

BREAKING

GROUND

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**IN THIS
ISSUE:**

**LIGHT AT THE END
OF THE TUNNEL**



TENNESSEE COUNCIL
on developmental disabilities



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LIFE IN THE MOMENT: A SISTER'S PERSPECTIVE

by Emily VanGilder



My sister, Sarah, is very similar to any typical, 19-year-old girl. She loves dancing in her room to loud music, she fights with her siblings, and she has a crush on every single cute guy she sees. However, Sarah has something that most other people don't have: an extra chromosome.

My sister has Down syndrome. When I was a little girl, I didn't even know what Down syndrome meant until my mom took me to a workshop for parents with children with Down syndrome. We walked into the room and I saw many children with slanted eyes, tiny noses and ears, and tongues too big for their mouths. I simply said to my mother how unfair it was that all of these children looked like Sarah and none of them looked like me!

My mom then explained to me how my sister is different, how she has special needs, and how she does things a little slower than everyone else.

Having a sister with Down syndrome has shaped me into the person I am today, because Sarah teaches me the things that matter most in life. Everything that I need to know in life, I learned from her.

Sarah lives in the present. She's always focused on what is happening right there and then, and doesn't always worry about the past or the future. I often find myself worrying about what I need to get finished or what will happen in the future. I also worry about bad things that have happened in the past. Whenever something doesn't go Sarah's way, she just says "Oh well!" and moves on. She's a wonderful reminder to just relax and take life one day at a time.

But she can also be the most stubborn person I've ever met, and sometimes living in the moment means that she must finish her movie before she agrees to do anything else. However, because Sarah really savors what is happening in this present moment, she sees things that others do not.

She knows what her jobs are and gets them done. When the dishes are clean she empties the dishwasher without being told. She notices when things are out of place and puts them away. She likes to help out whenever she can.

Sarah can create a happy moment in a mere car ride home by blasting Lady Gaga and giggling the entire time. She is absolutely the best cure for a bad day. She sees through any mask I put on, and she knows how I'm feeling whether I tell her or not.

Whenever I come home in a bad mood or I'm stressed or sad, my sister simply looks at me and says, "it'll be okay Emmie".

She has taught me not to get so caught up in the hard things in life. If I fail a test or lose a friend, Sarah is there to give me a quick hug and cheer me up. If she sees someone upset or angry, she's the first to comfort that person. When Sarah was a little girl, she ran up to a complete stranger, hugged him, and told him that everything will be okay. This stranger told us that he was having a difficult time being separated from his family overseas. He was amazed that this tiny little girl could see his pain and comfort him, without even knowing him.

Sarah is a pat on the back, or a high five when you do well. She is there for anyone, to remind them that life is difficult sometimes, but everything always works out.

Having a sister with a disability can be difficult. I sometimes find myself getting embarrassed because people giggle or point fingers. I wonder, "How can they laugh at this wonderful person standing before them?"

The most important lesson I have learned from my sister, Sarah, is to be yourself. Whether she's dancing at the dinner table, or playing tag while we're in the mall, or making funny faces in the mirror, Sarah truly knows how to be herself.

She's the one teaching me how amazing I am and that I need to love myself. Sarah looks up to me so much and she's so proud to have me as her sister, that she sometimes tries to be just like me. The truth is, Sarah has such self-confidence that I'm the one striving to be more like my amazing big sister!

She cannot speak well, or understand everything that is going on, but she's the most loving, happy person you'll ever meet. As her sister, I feel that it's my responsibility to be sure she knows how special she is, and how much everyone loves her. I try to tell her that I love her every day, but she's usually the one telling me first!

I have a favorite quote from Dr. Seuss: "Today you are you, that is truer than true. There is no one alive that is youer than you!" There are three valuable life lessons I've learned from Sarah: live in the present and savor the moment; don't stress too much because everything will be okay; and when someone points a finger and laughs at you, remember to be true to yourself, because you're amazing just the way you are.

YES, VIRGINIA, THERE IS

by Amy Petulla
Photos by
Amy Petulla



Chris Petulla wanted basically the same things everyone else his age wanted: to go to school where his siblings went, to be a part of his church community, to participate in extracurricular activities and to eventually have a job. He did not see his Down syndrome as a barrier to these goals.

Unfortunately, some adults who did not even know him were not so enlightened, which made his path more difficult. But for every uninformed person who insisted on making the path rockier, there thankfully was a forward-thinking spirit to help smooth it out.

Like many families of young people with disabilities, Chris's folks traded any thoughts of a "Most Popular Parents" ribbon for a figurative pair of boxing gloves, to make sure he got the education he needed in the company of his peers. They changed churches to attend one where he was welcomed in the religious ed classes. They sought out after-school programs where he could thrive, like the theatre programs at Chattanooga Theatre Centre and St. Luke's United Methodist Church, and the show choir at the Chattanooga School for the Arts & Sciences. And they thanked God for the arrival of several angels along the way, most notably paraprofessional Beth Anne Biddle and

teacher Shari Owens, who both offered up their creativity and time to make this journey with Chris.

And bit by bit, the payoffs from this incredible sojourn began to appear. Performance skills led to a work-study program as The Doctor of Laughter at Siskin Hospital, a job based on Patch Adams, who later wrote Chris to congratulate him on the work he was doing. It also led to some modeling jobs and extra parts in a few movies. Chris has recently signed up with the same talent agency that represents Lauren Potter, better known as "Becky" on Glee.

Volunteer work at Siskin and at The Creative Discovery Museum gave him experience that led to a paying job with Food Lion, where his bosses, coworkers and customers all loved him. Unfortunately, Food Lion pulled out of Chattanooga less than a year after he began there, so like many people with disabilities, he found himself unemployed at high school graduation. Chris, however, had already planned to attend a vocational program at the TN Rehabilitation Center in Smyrna after high school, so while his friends were all off at college, he likewise spent a year in a residential educational program, preparing for future employment in the food services field.

Graduation from TRC, however, did not result in an immediate job. Instead, he spent months waiting for yet more paper testing that did not take into account any of his recommendation letters or past performance. The discouraging recommendation was that, despite successfully holding a paying job with no supports before, Chris was only suited for an enclave (workshop) type job.

Rather than concede to this recommendation, Chris requested that his job placement services be switched to Orange Grove.

components so quickly. In short order, Chris has become a part of the team, utilizing the Chattanooga Area Regional Transportation Authority Care-A-Van service to travel to his job Monday through Friday. He does such a good job, the store has received multiple feedback responses through Moe's website, praising Chris. In fact, this trial employment was so successful, Moe's has gone on to hire employees with disabilities at other Chattanooga stores.

Moe's has been a shining example of a win-win partnership. Just ask their customers!

A LIGHT AT THE END OF THE TUNNEL: AN EMPLOYMENT SUCCESS STORY

He was sent to several worksites to allow Orange Grove to evaluate his job skills, and in fact was offered a job by one of these sites. However it was not in his chosen field of food service and would not have afforded him much customer interaction, so he turned that one down. The problem was that most food service jobs require employees to be able to do all jobs, including operating the cash register, and he had not yet been trained to do that.

Then along came Moe's. Moe's Southwest Grille in Chattanooga had just begun exploring the idea of working with Orange Grove to hire an employee with disabilities. Chris' caseworker quickly realized that it would be a perfect fit for Chris. Marshall, the manager at Moe's in Hixson, was seeking an employee to be the "dining room ambassador", to chat with guests, keep the area clean, stock the salsa bar, and of course shout their signature, "Welcome To Moe's!" whenever a guest entered. Chris' strong social skills and attention to detail were just what was needed!

While the initial plan was for Orange Grove to continue supervising as he learned the job, after about a week they were able to pull back, because he grasped all the

Amy Petulla is Chris's mom, an author, mediator, retired attorney, owner of Chattanooga Ghost Tours, and a graduate of the TN Partners in Policymaking™ Leadership Institute.



Chris Petulla and Moe's general manager, Marshall Watne.

THE HCBS SETTINGS RULE

By Lauren Pearcy

In January 2014, the Centers for Medicare and Medicaid Services (CMS) issued a final rule outlining requirements for home and community-based service (HCBS) settings. This federal rule will impact Tennessee's HCBS long-term services and supports programs: CHOICES and the 1915c Waivers (also known as "Department of Intellectual and Developmental Disabilities Waivers" or "DIDD Waivers") that serve people with intellectual disabilities. The final rule is known as the "HCBS Settings Rule".

The intent of the rule is to enhance the quality of life for people receiving home and community-based services that are reimbursed by Medicaid by ensuring that individuals have full access to community living and are spending time in "integrated settings", meaning alongside people without disabilities. In other words, the rule seeks to make sure that people with disabilities are not isolated or controlled. Instead, services must be provided in a way that ensures people with disabilities are afforded the same rights and freedoms as everybody else.

WHO WILL THE HCBS SETTINGS RULE AFFECT?

Tennessee's Medicaid agency, the Bureau of TennCare, is the lead state agency and point of contact for the HCBS Settings Rule because TennCare oversees the two programs that provide HCBS: CHOICES and 1915c Waivers. These programs are administered by the following entities:

- Managed Care Organizations (MCOs) in Tennessee (AmeriGroup, BlueCare, United Health Community Care) administer the CHOICES Program for adults who have a physical disability and people who are over 65 years old; and
- DIDD administers the state's 1915c waivers for people with intellectual disabilities.

Therefore, the initial review of the new HCBS Settings Rule, and demonstrating to CMS that the state is in compliance with the new rule, primarily affects TennCare, DIDD, all three MCOs, and residential and day program HCBS provider agencies across the state.

While the analysis and the implementation of the rule will be driven by all the groups listed above, ultimately, and most importantly, this rule will affect the individuals receiving residential and day services through CHOICES or the DIDD waivers, in ways that are intended to support and enhance their quality of life in the community.

A SUMMARY OF THE HCBS SETTINGS RULE

For the first time, CMS defines the requirements for home and community-based settings. This means that the rule is focused on the settings in which services are provided (i.e., where does the person live and spend their day?) in an effort to make sure people receiving HCBS are supported in a way that allows them to live independent and fulfilling lives alongside people without disabilities. Historically, people with disabilities had to live in institutions to receive the support they needed. This rule seeks to ensure that home and community-based services do not feel like institutional services to the people who receive them.

A related Person-Centered Planning Rule was released simultaneously with the HCBS Settings Rule but went into effect immediately in March, 2014. Per this Rule, CMS defines person-centered planning requirements for home and community-based services. Unlike the settings rule, the person-centered planning rule is focused on the planning of the services provided (i.e., Is the individual getting the right services? Does the person receiving the services get to direct the planning process?) The person-centered planning rule specifies that the service plan must be developed through a person-centered planning process. Tennessee is already using person-centered planning, but now the state is re-educating and re-emphasizing this process across all of Tennessee's programs to ensure that the expectations are fully met.

Further, the person-centered planning rule says that the plan must address both long-term services and supports and health needs. In the past, health needs have not been emphasized as part of the service plan. The intent of this rule is to make sure that support coordinators are looking at the person's needs more holistically to help prevent gaps and to connect services where appropriate. For

For more details on these components and others listed in the remainder of the article, please visit <http://www.tn.gov/tenncare/topic/transition-plan-documents-for-new-federal-home-and-community-based-services>

example, if a person's Physical Therapist recommends a new stretch or exercise, then the Day Services provider may be able to incorporate that exercise into the daily routine. Likewise, if a person has diabetes, then the Residential Services provider is responsible for helping support the person in managing that disease through assistance with meal planning and grocery shopping.

A SUMMARY OF TENNESSEE'S PLAN TO DEMONSTRATE COMPLIANCE WITH THE HCBS SETTINGS RULE

Tennessee was one of the first states in the nation to submit and gain approval from CMS on a transition plan for demonstrating compliance with the HCBS Settings Rule. Below is a short summary of the key components of Tennessee's transition plan:

- State Agency and MCO Self-Assessments: All rules, regulations, policies, protocols and contracts governing HCBS in Tennessee will be reviewed (and revised if necessary) to ensure they are in compliance with the HCBS Settings Rule.
- Provider Self-Assessments: Certain providers must conduct their own self-assessments using tools developed by the state. Providers are required to conduct a self-assessment if they provide either residential services and/or day services in the CHOICES program and/or the DIDD Waivers.

Examples of questions for residential providers:

- o Are individuals able to regularly access the community, and are they able to describe how they access the community, who assists in facilitating the activity, and where he or she goes?
- o Do all residents have a legally enforceable agreement with the setting landlord?
- o Do the residents have privacy in their sleeping or living space?
- o Can individuals have visitors at any time?

Examples of questions for day services providers:

- o Is the service setting is NOT located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment (a Nursing Facility, Intermediate Care Facility for Individuals with Intellectual Disabilities, a hospital)?
- o Do individuals shop, attend religious services, schedule appointments, have lunch with family and friends, etc., in the community, as they choose?
- o Are individuals able to come and go at any time?

HOW WILL THE PROVIDER ASSESSMENT WORK?

Using the tool, providers indicate whether or not their services are currently compliant with the HCBS Setting Rule. If not, the provider will submit a "Transition Plan" describing the provider's plans, including timelines, to change the way they provide services so that they are compliant with the Rule. It's important to note that providers are required to convene a stakeholder group to participate in completing the assessment. The stakeholder group must include, at a minimum, representation from persons supported by the provider, family members, provider agency staff and a disability advocate.

The intent of this year's assessments is to identify areas, if any, that need to be adjusted in order for the state's services to comply fully with the HCBS Settings Rule. Going forward, the assessments will be incorporated into annual quality assurance monitoring activities to ensure ongoing compliance.

Individual Experience Assessments: In addition to the provider self-assessments, individuals who receive residential and/or day services will also have an opportunity to complete an assessment to tell us about their perspective of the settings in which they receive services. The Individual Experience Assessment will ensure that the individuals receiving HCBS are actually experiencing those services in the way that providers, and the state, intend (and in a way that is intended in the HBCS Settings Rule). To ensure ongoing compliance, the Individual Experience Assessments will become part of the annual person-centered planning requirements.

WHAT'S NEXT?

At the end of this year (by December 31, 2015), Tennessee will submit to CMS an amended Transition Plan outlining all the activities identified through the processes above for achieving compliance with the HCBS Settings Rule, as well as timelines for completing those activities. In other words, the state will tell CMS which areas are in compliance with the rule, and how Tennessee plans to change things that are not in compliance, and the date by which these changes will be made. Over the next few years, the state will support providers needing assistance to come into compliance by working with them one-on-one, and by facilitating groups of providers to problem solve and support each other in achieving compliance.

Lauren Percy is Director of IDD Services, Division of Long Term Services and Supports, TennCare

THE CIL & METRO



By Emily Hoskins

SCHOOLS OUTREACH PROJECT

As an Independent Living Specialist at the Center for Independent Living (CIL) here in Nashville, I wear many hats. I have many responsibilities and programs I'm involved in, but my favorite by far is the peer support groups I facilitate with Nashville Metro School's Community-Based Transition Programs (CBTP). This is an initiative for students with disabilities that have completed high school with a special education diploma.

There are seven CBTP classes that offer an opportunity for students to learn work skills through various non-paid positions throughout the city. We all know that employment is a huge barrier for people with disabilities, and this program offers students a chance to develop their vocational skills with the hopes of obtaining a job upon exiting the program.

In the spring of 2013, Kathryn Deitzer, the Lead Community-

Based Teacher/Business & Community Liaison came into the CIL office to meet with us to discuss issues surrounding Social Security benefits. We began talking about how I facilitate peer support groups with some older adults, and then the idea of me doing the same for this group of young adults was proposed.

At first, I wasn't really sure what I was getting into. I didn't have any prior experience working with this population – young adults with intellectual/developmental disabilities. These students are between the ages of 18 and 22 and have diagnoses such as Down syndrome, autism and the like. The CBTP teachers were trusting that a stranger from a local nonprofit could come in and provide an hour's worth of valuable time for their students.

Well I must have done something right. At the time it was already spring, so the school year was almost over. Once

they started back in the fall of 2013, I was informed that these peer-support groups were now going to be a part of the Community-Based Transition Program. I initially started working with only one or two classes, but by that fall, I was contacted by all seven teachers wanting to know when I could come back and meet with their students.

I work with the teachers in scheduling a time that works best for their class's schedule. I see some classes on a weekly basis, and others I see every other week. I have one group that is made up of two classes together and we convene once a month. I meet the students at their classroom locations, which are spread throughout Davidson County.

During our first meeting of the school year, I tell the students that this is their hour. If there's something on their mind, we'll talk about it. If they have good news about what's going on in their life, we'll share it. If they are struggling with something in their life, we'll empathize.

Usually I'll come up with a "lesson plan" for our group to discuss that week. Often times these are related to job skills – like preparing for job interviews, or discussing why having a job is important. Other times, we work on personal skills – such as recognizing your own strengths or talking about self-advocacy. Sometimes I'll have more fun activities and creative thinking games.

This year one of the most enjoyable activities we had was when we discussed recognizing feelings and emotions. Students were assigned an emotion and then their classmates had to guess which feeling he or she was acting out. This particular activity had students asking if I could stay longer so that we could continue the game past our allocated hour.

Now this may sound like I'm bragging, but I'm not. The credit here goes to the students. My education is in psychology,

not special education or disability issues. On paper, it seems like I would have no idea what I'm doing. And to be honest, sometimes it feels that way! I do a little research on a topic and pull pieces from different sources to develop a lesson plan that I feel will be engaging to the students. I never know when inspiration is going to strike – in the shower, driving home from work, or sometimes from the students themselves.

The success of this program is because of them. It's because they are hard-working, caring, smart, funny and enthusiastic. They make my job so easy.

This spring we'll wrap up my second full school year with the CBTP classes. Over this time, I've really gotten to know these students and understand the things they care about and the dreams they have. Kelsey has ambitions of working in a children's hospital. Andrew rocks out on the bass guitar, and Erin's completely devoted to One Direction. Darko's developed a sense of responsibility and leadership within his class. Brittany is always fashionable, and Montel can remember numbers like nobody's business.

I feel so lucky and thankful for the chance to work with these amazing young men and women and their incredible teachers. Thank you to everyone in the Community-Based Transition Program for making this such a pleasurable part of my job.

If you're interested in learning more about the Community-Based Transition Program, please contact Kate Deitzer at 615.298.8400 ext 1180 or at kathryn.deitzer@mnps.org. For more information about peer support programs, contact me, Emily Hoskins, at 615.292.5803 or at emilyh@cilmtn.org.

Emily Hoskins is an Independent Living Specialist for the Middle Tennessee Center for Independent Living.

Emily Hoskins with high school students in the Community-Based Transition Program



Photos by Leah Samples

25 MORE PARTNERS GRADS JOIN THE TENNESSEE PARTNERS NETWORK

by Ned Andrew Solomon



The Tennessee Council on Developmental Disabilities completed its 21st Partners in Policymaking Leadership Institute in late

April. Partners, an intensive seven-weekend-session training for adults with disabilities and family members from across the state, recruits local and national experts in the field of disability to deliver a curriculum that includes the history of the disability experience; building inclusive and welcoming communities and classrooms; supported, customized and competitive employment; state services and resources; supported and independent living; assistive technology, conducting effective meetings; and the state and federal legislative process.

This year, 25 individuals graduated. Fifteen of those were individuals with disabilities; nine were family members. Throughout the Partners training, participants acquired valuable information, gained advocacy and leadership skills, and had the opportunity to talk about the challenges and successes of families and individuals that experience diverse



disabilities. A parent focused on their child with autism gets to “see” life through the eyes of an adult with a physical disability. An adult who is blind gets to hear about what it means, and takes, to

raise a child with an intellectual disability. Self-advocates get clued into a parent or sibling’s perspective; dads learn from moms, and vice versa.

A percentage of what they learned was derived from hired speakers and their presentations. As the director of this program since December of 2000, I have seen time and again how valuable the out-of-class time is – conversations that take place during meals, a smoke break, an evening stroll or a morning exercise walk, or on a couch in the hotel lobby. We at the Council can’t make those connections happen; they just do.

We are so very proud of the following people who traveled to the hotel each month, completed and recited homework assignments and supported each other in a multitude of ways, while putting their home and work lives on hold for a couple of days. Welcome to the Tennessee Partners graduate network!

Chad Beadles, Franklin
John Blake, Nashville
Rexcey Bowers, Memphis
Dawn Craik, Madison
H K Derryberry, Nashville
Melissa Dowdy, Pleasant View
Christina Earheart, Springfield
Evan Espey, Antioch
Chip Fair, Murfreesboro

Douglas Hall, Memphis
Michelle Hayes, Union City
Tiffany Horton, Murfreesboro
Amy Hostler, Franklin
Dr. Gladys Jones, Memphis
Robyn Lampley, Dixon
Promise Mata, White Bluff
Jonathan McLaughlin, Memphis
April Meredith, Christiana

Carolyn Meyer, Brentwood
Tara Mohundro, Bartlett
Wanda Myles, Smyrna
Chelsie Sue Nitschke, Hermitage
Rosa Robinson, Jackson
Carol Shehan, Mt. Juliet
Karen West, Gallatin

AND NOW, THE PARTNERS 2014-15 GRADUATES IN THEIR OWN WORDS:

“Making Connections with like-minded people is the most valuable thing I am taking away from Partners.”

“I will not be afraid to encourage persons to follow their dreams. {I will} let people know how to look for answers to issues they may have.”

“I want to focus on the bigger picture and tackle issues that may affect my family member, now or in the future, but also think about my whole community (or communities) and what they need and can contribute.”

“As a parent I’ve learned the importance of not limiting the possibility of what can be achieved, despite [my son’s] disability.”

“I have spent 7 sessions with a wonderful (new to me) networking group of friends...I will take all the knowledge with me and apply it to every facet of learning to better assist my family member, and our community. No time to stop or slow down!”

For more information about the Partners program, or for an application for the Partners 2016-17 class, please contact Ned Andrew Solomon at 615.532.6556, or at ned.solomon@tn.gov.

PARTNERS 2015

REUNION



JASON OLIVER



TELLS HIS STORY TO HELP OTHERS

by Ned Andrew Solomon

Jason Oliver's story is, sadly, way too common: child with misunderstood, "hidden" disabilities gets ridiculed, ostracized and left behind. What's less common was Jason's ability to, with the support of loving, dedicated parents and a few key, caring professionals, move beyond his limitations to write a book, and to become an advocate for other marginalized children and adults.

The story begins in second grade, in the early '80s. "I repeated second grade two times," said Jason. "No one really knew what was going on. They knew that I was a slow learner. They knew that there were some developmental issues going on, but couldn't really pinpoint what exactly the disability might be."

Without a definitive explanation for his challenges, Jason was left to languish in the "resource room". It would be middle school before he would have access to any kind of formal school system services.

Jason knew he wasn't learning like any of the other students – an awareness that was drummed into his fragile self on a daily basis. "Kids were mean; they'd laugh at me and call me slow," recalled Jason. "Teachers pointed me out in class, saying that I was so far behind everyone else. They would correct me in front of the class, because I'd be answering a question that had already been answered three questions ago. It was really a big social barrier for me, even in the earliest grades."

To cope with the mockery, Jason shut down, and shut himself in. He wouldn't answer any questions posed in class. He never volunteered to read out loud. He refused to do anything in class that would draw extra attention to what he felt were his "deficits"; and, in the process, fell further and further behind. No alternative tests or accommodations were offered.

THE OLIVER PRIVATE SCHOOL

His only salvation was his parents' willingness to take on Jason's education at home, on top of their other life responsibilities. "Now I refer to it as The Oliver Private School," explained Jason. "I would go to public school from 7:30 in the morning until 3:00 in the afternoon. I'd arrive at home around 3:30, have a break, and then Mom would pick up where the public school lacked during the day. I would attend my mom's 'school' for several hours each evening. She would read the books to me; she would help me with my homework; she would make sure I understood what was going on."

In the 4th and 5th grades, things began to brighten up a bit. Thanks to two teachers, a Ms. Slagle and Ms. Ward, who seemed to "get" Jason, and who had some creative ideas for educating him. Later in life, Jason discovered that both of these teachers had sons who had dyslexia, and their own particular learning difficulties. "They were the ones that gave me the opportunities, the ones that saw that I learned differently and could 'tune in' to the ways I was learning," said Jason. "Without their interventions, which I have leaned on over the years through work and college situations, I don't think I would have been as successful as I have been."

In middle school, Jason finally got access to special education services and accommodations, though he believes his teachers still struggled with how the accommodations could be incorporated into their classroom settings, and exactly how they would benefit Jason's unique learning needs. Jason received one-on-one supports during "pull out" sessions from the general education classroom, which wasn't ideal, but was a step above being "housed" in a segregated, CDC (Comprehensive Development Classroom) setting. During pull out, alternative tests were

read aloud to him, and he received extra tutoring for the subjects he struggled with the most.

These services were decided through the IEP (Individualized Education Plan) process, but Jason did not attend his own IEPs until he was a sophomore in high school. "It was not 'person-centered planning', at that point," said Jason. "The meetings and decisions were happening behind closed doors between my mom and my teachers."

TRANSITION BY TRIAL AND ERROR

There would, unfortunately, be no formal transition planning either. Although Jason had dreamed about going to college somewhere, he was constantly being told that he wasn't intelligent enough to do so, and that he should definitely take the "vocational route" instead of academic classes. One of those "too-difficult" courses was Spanish. Ironically, by the fourth week, Jason was tutoring the "A" students who were struggling with the content.

For Jason, transition planning was going to the guidance counselor's office and looking through book after book of colleges and universities – despite his reading learning disabilities. He was delighted to find some schools that advertised providing "services for individuals with disabilities", and finally settled on the University of Tennessee at Martin.

Even though there were student disability services, as advertised, Jason encountered more, unexpected obstacles. "One of the biggest barriers I experienced leaving Greeneville, Tennessee was that people didn't know me, and they definitely weren't aware of my disability," Jason said.

He was so used to walking into the guidance office in middle and high school, where his "reputation" preceded him, and being handed what he needed. He had had no training in self-advocacy, or even being able to discuss his own disability and what that disability would require, in terms of accommodations. "I never had to say I have a print deficit, I have a processing disorder called dyslexia, and this is my story and this is how I can be successful with your help," Jason said. "Just the name 'Jason Oliver' got me to that level of assistance. So now here I am, 400 miles from home, in an office where the name 'Jason Oliver' doesn't get me anything! And I'm like, 'Oh my gosh – what am I gonna do now?'"

This would become one of the most significant barriers for Jason throughout his life: moving through stages – preschool, elementary school, middle school, high school, post-secondary education and training, employment and independent living concerns – and successfully "carrying" the needed accommodations from point to point. It was as if the conversation had to start anew at each life stage,

and the advocacy strategies, untaught and learned by trial and error, had to be adapted over and over again. "I had learned how to self-advocate at the high school level, and a little bit at the post-secondary level," said Jason. "But I had no idea how to do it at the career or employment level."

GETTING IT ALL DOWN

Throughout his adult years, Jason's confidence grew. He also became more forthcoming about his disability, and through informal conversations and formal presentations he discovered more people who accepted him for who he was, and who had experienced similar challenges. Attending trainings and conferences like the Partners in Policymaking Leadership Institute and the TN Disability MegaConference made him realize his story of lessons learned had value, was worth telling, and might even help someone else on a similar journey.

Due to his reading and writing disabilities, getting that story down in book form was a 15-year process. It involved using three different software programs to make it happen. One was a speech-to-text program, and two were spelling and grammar check programs. Then a human colleague did some fine-tooth-comb editing prior to publication.

The final product, called "Dyslexic Boy: Overcoming All Obstacles", details, in a conversational manner, Jason's struggles and successes. "I hope readers will gain insight and feel a part of a tribe," said Jason. "When I went to a dyslexia conference for the first time, I was surrounded by other people in this circle, and we were talking, and I was having problems processing. I apologized for it, and they all laughed in a wonderful way and said, 'We all understand; no need to explain yourself.'

"That's the feeling that I want to give others with the book - that you're not alone," continued Jason. "The book is not the end-all to give all answers. It's just like a front door that opens up to a house. It starts the conversation."



Jason Oliver and his daughter.

DESHUN

AND YE SHALL

By Courtney Taylor

DeAnna is a single mother living in a suburb south of Nashville. Her son DeShun (age 9) has autism. DeAnna is a wonderful advocate for her son. She is dedicated to seeking out opportunities and supports that will help DeShun flourish in the many areas of his life.

Despite DeAnna's strong religious convictions and her history of involvement and membership in various churches in the area, she and DeShun no longer actively participate in a congregation. DeAnna's primary concern has always been to worship in a church that is inclusive of people with disabilities both socially and theologically. Their search has been filled with challenges.

"In the beginning when I had DeShun, we all went to a church," said DeAnna. "It was a great church. It was a loving church, but nobody knew what to do with DeShun. You know, I kind of expect the church to know what to do with him, but they don't know what to do. I understand it's not anything personal, but all those years ago it was hard not to take a lot of things personally."

As DeShun grew and DeAnna learned more about her son's disability and how it would manifest in his life, she came to accept that their church was not prepared to minister with them. So, she began to search for a church that would be compatible to the needs of her family.

In the search for an inclusive community, both DeShun and DeAnna have had disappointing experiences. DeAnna reports a general lack of understanding and awareness about disability that has led to practices that are exclusive rather than inclusive. DeShun has been placed in segregated settings, or in Sunday School classrooms with children far younger than he. In some cases, DeShun was pulled away from time with other students without his mother being notified. DeAnna explains that many of the obstacles they've faced in congregations are due to people viewing DeShun

as his diagnosis, rather than as a child.

"At first, my goals were focused on getting DeShun in an inclusive setting with kids his own age," said DeAnna. "Now that he's older and more mature, so are my goals for him. I want to make sure he's getting what he needs from the Word. I mean, he has a soul! He needs to understand about Jesus, and there's not really a picture [visual support] that can help explain that to him. He needs a church. He needs to know God."

DeAnna wants a church that's ready to teach and to believe in DeShun's abilities. She has no expectation of finding a perfect community - one that knows everything about disabilities and that will do everything right. She simply wants to find a faith community that's willing to walk alongside her family and learn together as they go.

This story is not uncommon. Though there are wonderful examples of faith communities that have made strong commitments to making sure families like DeAnna's are full participants, more often than not challenges are still present. Families report barriers related to communication, architecture, attitudes, programming and liturgy (Carter, 2007). These issues, when left unaddressed, can ultimately lead to a family's decision not to participate at all. In fact, nearly one third of parents report having changed their place of worship because their child with a disability was not included (Ault, Collins, Carter, 2013).

A recurring community participation survey conducted by the National Organization on Disability has indicated repeatedly that while almost the same percentage of people with and without disabilities say that their faith is important or very important to them, less than half of the respondents with disabilities attend a congregation on a regular basis. There is a wide participation gap when comparing that number to the number of people without disabilities who



attend on a weekly basis (Hanson, 2004).

When people with intellectual and developmental disabilities are excluded from faith community participation, they lose opportunities to worship, learn, fellowship and serve with others. Congregations miss out on the chance to receive the wonderful gifts, friendship and faith of a vital part of their community. And faith communities are incomplete without the presence and participation of people with disabilities and their families.

We are called to do better.

We know that a large number of religious leaders understand the importance of including people with disabilities, but these same leaders report not knowing how to put that into practice (Griffin, Kane, Taylor, Francis, & Hodapp, 2012). Their training rarely covers any type of preparation to address disabilities in ministry (Annandale & Carter, 2014), and thus the responsibility often falls to parents like DeAnna to educate and advocate in faith communities and to push for their right to worship in a welcome setting.

We are called to do better.

To download a free guide for congregations on recommendations for welcoming people with intellectual and developmental disabilities, visit:
<http://vkc.mc.vanderbilt.edu/assets/files/resources/CongregationPracticeGuide.pdf>

This story was compiled as part of a Tennessee Kindred Stories of Disability project collaboration with students enrolled in a class on Theology and Disability at Vanderbilt Divinity School. As part of the project, students conduct interviews and learn firsthand about encounters with education, health care, housing, employment, quality of life

and disability services.

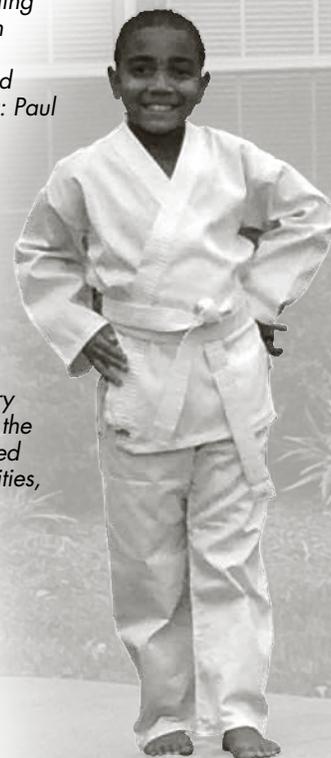
Topher Endress is a graduating Master of Divinity candidate whose work specializes in disability theories, inclusive faith practice and constructive theology. He is currently working on projects with the Vanderbilt Kennedy Center on topics of disability employment, as well as religious attitudes. Courtney Taylor, MDiv, is associate director of Communications and Dissemination; coordinator of the Disability, Religion, and Spirituality Program, and coordinator of Tennessee Kindred Stories of Disability.

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PEER-TO-PEER SUPPORTS:

PARENT²
FAMILY VOICES
TN PROGRAM **PARENT**



left to right, U.S. Senator Lamar Alexander, Kara Adams and Tonya Bowman of Family Voices of Tennessee, and U.S. Senator Bob Corker.

A little over a year ago in Breaking Ground we introduced Tennessee Parent-to-Parent (TNP2P), an initiative of the Family Voices of TN program. This grant, funded by the Tennessee Department of Health, Family Health and Wellness Division, was established to support families of individuals with special health care needs and disabilities, by providing opportunities for a parent, sibling or self-advocate to connect one-on-one with a self-advocate or family member with the same or a similar healthcare or disability experience.

The “experienced” self-advocate or family member becomes a trained and certified “Mentor”, who then volunteers his or her time to share their own challenges and successes, acquired knowledge about services and the service system and emotional support.

POUNDING THE PAVEMENT

In its earliest stages, Family Voices staff struggled to find those all-important mentors to match with the multitude of families who would benefit from these community connections. Now, with statewide reach, TNP2P has more than 60 mentors trained across the state. “They are all diverse in their experiences of a diagnosis,” said Kara Adams, Family Consultant/Project Coordinator, Family Voices of Tennessee. “We even have a couple of fathers, which is really exciting, and a few self-advocates as well. Our goal is to have at least 100 mentors by June, 2016. I think we’ll get there.”

“Getting there” hasn’t been easy, and it took some creative outreach strategies and lots and lots of hours and miles pounding the pavement. A primary target has been hospitals. “Our thought process was, since our state is very long, and we have kiddos in children’s hospitals throughout and on every end of the state, that we’d start there,” explained Kara. “We’re getting a lot of referrals, because those are the people that ‘touch’ those kids first.”

Family Voices also made an effort to give presentations at staff meetings at various clinics, social work groups, state agencies and disability-specific entities like the Autism Society. They toured rehab centers and newborn follow-up clinics. They distributed hundreds of brochures, and worked the social

media angle. “Basically, anyone who would give us the time of day, we have talked to,” said Kara.

SCREENING FOR SUCCESS

Potential mentors come to Family Voices from a variety of sources. They may be referred by a physician or some other healthcare professional, or a community leader who has recognized that an individual would fit the mentor role and requirements well.

From there, mentor applicants fill out an application on-line, or by paper copy available through Family Voices. Then Kara touches bases with each one by phone, and if the expectations are mutually understood, the applicant moves on to the training phase which is typically conducted in groups, but can also be done one-on-one.

THE TRAINING/CERTIFICATION PROCESS

The training typically takes about 2.5 hours. Kara prefers to work with a small group, no more than 10, which keeps the process intimate. The first step is allowing all the attendees to talk about their own family situations and experiences. “A lot can be communicated through these shared stories,” said Kara. “It tells us where we are in our journey, and allows us to see if we are really able to provide support for someone else.”

Participants are trained on communication and listening skills; family-centered care and communicating with healthcare professionals; confidentiality and HIPAA laws, and particularly how those laws impact social media. Mentor applicants have to sign a confidentiality policy agreement and must learn about the degree of information they can share with families that is medically-related. There are also lessons about boundaries – what mentors can share and what they can’t. “We’re not counselors; we’re not psychologists,” Kara said. “We are simply family members helping other family members out.”

"We also spend a lot of time talking about taking care of yourself, and recognizing where you are on your journey," continued Kara. "Because if you can really recognize where you are, then you'll be able to recognize where the family member is that you're helping, and how that family member needs support. Everybody needs support differently, because everyone is in a different 'place'. Some people are in survival mode, and just trying to keep their heads above water. Other people are at the point where they're searching for answers."

MAKING A MATCH

Once the mentors have completed the training they are certified to be matched up with a family who would benefit from having an experienced family member to talk to. The matching process is also complex, and takes some finesse.

Sometimes the match is very close: a parent who has a child with autism is paired with another parent of a child with autism. Or a self-advocate with a traumatic brain injury is supporting another brain injury survivor. But sometimes a match is simply made because there is a geographic connection, or an age similarity, or the family member in need just wants to talk to another family member who has lived with the experience and the challenges of supporting a family member with any kind of disability or healthcare issue.

The extent of the "need" must be matched too. Is the parent requesting a mentor looking for a person who can get together for coffee for an hour a week to just download, or are they needing someone who can accompany them to doctor appointments, or perhaps school meetings? Do they prefer communicating by email or by Skype, to meeting in person?

Conversely, how much is the mentor able to give? Even a certified mentor may go through periods of time when their personal issues, or their own family's needs, are too time-consuming to provide support for another parent. "Once we think we find a match, our first step is calling the mentor, and he or she still has the right, at that time, to tell us that this is not the best time," Kara said. "So, if that happens, we just search for the next best match to fill that role."

This is how it works: A family contacts Family Voices about wanting to be matched with a mentor. They fill out a form, or sometimes Kara conducts a phone session to discover how the family would like to be matched. Is it just diagnosis-based, or is there a particular topic of concern that the family needs support with? They may be looking for a particular age too – sometimes someone a little bit older who might have already experienced what the mentee family is going through right now.

From that point, Family Voices staff is not typically involved in, or aware of, the conversations that ensue between mentors and mentees. "The mentors have the right to create their own boundaries with the family members," said Kara. "It's really up



Mentor training in Nashville.

to that mentor what they're able to do."

FUTURE GOALS

The P2PTN program currently has 31 successful matches, with three more pending. Some are out of state. "When we first launched this, we got a lot of extremely rare circumstances and diagnoses," said Kara. "Of course, I'm always on the hunt looking, but we did not have any local matches. So we put it on the national listserv, obviously with the family's permission. We have a parent needing support here who found a match in Georgia, and a parent needing support from Pennsylvania, and the mentor match was found in Tennessee. Through social media, Skype, etc., it really doesn't matter if you're across the street, or across the country. Support can be delivered long distance."

With a statewide network established and continuing to expand, Family Voices has set its sights on other support initiatives. They are working on creating a "caregivers network", that will look different than one-on-one support. "This materialized because a need surfaced for a group to meet inside the hospital for cardiac patients at Vanderbilt, for patients whose families were still at the hospital," said Kara. "We trained one of our mentors to be a facilitator. So now, Family Voices sponsors a support group at the Children's Hospital."

Staff recently reached out to Fort Campbell too. "We're a military family, and my son has been part of the military's 'Exceptional Family Member' program for years," said Kara. "They don't have anything like this peer-to-peer initiative, and so we're hoping to give them that resource. It'll look a little bit different in the military setting, because those families come and go quite a bit."

The project is trying to bolster more supports for youth, siblings, self-advocates, dads, and even grandparents. Right now, the vast majority of pairings are a mom talking to another mom. They are also actively seeking mentors who speak different languages and who represent more diverse cultures and geographic locations.

For more information please visit <http://www.tndisability.org/tennessee-parent-parent>

TN SPOTLIGHT



We here at the Council are very proud of the work and accomplishments of long-time Council Member **Tommy Lee Kidd**, and his

family. Passionate about the rights and needs of persons with disabilities, the Kidds – Tommy Lee, his wife **Lesa** and their daughter, **Abigail** - are committed to establishing or encouraging more community integration opportunities, especially in the areas of employment and recreation. The recognitions and accolades have been numerous:

Tommy Lee Kidd:

Lawrenceburg Elks Citizen of the Year - 2013

Tommy Lee and Lesa Kidd:

TNCO (Tennessee Community Organization) 2014 Award of Excellence for Community Leader of the Year (nominated by Phil Garner at Buffalo River Services).

Abigail Kidd:

Governor's Volunteer Star Award - 2014

Tommy Lee, Lesa, and Abigail Kidd:

Lawrence County Citizens of the Year - 2014

Abigail's Plan, a baseball league for people with disabilities started by the Kidd family, just got a major boost. **Bridgestone Americas (Bridgestone)** recently announced that the non-profit organization is the winner of the second annual **Fuel the Cause** neighborhood transformation contest. Abigail's Plan will receive a \$25,000 gift from Bridgestone. The prize will help the organization build Tennessee's first **Miracle League** rubberized field. Playing on a regular field with a grass and dirt surface is often very difficult for players with mobility issues.

Jessica Tessanne of Lebanon won the title of **Miss Shining Star Nashville** on March 28. The pageant is sponsored by **Open Doors TN**, located in Knoxville. Its

mission is to provide families with children with disabilities opportunities such as camps, special events and sports activities.

SRVS' Astrid French was awarded **The Arc Tennessee Exemplary Educator of the Year** award at the **2015 Tennessee Disability MegaConference** in Nashville. French is the Curriculum Coordinator at **SRVS Learning Center** headquartered in Memphis. She was bestowed the honor for unprecedented application



Pictured with Astrid French are SRVS Executive Director Tyler Hampton and The Arc Tennessee Executive Director Carrie Hobbs Guiden

of Montessori teaching methodology in a disability setting for adults, leading to documented improvements in fine motor, hand/eye coordination and communication skills.



April Meredith is a graduate of the 2014-15 Partners in Policymaking Leadership Institute. She believes that the Partners program enhanced her leadership, public speaking, advocacy skills and knowledge. And, as a result of the training, April was invited to join the **State Legislative Committee for the National Federation of the Blind of Tennessee** to work on local and federal issues, such as eliminating sub-minimum wages. April "has longed for the

opportunity to help improve the lives of Tennesseans with disabilities, especially those who are blind".

SAVE THE DATE

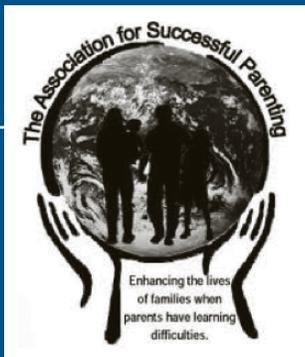
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International Conference A Chance to Parent: Advocacy, Policy & Practice

"We are dedicated to enhancing the well-being of at-risk parents with learning difficulties and their children. This primarily includes parents who may be identified as persons with intellectual disabilities or borderline intellectual functioning."

We know that family life is complex, and all families need support and rely on interdependent networks. As a result we seek to facilitate community partnerships and networking, offer educational/training opportunities, advocate for ongoing system change to achieve social justice, partner with self-advocates, and consult with partners in child welfare, early intervention, education, health care, disability services, family law and family support.

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