

# BREAKING

# GROUND

NUMBER 71 | SEPTEMBER 2013



Switched at Birth: A Transition Success Story

## IN THIS ISSUE

Governor Haslam  
Signs Tennessee STEP UP  
Scholarship Legislation



TENNESSEE COUNCIL  
on developmental disabilities

## CONTENTS



- 1 Switched at Birth: A Transition Success Story**
- 3 PK Goes to College**
- 5 Tennessee Disability Pathfinder's Autism Portal**
- 6 New Council Members**
- 7 Former Council Chair's Creative Work Becomes Permanent Part of MTSU Collection**
- 8 Governor Haslam Signs Tennessee STEP UP Scholarship Legislation**
- 9 Look at Me: Why Looking Past Disability is Toxic for Relationships**
- 10 Known for My Strengths: Rethinking Our Introductions**
- 12 Money Follows the Person Statewide Peer-to-Peer Training Project**
- 13 Hormones, and Hygiene, and Disabilities! Oh My!**
- 14 Student-Directed IEPs**
- 15 108th Tennessee General Assembly Recap**
- 16 New Federal Grant to Investigate Better Ways to Serve and Support Families**
- 17 TN Spotlight**

This publication was funded through a grant from The Administration on Intellectual and Developmental Disabilities, U.S. Department of Health and Human Services. CFDA No. 93.630.



Tennessee Council on Developmental Disabilities, Authorization No. 344067, May 2013, 32,400 copies. This public document was promulgated at a cost of \$.45 per copy.

# Switched at Birth: A Transition Success Story

by Karen Harrison

Many parents have pondered this question, "Was my child switched at birth"? I know I have. Generally we contemplate this when our children exhibit characteristics or behaviors that we can't see in ourselves. My confusion came - not associated with the fact that Sarah was born with multiple disabilities - as she showed an ongoing fascination with plants, animals and digging in the dirt... eek! (Something I abstain from). From her early years she chose books like "Jack and the Beanstalk", "Oh Say Can You Seed" and "The Hungry Caterpillar". Shows on TV that could cause her to sit still were HGTV and Martha Stewart! (Honestly).

I was advised by a wise friend early on to watch for what interested Sarah and "cultivate" that because it could lead to a satisfying hobby or even employment in later years. At an outing to the Greeneville Farmers Market one Saturday, at a time of morning starting with a "6" that I would only consider doing for Sarah, we visited a booth set up by Rural Resources. Their tagline was "connecting farms, food & families...for the future". Always on the quest for activities to fill the summer months, I noticed they had "Farm Day

**“ I was advised by a wise friend early on to watch for what interested Sarah and “cultivate” that. ”**

Camp". The activities described sounded perfect for Sarah: milking cows, making butter, testing stream water, gathering eggs, planting and growing vegetables, and all things "rural", with a mission in mind of learning where their food comes from in a very hands-on way. The first summer we paid for Sarah to attend several weeks and the next year and subsequent years, Greene County Schools covered the cost as part of Sarah's Extended School Year (ESY) program. (The journey of making that happen is for another article!)

Always keeping in mind Sarah as a future member of the



workforce, we kept a journal of skills she was learning, collected data on what she did well, the supports that were needed, the things she liked and the things she refused. One day during an outing to a chicken farm, she called and said, "Chickens scare Sarah Harrison". So, raising chickens is out! Early on she had a similar reaction to bunnies, of all things! Her mantra upon waking was loudly announcing, "NO BUNNIES TODAY"! Respecting that, bunnies were off the list too.

Moving into high school, Sarah chose classes like Greenhouse, Small Animal Care and Livestock. We continued to provide opportunities to expand her knowledge base and skill set to match her interests. Along with her classmates, Sarah grew plants and sold them. She is pictured on the cover of this magazine with her teacher, Mr. Harrison (not her dad), following very detailed steps to create a Bonsai tree. (Notice her with the sharp instrument; as parents we have to allow some risk.) She was the only student to successfully complete the project!

During Sarah's freshman year she brought information home about a program through Rural Resources called The Farm & Food Training Program for Teens. The program, over time, developed into a four-year, hands-on training and empowerment program. I assisted Sarah with filling out the application and she went onto a waiting list...sound familiar?

I informed the director of the program, Debbie Strickland, that when Sarah came to the top of the list, we would need to meet and discuss the types of accommodations Sarah would need to successfully complete the program. Ms. Debbie remembered Sarah from her years at the camp.

Switched continued on page 2

## Switched at Birth: A Transition Success Story

Continued from page 1

Sarah is now in her second year of the program. Over the course of the program young people are equipped with skills to grow food, get it to market, learn chef and catering skills, and develop and implement a business plan.

The first year of the program is dedicated to laying foundations. Teens begin by getting their hands dirty in the garden and charting the extensive journey that food takes from seed to table. They are paid a stipend for each hour of involvement in the program. Sarah has matured during



her time in the program, and I am so proud of her growing food, taking cooking classes, preparing food and most recently, catering an event and earning money!

I spoke with Debbie Strickland, Program Director, when I was asked to write this article. She reflected that it has been wonderful to see how much Sarah has learned already in the program. The process of supporting my daughter is one of continual learning. She sometimes tests the boundaries and authority - like most young people - and recently kept refusing tasks at a catering event until she got the task she preferred. I guess that is one form of empowerment, but we did have discussions later about the difference between something she "can't" do and something she "won't" do.

As she participated in planning the menu for the first catering event, it was so awesome to watch her with her peers, contributing to the discussion, voting on what items were on and off the menu, and her vote being the deciding



**The process of supporting my daughter is one of continual learning.**



factor that turned the menu into 100% "salads"; from fruit to tossed to chicken. The students are responsible for all aspects of preparing for the event to be catered: making the shopping list, determining how much of each thing to purchase based on the number of people, deciding how much prep time was needed, cooking, serving and cleaning up. So much learning and so much empowerment. (Did I mention she's making some money?)

Maybe my entire retirement won't be funded by profits Sarah makes worm farming, growing herbs, grooming pigs, or whatever employment opportunities this leads to. But the value of seeing a young lady filling her days with activities she loves, alongside peers who are passionate about the same things, and seeing her pride each time she cashes a check she has worked to earn is priceless! I'm so glad I switched my own thinking to embrace and encourage Sarah to develop her unique talents.

Here's my advice in a nutshell: Nurture whatever interests a young person has, help develop opportunities for interactions with others who share the same passion, and look for ways to turn the hobby into a job. Come to think of it, that's the same process I used to find a career I love!

For more information about Rural Resources visit <http://www.ruralresources.net>.

If you have a young person that is interested in the types of things described in this article, check with your local chamber of commerce to identify community co-ops and groups working on sustainability. Also check USDA and 4-H programs. The history of Rural Resources can be found at <http://ruralresources.net/index.php/our-story/history>.

**Karen Harrison is the executive director of STEP (Support and Training for Exceptional Parents). She is also a graduate of the 1997-98 Partners in Policymaking Leadership Institute.**

*Cover and Greenhouse photos taken by Greene County School staff.*

# PK Goes to College



by Dena L. Gassner, LMSW

My son, PK, is not traditional college material. I admit that. Diagnostically speaking, he's not a "Big Bang Theory" kid - more like a "Forrest Gump". But like Forrest, he will "run, Forrest, RUN!" to achieve.

### *The drive to succeed*

Because of this, we supported his decision to attend college due to his sheer determination and never-ending work ethic. He's not the most academically-gifted student - perfectionism wasn't an issue. He has Asperger's Syndrome and multiple learning disabilities. But he never quits. As you consider college for your student, recognize how critically important these qualities are. Many students are very intelligent and academically gifted but fear failure in an incapacitating way, or have such intense desires to learn

independently that class work is "boring". Others are insecure and not confident in themselves. College placements to support these needs are out there but burdensome to address, especially if you're looking at a long-distance placement.

Our trajectory to success started with him ordering his first Happy Meal. He graduated in 2010 with a 3.1 GPA from Centennial High School. When I intentionally took a travel job during his last two years of high school, we used the hockey team (he was the manager) and church to

provide peer-to-peer support so his dependency on me would lessen and learning to rely on others would expand. Note that we weren't trying to make him

independent, but dependent on others in an appropriate fashion. This is a crucially-needed ability.

### *Accommodations*

With the support of Dr. Jane Thierfeld Brown ([autismcollege.com](http://autismcollege.com)) and Dr. Marc Ellison at Marshall University, I identified "reasonable" accommodations for PK.

Accommodations that would be considered "reasonable" included:

- Access to a note-taker
- A weekly schedule of class responsibilities for better executive functioning
- Assistance in composing papers from the writing center
- Teacher Power Points and outlines
- Study guides for tests
- Digitized books for use by a Kurzweil reading device
- Separate testing
- A good campus "translator" who would speak on his behalf when he was confused or needed something from the professor

With their help, I also identified that we would need an off-campus intensive "external executive function" kind of tutor who would help PK coordinate his work and deadlines and to help him anticipate if multiple deadlines were ahead. Furthermore, the campus-based support program for autism would have to be willing to collaborate with them.

### *Just right*

After two tragically-failed postsecondary experiences, it was finally "just right" with Marshall University. Marshall is collaborative with families. While independence is what we strive for, we can't expect it on day one. Since MU embraces the philosophy that parents



PK continued on page 4

## PK Goes to College

Continued from page 3

know their kids best, they engage parents in strategizing, problem-solving and identifying goals for each term while maintaining a respectful level of privacy for the individual, especially during transitions. This is very different from local programs we interviewed that asserted involved moms and dads are “helicopter parents” and simply cut them off at the door. In my opinion this is the reason for most programmatic failures - it is not the student. Parents typically become overly involved on the front end because the program facilitators haven’t yet figured out the best ways to meet the individual students’ needs. Meet the kid’s needs and we are on our way!

### *Relationships*

Another unexpected benefit was the relationships PK was able to make independently. One retiring professor established such a close bond with PK that he agreed to

“ While independence is what we strive for, we can’t expect it on day one. ”

meet with him twice weekly during a summer class that’s taught online. PK independently found, embraced and now lunches with one of the surviving football coaches from the MU plane crash in ‘70. Unique lunch bunch, I know (all of “the guys” are over 70) but Coach is dedicated to my son. This rapport with Coach Dawson allowed PK to have a prize tailgating experience and a VIP pass to go down on the field. PK is aware of the pain it causes Coach to go down to the field, as was depicted by Matthew Fox in the “We Are Marshall” film. So this was quite an unforgettable birthday gift!

Marshall has a Regents Bachelor of Arts Diploma that does not mandate a foreign language or math, for students who have exited high school more than four years from HS graduation. While I wish PK had been more successful initially, the delays benefitted him by making him eligible for the RBA. His area of emphasis is History and he seeks



*PK with Coach Dawson.*

employment in a museum with this degree. Some students have gone on to graduate school with this degree.

### *They “get” him*

Lastly, they “get” the individual. We have collaboratively created a team at Marshall where they appreciate that given an Excel Spread Sheet schedule each Monday, PK is totally self-sufficient at navigating campus and his essential appointments. They see a “low drama” student who is very responsible and never gives up. They appreciate his higher independent living skills and personal organization. They respect that he spends in excess of 33 hours a week in tutoring or studying to accomplish 12 hours of coursework (with grades this term of A, B, B, C!). They understand what never missing a class or appointment means. They are committed.

### *This kid never quits*

That was the hardest part for me. None of the other programs could see his strong work ethic. I ached that this was not recognized, appreciated or validated. Here, at Marshall, that happens.

Oh, and by the way, I was only in the office twice this semester. How’s THAT for “independent”? The so-called “helicopter mom” has graduated.

**Dena Gassner is a writer, speaker and Partners 07-08 graduate.**

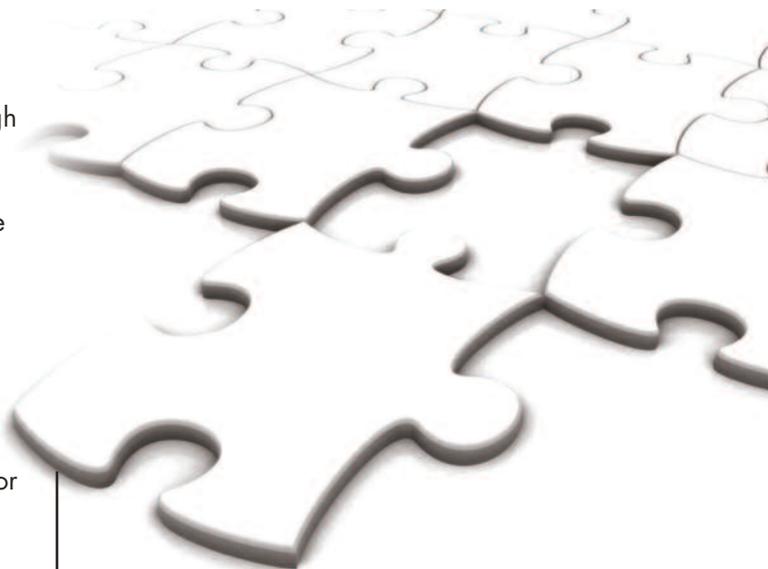
**All photos by Dena Gassner.**

# Tennessee Disability Pathfinder's Autism Portal

by Lydia Wingo Kane

A new Autism Resources Portal is being developed through the work of the Tennessee Disability Coalition and the Statewide Autism Planning Council. Last year, in their efforts to develop a statewide, coordinated system of care for children and youth with ASD (Autism Spectrum Disorders), the Planning Council conducted a needs assessment consisting of two parts: a family survey and a series of Community Conversations. A one-stop resource for autism information was chief among the needs identified in this statewide effort.

Since Tennessee Disability Pathfinder is a clearinghouse for disability information, it was selected to house the portal on its website, [www.familypathfinder.org](http://www.familypathfinder.org). Vanderbilt



**“ The portal is unique because it provides general information as well as resources in the community. ”**

Kennedy Center's TRIAD program is lending its expertise to the project by providing the content for the portal, which is being created in consultation with family-centered advocacy groups like the Autism Society of Middle Tennessee. Content will be continually updated with input from these groups, as well as TRIAD, to ensure that the information provided remains current and user-friendly. The purpose of the Autism Resources Portal is three-fold: it seeks to be a guide to autism information; to help families connect to resources and information in a more convenient and simple manner; and to provide access to agencies and services in families' communities across Tennessee. The development of this portal is important because there is so much information on autism and it can be confusing

for parents and individuals to decide what is good, relevant, accurate and research-based.

The portal is unique because it provides general information as well as resources in the community. Most websites only have one or the other. For instance, if a parent wants information on early intervention services, the portal provides a description of what those services are, who is eligible to receive the services, agencies in the area to go to for testing, and other connections to their community for early intervention resources and service providers.

The portal is also unique because it provides resources across the lifespan. Typically, autism resources focus on one select age group. Here resources for teens and adults as well as children are addressed.

The portal is set up using general questions that someone may have about autism, from an initial diagnosis to issues of adulthood and everything in between. Basic information is covered such as what is autism, how to access services and how to deal with the diagnosis. The aim is to make the information as accessible as possible by using language that is easy to understand, presented in a simple, clear format.

The portal should be ready for use later this year. When up and running, you'll be able to access it by going to [www.familypathfinder.org](http://www.familypathfinder.org) and clicking on the Autism Resources button. For more information on autism or disability-related resources, call 800.640.4636.

**Lydia Wingo Kane is the Information & Referral Coordinator for Tennessee Disability Pathfinder.**

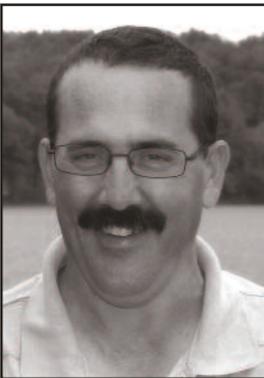
## New Council Members

Two new members were appointed by Governor Haslam and one returning member was reappointed to the Council on Developmental Disabilities in the spring of 2013. One important role of Council members is to share their valuable input about living as a person with a disability or as a family member of a person with a disability to help inform disability policies and practices in Tennessee. Our members, who are from communities across the state, guide the Council on Developmental Disabilities in sponsoring innovative projects and working to promote systems change for Tennesseans with disabilities.

### Please join us in welcoming the following:

#### William Lovell

William Lovell lives in Hohenwald, Tennessee. He has been working at Walmart since April 2002. He's an active member of the Blondy Church of God, People First of Tennessee and the Lewis County Historical Society. William also regularly assists with Meals on Wheels for the local Senior Citizens Center, waters flowers in the downtown area for the Lewis County Pilot Club and assists with October Heritage Festival Activities each year.



*William Lovell*

William has been involved with the Person-Centered Organizations program since 2008 and is a certified trainer for the People Planning Together program. He's traveled to many different agencies throughout Tennessee teaching others with disabilities how to write their own person-centered plans and how to find their voices. William won the Self-Determination Award for Tennessee in June 2008, and graduated from the Council's Partners in Policymaking program in 2011.

#### Phil Stevens

Dr. Phil Stevens and his family recently moved to Nashville from Florida, where he had served on the Florida Developmental Disabilities Council from 2007 until 2011. Phil and his wife, Lisa, have a 19-year-old daughter, a 16-year-old son, and a set of triplet 13-



*Phil Stevens and family*

year-old sons; one of the triplets, Jared, has cerebral palsy.

Currently, Phil works as the chief operating officer at the Infrastructure Corporation of America in Nashville and has had an extensive career as an engineer specializing in transportation and civil engineering.

#### Steve Sheegog

Steve Sheegog lives in Memphis with his wife LeVon and has two children, Steven II and Alisha. His son has autism and Steve also has a brother with Down syndrome and autism. Steve previously served on the Council from 2003-2011.



*Steve Sheegog and family*

Currently, Steve is senior vice president and senior audit consultant for the First Horizon National Corporation. He serves on the Advisory Board of the UT Boling Center for Developmental Disabilities and served on the Board of Directors for West Tennessee Family Solutions. He is a graduate of the 1996-97 Partners in Policymaking class.

Currently, Steve is senior vice president and senior audit consultant for the First Horizon National Corporation. He serves on the Advisory Board of the UT Boling Center for Developmental Disabilities and served on the Board of Directors for West Tennessee Family Solutions. He is a graduate of the 1996-97 Partners in Policymaking class.

# Former Council Chair's Creative Work Becomes Permanent Part of MTSU Collection

by Joyce Sievers

Two sources inspire me in the creation of those intimate vessels known as books, which I began making in 1981 and have been teaching the process in workshops for 25 years. The first source is the story/history of how all those before me were inspired to express what was in their hearts and minds in the time in which they lived. It mattered SO much to be able to say what it was like to be human in the time in which they lived for those who followed. Those "a-ha" moments individuals had, as to how to give visual form and power to their thoughts and feelings, are indeed gifts.

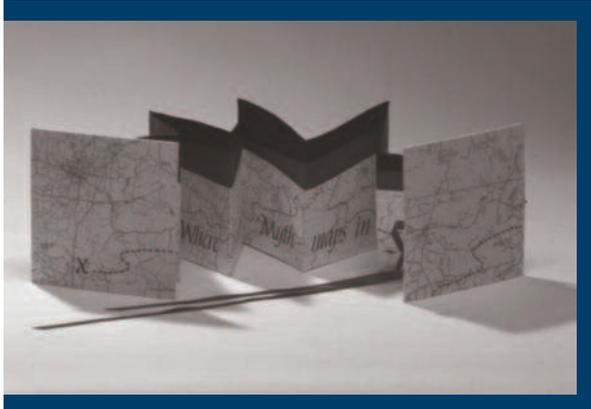
When I make books, I feel the presence of all those who came before me and their desire to both contain and reveal what was in their

hearts and minds. My second source is the materials I use, which I love, to create my books. No matter the medium, it has taken the entire cosmos to create that material. For paper, it takes the sun, the

moon, the rain, the earth, the cycle of seasons to create the plants used to make the material out of which most books are made. Here I am, participating in a Divine Dance of creativity, holding the past, the present and the future, as well as the entire cosmos creating the materials, SO intimately in my hands. To create books is a sacred gift for me and I am so grateful to be part of the process of containment and revelation!

The Special Collections Department at Middle Tennessee State University's James E. Walker Library has acquired 16 of my personal books. There, the books will be fully catalogued, placed in protective enclosures and made available to library patrons as part of MTSU's ever-growing Artists and Dimensional Book Collection. The books may be examined by students in the Art Department's Book Arts program to quicken their own imaginative engagement with paper, threads and other materials. The books will also contribute to MTSU's exhibit program and as teaching resources for lectures.

Joyce Sievers is a 1993-94 Partners grad, and former chair of the Tennessee Council on Developmental Disabilities.



by **Lynnette Henderson**

*This article was originally posted on TennesseeWorks.org*

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 Hope Scholarship to include students entering eligible postsecondary education programs for students with intellectual and

developmental disabilities in Tennessee. Advocating prominently for STEP UP were the Tennessee Alliance for Postsecondary Education and TennesseeWorks, a project funded by the Administration on Intellectual and Developmental Disabilities. Both groups have provided education and information about the importance of postsecondary education for students looking for future employment.

In addition to efforts by disability organizations like The Arc Tennessee and the Tennessee Disability Coalition, Next Steps at Vanderbilt students wrote to and met with their legislators, and testified in front of the House

## Governor Haslam Signs Tennessee STEP UP Scholarship Legislation



Education committee to share how participation in a postsecondary education program has improved their quality of life and job prospects.

Starting in the 2013-2014 academic year, STEP UP scholarship recipients will receive \$4,000 per year for a maximum of two 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. Eligible Tennessee postsecondary education programs are located at Vanderbilt University (Next Steps at Vanderbilt), University of Tennessee-Knoxville (UT Future), University of Memphis (TigerLIFE), and starting in January at Lipscomb University (IDEAL).

Governor Haslam signed the bill into law on Tuesday, June 4, 2013.

Representative Bob Ramsey and Senator Doug Overbey co-sponsored the STEP UP legislation.



**Lynnette Henderson has worked at the Vanderbilt Kennedy Center since 2005, and in the area of employment of people with disabilities since 2010.**

# Look at Me:

## Why Looking Past Disability is Toxic for Relationships

by Beth Hopkins

*This commentary was originally posted by the Huffington Post in March, 2013*

If there's one thing people love to do, it's dream of their perfect mate. We might not all admit to it, but we've all done it, repeatedly. I've passed many an hour at a slumber party (and, in more recent years, over a cup of coffee) doing just that. And it's good to dream. Dreaming gives us faith and hope for things to get better. It helps us set our expectations higher than we might have otherwise. But for people with disabilities, there is one area, when it comes to dreaming, where we need to raise the bar.

Invariably, when I'm at a Girls' Night with friends, the Perfect Mate topic comes up, followed by the list of ideal qualities: poet, rock star, Democrat, Republican, Anarchist, PhD, MD, and so on. I remember once, when it was my turn. I gazed wistfully into space and said, "And I just know that he'll be someone who can look past my disability." Everyone murmured and sighed in agreement, and I was immensely proud of myself for being so profound.

I shouldn't have been. The truth is, hoping to find a mate who will "look past" my disability was (and is) the wrong approach to finding the right person. It sounds noble, but what are the real implications?

In my experience, disability doesn't tend to disappear overnight. For myself, and many, it is permanent. If we want someone to look past that, we are asking, expecting, and hoping for him or her to avoid and ignore a big part of our reality. How can we talk about our lives, our challenges and our experiences apart from our disability? And how can our partner truly share any of that with us, if he or she looks past it?

While not defining me, per se, my disability is a part of

my identity. It has colored my perspective, shaped my career path and helped form my peer groups. Do I want someone to look past such a fundamental part of my life? Of course I don't. He would be left with an incomplete picture of who I am. And being with someone who doesn't really know who you are strains the relationship and fosters a sense of dishonesty. And it's just awkward and weird.



Beth Hopkins

I'm not immune to any of these pitfalls, by the way...I wouldn't be equipped to write this if I wasn't guilty of talking about "looking past" disability for the better part of my life. We live in a world so focused on physical ideals, it's hard not to do it. But every time I've done that, I've been settling. I've really been saying to myself, "There isn't a person who will accept and love you for who you are. He won't be able to truly find all of you attractive." Not only is that a lie, it is a lowered expectation that no one deserves to have for themselves, their partner or their relationship.

It's time for a change. Next time we're at a Girls' Night (or Guys' Night, for that matter), and discussion turns back to that Perfect Mate, let's drop the lackluster expectations. No matter if it's a disability, or some other difference, we have to talk (and think) of who we are honestly:

Looking past me isn't good enough anymore. It's time to look at me. This, everything you see, and everything you don't, is part of who I am. The perfect person for me is someone who loves and accepts all parts of me: typical and different.

Let's not settle for relationships where someone looks past, ignores, or avoids any part of who we are. Let's start to dream of someone who looks at us intently, and loves what they see.

**Beth Hopkins is on staff at The Arc Tennessee and is a graduate of the 2010-11 Partners in Policymaking class.**

# Known for My Strengths: Rethinking Our Introductions

by Courtney Taylor and Erik Carter

*Disability is a “natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society”.*

This simple statement is prominent within almost every piece of federal legislation focusing on people with intellectual and developmental disabilities. Being part of a community is at the heart of what it means to flourish as a human. Yet, the experiences and relationships that make up everyday community life remain elusive for far too many people with significant disabilities.

Although much progress has been made over the last few decades, many employers, community groups, congregational leaders and others still struggle to welcome and weave people with disabilities in the activities and relationships that are part of life in the community. They may have difficulty imagining a meaningful place for someone described as having Down syndrome or autism. They may be uncertain of what someone with a label of Fragile X syndrome or multiple disabilities has to bring to their business, civic organization, synagogue or neighborhood group.

Think about how we typically talk about intellectual and developmental disabilities within our professional circles. It is often in terms of what someone cannot or struggles to do. Such a message has inadvertent consequences. For example, when an employer considers the question, “What could a person with an intellectual disability contribute to this business?” or a youth ministry

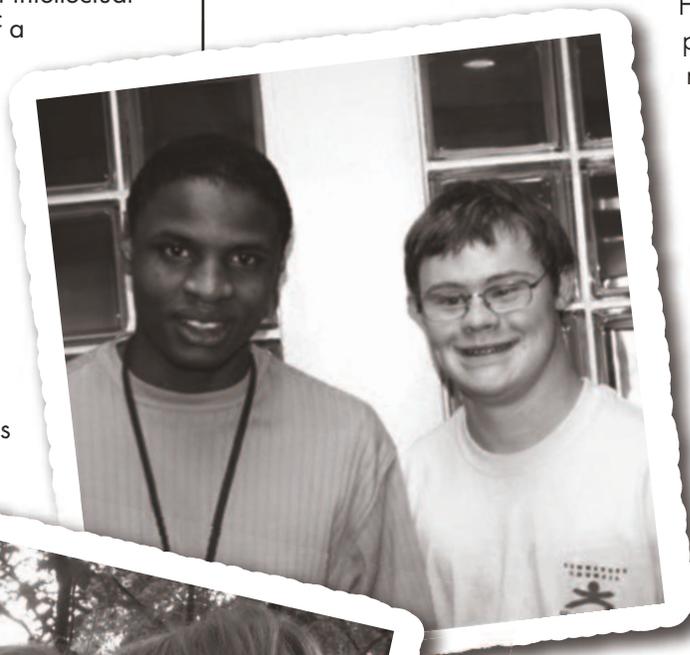
leader wonders, “How do we include a teenager with autism in our programs?” - all they might have to work from is an image of what a person with that particular label cannot do. Frankly, that makes for a challenging introduction. It is hard to envision a place in a community for someone only on the basis of a list of deficits.

How we introduce people surely matters.

As part of the Vanderbilt Kennedy Center’s Disabilities, Religion, and Spirituality Program, we are in the midst of a project focused on reshaping those introductions. With funding from the Martin McCoy-Jespersen Discovery

Grant in Positive Psychology, we have been conducting a statewide study focused on faith and flourishing in the lives of youth and young adults with intellectual disabilities and autism in Tennessee. One of the aims of the study is to identify the strengths these young people might have to share with others in their communities.

To this end, we asked more than 450 parents to complete a short scale focused on enviable qualities of these youth and young adults. The Assessment Scale for Positive Character Traits (Woodard, 2009) includes 26 different statements, each addressing the extent to which their child shows characteristics like kindness, humor, gratitude, empathy, optimism, forgiveness and courage.



Known for My Strengths continued on page 11

# Known for My Strengths: Rethinking Our Introductions

Continued from page 10

Gathering this type of “positive” data has exciting implications for fostering inclusion and community participation. What if we instead

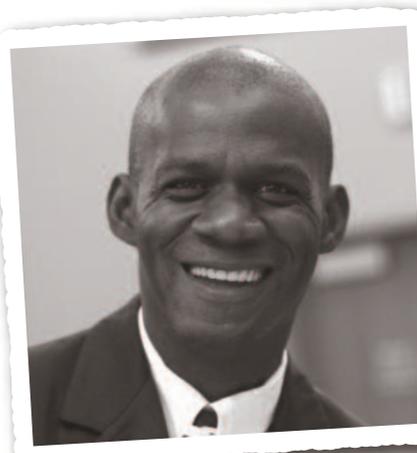


introduced young people to others by the strengths and gifts they have to bring to a community? Can we think of young people with intellectual and developmental disabilities in this way? Findings from our study to date suggest their

parents can see many of these assets.

Drawing from the hundreds of parents and caregivers who participated in our study, consider this small sampling of findings:

- **94%** of parents described their child as happy
- **86%** say their child had a great sense of humor
- **85%** of these young people were described as thoughtful and helpful to others
- **85%** said their child shows kindness to others
- **85%** of parents said their child is thankful for life’s simple pleasures
- **75%** of parents described their child as courageous
- **70%** said their child keeps on trying even when things get hard



The list of strengths goes on and on.

How many businesses would benefit from hiring someone with qualities like honesty, persistence and optimism? How many faith

communities can find a place for someone known for her gratitude, empathy and kindness? How many neighbors would be eager to develop a friendship with someone who is funny, happy and thoughtful?

Does describing people in light of their strengths make any difference?

Consider these two introductions: 1. Meet John. He has an intellectual disability, he can’t really read, and he is going to need lots of help to get around. 2. Meet



John. He has an incredible sense of humor, he loves meeting new people, and he enjoys learning new things. By the way, he has an unforgettable bear hug. Which John would you be more eager to meet?

Youth and young people with disabilities have wonderful strengths and gifts to share. But those potential contributions too often get overlooked. As we strive to equip communities to more meaningfully include people with disabilities, let’s not overlook the introduction. Leaders and members of all our communities must see people first in terms of the gifts they have to bring.

Information from this study will be made available through a practical guide. To receive an electronic copy, email [courtney.taylor@vanderbilt.edu](mailto:courtney.taylor@vanderbilt.edu).

## Reference

Woodard, C. (2009). Psychometric properties of the ASPeCT-DD: Measuring positive traits in persons with developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, 433–444.

---

**Courtney Taylor** is the associate director of communications at the Vanderbilt Kennedy Center.

**Erik Carter** is an associate professor of Special Education at Vanderbilt University.

# Money Follows the Person Statewide Peer-to-Peer Training Project

by Deborah Cunningham

In August 2012, the Memphis Center for Independent Living (MCIL) introduced its Statewide Peer-to-Peer Training Project, funded by TennCare. The project consists of a network of Peer Specialists that provide independent living skills training and peer support to nursing facility residents who are enrolled in the CHOICES program and are preparing to transition out of a nursing facility.

CHOICES is a TennCare program which provides long-term care services for individuals 65 years of age and older, or those with physical disabilities, 21 years of age and older.

Long-term care includes help doing everyday activities like bathing, dressing, getting around your home, preparing meals or doing household chores.



“ MCIL is currently seeking new Peer Specialists to join the project. ”

Individuals are referred to the Statewide Peer-to-Peer program by their CHOICES Care Coordinators. These Care Coordinators provide comprehensive coordination of care, including medical, behavioral and long-term services and supports, as well as assistance in transitioning from nursing facilities into the community.

The training curriculum for the project includes such topics as an overview of the CHOICES program, household budgeting, assertiveness, self-advocacy and stress management. MCIL's Project Manager assigns referred CHOICES members to local Peer Specialists, who help the members determine which Independent Living training modules will be most helpful in making their transitions successful. The Project Manager trains and supervises the

Peer Specialists, who conduct these training modules face-to-face in local nursing facilities.

Peer Specialists receive payment for each training module the individual successfully completes. Peer Specialists may accept multiple assignments if they demonstrate an excellent grasp of project training materials and thorough follow-up with their assignments.

Peer Specialists continue to work with CHOICES members after they transition to the community, helping them make connections with local community resources, visiting them in their homes, and providing post-transition support as they adjust to living independently.

MCIL is currently seeking new Peer Specialists to join the project. Peer Specialists must be individuals with disabilities who either have transitioned from nursing facilities themselves or have developed independent living skills to avoid institutional placement. If you are interested in being considered as a Peer Specialist in your area of the state, contact Deborah Cunningham at [deborah.cunningham@mcil.org](mailto:deborah.cunningham@mcil.org), Sandi Klink at [sandi@mcil.org](mailto:sandi@mcil.org), or by calling 901.726.6404.

**Deborah Cunningham is the executive director of the Memphis Center for Independent Living.**

# Hormones, and Hygiene, and Disabilities! Oh My!

by Courtney Taylor

When you ask parents of adolescents and teens with intellectual and 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 do, 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 Vanderbilt University Assistant Professor of Pediatrics Cassandra Newsom, PsyD, 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 that are especially useful for youth with autism or youth who are nonverbal. So that visuals and information fit gender, both 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, nocturnal emissions, and appropriate behavior in public vs. private settings.

"Puberty and sexuality are difficult topics," said Newsom. "There are cultural and societal taboos at play, and many parents just do not want to think about their kids as sexual beings. It also is not uncommon for parents to be under

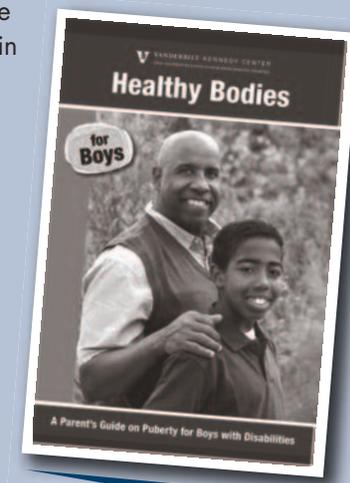
the impression that if a child is delayed developmentally, he or she will be delayed in puberty and in the development of their sexuality. This is not necessarily the case. In fact, some people with disabilities will enter puberty early. So, we wanted to develop this toolkit for parents to clear up some 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's 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. We know 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](http://kc.vanderbilt.edu/healthybodies).



# Student-Directed IEPs

by Loria Hubbard Richardson

Students with disabilities have always faced barriers. They have to work harder than their typically-developing peers and often have not been taught to speak up for themselves. Many students have not participated in their own IEP (Individualized Education Program) meetings. They tend to view the IEP process with fear and mistrust. However, with a little support and training, students can successfully lead their own IEP meetings.

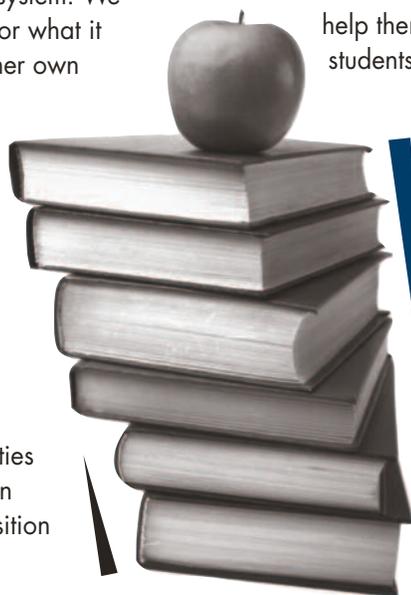
Dr. James Martin of the Zarrow Center at the University of Oklahoma created a program called Self-Directed IEPs. In his research, he found that students who direct their IEP meetings are more likely to go on to jobs and/or job training when they leave high school. The steps in the program include:

1. Begin meeting by stating the purpose
2. Introduce everyone
3. Review past goals and performance
4. Ask for others' feedback
5. State your school and transition goals
6. Ask questions if you don't understand
7. Deal with differences in opinion
8. State what support you'll need
9. Summarize your goals
10. Close meeting by thanking everyone
11. Work on IEP goals all year

The Arc Tennessee's staff found this information inspiring. We gave it a Tennessee twist and began working with students to lead their own IEP Meetings. For each of the last three years, staff has worked with a different school system. We helped prepare families and educators for what it would be like when the student led his/her own meeting.

The first thing we do is work with students, their families and teachers to learn some basics. We find this model works well. Each fall we have provided five trainings with these stakeholder groups. They are:

1. History of Disability/People First Language
2. Basic IDEA Rights and Responsibilities
3. The Process of Secondary Transition
4. Using Assistive Technology in Transition Planning
5. Overview of Student-Directed IEPs



We've had lots of comments about what's been learned in these trainings. One mom was brought to tears when she realized during the History of Disability/People First Language session that she had been saying that her son is ADHD, when actually he has ADHD.

The stakeholders go through the IDEA (Individuals with Disabilities Education Act – the federal law that governs the provision of special education services) training. It is usually new information for students and families, which is expected. It's frequently new information for teachers as well.

The Process of Secondary Transition training helps everyone understand how things should happen. The main theme is considering the student's wants, interests and needs in developing the Secondary Transition Plan. This means not just looking at what the student is not able to do, but what he/she wants to do and is interested in.

We've had the Local Education Agency (LEA) provide the session, Using Assistive Technology in Transition Planning. They talk about what technology is used in that school system. This year, the DeKalb County Special Education Director, Gina Arnold, also talked about the Family Support Program ([http://www.tn.gov/didd/family\\_support/index.shtml](http://www.tn.gov/didd/family_support/index.shtml)), and how families can access these funds to help purchase technology for the student to get and keep.

Lastly we talk about how the students will actually lead their IEP meetings. Some parents are skeptical. Teachers have been challenged to adjust to this different way of doing things, but have been willing to learn and change. Some students have been excited, while others have been hesitant.

After winter break, we begin working directly with the students in small groups, or one-on-one as the need arises, to help them learn how to facilitate their meeting. Seeing the students blossom into leaders is a beautiful thing. Some students have decided they were not ready to lead themselves, but participated more meaningfully in their meetings. With student leadership, input and buy-in, great IEPs have been created. Some of these students have also presented at the state-wide Transition Summit and at the Tennessee Disability Mega Conference.

For more information on Student-Directed IEP Meetings, contact Loria Hubbard Richardson at 615.215.2065 or Treva Maitland at 731.414.3521.

**Loria Hubbard Richardson is a Project Specialist in Education and Advocacy for The Arc Tennessee and the parent of adult children with disabilities.**

# 108th Tennessee General Assembly Recap

by **Tiffany Mason**

The 108th Tennessee General Assembly adjourned on April 19, 2013, the earliest legislative adjournment in two decades. The 2013 session featured the first Republican supermajority since Reconstruction, with the GOP holding 26 of the 33 Senate seats and 70 of the 99 House seats.

The General Assembly passed a balanced budget and adopted a wide range of significant legislation. Governor Haslam's \$32.7 billion budget included funding for the Family Support Program in the amount of \$7,383,600. The budget also included a rate increase of \$2,000,000 for health support systems providing services for people with intellectual disabilities.

There were over 1300 pieces of legislation filed this past session. Usually there are twice as many bills introduced, but Speaker Beth Harwell imposed a new 15-bill limit on House members. Let's highlight a few of those bills that are significant to persons with intellectual and developmental disabilities.

The Tennessee STEP UP Scholarship Program sponsored by Senator Doug Overbey and Rep. Bob Ramsey allows lottery dollars to be used for postsecondary education for students with intellectual disabilities. The \$4,000 scholarship will be available for two years for any Tennessee student entering postsecondary education programs for students with intellectual or developmental disabilities. The eligible student will have to graduate from high school, be accepted to an eligible university and enroll in the school within 16 months of graduation.

Governor Haslam included in his legislative package a bill removing the prohibition on including special education students in individual growth calculations. As a state, our largest achievement gap is between special education students and general education students. Thirty-three school districts have been placed on the Tennessee Department of Education's "In Need of Subgroup Improvement" list, with students with disabilities being that subgroup. By including special education students in teacher evaluations, efforts will be focused on decreasing this disparity in Tennessee's classrooms. This policy change went into effect immediately.

Senator Joey Hensley and Rep. John Deberry sponsored legislation requiring the state board of education to create an



Occupational Diploma for high school students with disabilities. The Council, along with other stakeholders, plan to work with the state board as the diploma is crafted to ensure appropriate standards and benchmarks for attendance, academic performance and job readiness skills are included.

Senator Ken Yager and Rep. Dennis Powers spearheaded legislation that created "Lynn's Law." After a mother left her adult daughter with a disability at a bar one mile from Rep. Powers' home, he decided to introduce legislation to deter others from repeating the offense. The bill strengthens adult protection statutes to include willful abandonment for persons with significant disabilities. It also specifies that the "caretaker" can include a parent, spouse, adult child or other relative who knows the adult with a disability cannot care for themselves without the assistance of others.

Working closely with stakeholders, the sponsor clarified language in the bill regarding "abuse and neglect" so it includes the caretaker's conduct resulting in or creating a substantial risk to the adult with a disability. The legislation also brought to light the substantial waiting list for home- and community-based services for persons with disabilities, and the desperation that can accompany the lack of this much-needed assistance.

There were a couple of bills that met some bumps in the road at the legislature and did not pass this year but will be considered again in January. They include:

- The "TN Choice and Opportunity Act" which would provide school vouchers to eligible students to attend private schools
- Legislation to repeal the law requiring helmets for motorcycle riders
- Legislation to increase the fine for not wearing a seatbelt
- Legislation to require health insurance policies to cover the diagnosis and treatment of autism spectrum disorders

Although the legislators have left Nashville, the work will continue in the form of departmental rulemaking hearings, study committees and individual campaign fundraising events. The Tennessee General Assembly will reconvene on January 14, 2014.

**Tiffany Mason is the Council's Public Policy Director.**

# New Federal Grant to Investigate Better Ways to Serve and Support Families

In May, the Administration on Intellectual and Developmental Disabilities (AIDD) funded a grant to identify and implement policies and practices that will serve as a national framework for states to use to support families with members with I/DD across the lifespan. AIDD chose the National Association of State Directors of Developmental Disabilities Services in partnership with UMKC Institute for Human Development, the National Association of Councils for Developmental Disabilities and Human Resource Services Institute to host a five-year Community of Practice.

A Community of Practice is a learning environment that helps promote an intensive exploration into current policy, practices, trends and barriers. Specifically for this project, five states – Connecticut, District of Columbia, Oklahoma, Tennessee and Washington - will be the focus of the Community of Practice with the learning being shared with the country at large. In addition, Missouri will collaborate as the demonstration state for the project.

Each state will form a team that is facilitated jointly by the state I/DD service system office (in Tennessee's case, the Department of Intellectual and Developmental Disabilities) and the state Council on Developmental Disabilities, with additional membership from self-advocacy and family organizations, universities, education, aging and other organizations interested in this topic.

"The Council is very excited and grateful that Tennessee has been selected for the supporting families

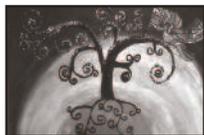
**“ The Council is very excited and grateful that Tennessee has been selected for the supporting families community of practice! ”**

community of practice!" said Wanda Willis, Executive Director, Tennessee Council on Developmental Disabilities. "As you know, we have a tremendous partner in the Tennessee Department of Intellectual & Developmental Disabilities. We look forward to our work over the next four years to learn as much as we can about the most effective ways to support families."

**For more information, visit [www.supportstofamilies.org](http://www.supportstofamilies.org).**



# TN Spotlight



Congratulations to **Laura Moore** of Memphis, whose artwork was selected to adorn program books and T-shirts for the 2013 Tennessee Disability MegaConference. Laura attended Madonna Learning Center and Bishop Byrne High School

and now attends Martha's Manor Day Activity Center. She is an active athlete in Special Olympics and has received ribbons in the sports of basketball, bocce, volleyball, tennis, golf and swimming.



The Tennessee Healthcare Campaign (THCC) has announced a new executive director - **Walter Davis**. THCC is a nonprofit consumer health care advocacy group which strives for all citizens to have affordable choices in health care. Educated at Kentucky Southern College and the University of Louisville, Walter has worked with Jobs With Justice of East

Tennessee, the National Organizer's Alliance and the Southern Empowerment Project.

YLF graduate **John T Farley** was selected to be one of eight students in the new TigerLife Postsecondary Program at the University of Memphis. John T also applied this past March to the National Down Syndrome Society for an O'Neill Tabani Scholarship. He was one of 16 youth awarded scholarship funds to assist in paying for postsecondary schooling or other training opportunities geared towards employment.



Partners 1993-94 graduate **Scott Finney** received the Roger Blue Lifetime Achievement Award from The Arc Tennessee during the Eleventh Annual Tennessee Disability MegaConference Awards Banquet held May 31 at the Nashville Airport Marriott.

**Roger Blue** was the executive director of The Arc Tennessee until his sudden death December 1, 1997. The recipient of this award shares Roger's philosophy of respect, dignity and the freedom of choice of people with intellectual and developmental disabilities, and has a history of caring for and supporting people with disabilities and their families.

Up until this year the Roger Blue Award has always been presented to a volunteer. But this year **Scott Finney**, a distinguished staff member, was selected to receive it for his dedication and duty. Scott has served on numerous boards and councils. He currently serves on STEP's board of directors and the Advisory Group of the National Council of Self Advocates of The Arc. He has been the face and voice of The Arc Tennessee for 25 years, and has been employed by The Arc longer than any other staff member.

There has recently been a "Changing of the Guards" at Tennessee Disability Pathfinder. **Carole Moore-Slater**, who began as director of Pathfinder and served in that role for 16 years, was instrumental in developing it into a robust and dependable information and referral program, as well as reaching out to and providing extensive resources for Tennessee's multicultural populations. **Megan Hart**, who has worked at Pathfinder for four years, is a Partners in Policymaking



graduate and a previous staff member with the State's Tennessee Technology Access Program, has stepped up as program director. **Tracy Beard**, former Council intern, is now assistant director. Tracy has been with Pathfinder for five years.

Executive Director **Tyler Hampton** of SRVS received the Agency of Distinction Award by The Arc Tennessee at the Tennessee Disability MegaConference on May 31. The award honors a public or private organization that provides exemplary supports for people with disabilities. SRVS is a West Tennessee provider of services for people with disabilities, offering a wide range of programs including a learning center, clinical services, community living, employment, elder care and family support to more than 800 individuals and families.

## Tennessee Council on Developmental Disabilities

Davy Crockett Tower, 1st Floor  
500 James Robertson Parkway  
Nashville, TN 37243

Return service requested

### MEMBERSHIP AND STAFF

#### COUNCIL CHAIRPERSONS

Stephanie Brewer Cook, Chair  
Roger D. Gibbens, Vice Chair

#### COUNCIL MEMBERS

Sheri Anderson, Murfreesboro  
Norris L. Branick, Jackson  
Rob Buttrum, Cookeville  
Cynthia R. Chambers, Jonesborough  
Tonya Copeland, Brentwood  
Rick Davis, Hixson  
Evan Espey, Antioch  
Tommy Lee Kidd, Lawrenceburg  
Diane T. (Sandi) Klink, Memphis  
Renee M. Lopez, Gallatin  
William Lovell, Hohenwald  
Bob Plummer, Johnson City  
Debbie Riffle, Humboldt  
Elizabeth Ann Ritchie, Knoxville  
Steven Sheegog, Memphis  
Phil Stevens, Brentwood

#### STATE AGENCY REPRESENTATIVES

Cherrell Campbell-Street, Department of  
Human Services, Division of Rehabilitation  
Services  
Joey Hassell, Department of Education,  
Division of Special Populations  
Debbie Payne, Department of Intellectual and  
Developmental Disabilities  
Ralph Perrey, Tennessee Housing Development  
Agency  
E. Douglas Varney, Department of Mental  
Health  
Richard Kennedy, Commission on Children  
and Youth  
Jim Shulman, Commission on Aging  
and Disability  
Michael D. Warren, Department of Health,  
Division of Maternal and Child Health  
Patti Killingsworth, Bureau of TennCare

#### UNIVERSITY CENTERS FOR EXCELLENCE REPRESENTATIVES

Frederick Palmer, University of Tennessee  
Boling Center for Developmental Disabilities  
Elisabeth Dykens and  
Elise McMillan, Vanderbilt Kennedy Center for  
Research on Human Development

#### PROTECTION & ADVOCACY

Lisa Primm, Disability Law & Advocacy Center  
of Tennessee

#### COUNCIL STAFF

Wanda Willis, Executive Director  
Mildred Sparkman, Administrative Secretary  
Alicia Cone, Director of Grant Program  
Lynette Porter, Deputy Director  
Ned Andrew Solomon, Director of Partners in  
Policymaking™ Leadership Institute  
JoEllen Fowler, Administrative Assistant  
Emma Shouse, Director of Public Information  
Tiffany Mason, Public Policy Director