

# BREAKING

# GROUND

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**IN THIS  
ISSUE:**

**PLANNING  
FOR THE  
UNKNOWN**

**SARAH**

**EMILY**



**TENNESSEE COUNCIL**  
on developmental disabilities

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# Planning for the

by Pam VanGilder

# UNKNOWN

My name is Pam VanGilder and I am a proud mother of three very unique individuals.

My son, Paul Sheridan, is 28 and a doctoral student in neuro-engineering, married to Jennapher and together they have a two-year-old daughter, Piper. My youngest daughter is Emily, 21, and a student at the University of Memphis in graphic design, and already working part-time for a graphic design firm in Memphis. Encircled between them is Sarah, 23, who is in the work-based learning program at Madonna Learning Center, where she is also very active in the Center's Visual Art, Theatre, Yoga and Dance programs. Sarah also happens to have Down syndrome.

The success and challenges of having a family member with disabilities has shaped each of us as individuals, and as a family.

As a parent you welcome your infant into the world, embracing the love you have to share and the responsibility you have to bear in helping your child grow and develop into the person he or she is meant to be. This is a huge task, one you eagerly embrace with all the love and devotion in your heart. The unknown is out there, but you know the future is full of possibilities.

When you give birth to a child with disabilities, the unknown and the future becomes overshadowed by worries and concerns of what is, and what could be. Those shadows disappear with each success, and reappear with each new challenge.

The first success had nothing to do with Sarah's developmental milestones. It had to do with us, my husband Paul and I, as we laid aside the fear and anxiety put upon us by a narrow-minded geneticist, and our anticipation of pity and sorrow from family, friends and the community. As we pushed aside those fears and anxieties, we discovered our deep love for our daughter, and each of her 21 chromosomes.

A physical therapist told us, "just love your baby", and we did.

The days have grown into years and, although we've made it through many transitions, where we are now seems the most challenging: transitioning out of a school-



based environment and into the "world". What will that look like? I have trouble even beginning to envision what may lie around the corner. The simplest transitions have always been a challenge to Sarah, even with preparation to ease the anxiety. How can we prepare her for the next phase of her life when we ourselves haven't thought enough about it to conjure up a vision, imagine a dream or create a plan?

Paul Sheridan and Emily are now on their way to creating their own path, making choices, living independently, not needing our help in their day to day lives. But what about Sarah? How can we prepare her to make her own choices? How can we include her in the decision-making process? What are her interests and her gifts? What part can she play in the community of life? And how do I explain these concepts to her in ways she will understand?

As I think about this and take a look at Sarah, our family, our friends, and the possibilities beginning to develop in the community for those with disabilities, I know a path will become visible.

We will make it through yet another of life's many transitions.

*Pam VanGilder is a graduate of the 2013-14 Partners in Policymaking class.*

# Learning with **LAZ**



Photo by Cynthia Chambers

by Lazarus (as told to Cynthia Chambers)

**M** My name is Lazarus. I

am a rescue cat who loves to snuggle, eat treats and nap often. That's

right; I'm a typical cat! However,

there is something unique about me too.

I was born with a cleft palate, leaving me with no nose or upper lip. I also have bottom canine teeth that protrude, which adds to my interesting appearance.

So what's a cat doing in Breaking Ground?

Well that's because I'm not only a cat who happens to have special needs, I'm also an educator and advocate! Let me tell you a little bit more about me and my journey.

I was rescued on September 11, 2012 by an East Tennessee State University (ETSU) student. I was homeless, malnourished, flea infested and had a severe infection in my mouth. The student connected me with Dr. Cynthia Chambers, an Associate Professor of Special Education, from ETSU. She's now my Mama! I was taken to the vet immediately and given a plan for recovery.

My health improved but I continued to have problems. One rescue group across the state offered medical support for me, but they wanted to keep me. Mama, being a special educator, couldn't send me off without



Photo by Josh Salyer

my very own advocate. In that moment, she pledged to keep me safe and to provide me with a loving home.

Mama started a Facebook page called Care for Lazarus. This site was created to reach out to others to gain informational and financial support for my care. The response was overwhelming! People around the world liked my page (i.e., today over 20,000 people) and responded in the

most unlikely yet positive ways. Given the generous support of Facebook friends and other animal lovers, I was able to have surgery at the University of Tennessee Veterinary School. This surgery has resulted in fewer infections and left me on a healthy trajectory.

My funny and inspirational Facebook page has become a place where everyone's unique qualities are celebrated. My international audience includes people of all shapes, sizes and abilities. The page also allows people to follow my journey. Steve Simpson, a Facebook friend with Asperger's Syndrome, wrote, "Lazarus has taught me that differences or disabilities don't make you less human or in Lazzie's case, less feline." Another friend, Deborah Day, shared that,

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# Learning with LAZ

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"Lazarus reinforces my belief that ALL animals and people with and without disabilities deserve our best effort. We all have the right to live a full life." These comments encompass what Care for Lazarus is all about!

My journey has led me down a path that no one could have ever anticipated, but comments like the ones above make me want to share my message with broader audiences. Given the generous assistance that was provided to me when I was a kitten and the difference my message is making online, Mama felt like we should give back in some way beyond the efforts of our Facebook page. One of those efforts is called Learning with Laz and it's where I went from Star Cat to educator and advocate! I am an advocate for the rights of all beings no matter how seemingly different they may be, because we are all more alike than different.

Learning with Laz is an educational program that shares my story but also addresses broader issues such as finding your own unique characteristics, celebrating what each person brings to the table, making your mark on the world as well as caring for animals. The Learning with Laz program has visited schools of all levels in the Tricities of East Tennessee, and the program's content is adapted in age-appropriate ways.

At recent visits to two Kingsport City Schools (i.e., Pre-K and 1st-3rd grade classes), Mama and I shared a lesson on ways that we are different and similar with the similarities being more plentiful than the differences. Another visit was conducted at a high school in the Johnson City School district. Mama and I talked about transitioning out of high school and building a positive



Photo by Nick Hubbard

legacy. The Learning with Laz program is open to school-aged groups with or without school affiliations. At the end of all of my visits, participants have the opportunity to pet me. I'm sure that's their favorite part!

I have met a lot of different people in my short life of almost two years. From young to old, somehow, through hearing my story and message, perspectives are being changed. From the child with a cleft palate who says, "I'm like Lazzie and that's okay", to an adult who says, "I can make a difference in the lives of others", becoming an understanding society of people with varying abilities often comes down to awareness. I hope my story can create some of that awareness.

To learn more about me or to follow my adventures, visit [www.facebook.com/careforlazarus](http://www.facebook.com/careforlazarus). Inquiries regarding the Learning with Laz program may be made at [careforlazarus@yahoo.com](mailto:careforlazarus@yahoo.com).

*Cynthia Chambers, PhD is on faculty at East TN State University, a Partners in Policymaking grad and a member of the TN Council on Developmental Disabilities.*

*Lazarus is the 2014 Star Cat of Modern Cat Magazine. Cynthia Chambers is an associate professor of special education at East Tennessee State University, a Council member, Partners grad and the proud mother of Lazarus.*

# ACM **LIFTS LIVES** through Music and Employment Skills Training by Ned Andrew Solomon

Two years ago, the Academy of Country Music (ACM) began an expanded initiative with the Vanderbilt Kennedy Center about the employment of more people with disabilities through its philanthropic arm dedicated to improving lives through the power of music.



**Photo by Joe Howell**

experienced aspects of the music business from song writing to mixing instrumentals and vocals, from recording to public relations to performance. The sessions provided a window into what professional artists and others in the music

The ACM Lifting Lives series is an innovative vocational experience for young adults with disabilities with the goal of helping participants learn job and social skills aimed at increasing employment opportunities within the music and entertainment industry.

ACM was already very familiar with the Vanderbilt Kennedy Center as the sponsoring organization for the ACM Lifting Lives Music Camp that just celebrated its 10th anniversary. At the week-long residential camp held on the Vanderbilt campus, 30 campers with Williams syndrome celebrate music by participating in a songwriting workshop, recording session, songwriter's night and a live performance at the Grand Ole Opry. The camp has a dual purpose of researching Williams syndrome while providing music enrichment through performance and education. Seeing the impact of the one-week summer camp led the ACM to expand its partnership. People at every level of Nashville's music business have responded.

In the first year of the career exploration series during an eight-month period, participants visited several historic music venues and met with music stars and key leaders in the music industry. Participants

industry have to do to become successful.

"We're thrilled at the fantastic opportunity that ACM Lifting Lives is providing," said Elisabeth Dykens, PhD, Director of the Vanderbilt Kennedy Center. "Individuals with intellectual and developmental disabilities are significantly unemployed or underemployed, when they have so much to offer. Helping to raise employment aspirations and develop employment skills are a high priority at the Vanderbilt Kennedy Center. ACM Lifting Lives and so many associated with Nashville's entertainment industry are making a huge difference by providing these vocational experiences."

"From the onset, one of the goals for this initiative was internships and paid employment," said Tammy Day, program director of Vanderbilt's Next Steps post-secondary program for students with intellectual disabilities. "The participants had a ball last year (see Seth Link's sidebar on page 6), and it clearly opened doors."

This year, an expanded planning team included Dykens; Hannah Martin, manager of ACM Lifting Lives; Tammy Vice, songwriter and music consultant; Julia Harrison, VKC staff; and Lindsay Krech, VKC Job Developer.

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## ACM **LIFTS LIVES** through Music and Employment Skills Training

Continued from page 5

Ten participants were selected for the pilot project. This year, 13 youth with disabilities are participating, with the goal of giving them exposure to the behind the scenes jobs that keep the music industry running. In addition, Vanderbilt graduate students have also been involved, adding significantly to their training and allowing them to share their talents. "For example, Carrie Glover, a master's special education student, used to be a songwriter in LA, and has these wonderful skills around transcribing music," Day said. "She's found a way to help our students access this information."

Lindsay Krech met with faculty from the Belmont University business department to help enhance this summer's educational topics. The initial orientation included presentations on how the music industry works - from the inception of a song, to production, marketing and performing. Participants are also learning about those jobs directly involved with music publishing, touring, recording and artist development. Simultaneously, they're learning about personal professional development topics like networking, making good first impressions, interviewing skills, conducting research, and identifying and communicating your strengths. In other words, transferable job readiness skills that would be useful for pursuing and maintaining employment in any industry.

"Two things are going on here," explained Day. "We're hoping that our participants can envision themselves doing these various jobs, and that the music industry is getting a wonderful opportunity to meet some great future employees."

This is the icing on an already pretty sweet cake. Because how many times do ordinary people, again, with or without disabilities, get the chance to meet "insider" music industry folks, even living in Music City? "We are so grateful for the opportunity that the Academy of Country Music Lifting Lives has given to the Kennedy Center, and to Greater Nashville," said Day. "That they have the desire to walk this walk with us and provide employment opportunities, and that they see the young people that we work with as viable employees."

## Learning the Ropes

by Seth Link



In 2013, I was chosen by the ACM Lifting Lives group to take part in a music business workshop with several others. We learned the "ropes" of the business, and how it all works together. The sessions spanned the entire process, beginning with "Songwriting" where we all had input about crafting a song with the help of Ms. Tammy Vice; "Getting Better with Practice", which I think speaks for itself; "Heading to the Studio to Make a Demo" - the group went to a professional recording studio for this one; "Pitching the Song", a conversation with someone at a record label; "You Want to be a Star", a professional development workshop; and finally "Stage Call" where we were on stage at the Ryman Auditorium at an Awards Show with a lot of country music stars!

I have benefited so much from the program. I had the chance to meet several people through the workshops, and even bond with some old friends too. We talked about independence and how we can use the skills we learned in the workshops to advocate for and support ourselves. We learned that in any business it's important to have confidence to apply for possible positions we might be able to have, whether in the music business or something else. We worked on many job-related skills, like how to behave professionally and how to write a résumé.

I currently have a full time job at Vanderbilt Case Cart Operations Center which I am extremely grateful for; however, I will use what I learned to help advocate for others like me who may have a more difficult time finding work, by encouraging employers to try to hire individuals with disabilities in their workforce. I also can use the things I learned to be a better employee.

I am now the drummer for a local rock band from my hometown of Gallatin, TN. We are called Mojo Express. We practice on the weekends three times a month. I also take lessons from the Creative Music Academy in Hendersonville on Thursdays. My teacher has really opened up my playing abilities over the time I've been taking lessons there, and I am thankful to him for helping us find opportunities to play.

As you can tell, music is a big part of my life and I really enjoyed getting to know all of the inner workings of the music industry through the ACM Lifting Lives program. The Academy of Country Music is very important in the work they are doing for people with disabilities, and I am so thankful that they actually see the ABILITIES we do possess.

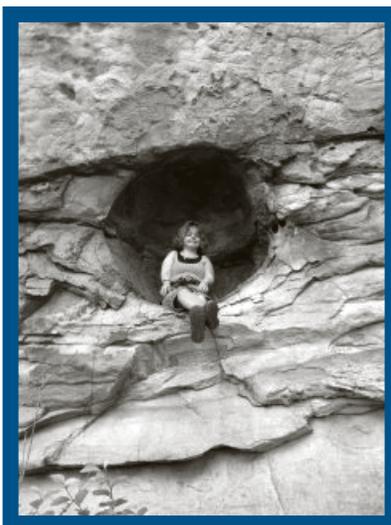
# COME ON Chattanooga and Knoxville



by Sharon Stolberg

Photos by Sharon Stolberg and Keiorg Urban

Chattanooga: the Scenic City, home of the Tennessee Aquarium, Chattanooga Choo-Choo, Coolidge Park, Walnut Street Bridge, Lookout and Signal Mountains, and miles of riverfront views and paths. Outdoor activities and adventures abound here, no matter the time of year. Kayaking, canoeing, rowing, stand-up paddle boarding, hiking, trail running, rock climbing, cycling, hang gliding and camping, just to name a few. There's always something going on in Chattanooga.



accessible using specialized adaptive equipment and dozens of dedicated volunteers. Attend an event such as cycling, and you'll find almost every type of hand cycle made, from upright to prone, trike and tandem. Check out water skiing and you'll see both regular and sit-skis, slalom and with outriggers, triple bars and tubes. At kayaking you'll notice a wide variety of boats, including tandem and kayaks with outriggers. As for snow skiing, the slopes are filled with sit skis, mono and bi skis, stabilizers and outriggers.

With all these activities, there's little reason to sit idle. But what happens if you, or your child, has a "disability"? Does this mean you can't participate in all that the Scenic City has to offer? Absolutely not! Right alongside organizations such as Outdoor Chattanooga, which provides introductory classes and trips to the able-bodied public for many of the activities found in our city, organizations such as the City of Chattanooga's Youth and Family Development Therapeutic Recreation Services, SPARC (Sports, Arts, and Recreation of Chattanooga, a Division of Disabled Sports USA), and Patricia Neal Innovative Recreation Cooperative (IRC), provide safe access to much of Chattanooga's (and Knoxville's) limitless possibilities.



Activities such as cycling, rock climbing, kayaking, stand-up paddle boarding, water skiing, tubing, snow skiing, hiking, camping and basketball are made

The City of Chattanooga's Youth and Family Development Therapeutic Recreation Services serves the community and surrounding areas with adaptive activities such as kayaking, stand up paddle board, cycling, water skiing, snow skiing, hiking, camping, golf, wheelchair basketball and rock climbing. It also provides social events, dances, summer camps, and other special events for individuals with disabilities, and is a supporter of Special Olympics with both basketball and bocce teams. Last year, it served over 600 participants just in the kayaking, rock climbing, and cycling programs alone.

SPARC was formed in 1992 and is a division of DSUSA. Its vision is that "every person, regardless of ability, has an equal opportunity to participate in

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# COME ON Chattanooga and Knoxville LET'S GO PLAY!

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sports and recreation in their community." SPARC is a 501 (c)(3) all-volunteer run organization which, with monetary support, donations, and extensive hours from volunteers, provides the personnel, facilities, and equipment necessary for adaptive cycling, water skiing and tubing, snow skiing, SCUBA and wheelchair basketball. Each year, SPARC serves close to 150 participants and relies on over 200 volunteers and instructors to provide the necessary support to ensure fun and safe events for all.

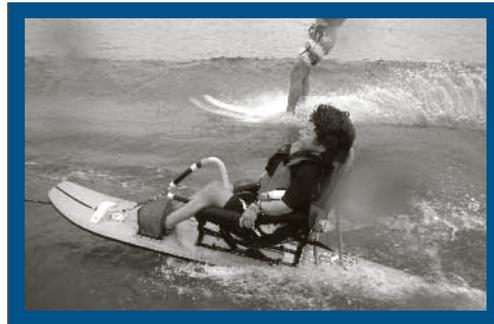
The Patricia Neal Innovative Recreation Cooperative (IRC) was created in 1994 to meet the needs of individuals who have experienced a life changing illness or injury in East Tennessee.



The program was designed to be part of a continuum of care in the rehabilitation process. The scope of the program is to host clinics under an umbrella of "education and awareness": education to teach leisure skills to enhance quality of life in a safe environment, and awareness to heighten the understanding of disabilities to the community.

In its existence, the IRC has seen over 10,000 participants and volunteers. The disability groups primarily serviced by the IRC include brain and spinal injury, stroke, and orthopedic injuries including amputees as well as neurological impairments. The IRC hosts clinics in water skiing, snow skiing, paddling, cycling, climbing, marksmanship and golf on a regular basis. Specialty clinics are hosted depending on interest and have included road racing, tennis, sled hockey, hunting, fishing, self-defense and camping.

All three organizations also welcome veterans, with the City of Chattanooga's Youth and Family Development Therapeutic Recreation Services having a chapter of



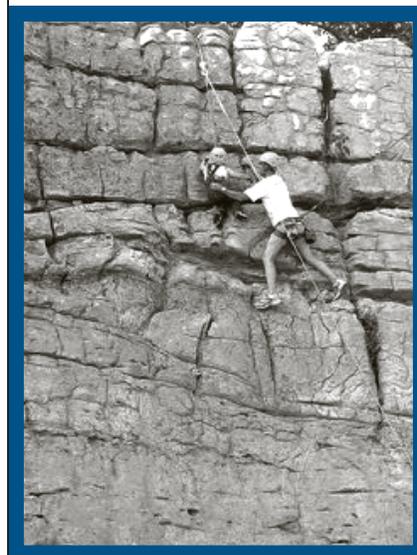
Team River Runner, providing kayaking to wounded warriors and their families. SPARC proudly sponsored the

Paralyzed Veterans' Handcycle Racing Team in May of 2014, and will do so at the U.S.A. Pro Cycling Nationals here in Chattanooga in 2015.

In order to provide these opportunities safely and successfully, SPARC, City of Chattanooga's Youth and Family Development Therapeutic Recreation Services, and Patricia Neal IRC, must rely on dedicated volunteers as well as monetary and equipment donations from generous citizens and businesses who believe that everyone, no matter their abilities, should be able to live life to the fullest.

For more information about the City of Chattanooga's Youth and Family Development Therapeutic Recreation Services, visit <http://www.chattanooga.gov/youthandfamily/recreation-fitness-sports-therapeutic-facilities/therapeutic-recreation> or contact Elaine

Adams at [adams\\_e@mail.chattanooga.gov](mailto:adams_e@mail.chattanooga.gov). Information regarding SPARC can be found by going to [www.DSUSA.org](http://www.DSUSA.org), SPARC's Facebook page or by contacting Jerry Hightower (SPARC's Vice President) at [jhightower@ctiengr.com](mailto:jhightower@ctiengr.com). Information on Patricia Neal IRC can be found by visiting [www.patneal.org/irc](http://www.patneal.org/irc);



donations can be made by calling the Ft. Sanders Foundation at 865.531.5210.

Self-Advocates Telling Their Stories,  
**BECOMING & EMPOWERED**

by Martine Hobson, Executive Director, Down Syndrome Association of Memphis and the Mid-South

In 2013, the Down Syndrome Association of Memphis & the Mid-South (DSAM) applied for a grant to begin a new self-advocate program for individuals with Down syndrome ages 15 and up. The program is designed to promote public speaking skills and develop self-confidence.

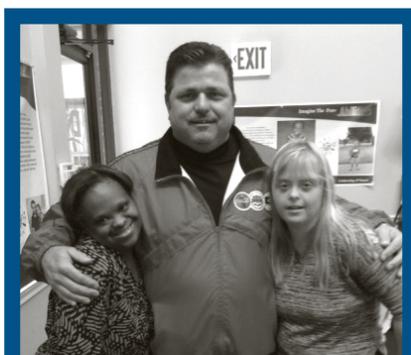
DSAM was one of eight Down Syndrome Associations from across the country awarded a grant from the Global Down Syndrome Foundation (GDSF) and the National Down Syndrome Congress (NDSC).

The National Down Syndrome Congress was founded in 1973, and is the oldest national organization for people with Down syndrome, their families, and the professionals who work with them. NDSC provides free technical support and information about issues related to Down syndrome throughout the lifespan, as well as on matters of public policy relating to disability rights.

The Global Down Syndrome Foundation's mission is to significantly improve the lives of people with Down syndrome through research, medical care, education and advocacy. "To deliver on this we need to help local Down syndrome organizations – nationally and eventually globally – to build capacity," said Michelle Sie Whitten, the Foundation's executive director. "Providing funding along with the NDSC to the Down Syndrome Association of Memphis & the Mid-South's Self-Advocate Program is a great example of how our grants are really making a difference, and that's something we can all be proud of."

**Telling their stories**

The starting point is for the self-advocates to make



*Jamila Morrow and Laurie Hobson present Mark Dote of Coca Cola an award for contributing to DSAM.*

**Photos by Martine Hobson**

PowerPoints about their lives. Mixing photographs and text, the self-advocates learn to tell their "story" through an informative presentation. Practicing giving speeches would be the next step, and ultimately, when ready, each self-advocate would have the opportunity to accompany me when giving a community talk about our organization, which would include his or her personal PowerPoint.

Besides practicing public speaking, self-advocates have been helping in the office, planning their own social events, sharing on social media such as Facebook and helping with fund raising activities. Their contributions have been invaluable!

"The Association's self-advocate program is making a real difference in the lives of men and women with Down syndrome in and around Memphis, by empowering them to take control of their own lives, and to become leaders within the community," said David Tolleson, Executive Director, National Down Syndrome Congress. "We applaud the work of the Association's board and staff and are hopeful that this initiative is replicated in other communities around the country and the world."

**Other leadership opportunities**

Each summer, the National Down Syndrome Congress holds its convention. The Congress traditionally has three self-advocates on its board. When these board members complete their terms, they automatically become part of a group called the Self-Advocate

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## Self-Advocates Telling Their Stories, **BECOMING EMPOWERED**

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Council. Numerous additional self-advocates wanted to be a part of this Council, so the Congress established a Self-Advocate Council Delegation. The Delegation provides an opportunity for self-advocates who aren't on the board to meet and network with past board members, and share the activities and events happening in their regions of the country.

This year DSAM will be sending two self-advocates to represent us on the Self-Advocate Council Delegation. They are so excited about this opportunity!

So far, self-advocates have been meeting every other week. A teacher has been hired to support the self-



*Our self-advocates working on their PowerPoints, helping around the office and fundraising.*

advocates, and their personal PowerPoint presentations are getting underway. While it's had a slow start, the enthusiasm for these leadership activities continues to grow.

And what's next? Maybe self-advocates presenting in your area!

For more information about our self-advocate

program, call the Down Syndrome Association of Memphis & the Mid-South at 901.547.7588, or visit [www.dsamemphis.org](http://www.dsamemphis.org). For more about the Global Down Syndrome Foundation, visit [www.globaldownsyndrome.org](http://www.globaldownsyndrome.org). For information about the National Down Syndrome Conference, visit [www.ndsc.org](http://www.ndsc.org).

## 2014 BREAKING GROUND

## ARTS ISSUE SUBMISSION INVITATION!

Do you write short stories, creative essays or poetry?  
Do you paint, sculpt, draw or take photographs?

**If so, we'd love to see your work for possible publication in the 2014 Breaking Ground Annual Arts Issue.**

**We will consider fiction, creative essays and poetry up to 800 words, photos and all other forms of artwork.**

Content is devoted to work by or about persons with disabilities. All accepted contributors will get a prominent by-line in the magazine, a biographical note and copies of the printed publication. Submissions for consideration must be accompanied by the artist or author's full name, contact information, and a one-to-two sentence bio. Please limit submissions to three (3) per person. Submissions should be sent electronically to [ned.solomon@tn.gov](mailto:ned.solomon@tn.gov), by September 15, 2014. If you have any questions, please contact Ned Andrew Solomon at 615.532.6556, or [ned.solomon@tn.gov](mailto:ned.solomon@tn.gov).

# TN Partners in Policymaking™ Leadership Institute Graduates its 21<sup>st</sup> Class

by Ned Andrew Solomon

In 1993, the Tennessee Council on Developmental Disabilities established the Tennessee Partners in Policymaking Leadership Institute, based on a curriculum created in 1987 by the Minnesota Governor's Council on Developmental Disabilities. Since that time, 475 adults with disabilities and family members of people with disabilities have completed the intensive, seven-weekend-session program, and have gone on to advocate for themselves, their family members and the disability community at large.

Many have made significant headway in overcoming obstacles in education, employment, recreation, healthcare, housing and other important issues



*Lynette Porter, Roger Kostiw and Ned Andrew Solomon*

that affect everyone's life. Some have started their own community programs, promoting the inclusion of people with disabilities. A few have run for public office. Hundreds have participated on task forces or committees, or served as members or chairs of community boards. The majority of the graduates have, at the very least, spread awareness about the rights of persons with

disabilities, and about the need for our society to be more welcoming to, and accessible for, persons with disabilities.

The 2013-14 class is no exception. Please welcome the following graduates to the ever expanding Partners network!

Christina Andrews, Memphis  
 Roxanne Carreon, Madison  
 Maureen Cook, Englewood  
 Vilma Cueva, Spring Hill  
 Penny Daniel, Fayetteville  
 Rebecca Dyal, McKenzie  
 Tabitha Gatlin, Lawrenceburg  
 Carol Greiner, Fairview  
 Cyndi Lou Griffin, Memphis  
 Lynn Jackson, Memphis  
 Christina Jones, Ashland City  
 Stephanie Jones, Memphis  
 Roger Kostiw, Nashville  
 Dawn Leonard, Limestone  
 Alicia McCann, Hohenwald  
 Ashley Miller, Bartlett

Yvonne Neubert, Knoxville  
 Jason Oliver, Greeneville  
 Joni Pinker, Knoxville  
 L. A. Richmond, Memphis  
 Jennifer Stambaugh, Knoxville

Elizabeth Stivers, Spring Hill  
 Pamela VanGilder, Germantown  
 Larry Walls, Hermitage  
 Hope Welch, White House





# ...and now it's time to introduce the new 2014-15 Partners in Policymaking Class!

by Ned Andrew Solomon

Thanks to the continued commitment of the Tennessee Council on Developmental Disabilities and the enthusiastic response from across the state from

applicants, the Partners in Policymaking Leadership Institute will soon begin its 22nd year in Tennessee.

Although invited speakers and some topics have changed over the years, the basic structure of this free leadership and advocacy training initiative has remained the same: participants attend seven once-a-month weekend sessions, September through April (but not December) that cover a wide range of fundamental disability topics. They include:

- The History of the Disability Experience
- Disability Sensitivity, Awareness and People First Language
- The Self-Advocacy, Independent Living and Parent Movements
- Best Practices in Inclusive Education

- Self-Determination and Person-Centered Practices
  - Building More Inclusive and Welcoming Communities
  - An Overview of State Services and Resources
  - Supported and Independent Living
  - Supported and Competitive Employment
  - Assistive Technology
  - The State and Federal Legislative Processes
  - Conducting and Participating in Effective Meetings
- ...and much more.

The goal of this training is to give adults with disabilities and family members of persons with disabilities the confidence and skills to speak up for themselves, their loved ones and others in their communities, so they can help move the state forward in its policies and practices that impact persons with disabilities and their families. If knowledge is truly power, then it is the Council's hope that our Partners program attendees will learn lots, and feel empowered to work toward change and a more level playing field for those who experience disability.

Chad Beatles, Franklin  
 John Blake, Nashville  
 Rexcey Bowers, Memphis  
 Dawn Marie Craik, Madison  
 H. K. Derryberry, Nashville  
 Melissa Dowdy, Pleasant View  
 Christina Earheart, Springfield  
 Lindsay Michelle Edwards, Fayetteville  
 Evan Espey, Antioch  
 Chip Fair, Murfreesboro  
 Susan Grant, Dickson  
 Douglas Hall, Memphis  
 Tiffany Horton, Antioch  
 Amy Lee Hostler, Franklin  
 Gladys Jones, Memphis

Robyn Lampley, Dickson  
 Promise Mata, Dickson  
 Jonathan McLaughlin, Memphis  
 April Meredith, Christiana  
 Carolyn Meyer, Brentwood  
 Tara Mohundro, Bartlett  
 Wanda Myles, Murfreesboro  
 Chelsie Nitschke, Hermitage  
 Robert Plummer, Johnson City  
 Larry Reid, Bartlett  
 Rosa Robinson, Jackson  
 Carol Shehan, Mt. Juliet  
 Tara Tate, Memphis  
 Heather West, Clarksville



## An Overview of the 2014 Disability Policy Seminar, and a Brief Chat with Self-Advocate Will McMillan

by Ashley Annestedt, LCSW, UT Boling Center for Developmental Disabilities

Professionals in the disability field, self-advocates and family members from around the country joined together in Washington, DC April 7-9 for the annual Disability Policy Seminar. This annual event was sponsored by the American Association on Intellectual and

Developmental Disabilities (AAIDD), The Arc US, the Association of University Centers on Disability (AUCD), the National Association of Councils on Developmental Disabilities (NACDD), Self Advocates Becoming Empowered USA (SABE) and United Cerebral Palsy (UCP).

Seminar participants heard from current and former legislators who have been champions for disability policy, such as Pete Domenici and Tom Harkin, as well as staffers and policy professionals from across the nation. As the seminar concluded, participants met with their state legislators on Capitol Hill to advocate for disability policies and rights. On April 9, Tennessee's Team, Wanda Willis, Frank Meeuwis, Elise McMillan, Ann Curl, Will McMillan, Carrie Guiden, Angela Webster, John Shouse, Cathy Mason and myself visited the offices of various Tennessee representatives to discuss key issues and to suggest ways that the representatives might be able to support the disability community and its concerns.

This year's key policy issues included making college tuition plans more practical for families of students with disabilities; the need for more support for those on the autism spectrum and their families; the continuing concerns about restraint and seclusion practices and policies; the low rate of employment for persons with disabilities; and the long overdue reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

During a short break in the Policy Seminar's busy agenda, I decided to take a few minutes to see if I could get a self-advocate's perspective on the trip. So I asked one of Tennessee's team members, Will McMillan – a graduate of the Tennessee Youth Leadership Forum, the Next Steps at Vanderbilt program and Project Opportunity – a few questions.



**AA:** Will, was this your first time at the policy seminar?

**WM:** Yep, this was my first time here and I've liked listening to all of the different stuff about policies.

**AA:** Yes, it was definitely two days filled with a lot of information. What policies are most important to you?

**WM:** All of the policies are important, but since I'm 25 and have a job - well I really have two jobs - I think the Workforce Investment Act is really important. I think people with disabilities should have jobs. That is really, really important!

**AA:** I agree! Hopefully through the Workforce Investment Act and others more people will gain employment in the near future. Do you think the representatives especially value hearing from self-advocates like yourself?

**WM:** I think everyone is important, but I think it's good for them to meet people with disabilities so they can think of that when they're voting on things.

**AA:** Not everyone will get the opportunity to come to DC to advocate. What would you say to people who feel like their votes or opinions don't matter?

**WM:** I would tell them they do matter! You have to tell the representatives what you want! Call them, send them an email, write a letter....do something because everyone matters.

**AA:** Any last advice for those interested in advocating on behalf of themselves or a family member?

**WM:** Yes, number one, do your homework and learn about the policies. And then TAKE ACTION!

**AA:** Thanks Will! Will I see you next year at the seminar?

**WM:** I hope so!

# YOU Need to Know About These Two Council Grants!

by Alicia Cone, PhD

The Council has two grant opportunities that can benefit persons with disabilities and families who experience disability. Applications for these two grants are accepted all year long, and funding awards are based on the content of the request, and the current availability of funds.

## The Education Travel Fund

The purpose of this fund is to assist Tennesseans with disabilities and their families to attend meetings, conferences and workshops held around the country and in Tennessee. It also assists Tennessee conferences by providing stipends for people with disabilities and family members to attend, and funding for conference presenters.

### Who can apply?

An individual with a disability; a parent, family member, or guardian of an individual with a disability; a representative of an organization seeking stipends for individuals with a disability to attend a conference; a representative of an advocacy organization seeking conference support for conference presenters presenting on a disability topic. Employees or compensated board members of a disability organization are not eligible for this fund. The applicant cannot work in the same field as the focus area of the conference being attended.

### How much can I apply for?

In order to extend Education Grants to as many people as possible, the following limits apply to requests: \$500 per person per year; \$1000 per family per year; and \$1000 - \$1500 to an organization for conference support. All awards depend on the availability of funds.

### How can the grant money be used?

The funds for this grant can be used for conference registration; attendant care; hotel/lodging; transportation; child care; respite care or meals.

### When do I get my money?

The Education Grant reimburses you for actual expenses. When you are approved for the grant, an award letter will be sent to you. Included in that letter will be the details on how you will be reimbursed for your approved expenses. You need to save all your receipts (e.g., food, hotel, gas, transportation). You will complete and submit the reimbursement forms provided to you after you return from the activity.

For further information, visit [www.tn.gov/cdd](http://www.tn.gov/cdd) to read the full program description with requirements and to

download an application, or contact me at [alicia.cone@tn.gov](mailto:alicia.cone@tn.gov), or 615.532.6615.

## The Community Development Grant

In 2013, the Tennessee Council on Developmental Disabilities received an Education Travel Fund request to travel to another state and look into a promising community-based program that was having good outcomes in the areas of employment, relationship building and community connecting. Unfortunately, at that time, we did not have a mechanism in place to support such a request.

### Now we do.

The new Community Development Grant has two components. The first pays for travel to the location of the program being visited and researched. The second provides seed money to implement a Plan of Action, to take the first step or two in replicating the program back here in a local Tennessee community.

### Who can apply?

An individual with a disability, or a parent or family member of an individual with a disability. Employees or compensated Board Members of a disability organization are not eligible for this fund. The applicant must not work for a company that will benefit from the project.

### How much can I apply for?

For each of the travel and Plan of Action components, \$500 per applicant per year. All awards depend on the availability of funds.

### How can grant money be used?

For the travel component, hotel; transportation; or meals. For the Plan of Action, examples include focus groups, community organizing, and information dissemination.

### When do I receive the money?

The Community Development Grant reimburses you for actual expenses. When you are approved for the grant, an award letter will be sent to you. Included in that letter will be the details on how you will be reimbursed for your approved expenses. You need to save all your receipts (e.g., food, hotel, gas, transportation). You will complete and submit the reimbursement forms provided to you after you return from the activity.

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# TN SPOTLIGHT



## William Lovell Named to National Leadership Circle



**William Lovell** from Waynesboro, Tennessee was honored for his accomplishments by being inducted into the National Leadership Circle for disability self-advocates on July 9, 2014. William was appointed to the TN Council on Developmental Disabilities by Governor Haslam in 2013, and is a graduate of the

Council's Partners in Policymaking Leadership Institute.

In 2008, William became a certified trainer for the Person-Centered People Planning Together project, the self-advocacy component of the Council's Person Centered Systems initiative. In that capacity, he travels to provider agencies and presents information to help individuals more actively participate in the development of their service plans.

The National Leadership Circle is a project of the National Association of Councils on Developmental Disabilities. This year 12 individuals from across the country were inducted into the Leadership Circle.

## Wanda Willis Recognized by National Association of Councils



**Wanda Willis**, Executive Director of the TN Council on Developmental Disabilities, received an award for exemplary service at the annual conference of the National Association of Councils on Developmental Disabilities. The National Association represents 56 councils from the United States

and six US territories. Wanda served as President of the National Association from 2010-12, and Past President from 2012-14. During this period the Board of Directors conducted a national search for a new CEO for the organization and Wanda served as interim administrator. The award recognizes her service over a five-year period.

## Tennessee Disability Pathfinder Welcomes New Staff



**Karen Mevis** has joined Tennessee Disability Pathfinder as its new Information & Referral Coordinator. Karen brings both professional and personal experience to the position as a former supports broker for The Arc Tennessee, a parent of a son with a physical disability, and a Partners in Policymaking Leadership

Institute graduate. Her primary responsibilities include performing efficient, appropriate needs assessments and resource linkage for Pathfinder clients with disabilities, their support networks, and public/private agencies looking for disability and related social services in Tennessee. *Photo by Alexander Santana.*



**Kimmie Jones**, a Brentwood native, is Pathfinder's new project assistant, focusing on the monthly newsletter and growing Pathfinder's social media presence. Along with a degree from Middle Tennessee State University in advertising/public relations, she brings to the table a love of advocacy and communication

that she has built through her blog of four years entitled, *That Girl in The Wheelchair*, and various other projects. *Photo by Carol Jones.*

## Tommy Lee and Lesa Kidd Honored



Council member, **Tommy Lee Kidd**, and his wife, **Lesla Kidd**, were recently awarded the Community Leader of the Year award by TN Community Organizations, an association that represents disability

service providers in Tennessee. The Kidds and their daughter Abigail live in Lawrenceburg. The award is given by TNCO for "outstanding dedication and contribution to the improvement and expansion of community services for persons with disabilities".

# AUTISM TENNESSEE:

## Fulfilling Our Mission of Supporting Individuals and Families

by Lynnette Henderson, PhD and Amanda Peltz, MEd

One in every 68 children born today will be diagnosed with an autism spectrum disorder. Autism is a neurological condition that can be frightening and mystifying to those whom it affects. It dramatically impacts how a person perceives the world and interacts and communicates with other people. When a family or individual first receives a diagnosis of autism, it can be overwhelming. Adults and parents of those with autism desperately need information about medical advances, therapeutic options, educational services, community programs and more so their loved one can grow to lead a full and meaningful life.

Our mission at Autism Tennessee (formerly the Autism Society of Middle Tennessee) is to enrich the lives and experiences of individuals on the autism spectrum, their families, and their surrounding community through support, advocacy and education. One of our core areas of service is the information and support provided by our three Parent Representatives who have a combined 40 years of experience serving the autism community. When people call looking for answers and hope, these women offer the compassionate shoulder, peer counseling and resource referral that families need as they are dealing with conflicting emotions and finding their way on their journey with autism.

Autism Tennessee's Parent Representatives respond to an average of 3,000 requests for resources and support a year. They are frequently on the phone for hours supporting a parent whose child was just diagnosed. They help people find the right psychologists, therapists, daycares, summer camps, support groups, etc. They can connect families going through similar situations with one another and make sure people affected by autism know they are not alone, no matter what their circumstance.

We know from consumer feedback that the information and support provided by our Parent Representatives is incredibly meaningful to those who call our office, but we wanted to measure and quantify how we were enriching people's lives. Over the past three years, we collected data on a subset of the resource and support calls we received as a part of two separate grants from the Baptist Healing Trust and the Vanderbilt Community Engaged Research Core.

Research has shown that stress and social isolation can have a significant impact on a person's mental and physical health. Social isolation can contribute to many emotional, behavioral and physical disorders including stress, anxiety, panic attacks, eating disorders, substance abuse, violent behavior and

overall disease. Stress alone can cause headaches, insomnia and heart disease, and can lead to self-medicating with drugs or alcohol. At Autism Tennessee we have seen how believing that "no one understands" can result in feelings of despair and hopelessness.

We looked at how our callers were coping with stress by looking at their access to needed services and how prepared they were to meet their loved one's needs. Did they feel overwhelmed and helpless, or ready to take action? We also evaluated their levels of stress, isolation and social connectedness. Lastly, we collected data on the callers' perception of Autism Tennessee as a source of ongoing support.

We believed that by connecting people to needed services and a community of support, we could reduce social isolation and stress of our callers and therefore play a role in improving their overall health. Were we succeeding in our goal of having this positive impact on people's lives?

### Here's what we found:

At two months after their initial call to Autism Tennessee, callers who used Autism Tennessee as an ongoing source of support were coping better, feeling more ready to meet their child's needs and enjoying better mental health than those who did not continue to use the support provided by Autism Tennessee. Autism Tennessee's assistance to these families in providing supports and guidance to resources was significantly correlated to them feeling more socially connected, better equipped to handle stress and more effective in meeting the needs of their loved one on the spectrum. We also found that Autism Tennessee's services were equally beneficial to those with young children (12 and under) and those with older individuals (13 – 43 years). Our assistance was also equally helpful regardless of the severity of the diagnosis.

We are encouraged that this data supports the anecdotal information we've been gathering for years. The support Autism Tennessee is providing is making a positive difference in the quality of life across the lifespan for individuals with autism and their families, improving their ability to actually meet the needs of individuals with autism and feel less stressed while doing so.

How can Autism Tennessee help someone you know with autism today? Contact our Parent Representatives at 615.385.2077, ext. 2, or at [support@autismtn.org](mailto:support@autismtn.org). More information is available by visiting [www.autismtn.org](http://www.autismtn.org).

## In Memory of Sara Ezell, Council Chair, 1999-2003

Sara Ezell, former Council on Developmental Disabilities Chair, passed away on July 9 at the age of 42. A Vanderbilt University alumna and staff member, Sara was dedicated to children's ministries and promoting policies and practices that benefitted Tennesseans with disabilities.

Born with a rare genetic disorder that caused chronic and painful health issues, Sara was never deterred from leading a full and active life and contributing to her community in countless ways.

Sara graduated from Hillsboro High School, one of the top academic students in her class. In 1994 she earned a Vanderbilt bachelor of science degree in style: graduating magna cum laude while double majoring in cognitive studies and mathematics. She continued at Vanderbilt Peabody College, and in 1997, earned a master of education in special education.

Sara's first job was at Vanderbilt's Equal Opportunity, Affirmative Action and Disability Services (EAD) office, coordinating disability services for students, staff, faculty and campus visitors.

In 2005, Sara became project coordinator for Project Opportunity at the Monroe Carell Jr. Children's Hospital at Vanderbilt, a Council funded internship program providing career training and job placement for young adults with developmental disabilities. To date, Project

Opportunity has steered 57 people with developmental disabilities into stable, competitive wage employment.

Sara may have spent most of her working hours providing services and resources for young adults with disabilities, but her true passion was simply hanging out with kids. Whether it was educating and playing with children with disabilities at the Susan Gray School, teaching Sunday school to children at her church, or just spending time with her adored and adoring nieces and nephews, Sara would come alive in their youthful, energetic, unpredictable presence.

In her leadership role for the Council, Sara was famous for her Council meeting icebreakers –name your favorite breakfast cereal, cartoon character, or superhero,

and explain. She was a graduate of the Council's Partners in Policymaking Leadership Institute, and took advantage of every opportunity to advocate for and spread awareness about the rights of persons with disabilities.

Intelligent, compassionate and truly, one of the funniest persons we've ever had the pleasure of knowing, Sara will be greatly missed. She leaves behind a grateful community and state, friends and family, who all carry lessons learned from Sara and lasting memories of an extraordinary life.



Photo by Steve Green

## Tennessee Council on Developmental Disabilities Welcomes Four New Council Members



**DAWN FRY**

Dawn Fry lives in Cookeville and has been an attorney concentrating on special education law since 1999, and as an adjunct professor of business law at Tennessee Technological University since 2009. She is a graduate of Tennessee Technological University and Nashville School of Law. Dawn is involved with several public service organizations and is a member of the Putnam County School Board. She has a son with autism and an uncle with Down syndrome.



**TECIA PRYOR**

Tecia Pryor lives in Smithville where she has been an attorney practicing law since 1997. She is a graduate of Belmont University and the UT Knoxville College of Law. Tecia has a child with autism and is active in Autism Tennessee (formerly the Autism Society of Middle Tennessee). She also served as a founding board member of Habitat for Humanity of Dekalb County, and currently serves as a member of their development committee.



**DEBORAH MCBRIDE**

Deborah McBride lives in Wildersville and works at STEP, Inc. of Tennessee as District Parent Trainer and Community Information Distributor. She is also a special education preschool teacher. Deborah is a graduate of Bethel University and earned her Master of Special Education at Grand Canyon University. She has developed special education curriculum for preschool students with disabilities, as well as arts, music and drama curricula for middle school students. She is also the proud parent of four children, two with intellectual disabilities and special health needs.



**KELLY NALE**

Kelly Nale lives in Dyersburg. She is a registered nurse and the staff development coordinator at Ripley Healthcare & Rehabilitation Center. She has taught courses as a medical assisting instructor at Delta Technical College, and has experience working with people with intellectual and developmental disabilities. Kelly is also the sibling of a brother with developmental disabilities.

## Tennessee Council on Developmental Disabilities

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Nashville, TN 37243

Return service requested

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Elise McMillan, Vanderbilt Kennedy Center for  
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Lisa Primm, Disability Law & Advocacy Center  
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