TENNESSEE

Date: 2017-09-22 14:09:17
To: My Senator
From: Karen Downer
State: Tennessee
Email: [redacted]

The Arc.

My sister is 60 years old. She is completely mentally disabled--severely retarded, autistic and unable to speak. A good day for her is 3-meals and the opportunity to move around a bit. She must be under constant supervision as she is a danger to herself.

She now lives in a group Intermediate (medical) care facility--ICF run by a non profit in Chattanooga. She was a resident for almost 50 years in a state facility recently closed as a result of decades of litigation against the State of Tennessee. Although, the care she now receives is at best marginal, it can not continue without the current Medicaid structure. I have worked all my life as has the rest of my family and paid into the Social Security and Medicare/Medicaid systems. They are the only thing that keeps my sister alive and safe. We should be working to improve the care of these individuals not to continuously strip it away.

Frankly, I find it irresponsible to think that the State of Tennessee who could not run their own DIDD institutions successfully and does not conduct effective oversight of its new and improved service provider structure could do "more with less money".

Vote no on Graham-Cassidy and find money somewhere besides from the most vulnerable part of our citizenship.

The Arc.

Date: 2017-09-23 17:11:34
To: My Senator
From: Doria Panvini
State: Tennessee
Email: [redacted]

Please vote NO on the Graham-Cassidy bill. Medicaid is critically important to people with disabilities. The proposed caps on Medicaid would be devastating to my son, Chris. Medicaid waiver services are the only supports available for him and the other most vulnerable citizens.

Chris, receives Medicaid Waiver services and I don't know what would happen to him without these long-term services and supports. He is 51 years old and will require supports throughout his live. Chris needs supports for everything he does: he cannot shop for food, prepare meals or manage his money; he needs help in the bathroom; he needs help with transportation and cannot safely cross the street. He has intellectual disability, severe hearing loss, attention deficit disorder, and intermittent explosive disorder. I am 79 years old and I can no longer provide these essential daily supports for him.

With the residential and day supports that Chris has, he is able to live successfully in his community. He volunteers delivering Meals on Wheels and with the Second Harvest Food Bank. These supports have also made it possible to reduce his psychotropic medications.

There are over 4000 people with intellectual and developmental disabilities on the referral, or waiting, list in Tennessee. If Medicaid is severely cut, there will be few options for those with the most significant disabilities, except perhaps a return to nursing homes or institutions.

Vote NO on the Graham-Cassidy bill and protect your constituents in Tennessee.

Thank you.

Doria Panvini

Nicole Jorwic

From: David Griffin [redacted]
Sent: Tuesday, July 18, 2017 3:07 PM
To: Nicole Jorwic
Cc: David Griffin
Subject: Medicaid

To Whom It May Concern:

I work for The Arc Tennessee, and I interview hundreds of individuals who live more independently than ever before. Without Medicaid, the tide would turn back to institutionalization where choices and engagement in the community will be removed.

DG

From: Lesa Grubbs [redacted]
Sent: Tuesday, July 18, 2017 11:51 AM
To: Nicole Jorwic
Subject: Better Care Reconciliation Act (Tennessee)

Dear Senator,

Medicaid matters to my family. Our 22 year old son Kenneth has Autism. We have just recently within the last month began receiving Medicare so we don't even know yet the impact this bill will have on his healthcare. We were also JUST approved for TennCare's Employment and Community First Choices program. We were so hopeful that would be the answer to our prayers. Since this is an optional program under TennCare, it is at high risk of being cut and we were counting on it. With this program, we would receive much needed respite as my husband and I both must work full time jobs to provide for our family. Our son also needs 24/7 supervision and we will care for him in our home for the rest of our lives. More importantly, with ECF Choices, we can keep our jobs and my son can continue to learn and grow on a job and in the community, as well as receive the transportation and the personal assistance he needs while we work.

There are so little services available for adults once they reach 22. Kenneth doesn't deserve to sit at home wasting away losing all the skills he has learned so far in school and in the community. We cannot afford to hire private help, even with our full time jobs. We don't like to ask for help, but we need it.

Please vote NO to the Better Care Reconciliation Act.

Thank you,
Lesa Grubbs

From: Williams-McGhee, Gloria [redacted]
Sent: Tuesday, July 18, 2017 10:49 AM
To: Nicole Jorwic
Subject: Medicaid Matters in Tennessee

My son has Autism through no fault of his own. He is approaching the age for removal from our insurance and his Medicaid is going to be crucial since he will not be able to secure a job that includes insurance. The Medicaid status also affects the assistance that is available through other avenues (if they are allowed to continue to receive funding) to enrich his life as much as possible. There is assistance in having someone to shadow the disabled in their employment, there is assistance in furthering their education to obtain some kind of employment and there are many other avenues that are possible because of the Medicaid status. There are too many cuts that have been suggested that affect our people with disabilities and it is not fair.
Thanks,

Gloria Williams-McGhee
[redacted]

Nicole Jorwic

From: Beatrice Jobe [redacted]
Sent: Tuesday, July 18, 2017 10:03 AM
To: Nicole Jorwic
Subject: Tennessee

Medicaid Impacts our daughter's life in that she is receiving valuable services through our state's new CHOICES program. She is assisted 10 hours per week by a support coordinator. She is helping her learn to shop, cook, operate technology, get a volunteer situation set up and in other ways. In the past her Part B of Medicare paid by Medicaid, but now Medicaid will act as a supplementary policy for her Medicare. She lives independently and has a part time job, but she could not be independent without these services.

Beatrice Jobe

[redacted]

Nicole Jorwic

From: Leisa A. Hammett [redacted]
Sent: Monday, July 17, 2017 9:48 PM
To: Nicole Jorwic
Subject: TENNESSEE

Our state has innovated by creating the ECF (Employment and Community First) CHOICES Program, funded by Medicaid. The first in the nation to respond to Centers for Medicaid and Medicare Services (CMS) ruling changes. It supports my daughter with autism to work, enabling her to pay taxes. No work, less supports = behavioral and physical health problems for individuals with disAbilities and their families long term. Which makes more sense? NO. MEDICAID. CUTS!!!

Leisa Hammett
Author. Blogger. Speaker. ARTism Agent.
[redacted]

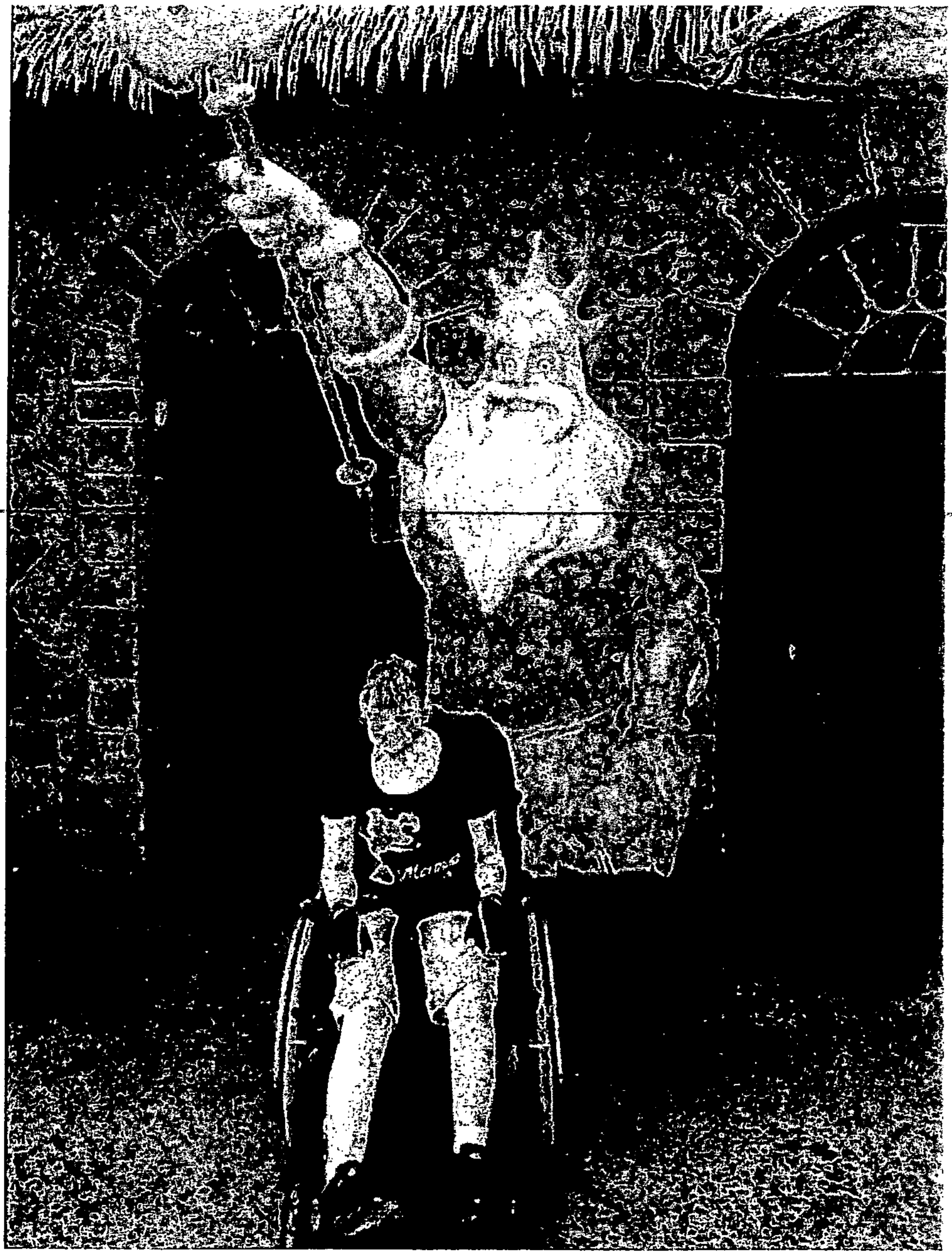
Nicole Jorwic

From: Linda Messamore [redacted]
Sent: Monday, July 17, 2017 10:00 AM
To: Nicole Jorwic; senator@corker.senate.gov; senator@alexander.senate.gov
Subject: Fwd: Why Medicaid matters to me in TN (and Florida)

Linda
Sent from my iPhone

Begin forwarded message:

> **From:** [redacted]
> **Date:** July 17, 2017 at 8:46:16 AM CDT
> **To:** [redacted]
> **Subject: Why Medicaid matters to me in TN (and Florida)**



This is my adopted daughter Jessica who is actually 30 years old(2-17-87) and has thankfully remained petite so I can care for her. We both have pre-existing conditions and I'm approaching 60 and retired after 32 years of teaching to care for her. Jess is very bright but has severe physical limitations which limits her access to services. We need affordable healthcare.

This is my brother James Alan who lives at Sunrise Community in South Florida. His home since our mother passed in 1979. Without funding where will he live, how will his medical needs be met??

This is Jess with her brother Joe, my former foster son who has dual sensory impairment(Ushers syndrome). Medicaid helps him thrive in our community but he needs services.

This piece of legislation is personal for me! It's a life or death choice for people I love!

Remember that when you chose how to vote!

Sincerely,

Linda Messamore

[redacted]

A Letter of Thanks

Thank you for taking the time to read this collection of stories that relays the experiences of Tennesseans with intellectual and developmental disabilities as they seek access to quality health and mental health care. Studies have shown that individuals with disabilities face a variety of health disparities, and it is clear from these stories that they often do not have access to the same quality, patient-centered health and mental health care opportunities as the general population.

The stories in this booklet were collected by students enrolled in a Vanderbilt University course that provides an introduction to the field of family studies, with special attention paid to families that include children and adults with disabilities. The course offers future educators, advocates, and researchers an opportunity to learn firsthand from families about encounters with education, health care, housing, employment, and disability services in Tennessee.

We would like to thank the individuals with disabilities and families who shared their stories in this edition. By reading them, you will receive snapshots in time of a diverse group, across a spectrum of disability, geographic location, socioeconomic status, and race. We would also like to thank Courtney Taylor for her coordination of the Kindred Stories project. By sharing these stories, we all hope to demonstrate the challenges individuals with disabilities and their families face when seeking out and receiving health and mental health care, and to encourage creative ways of addressing and removing those barriers.

To view additional stories from Tennesseans with disabilities, please visit:
kc.vanderbilt.edu/kindredstories

Doria Panvini

Doria Panvini
Community Advisory Council
Vanderbilt Kennedy Center

Robert Hodapp, Ph.D.
Professor of Special Education
Director of Research
Vanderbilt Kennedy Center

Carrie Hobbs Guiden

Carrie Hobbs Guiden
Executive Director
The Arc Tennessee

The Arc Tennessee
www.thearctn.org

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities
vkc.mc.vanderbilt.edu

Nashville, TN 37207-4241
Sent from my iPhone

From: Carolyn Naifeh [redacted]
Sent: Sunday, July 16, 2017 10:19 PM
To: Nicole Jorwic
Subject: Tennessee - Better Care Reconciliation Act

Professional Life - I run a non-profit in Nashville that provides affordable housing to adults with intellectual and developmental disabilities, in a supportive environment, with support to find gainful employment. These men and women all receive Medicaid and 9 out of 10 receive Employment and Community First (ECF) Choices benefits. The one who doesn't had a TBI after age 40 so isn't eligible. Their ability to live independently in the community, to be contributing members of the community, to receive the supports and services they need to thrive . . . it is incumbent on all of us -- including the Federal Government -- to help this vulnerable population. The rest of us are the beneficiaries; sharing life with adults with intellectual and developmental disabilities teaches the rest of us to appreciate all that we have, to enjoy the world around us, to live in the present, how to communicate more clearly . . . how to live a life well lived. Please do NOT make any cuts to the Medicaid program.

Personal Life - I get health insurance under the Affordable Care Act. Blue Cross/Blue Shield of Tennessee dropped 110,000 individuals in Memphis, Nashville and Knoxville in 2017. I switched to Humana because most of my doctors are included in network. Humana notified me in January, just weeks after my coverage started, that the company had also decided to drop individual members in 2018. God know what will be available to me in 2018, but if pre-existing conditions aren't included with coverage, I literally am a dead duck.

I can't count how many people I know in Tennessee who want Senators Alexander and Corker to take a stand for their fellow citizens and vote against the Better Care Reconciliation Act. Please do the right thing.

Carolyn Naifeh
Co-Founder and Executive Director
Nashville IDD Housing Group
[redacted]
Nashville, TN [redacted]
[redacted]

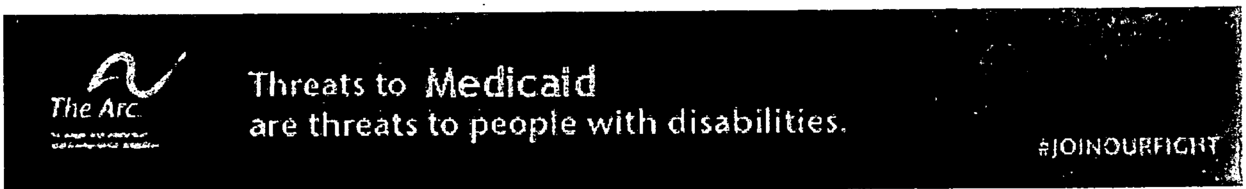
Nicole Jorwic

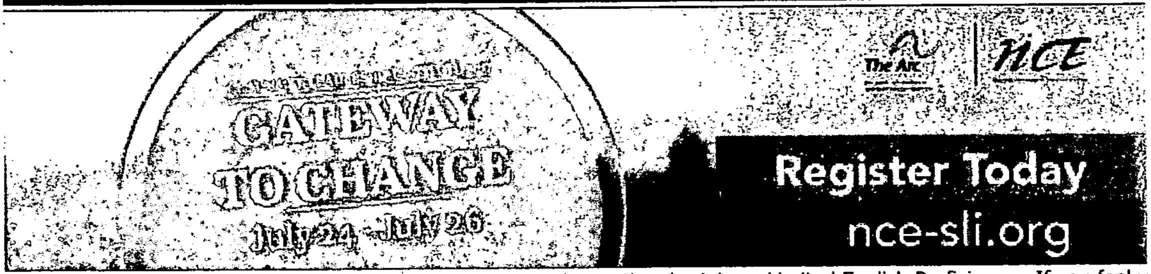
From: Carrie Hobbs Guiden [redacted]
Sent: Sunday, July 16, 2017 8:30 PM
To: Nicole Jorwic
Subject: Tennessee - Medicaid stories
Attachments: Jessica.pdf; Evan.pdf; Lorri.pdf; KindredStories-Lifeline-16.pdf; kindredhealthcare-17.pdf

Nicole,

I've sent your request out to our membership, but I've attached some stories from TN that you can share...I think you have these already but I thought I would send again. I realize they are "formal" stories, but stories nonetheless. Hopefully you can use them.

Carrie Hobbs Guiden
Executive Director
The Arc Tennessee
[redacted]





The Arc Tennessee does not discriminate based on race, color, national origin or Limited English Proficiency. If you feel you have been discriminated against please contact Peggy Cooper, Title VI coordinator, The Arc TN, 800-835-7077 ext. 15, pcooper@thearctn.org.

TENNESSEE KINDRED STORIES OF DISABILITY

With Congress continually exploring options to reduce federal funding of state Medicaid programs, it is important to understand how proposed changes such as block grants, per-capita caps, work requirements, and changes to eligibility and covered services can impact health care and other supports for Tennesseans with intellectual and developmental disabilities and their families.

The Vanderbilt Kennedy Center and The Arc Tennessee collected stories from families who utilize federally funded programs such as Medicaid.

Meet Jessica

My daughter Jessica is thirty-five years old and has Cerebral Palsy. I work part-time as a substitute teacher. I spent a lot of years as a single parent raising Jessica and her brother. I remarried a wonderful man in 2002. In September, 2011, Jessica moved out of our home and into residential living. Jessica uses a powered wheelchair. She is ambulatory but needs assistance with working the wheelchair.

Jessica currently receives the state Medicaid waiver. The waiver allows her to get assistance with medical needs, wheelchair upkeep and repairs, and various services such as doctor appointments, adaptive equipment, monthly physical therapy, a nutritionist, and in the past, has provided her with speech and occupational therapies. She also relies on TennCare for her healthcare needs and especially for supplying her wheelchair, which is critical for her mobility.

Jessica is a very social individual and currently has two roommates who she adores. She also loves being out in the community. Jessica likes to go shopping, follow friends and family on Facebook, watch movies, and dance. She loves going to parties and being around others.

Jessica visits home often where she will stay with us anywhere from a weekend to a week at a time. I'm in Mount Juliet and she's in Lebanon, so she's not too far from us. That was one of the things I was looking for when she did move out, was that she could stay close to us. We were all conflicted; emotionally torn, with her moving out of our home, but in the end, Jessica wants to live as independent of a life as she can. We all move out of our parent's home at some point.

I've taught her how important it is to be her own advocate. She sometimes gets nervous to stand up for herself, but she knows that it's a very element of her living independently with the help of staff. If I'm not there she knows she has to do it. She's even taken it upon herself to try and encourage her peers to advocate for themselves.

"Jessica needs help doing just about everything. It's a real problem that she does not have enough help."

Jessica needs help doing just about everything. No matter where she is, if she drops something on the floor she can't pick it up. If her foot itches she cannot scratch it. She cannot even get online by herself because her body just doesn't let her do that. That's a major problem for us, not having enough care. Otherwise, we're happy with the care and what services she does get; pretty much everything else is being met.

What would happen if services were cut? Jessica would have to move back home. There is no place else Jessica could go and be cared for. There would be no money for anyone else to care for her. That's the bottom line and it's a big worry for a couple of reasons.

First, as I have taken physical care of Jessica for over 35 years now, it has taken a toll on my physical well-being; I am becoming an aging caregiver. What happens if these cuts take place and she has to move back home? Safety for Jessica and myself, her caregiver, would become an issue as care would increasingly become more difficult. What happens when we are unable to take care of her? A couple of years ago, I had a hip replacement (due to the requirements caring for Jessica's physical care). I had limited abilities for several weeks. Thankfully, my mom was able to stay with us and help take care of Jessica. There was no agency that could provide assistance for us during this time, even though Jessica was on the waiver.

Second, Jessica does not want to limit herself by only having the choice of living at home with her parents. She is a grown woman. She wants a happy life of her own. That life includes her ability to get assistance and to live her goal out of living as independently as possible in her least restrictive atmosphere. Even though she requires assistance to live independently, she is happy and self-confident in her ability to do so. She doesn't want to live with her parents. She wants to be in her own home, just like most of us do.

Medicaid has been a lifeline for Jessica and our family. Without it, Jessica will lose her independence. She will be vulnerable to institutionalization. These scenarios are very real and very scary.

For more stories, visit:
vkc.mc.vanderbilt.edu/assets/files/resources/KindredStories-Lifeline-16.pdf

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FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

The Arc.
Tennessee

The Arc Tennessee, 151 Athens Way, Nashville, TN 37228, www.thearctn.org

TENNESSEE KINDRED STORIES OF DISABILITY

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The Vanderbilt Kennedy Center and The Arc Tennessee collected stories from families who utilize federally funded programs such as Medicaid.

Meet Evan

Our son Evan is 20 years old and the youngest of our children along with his twin brother. While his twin is typically developing, Evan has autism.

Evan has very significant support needs. His language abilities are very limited. Because of this, his self-help skills also are limited. In terms of being able to advocate for himself, he needs someone who really knows him to figure out what it is that he is trying to communicate. Even as his parents we don't always know what he is trying to say.

One of the biggest challenges we face with Evan are his significant behavioral issues. He is on several medications, but his behavior continues to become more challenging. We have even had to visit the ER, as Evan has injured both himself and us. We truly found ourselves in a crisis situation.

"Evan receives federal funding in the form of SSI and Medicaid (TennCare). Because his behavior issues are so severe, it is critical for us to have supports that help Evan. With the proposed federal funding cuts to Medicaid, it will be extremely difficult, if not impossible, for us to get these supports for our son."

Evan receives federal funding in the form of SSI. This started when he turned 18. Along with the SSI comes TennCare. Because of this support, we are able to work with professionals who assist Evan in improving his behaviors. It seems like we are finally starting to make some progress. Because his behavior issues are so severe, it is critical for us to have supports that help Evan with these things. With the proposed changes to Medicaid that would reduce federal funding, it will be extremely difficult, if not impossible, for us to get these supports for our son.

We cannot afford 24/7 care for Evan. To know that there is a possibility of being able to pay for these supports with the help of federal funding is a huge relief. When we hear about potential cuts coming and realize that those supports might not be as readily available as we thought, it is very, very scary. Because his needs are so great, we constantly worry about what his future will look like. Where will he live? Whom will he live with? How much of the caregiving is going to fall back on us, as aging parents? Or on his siblings, when we're no longer here. With Evan, we worry about what would happen if he had a behavioral meltdown with a caregiver other than ourselves. It is so important for him to get the intervention and support that the BCBA (Board Certified Behavior Analyst) provides while he is still at home and while we are still around.

Families and caregivers in our situation rely heavily on federal programs to help achieve any kind of quality of life for the people we love who have disabilities. It is heartbreaking to realize that we're right here on the cusp of being able to access some of the things that are so vital to Evan's well-being, and those services could be taken away because of the proposed Medicaid per capital caps that would drastically reduce the federal financial support for these programs.

For more stories, visit:
vkc.mc.vanderbilt.edu/assets/files/resources/KindredStories-Lifeline-16.pdf

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With Congress continually exploring options to reduce federal funding of state Medicaid programs, it is important to understand how proposed changes such as block grants, per-capita caps, work requirements, and changes to eligibility and covered services can impact health care and other supports for Tennesseans with intellectual and developmental disabilities and their families.

The Vanderbilt Kennedy Center and The Arc Tennessee collected stories from families who utilize federally funded programs such as Medicaid.

Meet Lorri

My name is Lorri. I want to share a little about myself with you. I am 50 years old and I live in Nashville, Tennessee. You should know that I love my dog, Holly. And Holly loves me too. She is very protective of me—once she even bit a new visitor! Not hard, though. Don't worry; no bleeding was involved. Apart from having a dog, I go to concerts. My favorite concerts to go to are the New Kids on the Block! I'm not afraid to admit that I still have a crush on Donny. Even my fiancé knows that I have a crush on Donny. Did I mention I have a fiancé? We're getting married next September! I also really enjoy going to see the Nashville Predators hockey team play. Most Sundays, I help out at my church during the morning services. I am frequently asked to speak at events. So I guess you could say that I'm a pretty good public speaker! I also think I'm a good listener.

I am diagnosed with Cerebral Palsy. And my IQ is typical. I cannot walk or talk on my own, but I use a power wheelchair to get around on my own. I also use an Augmentative Alternative Communication, or "AAC" for short, device on my iPad to talk with people. I type the message in using my knuckle and my iPad says the message out loud for me. It's pretty cool! Sometimes, if I'm typing a longer message, I let people read my iPad while I type. This way whoever I'm talking to can finish my thoughts for me.

"All of these supports—TennCare, Medicare, and railroad retirement—pay for my income, medical bills, and support staff. Really, these programs pay for everything I have."

There are some challenges to having Cerebral Palsy. For example, it's really hard to find qualified staff to help me live. It's really important that I have a staff member helping me to do things like run errands or cook dinner. It's hard because there's a lot of red tape that prevents me from finding a good staff. Luckily, I like my staff now. Her name is Patricia. Sometimes, Patricia and I even go to movies together!

I receive a mix of different supports and benefits. I receive TennCare and Medicare. I also receive railroad retirement funds because my dad also works for the railroad. All of these supports—TennCare, Medicare, and railroad retirement—pay for my income, medical bills, and support staff. Really, these programs pay for everything I have.

I'm afraid of what may happen if the funding for these programs is cut or reduced. If these financial supports were not available, I would be completely lost. It feels like some congressmen and other policy decision-makers don't understand that people like me need these programs to live. If funding for these supports are reduced, I may not be able to afford rent. For example, if programs like Section 8 housing are cut, people with disabilities cannot afford rent. Where would I live? Where would other people with disabilities live? Other people cannot afford nursing homes or in-home health support if TennCare is reduced. If my social security funding was reduced, I would not be able to afford anything. And it's not just me! People who receive social security wouldn't be able to afford anything.

Thanks for taking the time to learn about me and how I live. I hope my story motivates you to vote thoughtfully on reducing funding to government programs so that people like me can live.

For more stories, visit:
vkc.mc.vanderbilt.edu/assets/files/resources/KindredStories-Lifeline-16.pdf

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TENNESSEE KINDRED STORIES OF DISABILITY 2017

Access to Health Care

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for Excellence in Developmental Disabilities

The Arc
Tennessee

Table of Contents

Introduction

Thank you for taking time to read the stories in the booklet, and I add my thanks to the many families who shared their stories and the students who made this booklet possible. We are one of the families that shared our story, and as you read these stories, you will find consistent themes regarding health care. Individuals with disabilities face:

- Difficulties finding health care providers who are knowledgeable, willing and trained to care for people with disabilities.
- Difficulties finding health care providers who accept TennCare.
- Difficulties affording health care, if the individual is not on TennCare.
- Extreme difficulties finding mental health providers willing to provide medication management or trained to offer counseling to people with disabilities.
- Transportation barriers, particularly in rural areas of Tennessee.
- Communication barriers.

We share our stories in hopes that we may also to be part of the solution. The Vanderbilt Kennedy Center recognized the problems surrounding health care for people with disabilities, and the Center has launched efforts to improve care. I work at the Vanderbilt Kennedy Center as the program coordinator for the Developmental Disabilities Health Care Toolkit, which is also known as the IDD Toolkit. While the IDD Toolkit focuses primarily on the health care of adults with intellectual and developmental disabilities, great information and resources are available across lifespan at www.iddtoolkit.org.

We have partnered with a number of organizations and individuals to develop the IDD Toolkit, including the Special Hope Foundation of Palo Alto, California, the Tennessee Department of Intellectual and Developmental Disabilities, TennCare, the Boling Center at the UT Health Science Center in Memphis, The Arc Tennessee, and many health care professions, people with disabilities and their families. We now have:

- The IDD Toolkit website- www.iddtoolkit.org
- On-line training for health care providers and for people with disabilities and their families, which can be accessed from the website
- The ability to provide live videoconferencing telehealth training on key disability-related medical topics for health care providers

But there remains much to do. For additional information or if you have questions, don't hesitate to contact me. I can be reached at janet.shouse@vanderbilt.edu or call me at 615-875-8833.

Thank you again reading!

Janet L Shouse

Janet Shouse

Lorri

(age 50)

My name is Lorri. I am a little over fifty years young, and I have many gifts that make me who I am. I am emotionally supportive to others, I take care of a dog, and I work to facilitate research for people with disabilities. I have a lot of talents. Because I work and strive to remain active, there are often places I need to go and people I need to meet with. It is critically important that I remain in good health, and have fair and fast access to the doctors and the services that I need to not miss any of these meetings or appointments. Did I mention that I have cerebral palsy?

I have cerebral palsy. This is also an important part of who I am. I use my wheelchair for mobility, and I use an iPad to communicate. So, as you can imagine, there are frequent challenges that arise when it comes to accessing the healthcare services and supports that I need to keep being me.

I receive Tenncare and Medicare. While you might think that access to both of these would be helpful for me it is often difficult to find doctors who will accept these types of waivers and benefits. On the occasion that my caregiver or I have been able to schedule and secure appointments with clinics that accept Tenncare and/or Medicare, other obstacles often arise. I have had trouble entering inaccessible buildings because of my wheelchair, communicating with nurses and doctors in a timely way because of my AAC system, or receiving respect from professionals in clinics.

Just this past April my caregiver scheduled an appointment for me at a women's clinic right here in town. My appointment was scheduled for 7:00 a.m. in the morning. However, when we arrived, the clinic was not prepared for me or my wheelchair. They had no lift. I had to wait until almost noon (FIVE hours!) for them to secure a wheelchair lift so that I could enter the building and then the exam room. After I was inside, nurse practitioners and doctors scurried about the clinic trying to accommodate other patients, and seemed to forget me as I was trying to communicate with them about the purpose of my visit and complete paperwork with my caregiver. Finally, as I entered the exam room, the doctors continued to only communicate with my caregiver, and not with me. I have a voice. I could have answered their questions. But they look at me as a child, and often do not treat me like an adult. This clinic visit is only one example of many.

For me the issue of quality healthcare for people with disabilities in our state only begins with accessing sustainable benefits. I understand that changes in legislation often invite change within the systems that serve us (i.e., healthcare). But the challenge doesn't stop here. Financial access to this type of care doesn't always mean that doctors, therapists, or specialists are logistically prepared to serve me or others like me. It is important that these types of clinics or practices learn about developing physically accessible spaces for individuals who use mobility devices like wheelchairs. It is also important for them to understand that we are not children, and we deserve to be dignified by being treated as adults.

Like I said, I have a lot of gifts and talents and am a busy woman. No one has five hours to spend at the doctor waiting for a wheelchair lift! ■

Rhonda

(age 47)

I was born in 1969 with spastic cerebral palsy. My parents were told I wouldn't live past 48 hours and I'll be 48 years old in July. They were told I would never live independently or do any of that stuff. I have two college degrees. I have a degree in medical billing and coding. I don't like the coding part, but I do like the insurance part because I get to fight for people.

When I first moved to Nashville, one of my goals was to be off of government assistance, including government insurance. Being off of government insurance meant I could go to the doctor I wanted to go to. I don't want to be told how many times I can go to the doctor. I don't want to be told how many prescriptions I can have filled. I just don't want to be told where I can go, whom I can see, and what I can do. My current insurer is kind of getting that way but I've fought them big time. A lot of people don't understand insurance, but I do. That's one of the main reasons I went to medical billing and coding school, because I deal with it on a daily basis. I wanted to educate myself and help other people. Somebody should not be telling us what we can and can't do.

Last year, I got a new wheelchair because my old wheelchair was starting to fall apart. I had to fight for it, though. A representative at my insurance company said to me, "Do you understand this is a very expensive item?" I said, "Do you understand that I live in this chair? If you don't pay for this, you might as well cut my legs off, or should I cut off yours? Because that is the same difference." They paid for it.

I got my new chair on June 29th of last year and on July 5th, my insurance company stopped paying for my physical therapy. They ruled it no longer medically necessary, but didn't tell me, my doctor, or my physical therapist. I was the one who caught it and had to get documentation. And do you know they still fought me after 81 pages of documentation and pictures? Just because I got a new wheelchair doesn't mean my cerebral palsy went away.

Because of the awesome medical team I have now, I'm very independent. When I went through the fiasco with the insurance company, my physical therapist continued to treat me from October to February without getting paid. That is someone who cares. Also, when I had surgery in 2014, my doctor came and visited me more than the actual surgeon who performed the surgery on me. Although it took many years, I have finally found a solid medical team that I feel cares for me.

Although I've had many issues with insurance and health care, I've realized the importance of self-advocacy. No one knows our bodies better than us, and it is important for us to make sure that our needs are met. No one should be able to tell us who we can and cannot see and what therapies or services we can't have access to. It is important to fight for what we know we need. ■

Samuel (age 30)

I am a special education teacher living and working in Maryville, Tennessee. I have three sons and one daughter. My oldest son, Sammy is 30 and has multiple disabilities. He has autism and an intellectual disability. He is blind, hearing impaired, and non-verbal. He also has chronic ear infections and motor impairments. Sammy lives in Knoxville in his own home.

My son Sammy is currently on TennCare. It can be very difficult to find providers and specialists who are comfortable and trained to work with adults with autism and who accept TennCare. High quality neurologists are particularly difficult to find. There are not many neurologists in Tennessee who will accept TennCare. Additionally, we have great difficulty finding primary care physicians who will take his insurance where we live in Knoxville. We are extremely lucky that we have additional resources that allow us to continue to pay out of pocket for private consultations—not everyone is able to do this.

I have traveled a great deal to take my son to the best doctors possible. I realize not every family is able to do this. And, honestly, it is getting more and more difficult for us. Because of his age, present health, and behavior, it is currently not in his best interest to make these long trips. It is a constant battle between traveling and finding the best care.

Our current doctor is nice and I have nothing to complain about him in particular. However, it is extremely hard to switch from a doctor with whom you have a history and trust. I feel as though there is an overall lack of understanding in the medical field. For example, doctors occasionally want to put an IV in my son, yet they don't realize that you can't do that if he is awake. He will continuously rip it out. Additionally, doctors can seem frustrated when my son is not cooperative or engages in challenging behavior, but we often have to wait hours before receiving care. So, of course he's engaging in challenging behavior after being in the waiting room for hours.

I also think it is vital that physicians listen to the family, as our son doesn't have a voice. We are his voice—his advocates. For example, my son's appendix ruptured and we were in the emergency room for over eighteen hours. We don't know when exactly it ruptured because he didn't present the typical signs, there was no fever and he was able to walk when the ambulance picked him up. I just knew something was seriously wrong because I'm his mother and I know him.

It is a major worry to parents and family members. What will happen when you are gone? What would have happened if I was not there? Would my son have even gone to the emergency room? Would he still be here today? I understand that doctors are extremely busy, but you have to get to know the individuals with whom you are providing care. If you don't, how can you know the necessary care to provide? ■

Brian (age 39)

My name is Sue. I have three children, and we are originally from Michigan. When we retired 14 years ago, we moved to Tennessee with my now 39-year-old son Brian. We brought Brian with us because we did not want to leave him up there in Michigan; he was very lonesome after he got out of high school. Brian has something called William's syndrome.

There are some unique health issues associated with William's syndrome. There is a pretty prominent anxiety component. I'm a nurse, so I can advocate pretty well for the medical issues that arise. However, our challenge came when we first moved to Tennessee. Brian developed pseudo seizures. I thought he was having epileptic type seizures, and we have had him tested many times for epilepsy. He continues to have pseudo seizures, and while controllable, they have not completely gone away. They probably have an underlying cause of anxiety. In addition, four years ago, Brian had an acute anxiety break down and he was suicidal. As a result, the challenge became where to take Brian for something like this? Where do I take him for therapy? Although he is pretty high functioning, Brian does have an intellectual disability. Therapy might look different for him.

I've found out that a lot of adults with Williams syndrome have anxiety when they're younger, but it's usually associated with sounds and other various stimuli. As they age, anxiety levels can worsen and many individuals will face big challenges as a result in the adult years. I just couldn't find help for Brian. He was admitted to a psychiatric unit where they put him on drugs, then took him off drugs, and put him back on drugs again. I had him seeing a psychiatrist and a therapist. The therapist was just wonderful, but she had to totally adapt her techniques to Brian. She had to research Williams syndrome, and we were lucky she committed to that, but he was changing medications so fast that it was a challenging time.

There is another challenge as our sons and daughters with disabilities age. There seem to be a lot more health care professionals available to provide services to children with disabilities. Finding health and mental health providers who fully understand how to work with adults with intellectual disabilities has been a much bigger challenge.

We are lucky that Brian has had access to good therapists. When his last therapist retired, she actually went out to find him a replacement therapist. I thought Brian would

Finding health and mental health providers who fully understand how to work with adults with intellectual disabilities has been a much bigger challenge.

benefit from long term, in-patient care, so that he could receive the right type of medication and therapy for his anxiety and with observation, but there aren't places that will accept people like Brian.

We really have been through awful times. At one point, Brian was so drugged that people would ask if he was okay. After we visited the Lurie Center in Lexington, Massachusetts, our life changed for the better. Brian is off almost all of his drugs now and is doing well, but his mental health problems are our biggest challenge. Financially, it costs a lot to travel to Boston to see Brian's two doctors once a year. I have received some financial help from the Williams Syndrome Association, but not by any means does that cover all of it.

Brain's challenges have definitely impacted our family. I am not taking the trips in retirement that my peers take. Although Brian is doing well, we don't leave him overnight because he is just not comfortable alone. We do leave him during the day, but not at night, so we are limited in any travel. In addition, I'm going to be 68 and I still feel like I'm parenting a 12-year-old. I worry about his hygiene, and he doesn't have enough social outlets. I'm constantly trying to make plans for him. Transportation is another challenge. We will have to, eventually, move back to Michigan where my other children can help with Brian as our health deteriorates.

Insurance has also been a challenge. Since Brian has an IQ in the 70s, he has never been able to receive benefits through Medicaid waivers. He does receive Medicare insurance because he qualified for social security disability through a job he had in Michigan. He has a part of TennCare, which is just medical benefits. I do feel lucky because under Medicare and the TennCare medical benefit, everything is paid for, except for therapy for behavioral health issues. As a result, I pay for the therapy out of pocket.

We have been lucky in terms of medical needs. You need to find a primary physician that will really take the time, and that isn't always easy. We had to change doctors a couple of years ago, and Brain's current doctor will listen to me and take in the suggestions that I bring back from the conventions and the conferences. The Williams Syndrome Association has also worked hard to identify these health issues.

Brian has faced many social issues as an adult. When he was in school, there was a lot going on and he was being helped and included, but all that stopped when he left the school system. I'm sure his mental health issues have been exacerbated by his lack of social contact. It's not just that we need more connection and resources, but we also need more opportunities for our kids so that they don't need all these physicians and don't have as many health problems. ■

Rebecca and Nelda

(ages 60 and 58)

My younger sister Nelda and I were both born with congenital sensorineural hearing loss. I was diagnosed at age 2 1/2 and my sister's hearing loss was confirmed when she turned five. Once our hearing losses were confirmed, we immediately started intensive speech therapy and auditory stimulation in our hometown of Memphis, Tennessee. I wore one hearing aid in one ear and functioned and identified myself as hard of hearing thanks to good intervention. I lost my residual hearing in the better ear in my forties. I now have a cochlear implant in one ear and hope to have a second cochlear implant in the near future. Nelda has more profound loss. She wore her hearing aid in one ear until her teenage years, but then lost what minimal residual hearing she had. After high school graduation, she became more involved in the Deaf Community and began to embrace sign language to communicate as well as speech reading and talking (Total Communication).

Nelda was always sick as a child. She had strep throat infections, recurrent pneumonia, and kidney failure in her later years of childhood. A few years prior to her kidney transplant at age 15, she was on dialysis. Our mother donated the kidney, and Mom's kidney has lasted 42 years to date! Two years ago, Nelda had a stroke. It may have been largely due to her not being willing to take on a new medication for serious heart fibrillation. The stroke has left her paralyzed on the left side of her body. She can no longer use her voice to speak, her signing skills have significantly decreased. She has the additional challenge of previously acquired diagnoses including heart fibrillation, end-stage kidney disease, kidney stones, and being prone to skin cancer from anti-rejection medications for the kidney transplant. Since her stroke, I have taken on power of attorney responsibilities for her health care and finances.

I do believe Nelda has had access to good health care, both in Memphis and in Nashville. The current health system has done an incredible job of providing sign language interpreters for her various specialty appointments. The interpreters are for Nelda's communication need, not mine. I use speech reading and can speak with Nelda's medical personnel one-on-one. With that being said, we still have our struggles in the health care system. The main issue I have is working full-time during work week and having little time to respond to and navigate the phone calls for Nelda's health care and with her multiple insurance coverages. Due to the added challenge of my own hearing loss, I have asked repeatedly to communicate either by emails or text messages. I can respond to emails and texts during lunch breaks. Many companies have policies against alternative communication and yet the American's

Disability Act (ADA) is supposed to allow for this. At least that is my understanding. I do plan to pursue further inquiries on answers to my rights to alternative communication.

Immediately after her stroke, Nelda was placed in a rehabilitation facility for approximately one month. At the rehabilitation facility, a nurse was asking Nelda about her pain level during an assessment. I was at work at the time and an interpreter was not provided. To gauge her pain, the nurse provided Nelda a sheet with happy faces and sad faces. Nelda pointed to a sad face, and was consequently given pain medication. When I came by to check on her after work, I could immediately tell there was something wrong. Having learned she was given pain medication, I requested they stop. I did not believe Nelda was in pain, but actually conveying feelings of sadness because of her stroke. She was so out of it, and I knew her transplanted kidney likely wasn't able to process the medication well, so I was very concerned. Communication challenges can be potentially dangerous.

At the nursing home where she now resides, no one knows sign language. Over time, they have gotten to know her, but there is still a huge communication barrier between Nelda and her nurses. I stop by after work most days and Nelda will convey her needs and frustrations to me. I will then communicate to the staff. Another example where communication became an issue was of nurses giving laxative doses more than she needed. One reason this had been occurring is because assistants weren't always recording her intake and output levels accurately or diligently. Nelda wasn't able to communicate her distress and discomfort effectively. I pointed this out repeatedly, and the nurse practitioner finally surmised that the dosage was more than necessary. Again, this is an instance where communication is key to effective health care.

The main issue I have is working full-time during work week and having little time to respond to and navigate the phone calls for Nelda's health care and with her multiple insurance coverages.

Nelda has Medicare Part A, private health insurance, and also TennCare for long-term nursing home care. I spend hours on the phone going back and forth with insurance companies using captioning or relay service because of my hearing loss. Nelda also qualifies for Medicare—Wellcare Part D for medication coverage because of her low income. At first, Medicare—Wellcare did not want to cover her medications post-stroke because they didn't think they were responsible. In two instances, the nursing home said Nelda's medication coverage had been denied and that I needed to call Wellcare. Hours were spent using a telephone relay service, being on hold for an extended period of time, and being transferred to different divisions trying to resolve coverage. At that time, she was on around 21 medications and supplements that were supposed to be covered. Before her stroke, she was only on three medications.

All of these challenges have taken a toll on me emotionally, physically, and mentally. Being power of attorney for her finances and health care, caregiver, and advocate for her communication barriers, I feel I have no time to spare. I want to find a job that is 4 days a week instead of 5, so I have a solid day to devote to dealing with her case management needs. I was told the nursing home do not have case managers on staff. I visit her every day after work to be sure her health care needs are being met and to provide her with emotional support and company. I can tell she is getting depressed and tired. Her doctors are recommending treatments for her kidney stones that I know she is too exhausted for. She wants to just have a normal routine with no more stress or pain. She has recently entered palliative care because she declined a biopsy and other treatments for kidney stones. The nursing home nurse practitioner recently met with us, along with an interpreter, and reviewed her medication list. With Nelda's agreement, some medications were stopped due to the goal of palliative care and quality of life. With some medications out of her system, there is now a noticeable improvement in her spirits and she is expressing renewed interests in activities outside the nursing home. She is more alert and seems to have more energy. Her smile is beautiful and she is looking great!

Despite the challenges, I have discovered the joys in providing care to her. The communication challenges for both of us will always be there and self-advocacy remain a necessity. There is still much to juggle. Life is a journey and one we both learn from daily. ■

Heather
(age 40)

Heather, my daughter, has an intellectual disability and bipolar disorder. She lives at home with us and spends time volunteering at the Country Music Hall of Fame. Over the years, we have interacted with a lot of medical and mental health professionals and have faced a lot of challenges. Receiving Heather's bipolar diagnosis was a scary and frustrating time for us. We didn't have answers for a long time. Heather would have mood swings and confusion, and when I would take her to her doctor they would say it was a urinary tract infection. She was hospitalized several times trying to figure out what was going on and even experienced hallucinations. They did a spinal tap on her. They put her on an antipsychotic medication and that was one of the scariest things as a mom that I have ever seen.

We finally found a psychiatrist who diagnosed her with bipolar disorder. At one point she was placed in the psychiatric wing of the hospital and I was unable to contact her while she was receiving treatment. That was so hard for me because I couldn't go see her and I couldn't give the doctors any information. They had no idea what her baseline was, or who she is, or how she communicates. It was frustrating not to be there and serve as her advocate. But, Heather did continue to see the psychiatrist and we were beginning to gain some understanding together and then he left the practice. When he left, I cried. I didn't know what we were going to do. Thankfully, he referred us to another psychiatrist and I do think it has been a pretty good fit.

> ***Our family lives in rural Tennessee and there are a lot of barriers to accessing health care that come with where we live.***

Our family lives in rural Tennessee and there are a lot of barriers to accessing health care that come with where we live. There are not many medical and mental health professionals in our area who have strong knowledge about people with disabilities and about Heather's specific kinds of needs.

Currently, Heather has a very good primary care physician. She and Heather have a good relationship, but I just found out she is leaving. It's very stressful, because finding and building a good relationship with a doctor who works with people with intellectual disabilities is tough. Because Heather also has mental illness, finding doctors who can understand the way that dual diagnosis affects her is next to impossible.

I wish there were more doctors and mental health professionals with knowledge on how to work with those with needs like Heather's. I wish there were more support groups for families. I wish Heather had more opportunities to make friends who share common interests. I want Heather to be able to explore new learning opportunities and have community. ■

Evan (age 21)

My name is Janet and my husband of 33 years and I have three wonderful children—two boys and one girl. My sons are twins and one of them, Evan, has been diagnosed with an Autism Spectrum Disorder. Evan is now 21 years old and is currently a student in the transition program in Franklin High School in Franklin, Tennessee.

Finding and obtaining appropriate and affordable healthcare for Evan has been a struggle for our family since we were first attempting to get a diagnosis for our son. At about 18-19 months, Evan lost all of the language that he had developed up to that point. When I initially took him to his pediatrician at 19 months old, I was told to wait until he was 24 months—at his 2-year check-up—to do a developmental screening. When we finally did the screening, the pediatrician agreed that something was going on and recommended early intervention services, however we did not get any kind of diagnosis. At 27 months old, we got a speech evaluation for Evan, and after another 5 months, he was given a psychological evaluation, and we finally got a diagnosis.

After the diagnosis, we went to see a developmental pediatrician in Nashville. On our first visit, she recommended we bring Evan back in 6 months so we could talk about medications. We were confused because our only issue was that he couldn't talk. I asked her if she had a medication that could make him talk, and since she didn't we decided he did not need to be on these powerful medications. She was recommending atypical antipsychotics—what you would give to someone with schizophrenia—or antidepressants. For our 4-year-old!

By 16 years of age, Evan began presenting some significant behavior issues, such as putting his head through the drywall in our home, and lashing out hurting other people. At that point, we decided that putting him on medication for behavior management was reasonable, and began giving Evan atypical antipsychotics. Our biggest hardship was finding a doctor to provide mental health services and related medication management. Evan's pediatrician would not prescribe the medications that he needed—we had to go to a mental health specialist in order to keep Evan on his medication. So many of the psychiatric doctors we found, did not take our insurance (or any insurance), or had no experience whatsoever working with individuals with developmental disabilities.

My wish is for primary care and mental health providers to have a willingness and a working knowledge of how to care for our children and young adults as patients.

Now, at age 21 we are getting into an area of even more difficulty as Evan is having to move from pediatric providers to adult providers. Again, we are having tremendous difficulty locating providers who have any previous experience with adults with developmental disabilities. Some doctors we have been able to see for several visits, then they announce that they are leaving private practice or leaving the area, so we are left scrambling to find someone new. Currently, we think we have found a developmental behavioral pediatrician who has agreed to see him, even though Evan is 21.

In 2015, Evan put his hand through a window intentionally during one of his rages and he lacerated his arm badly enough to require a trip to the ER. He was 19 years old. By this time, he had already had a number of very serious episodes of self-injury and property destruction. This was the first time it was serious enough to warrant emergency intervention. The doctor in the ER thought we needed to hospitalize him in a psychiatric facility to see about changing his medications. My husband and I had never, ever thought about the possibility of Evan needing a psychiatric hospitalization. As we sat in the ER watching our son sedated and having his wounds stitched up, I sent a desperate text to our former psychiatrist to ask him, "What do we do?" Even though it was nearly midnight, he called me back immediately to talk, and said that given what I had told him, he also felt Evan needed to be hospitalized. Evan's current psychiatrist, his previous psychiatrist, and his developmental pediatrician all agreed that he needed to be in there.

It took five long and anxious days with both Evan and our entire family on edge, to even find a placement and make the arrangements, but they finally got him to a bed in the psychiatric hospital. I kept thinking that we were going to try to get him into the children's psychiatric ward. I just strongly suspected that they were not going to know how to deal with him on the adult side. It became really clear, really quick that they did not know what they were doing. They weren't showering him, or helping at all with his personal hygiene routines. They were allowing him to sleep in his clothes. I had to have a little heart-to-heart talk with the staff to say he needs to stay in a consistent and predictable routine. I had to explain how critically important such a routine is for people with autism. They had put Evan on the detox ward, because they said it was calmer and quieter on the detox ward than it was on the regular psychiatric floor with patients dealing with other mental health issues. The psychiatrist in charge of his case acknowledged right out of the gate to my husband and me that he had very little experience with people with intellectual and developmental disabilities. The staff tried to be accommodating, and there were several individuals there who did care, but they just didn't step up to the plate and do the things that needed to be done. It is likely they just simply didn't know how to properly support someone with his particular needs and limitations. But the reality is they are going to be dealing more and more with people like Evan, who are nonverbal, who may have an intellectual disability and may be diagnosed with an autism spectrum disorder.

My wish is for primary care and mental health providers to have a willingness and a working knowledge of how to care for our children and young adults as patients. The need is so great and growing. ■

Sadie (age 3)

"Sadie was a HUGE and beautiful surprise to us" Kristie says of her 3-year-old daughter, who has Down syndrome. She was born premature and was extremely resilient at birth. She waived some of the concerns about her early birth by being a vigorous feeder and not having any time in the NICU. Sadie was able to go home relatively quickly, but had to return back to the hospital due to a medical situation that could have been avoided.

"Sadie contracted the Respiratory syncytial virus (RSV) soon after her birth," said Kristie. "The horrible experience started with a questionable result on her PKU test with her thyroid. Her pediatrician at that time was insistent about doing an immediate retest through a blood draw. We found out that no one in our town could do the blood draw, so this forced us to drive her over an hour to Knoxville. We sat in an emergency room waiting area full of sick kids, completed our lab work at the hospital, and then drove back home. It was shortly after this visit that Sadie started showing signs of respiratory problems. We found out later that it was the worst RSV season in the history of that particular hospital, and Sadie was in the (took out extra "in") ICU for 17 days as a result of contracting RSV." "Sadie's previous pediatrician should have known that her immune system was compromised," said Kristie. Why didn't her initial pediatrician consider that going for a blood draw in another city could equal danger for Sadie in the middle of winter and at her age and condition? Why don't our doctors individualize more when treating people with Down syndrome or other disabilities?"

Sadie currently has a wonderful Primary Care team meeting her needs however, Kristie expresses frustration that they have little access to pediatric specialists close to home. The family lives in Crossville and often have to drive to Knoxville or Nashville. Kristie says even seeking out providers for a simple dental cleaning and certain therapies is a major challenge. Kristie says another challenge is the lack of collaboration and communication among Sadie's health care providers. Her specialists do not communicate with one another, and it falls upon them to keep track of her medical information and to navigate what is important or not important to share and with whom. She says it is a full-time job, given Sadie has seen 13 specialists to date, with keeping track of medical paperwork and to ensure that all of Sadie's health professionals are aware of what the others are doing.

Kristie says another challenge is the lack of collaboration and communication among Sadie's health care providers. Her specialists do not communicate with one another, and it falls upon them to keep track of her medical information and to navigate what is important or not important to share and with whom.

Kristie also says some doctors are actually hesitant to listen to them. When Sadie was 18 months old, she began exhibiting symptoms of severe gastrointestinal distress. Kristie believed Sadie was infected with C. diff bacteria from antibiotic use. When she brought up this concern to a gastroenterologist, they brushed her off and suggested it was simply a milk allergy. Sadie was actually prescribed an expensive formula that was 52% corn syrup solids. This medical call exacerbated the C diff as it thrives, as do other bacteria, on sugar. Over the next few months Kristie persisted with this argument. Instead of simply testing her for the bacteria, the doctors were hostile towards Kristie. Finally, after about three months, with Kristie's demanding a screen for C Diff they discovered that she did in fact have the infection. Sadie's months of illness could have been avoided had health care providers listened to Kristie from the beginning.

Sadie does not communicate verbally and is not able to express how she is feeling. Kristie must act as her voice. Kristie also notes that some children with Down syndrome may respond differently to medical treatment than do typically developing children. She wishes that doctors were more accommodating and more willing to think creatively when treating individuals with special needs. ■

Morgan (age 23)

Tammy and her husband have been happily married for 31 years and have two daughters. Their daughter Morgan is 23-years-old and has autism spectrum disorder. The Vice family lives in the Nashville area.

In terms of access to a health care professional, Morgan was fortunate to have a pediatrician with whom she had a great relationship. However, the family faced numerous challenges in the transition from pediatric to adult health care services. To start, neither the family nor the pediatrician could identify a medical professional to whom Morgan might transition.

"It's frustrating that there are not more doctors and specialists who have experience working with adults with autism," said Tammy. "Knowing that our daughter needed treatment and medications, and not being able to find a provider who could meet her needs and who would take our insurance before medications ran out, was very stressful. Parents should not have to worry about that."

Disability awareness and training are a must for medical professionals to adequately meet the individual needs of patients.

Morgan's first experience with adult health care was with a provider and staff who appeared to have no training or experience in treating patients on the autism spectrum. They did not communicate with Morgan directly. They spoke about her and treated her as if she wasn't there. Tammy says their interactions were fraught with stereotyped assumptions about autism, and about Morgan's behaviors and movements. One remark she remembers well was, "They all rock like that."

"Let's just say that we did not go back," said Tammy. "I didn't know how important it was to have a medical professional who saw Morgan as a person with individual needs, a professional who respected our experience and self-knowledge, until we didn't have that anymore. Disability awareness and training are a must for medical professionals to adequately meet the individual needs of patients. ■

Vanderbilt Kennedy Center for
Excellence in Developmental Disabilities
vkc.mc.vanderbilt.edu

The Arc Tennessee
www.thearctn.org

Tennessee Kindred Stories of Disability
kc.vanderbilt.edu/kindredstories/

Report compiled by Courtney Taylor, M.Div., Tennessee Kindred Stories of Disability Coordinator and Associate Director of Communications and Dissemination, Vanderbilt Kennedy Center

Nicole Jorwic

From: Reba McKee [redacted]
Sent: Sunday, July 16, 2017 6:24 PM
To: Nicole Jorwic
Subject: TENNESSEE MEDICAID

sent to: Senator Lamar Alexander and senator Bob Corker

I want to ask you to vote no on the extensive Medicaid cuts proposed in the Affordable Care Act revision. I know many families who depend on Medicaid for their children's health care and also many disabled people who will not be able to survive without it basically. My son is severely disabled from birth with a condition called Tuberous Sclerosis. He has seizures, is non-verbal ,autistic, has tumors in all vital organs that are being monitored, and needs 24/7 care. He depends heavily on Medicaid. He is 42 years old and unable to work since his functioning is that of a three year old. Please do not pull the rug out from under him and those like him who absolutely rely on Medicaid.

thank you,
Reba Smith
[redacted]
Chattanooga TN [redacted]

Nicole Jorwic

From: Beth Harrell [redacted]
Sent: Saturday, July 15, 2017 10:05 PM
To: Nicole Jorwic
Subject: Medicaid Matters

Dear Senators,

Medicaid Matters.

It matters to me because I care for Seniors. Some seniors are able to save some funds for a nursing home stay. Some are able to afford Nursing Home insurance.
In many cases even those that can afford to pay for some nursing home care will eventually have to rely on Medicaid to pick up their nursing home costs after other funds have been exhausted.
And there are many, many folks that are unable to afford any savings or insurance. You and I will be someday be seniors if you are not already.

Medicaid matters to me because my father-in-law is close to being in a nursing home. He does not have assets or insurance to pay for it.

Medicaid matters to me because I care for the disabled. My 36 year old son is special needs. Although he does not have Downs Syndrome, his issues are similar. He currently works part time, but will never be self-supporting.
He currently has Medicare instead of Medicaid because he has worked and paid into the system.
Medicaid matters because a lot of Charles friends are benefitting from the new program in Tennessee, ECF Choices. ECF Choices is enriching the lives of the IDD community. It is funded with Medicaid dollars.
Medicaid matters because I have a granddaughter who is severely handicapped. She has had several life-saving surgeries. Surgeries covered by Medicaid. Called Tenncare here in Tennessee.
She requires round the clock care and supervision. Our daughter is unable to work outside of the home because of her specialized care. Tabitha will require expensive medical services and medicines the rest of her life.
More than any single household could ever afford.

If you want to improve healthcare, do something about the cost of it, don't deny healthcare to Americans.

Medicaid Matters to all of us.

Beth Harrell
[redacted] *Murfreesboro, TN* [redacted]
[redacted]

From: diane miller [redacted]
Sent: Saturday, July 15, 2017 5:00 PM
To: Nicole Jorwic
Subject: Please protect Medicaid TENNESSEE

Twenty-four years ago, I adopted a special needs infant who had been exposed in utero to drugs and alcohol. At the time, I was assured that assistance would be available if he needed it.

My son Jimmy has required special education and medical therapy throughout his lifetime, but most of his support has been provided by my private insurance and my own personal funds. Now that he is an adult and no longer in school, his needs are even more substantial than when he was growing up.

Jimmy is the sweetest and most delightful young man you will ever meet, but he has an intellectual disability and cannot be left unattended. I had to quit a good-paying job so that I could stay home with him. I am now in my 60s and am no longer able to provide all the care he needs, but through Medicaid waiver funds, he is able to receive several hours per day of personal assistance to help with bathing and other activities of daily living. Without this assistance, I would not be able to keep him at home.

Please tell me how it makes sense to cut Medicaid for people like my son. At this point, I can keep him at home and require only minimal public resources. If you cut the services he currently receives, I will no longer be able to care for him at home, and he will need to move to a long-term care facility that will be tremendously more expensive than the assistance he receives currently.

Please do not cut Medicaid. I plead with you to vote no on the upcoming health care bill unless Medicaid funds are restored. To cut services for people like my son is not only bad fiscal management, but it also is immoral. I have supported you in the past, but I will no longer vote for anyone who could pass a bill as harmful to innocent people as the one you will be asked to vote on.

Thank you for your consideration.

Diane Miller

Chattanooga, TN 37415

Nicole Jorwic

From: Joanne Wilson [redacted]
Sent: Friday, July 14, 2017 3:06 PM
To: Nicole Jorwic
Subject: Say No Senator Corker in TN

Dear Sir
As a family in TN that pays a lot of money for health coverage for ourselves and our son with disabilities- I beg you to say NO to the proposed health care bill! When it becomes more important to vote yes -regardless of your gut feeling that it is wrong- just to gain favor with a political party- you have sold your soul for a few pieces of gold!

Our son relies on federal Medicaid waiver funds for community intervention- TN will never replace federal dollars if they are cut in new health care bill! Cuts will mean less service for disabled and more institutions REOPENED to care for adults who outlive their caregivers!

Please take a deep breath and just say NO to axing life changing services to those who have no other choices!

Please do not place politics over humanity with a rushed vote! I value my vote highly and study all sides before I select a button in that voting booth.
Please stand tall with the Tennesseans who cannot stand for themselves !

Vote NO on health care bill

Respectfully
Joanne Wilson
Clarksville TN
[redacted]
Sent from my iPhone

From: Joanne Wilson [redacted]
Sent: Friday, July 14, 2017 2:53 PM
To: Nicole Jorwic
Subject: Say NO Tennessee Senators!

Dear Senator Alexander
I have contacted you before about how the proposed health care policy you are debating now will affect our family!
We are the parents of a 49 year old son with multiple disabilities. Medicaid Waiver funding for programs in TN are the cornerstone of his life and happiness! There is no alternative! Do you understand? Do you care that you are devastating thousands of families in TN with a "yes" vote?
You were elected to serve the families of TN not serve the Republican Party big shots!
Passing the responsibility to fund the care of the weakest citizens of our state (TN) back to the states without federal support is signing the death warrant or the institutionalization of the disabled in our community.
I beg you senator Alexander- say No and take time to get it right!

Respectfully
Joanne Wilson
Clarksville TN
[redacted]

Sent from my iPhone

From: Tammy Vice [redacted]
Sent: Friday, July 14, 2017 2:35 PM
To: Nicole Jorwic
Subject: Tennessee Why Medicaid Matters to our family
Attachments: Fashion Show 8.JPG

Hello,

Our daughter, Morgan, is 23 years old. She is on the autism spectrum. There is a very BIG services cliff here, once adults with disabilities leave high school. I do everything I can to see that Morgan stays engaged in our community.

I don't want to need help, but It's not possible for me to do this alone,... indefinitely. Morgan's needs will far outlast my abilities. I'm only human.

Tennessee now has an ECF waiver which is beginning to provide services that help Morgan stay engaged in community. Medicaid cuts will make programs like this disappear. When making healthcare decisions, please consider that this is our family's lifeline.

Morgan's Mom,

Tammy Vice
Songwriter - Speaker - Author
Know The Hope
[redacted]

Check out 52 Blue Mondays

From: brenda629 [redacted]
Sent: Friday, July 14, 2017 12:50 PM
To: Nicole Jorwic
Subject: Tn Medicaid improves lives

Please do not cut the Medicaid budget. It has changed the life of my son and my family so much and it would be devastating to us all if my son's benefits were taken away or cut.

Thank you so much, Brenda Stroud parent of a disabled adult

Sent from my Verizon, Samsung Galaxy smartphone