

breaking ground

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Empowered Ladies

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A Path to the Future*
- *2018-19 Partners in
Policymaking™ Class Graduates*
- *People First of Tennessee*



Council on
Developmental Disabilities

Partners Annual Reunion Conference 2019

by **Ned Andrew Solomon, Director, Partners in Policymaking™, Council on Developmental Disabilities**

Photos by **Larry Graves, G & G Photography**

The Partners in Policymaking™ Leadership Institute has been a core priority of the Tennessee Council on Developmental Disabilities since 1993. Nearly 600 Tennesseans – adults with disabilities and family members of people with disabilities – have graduated, successfully completing the seven-session training.

One of the annual activities of Partners is a Reunion Conference. In March of this year, 125 people attended this event, bringing together Partners graduates from across the state to network, learn, and have fun with the current Partners Class, national and local presenters, and a few other “friends” of the Partners program.

Waverly Ann Harris kicked off the festivities Friday with a keynote speech on personal accountability. Russell Lehman, a young man who has experienced numerous challenges and successes as an individual with autism, provided an inspirational closing keynote Saturday afternoon. In between, Partners new and old heard about Tennessee’s post-secondary programs for students with intellectual and developmental disabilities; how to promote social opportunities for persons with disabilities; and current state and federal disability-related policy issues. They also listened to overviews of the Family Support Program, People First of Tennessee, and a Voting Project of Disability Rights Tennessee. And, no



bottom row, left to right: Martez Williams, Jessica Peggs, Adrian Campbell, Adrian Walker. top row, left to right: Jeannette Childress, Angelica Allsup, Sarah Bynum, Allen Nesmith and Cheron Evans

Partners Reunion would be complete without a Friday night dance with our favorite DJ, Ken Buono!

Hope to see you all back next year! The next Partners Reunion Conference will take place March 20 and 21, 2020, at the Franklin Marriott Cool Springs. For more information about Partners, please feel free to contact me at 615.532.6556 or at ned.solomon@tn.gov. You can access an application for the 2020-21 Class on-line at www.tn.gov/cdd/training-and-news/leadership-training-and-development/partners-in-policymaking.html.



Partners “getting down” at the Friday evening dance

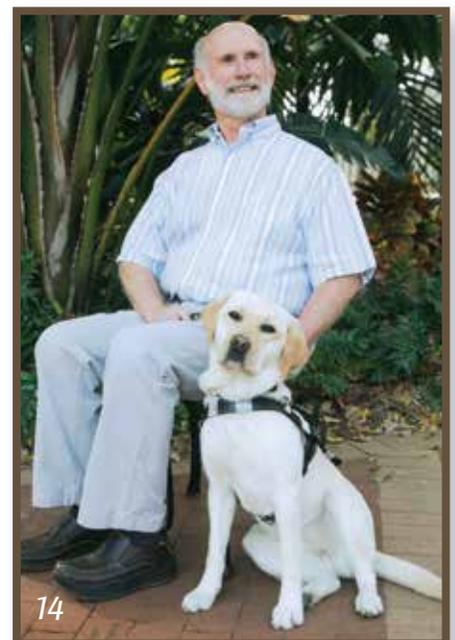
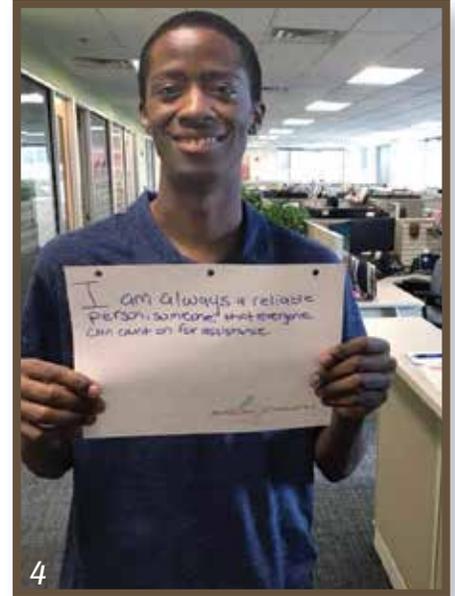
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Cover photo: Empowered Ladies Get Together for Lunch

From left to right, circling around the table: Ebony Cole, Clarisse Durnell, Laura Cox, Britt Cox, Rachel Batey, Lorri Mabry, Nicole Worthy, Albrice Alred, April Meredith, Becky Scott

Learn more about the Tennessee Council on Developmental Disabilities.
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Project SEARCH: A Path to the Future

by Jolene Sharp, Chief Public Information Officer, Council on Developmental Disabilities

It was a classic light bulb moment. Terrell Smith, Senior Director, Patient and Family Engagement for Monroe Carrell, Jr. Children's Hospital at Vanderbilt, was listening to a presentation at a national conference. Erin Riehle from Cincinnati Children's Hospital explained a program she'd founded called Project SEARCH.

"It was a true game changer for me to see young people with developmental disabilities working in a hospital doing meaningful work," Terrell said. "It opened up a whole new world of possibilities."

Erin described interns with developmental disabilities thriving in jobs Cincinnati Children's had previously

found hard to fill. Many of the young people went on to permanent employment at the hospital. "Erin was an emergency department nurse with a clinical background similar to mine," Terrell said. "I was, frankly, ashamed that I had been caring for these children as a nurse and never recognized their potential."

Just a few miles across town from Vanderbilt, the Tennessee Council on Developmental Disabilities was also interested in Project SEARCH. It didn't take long for the Council to connect with Terrell and launch Vanderbilt Children's as the first Project SEARCH site in the state.

Fast forward 14 years. Terrell Smith has an additional title as Vanderbilt's Project SEARCH Business Liaison. The program has surprised her along the way. "The program has far exceeded my expectations," she said. "This is not an act of charity. This is a sound business investment. Vanderbilt has graduates of this program working all over the medical center and in areas off campus."

Vanderbilt has also learned lessons. One has been the importance of involving parents in setting expectations for the interns' capabilities and professionalism. "We learned that parents needed to understand that these interns had the potential for real employment, and with real employment comes real responsibilities," said Terrell.

Ray Vaughns, Manager of Environmental Services, Patient Transporters, and CT1s at Vanderbilt Children's Hospital, currently supervises two Project SEARCH interns. "Our Project SEARCH team members bring another level of energy and appreciation for the jobs we can take for granted," he said. "This attitude helps each person to appreciate what we have. I have always known the value of diverse work groups, but have been blessed to experience our work environment through the eyes of our Project SEARCH team members."



Intern Rashad Ward with Angie Garay, his supervisor during a call center rotation at Amerigroup



Jacqueline Valiterra working in the Wilderness at the Smokies gift shop

Sam Nafzger is one of those team members. Sam said he's learned safety rules, how to navigate the many hospital floors, and how to properly move beds and cribs. He dreams of permanent employment. "I want a job in this department."

Ray Vaughns said Project SEARCH shows that employers should hire people with developmental disabilities. "Every organization can benefit from opening their doors to all members of our society and helping them find their voice in your organization."

More organizations are coming to the same realization. Tennessee currently boasts 16 Project SEARCH sites across the state, with more coming soon. The Council on Developmental Disabilities played a key role in replicating the project across the state, leading to the program's continued growth.

Two of the newest sites demonstrate the variety that is the future of the program: Wilderness at the Smokies, a Sevierville waterpark resort, and Amerigroup, a managed care company. Both joined the program this year.

Tina Stroupe is a prep chef intern with Wilderness at the Smokies. She is learning many things she didn't know before and can't pick a favorite part of the job. Like so

many fellow Project SEARCH interns, she has found a vision for her future. "I love everything there," she said. "I want to keep working as a prep chef in the kitchen."

Lisa Parm supervises another Project SEARCH intern in her role as Laundry Supervisor for Wilderness at the Smokies. Lisa said Tony Davis brings happiness to his work. "He is helpful and hardworking. I've learned that there are people who are willing to work and not afraid to do what's asked."

Those contributions have had a positive impact across the organization, said Talent Acquisition Manager Trish Cook. "All of our student interns have integrated into the Wilderness culture beautifully. Not only does this program help our interns to learn about the working world, but also is a positive program for all our employees. It has increased our appreciation of diversity in the workplace."



Left to right: Vanderbilt Children's Environmental Services –Marquise Fowler (last year's intern – now employee and mentor for other students), Taylor Bryant (intern), Sam Nafzger (intern), and Mr. Ray Vaughns, Manager of Environmental Services

“ It was a true game changer for me to see young people with developmental disabilities working in a hospital doing meaningful work. ”

“People with disabilities bring more to the workforce than just skills; they bring with them determination, loyalty, commitment, and hard work.”



Tina Stroupe loves everything about her job as prep chef for Wilderness at the Smokies

Employment Specialist Stephanie Potter said that positive impact has been felt at Amerigroup, as well. Amerigroup is a provider for TennCare’s Employment and Community First (ECF) CHOICES program. ECF CHOICES provides supports for people with disabilities to be as independent as possible. That includes supports for employment. Amerigroup felt it should lead by example in its own workplace.

“While we expected our employees to enjoy the experience [of working with the interns], we’ve been pleasantly surprised at the positive impact Project SEARCH has had on our associates’ understanding of and commitment to the people we serve. We have seen so

much growth in the interns, our own associates, and the program as a whole,” Stephanie said.

Rashad Ward takes pride in his growth. “The best part of my job is learning the skills of data-entry, an important trade needed to succeed in the workforce,” Rashad said. “The most important thing I have learned is that every task has a process, and when you learn about the steps needed to complete the tasks and follow them on a daily basis, then you’ll become an expert at what you do.”

Like his fellow interns, Rashad wants to find permanent work in the field he’s learning now. All these interns have excellent chances of doing just that; in 2017, 72% of Tennessee Project SEARCH interns went on to permanent jobs.

Stephanie Potter has words of advice for employers considering Project SEARCH. “Take a leap of faith and try something new. People with disabilities bring more to the workforce than just skills; they bring with them determination, loyalty, commitment, and hard work. The positive impact on your current workforce will astound you!”



Lisa Parm and Tony Davis in the laundry department at Wilderness at the Smokies

Chyna's Journey through Employment and Community First CHOICES

by Zennia Nesmith

My daughter Chyna's journey started at a transition meeting two years ago, at a local high school. At that meeting, I met a community advocate named Virginia, who told me about a program called ECF – Employment and Community First CHOICES. Virginia gave me the information to do an intake form online. I had no idea what it was; the program had started the year prior but was still fairly new. I did the intake form that following week and the next day received a call from a really nice lady who set up an appointment in our home.

Ten days later, Chyna and I and an ECF coordinator named Kristen had a meeting. It felt strange, because they asked a lot of questions of Chyna directly, and then Chyna would look at me to answer, since she was almost completely dependent on me at the time. I was very honest and told them I didn't know much about the program. Not knowing what questions to ask and not really being equipped at that time to advocate for my daughter, Kristen had to help me a lot.

I was given a listing of providers in my area. One stood out because they were so open with information over the phone. I agreed to meet with the ECF service provider, and

we selected traditional services from a provider agency. The provider would choose supports to help Chyna learn skills for independence and employment. We all sat down and talked some more about what Chyna wanted. It was a little uneasy in the beginning, because all of the people were talking to Chyna and not to me. At the time, I figured I knew what was best for her, but boy was I wrong!



Chyna at her cooking class



Chyna calculating her purchases in the grocery store

We set up a plan with our first provider, and it worked well for a long time. Chyna was becoming less dependent on her stepfather and me, and getting integrated in her community. She was doing things I never imagined she could do.

Sometimes providers have to change the way they provide services. Chyna's ECF provider did this in May 2018 because of a lack of staff, so we had to go elsewhere. I looked at some local providers and wasn't

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Empowered Ladies

by April Meredith

When Empower Tennessee Executive Director Brandon Brown encouraged me to pursue a personal passion that also addressed a need in our community, Empowered Ladies was born.

Empowered Ladies began in September 2017 as a peer support group run by and for Middle Tennessee women with disabilities. I created this group with the sole purpose of providing a safe, nonjudgmental environment where people with shared life experiences as both a female and as a person with a disability may openly

exchange stories, discuss issues, and connect with others who can relate.

Although these intersecting identities gave us a strong foundation to start meeting and talking once a month, we quickly discovered our mutual feelings of empowerment sparked a desire to be more as a group, and do more – as individuals and as a unified body of self-advocates. We wanted to prove to ourselves and demonstrate to our community that we were more than the labels placed upon us by society. Empowered Ladies provided the optimal supportive foundation for those involved to explore and



Breakfast at 2019 Women's Day on the Hill Seated, left to right: April Meredith, Becky Scott, Clarisse Durnell Standing, left to right: Nicole Worthy, Rachel Batey



l to r: Rachel Batey, Britt Cox, Laura Cox, Becky Scott, Clarisse Durnell and Natasha Wilkins

express who they are, become comfortable with every aspect of their intersecting identities, and confidently present themselves to the world.

It wasn't long before our diverse group of Empowered Ladies turned conversations into action. We gathered monthly, learned what mattered to each participant, respected our differences, and bonded on our foundational purpose.

Members reported increased sense of self-worth and belonging as well as a greater understanding of one's rights and responsibilities. For these reasons, and because several of us had completed or were currently part of the Partners in Policymaking™ program, we decided to expand our intimate group to include advocacy efforts at various Days on the Hill. We even became the first disability-focused group to co-sponsor

Women's Day on the Hill in 2018 and then represented ourselves and the disability community at the event again this year.

Empowered Ladies continues to be an active peer support and advocacy group, but we have an open invitation for new members to join us, wherever they are in life's journey. As I mentioned, some of us, including myself, have benefitted from the Council's Partners in Policymaking leadership and advocacy training. No doubt this has had a positive and overlapping impact on how I facilitate our group's systemic efforts and how some choose to be involved. However, not everyone has had this experience; not everyone is ready to speak with legislators. In Empowered Ladies, we recognize this. That is why women are encouraged to come as they are.

Something I often say to the ladies is, "No one is insignificant." We each have an important role in the group, and what that role is is entirely up to the individual and changes from time to time, depending on the situation and the participant's goals.



Senator Shane Reeves and April Meredith



l to r: Carol Francisco, April Meredith, Becky Scott, Clarisse Durnell and Natasha Wilkins

After all, Empower Tennessee is an organization that empowers people with choice, independence, and inclusion. This applies to each of our core services, and peer support is no exception. Therefore, through Empowered Ladies, social, educational, advocacy, and volunteer opportunities are provided. The individual decides if and to what extent they will engage in any given activity.

Women with beautifully diverse backgrounds and multifaceted interests are welcomed and encouraged to check us out. All are valued and respected. Each of us has chances to laugh, cry, learn, mentor, reflect, vent, share, listen, and grow, all while having fun. We connect with the community and with each other.

You may contact me at aprilm@empowertn.org or 615-292-5803 for more details. We meet for peer group discussions the 2nd Wednesday every month. In addition to participating in advocacy events, we also gather periodically

at local area restaurants to dine and socialize casually. Please reach out if you are interested in getting involved with any or all Empowered Ladies activities.

April Meredith is the Independent Living and Advocacy Specialist of Empower Tennessee and a 2014-2015 Partners in Policymaking graduate. She has Retinitis Pigmentosa (RP), loves her family, and lives life to the fullest.



l to r: Empowered Ladies Becky Scott and April Meredith

2018-19 Partners in Policy

by **Ned Andrew Solomon, Director, Partners in Policymaking™, Council on Developmental Disabilities**

Since 1993, the Tennessee Council on Developmental Disabilities has been offering its free leadership and advocacy training program – the Partners in Policymaking Leadership Institute - for adults with disabilities and family members of people with disabilities from across the state. We are approaching 600 graduates: participants who have successfully finished the intensive seven-weekend, seven-month training. The sessions are taught by national and local disability experts in the field, and offer limitless opportunities for networking.

Graduates have gone on to do great advocacy work in their communities. Several have run for public office. Many have “broken ground” for individuals and families that experience disabilities, by advocating for systemic change. Countless others have served on boards, committees, councils, and other entities, with and without a disability focus, but always bringing the “voice of disability” to those conversations.

The 2018-19 Class will be no different. Please welcome the following individuals to our TN Partners Graduate Network:

- Patrick Adams, Madison*
- Alison Bynum, Smyrna*
- Natalie Campbell, Knoxville*
- Jackie Collum, Nashville*
- Jessica Gant, Jackson*
- Annette Graves, Jackson*
- Stephanie Jackson, Nashville*
- Lacey Lyons, Whites Creek*
- Justin McBride, Memphis*
- Rosaline Mills, Nashville*

- Gabriela Mjekiqi, Knoxville*
- Donna Nasso, Germantown*
- Allen Nesmith, Chattanooga*
- Brittany Norrod, Maryville*
- Cindy Norrod, Maryville*
- Natalie Nunley, Tracy City*
- Patricia Powell, Antioch*
- Bonne Radtke, Munford*
- Yesenia Ramos, Clarksville*
- Joshua Riley, Brentwood*
- Ernie Roark, Oak Ridge*
- Jason Rogers, Chattanooga*
- Becky Scott, Murfreesboro*
- Birtha Street, Nashville*
- Karen Vest, Tullahoma*

For more information about the Council’s Partners in Policymaking Leadership Institute, or to apply for an upcoming Class, please contact me, Ned Andrew Solomon, at 615-532-6556, or by email at ned.solomon@tn.gov, or visit www.tn.gov/cdd/training-and-news/leadership-training-and-development/partners-in-policymaking.html.



Partners grad Gabriela Mjekiqi with her son, Albert



Partners Grad Jason Rogers with his mother, Caroline, and his father, Jim



Partners grad Annette Graves with her husband, Larry, and her son, Jonathan



Partners grad Joshua Riley with his mother, Andrea, and father, Chris



Partners grad Ernie Roark with his assistant, David

ymaking™ Class Graduates

Photos by Larry Graves, G & G Photography



Partners grad Bonnie Radtke with her husband and Partners grad, Bill



Partners grad Stephanie Jackson with her daughter, Teaka, and son, Tiwane'



Partners grad Natalie Nunley with her husband, Bobby



Partners grad Justin McBride with his assistant, Yomika



Partners grad Yesenia Ramos with her friend, Jeff



Partners grad Karen Vest with her husband, Jeff, and son, Jacob



Partners grad Alison Bynum with her husband, Brad, her daughters, Norah (standing), and Charlotte (seated)

“It has been empowering to be in a community of advocates and self-advocates who value the full inclusion and equality of people with disabilities.”



Partners grad Donna Nasso with her husband, Jim, and her son, Jack



Partners Director Ned Andrew Solomon with the 2018-19 Partners graduating Class

People First of Tennessee

by The Arc Tennessee Staff

People First of Tennessee has a long history of advocacy leadership by people with disabilities in this state, going back to the early 80s. In the 90s, People First and its advocates with disabilities, along with other disability organizations, led the way in the sweeping lawsuits against the state that resulted in the shutdown of the large, state-run “warehouse” facilities for Tennesseans with intellectual disabilities. This led the state to move toward supports for community living, offering far greater integration and inclusion for people with intellectual disabilities. Through policies that promote community engagement, inclusion, and self-directed services, the lives of Tennesseans with intellectual and developmental disabilities (I/DD) have greatly improved. We have collectives like People First and entities that support them to thank for much of this progress.

The importance and power of having a large, organized group of people with disabilities advocating for their rights to inclusion, self-determination, peer opportunities, and any other issues they face in their communities cannot be understated. It is with that thought in mind that we get to the vision of People First of Tennessee.

Over the years, the Council on Developmental Disabilities has provided grants and financial support for the People First initiative. The Arc TN received a two-year grant from the TN Department of Intellectual and Developmental



l to r: Scott Finney, Lorrinda Mabry, Breanna Atwell, Peggy Cooper, Dylan Brown and David Griffin

Disabilities to revitalize People First of Tennessee with the goal of re-establishing the premier advocacy organization in the state. We want to reach every corner of Tennessee and offer people with disabilities the opportunity to become members of People First Tennessee, and to help us become a stronger force of advocates linked together with all other People First members and chapters throughout the state. We want to help with the opening of as many local chapters of People First as possible. In the process, we will have a state full of active advocates working to make their communities more inclusive, accessible, and open to people with all abilities.

Since January, we have formed the staff for People First of Tennessee, led by our People First coordinator, David Griffin. He has a supporting staff comprised of Dean Fox, Lorri Mabry, Scott Finney, and Dylan Brown, all advocates with disabilities offering their unique experiences and talents. Three of us are graduates of the Council’s Partners in Policymaking™ Leadership Institute. In addition, Arc TN staff Breanna Atwell helps out with administrative duties and planning. We happily get mentorship, support, and guidance from long-time Arc TN staff member Peggy Cooper.

We have formed our statewide advisory council, and it is 100% comprised of people with disabilities. We have a Facebook page, “People First of Tennessee,” which we will update constantly to keep our members and local chapters connected and informed. We have had more than 100 new members sign up and have helped with the opening of two new People First chapters in Dickson County and Rutherford County. Both are now up and running, with elected officers with disabilities to lead them, ensuring that each chapter is truly directed by and for people with disabilities.

People First of Tennessee will continue to pursue and create a strong network of new local chapters. We will help with training opportunities for members at local chapters on topics like advocacy, self-determination, and public policy. We will support local chapters finding community resources and opportunities. We will have

Continued on page 17

MyRide TN

by Gloria Huber, Partners in Policymaking™ 2017-18 Graduate

People who are age 60 and over have many needs, but in Tennessee, transportation is by far one of the greatest. Over the course of our lives, my husband and I have needed someone from time to time to provide transportation. When the MyRide TN Southeast logo appeared in a local paper, it caught my attention. As I read about the upcoming launch of a new transportation service in Bradley County, I knew that I wanted to be involved.

The mission of MyRide TN is “to improve the quality of life for older adults by providing courteous and safe door-through-door volunteer transportation to those eligible for the service, enabling them to obtain essential services and maintain their independence, dignity, and quality of life.”

The program was first launched in West Tennessee, where it has seen great success. The Bradley County initiative launched on October 15, 2018 and has completed 179 trips as of this writing. I attended the October kick-off session of MyRide TN Southeast and later applied to be a volunteer driver.

There were a couple of concerns for me as a driver. One was liability, which I found is covered first by my auto insurance and then by excess auto, medical and liability insurance for all volunteers (purchased by MyRide TN). Both state and federal volunteer protection laws offer another layer of safety. The other concern involved my own limitations that could prevent me from fully participating in this “door-through-door” service. I discovered that I can choose to accept a trip based on physical abilities and needs of the individual rider, and that drivers are not allowed to lift or carry if doing so could harm them or the rider. My concerns addressed, I felt it was safe to volunteer and began to accept trips.

Volunteer drivers are asked to commit three hours per month to drive an older adult on an essential trip within Bradley County. We are encouraged to donate more time, but it is not a requirement. To date, I have completed four trips that included stops at the grocery, Walmart, Target, the bank, and medical appointments. My riders have ranged from those with vision issues to those with the inability to drive due to advanced age, to those under

temporary driving restrictions while recovering from surgery. Some riders used a rollator walker, while others were able to walk without an assistive device. All were people who live alone. Our conversations between stops have enriched my life and, I hope, theirs. I'm truly enjoying this new experience.

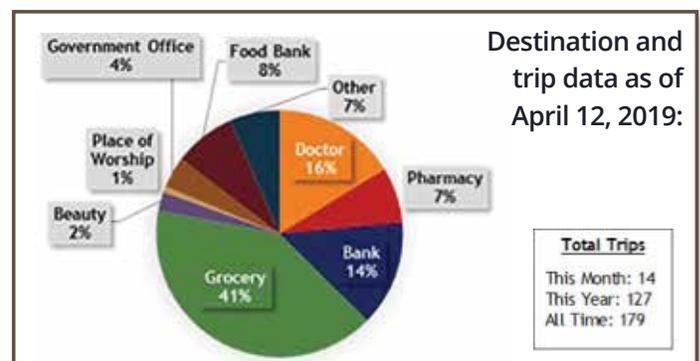


The benefits of becoming a volunteer driver go beyond the satisfaction that comes from helping others. Drivers indicate their availability and only drive when it is convenient for them. We have a dedicated Transportation Coordinator who is employed by the Southeast TN Area Agency on Aging and Disability (SETAAAD). The

Coordinator is committed to the success of the program, its volunteers, its riders, and provides support and technical assistance. We also have an opportunity to refresh our driving skills through the AARP SmartDriver Safety Course, either online or in class. MyRide TN will reimburse our cost of the course, and we may be eligible for a discount on our auto insurance. I'm currently enrolled in the online course and am not only refreshing safe driving knowledge, but also learning about technology that is now standard in newer cars.

I tell my friends about my experience with MyRide TN with the hope that they and their friends will consider volunteering. With the number of riders dependent upon the availability of drivers, volunteers are the very heart of the program.

My Ride TN is a statewide program of the TN Commission on Aging and Disability. To find out more about it, go to Transportation Assistance at tn.aging@tn.gov.



Getting a Life Back with Technology

by Mike Harrell

In 1980, I was 27, with a wife and 13-month-old daughter. We had just moved to Florida from Washington, D.C. so that I could start my new job as a respiratory therapist there. Bike riding was my favorite way of getting around. On my way home from work, three short months after the move, I was struck by a car and landed headfirst on the windshield. Thirteen weeks later, I was sent home from the hospital, blind and with no resources.

I was filled with fear as I was discharged from the hospital. How was I, a newly blinded respiratory therapist, going to support my family? Certain that God did not intend for me to sit around collecting a disability check each month, I went to work to find some way of getting back on the job in the profession in which I had just completed a Bachelor's degree.

Sight for me now is only limited light perception, but at that time, I could see print if magnified to about eight inches tall. I searched the phone directory for magnification devices I could use. (Search engines for the Internet were not exactly in vogue back then.) Somehow during that search, I was directed to the Florida Division of Blind Services. This was the door opening up all sorts of possibilities in my life.

To get me back to work, I was provided a CCTV - a closed circuit TV magnification system. Along with the help of a supportive workplace, this put me back on my professional path. Voice synthesized computer access was an up-and-coming thing, and working closely with the company making our lung function testing equipment, I began performing lung function tests using this brand new technology. Back in those days, the computer voice sounded very synthesized, so it was interesting to note the patient's reactions to the mechanical chatter going on as I performed their lung testing!

It was not long until the department manager left, and I became the hospital respiratory department manager. I served in that capacity for 25 years. Computer access

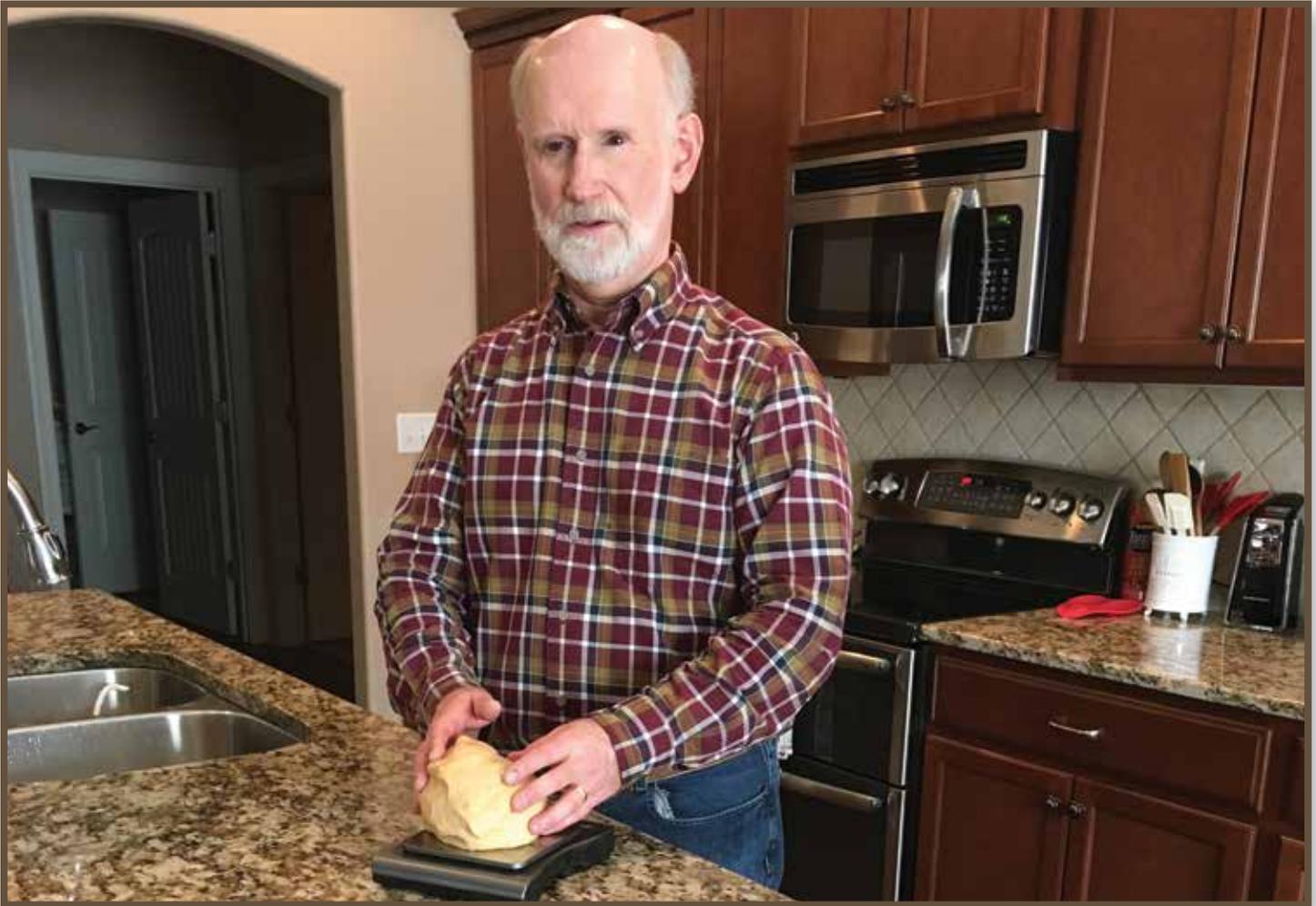
technology kept on advancing, and added significantly to my ability to perform my job successfully.

To learn to skillfully use the screen reading computer technology, I completed training provided at the Florida Division of Blind Services training center in Daytona Beach. The original training session meant a month-long stay away from home, with extra trips back to Daytona Beach as computer systems changed through the years. Not only did I learn computer access technology at the center, but I also learned skills to help me in my daily life.

They also had an excellent library of recorded books. As I love to read, the tremendous library provided to blind individuals through the national Library Services for the Blind has been a powerful contribution to my learning and life experience. Thousands of books, on a wide range of topics, are available at no cost to the blind and those with low vision. When I first began using this service, I received books recorded on cassette tapes in the mail. All those books are now in digital format and accessible for downloading from the National Library Services web site.

In 2005, I moved with my family to the great state of Tennessee, working as the Director of Clinical Education for a medical device company based out of California. I stay connected to the California offices via computer, which makes screen reader software key to my work function. I also travel and speak. For my presentations, I use PowerPoint, which I access through the screen reader program JAWS, which stands for Job Access with Speech. Since moving to Tennessee, I have received some very helpful personalized in-home training in the use of screen reader access to specialized applications.

At home, I use a variety of technologies to help make my life productive and meaningful. Aside from access to e-mail using the screen reader, I use the accessibility functions on my iPhone and Apple Watch, with all of their functions available to me as a blind person.



Mike engaged in a favorite activity: baking bread

Baking bread is a real joy for me, but it has been challenging in the past to get five similarly-sized loaves made out of one big ball of dough. Now I have a kitchen scale which “tells” me how much each loaf weighs as I cut it from the one giant ball. It is very rewarding to have five beautifully formed loaves of bread come out of the oven, hot and smelling delicious!

Alexa is present in three rooms in the house, helping me with all sorts of day-to-day functions. At work, I need to match future dates with days of the week, and Alexa is great at keeping this straight for me. Not knowing for sure if the lights are on or off, it is very convenient just to tell Alexa to “turn off the living room lights” and know that the lights won’t stay on all night. I even keep track of my weight by using a talking scale.

At 50, I developed type I diabetes. It is important to consistently check my blood sugar to keep this under

control, and to know how much insulin to inject for each meal. For several years, I have used a talking glucometer which tells me what my blood sugar is when I place a small blood sample on the test strip. Now I use a continuous blood sugar monitor, which is a small device attached to my abdomen that sends my blood sugar readings to my cell phone. I then simply use my accessible cell phone to check my blood sugar whenever I need or want to know.

Both in my personal life and my work, technology has been a significant part of my productivity and feeling of personal value. This has made every bit of effort I have spent to find and learn this technology more than worthwhile.

Mike Harrell is a respiratory therapist who lives in Ooltewah, TN with his wife, Sharon, and guide dog, Honor. He is the father of Council staff member Jolene Sharp.

Tennesseans of All Stripes Come Together for Children with Significant Needs

by **Lauren Percy, Public Policy Director,**
Council on Developmental Disabilities

Watching the effort to develop a “Katie Beckett” program in Tennessee is an experience I will never forget. As Public Policy Director for the TN Council on Developmental Disabilities, I am familiar with how policy is developed. It can happen a million different ways, but there are generally key factors common to success: data, political will, and human stories. Advocacy in some form shepherds the process along. Although I do not consider myself jaded, I have come to accept the fact that many proposals – even those with good stories, good data, and good advocacy – don’t make it through the policy process. That’s why it has been extraordinary to watch the legislation that passed this year to create a Katie Beckett program. It showed how groups can come together to solve a problem using the policy process.

The history behind the term “Katie Beckett”

The term “Katie Beckett” is short for Medicaid programs for children with significant disabilities and healthcare needs, regardless of their family’s income. The term was coined in the 1980s after Katie Beckett, a little girl who used a ventilator and lived her first three years in a hospital. The Beckett family helped reveal a public policy problem: private insurance would not cover the supports Katie needed if her family wanted to care for her at home, and because her family’s income was too high, Medicaid would only cover the cost of services and supports that took place at a hospital. Through incredible advocacy via their Congressional representatives and eventually President Ronald Reagan, the Beckett family prompted a change to federal law that allows states to create programs to support children like Katie at home. Read about the programs that exist all over the country today, thanks to this policy change, here: <http://www.kidswaivers.org/>

Katie Beckett Legislation in Tennessee: A case study in effective advocacy

During the 111th General Assembly, Representative Sam Whitson (R-Franklin) and Senator Kerry Roberts (R-Springfield) introduced legislation creating a dedicated Katie Beckett program in Tennessee. Previously, there was no waiver program with services just for children with significant disabilities and medical needs. Whitson, whose granddaughter has a disability, said he considers it “the honor of a lifetime” to be able to introduce and support the legislation.

Meanwhile, the Tennessee Disability Coalition helped organize those key ingredients for policy change: data, political will, and human stories told by families. Throughout the month of March, legislative hearings held discussions about the bill’s details. Who will the program cover? How much will it cost? How much detail will be included in the bill, versus leaving details to be decided later through rules and federal documents?

At the beginning of each hearing, families testified about what it’s like to care for a child with complex medical needs. They shared both heartwarming and heartbreaking stories that brought this legislation to life. As the chairman of one subcommittee put it, “I don’t know how this is possible, but my heart hurts and I’m smiling at the same time.” The director of TennCare later repeated that thought, letting his voice trail off and then apologizing that he went off script. Unguarded moments like those marked the hearings.

As the state’s policymakers and disability leaders discussed these complex issues and tough questions (i.e. how to decide who can enroll), it was striking how each one showed respect for their colleagues’ differing views, impressive understanding of the technical details, and real willingness to find a solution. When the bill passed out of the first subcommittee, the room erupted into applause, which is against the rules of legislative hearings. The chairman pointed this out and then added, “and I would not change a thing.” The

humanity of everyone involved – which is all too often forgotten during tough debates – was on full display.

Details of the Legislation

Two state agencies will share responsibility for the Katie Beckett law program: the Division of TennCare (the State Medicaid Agency in Tennessee) and the Department of Intellectual and Developmental Disabilities (DIDD). The bill requires TennCare and DIDD to work together to design and run the programs. It also creates two different programs for children with different levels of need.

Katie Beckett Program Part A

Part A would offer a way to qualify for Medicaid services, including home- and community-based services, for children (under age 18), no matter how much money their parents make. Details about exactly which children can enroll will be decided when the official proposal is sent to the federal government (more on that below). Part A is designed to help children with the most significant disabilities or complex medical needs whose families are most likely to have severe financial problems because of medical costs.

Katie Beckett Program Part B

Part B is designed as a Medicaid diversion plan, which means that children in Part B are not enrolled in Medicaid. Part B would be administered by the

Tennessee Department of Intellectual and Developmental Disabilities, offering benefits known as “wraparounds” to offer much-needed services for child health and family stability. These are the long-term supports and services traditionally provided as home- and community-based care. The cost of these services would be capped at \$15,000 per year, per child. Part B is designed for children who won't be in Part A, but still have needs Medicaid terms “at risk of institutionalization.”

What's Next

After the bill is signed by Governor Lee, TennCare and DIDD will design the program and submit it to the federal government, the Centers for Medicare and Medicaid Services (CMS), for approval. The program design will include details such as what kind of services are offered and who will be eligible. TennCare and CMS may have to work through different ideas about the details, which could result in more changes. Public comment periods will be part of the process; this is when you can say what you think about the plan.

The passage of Katie Beckett legislation is a proud moment for Tennessee. I've often thought to myself that it could be a case study in how grassroots (“bottom-up”) policy change can meet with buy-in from the highest levels of our government.

Be sure to sign up on our website for the Council's Public Policy Newsletter to track the next steps for this bill.

People First of Tennessee... *Continued from page 12*

semi-monthly, statewide, all-member conference calls to help keep all chapters aware of what other chapters are doing, and to build a strong statewide network of advocates.

How do you become a People First member and/or form a local chapter?

Anyone who identifies as having a disability can sign up and become a member of People First of TN for \$5. That comes with a People First t-shirt, access to our semi-monthly, statewide calls, and our weekly newsletter. In order to form a local chapter, you need five or more people with disabilities, a meeting location, and at least one mentor who can help with a chapter's vision. We will

help with finding a meeting location and identifying a great mentor for your chapter if you have a group of peers with disabilities in the same geographic location. You can sign up at: <https://www.thearctn.org/People-First>

Can people without disabilities become members?

Yes! People without disabilities can sign up to be a People First supporter for \$20. You can also be a Business Advocate for \$100.

For more information, please contact David Griffin at dgriffin@thearctn.org, or Dylan Brown at dbrown@thearctn.org. Both can also be reached at The Arc TN's main number, 615-248-5878.

Flying the Friendly Skies

by Jessica Gant, Partners in Policymaking™ 2018-19 Graduate

Just the thought of flying for some people is, well... overwhelming: airports, traffic, noise, long lines, and all those people! Traveling can be stressful, but it doesn't have to be.

I'm an 18-year flight attendant, a 2019 Partners in Policymaking graduate, and a mother of a son with a disability. Inclusive travel, awareness, and a better travel experience are needed improvements to help our passengers with disabilities.



Both the disability community and the airline industry can benefit by knowing the Developmental Disability Passenger Needing Assistance (DPNA) and Special Service Request (SSR) codes. The DPNA and SSR codes exist to help those with an intellectual or developmental disability and to alert airlines on how best to meet the needs of their customers with

disabilities. My goal is to bring awareness about the codes' existence, and to also share my helpful tips for an inclusive and improved travel experience.

Know the Codes

Every airline is different, so, before booking your flight, be sure to review the airline's policies for customers with disabilities. If the airline's customer service is aware of these codes, there are a few options they can provide: early boarding, keeping families seated together, providing help through long security lines, and holding an open middle seat.

I want to encourage those in the disability community to familiarize yourself with the DPNA and SSR codes and to use them whenever you travel. Currently, these codes are very under-used. I believe the main reason for that is a lack of awareness. Last year, the International Air Transport Association reported the DPNA code was only used 4,309 times out of 250 million booked flights. Using these codes when booking your flight, allows you the ability to share specific details on your needs.

Plan Ahead

After reviewing airline policies and booking your flight, call the airline and ask them to document your specific requirements using the DPNA or SSR code. Don't be shy or feel guilty for your request. We are here to assist you – reach out to us so we'll know the best way to help you! Also, I highly recommend you contact TSA Cares -- a security helpline that provides additional assistance for passengers with disabilities. At the airport, ask for a supervisor or passenger support specialist who can provide "on the spot" assistance.

Arrive Early, If Possible

This is SO important! Your airport arrival time sets the tone for your entire travel experience. No one likes to be late or rushed; it adds so much anxiety and stress on everyone. When I travel, I try to arrive at the airport 2.5 hours prior to my scheduled departure.

Be Prepared

Upon arrival, check in with the airline to alert them you've arrived and that you or someone in your party is traveling under the DPNA or SSR code. This will ensure the airline agents have your specific requirements (i.e. assistance through security, early boarding, keeping your family together). I think it's important to also keep in mind that airlines are not allowed to ask about your disability, so it's up to you to share or not. Most airlines will also assist with boarding, exiting the plane, or making flight connections between gates; but an escort won't be available to remain with or supervise a passenger while in the terminal or in-flight. If you require such assistance, inform the airline when booking your flight. Passengers who require personal, continuous attending care, or who are unable to follow safety instructions from airline personnel must bring a safety assistant with them.

Speak Up

Sometimes, no matter how well you prepare, the unexpected happens. If your expectations were not met, say something! Create a paper trail and follow up with a call to customer service. Your feedback helps us meet and exceed your needs. Give the airlines an opportunity to respond to your inconveniences and correct any mistakes.

Of course, if you have a great experience, we want to hear about that, too! Please take a minute to recognize the person who goes above and beyond to make your trip special. I love getting those letters, and most of us work very hard to ensure you feel like a valued guest in our "home."

Happy Flying!



Jessica's son Nate with the Memphis flight deck crew

Chyna's Journey through Employment ... *Continued from page 7*

happy with what I saw. In meeting with some, it seemed like they wanted to keep Chyna busy, but not necessarily prepare her for employment.

Finally, we met with a provider from Cleveland, Tennessee, and they appeared to line up with what we needed. We started services with them, but due to the office being located in Cleveland and us in Chattanooga, it was difficult to get things coordinated for Chyna's needs. I had to speak with Chyna's coordinator to see what her other options were; it had to be whatever was best for Chyna.

We discussed consumer direction, which is different than traditional services from a provider agency. In many ways, it gives the family and individual more control over their services. The family has to work harder and take on some additional responsibilities, though there is some assistance provided by the ECF program. We were assigned a broker with the Public Partnership agency, who handled the background checks and the portal to filling out the application for support staff, which is all done online. The broker came to our home and trained our initial staff and me. They also handled all the payroll issues for our support staff. We were able to decide how much we wanted to pay Chyna's staff person, but, obviously, the more we paid, the less hours of service we'd be able to receive. We

developed a plan based on what we were doing when our previous support services were going well. I went around our community and found things for Chyna to do: mostly activities that would prepare Chyna for work, including opportunities for her to volunteer.

I also hired three mentors to work with her, each with a specific role in decreasing Chyna's dependency. She has a mentor that goes with her to social gatherings with her friends. She has a mentor who supports her in her volunteer activities, as a job coach to assist her in building her skills. She also has a mentor who is a peer, a college student her same age, who encourages Chyna's independence. We have a Google calendar that we all share to keep up with Chyna's activities from week to week. It took a lot to get it established, but this works best for Chyna.

The most important thing to know about any program is that it's not going to be perfect for all of your needs. But if you see that it's not perfect, don't give up, and keep an open mind. Reach for positive outcomes and try to figure out what you can do to make it work better.

Zennia Nesmith is a Membership Account Specialist for Blue Cross Blue Shield Tennessee in Chattanooga, and a graduate of the 2017-18 Partners in Policymaking™ Leadership Institute.

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