

BREAKING

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**IN THIS
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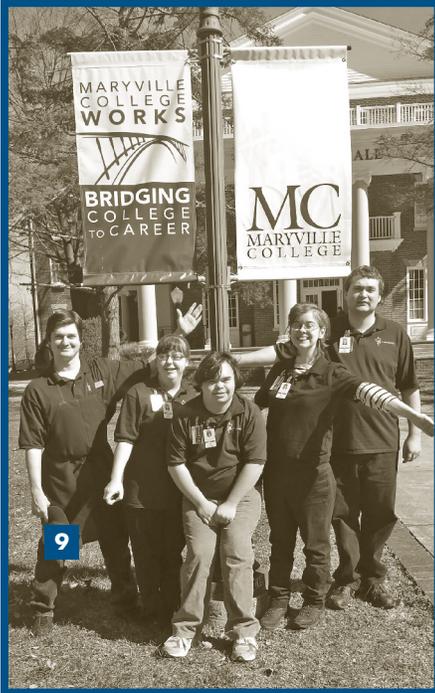
FRIENDSHIP HOUSE

CREATING AFFORDABLE
INCLUSIVE LIVING
OPPORTUNITIES FOR
INDIVIDUALS WITH DISABILITIES



TENNESSEE COUNCIL
on developmental disabilities

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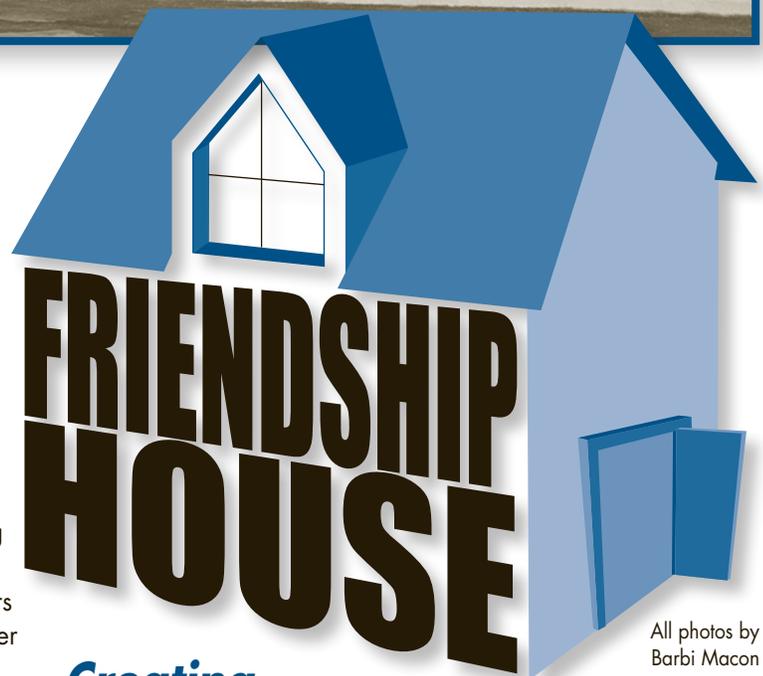
Ribbon-cutting for Divinity Friendship House at Vanderbilt

A small group of families banded together in 2010 to form an intentional Christian community called Castanea. They purchased a “broken” property, out of foreclosure, located near Trevecca Nazarene University. Since the property was a little too big and deteriorated for them to develop alone, Castanea sold half of the property to Urban Housing Solutions (UHS).

UHS set about writing grants to fund the acquisition cost and major rehabilitation that the property needed. The Tennessee Housing and Development Agency (THDA) provided a grant of \$285,000 and the Metropolitan Development and Housing Authority (MDHA) provided \$473,000 to give this project the necessary funding. With grants in hand, UHS hired contractors and oversaw the daily changes from desolation to beauty. After a year of work, the property was ready to operate.

It was during this period that Carolyn Naifeh, who was at the time the regional director for the Pujols Family Foundation, and Vanderbilt Divinity School professor, Jaco Hamman, co-founded a grassroots group called the Nashville IDD Housing Group (NIDDHG). Their goal was to make a dent in the crisis of affordable housing for individuals with intellectual and/or developmental disabilities (IDD) in Nashville. So many of these families had few options for where their loved one with an IDD could live once the parents pass away, leading those parents to spend an inordinate amount of time worrying about their son’s or daughter’s future well-being.

UHS and NIDDHG started meeting to discuss the need and design for IDD housing. These meetings coincided with the final stages of preparation of the Chestnut Hill property. One day, a light bulb went off and both groups simultaneously realized it would be the perfect place for Nashville’s first Friendship



All photos by Barbi Macon

Creating Affordable Inclusive Living Opportunities for Individuals with Disabilities

by Rusty Lawrence, Executive Director, Urban Housing Solutions and Carolyn Naifeh, Executive Director, Nashville IDD Housing Group

House, placing persons with and without disabilities alongside each other, with the added advantage of having the Castanea families as neighbors.

Fast forward to February 27, 2015: the date of the ribbon-cutting for Divinity Friendship House at Vanderbilt, a place providing a built-in community for young adults with intellectual

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Friendship House... Continued from page 3
and/or developmental disabilities (we call them “friends”) and graduate students, most from Vanderbilt’s Divinity School. The friends are required to be over the age of 21 and must work – for pay or by volunteering an unspecified number of hours per week.

An established 3:1 student to friend ratio seems to work very well. Our friends receive the support they need to live interdependently. They develop friendships with neurotypical students and socialize with them on a regular basis, from sharing meals and watching videos, to going camping or reading books to a Castanea neighbor’s child.

On the other hand, the students learn about living with disability, something they cannot do in the classroom or from a textbook. They see our friends’ challenges and victories first-hand. They also, importantly, move on to the next chapter in their lives as advocates for our community and agents for social change.

The Friendship House model is loosely based on L’Arche, founded in 1964 by Jean Vanier, a Canadian philosophy professor. Through his friendship with a Catholic priest, Vanier invited two men with disabilities to leave institutions where they lived and to share their lives with him in a small French town.

As L’Arche explains, “Vanier’s initial urge to ‘do something for’ [these two men] grew to become a commitment to ‘being with’ and ‘being a friend to’ these two men. With that shift in heart



Friendship House’s communal Thursday evening suppers

and consciousness, a core belief of L’Arche emerged: that strength is revealed through weakness and human vulnerability, which, given room to grow in trust, creates community. And, Vanier understood, the desire to love and to be loved is something every person longs to experience.”

Because of its rapid growth, NIDDHG became a 501(c)3 non-profit organization in June 2015, and Naifeh became the group’s executive director. It evolved in one year from an initial group of 20 stakeholders to having some 300 families, educators, community leaders and others passionately supportive of affordable housing and inclusion for those with IDD. Because of the NIDDHG’s partnership with UHS – Nashville’s largest non-profit provider of affordable housing and a champion supporter of fragile populations – a second Friendship House will open later this year just blocks from Divinity Friendship House at Vanderbilt, and about double in size.

The Divinity Friendship House has 11 apartments, four two-bedroom and three one-bedroom. The three friends each have a one-bedroom apartment. The eight graduate students share the two-bedrooms, two to an apartment.

The second Friendship House, slated to open in August, will accommodate 20 people. It will have 19 apartments, one of which is a two-bedroom, and will likely be “home” to eight students and 12 friends. This second has a spacious communal room that can be used for all of the residents to share a meal, watch videos or just hang out. There’s also a common laundry



Jordan, Leo and Alex

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Bailey congratulating Leo on getting a promotion at work

Friendship House... Continued from page 4

and mail room – just like a typical apartment dwelling.

There are two more projects in the pipeline, one very similar to the model above, and the other with a possible new pod-like arrangement, with one big apartment with four bedrooms, each with a bathroom, with all the living area – kitchen, living room and dining room - shared in common.

Currently, 35 people are on the NIDDHG’s waiting list – hoping for the opportunity to live in one of the Friendship Houses that will become available over the next several years. Most on this list are between the ages of 25-35. Diagnoses include autism spectrum disorders (including Asperger’s), Down syndrome, traumatic brain injury, Fragile X and cerebral palsy.

What do the people who live at Friendship House have to say about the experience? Kishundra, a Vanderbilt Divinity student, said, “Living at Friendship House has been an invaluable component of my first year in the graduate program. The communal environment, that unapologetically (and intentionally) includes friends, has stretched my ideas of what it means to be open and affirming in my everyday interactions.”

Another student said, “People can stay here as long as they want. That’s the biggest thing about Friendship House. The design is to be a place of social support, in longevity...Coming here is essential to one’s existence. It allows a person to learn all those necessary things you might not get when you are living under somebody else’s roof.”

Steven, one of the friends, said, "It’s changed people’s lives, and people’s thoughts on what young adults with IDD

could do. Back in the past they said I wasn’t going to amount to nothing and be institutionalized, but now most of us are employed and have friends and are going to college.”

Another friend Matt said, “What I have gotten out of this is getting to know new friends, getting to and from work and school. Plus, it’s also given me a time to be on my own, and, at times, get help from friends and family.”

Matt’s parent said, “Matt has blossomed in the new life he has; he is much more social and communicative than he was before getting his own place.”

Another friend’s parent said, “Leo is working on many of the skills needed to achieve full adult independence. Friendship House provides a safe, supportive environment where he can hone these skills among peers.”

And one of the Castanea neighbors, Stephani, said, “Having the folks next door has opened a window into our future – we see a version of the life our 10-year-old son with Down syndrome may live someday. We’re grateful for these relationships as they attempt to honor the fullness of life lived in all God’s diversity.”

For more information about the Friendship House model, visit www.nashvilleiddhousing.org and www.urbanhousingsolutions.org.



Eric and Steven

Movement on an Autism Presence at the State Level

by Beth Malow,
M.D., M.S.



Beth Malow, M.D., M.S.

In 2015, the State of Tennessee convened an Autism Task Force, consisting of legislators and individuals from state agencies, advocacy groups and healthcare organizations. It has been a privilege to serve on this legislative Task Force and have the opportunity to make a difference in the lives of so many individuals in our state, and their families, who are affected by autism spectrum disorder (ASD).

The Autism Task Force was created based on pioneering groundwork done by the Autism Summit Team, which met for the first time in 2009 and has continued to meet on a regular basis. This Summit Team brought together a diverse group of stakeholders from state agencies, academic health centers, community organizations and the American Academy of Pediatrics, as well as individuals with ASD, parents, psychologists, physicians and behavioral therapists. Co-chaired by Dr. Fred Palmer and Dr. Tyler Reimschisel, with the leadership of the Tennessee Boling Center on Developmental Disabilities and the Vanderbilt Kennedy Center, the membership of the Summit Team involved close to 70 members.

In addition to identifying the need for a comprehensive and coordinated system of care to increase accessibility and availability of services for individuals with ASD, the Summit Team produced a document of recommendations entitled the "Tennessee Autism Plan," which was published in 2014 and is available online at: <http://www.tndisability.org/tn-autism-plan>.

The Autism Legislative Task Force met in December 2015. Carol Westlake, John Shouse and I (representatives serving on the Task Force who also participated in the Summit Team) presented highlights of the Tennessee Autism Plan. After our presentation, the Task Force agreed to adopt the Tennessee Autism Plan.

The areas of emphasis, and recommendations, in the Tennessee Autism Plan include:

Early identification

With as many as 1 in 68 children diagnosed with an ASD, and evidence establishing improved outcomes for those receiving early intervention, early identification with reduced wait times for diagnosis is a critical factor. Recommendations

include expanding the capacity of community providers to recognize the need for ASD screening, with trainings for providers as well as an online hub of resources and linking families to available services ("connecting the dots").

Service coordination

Rated by 90% of families surveyed as very important, but only received by 6% of respondents, service coordination refers to the successful navigation of systems of care so that families and health care providers can communicate and receive/ provide care in a seamless fashion, without fragmentation of services. Service coordination also refers to the integration of care - for example, the collaboration of medical clinicians and behavioral providers in working with a person with ASD.

Information for families

Individuals and families who have access to information on evidence-based therapies and resources in their areas are empowered to be full partners in decision-making. Recommendations include increasing access to all existing sources of information, including websites that are easily navigable, multilingual and culturally competent.

Education

Students with ASD have unique needs, with a multidisciplinary and well-informed team of individuals necessary to construct a plan to enable children to reach their fullest potential. Through training of school personnel, as well as family trainings, the entire team of members responsible for a student's educational plan will be empowered to collaborate and communicate in an optimal fashion.

Healthcare

Access to high quality and affordable healthcare is a challenge our society is grappling with, and for those with ASD, the challenges are even more daunting due to shortages of clinicians with expertise in ASD, particularly in areas of

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Movement on Autism Presence ... Continued from page 6
behavioral health. Expanding ongoing training and support for health care clinicians to develop and improve their ability to serve individuals with ASD is a key recommendation. In addition, expanding access to behavioral services and home and community long-term supports and services are greatly needed.

Aging and Adulthood

The focus of ASD for many years had been on young children. However, given that autism is a life-long condition, and a sizable number of adolescents and adults have ASD, increasing attention is being given to providing supports for age groups beyond young children. Estimates from Tennessee indicated that in 1999-2000, there were 360 adolescents and young adults ages 12-21 with autism. In contrast, in 2013-2014, there were 3,619 adolescents and young adults ages 12-21, a ten-fold increase. Aligning policies, systems, and services to support the transition from youth to adulthood for individuals with ASD and their families, along with providing access to the tools, supports, and accommodations needed for independence, productivity and community life will create success for our adults with ASD. In addition, training first responders and emergency personnel

to interact appropriately and support individuals with ASD is a critical need.

What are next steps for the Tennessee Autism Task Force? Legislation (SB1390/HB1206) creating the Tennessee Council on Autism Spectrum Disorder was proposed during the 2016 legislative session*. This Council would provide a home for comprehensive ASD services in Tennessee, formalizing a mechanism within state government for state agencies and community partners to work collaboratively. We are eager to see this Council created and solidify the creative work of the Tennessee Autism Summit Team in multiple areas that touch the daily lives of individuals and families affected by ASD.

Beth Malow, M.D., M.S., is Professor, Departments of Neurology and Pediatrics Burry Chair in Cognitive Childhood Development Director, Sleep Disorders Division, Vanderbilt University Medical Center.

**Note: While there was support for the passage of the bill creating the Council on Autism Spectrum Disorder, funding was not allocated for the cost of this Council during the 2016 legislative session. Advocates will continue to partner with the involved state agencies and legislators to work towards establishing the TN Council on ASD during the next year.*

Updated Governor's Executive Order: Establishing the Council on Developmental Disabilities in Tennessee

The Council is extremely pleased to have our original Executive Order updated! Within the state, the Council is created by a Governor's Executive Order. Governor Bill Haslam signed Executive Order #50 in September 2015,



updating the Council's first Executive Order from 1975 that was originally issued by Governor Ray Blanton.

This updated Order aligns the Tennessee Council with current language

in the Developmental Disabilities Act, the federal legislation that created Councils on Developmental Disabilities. It serves to clarify the independent role of the Council by placing it in a budget code separate from any state agency that provides direct services to Tennesseans with disabilities. This ensures the Council is able to work in partnership across state government to facilitate improvements to all programs and services that impact individuals with disabilities and their families. This transition also means we will be presenting our budget and information about our work to the state legislature each year.

We are grateful to Governor Haslam's administration for assisting us with updating our Executive Order and affirming the critical role that the Council plays in the state of Tennessee.

Visit the Secretary of State's website at sos.tn.gov to read Executive Orders issued by Governor Haslam.

Governor Haslam and Council leaders celebrate the signing of the new Executive Order; back row, from left to right: Executive Director Wanda Willis, Governor Bill Haslam, Council Chair Roger Gibbens; front row: Past Chair Stephanie Brewer Cook and Vice-Chair Tommy Lee Kidd

REBUILDING MYSELF

from the Ground Up:

by Cody Barnes, UT Chattanooga Student and MoSAIC Program Participant

A Personal Perspective on the UT Chattanooga MoSAIC Program

MoSAIC is a multifaceted and comprehensive program developed to support the holistic needs of UT Chattanooga students with Autism Spectrum Disorders (ASD). In existence since 2008, MoSAIC was developed out of the request and expressed needs of students with ASD. The program is comprised of four primary components: a credit-bearing course with a fully established curriculum; academic/life coaching; peer/faculty mentoring; and required supervised study hours.

Metamorphosis is a very commonly used word, like a well-worn sock it has traveled far and wide adorning many a metaphorical foot. However, this is the most adequate way I can describe the level and intensity of changes that have occurred in, and around, my personality over the time I have been part of the Mosaic program. Like all metamorphic processes my change went through very distinct stages: the breaking down of pre-adapted structures, rearrangement of base material, and finally the construction of more well-adapted structures.

My first experience with the individuals who would later become some of the most influential people in my life was actually less than pleasant for my then quite neurotic state. After deliberating for over a semester on whether I would indeed request aid for my primary disability, a rare and debilitating visual disorder, I finally made my way to their front office. There I was met with what could only be described as a human dynamo. The cheerful, and as I would later learn almost inexhaustibly energetic, person who greeted me startled me so badly I barely uttered a nearly unintelligible handful of sentences, before all but fleeing the building.



Over the next few days I would return to sort out my documentation: birth certificate, insurance information, emergency contacts, and a set of documents intended for use in a program run by administrators of the Disability Resource Center that helped to train individuals with autism spectrum disorders. I had only heard of ASDs in passing a few times; I hadn't the faintest idea what sorts of challenges they presented to a person's daily life. After completing the package of questions, with some of them striking remarkably and eerily close to home, it felt like a travel pamphlet mentioning me by name and birth-date.

It was determined in short order that I would benefit from the Mosaic program.

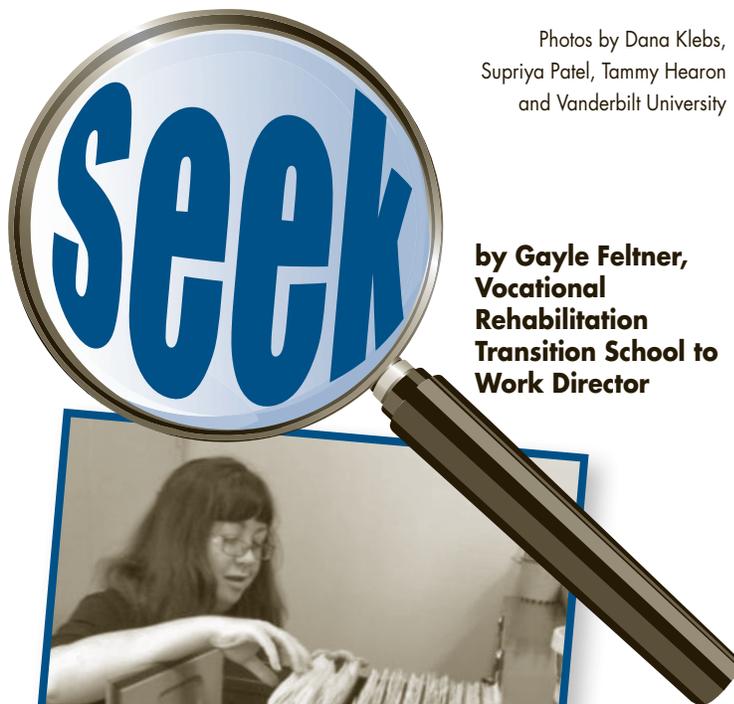
I'll spare you the details of my first class period, to say simply that I had picked an "outing day" to begin my illustrious career as a student in the ways of life. This consisted of a trip to a local market and many a realization that I honestly did not know how to approach some seemingly simple issues. For instance, navigating a crowded place, or even purchasing things from a cashier. Things that seemed so second nature to my mother and sister, and I had assumed would be second nature to me, were incredibly nerve-wracking; terrifying even.

This was quite distressing for me; I had always known I was strange compared to many of my peers, but this new sense of

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SEARCHers

Photos by Dana Klebs,
Supriya Patel, Tammy Hearon
and Vanderbilt University



by **Gayle Feltner,**
**Vocational
Rehabilitation
Transition School to
Work Director**



Trevor Fuller and Tiffany Riggs working at the Metz Café

a Meaningful Transition through Employment



*Brittany
Campbell filing
in the clerical
rotation.*

The Project SEARCH High School Transition Program and Adult Learning Programs are unique, business-led programs that take place entirely at a workplace. Total workplace immersion for one year ensures a seamless combination of classroom instruction, career exploration, and relevant job skills training through strategically-designed internships for youth and adults with intellectual and developmental disabilities.

Project SEARCH is driven by a collaboration of the following community partners:

- A host business, large enough to accommodate 8-12 students with a variety of internships
- A Local Educational Agency (LEA) (For the High School Program only)
- Vocational Rehabilitation (VR)
- A Community Rehabilitation Partner (CRP)
- A Long-Term Support Agency
- Families seeking competitive, integrated employment for their son/daughter

Previously, four Project SEARCH programs (three Adult Learning Programs and one High School Transition Program) existed at Vanderbilt Medical Center (launched by the Council), Montgomery County Government, University of Tennessee Medical Center and East Tennessee Children's Hospital. In 2014, the Tennessee Department of Human Services Vocational Rehabilitation Program and the Tennessee Council on Developmental Disabilities partnered to expand the Project SEARCH program to several more locations throughout Tennessee.

Through a three-year pilot program with Cincinnati Children's Hospital - the home of the original Project SEARCH - five additional programs have begun, and extensive training and

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*Cole Taylor working at the Mountain
Challenge House*

SEARCHers... Continued from page 9

technical assistance has been provided to all nine existing programs.

In FY 2014-15, the following three sites came on board:

- Embassy Suites Hotel, Broadway/Metro Nashville Public Schools
- Embassy Suites Hotel, Murfreesboro/Rutherford County Schools
- Le Bonheur Children's Hospital/Shelby County Schools

So far in FY 2015-16, the Jackson/Madison Regional Hospital/Jackson/Madison County Schools and Maryville College/Blount County Schools sites have been added.

The nine programs are operating with 72 interns with disabilities. Fifty-four (54) of the previous year's interns are employed for at least 16 hours per week in competitive, integrated employment, which translates into a 66% successful employment rate. Rutherford County Schools achieved 100% job placement in 2015, and Blount County reached 100% placement in 2016. A third to a half of the interns become employed at the host business where the job training occurs.

The interns benefit because they:

- Participate in career exploration through a variety of internships within the host business
- Acquire competitive, transferable and marketable job skills
- Gain increased independence, confidence and self-esteem
- Develop linkages to Vocational Rehabilitation and other adult service providers

The host business benefits because it:

- Has access to a new, diverse, talent pool with skills that match labor needs
- Involves interns/employees with disabilities who serve as role models for customers
- Experiences increased regional and national recognition through marketing of this unique program
- Establishes stability and retention in high-turnover, entry-level positions



Tiffany Riggs, Cole Piper and Trevor Fuller

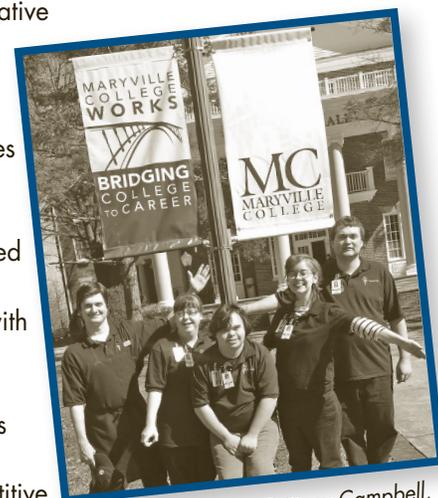
Focus on Blount County's Maryville College Program

Blount County Schools partnered with Project SEARCH for the 2015-16 school year to implement a transition program with students from one high school, with plans to include a second high school in the 2016-17 school year. The

mission for this collaborative project has been and continues to be for Blount County Schools' special service graduates to achieve career readiness, marketable work skills, and increased independent living skills through a partnership with parents, community stakeholders and local businesses. Stakeholders are providing unique opportunities for competitive employment and community relations to produce

productive and independent citizens. The jobs earned by the interns range from housekeeping to café work.

The success of the program can be credited to group efforts of the school and community. The steering committee includes VR, the Department of Intellectual and Developmental Disabilities, Sertoma Center, Maryville College and Blount County Schools.



L to R: Allen Denton, Brittany Campbell, Cole Taylor, Tiffany Riggs, and Trevor Fuller



James Dulin, Metz Cafeteria Manager with Brittany Campbell and Allen Denton, Maryville College interns

"I have always valued programs that engage multiple sets of learners, and Project SEARCH is just such a program," said Vandy Kemp, V.P. and Dean of Students, Maryville College. "Not only are the Project SEARCH interns learning, but Maryville College faculty, staff and students learn from day-to-day workplace experiences with the interns. I think the two best outcomes are that interns are learning marketable skills, and the Maryville College community is learning the value of hiring them. Those are outcomes of an exceptional

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SEARCHers... Continued from page 10

prevocational special education program!"

Tresa Taylor, mother of intern Cole Taylor, believes that Project SEARCH showed up just at the right time in her son's life. "Even though Cole graduated from William Blount High School, I was afraid he did not have the skills necessary to compete for gainful employment on his own. Project SEARCH



Tresa and Cole Taylor

has provided hands-on experience in a controlled environment in which Cole works on a multitude of useful skills. The different job rotations have given Cole an opportunity to actually try a few positions, resulting in a better understanding of what he likes to do and what he does not. He has learned to be confident in his abilities and take pride in his work. Cole has learned how to be an employee, and will graduate from the Project SEARCH Class of 2016 in April employed."

Focus on Vanderbilt Medical Center's Program: a Q & A with Brandon Melton and Chef George

Brandon Melton attended Project SEARCH at Vanderbilt in 2014-15. As an intern, he rotated through multiple departments including Nutrition Services, Patient Transport and the Athletic Dining Hall. He was hired in July 2015 by Nutrition Services, and is still a full-time employee there.

Q: How has working at Vanderbilt changed your life?

Brandon: Doctors thought I was not going to be able to take care of myself or work, but I can and working has changed my whole life. I love Vanderbilt. It is my future. It is a great opportunity for working and changing people's lives.



Brandon Melton

Q: How have you been able to help your family since you started work?

Brandon: I finished paying off my grandmother's bed. It is a nice wooden bed and Granny loves it. I help out with groceries, bills and I bought my momma new outfits and house shoes for Christmas. I am grateful that I have a job like this.

Q: How long do you plan to work at Vanderbilt?

Brandon: 30 years or until I retire, because I have a 401K and retirement plan.

Q: What advice can you give to new Project SEARCH Interns?

Brandon: Think positive, have a great attitude, come to work on time and never miss a day.

Interview with Chef George

Q: How did you first meet Brandon?

Chef George: I met Brandon through the Project SEARCH program. He was [job] shadowing in cold production. He was a quick learner with a bright personality, and the staff loved him.



Brandon Melton and Chef George

Q: Why did you choose to hire Brandon?

Chef George: Because he had a very positive outlook and he is a very hard worker.

Q: What has Brandon contributed to your department?

Chef George: Positivity. No matter what's going on, he's always positive. He is like a bright light every day with a smile on his face. Brandon demonstrates the joy of serving. Not everyone is able to demonstrate that quality; Brandon wears it daily.

In future issues of Breaking Ground, we will bring you more Project SEARCH success stories. For more information on Project SEARCH, visit www.projectsearch.us. If you are interested in speaking with someone about launching a Project SEARCH site in your local community, contact Gayle Feltner at susan.feltner@tn.gov or 615.313.5318.

For the past few years, staff at the Council on Developmental Disabilities have been brainstorming and exploring strategies for how we might address the leadership development of people who work in the field of intellectual and developmental disabilities in Tennessee. We know that oftentimes different departments that have disability programs or services have vastly diverse approaches to supporting their customers with disabilities. We recognize that there is a “greying” of the workforce of current leaders in the state’s disability field, and not enough emerging leaders being mentored, trained and prepared to fulfill leadership positions. We are also aware that there are often “silos” in state government, where multiple agencies are working towards solving the same problem, but not working together to come up with solutions using all the available expertise and resources.

Given all of these factors, the Council wanted a way to ensure that leaders who work in state government programs that serve Tennesseans with disabilities in any capacity could begin operating from a shared set of values, goals and principles and strengthen commitments to cross-agency collaboration. These conversations among the Council staff and, later on, with partners

Preparing Leaders in State Disability Services and Programs

by Emma Shouse, Director of Communications, Council on Developmental Disabilities

at the Tennessee Department of Human Resources led to the vision of a leadership academy.

In 2015, we surveyed all state agencies asking how many of their employees could potentially benefit from this type of training. Through the survey, we learned there are 16 state agencies with well over 55 separate programs that directly impact the lives of Tennesseans with disabilities. Nearly 7,000

Tennessee state employees work in programs where they are expected to regularly interact with customers with disabilities in various ways. It was clear Tennessee would benefit if leaders of these initiatives had a shared understanding of best practices, current research and important trends in the disability field.

The Council began meeting with the Department of Human Resources (DOHR) and its Strategic Learning Solutions office to bring this vision of a leadership academy to life. DOHR hosts a number of leadership development programs and academies for state employees, including LEAD Tennessee, Tennessee Government Executive Institute, Tennessee

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Rebuilding ... Continued from page 8

fear trying to do something that many people do without a thought was a poignant message that I was quite different in a very fundamental way. Many of the others seemed to be affected in a very similar manner, but no one stepped in. Everyone was expected to do what they needed to by themselves. This was my first experience with a task specifically designed to help us work through our own fears or discomfort. I, and almost every student there, would come to know these as challenges.

That day was the day things began to change in earnest. Over the next year we spent much time being taught about the various social structures inherent in society, and what would be expected from us in the future. My biggest challenge during this first year was accepting that the world did not in fact work the way I thought or wanted it to; that the interactions between people were not simply exchanges of words and information, but rather vast and complexly layered webs of signals and feelings that often were not entirely positive.

It was not long into the second year that I began to tear myself down, embracing the notion that I was subhuman and epitomized everything that was negative about my condition. As one would imagine, this was far from healthy for me and led to a very negative self-image overall. Seeing this, and the plight of another student going through a very similar process, the faculty made a decision: they redesigned the entire curriculum. Now year two is centered on reshaping our self-image into something positive through exercises involving community and a sense of acceptance of positive traits and an understanding of negative ones. An enormous amount of work went into helping me rebuild myself. Caring people who are not like us but still want to help give us a fighting chance in a world that doesn’t understand us, and that we in turn barely understand.

My experiences in this program caused me to fall to my lowest point, but it also gave me the tools to build myself back up higher and sturdier than ever. Now I’m looking toward my future with excitement, rather than trepidation.

The Rising Generation of Millennial Caregivers

by Feylyn Lewis

"This article originally appeared as What Millennials Want at <http://www.whatmillennialswant.com/wmw/millennial-caregivers.2>

Growing up in the early 2000s, I thought my older brother and I were the only Millennials with a family caregiving role. When I was 11 years old, my older brother dropped out of his sophomore year in college to take care of my mother. She had undergone a spinal surgery that went horribly wrong, leaving her in debilitating chronic pain.

As a young Millennial, my brother became responsible for my mother's medical care and our household finances. With a seven-year age difference between us, my brother's caregiving role also included looking after me, making sure that I made it to school each day, dressed and fed. My brother acted as the primary caregiver in our home, sacrificing his own dreams so that I might be able to pursue mine. As my mother never fully recovered from her surgery, his caregiving role continues to this day.

In the nearly two decades of our caregiving journey, I had never heard of the term "Millennial caregiver". Moreover, I didn't even see myself as a caregiver until I came across the work of my now-PhD supervisor Dr. Saul Becker in England. His work with children and young adults who provide unpaid care in their families has spanned decades and has shaped the creation of legislative policy and supportive programs in the United Kingdom. Called "young carers" in the UK, I finally discovered there were other young people with family experiences similar to mine. My brother and I weren't alone.

The latest figures released from the National Alliance of Caregiving and the AARP Public Policy Institute show that Millennials (ages 18-34) make up nearly a quarter of the approximately 44 million caregivers in the United States. There is an equal chance that a Millennial caregiver identifies as male or female. According to the NAC and AARP report, the "typical" Millennial caregiver is 27 years old and provides support for a parent or grandparent with a physical condition requiring care. Millennials may also provide care for spouses, siblings, close family friends and their own children. The person being supported may have care needs related to a mental illness, substance abuse issue, developmental or learning disability, HIV/AIDS diagnosis or an age-related disease such as dementia or Alzheimer's. In addition,



Feylyn Lewis and family

Millennials are increasingly providing care for their loved ones with injuries sustained in military service (e.g., traumatic brain injuries).

Caregiving can look very different across families. The types of tasks caregivers may perform include physical care such as lifting a person into bed, personal care (showering, dressing), and administering medicines. They may also be responsible for grocery shopping, household bill payment, cleaning and cooking. Millennial caregivers who also look after their siblings can be found helping with homework or driving them to and from school. For some families, the Millennial caregiver provides emotional support, serving as the voice of reason or the shoulder to cry on during times of stress.

In the interviews that I've conducted around the country, Millennials are sometimes hesitant to label themselves as caregivers. They may not feel that the help they provide to their families "counts as caregiving" because the time devoted to care-related duties amounts to a "few hours a week", or because another family member also provides care in the home. Those who live away from their family are even more reluctant to identify as caregivers, saying that returning to the family home on the weekends or on holiday breaks, i.e., "caring at a distance", somehow reduces their role as a caregiver. In addition, the types of care Millennials provide also plays a significant factor into how they view themselves: those who provide emotional support or help care for siblings may feel disqualified from the title of caregiver.

The issue of self-identification for Millennial caregivers has reverberating consequences, namely, how they are perceived

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Millennial Caregivers... Continued from page 13

by society at large. When Millennials disqualify themselves from the title of caregiver, the way we view their important role in the family is at risk for demotion. On a macro-level, Millennial caregivers are essential participants in our nation's health care system. They help contribute to the estimated \$470 billion worth of unpaid care provided by family caregivers, helping to relieve the burden on our health care system. It is essential that Millennial caregivers recognize their significant value in their individual families but also society at large.

Millennial caregivers remain overlooked in public policy, particularly with regards to respite care funding. National advocacy organizations and community support groups tend to focus on the needs of older caregivers, neglecting to address the realities facing caregivers in college or those without a stable career. Similar to older caregivers, Millennial caregivers are at risk for social isolation, particularly when the demands of caregiving are high and time-consuming. Without supportive programs that directly attend to their distinctive needs,

Millennial caregivers can feel lonely, isolated, and forgotten.

We need a more inclusive conversation about caregiving. Caregivers of all ages are vital members of society and deserve our recognition and support. Millennial caregivers do exist and are not rare. We must champion their cause and direct our attention to addressing their needs in policy, services and funding. The way we view caregiving must also broaden in scope, ensuring that those who "care at a distance" or provide care in conjunction with other family members feel valued. Every act of caregiving is important. By expanding our conversation about caregiving, we lift up the Millennial caregiver to a place of appreciation.

Feylyn M. Lewis is a PhD student in Social Work at the Institute of Applied Social Studies at the University of Birmingham in England. A native of Hendersonville, Tennessee and graduate of Vanderbilt University, she is a nationally-certified mental health counselor. Her doctoral research focuses on the identity development of young adult caregivers living in the United Kingdom and United States.

Preparing ... Continued from page 12

Government Management Institute and many department-specific leadership trainings. We worked with Dr. Trish Holliday, MA, SPHR (Assistant Commissioner and Chief Learning Officer at DOHR) to develop the concept of the State's first-ever "discipline-specific leadership training", which would cut across agencies and focus on state employees who touched the lives of Tennesseans with disabilities through government programs.

An Executive Leadership Council was formed to provide guidance about the structure of the academy, select leadership competencies, and influence curriculum development. This team includes Commissioners or high-level leadership from the Departments of Intellectual and Developmental Disabilities, Education, Health, Human Services, Human Resources, Mental Health and Substance Abuse Services, Veteran's Affairs, the Commission on Aging and Disability, the Council on Developmental Disabilities and others. The Executive Leadership Council members chose competencies for participants to study related to managing diversity, process management, organizational agility, innovation management, developing the abilities of employees who report to them and many other areas linked to skilled, trustworthy and expert leadership.

Between 25 and 40 participants from a variety of agencies will be selected for the first Academy, which will take place over 12 months and culminate in a final project

that aims to strategically improve some aspect of state programs or services for people with disabilities. Subject matter experts and Commissioners or departmental leaders will speak at each session. Classes will include generic leadership development presentations and tie those competencies to improving how the State serves customers with disabilities and their families. Core values of self-determination for individuals with disabilities, a lifespan perspective, community-based and integrated supports, person-centeredness, and collaboration will be emphasized throughout the Academy.

Developing this Leadership Academy has required the time, energy, expertise and commitment of many partners across Tennessee state government. According to Human Resources Commissioner Rebecca Hunter, "This Academy will create a growing pool of state employees who have consistent values and learn early on to work across department boundaries."

Council on Developmental Disabilities Executive Director Wanda Willis stated, "We know that through strengthening our collaboration and aligning our goals and values, we can decrease barriers to services, eliminate silos between agencies and increase our collective impact."

Ultimately, we believe this ongoing training program will provide numerous long-term benefits to Tennesseans with disabilities and their families by improving their experiences with all state services.

New 'Employment & Community First' Program

by TennCare Long-Term
Services and Supports
Team

An Effort to Serve More People and Expand Options

Beginning July 1, 2016, individuals with intellectual and other developmental disabilities in Tennessee will be able to apply for long-term services and supports through a new TennCare program called Employment and Community First CHOICES (ECF). Long-term services and supports programs for individuals with disabilities or the elderly are also known as "Medicaid waiver" programs.

ECF was developed through several years of planning and public feedback. To gather this feedback, TennCare partnered with the Tennessee Department of Intellectual and Developmental Disabilities (DIDD) to host community forums in each grand region of the state. The meetings included people currently receiving long-term services and supports

and people who are not receiving services, their families, disability advocates and providers. Participants were split into groups based on those five categories so that each could give feedback based on their unique perspectives.

TennCare created the new program design based on this feedback in an effort to ensure it will provide the services and supports people and their families say they need most. TennCare's objective is to provide services and supports more cost-effectively with a long-term goal of serving more people, including those on the

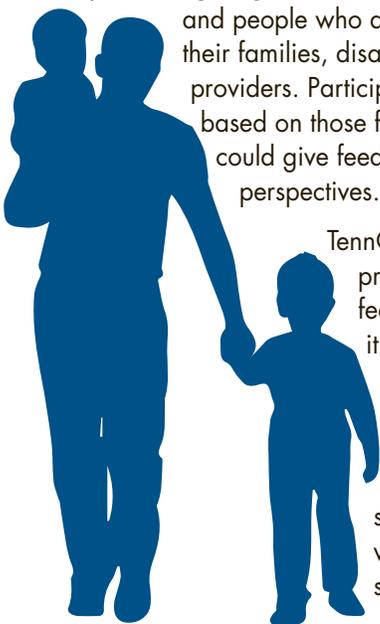
waiting list and people with other kinds of developmental disabilities, a group previously unserved through the State's existing Medicaid waivers, which based eligibility on intellectual disability, defined as an IQ of 70 or below.

With ECF, Tennessee will become the first state in the country to develop and implement a home- and community-based services program that coordinates all health and long-term services and supports, aligning incentives toward promoting and supporting integrated, competitive employment and independent living as the *first and preferred* option for people with intellectual and developmental disabilities.

Who is ECF for?

ECF will provide long-term services and supports for people with intellectual and other developmental disabilities who are not currently receiving services. People in current waivers through DIDD will not be impacted, but can choose to move to the new program later on. That means if you are enrolled in a current waiver program, your services will not change unless you choose to apply for the new program in the future.

Initially, the new ECF program will be available only for people who are not receiving services. It will take time to be able to serve all of the people who need support. Initial enrollment will target groups that were identified by stakeholders including people with aging caregivers (defined by state law as age 75 or older), young adults transitioning from school and other people who need employment supports. Approximately 1,700 people will be enrolled in the first year of the program.



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Employment and Community First ... Continued from page 15

What will ECF offer?

Three benefit groups were designed to offer available services and supports based on each person's specific assessed needs and goals. The benefit groups are called:

- *Essential Family Supports*, which targets people of all ages who live at home with their families;
- *Essential Supports for Employment and Independent Living*, which targets people who are 21 or older who are living or want to live independently and pursue employment and community living goals; and
- *Comprehensive Supports for Employment and Community Living*, which targets people who are 21 or older who need a more comprehensive level of support to meet their employment and community living goals.

These benefit packages will focus on employment and independent living in the community. Each package will offer an array of employment services and supports, which were designed in consultation with experts from the federal Office on Disability Employment Policy.

The employment supports target a "pathway" to employment and career planning, focused on services that meet people wherever they are on their career path: from exploring their interests and skills, to on-the-job supports, to career advancement. Also, many new self-advocacy supports will be offered to empower individuals and families toward independence and integration, like Peer-to-Peer and Family-to-Family Supports, help with navigating health insurance forms and accessing decision-making supports. Plus, people and their family members can receive reimbursement to attend conferences or other opportunities to learn about directing their own service planning and understanding their rights and choices.

For people who need more comprehensive supports, the program includes a benefit package that recognizes exceptional medical and behavioral needs, and offers residential services that may include up to 24-hour support, in addition to the employment and community services offered in the other benefit packages.

What else do I need to know?

The new program will be different from the current waivers because it will be operated by TennCare health plans (Managed Care Organizations or "MCOs"). In an effort to improve service coordination, all people receiving services and supports will have a "Support Coordinator" who develops

a document called a "Person-Centered Support Plan", outlining the person's goals, lifestyle preferences, support needs and services authorized through the new program. This plan also includes services and supports the person may access from other programs or from people who care about them, known as "natural supports".

The MCO Support Coordinator's role includes assessing and coordinating things like goals related to employment, community living, and health and wellness; access to physical and behavioral health services and Long-Term Services and Supports; the role of one's natural and social supports; and the person's choices and preferences with respect to services, settings and delivery options.

People enrolled in the program can use providers contracting with their MCO, or may be able to hire their own workers through "consumer direction". Consumer Direction allows people to recruit, hire and train their own workers instead of using workers from a provider agency for certain services.

DIDD will assist people who are not Medicaid-eligible in applying for the new program, and will partner with TennCare on certain aspects of ECF, like intake, quality monitoring and critical incident management. If someone already has TennCare (Medicaid), their health plan (MCO) will help them apply for the new program.

When will the new program be implemented?

ECF was approved by the Centers for Medicare and Medicaid in February of 2016. TennCare's anticipated start date for the new waiver is July 1, 2016. Starting July 1, people who are interested in applying for the ECF waiver can contact DIDD regional intake offices or, if the person already has Medicaid, their assigned MCO.

For more information on TennCare Long-Term Services and Supports, please visit <http://www.tn.gov/tenncare/section/long-term-services-supports>.



Kindred Stories Underline Gaps in Services and Families' Efforts to Make It on Their Own

by **Ned Andrew Solomon**, Director of Partners in Policymaking™ and Editor-in-Chief of Breaking Ground

Since 2004, many Tennesseans with disabilities, families and disability service providers have shared their stories with the Vanderbilt Kennedy Center's Kindred Stories of Disability project. The submitted stories and interviews serve multiple purposes. They help others with similar stories cope and learn; create awareness of disability issues in our state; educate service providers, state policymakers and the general public on issues of disability; and promote positive change in the community.

Tennessee Kindred Stories of Disability is a website, a series of print booklets primarily for legislators, and a service-learning project for students at Vanderbilt and Belmont Universities. Kindred Stories gives individuals with disabilities and their families an opportunity to share their voices and stories. The stories give legislators, who are making important policy decisions, a chance to better understand the experiences of constituents with disabilities and their families. Participating students get a chance to learn about the challenges and successes that people with disabilities and families experience.



Iris Miller with daughter

A collaboration with the Supporting Families initiative

In 2013, Tennessee was one of six states selected to participate in a Community of Practice – a gathering of different entities who are working on a common goal – called the Supporting Families project. In Tennessee, this initiative was spearheaded by staff at the TN Council on Developmental Disabilities and the Department of Intellectual and Developmental Disabilities. The idea was to focus on families that experience disability, in an effort to identify and develop supports for the whole family in a fiscal environment of limited government services. What could be done to help ALL families, not just the small percentage that are aligned with government supports, and how can we learn from those

families who are somehow making their way without the support of long-term disability services?

At the heart of all this work was an end goal – that individuals with disabilities and their family members live meaningful, satisfying lives, and that they are not isolated, but significantly engaged with their communities throughout their lives. The initiative aims to enhance the capacity of families to support their family member with a disability across the lifespan and in building skills of self-determination, self-advocacy and community participation.

How better to find out what families need, and how they have overcome their challenges and enjoyed their successes, than to talk with them? So that's exactly what we did. Using the Kindred interviewing model, we recruited several families and enlisted a number of Vanderbilt students to interview them to determine their struggles and accomplishments with forging connections to their communities.



Deborah Duncan Hyde and her son, Luka



Morgan and her mom

Common themes

There are common themes that surface throughout these family interviews. Viewed in the most positive light, families will recognize that they are not alone, and that some families have figured out ways to work around the biggest obstacles. However, many families expressed

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Kindred Stories ... Continued from page 17

similar challenges or barriers to achieving the type of meaningful and productive future they wish for their loved one with a disability.

These are the most commonly noted challenges:

- The lack of public transportation options, accessible or otherwise, in many communities severely inhibits the ability of individuals with disabilities to go to work, attend classes or training, or participate in community and social activities.
- Most parents, and in some cases siblings, have some level of fear or anxiety about the future, in terms of who will care for or support their family member with a disability when they are no longer around or able to.
- Individuals with disabilities and their family members frequently battle the low expectations of others, including those of medical professionals, teachers and sometimes other family members.
- There seems to be a pervasive need for, and lack of, qualified, dependable respite services.
- Most parents feel like they are the only ones who are able to, or care enough to, provide supports for or advocate on behalf of their loved one with a disability.
- Many individuals with disabilities, as well as their family members, frequently feel isolated.
- There are too few services for those with developmental disabilities other than intellectual disabilities.
- Many families and individuals lack a social network, even those who are successfully employed.



Patti Lehigh with family

However, on the good side:

- Some have been able to access natural community supports, instead of waiting for disability services to provide or develop supports.
- Several families have recognized the need to thoughtfully prepare for life's later stages.



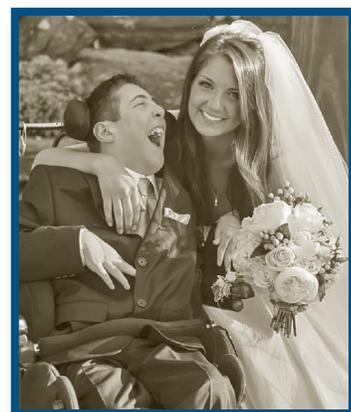
Amy Harris with daughter, Sara Solomon

- Some families do enjoy a supportive network of close friends and nearby extended family members.
- A number of parents have risen to the levels of leaders in their communities by making efforts to improve outcomes for all families who have members with disabilities, not just their own family.
- Families feel empowered by having access to information which enables them to make their own informed choices and decisions.
- Some have discovered that minor supports and accommodations can make a huge difference in a successful employment placement.
- Families have found community integration opportunities for their sons and daughters through volunteering.
- Individuals with disabilities and family members truly appreciate when a person's gifts and strengths are recognized, instead of focusing on "deficits".
- Faith communities can be a wonderful resource – if the parish or congregation is a supportive one.
- Community engagement, in all its forms, seems exponentially easier when the individual with a disability is personally driven to work or be socially engaged.
- Among many parents there is a strong desire to respect their child's autonomy to make his or her own decisions.



The Olden Family

We keep learning important lessons about what families deal with on a daily basis, and about what families need as they navigate their lives and support the meaningful community engagement of their loved ones with disabilities. We will continue to highlight these family stories in Breaking Ground, and in the Kindred project's website and printed materials.



Taylore and Jacob, son & daughter of Joanne Cunningham

Partners 2015-16 Class Graduates

by Ned Andrew Solomon

It's hard to believe that another Partners in Policymaking year has come and gone. And with it, the Council ushers in a new group of graduates who will, hopefully, take their training and teach others in their communities about what they learned.

So, what exactly did they learn?

How to better advocate for themselves, their loved ones and the concerns of the disability community at large.

That the history of the disability experience is filled with troubling and sad stories, but also the positive and productive accomplishments of persons with disabilities and family members, just like them.

That our communities are better and richer when we work to welcome and meaningfully include people with a wide range of abilities, gifts and talents.

That technology can be just the right tool that enhances a person's ability to be successful in school, in the workplace and living in their own home.

That sometimes a bill becomes a law when an average, non-elected citizen with a passion and a plan brings up an idea, and doesn't give up when told it will never work.

That having information about services and resources and how systems work can be empowering and life changing.

That persons with disabilities need to have choices and hopes and dreams just like anybody else.

That none of us are truly independent, and that all of us benefit from the support of someone who has different skills than we have.

That we are not alone in this disability journey.

And much, much more.

The following individuals put in their time, faithfully attending a series of weekend sessions – no matter what else was happening in their busy lives. We are so very proud to call them Partners Grads!

Jacquelin Applewhite, *Memphis*

Shannon Christie, *Spring Hill*

Louvisia Conley, *Memphis*

Greg Costa, *Nashville*



Parish Lakenzie Crawford, *Knoxville*

Joan Estes, *Munford*

John T Farley, *Memphis*

Roslyn Fleming, *Mt. Pleasant*

Dawn Hancock, *Rockvale*

Beth Harrell, *Murfreesboro*

Jesee Hill, *Watertown*

Clancey Hopper, *Antioch*

Samantha Jarrell, *Murfreesboro*

Karen Jones, *Memphis*

Suzanne Lane, *Germantown*

Leigh Peters, *Knoxville*

Larry Reid, *Bartlett*

Amy Smith, *Murfreesboro*

Tara Tate, *Memphis*

Iseashia Thomas, *Memphis*

Marc Walls, *Pleasant View*

Robert Wells, *Madison*

Three pictured 2015-16 Partners – Tom Bryant, Iris Miller and Chris Meyer – will be completing their coursework and graduating with the 2016-17 Partners class.



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