

How Cuts to Federal Programs Would Affect Tennessee Families



Photo by: www.johnnytucker.com



VANDERBILT
KENNEDY CENTER
for Excellence in Developmental Disabilities



A Letter of Thanks

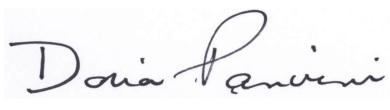
The stories in this booklet were collected by students enrolled in a Vanderbilt University course that provides an introduction to the field of family studies, with special attention paid to families that include children and adults with disabilities. The course offers future educators, advocates, and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

The Arc Tennessee and the Vanderbilt Kennedy Center partnered to produce this collection of stories from individuals with disabilities and their families on the topic of potential cuts to "lifeline programs," such as Medicaid, SSI (Supplemental Security Income) and/or Social Security Disability Insurance (SSDI).

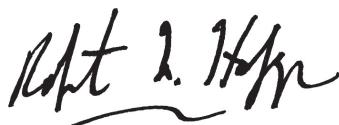
The students from Vanderbilt spoke with individuals with disabilities and/or family members who shared candidly about what these programs provide (e.g. health care, Medicaid waiver services, income to help with housing, food, clothing, other medical expenses not covered by insurance, etc.) and what might happen if these programs/financial supports were not available.

The Vanderbilt Kennedy Center and The Arc Tennessee thank all the families who shared their stories in this edition. By reading them, you will receive snapshots in time of a diverse group of individuals with disabilities, across a spectrum of disability, geographic location, socio-economic status, and race. By sharing these stories, the students and families hope to demonstrate the great importance of not overlooking the unique needs and concerns of individuals with disabilities and their families.

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



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
Executive Director
The Arc Tennessee

The Arc Tennessee
www.thearctn.org

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

Table of Contents

Introduction	4
John (age 15)	5
Evan (age 20)	8
Terrell (age 20)	10
Jessica (age 35)	12
Scott and Michael (age 38 and 42)	14
Morgan (age 39)	16
Lorri (age 50)	18

Introduction

When one thinks of the word “lifeline” many different items may come to mind. Some people may think of a rope. Others may think of the “calling a friend” option on “Who Wants to be a Millionaire.” Others may think of a person—like a parent, friend, sibling or spouse as that “lifeline.” And for our younger generation, that “lifeline” may be their smart phone or other similar technology. Whatever one thinks of, there is a common thread among them all—a “lifeline” is something regarded as indispensable for maintaining or protecting one’s life.

For many people with intellectual or developmental disabilities and their families, their “lifeline” may be something that the general population rarely considers—their Medicaid, Supplemental Security Income (SSI), Medicare or Social Security Disability Insurance (SSDI). For this population, these programs ensure that they have their most basic needs met. Many people with intellectual and developmental disabilities have medical or other needs that prevent them from working full-time or having access to private medical insurance. These vital government programs ensure they can purchase a wheelchair for mobility; have a nurse come into their home to monitor ventilators, g-tubes and other medical equipment; have prescriptions filled to control seizures or other chronic health conditions; have a support staff to help them access the community or to be employed; and so much more. These programs also provide them with income to ensure basic human needs such as shelter, food and clothing can be met.

These “lifeline” programs are frequently targets of federal budget cuts. These proposed cuts often originate from the faulty assumption that people who rely on these programs are “lazy” or otherwise unfairly benefiting from the government’s generosity. This assumption couldn’t be farther from the truth. There are many people with intellectual and developmental disabilities who work and do everything they can to be as independent as possible, but their disability limits them from fully realizing that “American dream.” For this small population—our country’s most vulnerable—Medicaid, SSI, Medicare and SSDI are what keep them safe and healthy. These programs are vital to their very existence. The federal government cannot continue trying to balance the national budget on the backs of its most vulnerable citizens.

These stories were collected to raise awareness of the critical importance of these programs to people with intellectual and developmental disabilities and the families that support them. This collection of stories from across Tennessee highlights the value of these programs for the individuals and families who rely on them for survival.

~Carrie Guiden
Executive Director, The Arc Tennessee

John (age 15)

John, my son, was born with significant physical disability. He had a spinal cord lesion, which resulted in very severe muscle weakness, near paralysis, and pulmonary complications. He is 15 years old, a sophomore in high school, and is in love with his dog that we adopted about a little over a year ago. Also, he is a big reader and he loves to go to the library. He is good at school and you can't get him to say what his favorite subjects are because he likes them all!

John has challenges though. He doesn't have a functional grip in either hand. His pulmonary function is less than a third of what it should be, so he's at great risk for respiratory problems. He uses a power wheel chair for mobility, because he cannot stand or walk. He needs assistance for toileting, bathing, transfers, meal setup, dressing, and many other routine activities like homework. My biggest challenge is keeping him safe and healthy by having someone with him to help do the things he needs to do. He has an assistant with him at school and he has to have someone with him at home as well.

I am a single working parent. It takes me an hour and a half in the morning to get him ready for the school bus. I have an assistant with him after school from 2:45-5:45 and then we get to have dinner together.

If there's any homework still left, we work on that and then I put him to bed. One night a week I have a meeting and a class so we need an assistant 6 hours that night. There are also school breaks to cover. When school is in session, on average, John's personal assistant is with us 18 hours a week. In addition to working 40 hours, and commuting 10 hours, John's assistance and medical coordination takes every other bit of my time that there is, and then some. John needs help 15 hours a day plus through the night I have to get up several times and turn him and/or do a procedure.

“Even if my income was significantly higher, we would not be able to survive financially because of the things that private insurance does not pay for like durable medical equipment (DME) and supplies.”

it does cover a few hours after school and some of the time out of school. When I was working from home that worked really well and I could be the backup for the personal assistant. My current job has more hours though, and I can't work from home.

My last job I actually had to cut my hours in order to keep John qualified for SSI and consequently TennCare, because I would not have been able to afford his medical health care needs on the private insurance that was offered. And that's still the case

I have a small PASS grant which is Personal Assistance Supports and Services that helps pay for a personal assistant. The PASS grant doesn't cover all the time that I need John covered, but

“So regarding SSI, it’s the fact that it qualifies him for Medicaid—TennCare—that is the most important factor for us. It means access in-home nursing; the equipment that John needs; the specialists he sees; and the prescriptions he has to have.”

today. John receives SSI and he would not receive it if my income was much higher. He gets about \$180 a month right now (parents' income is factored in), and needless to say my income is pretty low. I have done the math. Even if my income was significantly higher, we would not be able to survive financially because of the things that private insurance does not pay for like durable medical equipment (DME) and supplies. So we live without assets, paycheck to paycheck, with lots of prayers and God's help. The few hundred dollars a month that SSI does pay for my son's care, comes in very handy. I typically use it on groceries at the end of the month if we can.

When John was a year and a half old, it was thought that his physical growth had exceeded his lungs' capacity to provide oxygen for him, and he had congestive heart failure. As it turned out, they used a ventilator to help expand his chest cavity so that his lungs could grow and provide more oxygen. After John had been on the ventilator almost a year, our private insurance put a cap on the DME so that only a few months of the ventilator expense was covered. The ventilator and respiratory supplies at that time was only one category of DME that my child has to have. At that point, the respiratory therapist, DME provider,

and another medical therapist were all telling me that I should get him on TennCare and we did. They were right! He hasn't been on TennCare his whole life, but he is now and at that time early on; it was the only way his complicated medical needs could be met without us becoming homeless.

One of the key reasons that John needs to stay on TennCare is because if I were to have a wreck going home tonight, and/or had to be in the hospital for any period of time, he would need a nurse. He is eligible for home nursing because of the procedures he has to have done through the day and night. Although we prefer to use a personal assistant we can't always find someone.

So regarding SSI, it's the fact that it qualifies him for Medicaid—TennCare—that is the most important factor for us. It means access in-home nursing; the equipment that John needs; the specialists he sees; and the prescriptions he has to have. Besides a power wheelchair, which is significantly expensive, he uses a shower/commode chair, a stander, an air bed, and orthotics. He sometimes has to see a physical therapist, an occupational therapist, and a respiratory therapist. He has pulmonary equipment—a cough assist machine, a bi-pap machine and related supplies—and

“My son hasn’t been on TennCare his whole life, but he is now and at that time early on; it was the only way his complicated medical needs could be met without us becoming homeless.”

we have to keep oxygen in the home for emergencies. He needs medications and currently a neurologist, pulmonologist, sleep pulmonologist, urologist, orthopedist, and of course his pcp.

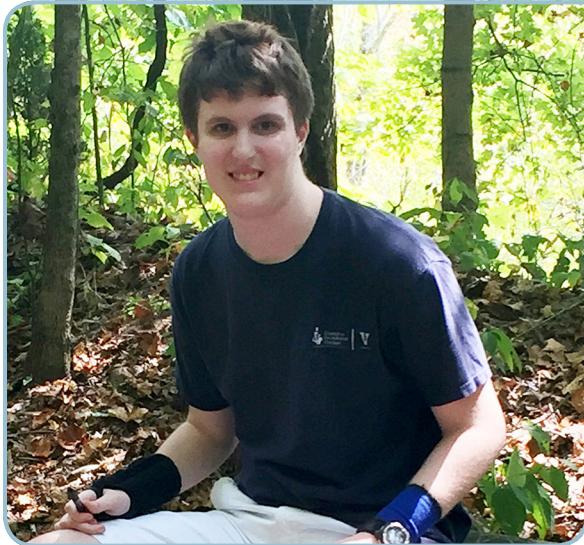
Without these supports, we would not make it. Even with private insurance, I would have to spend all of my income on medical-related expenses. Some of the medical interventions, and one drug in particular that John needs, are quite expensive. I don’t know what I would do. I honestly don’t. What could we do? Sell the house and use that money up and then what? Not have enough even to pay rent? It doesn’t work to be homeless and have a child who is severely medically fragile. Homeless shelters don’t take persons with disabilities. Many of the people I know cannot imagine the stress parents of children with disabilities live with and endure.

If I have a ‘biggest worry’, it’s that I’ll die before John can complete college, find a good job, and line up the supports that he needs to live independently and have a good life. We all deserve a chance at that. In my current position, I talk with a lot of people who have disabilities and some are homeless. Their stories sometimes make me feel like my story, with all of our challenges,

is nonetheless a walk in the park. It’s hard to imagine that SSI could be cut. It would be devastating to us. And honestly, it’s not about the money. It’s getting adequate healthcare for my son.

True, it’s not easy juggling a job and doctor appointments and all the caregiving including getting up multiple times a night, every night, and all of it... It’s not easy. I don’t say any of this so you’ll feel sorry for us. I’m saying it because there are a lot of us—family members of persons with severe disabilities—who are dealing with major challenges and we’re unsure how things could possibly work out if cuts are made. You may not understand this, but I really do count my blessings, and I know I am blessed. I love my son and am so happy that he is verbal, smart, and funny. Look at me. Now I’m bragging. ■

Evan (age 20)



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 enjoys watching animated movies and Disney classics, listening to music, and being outdoors. He also has a particular interest in using Google to learn about whatever he is interested in at the moment. He is definitely an information guy!

Evan and his brother have a very powerful connection. When things aren't going well with one of them, it really impacts the other. When his brother went off to college, we didn't have any idea how deeply it was going to affect Evan. When he left, Evan started wearing his brother's old ball cap, and an old wrist brace that his brother had gotten when he'd sprained his wrist the year before. Evan has continued to wear it daily for a year and a half. We have never asked his brother to bear the responsibility of being a caregiver for Evan, but they nonetheless are very connected to each other.

Evan has some 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, there has to be 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. He has an Ipad with Proloquo2Go on it, but it has never become his voice. Part of communication is the intent behind it, and Evan seems to have little communicative intent. So while Evan will respond to direct questions and make basic choices, the conversational sort of thing just isn't there.

One of the biggest challenges we are facing with Evan, and have struggled with for years, are his significant behavioral issues. He is on several medications, but it seems as though the behavior has gotten worse and worse. It has gotten to the point where we have had to go to 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. This started when he turned 18. Along with the SSI comes TennCare, which for Evan, is secondary insurance. This insurance picks up the things that his primary insurance does not. One of the things that it is currently helping pay for is a behavior analyst. His primary insurance would not pay for a BCBA, but through TennCare, we were able to finally get one to come work with Evan. Currently we are right on the front end of that. It seems like we are finally starting to make some progress as far as Evan's behavioral issues go. Because his behavior issues are so severe, it is

critical for us to have supports that help Evan with these things. Without TennCare it would be extremely difficult to get these supports.

Evan has also recently been approved for the Medicaid Statewide Waiver, after being on the waiting list since he was 8. Because of the extreme behavioral issues and the potential threat to himself and others, Evan was elevated to the crisis category. We are not sure how all of this will work quite yet, but one of the things we are looking at is Evan potentially living away from us. When we created his PATH, his person-centered-plan for life beyond high school, that was one of the things he indicated he wanted. The waiver brings with it services that can make that happen, and the majority of funding for the waiver is from federal dollars, with a nearly a two to one match. It's a huge asset for many families.

As parents, one of the things we worry about the most is what is going to happen when we are no longer around, and how on earth we are going to be able to afford these supports. 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 both state and federal funding is a huge relief. Then when we hear about potential cuts coming

and realize that those supports might not be as readily available as we thought, it's 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.

One issue that has come up is the quality of care Evan will receive in a supported living situation. We have spoken to several agency providers that hire individuals to support people like Evan, and they, too, are in a crisis situation. Few people want to do this kind of work because it can be a difficult working environment that is potentially dangerous, and the pay is little. If the funding gets cut for the families that have to use those funds to pay for these services, it is going to make it even harder. It is already in a situation where to create a meaningful service plan, you have to be really, really creative. 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 provides while he is still at home, so his transition to a supported living situation will be as easy as possible.

“Evan receives federal funding in the form of SSI. This started when he turned 18. Along with the SSI comes TennCare, which for Evan, is secondary insurance. This insurance picks up the things that his primary insurance does not. One of the things that it is currently helping pay for is a behavior analyst.”

Families and caregivers in our situation rely so 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 budget cuts. ■

Terrell (age 20)



My son Terrell is 20 years old. He is an athletic young adult who loves basketball and track and field. He also loves working with children. At church we have a special needs ministry and Terrell is very involved. He began with having a peer to assist him through Sunday worship. He has done so well becoming involved with worship service he has moved to one of the preschool classrooms working independently with the lead teacher. Terrell is definitely a caregiver. If anybody is hurt, he will tend to them and ask if they are feeling okay. When visiting family in the hospital he will pray over them. He has a heart for people and wanting to help. If he believes that you are in pain he will come to you, get eye level and ask "are you okay?" He can if sense something is wrong, even if most other people don't know, he does.

Our biggest concerns for Terrell at this point are employment and housing. Finding Terrell a job has proven to be a challenge. Although Terrell has been volunteering for

the past three years at a local thrift store there are still a lot of barriers to gaining sustainable employment. We're also concerned about his housing. Terrell does not need one-on-one care, but he does need support. Our hope is that he will get to the point where he can pay his bills and live apart from us. Sometimes we ask him if he would like to live in his own apartment. We can tell he has been thinking about it, but he is not at that point yet. Though the opportunity isn't before us, I want to make sure he understands that he can be okay on his own.

He currently receives support from TennCare and SSI. Terrell is still on primary insurance through his dad's work and we use TennCare as secondary. TennCare has been a really big help especially with his dental needs. We are fortunate that Terrell has very few medical needs. Once, he fractured a bone in his leg, and the x-rays were about \$1000 each time he went. Between primary insurance and TennCare, the only out of pocket expenses were co-pays, so, TennCare helped a lot. If these services were cut, my biggest concern would be losing TennCare.

SSI pays for his respite care which he attends two days a week. His teacher is Callie Ford and the name of her respite care is Days Journey in Smyrna, TN. Ms. Ford works on academics, holds Bible time, takes them out to volunteer at local businesses and on field trips. As part of the respite care, Terrell volunteers at a thrift store once a week which he absolutely loves. He works the dressing room, works on the floor straightening the clothes and

“SSI has helped him to feel a sense of independence because he is able to see money in his account and learn how to budget.”

pulling the hangers. He can basically do anything but the register. Ms. Ford will give him tasks to do and she is able to let him work independently. Going out to volunteer gives Terrell a sense of responsibility which has been a great accomplishment for him. SSI has helped him to feel a sense of independence because he is able to see money in his account and learn how to budget.

When we first started receiving SSI, Terrell went through a major growth spurt; SSI was a great help in allowing us to buy clothes for Terrell. Terrell was able to take his own money and make purchases. By seeing money in his account, this has encouraged Terrell to ask about seeking employment. If SSI were not in place this would be hurtful overall. Along with having to explain to him why we are making adjustments (if SSI were not available), it could hurt his opportunity to attend respite care and participate in the community.

We want to increase his independence as much as possible. Terrell sees his brother, Myles, moving on with his life (working and graduating from college) and he wants to be just like him. Terrell thinks the world of the

Myles and loves him as a big brother. We know that SSI has been very instrumental in giving Terrell the opportunity to become more independent, but, we believe that Terrell has the capability to work full-time and live mostly independent with minimal support. ■

Jessica (age 35)



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 is a very social individual and currently has two roommates who she adores, but the home is a little crowded for her liking. Jessica requires a lot of care and often feels slighted with two other individuals in the home, but she does love spending time with them. 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. 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. The state does not give her a one-on-one assistant. 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.

“Jessica needs help doing just about everything. It’s a real problem that she does not have enough help.”

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 does get one hundred dollars a month in food stamps. This has become a financial battle for her because she is currently on a nutritional plan to prevent weight gain. A hundred dollars a month is not conducive to anyone trying to eat healthy on such a small budget.

Jessica also receives SSI. The residential agency provides rental housing which includes supplemental monies from the federal government. Jessica pays for her portion of rent and utilities out of her SSI. Staffing that cares for Jessica so she can live on her “own” is also paid to the agency provides through her waiver. 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. ■

Scott and Michael (age 38 and 42)



My husband and I have two sons with intellectual disabilities. Michael is 42 and Scott is 38. Both of my sons enjoy the simple things in life. They like being outdoors and soaking up the sunshine, spending time with family, and home cooking. Both Michael and Scott live in a group residence through a local agency, which uses the money they receive to provide for their needs.

The group residence is about 10 minutes from our home. They live with two other roommates. All the men have individual rooms, but Michael and Scott are right across the hall from each other. The house that they live in is provided through public housing and is owned by a local agency. Each roommate's room and board is paid with the money they receive from SSI and SSA and goes into a subsidy pot to cover the household. Michael, Scott, and their

roommates also have a shift staff of fifteen people who rotate through 3 daily shifts providing 24/7 care. The staff take them on outings into the community.

Michael and Scott receive health care through TennCare and Medicare. Having health care has been extremely important over the last year. Both Michael and Scott have had health concerns that led to hospitalization. Michael has been battling aspiration pneumonia since March and he's been hospitalized seven times with pneumonia or complications from the pneumonia. Luckily, Medicare will cover the hospital costs but it does not cover pulmonary rehabilitation or supplemental oxygen for individuals who have a diagnosis of aspiration pneumonia. Whether Medicare will cover the specialty care that is critical to Michael's long-term recovery is yet to be determined. That's a big concern right now.

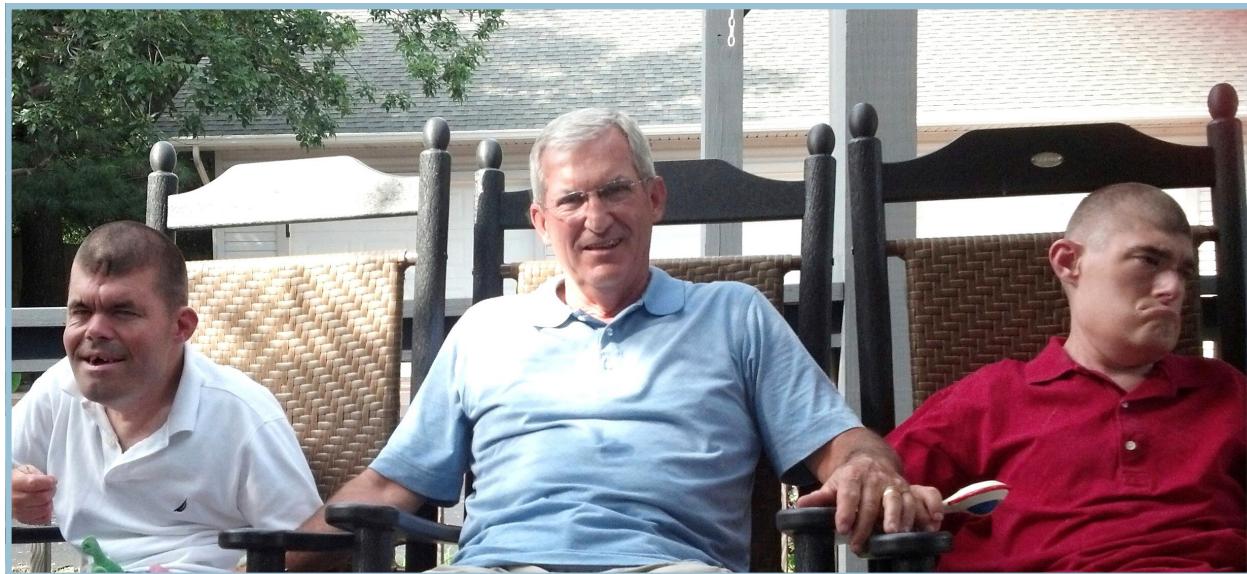
Michael and Scott also receive support through the Medicaid waivers. Michael is in the large state Medicaid waiver which covers care in a residential setting and Scott is in the capped, \$30,000 per year, Self-Determination Waiver. Fortunately Michael, who has immediate health concerns, is in the large state waiver. He qualifies for nursing care and is able to have a nurse on staff, each shift, at his home. However, Scott's \$30,000 does not cover anything of a residential nature. He and Michael use the money they receive through SSI and SSA (as my husband and I are both retired) to pay their rent (room and board) at the group residence.

“Scott and Michael use the money they receive through SSI and SSA to pay their rent at the group residence.”

The funds which Michael and Scott receive from Medicaid, SSI, and SSA are critical as the agency's ability to provide staff and services are dependent on the funds each individual in the house receives. The Medicaid waiver pays the staff's salary and pays for the nursing care that Michael requires. The impact of losing funding would be tremendous. The agency itself would suffer if the individuals in their care lose their funding. The agency would be limited in what they would be able to offer if funds were cut.

Additionally, the funds Scott receives from SSI and SSA allow him to support himself and pay room and board. The Self-Determination waiver does not cover housing, so if the money from SSA and SSI were cut, his dad and I would increase our portion of the out of pocket private pay in order for him to continue to live where he is. Of course, we

would do all we could to ensure he stays put. We would work with the agency that provides their home and the staff so they could stay. There is no thought of the boys not being where they are together in the same home. We are fortunate to have financial resources to fall back on, but not all families are fortunate in that respect. The federal programs that pay for support services are critical for so many people. It's critical that those programs continue in some shape, form, or fashion. ■



Morgan (age 39)



My name is Patricia. I have a 39-year-old son named Morgan who has autism spectrum disorder (ASD). My son is a loving man who enjoys listening to country music and looking at family picture albums. We both love going on walks around the neighborhood and riding around town. Every morning, my son and I go on a two-mile walk.

We are extremely blessed to receive monthly SSI benefits and Medicaid. The federal funding has enabled my son to be connected to meaningful community opportunities through Developmental Services of Dickson County. There, he is involved in Meals on Wheels, they are able to transport him to his work program at Sister's Restaurant, and they provide various community activities throughout the day. Developmental Services allows Morgan to

get into the community. Every week they go shopping, bowling, and stop at local restaurants. These services that we receive are everything to us. The program gives him personal connections, self-esteem, and a purpose in life. It has allowed Morgan to become a member of the community. If he did not have this program, all of that would come to a screeching halt. He would just sit in his room all day.

I look at Morgan's life and I feel so totally blessed that it has meaning for him. If our federal funding was to be cut, we would do everything we could to maintain his sense of connection, but it would be difficult. I know a lot of families in the program who could not do it. They don't have anything except their government support and day program. I know a lot of people solely depend on funding for medical care, housing, and food. If this is cut, they don't have anywhere to go. They don't have anything else to depend on. This is it. This is their livelihood.

My husband and I are 69 years old. Our biggest concern is that we will not be able to take care of Morgan. Our other children have graciously said they will care for him when the time comes. However, they would not be financially able to take care of him without some sort of federal funding or support. The SSI benefits help compensate for transportation, medication, and utilities. There is just always another bill. The thought of funding being cut is truly scary. These funds provide meaningful lives for so many people. ■

“These services that we receive are everything to us. The program gives Morgan personal connections, self-esteem, and a purpose in life. It has allowed him to become a member of the community. If he did not have this program, all of that would come to a screeching halt. He would just sit in his room all day.”

Lorri (age 50)



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.

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

“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.”

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. ■



“These services that we receive are everything to us. The program gives Morgan personal connections, self-esteem, and a purpose in life. It has allowed him to become a member of the community. If he did not have this program, all of that would come to a screeching halt. He would just sit in his room all day.”

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/