Breaking Ground Issue #96, March 2019 – text only

On the cover: Using Technology to Promote Independence. There are four photos on the cover of Brad Presnell, an adult with Down syndrome who uses enabling technology to help him at work, at home and throughout the community. In the first photo, Brad is pointing to a black iPad that has a white power cord attached to it. In the second photo, a smiling Brad is opening the front door of his home. In the third, largest photo, Brad is wearing a red polo shirt with the word “ingles” on it, which is the name of the grocery store he is working in. He is standing near a display of pumpkins and floral arrangements. In the last cover photo, Brad is intently reading something on his iPad.

The cover also contains a list of other articles that appear in the magazine. These article titles will be described in the table of contents on page 3. The last item on the cover is the Tennessee state logo for the Tennessee Council on Developmental Disabilities.

Page 2: This page is a flyer promoting an event. It reads: Empower TN, STEP, and the TN Council on Developmental Disabilities invite young people between the ages of 16 and 24 to apply to participate in the I Am More Than…Youth Leadership Academy, July 17 & 18, 2019 in Nashville, TN. Further down there is a box that has the following text: Participants will learn about speaking up for yourself, getting comfortable with who you are, working toward independence and more, all while having fun! In other section it reads: This program will be offered at no cost to participants. Application deadline is April 30, 2019. To register online, please visit bit.ly/YLA2019. For a paper application, please email information@tnstep.org or call Lisa Gosnell of STEP at 800-280-7837. If you have questions about the program, please call Paul Choquette of EMPOWER TN at 615-515-8612.

In the middle of the flyer there are three photos. The first shows several young people and a couple of adults sitting on big comfy chairs in a meeting room setting. The second photo shows a young lady with red hair and a pink shirt holding up a sign that reads: be proud of who you are. The third photo is a group shot of all the people who participated in last year’s Youth Leadership Academy. At the bottom of the page there are agency logos for EMPOWER TN, the TN Council on Developmental Disabilities and STEP, Support and Training for Exceptional Parents.

Page 3: Table on Contents.

The table of contents has three photographs that appear in three different articles. Those photos will be described along with the article text. The articles that appear in this issue are:

Edward Mitchell: ABLE Program Ambassador

A Life-Changer: Using Enabling Technology to promote independence

TriStar Centennial Offers Sensory-Friendly Rooms for Kids with ASD

Reflecting on the Great Wisdom of Families

State Leadership Academy for Disability Services—Year Two

Have you heard? TRC-Smyrna is Changing!

My Brother Does Not Speak, but Supported Decision-Making Can Still Work

Deaf Children, Hearing Parents, One

At the bottom of this page it reads: Tennessee Council on Developmental Disabilities, Authorization No. 344067, Dec. 2018, 30,000 copies. This public document was promulgated at a cost of $0.61 per copy. Learn more about the Tennessee Council on Developmental Disabilities. 615.532.6615 | www.tn.gov/cdd www.facebook.com/TNCouncilonDD | Tnddc@tn.gov . Subscriptions to Breaking Ground are free and available through the Council office. Contact us by phone or email with subscription updates or requests, and please include name and mailing or email address.

Page 4 Article: Edward Mitchell: ABLE Program Ambassador by Ned Andrew Solomon, Director, Partners in Policymaking Leadership Institute, Council on Developmental Disabilities

This article contains one photo. There are three men posing in a federal government meeting room in Washington, DC. They are Senator Bob Casey, Christopher J. Rodriguez, Director of Public Policy, and Edward Mitchell, the subject of the article. All three men are wearing suits and ties, and Edward Mitchell is sitting in a power wheelchair.

The article begins here:

Edward Mitchell works very hard. He recently completed his Master of Business Administration program. He’s an Independent Living Specialist at the Center for Independent Living in Jackson, Tennessee. He has a part-time job in Fan Relations for the Jackson Generals, the minor league, Double-A affiliate of the Arizona Diamondback baseball team. He also spends part of the year going around the country as a national spokesman for the ABLE (Achieving a Better Life Experience) program, a financial savings initiative designed to help individuals with disabilities put aside money to pay for qualified expenses, so they can maintain independence and enjoy a better quality of life.

As an ABLE spokesman, Mitchell was invited to address congress last year, to talk about the struggles people with disabilities have when their income is severely restricted in order to maintain benefits. That invite came from Tennessee Senator Bob Corker, who wanted to bring in a person with a disability who’s working and someone who, according to Mitchell, was also trying to “blaze a trail”. Enter Edward.

Fifteen years ago, Mitchell was riding his bike with his younger brother. A truck crossed over the double lines and clipped him from behind, catapulting Mitchell into a ditch. He landed on his back and neck, causing an incomplete fracture to his C5- C6 vertebrae. The person driving the truck drove off and has never been found.

Mitchell is living proof that life can change in a moment. He’s also living proof that with enough gumption, you can get back to living a high-quality life, assisting others with disabilities overcome their own obstacles.

The way back

After being stabilized in Jackson General Hospital and receiving preliminary physical and occupational therapy, Mitchell’s family heard about the Shepherd Center in Atlanta, Georgia, which specializes in helping people recover from spinal cord injuries.

“My mother had an expression, ‘while others work and you play, you’ll get further and further behind’, and that was my motivation,” recalled Mitchell. “I wanted to stay with my peer group, which is why I devoted summers to going to therapies at places like the Shepherd Center.”

Mitchell also put in time at the Fraser center in Louisville, Kentucky, the Shriners Hospital in Oak Park, Chicago and the Tennessee Rehabilitation Center in Smyrna. Through his perseverance he was able to return to high school for the start of his 11th grade year at North Side High School, as well as his job with Little Caesars Pizza. “Before my accident I always came into work on time, and always completed my jobs to a satisfactory conclusion, and my boss, Kevin Colbert, knew I had the ‘make-up’ to continue and try to get back to work,” said Mitchell. “He wanted me to work like any other high school student, and he didn’t want to lose a good employee! He also had the foresight to make his place of employment truly accessible, with zero barriers. He really saw something in me and wanted me back as an employee. “

Determined to go to college, Mitchell and his parents started researching options, and contacted Tennessee’s Vocational Rehabilitation program. One particular college had its eyes on him. “The president of Lane College, Dr. Wesley Cornelius McClure, had taken a keen interest in me,” said Mitchell. “Lane College is a Historically Black College/University. President McClure said to me the Sunday after my high school graduation that Lane College is where I needed to be.”

However, none of the students at Lane had a disability like Mitchell, and the family was concerned about accessibility challenges. Dr. McClure assured Mitchell that Lane would be accessible by the time he arrived, and that he would live on campus just like other freshmen. “He was going to make it happen and that my attending Lane would also make it possible for others to attend,” Mitchell said.

As it turns out, Mitchell graduated from Lane College, magna cum laude. He followed that up with an MBA from Union University’s McAfee School of Business program.

A lifeline

“One evening my mother stumbled onto the Tennessee ABLE program,” said Mitchell. “We thought it was a lifeline. It would allow me to start saving without penalizing or jeopardizing my benefits. You see, my parents worry what will happen to me when they’re no longer able to help or they have died.”

ABLE Accounts are tax-advantaged savings accounts for individuals with disabilities and their families. The federal ABLE Act, passed in 2014, paved the way for new state programs modeled after 529 savings plans, allowing those with disabilities and their families put aside up to $14,000 a year to be used for a wide variety of disability-related costs, including living expenses. Money in these accounts do not count against a person’s $2,000 asset limit.

After signing up for an ABLE account, Mitchell applied to be an ABLE Advisor after responding to an email blast. “They were seeking ABLE account holders who could really tell their story, and what they had encountered, to help build the ABLE brand,” explained Mitchell. “There was a three-month-long interview process for that. I happened to make it down to a select few to be the first ABLE Advisor Spokesmen for the national program.”

The dilemma

Even with a Master’s degree under his belt, and acquiring work experience in a variety of settings, Mitchell still can’t accept a full salary, primarily because it would impact his nursing benefits. “I would not make enough to directly pay for nursing care, even if I gave the home care agency my entire check,” Mitchell explained. “Of course, if I did that, then how would I pay for medical expenses, car insurance, car repairs and gas? I need money to have my vehicle maintained at a dealer who is 85 miles away, the only authorized mobility dealer in the area. And, I pay a portion of my income for rent to live at home. I don’t want to put more of a burden on my family.”

With limited nursing hours – currently 27 hours - through a Medicaid waiver, Mitchell’s mother still provides at least 35 hours of his support a week. And sometimes the 27 hours aren’t used because the agency can’t locate a nurse to support Mitchell. “It would be better if individuals like myself could continue to advance in our careers without losing our benefits,” said Mitchell.

One solution is to use a special needs trust, which provides a mechanism for saving money that can be used for the benefit of the person with a disability, without affecting his or her eligibility for benefits. However, special needs trusts must be controlled by a trustee or trustees, not by the person with a disability who benefits from the trust. “Not only does this leave the individual with the disability with little control over his or her finances, it also limits the person’s independence,” said Mitchell.

ABLE accounts give individuals with disabilities the opportunity to manage a modest bank account without penalty against their eligibility for SSI, Medicaid, or other government benefits. Contributions are capped at $15,000 per year and the account cannot exceed $100,000. Funds must be used for qualified disability expenses such as housing, education, transportation, employment training, health and wellness, financial management, legal fees, and more.

Mitchell goes to Washington

That was the message that Mitchell delivered to the Senate Special Committee on Disability & Aging at the Dirksen Senate Office Building in Washington D.C. last July. The hearing was titled, “Supporting Economic Stability and Self Sufficiency as Americans with Disabilities and their Families Age”.

Mitchell had to “pass” a round of questioning from Democrats and Republicans before being selected to present. His trip was paid for by Bob Corker’s office and the ABLE National Resource Center.

To Mitchell, members of the committee seemed receptive to looking into changes to Social Security, and to addressing some of the “outdated laws that on the books”. The Council applauds Mitchell’s efforts to inform our policymakers, and hopes that through programs like ABLE, people with disabilities and their families will be able to live and work to their fullest potentials.

End of article.

Page 6 Article: A Life-Changer: Using Enabling Technology to promote independence, by Krystyne Brown, Public Information Officer, TN Department of Intellectual and Developmental Disabilities.

The article contains two photos. One was described on the cover. The second is a casual photo of Brad Presnell relaxing on a living room couch with his parents, Tom and Paulette.

The article begins here: On a sunny October morning, Brad Presnell gets up from a small, shaded bench on his front porch, opens his glass door and walks into his new home on a quiet street near downtown Kingsport, Tennessee. He finds a comfortable spot on the couch next to his TV and sits back down to relax on his day off from his job at a local Ingles grocery store. He keeps his phone close in case his parents call from their home just minutes away. It’s a life of independence with a place to call his own and it’s the life Brad knew he always wanted.

In May 2018, Core Services of Northeast Tennessee successfully moved another person they support into a home of his own with technology supports through the Department of Intellectual and Developmental Disabilities’ (DIDD) Enabling Technology test program. After seeing how successful it was, they met with Brad and his parents to begin making person-centered plans and decide how technology could also help him meet his goals for his future.

“The ultimate goal is to live as independently as possible and I think this is a huge, huge step for the state of Tennessee and a huge step for anybody that is involved,” said Raymond “Geeter” Lowe, Brad’s Direct Support Staff of six years. “You very seldom [see] life-changers in your life, especially in your job. But this is a life-changer for everybody.”

Together Brad, Core Services, a DIDD Case Manager and his circle of support found a duplex that fit his needs and identified technology that would blend seamlessly into his new home and increase his self-reliance. Video doorbells were installed to screen visitors and sensors were placed on his stove for cooking safety. He was given a medication administration button, a panic pendant to press for emergencies, and an iPad to assist him to communicate and video chat with Geeter or family remotely when he needs them.

Brad’s parents, Tom and Paulette Presnell, were apprehensive at first, but the outcome was one they dreamed of while they were raising him on their farm in East Tennessee. After months of settling in to his home, his parents feel more confident about the technology, his safety, and his ability to navigate his community on his own.

“It’s just unbelievable. Brad’s an only child and we’ve always known in the back of our minds that we won’t always be here and we want to set him up as good as we can,” Paulette added. “This just has been a dream come true. It truly has.”

As DIDD has expanded the use of Enabling Technology, the partnership and buy-in from families is an important factor. As in Brad’s case, family members have been key advocates for the use of technology to promote independence for their loved ones, and it offers them peace of mind knowing help is not far away should an emergency arise.

The technology has taken some time to get used to, but now Brad isn’t afraid to ask visitors for some time alone in his home to enjoy his space. When asked if he loves his new house or independence, he nods and says, “Yes.”

DIDD is now receiving recurring state dollars to continue making Enabling Technology available to transform the lives of Tennesseans with disabilities and assist them in living the lives they choose.

End of article.

Page 7 article: The Enabling Technology Initiative, Year 2, by Cara Kumari, Communications Director, TN Department of Intellectual and Developmental Disabilities.

The article begins here: The Department of Intellectual and Developmental Disabilities (DIDD) is currently in year two of its Enabling Technology Initiative. “Enabling technology” refers to any number of ways that technology devices or strategies can be used to support someone’s independence and goals, in a way that is totally drive by the needs and desires of that individual. After a successful pilot year where Enabling Technology supported several persons who receive DIDD Medicaid waiver services to live more independently, Governor Haslam and the General Assembly provided $500,000 in recurring funds to expand the program.

The highlight of this year’s initiative is Agency Transformation. Three DIDD provider agencies - Core Services of Northeast Tennessee, Prospect, and New Horizons - have been selected to become the state’s first Technology Now agencies. This innovative approach to education, training, exposure and implementation of Enabling Technology, combined with a commitment to person-centered practices and Employment First, will serve as a model of best practice for fostering independence and improving the quality of life for persons supported. Through this initiative, these agencies are receiving assistance from subject matter experts from SimplyHome and AbleLink Smart Living Technologies to develop transformation plans and create a sustainable approach to utilizing Enabling Technology.

The goal is to create culture change within the agencies so that Enabling Technology is a foundational component of supports provided to people. In addition, these agencies have also committed to serving as mentors to other provider agencies as more and more people look to technology as a means of supporting people to live more independently.

In addition to the Technology Now Agency Transformation Initiative, St. John’s Community Services is expanding their Enabling Technology program, and both SRVS (Shelby Residential and Vocational Services) and Emory Valley Center have been selected to receive start-up funding to implement Enabling Technology for the people they support.

End of article.

Page 8 article: Tristar Centennial Offers Sensory-Friendly Rooms for Kids with Autism Spectrum Disorders, by Ned Andrew Solomon, Director, Partners in Policymaking Leadership Institute, Council on Developmental Disabilities.

This article contains two photos. The first is of a pediatric emergency room waiting area at Tristar Centennial. The room is equipped with adaptable multi-colored lights and specialized toys for children who may be on the autism spectrum. The second photo is of Dr. Donna Perlin, who is seen posing in front of the pediatric emergency entrance to the hospital.

The article begins here: As a father of two children on the autism spectrum, I feel like I have a pretty good grasp of what sensory overload looks like for individuals with autism. I can’t say I can feel exactly what they’re feeling when my children are experiencing an overwhelming amount of sensory input, but I do understand why they may react the way they do. I know from our experience that going to see a new-to-them doctor, in a new-to-them building with a new-to-them nursing and check-in staff can be extremely daunting – not to mention the anxiety brought on by a mysterious ailment.

So, imagine how this must feel for a child with autism going to a hospital emergency room for the first time – with a waiting room packed with uncomfortable people in varying degrees of distress, perhaps an ambulance or two with sirens and flashing lights as they drop off patients, or just the extended “waiting” part of the waiting room.

TriStar Centennial in Nashville recognizes these challenges, and has made some innovative changes to be more accommodating for kids on the autism spectrum. Donna Perlin, a pediatric emergency doctor who helped initiate Centennial's efforts, noticed that incoming sensory information from noisy rooms, beeping machines and bustling doctors and nurses could often distract the kids from paying attention to the medical professional who was trying to interact directly with them and cause distress.

“I cared for a nonverbal autistic child in our Emergency Department who presented with gunshot wounds,” recalled Dr. Perlin. “I watched our nurses start IVs with the child standing on the stretcher, clinging to his mother. I saw how they adapted their care to his disability. It was a positive experience that made me realize that this could be done. The staff adapted since it was harder for the child to do so.”

TriStar reached out to Autism Tennessee for help thinking through possible accommodations. Based on that feedback, there are now rooms in the emergency area that have dimmable lighting, soothing toys, weighted blankets, and noise cancellation headphones. Staff can use visual communication boards (for example, to show the child photos of equipment before it is used) and “First, Then” stories with photos of what will happen and what reward will come afterward. It is routine now for the hospital to ask families as they arrive if their child has any special needs, and if so, what triggers anxiety and what calms their child down. This survey is included in the patient’s chart so all staff remain aware of this information. Beeping monitors no longer go off constantly in these more sensory-friendly rooms, just at the nursing station. There is also an effort to reduce the number of different nurses that any one child has to interact with. The hospital’s Child Life specialists have been integral in coordinating these efforts to better support children and families.

Dr. Perlin has a family connection to the autism community. Her efforts at TriStar Centennial began when she with a friend in Tampa who is a parent of a child with autism, and an Emergency Department (ED) nurse. Perlin found out that the University of Florida Center for Autism and Related Disabilities (CARD) was providing resources for local healthcare facilities to help make them more autism-friendly. “She mentioned a difficult hospital encounter with her daughter and we discussed how wonderful it would be to have a program to make caring for these individuals easier for the children, families and staff.”

Dr. Perlin then sent an email to Joann Ettien, Chief Operating Officer of the TriStar Centennial Women’s and Children’s Hospital asking for permission to make a few small changes in the ED and to use the facility name in seeking resources. “My request was immediately granted and she took it farther and suggested that we make these changes facility-wide. She provided the resources and the support to take the program even farther than I had hoped. She said it was the right thing to do for our patients.”

A staff committee was developed, including many staff members who have children or grandchildren on the autism spectrum. According to Dr. Perlin, the committee’s work became a “passion project”.

Fortunately, the program has been very well-received among families that have used the new resources, as well as those families in the autism community who have only heard about it. Dr. Perlin is very grateful for the support of Autism Tennessee, whose executive director, Babs Tierno, has toured the facility and is pleased with the results.

Plans are underway to make more sections of the hospital more comfortable to patients with sensory issues. In addition, HCA Parkridge East Hospital in Chattanooga has toured TriStar Centennial and is committed to starting the program in its own ED. Other HCA-owned facilities are also considering moving in this direction. “We hope to see this spread nationwide as a standard of care,” said Dr. Perlin.

End of article.

Page 10 article: Reflecting on the Great Wisdom of Families: Why collaboration across Tennessee’s Developmental Disabilities Network matters, by Lauren Pearcy, Public Policy Director, Council on Developmental Disabilities.

This article contains one photo and a graphic. The photo shows three women and one man, all professionally dressed, posing at the Association of University Centers on Excellence in Disabilities Conference. The people in the photo are Elise McMillan of the Vanderbilt Kennedy Center, Bruce Keisling of the Boling Center, Wanda Willis of the Council on Developmental Disabilities and Lisa Primm of Disability Rights Tennessee.

The graphic shows three concentric circles. Each circle has a brief description of an agency in the Tennessee Developmental Disabilities Network. The Boling Center for Excellence in Developmental Disabilities provides training for professionals, advances research and provides technical assistance. Disability Rights TN protects the rights of individuals with disabilities, prevents abuse, and provides advocacy and legal services. There are also two descriptors about the Developmental Disabilities Act. The Act was established by Congress and written by families impacted by significant disabilities. The Act creates 3 programs, the DD Network, each addressing the stated needs of families who authored the law.

The article begins here: More than 50 years ago, people with developmental disabilities and their families helped Congress envision, author and enact the legislation we now know as the Developmental Disabilities Act (DD Act) . Today, this law guides our work at the TN Council on Developmental Disabilities by setting our principles and articulating the fundamental belief that “disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.” That quote serves as the opening paragraph of the DD Act, which explains why the Council’s Executive Director, Wanda Willis, often calls it “the most beautiful piece of federal legislation you will ever read”. The values set forth in the DD Act have long served as a guidepost to the national disability landscape, reminding us that everything we do should reflect the principles of self-determination, independence, productivity, integration and inclusion in all facets of community life for individuals with developmental disabilities.

Beyond the philosophical legacy, the DD Act’s authors envisioned and established a trio of programs that could help put the Act’s values into practice. Specifically, these families and advocates saw the need for research and training; for protection of rights; and for collaboration of stakeholders including people with disabilities, their families and policymakers around the same table. To this end, the DD Act conceptualized three distinct entities that would work together as a network: University Centers for Excellence in Developmental Disabilities (UCEDDs); Protection & Advocacy Systems (P&As) and State Councils on Developmental Disabilities (Councils), respectively. In Tennessee, the DD Network’s programs are:

The Tennessee Council on Developmental Disabilities

Two UCEDDs: Vanderbilt Kennedy Center for Excellence in Developmental Disabilities, University of Tennessee Boling Center for Developmental Disabilities

P&A: Disability Rights Tennessee

Tennessee stands out as a model for how the three programs can operate as a network that draw on each other’s unique expertise, as the DD Act’s authors envisioned. In the past year, for instance, Tennessee’s DD Network came together, alongside other partners, to research and disseminate information about Supported Decision-Making - an emerging national best practice about protecting and empowering the decision-making rights of people with disabilities. Tennessee’s work on this topic illustrates how the programs collectively achieve more, collaborating regularly but also delegating certain tasks to fit each other’s unique expertise. In Tennessee’s Supported Decision-Making initiative, the Vanderbilt Kennedy Center helped initially identify the emerging best practice and convened Tennessee’s Supported Decision-Making workgroup comprised of DD Network partners and other key stakeholders; Disability Rights TN contributed legal expertise that has been critical to understanding and explaining the topic; and the Council has been able to design, sponsor and lead events that reach diverse audiences with resources and information. The impact: in just over one year, we reached over 2,500 Tennesseans of all types of backgrounds (individuals with disabilities; families; judges, lawyers and legislators; medical professionals; professors and educators; state agency personnel; etc.). Working as a network expanded each organization’s relatively small capacity, rounded-out our understanding of a complex issue, and ultimately strengthened the impact we were able to have for Tennesseans with disabilities.

Other ongoing examples of Tennessee’s DD Network joint projects benefiting Tennesseans include:

Promoting employment for Tennesseans with disabilities: shared leadership on statewide employment initiatives such as the Employment Roundtable convened by the Council, TennesseeWorks coordinated by Vanderbilt Kennedy Center, and the Employment First Task Force hosted by Disability Rights Tennessee;

Partners in Policymaking™ Leadership Institute: led by the Council and evaluated by the UT Boling Center, this program is a free leadership and advocacy training program for adults with disabilities and family members of persons with disabilities; and

Tennessee Disability Pathfinder, funded by the Council and operated by Vanderbilt Kennedy Center, “Pathfinder” is the state’s comprehensive information and referral source for disability services.

In November, Council Executive Director Wanda Willis was honored with a Lifetime Achievement Award in Washington D.C. during the annual conference of the Association of University Centers on Excellence in Disabilities. The award is given annually to honor an outstanding leader for a lifetime of dedication to people with intellectual and developmental disabilities and their families. It is a testament to the strength of our Tennessee DD Network that a leader from a Council received this prestigious national award, given by the association for UCEDDs. In recognition of this, Wanda invited the leaders of all Tennessee’s DD Network programs to join her in accepting the award.

End of article.

Page 12 article: State Leadership Academy for Disability Services, Year Two, by Ned Andrew Solomon, Director, Partners in Policymaking Leadership Institute, Council on Developmental Disabilities.

There are two photos in this article. The first photo shows one of the Academy graduates, Blake Shearer of the Department of Education, Division of Special Populations, giving a speech from a podium. The second photo is a group shot of all the people who graduated from this year’s program.

The article begins here: The state’s Leadership Academy for Excellence in Disability Services (LAEDS), which the Council on Developmental Disabilities helped to create and launch in conjunction with Tennessee’s Department of Human Resources, has completed its second year. LAEDS is a training program for state employees whose work has a direct impact on individuals with disabilities and their families in Tennessee. The objective of this joint venture is to ensure that leaders who work in state government programs that serve Tennesseans with disabilities operate from a shared set of values, goals and principles while strengthening all agencies' commitment to collaboration.

“I was very interested in bringing together all departments who served citizens with disabilities to ultimately create more effective and efficient services by operating through a collective impact framework,” said Dr. Trish Holliday. “I believe everyone wins when we share resources and collaborate on processes and procedures to ensure maximum efficiencies. I was excited about the possibilities of bringing so many different methodologies together to discover how we could improve the lives of citizens with disabilities.”

Like other employee leadership programs sponsored by the State of Tennessee and facilitated by staff at the Department of Human Resources, LAEDS is comprised of several monthly training sessions that adhere to certain themes – competencies – which are meant to educate and increase the skills of those employees who have a desire to develop professionally.

The Council congratulates 31 leaders from across state government who successfully completed this year’s program. The 2018 LAEDS graduates include representatives of seven state departments: Dept. of Education; Dept. of Intellectual and Developmental Disabilities; Dept. of Health; Dept. of Human Services; Dept. of Mental Health and Substance Abuse Services; Dept. of Veterans Services; and the Division of TennCare.

“The number of graduates and the departments they represent tell us this training will reach broadly across state government, in all the places we are serving people with disabilities,” said Wanda Willis, Executive Director of the Council on Developmental Disabilities. “We partner to provide this program because it goes to the core of the Council’s mission to improve services for Tennesseans with disabilities.”

Dr. Holliday said, “I am proud we have been able to create a leadership development platform that supports the aligning of multiple agencies with various responsibilities and goals. It is a true testament to our state executive leadership who recognized early the value of collective impact and the power of community.”

Competencies

Each of the LAEDS sessions emphasizes a particular “competency” or themed learning module, and presenters are selected who can deliver that content. Competencies include Organizational Agility and Adaptability; Innovation Management; Managing Vision and Purpose; Composure; and Managing Diversity.

“We reviewed Managing Diversity with Dr. Herbert Marbury of Vanderbilt University who emphasized that a diverse workforce is necessary to serve our customers and that we must be diligent on the front end through our hiring process to ensure a diverse culture is created and maintained,” said 2018 LAEDS Graduate, Blake Shearer. “He also challenged us to not have a fixed mindset, that all of us have backgrounds that cause us to see diversity differently, but to never stop growing.”

Shearer, who is Director of Support Services for Student Readiness in the Department of Education’s Division of Special Populations, was particularly inspired by the Driven for Results competency, presented by LaConya Parham of the Dept. of Human Resources. “To me this is what we have to be all about - driven for results!” he said. “Our customers’ lives may very well depend on it. Certainly their quality of life does!”

Dr. Holliday is convinced that technical experts are vitally important to the leadership competencies being studied. So much so that recruiting technical experts in different disability topics became a critical component to planning LAEDS year two, as well as creating a framework for other leadership academies within the State. “The technical track brought subject matter experts to participants and offered an open forum for discussing challenges in particular situations and scenarios state leaders were experiencing in their roles,” explained Dr. Holliday. “The leadership competency studies offered reinforcement to how to apply what they were learning and drive performance excellence throughout their own divisions and teams. The combo approach created a powerful framework for advancing leaders in the area of serving citizens with disabilities.” For LAEDS year two, disability subject matter experts covered topics and best practices like supported decision making, person-centered planning, and the Supporting Families LifeCourse framework.

More than a training program

Under Dr. Holliday’s guidance, LAEDS is constantly evaluated in an effort to improve its offerings. Each session, participants are encouraged to make comments and give criticism which is reviewed by Human Resources’ staff in order to better meet the needs and expectations of those who attend. “By receiving consistent feedback on what is working and what opportunities for improvement existed, participants knew we were ensuring a customized learning experience built to equip them with the most current and relevant skills and practices to apply to their own roles,” said Dr. Holliday.

Through the process of continual improvement and by being responsive to its students’ needs, Dr. Holliday believes LAEDS has evolved into something much more than just a “training program”. “I have witnessed the unfolding of an amazing collective impact opportunity as participants have learned more about their industry together as well as create a larger network of professionals for problem solving and solutions sharing,” she said. “Participants have had the opportunity to explore a common agenda for bringing positive change to serving citizens with disabilities. Most importantly, I believe LAEDS has created more open and continuous communication across the many players to build trust, assure mutual objectives and create common motivation.”

For LAEDS 2018 graduate Shalita V. Wells, brainstorming, problem-solving, and just interacting with her peers from diverse state agencies was one of the most vital aspects of the training. “We got to network and learn about other departments,” she said. “We socialized and we bonded - an experience that will be helpful and taken into account as essential resources.”

“In order to commit to a common agenda, shared measurement systems and joint action plans, we have to develop collaborative mindsets and demonstrate our need to trust each other, and know that our collective interests are equally valued and protected,” explained Dr. Holliday. “Continuous communication provides the platform for trust to be developed, concerns to be addressed, and ideas to be discussed between state departments, thus reducing silos.”

Team Projects

LAEDS is unique because it also includes a team project requirement. This year the class undertook team projects spanning various topics in disability services. One project evaluated the State’s resources for Americans with Disabilities Act (ADA) compliance. Another project looked at developing a statewide strategy for “cross-system” person-centered planning, practices, and services with a focus on increasing employment opportunities, independence and community living options for Tennessee’s citizens with disabilities.

“I am personally passionate about this, as I am a mother of a son with a disability and know the difficulties of navigating services between departments that assist with my son’s needs,” said Dr. Holliday. “The more alignment within state government, the more the citizens receive top quality services with minimal redundancy or extra layers of processes and procedures.”

A third project involved coming up with a marketing strategy to attract and increase the number of employees with disabilities working for the State. At the end of this year’s Academy, all the teams presented their projects to the Executive Leadership Council, which is composed of top leaders from all participating agencies in LAEDS.

Listening to those who experience disability

During the final summit, LAEDS participants heard from a panel of Tennesseans who receive state disability services. For many in the class, that component brought the purpose of the year-long training all together. “This moment was so vital to us as a class, because it reminded us of who we are and what we are called to be,” said Wells.

“I am reminded of the first time we came together as a group,” said Shearer. “I recall a statement made, that across 21 different state agencies, there are dozens of state programs that affect over 1 million people with disabilities in Tennessee. We were challenged to think about the collective impact we can have when we work together!

“On our final summit when we had several individuals and self-advocates speak to us, the resounding message was that state services are improving but we had to continue to be driven to improve our results that impact their lives,” continued Shearer. “We cannot ignore or be in denial about real life challenges that people with disabilities face on a daily basis, whether it’s [navigating] a complex service system, securing competitive employment, finding reliable transportation, or having consistent service providers - just to name a few. However, what we can do is to be driven to improve those results.”

End of article.

Page 14 article: Have You Heard? TRC-Smyrna is Changing! by Patricia C. Wade and Becky Rhea, Tennessee Department of Human Services/Tennessee Rehabilitation Center – Smyrna. Patricia is the Accreditation Coordinator at TRC-Smyrna. Becky is the TRC Outreach Services Administrator.

There is a collage of five photos in this article. The photos show different views of a pharmacy, which has been set up so TRC students can practice working in one of these sites.

The article begins here: It’s true! “The times they are a-changing” certainly applies to the Tennessee Rehabilitation Center (TRC) in Smyrna, and the timing is perfect. Always focused on finding new and innovative ways to train and put students with disabilities to work, the Center is in the midst of its own “perfect storm” of change. As one of only eight rehabilitation centers in the nation with 40 years of serving individuals with disabilities, TRC-Smyrna’s Administrative staff has had their sights set on the future for some time.

Constantly examining existing programs and services, as well as determining critical components of success, TRC-Smyrna began blazing a trail of change several years ago to improve service delivery, promote self-sufficiency, and increase employment potential for persons with all types of disabilities. The TRC-Smyrna Strategic Plan moves the Center into perfect alignment with the Workforce Innovation and Opportunity Act (WIOA) and federal guidelines around employment programs for persons with disabilities, so the path that is now being taken is indeed headed to new ground, in the right direction.

Approximately one year ago, TRC-Smyrna began performing the groundwork for transition to a Career and Technology Model. The new model will replace the current program design with courses of study that will enable individuals studying at TRC to obtain the skills, certifications and/or credentials needed to succeed in today’s labor market.

Future courses and exciting partnerships

TRC-Smyrna is partnering with CVS Pharmacy to offer a Pharmacy Tech program. The program will be 19 weeks and include two sections of training. The first section covers Store Front (Customer Care), in which students will be introduced to the general functions and services of a CVS Pharmacy, including store layout, safety- related and store-specific policies, and retail-specific customer service skills and merchandising responsibilities. The second section, the Pharmacy Tech Program, is offered to students who have completed the Store Front training. Pharmacy Tech students will be trained to support pharmacological services by learning the basic pharmacy operation, layout, inventory management and prescription medication measurements. Upon completion of both Phase I and II, the student will receive a National Certification as a Pharmacy Technician.

The Certified Production Technician program will soon be added to the list of available programs at TRC-Smyrna. This program is in addition to the current Warehouse and Logistics program and is offered in partnership with the Tennessee Department of Labor and Workforce Development, Tennessee College of Applied Technology Murfreesboro, and the Rutherford County Chamber of Commerce Manufacturing Council. A student completing the expanded manufacturing program may earn a maximum of six industry certifications in three different training areas: ACT National Career Readiness Certificate; OSHA 10 Hour General Safety Course Certificate; Manufacturing Skills Standards Council/Certified Production Technician Certificate in Safety, Quality Practice and Measurement, Manufacturing Processes and Production, and Maintenance Awareness.

Leaders of the future

TRC-Smyrna is also preparing students through the Student Leadership Academy, Student Government and the Student Ambassador program.

The Student Leadership Academy provides a nine-week series of classes that include training in essential leadership skills such as communication styles; active listening; how to respond and/or react to a variety of employee situations; feelings and choices; teamwork; incorporating diversity; and the difference between facts and opinions.

The Student Council is a representative structure for students to engage and participate as involved partners at TRC-Smyrna. The student body elects a President, Vice President, Sergeant-at-Arms and five Executive Board Members to represent them in all aspects of campus life. They also assist faculty by providing suggestions and recommendations for improvements. The elections are held three times a year after each quarter. Meetings are held once a month with the student body and faculty. The Rutherford County Election Commission works with TRC-Smyrna to provide voting machines on the day of the election to introduce students to the actual election and voting process.

The Student Ambassador program provides peer support to new students on campus. Students are selected through an application process and complete training regarding strategies for providing peer assistance prior to becoming a designated Ambassador.

To the future

Transformation is underway and it will not only impact the way TRC-Smyrna has operated for the past 40 years, but will bring about positive change. Each step we take to provide quality services and supports to individuals with disabilities, we are contributing not only to one individual, but to the total welfare and socio-economic status of generations to come.

Located 25 miles south of Nashville, TRC-Smyrna is a state-operated comprehensive residential rehabilitation center serving clients of the Tennessee Department of Human Services, Division of Rehabilitation Services from all 95 counties of the state. TRC-Smyrna guided tours are available. For more information, contact TRC-Smyrna at 615-459-6811.

End of article.

Page 16 article: My Brother Does Not Speak, but Supported Decision-Making Can Still work, by Emma Shouse Garton, Communications Director, Council on Developmental Disabilities.

This article has one photo. It is a sweet up close photo of Emma – the article author – and her brother Evan. Their foreheads are touching and they are both smiling.

Author’s note: This article is printed with the permission of my brother, Evan. After writing it, I read it aloud to him and then, by typing, asked him if it was okay for this article about him to be in a magazine that lots of other people will read. He typed “yes”. Thank you to my Council colleague, Ned Andrew Solomon, for encouraging me to “practice what I preach” in this article by allowing my brother to choose what is shared publicly about his life!

The article begins here: My brother Evan is 23 years old and loves the outdoors, swimming, animated movies, listening to music and collecting all things medieval – you’ll rarely find him without a trusty figurine of a knight in shining armor, complete with a sword and steed. He enjoys hiking with our parents and watching movies with his twin brother Brendan. He also enjoys showing off his impressive knowledge of movie trivia when we play online quizzes together. He has an infectious smile, an incredible memory and a keen perceptive sense of how others are feeling.

Evan also has autism, and experiences many barriers in communicating with others using verbal and written language. He completed his school transition program in May at age 22 and for the past year has been living in his own apartment in Franklin with the support of a provider agency called Capital City, which is funded through Medicaid waiver services from the Dept. of Intellectual and Developmental Disabilities.

Evan does not speak very often, and when he does, it is sometimes difficult to understand him or it may not be the most accurate representation of what he wants to communicate. Often he may repeat the last thing or choice someone has said to him when he is asked a question. While he can read words, type words and write words, he very rarely does this independently to communicate what he is thinking or feeling or wanting. When he is able to type or write to tell us information, it’s usually single words or short phrases in response to a question, not proactive communication to tell us something he wants to say.

Over Evan’s lifetime, our family and his teachers, therapists and other professionals have tried all kinds of assistive and alternative communication devices and strategies. None of these technologies or programs has resulted in a reliable way for him to really communicate with us – yet. However, we know from observation that his receptive language is strong and he understands a lot of what is said to him, about him or happening around him – much more than many people realize. He taught himself how to Google things he is interested in and does this frequently, which is another way we get a glimpse into what he enjoys. He is very expressive and it is easy to know, after spending some time with him, how he is feeling about where he is and what’s going on from his body language, actions and facial expressions.

Using Supported Decision-Making to support Evan

“Supported decision-making” is a model that allows people with disabilities to make as many of their own decisions as possible. At the Council, we have been working for the past few years with many partner agencies (including Vanderbilt Kennedy Center, Disability Rights Tennessee, The Arc Tennessee, Family Voices of Tennessee and STEP, Inc.), to educate families and others about this best practice in helping people with disabilities live self-determined lives. While we often talk about supported decision-making as an alternative option to try out before assuming conservatorship is needed for people with disabilities, we fully believe that supported decision-making can and should be used even within a conservatorship. Supported decision-making is any set of practices or strategies that give people with disabilities the help they need to make their own decisions, rather than having others make choices for them, and instead of taking this person’s rights away. So, while my parents do serve as Evan’s conservators (and I am listed as his co-conservator), we try to find ways to support Evan – even with his significant communication challenges – to make as many choices about his life as possible.

How Evan communicates choices & preferences

One typical way we try to find out what Evan wants is to write down, often on a white board or paper, a short list of choices for him to pick between by circling or pointing to his choice. Sometimes, I will type a question for him on my notes app on my phone and give it to him; depending on the type of question, he will often respond independently and appropriately with a couple of words. Other times, this method doesn’t quite seem to “click” and he’ll just hand the phone back to me. If it’s an important question, I will then try to find another way to present the information to him and do my best to get an answer.

Based on my understanding of my brother, these things are important in understanding how to support him in making choices:

If needed, start with basic information about the topic in simple language

Provide choices for him, write those down and read them aloud, so he can process the information both in an auditory and visual way

The temperament/attitude of the person talking to Evan – he responds best when someone talks calmly, quietly and patiently, giving him time to respond

Creative thinking! If one way of writing things down or asking him verbally doesn’t work, is there another way to phrase the question? Show him choices (photos or objects he can point to)? What haven’t we tried?

Be observant! Body language and facial expressions communicate a lot. If Evan refuses to engage with the choices I provide, or seems distressed, maybe he doesn’t like ANY of the choices I provided, or feels confused or frustrated by the question. Maybe he needs a break and I need to rethink how I’m offering the information and asking the question.

Supporting my brother’s decisions in planning meetings

For many years, my family and Evan’s teachers assumed that because of his communication and behavior challenges that he would not be interested in attending his IEP meetings. But a few years ago, we began inviting him to join us at the beginning of the meeting, and offered him the written option every few minutes to “stay” or “leave” so he knew that he had a choice. Sometimes he stayed for the whole meeting, wandering around and listening, or sitting at the table with a fidget toy. Other times, he’d choose to leave to go back to his classroom pretty quickly, and the team decided to meet without him, hoping that we would make decisions in his best interest.

He’s now had a few Individual Support Planning (ISP) meetings – kind of like an Individualized Education Plan (IEP) at the adult level - where we practice the same thing: assume that he should and wants to be there until or unless he wants to leave. This is a work in progress; maybe at some point, if we are really “meeting Evan where he’s at” the whole team can take some breaks, have some snacks, meet somewhere more comfortable than a conference room, do some preparation with Evan beforehand about things we plan to talk about, and really support him to feel comfortable enough to participate as much as he is able, with no decisions made without him unless absolutely necessary.

One way that I’ve tried to help Evan participate in these types of meetings is by sitting beside him with a pen and pad of paper, and trying to write down and “translate” some of the complex topics that we discuss into plain language, while offering him a chance to weigh in if he wants to and is able. This is not a perfect system – it’s hard to really know how much he understands and if I’m succeeding in giving him enough information to form an opinion and make a choice.

This past spring, we held our first meeting with Evan’s Vocational Rehabilitation counselor to discuss employment goals and we tried something new. I noticed that while the meeting opened with the counselor talking directly to Evan, because he did not verbally respond, soon the entire group (our parents, his support staff and other professionals in Evan’s life) began discussing potential employment options that they thought seemed best for Evan amongst themselves. Evan sat at the table, looking bored. Sitting next to him, I tried to quickly take notes in plain language and create choices for him on a notepad so he could weigh in, but the conversation was moving fast. I think we were both getting frustrated.

I noticed there was a large whiteboard in the room, so I stood up and asked if we could pause while I wrote on the board for Evan. I wrote “If I had a job, I would like to work at … “, and “If I had some money, I would like to buy…”. We started brainstorming aloud together about possible types of jobs or workplaces, and I kept a list on the board. Evan leisurely paced around the room and every so often would come by, take a marker and circle some items on the board. We talked about the possibility of finding him a job that would let work outdoors, maybe at a state park – he wrote “park” on the board, which seemed to indicate he liked that idea! Again, it wasn’t a perfect system and looking back, I know we can do better by explaining various options more clearly, being more patient and having a more organized process.

Supporting someone like my brother to make decisions effectively requires some forethought and commitment on behalf of everyone involved in the meeting to “listen” to someone who has not yet figured out the best way to make himself “heard”. It’s my hope that we’ll continue to think creatively as a group about supporting Evan in these ways not only in formal planning meetings or doctor’s appointments or job visits, but in the small daily instances where he could be exercising more choice and control in his life.

Ensuring my brother’s ‘voice’ is heard

As family members, we have spent a lot of time speaking FOR Evan, because we have yet to truly figure out consistent ways to support him to “speak” or communicate for himself and decisions do have to be made in the meantime. I’m learning more and thinking more about how to make sure he feels involved and included in these conversations about his life, and that he truly knows we care about his voice and feelings first and foremost. I’m learning that modeling this for others in Evan’s life – family, friends, professionals and strangers alike - is powerful and makes a difference in the way that they hold conversations in front of him, and how they interact with him. I’ve observed that he seems more engaged and interested and willing to tolerate being at these planning meetings for long stretches of time when someone is doing this sort of support and accommodation for him.

Since learning about supported decision-making, I have grown even more committed to ensuring that Evan’s wishes, dreams and desires are the guidepost for all that happens in his life. It is critical for all of us to find ways to listen and support him in learning about options, so he can have as much control over his own life as possible. After all - this is what each of us wants and expects of our own life.

End of article.

Page 18 article: Deaf Children, Hearing Parents, One World, by Lesley Guilaran, Council Member for Southwest TN Development District, Council on Developmental Disabilities.

The article begins here: I distinctly remember feeling the sense that someone was following me one day when I was with my boys in the local craft store picking up art supplies. I noticed that there was a man and woman who were, indeed, following us. Of course, this made me quite nervous and I had us make our way to the main aisle of the store. At one point, I turned around and the man and woman were standing right next to me. Suddenly they began signing to me and I quickly realized what was happening - they had seen me signing to my kids and wanted to come say, “Hello!”

The first question they asked me was, “Are you Deaf?” I explained to her that I am not actually Deaf, just a hearing mom who was determined to learn her boys’ language. I was honored by the ask, and the shock of joy on their face at finding out I was hearing and chose to learn sign language for my boys brought actual tears to their eyes. They were so kind in communicating with our family and never batted an eye that our boys had cochlear implants. They told me that as children, their parents never learned to speak their language - American Sign Language (ASL). They were thrilled that my husband and I had made the choice to do so.

This scene has played out more than once with our family and honestly, I still brace myself when it happens, waiting for the negative comments about my boys and their Deaf identity in regards to their cochlear implants, because cochlear implants are so controversial. But that has never actually happened to me. Each interaction has been kind and a true gift each time.

Our family was uniquely built through the miracle of adoption. Our oldest son came to us at age four with only the diagnosis of a vision loss. However, we quickly realized that he was not hearing us. After many doctor appointments, we learned that he was indeed profoundly Deaf. After two years in a pre-school where the teacher was fluent in ASL and with parents who signed at home, our son was still not communicating. He was diagnosed with autism and we understood then that the road might be a long one in order for him to learn to communicate.

Eventually, he received a cochlear implant when he was seven years old. We know the decision to obtain cochlear implants is divisive within the Deaf community because it is sometimes viewed as trying to remove the Deaf identity of the Deaf individual. The decision for our family was not made lightly and we truly spent a great deal of time taking in all the different viewpoints and perspectives. However, we found that we were unique in our decision making because speech for our children was never our goal. The goal was always ASL acquisition.

In our experience, we have found that most hearing parents don’t understand how important it is to learn to sign with their Deaf children. Learning sign language feels overwhelming to people at times, but it is so worth it for both the children and the parents. Amazingly, for our oldest son, the sign language connections began to come after receiving his implant. Somehow hearing us speak and seeing the signs made a connection in his mind and he began to communicate in sign language. It still took him a few years to learn to have conversations, but the point is that he can!

I have talked to several parents of Deaf children who also have autism, and they have found the same connection to be true. Our brains are a truly unique and amazing organ in our body system.

Both of our sons are Deaf and they attended our local Deaf school when they were younger. The school was just for lower elementary school students, so currently our sons attend hearing schools and have sign language interpreters with them all day. Our youngest transitioned to a hearing school when he was in the third grade and has even taught a sign language class to his peers several days each week. We are pursuing Deaf mentors for both our boys and have been teaching them with a special curriculum that helps to bridge ASL and written English. We read aloud (and sign) books and watch videos of Deaf people and the remarkable things they accomplish. We are also starting to add Deaf art to our home which displays the beauty of sign language using vivid colors and drawings to illustrate and convey the meaning of words in ASL.

As hearing parents, we have tried hard to do the best we can to foster Deaf pride, to help our children understand that their Deafness is a beautiful thing because that is how they were created. Sign language is a way for us to enter into their world instead of always trying to make them fit into the hearing world. When hearing parents choose to learn their child’s language, it can be one way to show love to their Deaf children. It helps to communicate that their language and identity is important and that they are not broken in any way; that they were uniquely created. We are by no mean experts in this area, just two hearing people trying to understand and love their children the best way we know how.

We are thankful for the Deaf people and hearing people who know sign language in our lives who have helped and guided us. If you have access to a sign language class in your community, I highly recommend you learn. It is a beautiful world to enter and you won’t regret it!

End of article.

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