had two great kids, Ally and Matt. She was a graduate of the 1994-95 Partners in Policymaking Leadership Institute and a member of my family church, the Saturn Baptist Church. Good-bye my sister. I love you.

Lorri Mabry is a self-advocate and is a graduate of Partners in Policymaking (00-01).

NEW STATE PLAN GOALS AND OBJECTIVES – PUBLIC REVIEW

BY ALICIA CONE, PhD

The Tennessee Council on Developmental Disabilities is in the process of developing its new five-year State Plan. This plan will be in effect for federal fiscal years October 1, 2011 through September 30, 2016, and will be submitted to our federal oversight agency, the Administration on Developmental Disabilities, on August 15, 2011. The State Plan will serve as a framework for our planning, implementing and evaluation activities for the next five years. The plan will be updated each year, particularly the goals and objectives sections.

PUBLIC INPUT

Public input and public review are key components of the process of developing the State Plan. Public input typically happens during the needs assessment aspect of the plan development. Through various activities, the Council solicits information from the public regarding how the Tennessee service system is working, where the gaps in services are, and what the major issues are that need to be addressed in the service system. The information gathered from these activities drives the development of the goals and objectives for the new State Plan.

We were able to obtain data from 15 different sources using the following activities: needs assessment surveys (mailed and on-line), project summary reports, research results, program evaluations, a series of person-centered planning tools, review of Developmental Disabilities Network agency state plans, customer satisfaction surveys and stakeholder forums. Additionally, we sent out surveys to all pertinent

State agencies asking for program, outcome and resource allocation information. We gratefully acknowledge all the responses and assistance we received during this phase of the development of our State Plan.

Through this process we learned that Tennessee has a plethora of needs:

Area of Need: **EMPLOYMENT**

Summary of Needs

Increase and improve employment and employment related services; work/employment outcomes; job placement and support; training and mentoring for job coaches and developers; expertise in customized employment; job retention; and transition from school-to-work outcomes. Additionally, respondents wanted problems with existing state Employment First policies addressed.

Area of Need: **EDUCATION**

Summary of Needs

Stakeholders identified the following lack of resources and services: postsecondary education opportunities; access to appropriate special education and early intervention services; and autism spectrum disorders services, training, and awareness. Stakeholders wanted to increase and improve IDEA training and education; sharing of information gained through research; dissemination of information; seclusion and restraint policies and training; assistive technology in education; professional development for those serving people with I/DD (intellectual and developmental disabilities); IEP

(Individualized Education Plan) and 504 accommodations; and transition planning.

Area of Need: COMMUNITY SERVICES

Summary of Needs

Gaps in specific community services were identified as information and referral services; respite; assistive technology; personal assistance; service coordination/case management; day services; homemaker services; personal emergency response systems; legal services; financial services; support groups; in-home assistance; assistance navigating the Social Security system (that is, SSI/SSDI); flood relief; autism resources; and services targeted to the Hispanic/Latino communities. Additionally, the following issues were identified: the need for more money for DSP (Direct Support Professional) training; decrease in DSP turnover; more money for increased community services so people can live in the community; lack of HCBS (home and community-based services) for people with I/DD; lack of services in rural areas; need for increased family support funding; and more consumer and self-directed services.

Area of Need: HOUSING

Summary of Needs

Increase funds for home modifications; residential services; homeownership opportunities; affordable housing; home repair and habilitation; number of homes that are visitable; adherence to fair housing laws; accessible housing; and housing with Universal design.

Area of Need: HEALTH

Summary of Needs

Gaps in health care resources and services were identified as therapies (occupational/physical/speech); behavioral services/adaptive interventions; nursing; mental health/mental illness resources and services; dental care; affordable medications/prescriptions; food supplements; supplies and equipment; eye care; futures planning; emergency planning and preparation; end of life documents; access to health care and insurance; education and support for aging persons with I/DD; research and support for healthy aging in persons with I/DD; and decreasing infant mortality rates.

Area of Need: CHILD CARE

Summary of Needs

Increase child care (before and after care) for children with disabilities and other healthcare needs; access to developmental assessments; information and training on learning disabilities; access for students with disabilities to appropriate services when in, or are at risk for entering, the juvenile court system; and children with disabilities in State custody who have had a trauma receiving best practice in mental health treatment and services.

Area of Need: TRANSPORTATION

Summary of Needs

Increase available, affordable, accessible public or private transportation; funds for vehicle modification; transportation to employment sites and employment opportunities; and accessible parking.

Area of Need: RECREATION

Summary of Needs

Increase inclusive recreation and arts opportunities (for example, camps, Scouting, hand-cycle racing).

Area of Need: SELF-ADVOCACY/ LEADERSHIP, ADVOCACY AND DIVERSITY

Summary of Needs

Increase support for self-advocates; self-advocate participation in some areas of the State; use of different approaches in rural versus urban areas; advisors for local chapters; strong leader development; outreach to young people in school; the development of the next generation of self-advocates; the education of lawmakers about self-advocacy; the implementation of self-advocacy programs in high schools and colleges; research about programs that are working and replication; and use of People First language.

In the area of diversity (ethnic/race barriers), address unserved and underserved populations and language barriers, and promote self-determination.

In the area of advocacy, increase advocacy training for families; involvement in decision-making; building of an advocacy base; law enforcement training regarding I/DD; inclusion of people with I/DD in the research process; and accessible communities (programmatically and attitudinally).

GOALS AND OBJECTIVES

Goal 1: LEADERSHIP DEVELOPMENT

Annually, the Council will, in partnership with Tennesseans with disabilities, families and other partners, provide training, education and informational opportunities that result in private citizens who are better able to access services, serve on cross-disability and culturally diverse leadership coalitions, influence policy, communicate needs, and build relationships in their communities

Objectives: LEADERSHIP DEVELOPMENT

1.1 Yearly, provide seven weekend sessions of Partners in Policymaking to train approximately 10 self-advocates and 15 family members on disability policy and practice in Tennessee and nationally.

1.2 Yearly, provide opportunities for individuals with disabilities and family members to develop their knowledge and leadership skills via four activities: funding and strengthening People First of Tennessee (PFT); strengthening other self-advocacy initiatives in Tennessee led by individuals with disabilities; funding and operating the Consumer Education Stipends so 150 people are assisted; and, in partnership with other advocacy groups, funding and co-sponsoring the annual Tennessee Disability MegaConference.

1.3 Each year of the plan, provide the Tennessee Youth Leadership Forum (YLF) to support approximately 15 youth in high school

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MULTISENSORY ENVIRONMENTS AND THE DENTAL CLINIC

BY KRISTIN COMPTON, DMD & BEN TYBER, DDS

For many individuals, a trip to the dentist is like going down a rabbit hole. This expression has become symbolic of going on an adventure into the unknown. The immediate dental office smell, the dentist, the hygienist and the dental assistant are just the beginning. The sights, sounds, smells and tastes involved in the least invasive dental exam can be translated into a frontal assault on your senses, well-being, comfort, security and emotions. From hearing, "Open wide" until you hear, "We're all done now. That wasn't too bad now was it?" is an excursion that tests our limits and turns our individual and collective senses into a whirlwind. For individuals with a normal semblance of sensory stability, the experience can be extremely anxiety producing; for individuals with "out of synch senses", the experience can be traumatic.

For individuals with intellectual and developmental disabilities, oral health remains the number one unmet healthcare need. While lack of access to dental care is one of the main reasons for this, many patients with disabilities who have had traumatic dental experiences opt never to return to the dentist. In addition to the myriad problems that are associated with poor oral care and dental disease, the recent appreciation of the oral-systemic health connection—by the medical community—raises the concern of both dentists and physicians.

While technological advances in dental techniques (that is, virtually painless laser drills) have relieved much of the pain and discomfort involved with many dental procedures, the challenge of providing a sensory-enriched environment still remains an obstacle.

There are many devices and tools available to enrich the sensory environment in a dental or medical office. However, there is one essential element...the staff. All sensory enriched offices and clinics must begin with a staff dedicated to the appreciation of cultivating an environment that is sensitive to the sensory chaos that "placing a sharp explorer into someone's mouth" will initiate. The sensory enriched environment (SEE) begins before the patient is placed in the "chair".

The waiting room is the first opportunity to announce the culture, the support and the sensitivity that awaits a patient. Lighting is important and should be controlled by a rheostat switch to allow for lowering the intensity of the light, along with soft and comforting colors. The chairs should be comfortable and the material should offer choices from smooth to coarse. The number one underlying consideration of creating the SEE office is offering "choices". Every individual has a unique "sensory diet", a combination of sensory variables that may not be consistent or predictable.

Another key component of the SEE clinic is the appreciation for "apprehension desensitization". One or more initial visits to the dentist



Photo by Dennis Wilkes

Dr. Compton encourages her patient to enjoy a hand-held patient-controlled device delivering an enticing light show.

or physician may not progress to the actual examination phases. The need to adjust or acclimate to new people, new smells, new sights and new anxieties may require several "non-clinically productive" encounters. These non-productive visits translate into non-billable visits which often challenge the "business model" that unfortunately dictates the pace and flow of a mainstream dental or medical practice.

For those clinicians who are dedicated to treating individuals with disabilities, these initial "introductory sessions" prove invaluable in the future. Patients who were originally reluctant to even "open wide", can become model cooperative and compliant patients with the initial investment of several "desensitization" visits.

Often a simple, inexpensive stuffed animal laid in the lap of the patient can serve to promote tranquility and security. The "weight" of the stuffed animal also can ameliorate the need for tactile security for the patient with autism. There is an abundance of haptic (touch) literature that indicates that stroking an animal (even a stuffed toy) can have a tranquil effect on anxiety-prone individuals.

A television monitor mounted on the ceiling above the dental chair allows the patient to view favorite movies and videos. Charting their preferences (including the use of headphones) allows the video to be in place before they climb into the chair. This video allows for both patient distraction and for fortifying their sensory diet.

SEE equipment available to address visual, auditory, somato-sensory and tactile stimuli include (as described in M. Shapiro, *et al*, "Behavioral

and physiological effect of dental environment sensory adaptation on children’s dental anxiety”, *European Journal of Oral Science*, 2007, 115: 479-483) the following.

Visual sensation: dimmed upward reflective fluorescent lighting (30-40,000 Hz). Slow-moving, repetitive visual color effects using a “solar projector” shining onto off-white netting (in the patient’s visual field). The dental hygienist uses a head-mounted narrow-spectrum light emitting diode (LED) source lamp directed into the patient’s mouth.

Auditory and somato-sensory stimuli include rhythmic music via loudspeakers, while a bass vibrator connected to the dental chair produces soma-sensory stimulation.

Tactile stimulus consists of the regular dental X-ray vest, providing a deep “hugging” pressure effect.

Modification of the clinical environment not only affects the patient but also the staff and the parent or accompanying direct support professional. When the level of the patient’s anxiety is reduced, the level of anxiety from the supporters and providers is also decreased, allowing for a more relaxed, productive and rewarding experience.

For many patients with intellectual and developmental disabilities who are not given trials and exposure to the SEE dental approach, the

remaining option is sedation, a trip to the operating room with general anesthesia, or, worse, the deferral, postponement or cancellation of potentially life threatening oral disease. Additional information can be obtained from The American Association on Multi Sensory Environments (www.aamse.us) and the American Academy of Developmental Medicine and Dentistry (www.aadmd.org). All “sensory enriched” dental clinics and dental care begin with a dentist who believes the initial investment in time, energy, patience and equipment will reap great benefits in the satisfaction derived from delivering optimal care to vulnerable individuals.

The senses should not be thought of as obstacles to the delivery of competent dental or medical care, but as an opportunity to engage the patient in a secure, trusting and confident experience that is mutually rewarding. The SEE clinical environment should capitalize on Diane Ackerman’s observation from *A Natural History of the Senses*, “the senses don’t just make sense of life in bold or subtle acts of clarity, they tear reality apart into vibrant morsels and reassemble them into a meaningful pattern.”

Kristin Compton is director of Dental Services, Project Open WIDE, Orange Grove Center, Chattanooga.

Ben Tyber is a consultant at the Orange Grove Center Dental Clinic.

← NEW STATE PLAN CONTINUED FROM PAGE 9

with disabilities to develop and serve as leaders and mentors to their peers.

1.4 For a minimum of FY 2012 and 2013, expand the number of members in Next Chapter Book Clubs from 50 to 75.

Goal 2: SERVICE SYSTEM IMPROVEMENT

Annually, in collaboration with individuals with disabilities, families, professionals and policymakers, fund and replicate demonstrations of best practice, support public policy development, and coordinate coalitions so that the Tennessee developmental disability service system is person- and family-centered and supports individuals with developmental disabilities to be independent, productive and included in all facets of community life.

Objectives: SERVICE SYSTEM IMPROVEMENT

2.1 For FY 2012 through 2014, facilitate replication of Project Opportunity to two additional sites in Tennessee.

2.2 Research demand-side employment demonstration projects.

2.3 Annually, work with the Tennessee Employment Consortium and the Tennessee Alliance for Full Participation to fully develop and implement the TAFP plan to double the number of individuals with I/DD working in competitive employment.

2.4 Yearly, form, support or serve on public policy coalitions in order to advocate for and educate policymakers on best policies and practices in services for people with DD. Note – the focus of

the coalition can be employment, housing or any other topic relevant to the DD Act.

2.5 Annually, fund a minimum of four demonstration projects in order to highlight models such as self-directed services, person-centered thinking organizations, or other community-based best practice models. Note – this can be accomplished through either the Call for Application or Continuation Proposal processes.

Goal 3: INFORMATION AND OUTREACH

Annually, Tennesseans with disabilities, family members, professionals, organizations, policymakers and the public have a reliable source of, and are provided with, information about disability issues, services and supports which can be used to increase access to services and drive systems change.

Objectives: INFORMATION AND OUTREACH

3.1 Yearly, provide information on disability issues and topics through a magazine format.

3.2 Yearly, provide educational information on policy and legislation at the state and federal level through a newsletter format distributed via mail, e-mail, conference calls, and the Internet.

3.3 Yearly, provide information, referral, and support to people with disabilities and families seeking to access and use services.

Alicia Cone is the director of the Grant Program of the Council on Developmental Disabilities.

SIBCAMP!

BY TINA PROCHASKA

“Can we do this again

tomorrow?” It’s a question I’ve often heard during my almost 20 years of leading Sibshops at the Tennessee School for the Deaf (TSD). Sibshops are an internationally known sibling support program designed for children ages 8-13 who have siblings with disabilities. For the children who attend, Sibshops are both loads of fun and helpful support during what can be confusing times. Our Sibshops meet five times a year for four hours each session, and our families think that’s just not long (or often) enough. A Sibshop mother recently told me, “The more Sibshop time my kids have, the better they love it!”

When parents ask me to describe the sibling support we do, I try to compare it to a parent meeting. Most parents of children with disabilities remember the instant connection they felt when they first met another mom or dad whose child was like theirs. For young children, the connection is exactly the same. As a young sib told me, “Finally, somebody else gets my life!” Add in the fun, games, crafts and cooking at a Sibshop and you can see why the kids want more time together.

Sibshops at TSD are not the only sibling support offered in Tennessee for young children. Among others, the Vanderbilt Kennedy Center for Excellence in Developmental Disability has its SibSaturdays program and East Tennessee State University has Siblings United. SibSaturday’s Ashley Coulter, Siblings United’s Cindy Chambers and I were at an adult sibling gathering (we each have a sibling with a disability ourselves) when we began talking about our respective support programs. As we shared stories of how the kids love to be together, the idea of a sibling camp came up. We knew all our kids would love to attend; the question was could we pull it off? In short, with the enthusiastic support of all three programs, the answer was yes. And so, the first ever SibCamp in the State of Tennessee was born!

Photo by Joe Butt



Sibshop kids at Tennessee School for the Deaf

SibCamp is scheduled for July 7-9, 2011, and will be held on the beautiful campus of the Tennessee School for the Deaf in Knoxville. Just like the Sibshops, SibCamp is designed for children ages 8-13 who have siblings with disabilities. SibCampers will stay in the cottages at TSD; SibCamp leaders will be adults involved in the three sponsoring sibling support programs. There will be a nurse on duty during camp to deal with any scrapes, etc. In addition, selected teen-aged Sibshop graduates will serve as junior leaders during the three-day stay.

Sarena Duncan, a teen Sibshop attendee, had this to say about SibCamp: “I’ve been participating in the Sibshop experience for eight years, and never would I have dreamed of something like this! Sibshops are only held once every few months, and even though it’s at least four hours long, the time never ceases to fly by! I can’t wait to be a junior counselor for SibCamp; this is going to be three days of nonstop excitement.”

SibCamp will be similar to traditional camps. There will be lots of cookouts, campfires, crafts and water games. What will make SibCamp unique is that there also will be sibling support activities planned for each day. SibCampers will arrive on Thursday afternoon and their families can help them get settled in the cottages. Once the families leave, the SibCamp fun begins! SibCamp will close on Saturday afternoon with a Family Celebration. SibCampers’ parents

and siblings will be invited to join us as we honor and celebrate all that makes our families special. After learning about SibCamp from her son, a Sibshop mother told me, “Every kid wants Summer to come, but now he’s really looking forward to it!”

Space for SibCamp is limited to 30 children and we expect interest to be high. To be eligible for SibCamp, children must be involved in a local sibling support program and be between the ages of 8 and 13 on July 7, 2011. SibCamp application forms are available from the sponsoring sibling support programs or by e-mailing me at tinap@tsd.k12.tn.us. Cost for the three-day camp is \$50 per child and covers all food and materials. Some scholarship help will be available. Transportation to and from Knoxville will be the responsibility of the families.

It’s our hope that this first SibCamp will not be the last and that each year we will be able to serve more children. After all, we’re working with the people who have the potential to have the longest lasting relationship with their siblings. When we respect siblings’ needs and feelings, it ultimately improves the family experience for everyone. And if SibCamp is lots of fun, all the better. Break out the s’mores!

Tina Prochaska is the Tennessee School for the Deaf Sibshop coordinator.

AN EDUCATIONAL, PERSONAL EXPERIENCE WITH THE APPEALS PROCESS

BY CAROLE MOORE-SLATER

For the last 35 years, I have worked in the disability community and

throughout my career I have known individuals whose insurance denied a medical request important to their health. My usual response has been to “appeal” the decision—insurance companies don’t know individual circumstances, only you know your individual needs. Although easily said, it is not easily done, but that has never been a deterrent.

Recently I had the “opportunity” to personally “walk the walk” and appeal a decision made by my insurance company. I kept careful notes with the intention of producing a “short cut” for others because I knew this process would be challenging and would require persistence, specific medical documentation, information gathering, numerous phone calls to the insurance company, letter writing...did I mention persistence? But when an appeal is reversed and your quality of life is improved, the efforts made are worthwhile.

For me, it started in October, 2010, when I fell on my ankle, breaking it in three places. I spent the next three days in the hospital. Those days included ankle surgery, a heavy cast and the knowledge I would not be able to put any weight on my left foot for 8-12 weeks. Following this type of surgery, most patients receive crutches from the physical therapist and are discharged home without incident. But I have one hand and could not use crutches, a wheelchair or a walker, regardless of the type the physical therapist brought for me to try.

I was “stuck” in bed unable to do anything for myself, frantically trying to think of solutions. I called a rehabilitation physical therapist friend of mine for recommendations and she suggested a motorized scooter. The motorized scooter was delivered in the hospital and gave me the independence needed to care for my personal needs at home. I was told by the equipment vendor that my insurance would probably not pay for this equipment but I knew I would appeal.

STEP ONE: MEDICAL CERTIFICATION LETTER

A medical certification letter is required for equipment requests. When a medical certification request is not routine, it is very important to discuss specific needs with your medical provider because additional documentation to the insurance company will be required. Details were included in the medical certification letter I provided him (in writing) with reasons why I needed this equipment, especially as it pertained to my independence to do personal care activities at home, unassisted. I also requested a copy of this letter for my records. My doctor sent the medical certification letter and I crossed my fingers. The claim was automatically denied.

STEP TWO: CONTACTING THE INSURANCE COMPANY

Contact customer service (or the number on your insurance denial letter).

Request a copy of their policy pertaining to the denial of the medical request. This may require multiple calls to service representatives and their supervisors but there is a written policy somewhere! Keep track of your calls.

Request a copy of the insurance appeal process. It is important that you follow guidelines outlined by the insurance company.

Remember that it is VERY important that you keep a log of dates, names of people you talked to (with job titles) and telephone numbers. Without specific information (names and dates) your requests may not be taken seriously.

STEP THREE: THE APPEALS PROCESS

Review the appeals process sent to you by your insurance company. There will be specific requirements needed from you and your medical provider, along with deadline dates for filing an appeal. Don’t forget this time-sensitive process!

I was required to write a personal letter of appeal to the insurance company. To make it “easier to read” I divided the letter into sections: MEDICAL CONDITION (Information included why I needed a motorized scooter and the impact on my life without it.)

MEDICAL RECOMMENDATION (Verifying that my doctor wrote a letter of medical recommendation outlining those medical reasons.)

PROBLEM (The scooter was denied and appeared to be a “discriminatory” practice because I was a “non-traditional” patient.)

PLAN (Filing an appeal requesting that my insurance pay for rental fee payment required.)

Another medical certification letter will be required and NEW medical information is required. I contacted my physician and sent a copy of my letter so that he could add additional details. By this time, I had been seen again in clinic so further justification for a motorized scooter could be made. I requested a copy of this letter for my records. It was very important that my doctor and I be on the same page.

Obtain legal representation if necessary. In my case, I was represented by Martha M. “Martie” Lafferty who is managing attorney at Disability Law & Advocacy Center (DLAC) of Tennessee. Ms. Lafferty wrote a letter in support of my appeal and explained that for me, due to my disability, a scooter is the equivalent of a wheelchair. She also explained that the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability.

[Note: DLAC cannot help with all insurance appeals. DLAC can only help with issues which fall under its current priorities and objectives. If you need assistance with any disability related issue, you can contact DLAC at 1-800-342-1660 to see whether your issue is one with which they can help.]

In February, 2011, I received a response to my appeal. The response noted that scooters are excluded from coverage under my health plan. Nevertheless, my insurance plan agreed to pay an amount equal to the plan’s payment for two months of wheelchair use. So, my persistence paid off.

Carole Moore-Slater is program director at Tennessee Disability Pathfinder, a statewide bilingual information service of the Vanderbilt Kennedy Center and Tennessee Council on Developmental Disabilities. If you would like to discuss the appeals process with Ms. Moore-Slater, she can be reached at 615-875-5085, or carole.moore-slater@vanderbilt.edu.

GRANDPARENTS AND OTHER RELATIVES RAISING CHILDREN

Shelby County Relative Caregiver Program

MULTICULTURAL SERIES — PART FOUR

BY JUANITA WILLIAMS

Raising 10 children

alone is a challenge. But what do you do when one of your 10 adult children is murdered, leaving behind three children under the age of 11? Imagine the grief and hopelessness you'd feel knowing the daunting responsibility of assuming the role of parent. That's how Ms. Washington, a 78-year-old grandmother, felt as she found herself raising children once again. The difference is, this time she is 35 years older and much less energetic. Ms. Washington is one of the increasing number of grandparents and other relatives who are reaching out to the community for help as they struggle to keep their grandchildren out of State custody.

In the late 90s, social workers at University of Tennessee Health Science Center's Boling Center for Developmental Disabilities (BCDD) in Shelby County began noticing a significant number of children coming in for clinic appointments with grandparents and not birthparents. With the support from the United Way of the Mid-South and the Duration Club, funding was secured to provide educational sessions and support groups for grandparents. As small as this effort was, it influenced the implementation of the current Relative Caregiver Program.

Relatives raising other relatives' children is not a new concept, especially in the African American community. What is new, however, is the magnitude of grandparents and other relatives stepping up to raise related children long term. According to 2000 census data, an estimated 4.5 million children are being raised by grandparents and other relatives. As the children's parents struggle with substance abuse, mental illness, incarceration, economic hardship, divorce, domestic violence and other challenges, these caregivers provide a vital safety net for children. As caregivers step in,

the children remain connected to their family of origin, thus preventing them from entering State custody.

Tennessee is one of a handful of states that responded to the urgency to address the increasing number of children being raised by their non-biological parents and who are at risk of placement in the foster care system. On June 9, 2000, the Tennessee General Assembly passed legislation allowing for the development of the Relative Caregiver Program. Funds were allotted for a two-year pilot program through a TANF (Temporary Assistance to Needy Families) block grant administered by the Department of Children's Services (DCS).

Two urban and one rural community-based agencies were selected to pilot the program: the Boling Center for Developmental Disabilities in Shelby County, Family and Children Services in Davidson County and the Upper Cumberland Development District in the Upper Cumberland Region. The Relative Caregiver Program is now statewide with programs in all 12 regions. The program developed out of the recognition that abused or neglected children or children whose parents are unable to provide for them are best served if cared for by other suitable family members, instead of in foster care with unrelated caregivers.

While relatives may be willing to care for these children, doing so often requires additional financial obligations as well as an array of needed community resources. As one of the original pilot programs, the Shelby County Relative Caregiver Program began serving families in 2001. The mission of the program was to create a public/private collaboration designed to support children, whose parents are not able to raise them, by offering the following services: caregiver



Photo by Rhonda Ferguson

Ms. Betty Coffee and her grandchildren, Briana Williamson, Bayla Williams, Taylor Davis, and Mallory Davis.

support groups, information and referral, groups for children and teens, educational and informational workshops, respite and enrichment events, family advocacy and emergency financial or start-up assistance.

Demographically, 97% of the caregivers in the Shelby County Relative Caregiver Program are African American females between the ages of 50–59. On average, these women are raising three children and working at least part-time. The average age of a child in the program is nine, and 25% of the children have a developmental disability.

The staff of six well-trained Family Advocate Counselors and two support staff work very closely with families to ensure a comprehensive coordination of services. Examples of these activities are as follows.

- Conducting intakes and assessments for eligibility into the program;
- Identifying family strengths and barriers;
- Conducting mandatory home visits;
- Facilitating support groups;
- Coordinating and facilitating youth activities;

Providing information and referral services;
Crisis Intervention; and
Emergency Financial Assistance.

OUTCOMES AND NEXT STEPS

Since 2001, the Shelby County Relative Caregiver Program has provided some level of service to 3,191 caregivers and 6,687 children. In terms of cost, the Shelby County Relative Caregiver Program spends an average of \$500 per year for each relative care child in comparison to \$8,000 or more spent for a child in foster care.

Through its coordinated network of support and services, the Shelby County Relative

Caregiver Program is providing caregivers with tools to sustain permanency, safety and well being for the children.

Client surveys show a high level of satisfaction with the program.

"Thank you and you're doing a great job! Program much needed. I am so happy for the Program because it has given my child the ability to improve her self-esteem with clothes like other children have."

"I think that this program is for all persons who are caring for their loved ones. The support that is offered has meant so much to me. I truly feel that my family has benefited so many

ways, especially in keeping me sane."

"I think this is one of the best programs available for people like me who need help in being the best we can be, because many of us don't know what to do when we get our kids. The staff at UT provides the total package."

As we enter the 10th year of the program, the primary goal continues to be a county-wide outreach effort to recruit and serve caregiver families in need of information or assistance.

Juanita Williams is project director at the Boling Center for Developmental Disabilities in Memphis.

CAREGIVER RESOURCES

COMPILED BY COURTNEY TAYLOR

support for people caring for individuals with ALS (often referred to as Lou Gehrig's Disease). However, the "Patient, Family, Caregivers" section of the Web site has resources appropriate for all caregivers. There are resources on how to cope with burnout, respite care, facts about family caregivers, tips and hints and more.

www.alsa.org

CARING FROM A DISTANCE is an independent, non-profit organization that provides assistance to long-distance caregivers. It assists in finding local resources, provides access to telephone counselors and has an online library.

www.cfad.org

THE DISABILITY INFORMATION AND RESOURCES Web site has an extensive list of resources for caregivers.

www.makoa.org/caregiver.htm

FAMILY CAREGIVER ALLIANCE (FCA) was the first community-based non-profit organization in the country to address the needs of families and friends providing long-term care at home. Long recognized as a pioneer in health services, FCA now offers programs at national, state and local levels to support and sustain caregivers.

www.caregiver.org

HEALTHFINDER.GOV is a government Web site dedicated to providing information and tools to help individuals stay healthy. The Web site has an article on recognizing caregiver stress.

www.healthfinder.gov/news/newsstory.aspx?docID=640246

THE ALS ASSOCIATION provides education and

THE NATIONAL ALLIANCE FOR CAREGIVING is a non-profit coalition of national organizations that focus on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency and corporations. The Alliance was created to conduct research, do policy analysis, develop national programs, increase public awareness of family caregiving issues, work to strengthen state and local caregiving coalitions and represent the U.S. caregiving community internationally.

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

THE NATIONAL FAMILY CAREGIVERS ASSOCIATION (NFCA) educates, supports and empowers more than 65 million Americans who care for loved ones with a chronic illness or a disability. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being.

www.nfcacares.org

THE RURAL CAREGIVERS Web site offers supports to caregivers in rural settings. The project was created to address the challenges of providing support with barriers such as geographical isolation, gaps in rural service delivery systems and the unique needs of agricultural workers with disabilities.

www.ecn.purdue.edu/~bng/BNG/Caregiving/index.html

Courtney Taylor is associate director of Communications and Dissemination at the Vanderbilt Kennedy Center.

All families need support, especially families who have children with disabilities. Depending upon a family's needs, support can take many forms, including financial assistance, emotional connection, information sharing and care giving responsibilities. The following resources provide support to families in the State of Tennessee.

Vanderbilt Kennedy Center's Parent Stress Intervention Program

This program, offered by the Vanderbilt Kennedy Center, is a research study comparing two different support group models to determine how each reduces stress for parents and caregivers of persons with disabilities. The two stress reduction approaches utilized are positive parenting stress reduction (a cognitive behavioral approach) and mindfulness-based stress reduction (which focuses on the mind and body connection). Participants are randomly placed into one of these two approaches at the beginning of the program and then meet for one and a half hours each week, for six weeks. The program is free but participants are asked to fill out questionnaires throughout the program and give cortisol samples. Free child care is available. Please contact Roxanne Kennerly for more information at 615-875-5080 or roxanne.kennerly@vanderbilt.edu .

Pathfinder's Parent Support Group for Spanish-Speaking Families

Pathfinder, through its Camino Seguro program, has created two support groups for Spanish-speaking parents and caregivers of people with disabilities. One of the groups is open to the public and designed to be both educational and therapeutic. This group meets on the second Monday of each month from 6:00 to 7:30 pm. Representatives from different agencies, such as TRIAD and the Nashville Children's Alliance, present information about the services and supports they provide to people with disabilities. There is also a closed support group that is purely therapeutic and not open to the public. For more information about support groups for Spanish-speaking families, please contact Carolina Meyerson at 615-400-4422 or eva.meyerson@vanderbilt.edu .

Pathfinder's Statewide Support Group List

The Pathfinder's Statewide Support Group list is published on the Web site and updated annually. This list is divided by disability and region, and contains contact information for over 100 support groups across the State. You can find this list on the Pathfinder homepage under the "Spread the Word" icon.

Family Support Program

Family Support is a program of the Department of Intellectual and Developmental Disabilities (DIDD), which provides financial assistance to individuals and families with severe disabilities. For more information about the Family Support Program, contact Jan Coatney, Family Support State Coordinator, at 800-535-9725, 615-532-6552, or jan.coatney@tn.gov

Tennessee Respite Coalition

Tennessee Respite Coalition is a non-profit advocacy organization that supports statewide planned and crisis respite services. This program operates respite voucher programs in certain areas of the State and provides information about and referral to community respite providers. Contact Jennifer Abernathy, Executive Director, at 888-579-3754, 615-269-8687, or jennifer.abernathy@tnrespite.org .

Parentsknowkidsgrow.org

This Web site, an initiative of Signal Centers in Chattanooga, is a great resource for parents and caregivers of children with disabilities. It not only provides resources and information on topics relating to disabilities, but also on topics such as child safety, healthy living and school readiness. Please contact Sonua Bohannon at Sonua_Bohannon@signalcenters.org for more information.

Pathfinder is the statewide clearinghouse for disability-related resources with bilingual and culturally competent staff to assist individuals, families, caregivers and service providers with disability-related information and resources in the community. Visit www.familypathfinder.org or call 1-800-640-4636 and our staff will be happy to assist you.

Pathfinder is a disability information resource center with a statewide bilingual helpline and Web site including local, state, and national resources; a project of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities.

Visit our Disability Resources Library at <http://kc.vanderbilt.edu/tennesseepathfinder/resources/default.aspx>

1211 21st Avenue South, 539 Medical Arts Building, Nashville, TN 37212
 1-800-640-4636
 615-322-8529
 Fax: 615-322-1700
www.familypathfinder.org

Hispanic Resources
www.caminoseguro.org

Angela Bechtel, MSSW, 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

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.**

NEW COUNCIL MEMBERS APPOINTED

On November 23, 2010, Governor Phil Bredesen named three new appointments and two reappointments to the Council on Developmental Disabilities. As part of his remarks, the Governor said, "I thank these individuals for their willingness to serve the state ... Tennessee's reputation as the Volunteer State is reflected through these citizen's willingness to contribute their time and talents to improve our state ..."

Photo by Lynette Porter



TINA BURCHAM lives in Counce and will represent the Southwest Development District. Ms. Burcham is a stay-at-home mom with three daughters. Her youngest daughter was born with profound sensory neural hearing loss with auditory neuropathy. Ms. Burcham has been dedicated to the education and advocacy of her deaf daughter for the past four years. As part of her advocacy, she has

conducted ongoing research of disability laws including the Americans with Disabilities Act and the Individuals with Disabilities Education Act and is self-taught in American Sign Language and Signed English.

Some of Ms. Burcham's previous jobs outside of the home include technician and civilian contract jet engine mechanic and she is a United States Air Force and Reserve Veteran.

Photo by Errol L. Elshain



NORRIS BRANICK, of Jackson, also will represent the Southwest Development District, as the Council seats two representatives from each of the nine Development Districts in Tennessee. Mr. Branick has been the advocacy outreach coordinator for the Jackson Center for Independent Living for the past seven years and for the last three years has been a people greeter at Wal-Mart.

Mr. Branick has been very active in the disability community for many years, including serving as Southwest Vote Campaign Chairman in 2004. Mr. Branick also serves on the State Rehabilitation Council and the West Tennessee Housing Resource Network Board.

Photo by Carole Moore-Slater



ALEXANDER SANTANA, of Antioch, was appointed to represent a Local Nongovernmental Agency. He is the multicultural program coordinator for Tennessee Disability Pathfinder at the Vanderbilt Kennedy Center.

Mr. Santana has a BA in Arts of Education with a dual major in Speech Therapy and Special Education from the Felix Varela Pedagogical Superior Institute in Cuba. Since June of 2010, in his position with Tennessee

Disability Pathfinder, he has been identifying and working with Spanish-speaking families who have members with disabilities. Prior to that, Mr. Santana worked as an outreach coordinator for First Steps, Inc. in Nashville, and was a special education instructor and community educator at the Felino Rodriguez Mental Health Clinic and special education instructor in Villa Clara, Cuba.

Mr. Santana has extensive experience working with children with disabilities and their families and serving as a liaison to resources in the community.

JOYCE ELAINE SIEVERS, past Council chair, lives in Smithville and represents the Upper Cumberland Development District.

STEVEN SHEEGOG, of Memphis, is past Council vice-chair and represents the Memphis-Delta Development District.

Ms. Sievers and Mr. Sheegog were reappointed to the Council.

TENNESSEE SPOTLIGHT

Photo by Britt Simmons



Jon Kent, president of **Kent Creative** in Nashville, recently traveled to Thessaloniki, Greece, where his first documentary feature film, **Embraceable**, premiered at the **Thessaloniki International Documentary Festival**. *Embraceable*, an inspiring film about a rare genetic condition called Williams Syndrome, was selected as part of the Festival's tribute to the International Special Olympics, which Greece will be hosting this year. The film provides an intimate look into the fascinating lives of people with Williams Syndrome whose overly-social personalities, remarkable gifts for expressive language, and striking passion for playing and listening to music often masks some of the medical, cognitive and social challenges associated with the disorder. Interviews with top researchers at the Salk Institute, Harvard University and other leading institutions are intertwined with the film's narrative. The film trailer and other information can be found at www.embraceablemovie.com.

According to the Williams Syndrome Association, the disorder affects 1 in 10,000 people worldwide—an estimated 20,000 to 30,000 people in the United States.

John Bryan, son of Partners in Policymaking graduate and Brain Injury Association of Tennessee executive director, Pam Bryan, was awarded the **Male Spokesperson of the Year** for 2011 for the Sports 4 All Foundation. He will represent Sports 4 All at conferences and special events throughout the year. In addition, **Natalie Herndon** received the award for **Female Spokesperson of the Year**, and **Mallory McGough** was named **Volunteer of the Year**.

Special Olympics International has elected three new members to its Board of Directors, including a renowned figure skater, a Special Olympics athlete and a leading scholar in the field of intellectual disabilities. The new Board members are figure skating champion **Michelle Kwan**, Special Olympics Canada athlete **Matthew Williams**, and **Elisabeth Dykens**, PhD, Annette Schaffer Eskind Chair and director, Vanderbilt Kennedy Center.

The Special Olympics International Board of Directors is the ultimate governing authority for the Special Olympics movement and is composed of leaders in the areas of business, government, disability, sports and entertainment. The Board is responsible for the global affairs and strategies of Special Olympics, determines its policies and programs and oversees all top-level management.

The Upper Cumberland Human Resource Agency (UCHRA), which operates in fourteen Tennessee counties, was recently recognized by the Federal Transit Administration (FTA). The FTA presented **Phyllis Bennett**, UCHRA executive director, and **Rebecca Harris**, UCHRA transportation director, an award for **Outstanding Public Service** for rural transportation, one of only six given nationally. The Tennessee Department of Transportation was represented by **Dironna Belton**, planner IV.



Elise McMillan, JD, Partners graduate and co-director of the **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities**, testified at the "Envisioning the Future Summit Series" held by the Administration on Developmental Disabilities (ADD).

Sharon Lewis, ADD commissioner, invited advocates, family members, allies and professionals to share their vision

for the future of individuals with developmental disabilities at one of five Summits being held across the country, October-December 2010. Ms. McMillan testified at the Summit held in Orlando, Florida, on November 8th. Ms. McMillan spoke both as a representative of the **Tennessee Developmental Disabilities Network** and as a parent of a young adult son with Down syndrome.

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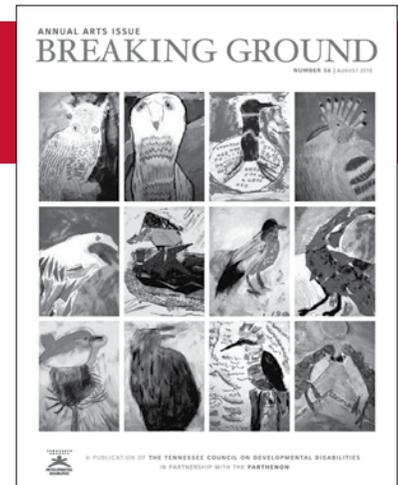
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