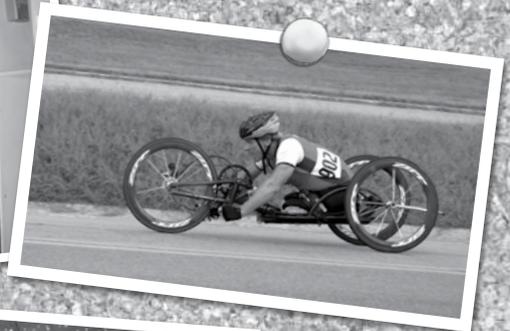
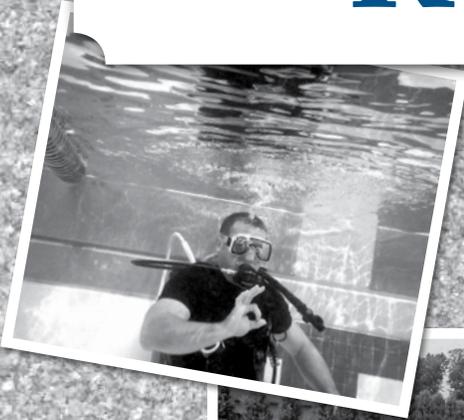


BREAKING GROUND

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SPECIAL ISSUE ON HEALTH

Rec-*ing* It!





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Council Staff Changes Announcement

In April, two staffing changes were approved for the Council. **LYNETTE PORTER** was promoted to Deputy Director of the Council. In this role, she will assume expanded administrative duties including, managing federal and state administrative requirements and communications, budget and finance, and assisting with critical partnerships with other agencies.

EMMA SHOUSE was appointed as Director of Public Information for the Council. Ms. Shouse, who served as a public policy intern for the Council in the Summer of 2010, will be the Council's chief information officer and will primarily focus on public information activities, Web site/social media development, and DD Network collaborations.

In May, **ERROL ELSHTAIN**, Director of Development, editor-in-chief of *Breaking Ground* and long-time Council employee, announced that he would be retiring at the end of June in order to spend time with his family. Mr. Elshtain has worked with the Council for over 20 years and served as a Council member before becoming a staff member. The Council, its constituents and partners will miss him greatly!

Council executive director, Wanda Willis, stated, "The Council is incredibly fortunate to have the dedicated and gifted staff that we have. Lynette and Emma bring enormous skills to their new positions. It's also a bittersweet occasion as we say farewell to Errol Elshtain, an amazing colleague and friend, who has been with me through many formative years at the Council. However, I am excited for him and the time he will have for his family, particularly the grandchildren that he treasures so deeply."

CONTACT INFORMATION



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Rec-*ing* It!

BY DENNIS CLARK

After recuperating from a spinal cord injury 11 years ago, I realized I was becoming much less physically active. It was a big hole in my life. I just sat in a wheelchair all day long. That's a great way to gain weight. No running, no riding, no sports. No fun. I had to do something, and the Patricia Neal Rehabilitation Center (PNRC) in Tennessee came to the rescue.

PNRC has a program called the Innovative Recreation Cooperative (IRC), where people with disabilities can attend a variety of recreational clinics. Its goal is to educate folks on life skills through recreational activities and awareness about being active. That meant I could try a bunch of sports without having to buy any of the adaptive equipment. I had no idea that there were so many recreational opportunities for people with disabilities! I tried as many of the activities as I could and enjoyed them all. Perhaps you can, too. Here are some I experienced for myself.



INDOOR RANGE

At a local indoor armory, I discovered that many people with disabilities enjoy hunting, and they sharpen their aim indoors. The only adaptive equipment I needed was a table to hold ammunition and gun cases, etc. I have a friend with quadriplegia who hunts deer. He uses a homemade gun tripod with a copper wire trigger-pull. He perfected that adaptation by testing it at the indoor range.

TRAP SHOOTING

Trap shooting is another entertaining way to spend an afternoon, although I think I'd be more effective with a wide-angle blunderbuss.

ALPINE CLIMB

You don't find too many Alpine Climbs floating around. The folks at IRC discovered one at Warren Wilson College in Swannanoa, North Carolina. It's a 65-foot

tower made from telephone poles, ropes, handholds, planks and ladders. The folks at the liberal arts college combine academics, work and service in a learning community committed to environmental responsibility, cross-cultural understanding and the common good. That cross-culture includes people with disabilities. They use the Alpine Climb to develop leadership, cooperation and self-confidence. Although it seems like a scary activity, it's one of the safest activities around.



GOLF

I ran track in high school in the '60s, when "cross-country" meant a two-mile run on golf courses. Now, let's face it, I was never a good golfer. Never broke 100, but it was so beautiful out on the golf courses, I just had to run. I'd hit that little white ball and take off

running even before it rolled into the sand trap. I'm not any better at golf today, but I can play. And I've met people with disabilities who are phenomenal golfers. As a person with paraplegia, I can hit the ball one- or two-handed, I can use an adaptive golf cart or a fat-wheeled wheelchair and there are golf clubs that can be used from a sitting position.



RIVER KAYAKING

River kayaks are great fun as long as you're comfortable in the water. They don't cost too much, and you don't have to buy any additional adaptive equipment. The only extra equipment I use is a seat pad made out of firm memory foam. Remember to wear your life vest. Not only can it save your life, but as long as you're wearing it, the Coast Guard won't fine you!

continued on page 4

WATER SKIING

I never thought I'd water ski again. I don't have an adaptive water ski. Come to think of it, I don't have a boat either. Thanks to the IRC water ski clinics, I had access to both, plus people who love to water ski themselves. All sorts of adaptive equipment exists for people with disabilities. There are adaptive water skis with or without outriggers and even modified wake boards. If you're interested, just Google "adaptive water skiing". Heck, I figure one of these days I'll see a person with a disability skiing on an air chair.

SNOW SKIING

Snow skiing is great fun if you like mountains, snow and moving fast. There are many programs around the country to teach people adaptive snow skiing. Google "adaptive snow skiing", and you'll find dozens of links.

SWIMMING

I'm not a fast swimmer, but I can plow through the water all day long. Swimming is one

of the best aerobic activities for almost anyone. Our community has an indoor pool with an electric pool lift. For the outdoor pool, there is a wheelchair that can be used on the sloped entry. The indoor pool even has an accessible bathroom where people with disabilities can change clothes and shower. I also found several local swim coaches who were interested in teaching people with disabilities.



SCUBA

I'd just as soon be in the water as on dry land. I don't even mind being under the water as long as I can breathe. With SCUBA gear, I experience a freedom that cannot be matched on land. Since SCUBA is a safety first sport, I dive with two buddies instead

of just one. Believe it or not, the second buddy is not for my safety—it's for their safety because it would be difficult for me to rescue them.

HANDCYCLING

Moving rapidly gives me a sense of freedom. I move around in my wheelchair but it's slow. Handcycling gives me the chance to move 20 or 30 miles at a time while being out in the sun. It gives me a great cardiovascular exercise that my wife and I can both enjoy at the same time. I like it so much that I even race in the United States Handcycle Federation series of races. It gives me the opportunity to race with Olympic caliber athletes (even though I'm not), and I get to meet some really great people.

GET OUT THERE AND REC-IT!

As the IRC program says, "Use your potential. Re-create your life." There are so many wonderful recreational activities to experience. Choose one you like, but make sure

it's fun and gets you moving. After all, movement is part of the definition of life. We're all lucky to be alive and, as Helen Keller said, "Life is either a great adventure, or it is nothing." I prefer the great adventure!

Visit these Web sites for more information about the programs referenced in this article.

Innovative Recreation Cooperative (IRC) at <http://www.patneal.org/IRC>

The Air Chair hydrofoil waterski: <http://www.airchair.com/>

An interesting "tech guide" for snow skiing can be found at <http://www.usatechguide.org/techguide.php?vmode=1&catid=408>

Check out the US Handcycle Federation at <http://www.ushf.org/>

Dennis Clark lives in Oliver Springs, is a 2008-09 Partners graduate and an avid and active athlete.

FAMILY SUPPORT FULLY FUNDED *for* FY 2012 - 2013

BY WILLIAM EDINGTON

The Family Support Program, administered by the Department of Intellectual and Developmental Disabilities (DIDD), that is so important to many persons with disabilities has been funded for the last three years with temporary federal and state funding. The program's annual budget is slightly over \$7,300,000, with all but \$200,000 being provided through those temporary funds, also known as nonrecurring funds. Nonrecurring funds can be committed for only one year at a time, so the use of that funding structure has required people to advocate annually for the program to be funded for each following fiscal year.

In his initial budget, submitted in January of this year, Governor Bill Haslam proposed to provide the program with \$4,500,000 in recurring (or ongoing) funds. If approved by the General Assembly, that amount, along with the \$200,000 of current recurring funding, would have granted the program \$4,700,000. However, in his April budget amendment, Governor Haslam included an additional \$1,000,000 in nonrecurring funds for the program. Late in the legislative session, the legislature approved the Governor's proposed funding but also passed a budget amendment that added over \$1,600,000 in nonrecurring funds to give the program full funding for the fiscal year beginning on July 1, 2012.

Families and advocates have been working since the Summer and Fall of 2011 to accomplish this outcome. We are very grateful to Governor Haslam and the General Assembly for providing the program with \$4,700,000 in recurring funding and \$2,600,000 in nonrecurring funds to fully fund the program for Fiscal Year 2012-2013. This will ensure that families currently supported by the program do not lose those services during the coming fiscal year.

William Edington is public policy director with the Tennessee Council on Developmental Disabilities.

EARLY BIRDS

Create Accessible Hunting Experiences

BY TRACEY FARR



Dale Bayless and Caden Middlebrook

Photo by Tracey Farr

Up early this morning with thoughts of the East Tennessee woods and wild turkeys, it seems only fitting for me to share my experience at yesterday's (Saturday, April 28, 2012) Wheelin' Sportsman/Wounded Warrior Hunt in Campbell County from this pre-dawn perspective. Many of these folks were up and out of the house before 3 a.m. so they could participate in an accessible wild turkey hunt hosted for its 8th year by the National Wild Turkey Federation, an organization whose mission is to conserve the wild habitats for the often elusive wild birds, hunt these birds for sport and share their experiences with others. An initiative called the Wheelin' Sportsmen aims to provide outdoor opportunities for people with ALL abilities.

A true collaboration—almost as rare as the turkeys themselves—this event was bolstered with enthusiastic support from several other organizations, such as the Tennessee Wildlife Resource Agency, Campbell Outdoor Recreation Association, Tennessee Wildlife Federation, the Pine Mountain Longbeards, Tennessee's chapter of the International Dutch Oven Society, and businesses and families from all over the State. Watching these groups come together to create accessible hunting experiences was so much fun and

was made even more rewarding after speaking with some of the sportsmen with disabilities who were enjoying the day.

Jason Seaton from Sevier County found out about the hunt from Mitchell Amann of the National Resource Conservation Service, a friend who met him through their work together to turn Mr. Seaton's farm into a natural habitat. Mr. Seaton was exhausted from the day and we talked about how far up into the woods they went. Using large ATVs, they traversed up a mountain that Mr. Seaton said looked like there was no way they'd be able to!

A bumpy ride to say the least, they saw and heard several wild turkeys but could not get close enough to take a shot. If they could have gotten a bird, Mr. Seaton would have used an AccessAcc mechanism that he and Mr. Amann have developed that allows him to fire the gun using a breathing apparatus, similar to sip-and-puff technology. Clearly exhausted from such an intense ride and long, early morning, Mr. Seaton was in great spirits after his first time with this group, and his mom said this is the best event of this kind they have attended.

I never saw Dale Bayless without a smile on his face. This was his first time turkey hunting and I think he's hooked! Mr. Bayless heard a lot of birds in the

distance, but was happy as can be without getting to shoot one.

"Harvesting a turkey is not the total goal, just the icing on the cake," stated event organizer Terry Lewis as he invited me to come from the East Tennessee Technology Access Center (ETTAC) to share in the experience and fellowship, which included a great meal of barbecue, grilled hamburgers and hotdogs with all of the trimmings. Speaking of cake, the Tennessee Dutch Oven Society was busy all morning preparing fresh cobblers and other delights (coconut macaroon, pineapple upside down cake, and Mississippi mud pie are just a few of the ones I tried) to serve as desserts for the crowd.

With beautiful East Tennessee weather and so many great organizations participating in this cause, this day really was a sweet treat for me. And as you can see here with Caden Middlebrook, who got a bird, it's also nice to get some of that cake!

For more information about this annual event, contact Terry or Jane Lewis at 865-414-0057 or e-mail terry@t-lewis.com.

Tracey Farr is development coordinator with the East Tennessee Technology Access Center (ETTAC). For more information about ETTAC, call 865-219-0130.

2011-12

Partners Graduating Class

“Has Just Begun”

BY NED ANDREW SOLOMON



Photo by Lori Israel

On Saturday, April 21st, 24 members of the 2011-12 Partners in Policymaking™ Leadership Institute graduated in a ceremony at the Nashville Airport Radisson Hotel. This extremely diverse class of individuals with disabilities and family members successfully completed the seven Partners training sessions, along with homework assignments and in-class reporting. We at the Council on Developmental Disabilities are very proud to welcome the following community leaders into the extensive Partners graduate network.

- GEROME BOWEN**, Nashville
- BRANDI BROWN**, Lenoir City
- JANIE CAMERON**, Franklin
- CYNTHIA CHAMBERS**, Jonesborough
- MARY ELLEN CHASE**, Memphis
- KASONDRA FARMER**, Nashville
- KAY FRENCH**, Memphis
- VIRGINIA FRIZZELL**, Gainsboro
- LAURIE HOBSON**, Germantown
- MARTINE HOBSON**, Germantown
- LARRY JOBE**, Lebanon
- KEVIN KOVACS**, Murfreesboro
- REBECCA LEWIS**, Erwin
- BILL MARTIN**, Lascassas
- DANAE MATLOCK-BRIGGS**, La Vergne
- DEBORAH MOREHEAD**, Nashville
- REBECCA NEWBORN**, Iron City
- LYNISE PARISIEN**, Antioch
- JOHN RICE**, Chattanooga
- CASSEY SHARPE**, Summertown
- DOROTHEA THOMPSON**, Murfreesboro
- ERIN THOMPSON**, Knoxville
- DELORIS WESTBROOKS**, Memphis
- LASHUNDA WESTBROOKS**, Memphis

AND NOW, IN THEIR OWN WORDS

“Knowledge is power. With the knowledge I have obtained, I have the power to make essential changes in my immediate community. Sharing knowledge with others equals giving empowerment to them. Empowering others and seeing the successes they obtain is the reward.”

“For the first time, I’ve let myself dream of ways to help my son and to help others. It’s not over now. I’ve just begun.”

“It has given me knowledge and exposure to people, information and options which I know will make an impact on the life of my family member.”

“It has helped me focus my advocating in ways that I was not initially directing my efforts. For example, advocacy at the legislative level.”

“I know how to research information. I know who to go to. I am not afraid of talking to the policymakers.”

“I gained valuable knowledge that will, and has already, helped me advocate. I now have a valuable support network of friends I have met. I have more awareness of the needs of others.”

“I have a broader view of where and when I can be an advocate.”

“Partners has supplied me with the tools (that is, information about resources) and educated me about the processes to help me better advocate for myself and others. First, the program will help me to find services to keep me living independently at home. In the long term, I plan to help people in the community advocate for themselves. But the most significant way that the Partners training has helped me learn is how to, and that we need to, communicate with our representatives and local politicians about the issues affecting myself and those in my community.”

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

DIDD Official Says Medical Profession Needs Broader Training

BY ELLEN MARGULIES



Tom Cheetham

Everyone tends to have a story about why they chose to get into the field of researching or caring for people with developmental disabilities, but Tom Cheetham’s tale is different than most.

He was pursuing his undergraduate degree when his late wife, the sole wage-earner in the family at the time, came home one night and told him, “We have a new job.”

“The ‘we’ was puzzling to me, because she was the person employed,” said Dr. Cheetham, who heads the Office of Health Services for the Tennessee Department of Intellectual and Developmental Disabilities.

The “we” job, it turned out, was being live-in house parents for 10 adults with intellectual and developmental disabilities (IDD). “That was my introduction to the field, and it’s been my career ever since,” he said.

Dr. Cheetham, who has been Tennessee’s Department of Intellectual and Developmental Disabilities (DIDD) Health

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Project OPEN WIDE

BY RICK RADER, MD

Comprehensive dental care is the number one unmet health care need of people with intellectual and developmental disabilities. The variety of reasons for the lack of access to adequate care range from the lack of training in dental schools and training programs with little or no exposure to patients with special needs, to poor reimbursement rates from funding sources and insurance companies. Although the Orange Grove Center (OGC) in Chattanooga has always recognized the utmost importance of dental care, this lack of training made it difficult to find a full-time dentist and provide a continuity of care for our patients.

The impact of limited dental care access includes loss of teeth, nutritional complications, gum disease and its relationship to both heart disease and stroke, loss of self-esteem, and chronic pain and its translation to sensory and behavioral misadventures.

As Director of Habilitations at Orange Grove, my vision was to develop a full dental program, providing comprehensive care to not only the people served by Orange Grove but also any individual with a disability in East Tennessee. Along with Dr. Sandy Fenton (former Chair of the Department of Pediatrics and Community Dentistry, University of Tennessee School of Dentistry), we made a proposal to the Tennessee Council on Developmental Disabilities in hopes of building a sustainable dental clinic that would fill the void in our approach to health care. The Orange Grove Center's Project OPEN WIDE was awarded a \$100,000 grant, renewable for up to three years, to make this vision a reality.

The epicenter for training graduate dentists in "developmental dentistry" is the Underwood and Lee Clinic in Louisville, Kentucky. Under the leadership of Dr. Henry Hood (a founder of the American Academy of Developmental Medicine and Dentistry), this is the only teaching entity that provides Fellowship level training for dentists with an interest in oral health care for individuals with intellectual and developmental disabilities. Part of the Fellowship curriculum includes an attachment to the Orange Grove Center in a unique program called the Total Immersion Clerkship. This allows the dentist to be "embedded" in the Center to observe, participate and appreciate the "big picture" of the spectrum of life-long supports available in the community. Through this partnership with the Fellowship program, OGC was able to identify the individual

who would lead Project OPEN WIDE to its envisioned heights.

Dr. Kristin Compton, one of only seven Fellowship-trained dentists in the United States, has not only the clinical skills but the compassion, empathy and commitment to see her "patients" as "people" and to appreciate their challenges and contributions. She was recruited with a simple mission: to create not only a clinic but a "culture of care."

Dr. Compton's first order of business was to make the dental clinic a fun and relaxing environment. The walls were painted a calming aquamarine. Pictures of patients line the walls, along with encouraging phrases, including "Every day holds the possibility of a miracle." Dr. Compton introduced music therapy with the use of a jukebox and had flat screen televisions installed on the ceiling so patients could watch movies during their treatment. An open door policy allows patients to "wander" into the clinic and observe, without any pressure of pursuing treatment, allowing each patient to become comfortable at their own pace. Many individuals simply visit the clinic to dance, watch a video or select a spritz of their favorite perfume.

The real highlight of OGC's dental clinic, however, is the staff. Jeanette Hames, CDA, has been in the clinic for 34 years and has an intimate knowledge of our patients. Our two part-time hygienists, Sonya Lane, RDH, and Nadia Marandi, RDH, each have become close with many patients and continue to bring new and exciting ideas. This compassionate connection of our staff with our patients is what allows the Orange Grove dental clinic to move away from sedation and toward desensitization.

The clinic's sedation rate is less than two percent, 20 percent lower than the national average. This is due, in part, to our belief that not every visit needs to result in a purely clinical encounter. It is a sensible model that allows for a slow and gradual, stress-free transition that contributes to the clinic's impressive ability to provide office-based care to individuals previously sent to a hospital's operating room and subjected to the use of general anesthesia.

With all this, plus the ability to work with other health care departments, including physical therapy for positioning and occupational therapy for oral home care training, the OGC dental clinic is able to provide care for approximately 475 patients in Chattanooga and the surrounding area. Every patient

initially is provided a comprehensive exam, including an oral cancer screening, cleaning and fluoride treatment. Plans of care are individualized, based on the findings of the exam, and may include restorations (fillings), crowns, extractions or dentures/partial dentures, with each patient then placed on a four-month recall cycle.

Dr. Compton and the OGC dental clinic have a partnership with Chattanooga State College that requires both dental assisting and dental hygiene students to spend eight hours in our clinic learning the ins and outs of working with patients with intellectual and developmental disabilities. Dr. Compton also provides didactic lectures at the college. This is an effort to curtail the lack of education in the dental community, with the hope that our students will carry their newfound knowledge and sensitivity into private dental practices.

A vital component of the clinic's blueprint involves the education of DSPs, or Direct Support Professionals. These front line staff are the lynch-pin for the oversight of needed home-based dental care. Through lectures, demonstrations and competency-based training, the DSPs learn techniques to assist individuals with physical, sensory and behavioral challenges to achieve optimal oral health care. Dr. Compton frequently lectures at conferences and meetings, including the Southeastern Autism Symposium and the Chattanooga Area Dental Hygiene Society, as well as numerous state and national dental association meetings.

An additional welcome piece to the success of Project OPEN WIDE was the creation of its Consumer Advisory Board (CAB). This board, consisting of "patients" and "parents", provides ongoing input to what works and what doesn't. There have been several initiatives in the program that were suggested by the board. Health care is a dynamic process that requires a commitment to improving the environment, the care delivery system and ways to better define the "patient experience."

Dr. Compton has been appointed as the State Clinical Director for the Special Smiles program for Special Olympics. This is the oral health component of Healthy Athletes, the division of Special Olympics that addresses the health care screening and referral of athletes.

The backbone of Project OPEN WIDE was the mandate to create a sustainable model to continue its groundbreaking work beyond the scope of the three-year grant. All too often programs that were initiated by start up grants are unable to continue when the funding pipeline is curtailed. Project OPEN WIDE has a bright future of continued growth thanks to addressing the sustainability concerns from the very first day.

Thanks to the support of the Tennessee Council on Developmental Disabilities, its active guidance and engagement, the "culture of care" at Orange Grove and the commitment of Dr. Compton and her staff, Project OPEN WIDE will continue to serve as a model for a cost-effective, clinically efficient and compassionate center where individuals can listen to their favorite juke box hits and receive optimal oral health care.

Dr. Rick Rader is director of the Morton J. Kent Habilitation Center at Orange Grove and editor-in-chief of Exceptional Parent Magazine.



Dr. Kristin Compton

Photos by Dennis Wilkes



HEALTH CARE *Disparities*

BY COURTNEY TAYLOR



Photo by Tony Maupin

Disparities for individuals with disabilities in the areas of health and mental health continue to persist. Vanderbilt Kennedy Center Director, Elisabeth Dykens, has thought quite a bit about the causes for these disparities and much of her work is geared toward addressing them. She has a keen interest in investigating the effectiveness of interventions. Her studies often highlight the strengths and skills of people with developmental disabilities and their families, and aim to identify practices that contribute to their health and well-being.

Dr. Dykens currently is working with the Vanderbilt Evidence-based Practice Center (EPC) to develop lists of priority topics for future comparative effectiveness research in the areas of health care for and mental health of individuals with intellectual disabilities (ID). In a report emphasizing the need for research in these areas, Dr. Dykens outlined the likely causes for the health disparities. These possibilities include:

- High rates of diverse and co-occurring medical or psychiatric conditions;
- Inadequate preventative or routine care for people with ID (for example, breast exams and dental check-ups);
- Fragmented health services, especially as children transition out of pediatric care into adult services;
- Health care provider unease in treating individuals with ID due to a lack of training;
- Trends for physicians who are not board certified in any discipline to treat individuals with ID, especially those who do not live with their families;
- Refusal to treat individuals with ID among qualified practitioners;
- Unwillingness to consider people with ID as good candidates for complicated medical procedures (for example, transplants);
- The downward economic drift experienced by families over the lifespan of their child, which limits their health care options; and

- Insufficient health promotion practices in family, group home and community settings (for example, exercising, making healthy food choices and not smoking).

With this daunting list in mind, the EPC study team has facilitated focus groups with self-advocates, disability service providers and family members or caregivers of individuals with intellectual disabilities. The perspectives coming from the focus groups have been crucial to the project and, at times, surprising in nature.

“One of the areas that we need to improve has to do with routine preventive care,” said Dr. Dykens. “That would be getting your eyes checked, your ears checked and getting a flu shot. It has been very interesting to hear from parents, who are clear advocates for their children, saying, for example, that they don’t take their daughter in for a routine pap smear because their doctor told them it wasn’t necessary. Why is it that if you have an intellectual disability, you don’t need the kind of care that every woman deserves to get?”

In 2005, Special Olympics conducted a medical and dental curricula survey and found that 52 percent of medical school deans, 53 percent of dental school deans, 56 percent of students and 32 percent of medical residency directors reported that graduates were “not competent” to treat individuals with intellectual disabilities. Most of the medical school deans (81 percent) identified a “lack of curriculum time” as the reason for inadequate training.

“We have a ton of work to do in the area of pre-service training,” Dr. Dykens said. “I think part of it is the perception that people with ID have such complicated medical and psychiatric needs that they’re really challenging to take care of. You have to take more time with them, order more tests, and to some extent that is true. I think it has turned off a lot of medical and psychiatric providers because they might need to pause and get to know the person and review their history. It can be very complicated. So you have a person with medical complexities and you have a system of doctors and nurses who have never been trained to work with them. It’s not a good combination.”

Dr. Dykens refers to programs like Special Olympics Healthy Athletes, which is run by volunteers who step in to fill some of the gaps. Healthy Athletes has trained more than 100,000 health care professionals to treat people with intellectual disabilities and has provided 1.2 million free health screenings (for example, dental, hearing, vision, physical fitness and nutrition) in over 100 countries. Dr. Dykens is a board member and was fortunate to witness the Healthy Athletes program at work in Athens, Greece.

“I was blown away,” said Dr. Dykens. “It was remarkably efficient. There was ample labor power, clearly the volunteers and physicians had been well trained, and people left with what they needed. They didn’t screen them and send them home telling them they needed to go get glasses. They created custom-made glasses on site. I was so impressed. I came home and we set up hearing

tests for our ACM Lifting Lives campers and 50 percent of them failed their hearing test. We have a long way to go.”

Dr. Dykens sees other rays of hope. She has confidence in the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs funded by the Maternal and Child Health Bureau. LEND programs prepare health professionals to assume leadership roles and develop advanced clinical skills in order to meet the complex needs of children with disabilities. There are 43 in 37 states. She’s also impressed by a handful of transition clinics that are sprinkled throughout the country that specialize in the health care needs of kids who have chronic

illness and developmental disabilities. Her own work has been influenced by all of these factors, and she is now focusing much of her research on practical applications.

“I have been bitten by the intervention bug,” said Dr. Dykens. “I just want to do. I’m tired of describing. I don’t want to read another white paper that says there are health care disparities. I want to do something about it—truly.”

Courtney Taylor is associate director of Communications and Dissemination, and coordinator of the Disabilities, Religion & Spirituality Program at the Vanderbilt Kennedy Center.

Towards Promoting Health throughout Tennessee

BY MEGAN GRAF

Calling all health advocates in Tennessee! Sports 4 All Foundation launched their very first Project HEALTH Certification Workshop on June 1 and 2, 2012, at the Nashville Airport Marriott, during the 2012 Tennessee Disability MegaConference. It was a great opportunity for more people to become certified HEALTH Instructors and to share the gift of health with people of all ability levels!

Project HEALTH (Helping Every Ability Learn To Be Healthy) is a program of the non-profit 501(c)3, Sports 4 All Foundation. Currently, Project HEALTH serves Davidson, Rutherford, Wilson, Giles, Marshall, Hickman and Maury counties of Tennessee. This program provides free-of-charge community and fee-based private adaptive fitness and nutrition classes to people of varying ability levels.

Unfortunately, in 2011, the Centers for Disease Control and Prevention ranked Tennessee as the 4th most obese state in the country. As if living a healthy life style wasn’t tough enough as a resident of this State, people with disabilities face even more barriers to a healthier lifestyle than other residents of Tennessee. Increasing exercise is directly correlated to decreases in depression, social isolation, waist measurements, blood pressure and weight.

Although we know the benefits of exercise, it is often easier said than done. For this reason, Project HEALTH is

designed so that anyone can get involved! Lesson plans for classes include fun games, upbeat music and movements that will make you sweat. It is our goal to make health more accessible to people of all abilities in Tennessee, but to do this, we need your help. We need enthusiastic leaders to help us promote health STATEWIDE by getting certified in Project HEALTH!

A Project HEALTH Certification grants you the ability to teach adaptive fitness and nutrition classes in the community as a contract worker of Sports 4 All Foundation or to lead HEALTH classes in a private setting for the agency that currently employs you. This means that, with your help, the Project HEALTH program can expand throughout the entire State of Tennessee!

This certification is great for someone in the fitness world who wants to start an inclusive class in his/her community, and it is also an option for agencies or schools that serve people with disabilities that would like to host Project HEALTH classes on campus for their participants.

The typical Project HEALTH Certification Workshop is a two-day course. All registrants are provided an electronic copy of the Project HEALTH Curriculum Book, which contains over 100 adaptable activities, games and healthy recipes created by licensed professionals, including Occupational Therapists,



Photo by Austin Luke Griffin

Certified Personal Trainers and Registered Dietitians. Special guest speakers, interactive sessions and educational lectures will prepare attendees for the practical and written HEALTH exams at the end of the Workshop. All participants must pass these tests in order to gain their HEALTH Instructor Certification.

“I’ve never led a fitness class before... I’ve never worked with people with disabilities...I am a poor test taker....” Put these negative thoughts behind you! The purpose of the workshop is to provide you with the necessary education and tools to pass our testing and earn your certification. The only pre-requisite necessary to register is a current First Aid/CPR certification.

To register for future workshops, visit our Web site, <http://s4af.org/resources.html>. Please call the Sports 4 All Foundation offices at 615-354-6454 for more information, including fees associated with this training. Everyone has abilities, so let’s give them opportunities! Help us spread health throughout Tennessee.

Megan Graf is the former wellness/volunteer coordinator for Sports 4 All Foundation.



BY SARAH HART

ACHILLES INTERNATIONAL NASHVILLE is a non-profit organization that partners runners who are able-bodied (Volunteer Guides) with athletes with physical disabilities (Member Athletes). Membership is absolutely free.

MISSION

Our mission is to enable people with disabilities to participate in mainstream athletics in order to promote personal achievement, enhance self-esteem and lower barriers to living a fulfilling life.

HISTORY

In 1976, Dick Traum, an above-the-knee amputee, found himself out of shape and approaching middle age. After joining a local YMCA, Mr. Traum began running—small distances at first and eventually several miles. Within a year, Mr. Traum became the first amputee to run the New York City Marathon. The experience was life-changing, bringing a powerful sense of achievement and self-esteem. In 1983, seeking to provide that same opportunity to other people with disabilities, Mr. Traum created the Achilles Track Club, now called Achilles International.

Today, this non-profit organization has chapters and members in over 65 locations within the United States and abroad. Every day, in parks, gyms and tracks all over the world, Achilles provides athletes with disabilities with a community of support. Within this community, runners gain measurable physical strength and build confidence through their sense of accomplishment, which often transfers to other parts of their lives.

While Achilles programs focus on athletics, the truth is that sports are simply the tool for accomplishing the main objectives: to bring hope, inspiration and the joys of achievement to people with disabilities.

WHY RUN WITH ACHILLES?

People join Achilles for many reasons and with many goals: to improve physical strength; to build confidence; or to help

someone achieve their dream. All of our members and volunteers work hard to achieve any or all of these goals.

But something else happens at Achilles that few expect but everyone cherishes. It is the sense of friendship, encouragement and community that people find with Achilles. In training and racing together, athletes with and without disabilities learn to support each other and focus on what brings them together, rather than what might keep them apart.

CHAPTER WORKOUTS

Since 1983, when founder Dick Traum's first Central Park gathering of runners with disabilities began to train and encourage each other, Achilles chapter workouts have brought athletes together in cities and towns throughout the world. The key element of success in chapter workouts is the strong community of friendship and support that forms among members.

Chapter running groups contain a mix of athletes and volunteers who meet and train on a regular schedule. The workouts aren't intended to push participants beyond their capabilities, but rather are focused on encouraging them to set goals, measure successes and value accomplishments.

VOLUNTEER GUIDES

A volunteer Guide functions as an athlete's eyes, ears, guide and motivator. Volunteers can participate in many ways and commit as much, or as little, as their time allows. Volunteers may:

- Help runners with disabilities become familiar and proficient with special equipment;
- Participate in weekly workouts;
- Provide guidance and running advice during races and marathons; and
- Help with race-day logistics.

MEMBER ATHLETES

Achilles welcomes and encourages anyone with a disability or physical challenge to RUN!

In Achilles parlance, running means many things. It means conventional running, of course. But it also refers to walking, wheeling, hopping or swinging through crutches. In other words, any form of locomotion that gets you through the route!

Physical challenges include, but are not limited to, amputation, cerebral palsy, cancer, multiple sclerosis, organ transplants, paraplegia, stroke, traumatic brain injury and visual or hearing disabilities.

To learn more, visit www.achillesinternational.org or <http://www.facebook.com/AchillesInternationalNashville>

Achilles International Nashville Chapter

Sarah Hart - President, Achilles International Nashville
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Melanie Yappen - Secretary, Achilles International Nashville

Advisory Board, Achilles International Nashville*

Misty Adfield - Program Director,
McCabe Community Center

Matthew Bulow - Owner, Bulow Biotech
Prosthetics

Lori Cutler-Turner - Executive Director,
Sports 4 All Foundation

Matt Davis - National Wheelcats

Ricky Jones - Executive Director,
Tennessee Association of Blind Athletes

Zac Koffler - Founder,
Run Walk Wheel & Roll

Peter Pressman - President,
Nashville Striders

Rick Slaughter - Founder, ABLE Youth

Ned Andrew Solomon - Tennessee
Council on Developmental Disabilities

**These individuals generously share their passion, knowledge and energy with Achilles Nashville—and we thank you!*

McCabe Community Center in Nashville

Every Wednesday, 6:30-8 PM

RAIN OR SHINE

Tennessee Association of Blind Athletes

BY RICKY JONES

The Tennessee Association of Blind Athletes (TNABA) is a 501(c)3 non-profit organization providing sports and recreational activities for Tennessee's men, women and children who are blind and visually impaired. We are the state chapter of the United States Association of Blind Athletes (USABA) and are recognized by the U.S. Olympic Committee as a Paralympics Sports Club that provides world class programs for adaptive athletes and wounded warriors of all kinds.

We provide adaptive programs on three different levels: leisure recreation, health and fitness, and competitive sports. Together with USABA, we provide local, state, regional, national and even international opportunities for our members. TNABA also provides consulting for physical education teachers, coaches, parents, students and other community members to ensure that individuals who are blind are involved in adaptive physical education classes, after school extracurricular activities and community-based programs that allow them to participate in activities alongside their sighted peers.

TNABA was formed originally in 1979 and reestablished in 2009. Over the course of 32 years, over 21 blind Paralympic athletes have come from Tennessee, 10 of whom have won gold metals. TNABA has provided over 300 athletes with the opportunity to participate in a variety of different sports and health programs, including swimming, track & field, golf, tandem cycling, exercise and fitness classes, yoga and nutrition, bowling and goalball, to name a few.

Obesity is one of the most crippling problems facing our society. It not only affects people's health, but activity levels, productivity and their social lives. This is especially true with the blind community. Blind people have one of the highest rates of obesity out of all of the minority groups.

An estimated 52,000 children who are blind and visually impaired are registered in public schools systems nationally every year. Of those students, only 17-20 percent of them are included in modified adaptive physical education classes or extracurricular sports and recreational activities. Once they graduate from high school, that percentage drops to 10-14 percent of adults who stay active. More alarming is that less than six percent of our beloved seniors over age 55 are active socially.

According to a study conducted by Elizabeth Holbrook at Middle Tennessee State University in 2009, adults with visual impairments are 1.5 times more likely to be obese or morbidly obese compared to the general population. Reflecting a growing health disparity with the general population, adults with blindness are taking an average of eight daily prescription medications to manage co-morbid conditions, including cardiovascular, metabolic and musculoskeletal diseases.

Although in its infancy, research in this area indicates that the heightened disease rates among adults with blindness are hypokinetic in nature; meaning, they are due to low levels of physical activity. Whereas adults without vision loss average roughly 7,600 steps per day, adults with visual impairment engage in considerably lower levels of physical activity, averaging just 4,500 steps per day. This



level of activity is substantially lower than that needed to produce health benefits and is typically engaged in at very low intensities. The disparity that exists between persons with and without visual impairment begins very early in the lifespan, with noticeable differences in physical fitness appearing during childhood.

Staying active, both physically and socially, is extremely important for anyone with a disability or without. Those with disabilities have greater need to stay active to help stimulate body movement and brain activity, which are essential to personal growth and development. Studies have clearly shown that a body in motion stays in motion. In other words, those who are active socially or recreationally are more likely to be active and productive in their community.

People who exercise regularly are more productive and also more likely to be employed. Exercise and social interaction allows our brain to produce chemicals necessary for our mind and body to function at their maximum potential. That's why participating in adaptive sports and recreational programs like TNABA, or other U.S. Paralympics Sports Clubs around the State, is so important. You can find a sports club in your area at www.usparalympics.org/sportsclubs.

As TNABA executive director and a Partners graduate, I have a vision for TNABA and adaptive sports in Tennessee. Though TNABA is located primarily in Nashville, the organization is working hard to expand across the State. Even if TNABA is not in your part of the State yet, we can still give assistance and consultation upon request. Our goal is to build chapters throughout Tennessee to provide everyone with the opportunity of adaptive sports and create local in-state sports leagues for people who are blind.

I am hoping for something even bigger for the future, which will be beneficial not only to the blind community, but to all people with disabilities. My dream is to create an adaptive sports and resource center for persons with disabilities called PART (Partners for Adaptive Recreation of Tennessee). This would be a centrally located center that could offer adaptive facilities for recreational play and competitions, training for elite athletes, physical and occupational therapies and other self-advocacy resources. Though this dream seems big, it certainly is obtainable with community programs combining their resources and coming together to truly change the lives of people with disabilities.

For more information about TNABA or any information in this article, please contact me, Ricky Jones, at tnaba@bellsouth.net or by phone at 615-544-5222. You may also visit www.tnaba.org or at www.facebook.com/tnaba.nashville.

What the **AFFORDABLE CARE ACT** *Means for People with Disabilities*

BY BETH USELTON

Health reform became a hot topic of debate all over again as advocates celebrated the 2nd anniversary of the law on March 23, 2012, and the Supreme Court heard arguments against the law the following week. Despite this renewed attention on “Obamacare”, many Tennesseans remain confused about what the law actually means for them, their families and their loved ones.

At its core, the Affordable Care Act (ACA) does three main things: expand affordable health care coverage, ensure robust consumer protections and promote payment reforms that focus on quality in the medical delivery system. Though many protections have already taken effect, the biggest changes will happen in 2014. For Tennesseans with disabilities, chronic conditions or special health needs, the ACA contains several provisions that can dramatically improve access to appropriate, affordable, comprehensive medical care.

ENDING DISCRIMINATION BASED ON PRE-EXISTING MEDICAL CONDITIONS

In 2010, the year the law was enacted, the ACA prohibited insurance companies from denying coverage to children under age 19 due to pre-existing medical conditions. Also in the first year, the law made it illegal for insurers to drop a person from coverage because they became injured, disabled or diagnosed with a new health condition.

On January 1, 2014, no one can ever again be denied care or coverage based on a pre-existing medical condition or charged more due to their gender, health status or disability. Insurance companies will no longer be allowed to deny you

outright or put a rider on your policy exempting certain medical conditions from coverage. For people with special health care needs, this is a dramatic improvement over the current system, which often prices out people who need health care the most.

The law also created the Pre-existing Condition Insurance Plan as an option for adults who may still be denied private coverage until 2014. This high-risk pool has lower premiums than AccessTN, but requires that a person be uninsured for six months to become eligible. For more information, visit www.pcip.gov.

REMOVING CAPS ON COVERAGE

In 2010, the law made lifetime caps on coverage illegal, meaning that insurance companies can no longer set a limit at which you or a family member “max out” your coverage and they stop paying for care. In 2014, annual caps on coverage will be eliminated as well. These protections are particularly important for adults and children with chronic conditions or disabilities that require expensive care.

EXPANDING AFFORDABLE COVERAGE TO UNINSURED TENNESSEANS

In 2010, the law gave parents the option of adding their young adult children back onto their family plan until age 26. In 2014, states will have to give children aging out of foster care the choice to stay on TennCare until age 26. Young adults are the age group most likely to be uninsured and these provisions ensure stable, affordable coverage for them during a time of transition.

The ACA expands and simplifies Medicaid eligibility rules so that in 2014 all Tennesseans at or below 133 percent of the federal poverty level (about \$14,500 for an individual) can qualify for health care coverage through TennCare.

Also in 2014, Tennessee will set up a Health Insurance Exchange, which will be a competitive on-line marketplace for private health insurance plans. Tennesseans between 133 percent and 400 percent of the federal poverty level (about \$14,500 to \$44,000 for a single person) will qualify for sliding-scale tax credits to help them purchase private health insurance plans through the Exchange. Small businesses and non-profits with 50 or fewer workers also will be able to shop through the Exchange to get coverage for their employees and many will qualify for a special tax credit.

ESSENTIAL HEALTH BENEFITS

The ACA states that insurance plans sold through the Exchange and offered through the TennCare expansion will have to meet a set of 10 essential health benefits, creating a minimum standard of coverage.

1. Ambulatory patient services;
2. Emergency services;
3. Hospitalization;
4. Maternity and newborn care;
5. Mental health and substance use disorder services, including behavioral health treatment;
6. Prescription drugs;
7. Rehabilitative and habilitative services;
8. Laboratory services;
9. Preventive care and chronic disease management; and

10. Pediatric services, including oral and vision care.

Every state will get to pick a “benchmark benefit plan” that will set the coverage standards for these benefits. This means that it is up to Tennessee to decide, for example, how many days of hospitalization must be covered in new plans or which drugs should be covered in the prescription formulary. This is an important issue that people with special health needs will want to pay attention to, especially since state benefit mandates like autism coverage will likely be renegotiated or could be eliminated altogether.

TENNCARE/MEDICAID FUNDING

The Affordable Care Act authorized several financial incentives to state Medicaid programs to stabilize coverage and improve care. The ACA also extended grants such as the Money Follows the Person grant, which will continue now until 2016. It increased the federal matching funds for programs such as the Community First Choice Option and provided funding for a program to improve care coordination for people on both Medicare and TennCare.

MEDICARE

The law protects all guaranteed Medicare benefits and added new free preventive health services like cancer screenings, vaccinations and an annual check-up. Medicare beneficiaries who fall into the prescription drug coverage gap, or “doughnut hole”, will receive discounts on their medication until it is completely closed in 2020.

Beth Uselton is executive director of the Tennessee Health Care Campaign.

continued from page 7

Services director for about a year, might otherwise have gone down the path most MDs take, never stopping to consider the incredible challenges and rewards that come from specializing in the field of intellectual and developmental disabilities.

He was director of the Developmental Disabilities (DD) program at the University of Western Ontario, Canada, and for four or five years was in charge of a 24-bed dual diagnosis psychiatric unit, at the equivalent of a state psychiatric hospital. He practiced family medicine and later moved on to Queen's University in Ontario. He worked at three developmental centers, one of which, at its peak, had 2,500 people living there. When Ontario closed all of its developmental centers in 2009, Dr. Cheetham found himself a one-year gig at the Orange Grove Center in Chattanooga, a private non-profit that serves adults and children with DD.

After a brief time back in Toronto, Dr. Cheetham learned about the State job, “thinking, there's no way I would ever get that, but it would be fascinating—and here I am,” Dr. Cheetham said. “In some ways, I guess I viewed this as a culmination of a very varied experience that most physicians would not have in this field.”

The lack of that broad experience is, in fact, one of the biggest challenges facing Dr. Cheetham's office. Many health care professionals simply don't know what they're missing. And even though certain conditions are much more prevalent among people with IDD, the medical community has been slow to respond to the differences

between IDD and general populations.

“Epilepsy is a good example,” Dr. Cheetham said. “About one person in a hundred has a seizure disorder. A person with a mild to moderate intellectual disability, it is probably one in four or one in five, and as you get to the profound end of the continuum, it's probably beginning to approach one in two. So there's a condition that is far more prevalent in people with disabilities compared to the one in a hundred in the general population. And I think that is a small example which illustrates the complexity of people with disabilities.

“If a person who didn't have a disability called me up and said, ‘I fell; my hip hurts, but I'm walking on it,’ of course I'd want to see them and X-ray them, but I'd be pretty sure just from that information that they didn't have a fractured hip,” continued Dr. Cheetham. “I would not think that for a moment, if the person had an intellectual disability.”

That's because people with IDD can act very differently than the general population in response to pain. “Sadly, that gets translated into people with disabilities don't feel pain,” said Dr. Cheetham. “That is absolutely untrue. Pain is a very complex construct, and people do not exhibit the same pain behavior you or I would with a fractured hip.”

Dr. Cheetham acknowledged that there are groups working toward a national curriculum for IDD medicine—Special Olympics, the American Academy of Developmental Medicine and Dentistry, and others—with a long-range goal

of certifying people as having added competency in that area. “But it's still early days, even though the curriculum is coming along very well,” he said.

“The first thing I did was change my title from Medical Director to Director of the Office of Health Services to reflect a more inclusive approach and a recognition that many disciplines, many clinical disciplines, are important in providing health care to the people that we serve,” continued Dr. Cheetham.

Tennessee's Commissioner of the Department of Intellectual and Developmental Disabilities, Jim Henry, has charged Dr. Cheetham with producing a comprehensive health care plan, something that will be dependent on not just medical professionals and researchers, but also policymakers. Doing so will have a far-reaching impact, not just on the 8,000 or so people the Department serves—and the 7,000 on its waiting list—but for health care for everyone across the State.

“I see no reason why Tennessee can't be a leader in health care for this population,” Dr. Cheetham said. “I think that it's (Commissioner Henry's) emphasis on health, it's the structure, it's being able to engage with the Governor and his agenda. And, so much work has been done, we don't need to invent all of this, we just need to take the best and learn from many other people to develop a made-in-Tennessee solution.”

Ellen Margulies is a former communications coordinator for the Vanderbilt Kennedy Center.

News From **Pathfinder:** A Focus on Health & Recreation

BY NANCY W. MUSE

The Pathfinder database is filled with many wonderful health-related resources. A good place to start is the Sports and Recreation category for your county or region in Tennessee.

We have resources for all kinds of sports, including swimming, bowling, baseball and basketball. We have archery, yoga and dance. There is even a service category for Horseback Riding Therapy! This edition of Pathfinder News presents just a sample of healthful, fun opportunities available through agencies in Tennessee.

Organizations like Special Olympics Tennessee, the Tennessee Association of Blind Athletes (TNABA), and TOP Soccer, serve the entire State. Special Olympics provides year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities. TNABA is a non-profit organization dedicated to using physical fitness to enhance the lives of individuals of all ages who are blind or visually impaired. TOP Soccer is an outreach program of the Tennessee Soccer Association that provides athletic opportunities for youth with intellectual or physical disabilities interested in soccer.

At MidSouth Adaptive Sports and Recreation (MASR) in Cordova, sports and recreation opportunities for individuals and families with physical disabilities abound. There are swimming lessons and swim team, wheelchair basketball, family biking, track and field, archery, sports skills and motor skills development.

The Raymond Skinner Center in Memphis offers a marvelous array of activities for individuals of all ages and types of disabilities. There is a therapeutic, heated indoor pool, a game room, a ceramics

studio and a gym, as well as a busy schedule of activities that includes “high bo” exercise, bingo and, every Friday night, a dance for socializing. Furthermore, the Skinner Center offers Summer camp, holiday cookouts and celebrations, and weekly field trips in addition to such classes as daily skills training and sign language.

The Exceptional Development Family Treatment Center (EDFTC) in Memphis offers a wide range of programs that address the social and recreational needs of individuals with developmental disabilities. These include social skills classes with typical peers, speech classes for the parent and child, occupational therapy and a Summer camp program.

Special Needs Athletics in Beech Bluff has expanded from just baseball to bowling, basketball, mini-golf and soccer as well, and they are now operating year-round. Athletes ages four and up are welcome, and nobody sits on the bench: everybody plays, whatever their level of ability. The healthful attitude extends beyond the games themselves to include encouragement by coaches and volunteer teammates.

Park Commissions in various cities across the State have programs that contribute to good health. In Chattanooga, the city’s Parks and Recreation Department provides various recreational and leisure programs, including, but not limited to: wheelchair sports, Summer camp, social groups, sports for individuals who have intellectual disabilities, arts and special events.

Metro Parks and Recreation Department in Nashville has activities throughout the year for those seven and older. They offer sports training, a bowling league, Summer camp, Special Olympics and even canoeing.

Many other agencies offer Summer camps. Registration deadlines and start dates vary. Please see the “Camps and/or Summer Programs” service category. You can also look for Summer camps in Tennessee, as well as national camps, in our Disability Resources Library. Our 2012 Summer Camp Directory has camps across the State divided by region, as well as National Camp Programs.

The Star Center in Jackson is a resource and training center that offers many services related to health, including assistive technology, vision services—such as orientation and mobility—and art and music therapy.

“Physical/Occupational Therapy” is another service category related to health. The Pathfinder database has quite a few resources for physical and occupational therapy across Tennessee. Some, like the Kiwanis Centers in West Tennessee and the Therapy and Learning Center in Jackson offer aquatic therapy, and many also offer speech therapy.

The Therapy and Learning Center also offers horseback riding therapy, or hippotherapy. Others in the “Horseback Riding Therapy” service category are Saddle Up!, and Paradise Ranch in Middle Tennessee, and Ridin’ High and Shangri-La in East Tennessee.

Another service category to search for health-related resources is “Specific Disability Related Organizations”. The Down Syndrome Association of Middle Tennessee, for instance, hosts social and recreational activities, while the Muscular Dystrophy Association has free Summer camp for children who are registered with MDA.

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**.

Other service categories related to health might be “Adult Day Services”, “Assistive Technology Equipment”, “Health Care Services”, “Health Insurance Information”, “Mobility/Wheelchair Clinics” and “Prescription Assistance.”

The Pathfinder database contains resources for almost everyone. Please feel free to call or write. We will be more than happy to

help. We invite you to explore our Web site at www.familypathfinder.org, e-mail us at tnpathfinder@vanderbilt.edu or give us a call at 1-800-640-4636.

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

• **FOR FURTHER INFORMATION**

• Tennessee Disability Pathfinder
• English & Español
• (615) 322-8529
• (800) 640-4636

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

• www.familypathfinder.org
• tnpathfinder@vanderbilt.edu

HEALTH RESOURCES

COMPILED BY COURTNEY TAYLOR

American Association on Health and Disability (AAHD)

The mission of AAHD is to contribute to national, state and local efforts to prevent additional health complications in people with disabilities and to identify effective intervention strategies to reduce the incidence of secondary conditions and the health disparities between people with disabilities and the general population. AAHD accomplishes its mission through research, education and advocacy. www.aahd.us/

Centers for Disease Control and Prevention (CDC)

The CDC works to promote health and wellness and improve the quality of life for people of all different abilities. Its Web site offers a section on disability and health for people with disabilities, health care providers, family caregivers and policy makers. www.cdc.gov/ncbddd/disabilityandhealth/

County Health Report

The latest report has been released by the University of Wisconsin Population Health Institute and the Robert Wood Johnson Foundation. It provides detailed information on health-related data for most counties in the United States, including rankings on health behavior, clinical care, social and economic factors, and physical environment and data on health-related factors from teen pregnancy to the concentration of fast-food restaurants. www.countyhealthrankings.org/

HispanicHealth.info

This resource was developed by the National Hispanic Medical Association as a portal to share key information to improve the quality of health care delivered to Hispanic populations. The information is directed to health professionals and the public. <http://hispanichealth.info/>

National Healthcare Quality & Disparities Reports

The National Healthcare Quality Report tracks the health care system through quality measures, such as the percentage

of heart attack patients who received recommended care when they reached the hospital or the percentage of children who received recommended vaccinations. The Report summarizes health care quality and access among various racial, ethnic, and income groups and other priority populations, such as residents of rural areas and people with disabilities.

www.ahrq.gov/qual/qrd10.htm

Overweight and Obesity among People with Disabilities

This National Center on Birth Defects and Developmental Disabilities fact sheet covers the challenges facing people with disabilities, physical activity for people with disabilities, obesity on a national level, health consequences of overweight and obesity, as well as related resources and links.

<http://1.usa.gov/rcAsdV>

Patient-Provider Partnerships: Optimizing Outcomes for Children with Disabilities

Children with disabilities require high-quality medical homes that provide care coordination and transitional care, and their families require social and financial supports. This report explores the challenges of developing effective community-based systems of care and offers suggestions to pediatricians and policy makers regarding the development of partnerships among children with disabilities, their families, and health care and other providers to maximize health and well-being of these children and their families.

<http://pediatrics.aappublications.org/content/early/2011/09/21/peds.2011-1467.full.pdf+html>

Rural Policy Research Institute (RUPRI)

Rural Health Futures Lab

This study offers recommendations for improving rural health care in the areas of affordability, accessibility, community needs and quality. http://ruralfutureslab.org/docs/Pursuing_High_Performance_in_Rural_Health_Care_010212.pdf

Special Olympics Healthy Athletes

The Special Olympics Healthy Athletes program has offered health services and information to athletes in dire need. In the process, Special Olympics has become the largest global public health organization dedicated to serving people with intellectual disabilities. www.specialolympics.org

Courtney Taylor is associate director of Communications and Dissemination, and coordinator of the Disabilities, Religion & Spirituality Program at the Vanderbilt Kennedy Center.

Tennessee Spotlight

Members of the Tennessee musical ensemble, **Lake Rise Place**, were recognized as the **VSA 2012 Excellence in Leadership Award** Winners. The award was presented by **Ambassador Jean Kennedy Smith**, founder of VSA and sister to **President John F. Kennedy**. The young men received this award for their support of the VSA ideals and for assisting with numerous VSA programs. They are the first Young Soloists to receive this award.



Photo by Melissa Adams

research dollars for 43 different types of muscle diseases. Ms. Adams began forming her “team” and raising dollars for **Limb-Girdle MD** research very early and won the **“Strength in Numbers” Award** for having the most walkers on her team.

This year, for her birthday, Ms. Adams asked that friends and family donate to her walk team for research rather than buying her birthday presents. She subsequently raised over \$2000. With more than 40 individuals walking on her team—all wearing pink—Muscles for Michele definitely stood out at Nashville’s Bridgestone Arena on March 24th. In addition, Ms. Adams was recognized as an **Honorary Alabama Cheerleader for a Day** at the **University of Alabama** during the Alabama vs UT game on October 22, 2011.

YLF graduate and volunteer staff member **Tina Williams** is a proud freshman at the **University of Mississippi**, majoring in Occupational Therapy and Communication Science Disorder (Speech Pathology). “At Ole Miss, the student disability services are great,” said Ms. Williams. “They work extremely hard with my professors to make sure all of my accommodations are granted to ensure I had a successful semester.”

This Summer, Ms. Williams will be interning with **Therapy Zone** in **Southaven, Mississippi**. “This internship will allow me to determine which field I’ll enjoy the most,” Ms. Williams said. “I’m ecstatic about my first Summer internship as a freshman!”

Volunteers from **Tennessee Housing**



Photo by Corey Blount

Development Agency (THDA) teamed up in early May with **United Cerebral Palsy of Middle Tennessee (UCP)** to commemorate construction of the partnership’s 2,000th wheelchair ramp on to the home of a person with a disability.

The new ramp will benefit **Buddy**, a 24-year-old man who has a severe mobility disability. He looks forward to having a ramp so he can use a power wheelchair to enter and exit his home independently.

The collaboration between THDA, UCP and a variety of statewide organizations has addressed an immense unmet need in Tennessee for persons of low income who have disabilities and have no way to get in and out of their homes without this essential accommodation. THDA dollars have paid for lumber and supplies. UCP and the partner agencies coordinate the ramp builds and provide labor.

Matt Moore, YLF graduate and son of Partners grad and former Council member, **Richard Moore**, and Council member **Sheila Moore**, is one of **Nashville Zoo**'s newest employees. Mr. Moore began working at the Zoo on Friday, May 4th. He is thrilled to work there, having made many visits to the



Photo by Britt Simmons

Council member and 2011-12 Partners graduate **Cynthia Chambers, PhD**, is the recipient of **The Arc Tennessee 2012 Community Service Award** for her extensive efforts toward creating artistic, social and recreational opportunities for individuals with disabilities. In addition, **POP (Power of Performing) Arts**, an entity that Dr. Chambers co-founded, recently won the **2012 Outstanding Community Support Award** through **East Tennessee State University’s Clemmer College of Education**. This award is given to an individual or group making significant efforts to provide educational opportunities in and service to the community.

Strength in numbers was definitely the theme for **Team Muscles** for Youth Leadership Forum (YLF) graduate and volunteer staff member **Michele Adams** during this year’s **Music City Muscle Walk** benefitting the **Muscular Dystrophy Association**. This annual walk is held to raise potentially lifesaving

Photo by Sheila Moore



Matt Moore



(left to right): Commissioner Henry (DIDD), Sheila Moore, Dr. Cheetham (DIDD) and Jim Crowley, interim director, DSAMT

Photo by Elizabeth Ralph

Zoo himself over the years. He will be helping with clean up, assisting other Zoo employees and working with his team to keep the popular site enjoyable for others.

On February 14th, Council member **Sheila Moore** became the new executive director for **The Arc Davidson County**.

Ms. Moore—besides being a dedicated advocate for her son Matt—was the former executive director and co-founder of the **Down Syndrome Association of Middle Tennessee (DSAMT)**, established in 1996.

Towards a Comprehensive Tennessee Autism Plan

BY SARAH SAMPSON



Cory Bradfield

The increase in prevalence of Autism Spectrum Disorder (ASD) diagnoses splashed across the news this Spring. This media coverage also has spread awareness about the disorder and the high demand for treatment.

To address the increasing number of children and youth who need treatment, stakeholders across the State are collaborating on the Tennessee Autism Plan. This Plan is working towards a comprehensive, coordinated

system of health care and related services for children and youth with an autism spectrum disorder and other developmental disabilities.

To support this effort, the Tennessee Disability Coalition has brought Cory Bradfield on staff to serve as project coordinator of the Tennessee Autism Plan. Mr. Bradfield comes to the Coalition, an alliance which promotes the full and equal participation of individuals with disabilities in all aspects of life, after spending the last five years at the Tennessee General Assembly as legislative assistant to State Senator Beverly Marrero of Memphis.

Mr. Bradfield will be working with the Coalition's Family Voices of Tennessee, a network of families and friends speaking on behalf of children with special health care needs, to keep the focus on a community-based and family-centered system of care for

children and youth with ASD.

Funding for this two-year project is provided by a grant from the Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services.

Already in full swing, we are gathering family input through a survey put together by partners on the Autism Summit Team. A key contributor to the Tennessee Autism Plan, the Autism Summit Team, with leadership from the Vanderbilt Kennedy Center and University of Tennessee Boling Center, will continue looking at challenges and opportunities presented by the current state of ASD services.

Started in May, a series of seven Community Conversations brought and will bring together the voices of our partners in this plan. Families, providers, professionals, funders and policy makers are all invited to the table to talk about improving ASD services in our State.

To join us or for more information, e-mail: autism@tndisability.org and go online to: www.tndisability.org/autism.

Sarah Sampson is communications coordinator for the Tennessee Disability Coalition.

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