Counselors and campers alike benefit from learning experiences at SENSE Theatre.

**Summer Learning, Ripples Broadening**

*Trainees Gain Experience*  
**BY COURTNEY TAYLOR**

Summer programs at the Vanderbilt Kennedy Center are in full swing. Adolescents and young adults with disabilities are acting in the theater, singing on the stage of the Grand Ole Opry, and learning what life at college is all about. The summer programs’ activities and goals encourage self-esteem, self-respect, and compassion in the campers while teaching valuable life skills and providing much needed social opportunities. However, campers are not the only ones benefiting. Typically developing high school, undergraduate, and graduate–level students are serving as peer partners, counselors, and investigators and are gaining valuable professional and personal development experience working with people with disabilities.

SENSE Theatre Camp: It Takes a—Troupe!  

“I’ve been acting for 6 years,” said University School of Nashville sophomore Isaiah Frank. “I love theatre, and I thought it would be a lot of fun to be a peer counselor. I didn’t know much about autism, but now I feel like I have learned so much about it. Joey, my peer, wasn’t interested in participating at first, but I just helped him. When we did exercises, I would kind of exaggerate what I was doing and be really happy and show him how much fun it was. Eventually he joined in with me, and we started having fun together. That was really cool.”

At SENSE Camp, peer counselors like Isaiah are actors, but they also serve as interventionists. Their primary role is to model appropriate social and emotional behavior while playing theater games, performing, and interacting socially with the campers with autism. They are essential to the SENSE Theatre program’s treatment core, and therefore need to be highly motivated and compassionate individuals.

“It takes a unique person to be a successful peer counselor in our program,” said Blythe Corbett, Ph.D., assistant professor of Psychiatry and SENSE Theatre founder. “Children, by nature, are pretty self-focused. Our program requires that our peers are focused on others and are really thinking about the well-being of the camper. That’s hard.”

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**New Knowledge From Summer Fun**  
**BY COURTNEY TAYLOR**

While Vanderbilt Kennedy Center (VKC) summer programs provide meaningful growth and development opportunities for campers and valuable educational experiences for trainees, they also provide unique venues in which to investigate development and learning through research. In the summer programs, researchers are developing innovative treatment models and are even debunking commonly accepted characteristics of a genetic phenotype.

The Question of Approach

When ACM Lifting Lives Music Camp director Marisa Fisher, Ph.D., began investigating the social behaviors and characteristics of individuals with Williams syndrome, she did not expect her findings to challenge the widely accepted scientific literature. However, shifting what we think we know about people with Williams syndrome has not been an uncommon occurrence in the Music Camp research. Last year, Miriam Lense, a graduate student in Clinical Psychology, conducted a study to investigate a reported aptitude for music and uncovered instead amusia, or tone-deafness, in many of the campers. This year she explored the mechanics of music by looking at emotional carryover and assessing the ability to keep beats and to recognize patterns in music.

Fisher’s current research also builds upon data she collected at the 2012 Camp. People with
**Director's Message “Determined Action” Needed to Reduce Health Care Injustice**

In 2002, the Surgeon General’s groundbreaking report *Closing the Gap* documented and recommended actions to address health disparities of persons with intellectual disabilities. A decade later, we are frustrated by lack of progress on closing this health care gap. In his Foreword, U. S. Surgeon General David Satcher wrote, “…this report will just sit on shelves unless we turn it into action. It is important to listen to those affected to learn what needs to be done, but to listen and not respond with determined action will only heighten the injustice this community has too long endured.”

Special Olympics International has documented the national and international injustices in health care for persons with intellectual disabilities and has taken “determined action” with its Healthy Athletes program. Nearly 40% of Special Olympics athletes have obvious, untreated tooth decay; 16% have an eye disease; 26% fail a basic hearing test; 20% have low bone density, putting them at risk for injury and osteoporosis; 36% are obese. The *World Report on Disability* (WHO, 2011) found that “A shockingly high percentage of people with disabilities, especially in high-income countries, reported that they ‘tried but were denied care.’” In an article for Global Health and Diplomacy, Special Olympics CEO Tim Shriver wrote, “Discrimination in health care should be a source of outrage. Instead, it is often overlooked or ignored.”

At the Vanderbilt Kennedy Center, we are determined to take action. We are partnering with health care providers to provide training and tools so that they can care effectively for adults with intellectual/developmental disabilities. For example, with support from the Special Hope Foundation, we are adapting, for U.S. health care practices, *Tools for the Primary Care of People with Developmental Disabilities* (2011 edition, Surrey Place Centre, Ontario). These tools will be readily accessible via electronic devices.

The Vanderbilt Autism Treatment Network (ATN) is a member of the ATN Network supported by Autism Speaks. ATN is a network of hospitals, physicians, researchers, and families at 17 locations across the U.S. and Canada working together to develop the most effective approach to medical care for children and teens with autism. The Vanderbilt Down Syndrome Clinic and Fragile X Clinic bring together a multidisciplinary team of medical providers to provide specialized, personal care. Tennessee’s Department of Intellectual and Developmental Disabilities has made health care a priority.

We invite you to partner with the Vanderbilt Kennedy Center, with local health care providers, with foundations and philanthropists, with state and federal agencies, and with family disability organizations to take “determined action.” This definitely requires “a village!”

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**NEW KNOWLEDGE FROM SUMMER FUN from page 1**

Williams syndrome are typically viewed as being overly social, a trait that might make them more vulnerable to abuse. Fisher designed a study to assess whether they could be taught to say “no” to strangers, which the research literature suggested might not be possible. When the campers first arrived, Fisher’s team collected baseline data by planting strangers who would approach the campers to initiate conversations or ask for help. While campers did not respond with a definitive “no,” the majority said something like, “I can’t right now.”

“That was a bit unexpected,” said Fisher. “So, we administered stranger safety training with the group and re-tested them at the end of camp. They all said “no” to the strangers. I was surprised. I went back to the literature to explore methods, because what was being reported was not what we found. It turns out this characteristic is measured by parent reports, anecdotal evidence, and unrealistic lab observations, but never in real social situations. This year, we are observing them in public places. We have coders who will take extensive data on social activity. We also will record EEGs while the campers look at pictures of strangers with different emotional expressions, asking whether they would go up and talk to them. We can compare what they say with what their brains say. So far, it’s been very interesting and while they are definitely social and love talking with people, they don’t seem to be as socially inappropriate as the literature has reported.”

Looking at sociability from a mental health perspective is another research aim at the 2013 Music Camp. While people with Williams syndrome are friendly and outgoing, many have problems with anxiety, fears, and depression, which are often missed because of the misperception that they are always happy. Senior research specialist Elizabeth Roof, M.A., says that parents started calling her between camp sessions reporting that their children were having serious issues with anxiety. Roof and her team are now conducting detailed interviews with families exploring these issues.

“We need to find out who is at risk,” Roof said, “and from the people who are doing well, we need to find out what is in place for them that adds to their sense of well-being.”

**Social vs. Nonsocial Stimuli in Autism**

Behind the scenes at SENSE Theatre Camp, a number of research activities take place with the goal of improving the social and emotional functioning and reducing stress in children with autism. Diagnostic and psychological assessments are conducted to look at language and social perception. Saliva is collected pre- and post-camp to measure cortisol (stress hormone) levels. Parent questionnaires are collected to gain insight into the campers’ behaviors as well as to measure parental stress levels. Campers also take part in a playground study in which the children with autism

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but it must be a primary quality. A lot of the kids with autism we work with have been bullied, or treated negatively by their peers. So, it is important for the success of our program for our campers to be paired with someone who wants to be there with them.”

In addition to the peers, pre-service professionals serve as lead counselors. They come from a variety of backgrounds and disciplines. Undergraduate and graduate students studying psychology and psychiatric nursing bring a range of valuable skills and interests to the intervention team. Corbett says they are essential in that they bring an incredible amount of energy, excitement, and the latest knowledge from their fields.

“Their contributions are many,” said Corbett. “I hope when they leave camp that they take away the understanding that the research environment can be brought into a community. It doesn’t have to take place in a lab or in a clinic. We can turn community-based intervention into an empirical investigation. I also hope that they continue to think more broadly about how we can go about treatment, and truly understand that they aren’t the only interventionists. It takes a team.”

Next Steps Institute Opens Trainees’ Eyes

“The Next Steps Summer Institute [NSSI] is designed to give students with intellectual disabilities a peek into college life,” said Kelly Wendel, Next Steps program coordinator. “Trainees learn so much working with our students, and I really think their eyes are opened. Oftentimes, it is the first time these counselors have had a chance to work with students with intellectual disabilities, and it is often the first time they recognize the importance of postsecondary education for our students. They learn hands-on about everything from structuring a shower schedule for 20 young adults who have never lived in a college dorm, to implementing behavior management strategies. We teach them about visual supports, interventions, and provide them with valuable teaching experience. These are things they can take with them into their careers.”

Counselors came to NSSI this year from the disciplines of Special Education, Psychology, and Divinity and are in the same age range as the students (17-24) themselves. Wendel says including same-age counselors is an essential component. The students are naturally willing to listen and learn things from their peers that they might not be willing to learn from a staff or faculty member. Peer inclusion builds camaraderie and is an important element of good inclusive practice.

ACM Lifting Lives Music Camp and the Ripple Effect

“We can only touch so many people in our camp program each year,” said Elizabeth Roof, senior research specialist. “The nice thing about incorporating trainees as counselors is that these people create ripples. They go out and work in whatever field they are in, and it gives them a whole new perspective to touch hundreds of people in their careers. Our trainees have gone on to have their own classrooms, their own research programs, and they now have these perspectives that were, in part, shaped at camp. It’s a great responsibility and an honor to be a part of that training.”

This year, Music Camp counselors hailed from Special Education, Clinical Psychology, and...
You’ve Got a Friend: Best Buddies With Vanderbilt Medical Students

BY ELIZABETH TURNER

You can’t put a price tag on friendship. Good friends enrich us in ways we couldn’t imagine. That certainly rings true for the participants of Best Buddies, an organization dedicated to cultivating one-to-one lasting relationships between people with intellectual and developmental disabilities and their typically developing peers.

Founded in 1989 by Anthony K. Shriver, Best Buddies is flourishing in Tennessee and at Vanderbilt University (VU). Medical student Jessica Solomon was touched so profoundly by her involvement as a Vanderbilt undergraduate that she is developing a chapter within the VU School of Medicine.

“When I was applying to colleges, I didn’t know exactly what type of career or major I wanted to pursue,” said Solomon. “All I have always known is that I have a passion for including everyone around me and ensuring that all of my peers have the opportunity to experience extraordinary things in life, like friendship, exploration, and independence.”

“I was extremely lucky to become an Ingram Scholar. Through this community service scholarship program, I formed strong connections with student leaders around campus who were instrumental in organizing volunteer projects and social action initiatives around the community and abroad. A few of the Ingram Scholars were founders and leaders in Best Buddies, an organization I had never heard of before but was immediately eager to pursue.”

During her first month of college, Solomon attended a “match party” and met Christy Martin, who has been her Buddy for 7 years now. “My Best Buddy became the staple of my college experience. She knew all of my friends, and we explored events on campus and in Nashville together. We attended Best Buddies events, enjoyed getting to know each other’s friends and families, and had the time of our lives….Together, we were an unstoppable team,” said Solomon.

Solomon and Martin rose through the ranks of Best Buddies Vanderbilt student leadership and worked with others to plan outings, organize community service projects, and spread the word about Best Buddies to other campus organizations.

Their efforts paid off. In the past 7 years, the number of Vanderbilt students participating has quadrupled, making Best Buddies Vanderbilt one of the largest student organizations on campus. Seeing such impact on the Best Buddies and their College Buddies, Solomon sees great potential in a Best Buddies VandyMed chapter. “The goal of Best Buddies VandyMed is two-fold: one, to enhance the lives of individuals with developmental disabilities by providing opportunities for one-to-one friendships, which is Best Buddies’ mission; and two, to expose the greater medical center and medical school community to the needs of the population with developmental disabilities, and allow for quality experiences between medical students and buddies with disabilities to better prepare medical students to serve this population effectively as future physicians.”

“Best Buddies has had a profound influence on the way that I think about and interact with people with disabilities. This organization has exposed me to the immense pride, achievement, and talents that exist within a community of individuals supporting each other through friendship,” said rising third-year medical student and VandyMed membership coordinator Kelly Boquette. “My Buddy has shown me how she is always able to reach higher and achieve more than I expected—from rock climbing to speaking in public to competitive power weightlifting! I know that participating in Best Buddies has changed the way that I will practice medicine. I will encourage families living with disability to seek out community resources and to push the limits of what they think is possible.”

VandyMed students have bonded with their Best Buddies over bowling, pottery painting, holiday parties, and go-kart races, among other activities. A medical school chapter of Best Buddies has no precedent, so Solomon and her fellow students are learning as they go along in developing the chapter.

“We are not only starting a new chapter, but we are working on starting a new ‘branch’ of Best Buddies outside the existing structure of...”

Kindred Stories of Disability: A Shift From “Me” to “Us”

BY COURTNEY TAYLOR

We are drawn to stories. We share our stories in an effort to communicate and connect. Stories can educate us, persuade us, and improve our understanding of others. Through Tennessee Kindred Stories of Disability, the Vanderbilt Kennedy Center and The Arc Tennessee disseminate stories from individuals with disabilities and their families to policymakers. Students from Vanderbilt and Belmont Universities collect the stories as a course assignment. Stories are then shared through the Kindred Stories Website and through an annual print booklet distributed at Tennessee Disability Day on the Hill and at the Federal Disability Policy Seminar in Washington.

The stories cover a range of topics from raising awareness about the huge number of people on the waiting list for Home and Community-Based Waiver services to highlighting the unique challenges that immigrants and refugees face when navigating an unfamiliar culture and disability service system. Stories come from people of all ages living across the state. Some are told by adults with disabilities, while others are based on interviews with family members. No matter who the storyteller is, they are sharing their experiences to help others going through similar experiences and are creating awareness of disability issues. They are educating policymakers and the general public to create positive change for themselves and for future generations.

“It is important to share your story,” said participant Frank Meeuwis. “I tell people about what...”

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Be Who You Are  

BY CRYSTAL FINLEY

The Ambassadore program connects Vanderbilt students with Next Steps students. Excerpts follow from remarks of Ambassadore Crystal Finley (’13) at the 2013 Next Steps graduation ceremony. She’s entering VU Special Education Master’s program in Fall 2013.

Thank you for the opportunity to be with you today, as we honor the accomplishments of three amazing graduates, Matt Moore, Will McMillan, and Carrie DePauw. Perhaps like you, participation in Next Steps has been the instrumental and formative part of my college experience.

I am finishing my undergraduate degree in Special Education. If you asked me when I graduated high school what I would study in college, I would never have told you that I wanted to become a teacher. I elected to study engineering, assured by many that this was a great choice that would lead to success. Little did I know that I would learn different meaning for what it is to find success in life.

I will be forever grateful to six friends I made during my freshman year who personally opened my eyes to this. These six friends were part of the first class of students in Next Steps at Vanderbilt. I immediately saw a difference from my other friendships at school, a difference noted in their unshakeable optimism, infectious enthusiasm, and unconditionally loving hearts.

There were few things in my first year of college that made me feel like the person I wanted to be, but there was one activity that I cherished wholeheartedly: being a Next Steps Ambassadore.

The fall semester of my sophomore year was one of my most challenging. This was the first time in my life that I failed academically. Thankfully, I found the courage to make a change and to shift my perspective of success. I transferred into Special Education. This decision remains the best I have ever made.

I was wrong when I thought that success meant I would never fail at something. I was also wrong when I thought success meant that I should be something just because others thought I should. I found that success was being the person that I wanted to be.

I am incredibly grateful for the opportunity to be a Special Education teacher, a career that I would not have realized I loved so much until I began this program. I have learned that success is not measured by the magnitude of the things you do, but rather the magnitude of the love and dedication you have for what you do. Matt, Will, and Carrie, your impact on the world does not stop here; in fact, it will be even greater. I urge you to go confidently, and be exactly who you are. You have given me so much, by doing just that. ■

Peer Mentoring It Can Change Your Life  

BY REBECCA MOODY

My name is Rebecca Moody. I am a third-year student at Vanderbilt University studying Special Education. I am writing to share how the Next Steps at Vanderbilt program has impacted my life.

Back in high school, I was involved in a service learning class where I volunteered in a self-contained special education classroom. This was my first real introduction to students with special needs. After a year of working with the students, I graduated and was headed to Vanderbilt University. When I went to say goodbye to the students, I was heartbroken to discover that they had very minimal plans for their futures. Many did not know what they would do after graduating. I was shocked to find out that this situation was not unique to my high school, but that students with disabilities all across the U.S. also were unsure of their futures.

Coming to Vanderbilt and finding Next Steps, a program for students with intellectual disabilities on campus, changed everything for me. Just months before coming to Vanderbilt, I had seen firsthand the need for students with disabilities to have college opportunities. Seeing that this was possible helped me to find my passion for the field of postsecondary education. I wanted to be a part of Next Steps to help students achieve their future goals, whether that be college, a job, or other experiences.

I immediately signed up to become an Ambassadore (a peer mentor, the name being a play on our Vanderbilt mascot, the Commodore). Since freshman year, I have tutored seven different Next Steps students and developed a meaningful relationship with each person in the program. After one semester as an Ambassadore, I declared Special Education as my major and am working towards the goal of becoming a transition professional.

The students are by far the hardest-working I have ever met. At internships, they work hard to be the best employees possible. Through their unwavering positive attitude, I have felt a change in how I view my time here in college. The appreciation that Next Steps students have for being a part of a university community is something that many college students take for granted.

I see my enrollment differently now. I see it as an amazing blessing and an opportunity to make a difference so that more people can feel this way, too. All students should have access to a community that supports their dreams and works with them to achieve their goals.

Next Steps has given me a clear picture of what I want to do after I graduate. The students in the program are so much more than students. They are my peers and friends. I hope that I can continue making a difference in their lives in the same way they have made a difference in mine. ■
Families First, Growing Strong  BY JAN ROSEMERGY

When parents learn that their child has been diagnosed with an autism spectrum disorder (ASD), they quickly realize that they need guidance in learning how to support their child’s development and to navigate autism services. Thanks to a founding gift from the late Ann and Monroe Carell, Jr., TRIAD’s Families First workshop series began in 2008 with the goal of serving 150 families. To date, Families First has touched over 2,500 participants. Although the founding gift was expended by March 2011, TRIAD leaders have continued to provide the workshops, at no cost to families, through other gifts and training funds.

A mom of a 3-year-old son with ASD wrote, “You put air back into our lungs, hope into our hearts, most important the fight back into our spirit. You gave us information, educated us, and brought families together.”

The goals of Families First are to equip parents and caregivers with practical tools and strategies to support their child at home and in the community, and to provide parents and other caregivers an opportunity to meet parents with similar concerns. Topics address what parents have said they need: addressing challenging behaviors, developing beginning communication, improving communication in children who are talking; toilet training; promoting peer and sibling play; enhancing social interaction; developing play routines; daily routines; “out and about” in grocery stores, restaurants, playgrounds; safety; preparing for holidays; including children with ASD in religious education; understanding Applied Behavior Analysis (ABA); developing successful sleep and feeding habits. Strategies discussed are based on ABA principles.

Families First reaches mothers, fathers, immediate and extended relatives, students, and such community service providers as language and speech pathologists, teachers, therapists, and child care providers.

“We try to give parents and caregivers a base understanding of strategies and information that they can then take back to their family members, therapists, teachers, and communities to think about how to individualize those strategies to best work for their child,” said Whitney Loring, Psy.D., assistant professor of Pediatrics and Families First coordinator. “We also want participants to meet other families who may be struggling with some of the same types of challenges. So often, parents feel alone or overwhelmed when they first receive a diagnosis, and it’s great to remind them that they are the true experts when it comes to their own children. We are here to provide them with strategies, but ultimately, we are here to support them in the work that they do so well.”

In 2012, Families First reached over 330 parents and caregivers not only through training held at the Vanderbilt Kennedy Center but also through outreach partnerships with Tennessee Disability Pathfinder’s Multicultural Outreach Program and Memphis City Schools/Shelby County Regional Special Education PTA. TRIAD also has collaborated with the Tennessee Early Intervention System (TEIS) to provide training and support so that TEIS staff can provide similar parent training in other regions of Tennessee.

“The founding mission of Mr. Carell has resonated with me throughout my career here at Vanderbilt,” said Zachary Warren, Ph.D., TRIAD director and associate professor of Pediatrics. “This program has touched so many families affected by autism in a powerful way. It is our goal to continue to develop philanthropic and community partnerships such that every parent of a child with autism in Tennessee will have the opportunity to benefit from this program.”

Technology and Toilet Training  BY JAN ROSEMERGY

Along with learning to feed and dress oneself, becoming toilet trained is an important step in a child’s personal independence. The main components of autism spectrum disorders (ASD)—social communication deficits and restricted interests/repetitive behaviors—can interfere with toilet training.

First, children with ASD may be less responsive to learning purely through imitation and to social rewards like praise. Second, children with ASD often have difficulty understanding and following verbal directions and may have limited communication skills to express toileting needs. Finally, because children with ASD have difficulty with change in their routines, they may be resistant to the steps in toilet training or may have sensory sensitivities that interfere.

Autism specialists help parents of children with ASD adapt the strategies of Applied Behavior Analysis (ABA) to toilet training. Although effective for many children, the process typically takes an extended time, and some children do not become toilet trained.

Now researchers are conducting a small, multisite trial to test the feasibility of using a wireless moisture pager to augment the ABA toilet training approach. They are testing whether this technology is effective in reducing the length of time to accomplish toilet training and effective in toilet training children for whom behavioral strategies alone have not worked.

The study is led by researchers at the University of Rochester, where the technology was developed, Nationwide Children’s Hospital (Ohio State University, Columbus), and Vanderbilt. The Vanderbilt study is led by Whitney Loring, Psy.D., assistant professor of Pediatrics and Psychiatry. Families for the Vanderbilt study will be recruited through the Vanderbilt Autism Treatment Network site.

A small module, about the size of the unlock buttons on your car’s keyless entry remote, snaps into place on a disposable sensor, basically a commercial panty liner with conductive thread sewn in. This is then placed in

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When a child successfully makes it to the bathroom, caregivers can log it at the touch of a button and a reward screen appears. From that screen, children or caregivers can launch a favorite video, song, or even choose a picture of a snack on a reward screen. From that point, the child gets a reward with a tone and a message on the screen with a picture of the reward. A child can choose a reward, which should be a great addition to what is done in behavioral toilet training.

The study is being funded by the Autism Treatment Network/Autism Intervention Research Network on Physical Health.

Note: Toilet Training and Autism Spectrum Disorders (4 pages) can be downloaded from the VKC website.
When you ask parents of adolescents and teens about developmental disabilities about the challenges their families are currently facing, more often than not issues related to puberty will make it to the top of the list. While young people with disabilities will go through many of the same physical and emotional changes that typically developing young people will experience, unique challenges may make this a somewhat stressful time for families.

A new toolkit Healthy Bodies: A Parent’s Guide on Puberty for Adolescents with Disabilities addresses the needs of these families and is a response to the limited number of practical resources about puberty and disabilities. The toolkit was developed by Cassandra Newsom, Psy.D., assistant professor of Pediatrics and trainees in the Vanderbilt Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Training Program. It has been produced and is being disseminated by the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities.

The toolkit is written for a broad range of disabilities and provides a wide variety of visual supports and social stories, which are especially useful for youth with autism or youth who are nonverbal. So that visuals and information fit gender, male and female toolkits have been produced.

The toolkit deals simply and directly with practical matters of puberty. Examples of topics and supports include hygiene, menstruation, or she will be delayed in puberty and in the development of their sexuality. This is not necessarily the case. In fact, some people with disabilities will enter puberty early. So, we wanted to develop this toolkit for parents to clear up some of these taboos and misperceptions. We also wanted to be sure that parents understand that just because their kids might not be talking about dating or sex, it does not mean that their bodies are not changing, that their hormones are not running rampant, that they don’t need to be introduced to these topics.

In fact, it is suggested that parents start talking with their kids about the changes they can expect before they enter puberty. And as with teaching any new skill, many young people with autism and/or intellectual disabilities will benefit most from simple, clear, and concrete information with opportunities for repetition, practice, and application. Empowering adolescents with a greater understanding of their own bodies can reduce anxieties and increase personal comfort and independence.

In addition, there are issues of personal safety. Evidence indicates that people with disabilities are at a higher risk for being taken advantage of, for abuse, or for behaving in ways that may be considered socially inappropriate and getting in trouble for it. By opening a dialogue and teaching about appropriate and inappropriate behaviors, youth will be better equipped to handle uncomfortable or perilous situations. In fact, the American Academy of Pediatrics has stated that the likelihood of abuse is reduced or eliminated when sexual questions and behaviors are freely discussed within a family.

Healthy Bodies: A Parent’s Guide on Puberty for Adolescents with Disabilities may be downloaded free of charge at: kc.vanderbilt.edu/healthybodies.

Submit or read a story at kc.vanderbilt.edu/kindredstories.

“Many of my general education students have never met or interacted with a person with a disability,” said Lacey Lyons, adjunct instructor of English at Belmont University. “As a result, my English course topic, interviewing people with disabilities, is a culture shock for them. At the same time, undergraduate education is a time when students are open to new possibilities.”

Students have indeed been open. Some have reported a change in career plans after participating. Special Education has been declared as a major on several occasions. Many students have been so touched by the lives of the people they interviewed that they have sought out information on supports and services to share with families. This was because they listened to a story.

Stories have the innate potential to inspire change in the world. They can make us care and act, and can facilitate a shift from “me” to “us.”

Submit or read a story at kc.vanderbilt.edu/kindredstories.
Advocacy Success in Tennessee
STEP UP Legislation
Students and graduates with intellectual disabilities enrolled in Next Steps at Vanderbilt played an active role in the successful passage of Tennessee STEP UP Scholarship legislation. The legislation expands the Tennessee Lottery Scholarship to include students entering eligible postsecondary education programs for students with intellectual and developmental disabilities in Tennessee.

In addition to efforts by disability organizations like The Arc Tennessee and the Tennessee Disability Coalition, Next Steps students wrote to and met with their legislators. They testified before the House Education Committee and the Tennessee House of Representatives to share how participation in a postsecondary education program has improved their quality of life and job prospects.

“Going to college taught me how to be more independent,” said Will McMillan, Next Steps graduate (2013). “I now want to live on my own and college helped make that possible….I really liked my classes and learned different things. I’ve learned so much about myself that I didn’t already know: like the challenges I’ll face. By being in college, I got to have internships. I’ve worked with the sports and athletics and two different libraries. All of my internships I liked and I now know what I want from a job.”

Starting in the 2013-14 academic year, STEP UP scholarship recipients will receive $4,000 per year for a maximum of 2 years. To be eligible, a student must be a Tennessee resident, graduate high school in his or her own Individual Education Program, and be admitted to and enroll in an eligible postsecondary institution no later than 16 months after graduation.

Governor Haslam signed the bill into law on Tuesday, June 4. Next Steps student Haley Kellar was among only four students present.

States Focus on Disability Employment
Local advocates, including Elise McMillan, J.D., VKC UCEDD co-director, attended the National Governors Association Institute (NGA) “A Better Bottom Line: Employing People With Disabilities” in Seattle. Attendees discussed the employment challenges that affect individuals with intellectual and other significant disabilities and examined the role that state government and business play in advancing opportunities for individuals with disabilities to be employed in the competitive labor market.

The Institute was hosted by Gov. Jack Markell (Delaware), Gov. Jay Inslee (Washington), and Gov. Dennis Daugaard (South Dakota). On his reasons for selecting the topic of employment and disabilities for this year’s meeting, Gov. Markell stated, “Americans with disabilities are facing disproportionately high rates of unemployment compared to Americans without disabilities…. Individuals with disabilities should have, to the maximum extent possible, the same opportunities

Disabilities), Susie Bourque (Department of Labor and Workforce Development), Ruth Brock (Vocational Rehabilitation), Sue Kerber (Department of Mental Health and Substance Abuse Services), and Wanda Willis (Tennessee Council on Developmental Disabilities). All were invited by Governor Haslam to be part of the Tennessee Team. The NGA will issue a Blueprint Report on Employment based on findings in these meetings later this summer.

Inclusive Education at University of South Africa
The Vanderbilt Kennedy Center (VKC) and other UCEDDs hosted June visits from a 3-person delegation from the University of South Africa (UNISA) in Pretoria led by Nareadi Phasha, professor and chair of the new Department of Inclusive Education in the College of Education. The goal of their visits was to develop their strengths in Inclusive Education, including Special Education, a national priority in South Africa.

They are establishing a Centre for Excellence in Disabilities that will focus on diagnosis, research, and teaching. The UNISA delegation also included Dr. Siva Moodley, director of Centre for Advocacy on Disability, and Dr. Francina Mahlo, senior lecturer in Inclusive Education.

During their 2-day VKC UCEDD visit, they met with faculty and staff leaders in special education research and research training, assistive and augmentative communication, visual impairments, assessment and diagnosis, information and referral, multicultural programming, reading instruction in special education, autism services and training, inclusive early childhood special education, postsecondary education for students with intellectual disabilities, employment, and self-advocacy.

Their planned U.S. visits included other UCEDDs and the Perkins School.
A Win-Win Situation  Rodes Hart Susan Gray School Teaching Fellows  

BY ELIZABETH TURNER

It's a true portrait of "paying it forward." H. Rodes Hart, former chairman of Franklin Industries and a Vanderbilt University Trustee for 30 years, had an administrative assistant whose daughter was having difficulties in preschool. She had been asked to leave one school and was at risk of being dismissed from another. Hart mentioned his assistant's dilemma to then-director of the Susan Gray School (SGS) Ruth Wolery. SGS is a research-oriented school devoted to educating young children with and without developmental disabilities in an inclusive setting. Wolery welcomed the child into a SGS classroom, where she thrived. As a way to thank Wolery and SGS for their kindness, Rodes and Patricia Hart donated $100,000 to the School to use as they thought best.

Since Wolery's retirement, the School has been led by Ann Kaiser, Ph.D., Special Education faculty members, who saw that establishing a Teaching Fellow program would benefit teaching quality in the School while also benefiting student training. With the support of Peabody College Dean Camilla Benbow, Ed.D., a scholarship program was created for students working toward a master's degree in Special Education or Early Childhood Special Education. In exchange for tuition (provided via scholarship through Peabody) and stipend (provided through the Harts' donation), these master's-level students work part-time in SGS classrooms while completing their degrees.

In addition to providing an extra set of qualified hands in the classrooms, these Fellows are gaining valuable firsthand experience working with children similar to those they will be teaching after they graduate. The Fellows begin their SGS work in the Fall term, and they remain in the program for 1 or 2 years, depending on their studies and student teaching requirements.

"These students are becoming more integrated into research by being in the classroom because of Rodes Hart and his donation," Kaiser said. "It's a win-win situation." "It has been such a blessing to be involved in this fellowship program," said Teaching Fellow Janey Gibson. "There's so much to be learned in my own master's classes at Vanderbilt about children's development, what good teaching really looks like, and about research in this field, but I think the true measure of what we learn lies in how we can apply the knowledge that we've been given. Being part of the fellowship program has given me the opportunity to take some of the ideas I'm learning about in my own classes and try them out in a real classroom, as well as think about how what is happening in the classroom I'm working in at Susan Gray School can help inform and direct research in this field."

Rodes Hart's generosity has continued. To date, he has donated $300,000 to the Susan Gray School Teaching Fellows Program. During the 2013-14 academic year, there will be nine Peabody master's-level students—four returning from the pilot session, and five new Fellows—who will be benefiting. "We're so grateful for Rodes Hart's support. The Fellows got a chance to meet him and tell him their stories, and it was a nice opportunity for the Fellows to make that connection with Hart as well," said Kiersten Kinder, associate director of Susan Gray School and training director of the Fellowship program. "I think it's rather fitting that this whole thing got started out of a mother's desperation. We often get similar calls of desperation from parents. Not only is Mr. Hart’s gift supporting these young teachers, but these same teachers also can provide support to parents in similar situations."

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"colleges," and expanding to include graduate and professional students, such as medical students," Solomon said. "For the past 3 years, we have had more medical students interested in Best Buddies than we have available Buddies with disabilities. If we meet a person with intellectual disabilities, we have been sharing flyers and inviting individuals who do not yet have Buddies to join our 'chapter' and be paired with a medical student."

The fledgling VandyMed BB chapter has more than 50 medical students, with 18 successful one-to-one friendships this past year. Solomon hopes to double the number of Buddy pairs next year.

"We already have been contacted by several medical students from other medical schools who are interested in starting Best Buddies chapters at their institutions," said Solomon. "We know that having experience with peers with intellectual disabilities is an invaluable addition to a medical education."

Now in her third year of medical school, Solomon still maintains her close friendship with Martin. She doesn't know what the future holds as far as her residency placement a year from now, but she does plan to have her Best Buddy by her side—a spot dedicated to family members and loved ones—when she ascends the stage and is handed her envelope on Match Day.

"While I have been able to play an important role in Christy's life, Christy has been the most pivotal support figure in my life throughout college and medical school. To me, my Best Buddy is my family in Nashville, my best friend, and my biggest encourager for everything that I do." "We look forward to partnering with Best Buddies Tennessee and Best Buddies International to support this innovative program for medical students," said Elise McMillan, J.D. faculty director Best Buddies Vanderbilt chapter.
Hope Is Why We Do This  Bob Romeo  BY ELIZABETH TURNER

Bob Romeo, CEO of the Academy of Country Music (ACM), has been in the entertainment business for 35 years. He’s seen a lot of things and has worked with a lot of big-name country stars that many dream of meeting someday. But in discussing his work with the ACM Lifting Lives Music Camp, Romeo speaks with the enthusiasm of the campers’ biggest fan.

The Vanderbilt Kennedy Center and the ACM came together 4 years ago when the Academy’s newly formed charitable arm, ACM Lifting Lives, was trying to find a presence in the Nashville area. “We’d heard about the Kennedy Center and how they work with kids with Williams syndrome, and how some of those kids have an affinity for music, and that’s when the bell rang,” Romeo said. “Our mission statement is ‘Improving Lives Through the Power of Music,’ and the power of music helps these campers who have this disorder, and we were like, ‘Wow, how can we get involved with that?”’

Romeo and his staff members haven’t looked back since. He had heard repeatedly from his staff what a profound impact the campers were having on them, but Romeo said that the defining moment for him was when he was sitting backstage at the Academy of Country Music Awards while the 2011 Music Campers were rehearsing to sing onstage with Darius Rucker for a live television taping. “I was in the back of the room where the families of these campers are watching it unfold from backstage. Those pictures of the story couldn’t be captured for TV, but to see hope in their eyes, watching their sons, daughters, nieces, and nephews onstage singing—I still get emotional talking about it. That’s when I felt like, ‘That’s why we do this. It’s not just about helping people with these disorders, trying to find new ways to bring new research, but it’s also about these families and caregivers and everyone else who these people touch.’”

The initial goal was to help the Vanderbilt Kennedy Center provide these Music Campers a memorable week surrounded by music and fun while also taking part in research, but the positive impact spread to ACM staffers participating in the camp. “My staff came back afterward, sitting around the table just talking about how outgoing, loving, supporting the campers are. When they were writing their song during the songwriting session, as people were coming up with suggestions, they were just so encouraging to one another, and my staff came back totally motivated by it,” Romeo said. “I was watching some footage of the campers talking, and one of them was talking about how he wondered if he mattered. It would be unbelievable to tell the story of how much they do matter, and how much they touched my staff and me. I don’t know if they even realize it.”

Campers have told ACM staffers how much they look forward to June, because it means they get to go to camp. One week a year was great, but Romeo was starting to think bigger. He and Elisabeth Dykens, Ph.D., principal investigator for the research component of camp, met with Jeff Balser, M.D., Ph.D., Vice Chancellor for Health Affairs, to discuss a broader scope in which the VKC and ACM could serve the Williams syndrome population.

“In Nashville, there’s this program called Leadership Music. You meet once a month to take part in a different subject for two days. One month is radio, one is songwriting, one is broadcasting, and so on,” he said. “You get to watch how the industry works, and you learn a lot. It was that program we shared with Dr. Dykens as a pattern, where participants could come once a month and do a specific job.”

From those early discussions grew the ACM Lifting Lives Series, currently being piloted. Romeo has dreams of expanding the program and making the experience a gateway to meaningful employment. “We’re hoping that maybe we can create opportunities where these students might be able to get some internships. Here could be one of those perfect situations for them, whether it’s working in the mailroom at CAA, or interning at the Academy of Country Music show for a month,” Romeo said. “The ACM Lifting Lives participants can go through the 9 months and say, ‘I really liked working in the studio,’ or ‘I really liked working in the agency business.’ And if it’s one label, one agency, one organization that could take just one camper and make that person a productive member of society as far as contributing and earning some money, think of how many doors that could open and create a windfall of people who could become a great asset in the industry.”

“Creating employment opportunities for adults with intellectual and developmental disabilities is a major area of emphasis for our University Center for Excellence in Developmental Disabilities,” Dykens said. “We’re so grateful to Bob Romeo, the Academy of Country Music, and ACM Lifting Lives, not only for their marvelous philanthropy, but also for their expansive, inclusive vision.”

SUMMER LEARNING, Ripples Broadening, from page 3

Nutrition Studies. For the most part, trainees are motivated to be there because they, like the trainees in the other camps, have had little to no interaction with people with disabilities in their programs and clinics.

“There are not a lot of clinicians out and about in the world working with people with disabilities,” said Marisa Fisher, Music camp director. “They are not getting the exposure in their training, so we are providing them with experiences they might not have had otherwise. That is very important. They might now feel more comfortable to work with people with disabilities, and to incorporate them into their clinics and research agendas. To open the door to more services and supports for people with disabilities is a worthy outcome indeed.”

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Create visual stories using your iPad to help reduce your child’s anxiety about what’s coming next. Turn a routine like going to the doctor or bedtime into a series of simple steps. It’s easy to use.

1. Create a storyboard
2. Add tasks
3. Play the story.

Available on iTunes. Created for providers and families in collaboration with Developmental Medicine specialists at the Monroe Carroll Jr. Children’s Hospital at Vanderbilt.
Unless otherwise noted, events are free and open to the public. Events are subject to change. Please check the website calendar at kc.vanderbilt.edu or contact (615) 322-8240 or toll-free (1-866) 936-VUKC (8852).

Please keep this calendar and check the Event Calendar on the VKC website for updates. If you wish to receive event announcements by email, send your email address to kc@vanderbilt.edu.

For disability-related training and other events statewide and nationally, see the searchable Pathfinder Disability Calendar www.pathfinder.org.

*Event will be held in Room 241 Vanderbilt Kennedy Center/One Magnolia Circle Bldg (110 Magnolia Circle).

**VKC Member or Investigator

**AUGUST 17**
TRIAD Families First Workshops Addressing Challenging Behaviors Register at kc.vanderbilt.edu/registration. Info (615) 322-8027 or families.first@vanderbilt.edu Saturday 9 a.m.-12 p.m.

**SEPTEMBER 4**
Developmental Disabilities Grand Rounds TBA Topic and Speaker Wednesday 12-1 p.m.

**SEPTEMBER 10**
Statistics and Core Methodology Training Seminar Designing Questionnaires Mario Davidson, Ph.D. Instructor of Biostatistics Register at kc.vanderbilt.edu/registration Tuesday 12:30-1:30 p.m.

**SEPTEMBER 13**
Community Advisory Council Meeting Info (615) 936-8852 Friday 9 a.m.-2 p.m.

**SEPTEMBER 18**
Neuroscience Graduate Program Seminar Series Synapse Molecular Diversity: Why It Matters and How to Measure It Stephen J. Smith, Ph.D., Professor of Molecular & Cellular Physiology, Stanford University. Co-sponsor Vanderbilt Brain Institute Room 1220 MRB III Lecture Hall Wednesday 4-10 p.m.

**SEPTEMBER 26**

**OCTOBER 2**
Developmental Disabilities Grand Rounds Reward and Interests in Autism: Of Men and Mice Jim Bodfish, Ph.D., Professor of Hearing & Speech Sciences and Psychiatry Wednesday 12-1 p.m.

**OCTOBER 6**
Developmental Disabilities Grand Rounds Circadian Rhythms and Learning and Memory: What We Can Learn From a Cockroach Terry Page, Ph.D., Professor of Biological Sciences, Director of Neuroscience Studies Program Wednesday 12-1 p.m.

**OCTOBER 16**
disAbility Mentoring Day Nashvillians with disabilities have an opportunity to job-shadow medical center professionals. Info Lynnette.Henderson@vanderbilt.edu Wednesday 8:00 a.m.-2:00 p.m.

**OCTOBER 16**
Neuroscience Graduate Program Seminar Series TBA Nenad Sestan, M.D., Ph.D., Professor of Neurobiology, Yale University. Co-sponsor Vanderbilt Brain Institute Room 1220 MRB III Lecture Hall Wednesday 4:10 p.m.

**NOVEMBER 6**
Developmental Disabilities Grand Rounds Circadian Rhythms and Learning and Memory: What We Can Learn From a Cockroach Terry Page, Ph.D., Professor of Biological Sciences, Director of Neuroscience Studies Program Wednesday 12-1 p.m.
**NOVEMBER 13**
Research Ethics Grand Rounds
Panel: Challenges of Health Disparities in Individuals With Disabilities
**Tyler Reimschisel, M.D., Tom Cheetham, M.D., JoAnn Drumright**
Wednesday 12-1 p.m.

**DECEMBER 4**
Developmental Disabilities Grand Rounds
Why Do I Hurt If the Doctor Can’t Find Anything Wrong?
**Lynn Walker, Ph.D., Professor of Pediatrics and Psychology, Director of Division of Adolescent Medicine and Behavioral Science**
Wednesday 12-1 p.m.

**DECEMBER 13**
Community Advisory Council Meeting
Info (615) 936-8852
Friday 9 a.m.-2 p.m.

**ARTS AND DISABILITIES EXHIBIT**
Monday-Friday 7:30 a.m.-5:30 p.m.
Lobby VKC/One Magnolia Circle Bldg. Info (615) 936-8852

**AUGUST-SEPTEMBER**
Sandhill Cranes, Owls, and Elephants. Artists of Pacesetters, Inc.

**OCTOBER-DECEMBER**
Creative Expressions XIX. Mayor’s Advisory Committee for People With Disabilities

**AUTISM TRAININGS FOR K-12 PERSONNEL**
With the TN Dept of Education, TRIAD offers free autism-specific workshops for school personnel, parents, and the community in locations across TN. For dates/locations, see kc.vanderbilt.edu/TRIAD/events

**LEARNING ASSESSMENT CLINIC**
Multidisciplinary academic assessments of students, 5-25 years, to identify learning strengths and challenges and to recommend strategies to improve academic learning. Info (615) 936-5118 or LAC@vanderbilt.edu

**NEXT STEPS AT VANDERBILT**
A 2-year certificate postsecondary education program for students with intellectual disabilities providing individualized Programs of Study in education, social skills, and vocational training. Info (615) 343-0822 or NextSteps@vanderbilt.edu

**READING CLINIC**
Tutoring students with reading challenges through middle school. Space limited. Info (615) 936-5118 or readingclinic@vanderbilt.edu

**TABS (Tennessee Adult Brothers and Sisters) Network**
TABS Facebook page www.facebook.com/tabs.siblings
Info tabs@vanderbilt.edu

**TAKE PART IN RESEARCH**
VKC Research Studies
For children and adults, with and without disabilities. Lynnette Henderson (615) 936-0448
Toll-free (1-866) 936-VUKC [8852]
• StudyFinder kc.vanderbilt.edu/studyfinder
  View lists of studies, criteria, and contact information
• Research Match www.researchmatch.org
  Register and be notified of research studies
• See also VUMC Clinical Trials www.vanderbilthealth.com/clinicaltrials

**TASA (Tennessee Allies in Self-Advocacy)**
Info megan.hart@vanderbilt.edu or vkc.mc.vanderbilt.edu/tasa

**VOLUNTEER ADVOCACY**
Fall 2013 training (11 weekly sessions) in special education law and advocacy strategies. Info lynise.parisien@vanderbilt.edu

**ASMT EVENTS**
Autism Society of Middle Tennessee www.tnautism.org

**DSAMT EVENTS**
Down Syndrome Association of Middle Tennessee www.dsamt.org

The VKC Reading Clinic, which provides one-on-one tutoring for struggling young readers, is accepting applications for its Fall Session.