TENNESSEE KINDRED STORIES OF DISABILITY

2021



Direct Support Professionals













VANDERBILT KENNEDY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES



Letter of Thanks

Thank you for reading this collection of stories from individuals working as Direct Support Professionals (DSP) in Tennessee. The stories were collected through interviews conducted by Vanderbilt University students as part of the 2020-21 Tennessee Kindred Stories of Disability project. This annual project gives students, who are future educators, advocates, and researchers, an opportunity to learn firsthand from individuals with disabilities, families, and disability professionals. The project's culminating booklets are shared with legislators and policymakers each year to educate them about issues that impact their constituents with disabilities.

We would like to thank the DSPs who shared their stories this year. As the interviews took place in 2020 during the COVID-19 pandemic, there were added challenges. The entire project was conducted virtually, and we truly appreciate the flexibility of everyone involved. The booklet does not include every story we heard, but all were equally compelling and all shared very similar themes.

The images of the DSPs and their clients that accompany the stories were taken by photographer Jen Vogus and members of the AbleVoices Photography Club. We are so grateful for the partnership with AbleVoices, which provides photography programs for individuals with disabilities as a means for self-expression, empowerment, and advocacy. All photo shoots were conducted virtually this year, so new skills in virtual photography were gained by all!

An additional heartfelt thanks to Vanderbilt University graduate student Aunna Colter, who coordinated the Kindred Stories project this year. She kept the students, DSPs, and photographers connected and Zooming forward. Thank you for all your hard work, Aunna!

Finally, we are grateful to each member of the <u>Vanderbilt Kennedy Center Public</u> <u>Policy Team</u>, which includes some of our community and Tennessee Developmental Disabilities Network partners. From selecting impactful interview topics to disseminating booklets during legislative visits and events, we could not do this work without our amazing policy collaborators. We especially thank The Arc Tennessee for the longstanding partnership.

Now, it's time to read the stories and to learn more about the experiences and impact of Direct Support Professionals in Tennessee.

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To view past Kindred Stories collections, visit vkc.vumc.org/kindred.

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Introduction

Direct Support Professionals (DSP) are individuals who are employed to provide a wide range of supportive and instructional services to individuals with intellectual and developmental disabilities on a day-to-day basis. DSPs generally attend to the health, safety, and well-being of the people they work with by providing daily personal care, teaching life skills, and supporting people to be actively engaged and working in their communities.

Across the country, there are approximately 1.4 million individuals who require services from DSPs to live full, meaningful lives in their communities. And unfortunately, the DSP workforce is in crisis. There are high turnover and vacancy rates, issues with tenure, burnout, and low hourly wages that contribute to a nationwide shortage of DSPs.

The stories in this edition of *Kindred Stories of Disability* come from DSPs living and working in Tennessee, but their issues are not unique to this state. The critical issues of low wages and high turnover are threaded throughout the stories of DSPs across the country. Additionally, DSPs are on the frontlines during the COVID-19 pandemic, and the pandemic has only increased the already critical workforce shortages.

What DSPs Do

- Help with housekeeping, meal preparation, attending appointments and running errands
- Administer medications
- Implement behavioral management plans
- Teach life and employment skills
- Maintain a safe living environment
- Assist with money management, personal hygiene and other routine needs
- Provide transportation
- Maintain paperwork
- Provide crisis intervention

The DSP workforce is in crisis. There are high turnover and vacancy rates, issues with tenure, burnout, and low hourly wages that contribute to a nationwide shortage of DSPs. According to a recent study by the University of Minnesota Direct Support Workforce Project and the National Association of Direct Support Professionals, "nearly half (42%) of DSPs said that they know of staff who left their jobs due to the pandemic, 74% reported that they are their family's primary wage earner and only 24% reported earning extra pay due to COVID-19 risks. Once again direct support professionals are anonymous – this time while supporting highly vulnerable people during a once in a century pandemic. Since the onset, they have been risking their lives on the frontlines in every community in this country, often without recognition, adequate resources and with significant challenges."

While the stories in this booklet highlight many of the historical and current challenges for DSPs, they also illustrate how dedicated, caring, and skillful successful DSPs tend to be. Many of the individuals who were interviewed became DSPs because they knew someone or had a family member with a disability. Some refer to and think of the people with disabilities they work with as "family." Most say working as a DSP brings real meaning to their lives. They talk about the importance of working with their clients to increase self-direction and independence as well as the value and pride that comes when they see their clients succeed.



Know DSP staff who left their jobs due to the pandemic



DSPs are their family's primary wage earner



DSPs earn extra pay due to COVID-19 risks

Mattie (Spring Hill, TN)

My name is Mattie. I am married to my high school sweetheart and am a mother to a 19-month-old daughter. I moved to Tennessee when I was in kindergarten, so I have lived here for most of my life. I have two older sisters, and my oldest sister has a disability. While she does not have a diagnosis, she is nonverbal and uses a wheelchair. She plays a huge part in my story of becoming a DSP.

I graduated from Middle Tennessee State University with a bachelor's degree in Industrial/Organizational Psychology. When I graduated, I did not know what I wanted to do. My sister participates in a day program and occasionally my mom would mention that there had been some turnover there. During one of these conversations, it dawned on me to apply and I began working at the agency with the Employment and Community First Choices Program¹.

I meet with people with disabilities and provide very individualized services, such as job coaching, community integration services, and teaching independent living skills. On a typical day I may pick someone up from their house around 8 AM, take them to their job, and support them while they work for several hours. After taking them back home, I will pick up someone else who may have community integration services. These services look different for each person depending on their interests and their goals. For example, this service could include picking up lunch from a restaurant (which for some is an opportunity to build skills around money management and/or making healthy choices) or going to the park to eat and then walking around to get some exercise. When I drop this person off at work or home, then I move on to support the next person. The days can definitely seem long, but it is also so rewarding knowing that I am helping people to live the lives they want.

Given the situation with COVID-19, our support services look a little bit different than they did previously. The number of people we support is different and our activities have shifted from going bowling or going to the YMCA, to doing primarily outdoor activities, like visiting the park. Unfortunately, many of the people that we support have lost their jobs due to the COVID-19 pandemic. We are in the process of helping them search for new jobs.

DSPs do not get paid very much. Wage increases are one thing that we are really fighting for. When I started my job three years ago, I started at \$10 an hour and was only able to continue this job because I had two other jobs as well. You find that a lot of people in this field have multiple jobs. The

^{1.} The Employment and Community First Choices Program (ECF) is overseen by TennCare through contracted managed care organizations and offers a wide range of services for individuals with intellectual and developmental disabilities. Services in the program will help people become employed and live as independently as possible in the community.



Mattie points out something she notices to her client who loves photographing nature.

limited pay makes it hard to find quality staff who will stay, and the constantly changing staff can be difficult for the people we support. A lot of times the people we support need consistency and it's hard when there's always changing staff. We should be able to offer an opportunity to work as a DSP with a wage for them to live off of a 40-hour work week.

Eventually, though, there's a possibility that I will need to make more money. Maybe there will be an opportunity for an increase in pay and I can stay. Part of the reason that I would stay is the individuals that we support. Also, the staff are great! I also love that I can see the impact our work has on the people we support. We support people in building opportunities. It is important for people to be involved and feel like they are a part of a community. It is important for people to be able to make decisions and feel that they have a sense of control over their lives. Now more than ever we see the importance of DSPs and the work that we do.

"We support people in building opportunities."

Terry (Jonesborough, TN)

My name is Terry. I've lived in Tennessee almost my whole life. I did live in Ireland for 5 years and in Africa for a while. I have a doctorate degree in psychology that I earned from Trinity College in Ireland, and I've been a DSP for 20 years.

As a DSP, I'm responsible for three guys who live within a residential home. I also facilitate iPad trainings for people who do not use spoken words to communicate and can use the iPads for communication. It's truly amazing to see what the technology can do for a person's communication. It helps them to express their wants and needs! Truly remarkable.

A typical day on the job for me begins at 8:00 a.m. and ends at 8:00 p.m. I work 12-hour shifts. My responsibilities include checking all the medications, counting the money, and checking the calendar for appointments. We have a lot of appointments, especially doctor's appointments. I also talk to each individual to see what it is they want to do for the day. If they can't make up their minds, I offer them choices. The three guys here usually want to go hiking and do picnics, so we pretty much go hiking and have picnics every day. I currently support two brothers - one is 75 and the other is 64. The third individual I support is 56 years old.

In terms of training prior to my position, I did take some classes on people with disabilities, but they really did not train me much on how to actually work with people with disabilities. My agency does offer a computerized training platform called RELIAS. I've probably taken about 600 professional development courses through RELIAS. I have also participated in the National Alliance for Direct Support Professionals Certification Program. My agency will pay for our participation and for each of the three levels you complete, you qualify for raises.

When I first started as a DSP, my agency wasn't using person-centered practices. We came into the job and felt like we had to service these individuals. They didn't do anything for themselves. We chose where they would go, we chose what they would eat. As you can imagine, that would frustrate them. My agency has switched to person-centered thinking, and the individuals have become much more independent and much more empowered to think for themselves. We help them to help themselves and that makes everything so much better.

I get so much enjoyment from the individuals I work for. They are amazing. I would say my favorite part about the job is being able to see that their dreams can come true. Obviously, with the COVID-19 pandemic, we can't go on as many adventures as we would like. We still go hiking and do picnics, though. We also have been going to outdoor movies, which has been great. The individuals in the home are wearing their



Terry plays Bingo with his client, one of their favorite games.

masks and practicing social distancing. They do well with all of that. Of course, they're sad that we can't go on trips, but it really hasn't been too bad.

I feel really valued at my job, too. Not only by the agency, but by the individuals I work for and the people I work with. The agency I work for makes sure to back up anything we may need. I support them, and they support me. We have a great agency. I feel very lucky. "I get so much enjoyment from the individuals I work for. They are amazing. I would say my favorite part about the job is being able to see that their dreams can come true."

Brandy (Sharon, TN)

My name is Brandy and I am a proud Direct Support Professional (DSP). I have lived in Tennessee my whole life. I graduated from University of Tennessee at Martin in 2002, with a bachelor's degree in K-8 Education. I am married and have two lovely daughters.

I have been a DSP for 18 years, almost half of my life. I work with three ladies. I support their needs and offer companionship. I have been working with them for the entire 18 years of my career. They live in the same house together. One of the women is legally deaf and blind. Communication with her can be difficult sometimes, but after spending 18 years together, I know her moods and habits. I can tell when she is having a good day or a bad day. The other two women I work with need assistance to the restroom, one is in her sixties and the other one is younger. My ladies view me as reliable. They want me to be a part of whatever they are doing and going through. They know that I am supposed to be with them. When I am not there, they want to know where I am. When I take off from work, they wonder when I will come back. My ladies help me stay devoted to my job because I know they value my presence and company, just as I value theirs.

I see these ladies as my family. I need them just as they need me. As a DSP working so closely with people with disabilities, it is impossible for me to not get attached. The most challenging part of my job is losing someone. I don't want to think about this because I work with older adults, but things inevitably happen. When a person I work with passes away, it feels like a little piece of my heart goes too.

The ongoing COVID-19 pandemic has turned everything upside down, including the life of people with disabilities. We are adapting to this situation and doing the best we can. We used to volunteer doing meal delivery at least twice a week in our community here in Martin. Engagement in these services helped my ladies stay active as community members and maintain a healthy daily routine. Unfortunately, we can't continue anymore due to social distancing regulations. I know that my ladies miss the connections that they had. It is difficult for them to comprehend what is going on and why they need to stay in the house all the time. I try to keep them occupied indoors with different kinds of activities, such as playing puzzles, sorting objects, doing arts and crafts, and most importantly, getting their nails done every week.

I also stay in contact with other DSPs to help my ladies maintain social bonds with their friends and families. DSPs at other houses will arrange events twice a month so that we can get together with other people to celebrate birthdays or holidays. One of my ladies has a brother who lives in another service house in our community, so I collaborate with the DSP at her brother's house to make sure that they get to see each other with their health and safety under protection. We will call each other and arrange a meeting time: "I'm gonna come to your house and sit on your driveway until you can come out on the porch". All DSPs are putting in great effort to make the best out of the worst situation.

My perspective about people with disabilities changed so much after I became a DSP. I have heard people say that the people I work with cannot offer much to our society. However, to me, they are leading good lives. They are enjoying their every day to its fullest. My job has also shaped how my daughters see people with disabilities. They have stood up for children in need when they hear other kids say something disrespectful. I could not be prouder of them. The positive impact my job has had on my children is another reason that motivates me to continue working in this field of service.

I have been offered several times for advancement into office jobs, but I rejected them. I value the daily interactions I have with the three ladies I care deeply about. I also feel the urge to advocate for people with disabilities and for the work DSPs do. During this pandemic, DSPs are essential workers who risk their own health for people with special needs. Our government should take the time to understand our duties and the community we support. In addition, we encourage the community to get more involved. Knowledge is the cornerstone to erase bias and prejudice.

"I have been offered several times for advancement into office jobs, but I rejected them. I value the daily interactions I have with the three ladies I care deeply about."

Tony (Martin, TN)

My name is Tony. I have lived in Tennessee all of my life. I have a high school education and worked as a nurse's aide on and off during my younger years. I have five kids, one of whom got a traumatic brain injury in a motorcycle accident in 2007. After her accident, I started taking care of her full time. After about 9 years, I decided that I wanted to work for a company that worked with people with disabilities.

On a typical day, I am responsible for working with three individuals. I pick up the people I support and get them out into the community. We volunteer at different sites including Meals on Wheels, The Boys

and Girls Club, and Good Samaritan, a place you can go to receive free medical care. After volunteering, we would have lunch and spend the rest of the day doing whatever the guys wanted to do, like going for a walk around Reelfoot Lake State Park or going to a senior center to visit with seniors that they have made friends with over the years. Unfortunately, COVID-19 has changed how I

For my current position, I received some medical training and Professional Crisis Management (CPM) training. These trainings were incredibly helpful. I am also connected to a broader DSP peer support network that has been very beneficial.

Lawmakers could definitely support us in our work by increasing our pay. Other than that, I'm happy with my job. More pay would help us to support our own lives better.

Before my daughter was injured and I began working with people with disabilities, I didn't give it a whole lot of thought. If I was around someone that had a disability,

> I would always be kind and respectful, but never gave it a whole lot of thought until my daughter's accident and my family was thrown into it 100%. My daughter and my work have given me more patience and more understanding. Interacting and spending time with them has expanded my perspective and understanding of disabilities.

do my job. We're unable to go out into the community and interact with those we have created relationships with, which confines what we are able to do. My job is very rewarding, and I hope that I continue to work as a DSP until I retire. My favorite part of my job is spending time with the guys out in the community. I enjoy seeing how they light up about something



Tony and his client often enjoy singing "Elvira" and playing the guitar.

that I would typically see as normal; they look at it in a different light and with a different perspective. This lightens their light, and it also lightens mine. The most challenging part of my job is when one of our individuals has a bad day. It can be rough on them, and also rough on us. I typically handle these difficulties with patience, a lot of talking, and some hugs.

"Lawmakers could definitely support us in our work by increasing our pay."

Eddie (Dresden, TN)

My name is Eddie. I have lived in Dresden, Tennessee most of my life. I knew for a while that I wanted to work with people with disabilities. When I lived in Texas, I was in Boy Scouts. We went to a summer camp and I ran into a troop of guys that were a mixture of guys with developmental disabilities and physical disabilities. I ended up pushing a guy around in a wheelchair and hung out with him and his friend who had Down syndrome. That was my first real exposure. I loved getting to know them and that experience had a big impact on me and my life direction.

My job is to help adults with disabilities become as productive as

possible at their jobs. I'll support them in a factory setting, a bakery, or wherever their job placement is. I am there to help guide them, supplement their work if necessary, help them stay on task, and quality check their work. I help them learn to work independently so that they may get to a point where they don't need my support. The goal is to fade

want to have their own place. They want to have a boyfriend, a girlfriend. Some of them reach those goals, or I try to get them as close to their goals as I can. I try not to treat them any differently than I would anybody else.

My favorite thing about my job is seeing an individual's light bulb go on, basically them realizing that they have the ability to do something they didn't know they could do. I think seeing somebody achieve their goal basically is the best thing you can hope for.

There are a lot of great folks, and they don't want to ever be in a position again where

> they're stuck at home with mom and dad with nothina to do because the state has stopped funding programs like what I do. We want everybody to have the have jobs and the community opportunities. I think that it's wonderful that a person with disabilities can get up, get dressed, and have a purpose in life - just like every other person does. We have ebbs and flows in our funding. It changes. This

my assistance and have them learn to use natural supports in the work setting, such as the other employees and their employer.

One thing that I've learned from my line of work is that folks with disabilities are still just folks like us. They're just folks. They have the same desires. They want to work. They

program isn't getting the funding that it used to, and they are limiting job coaching. The more lawmakers and legislators are aware of the value of programs that support individuals with disabilities, the better off we'll be.





Eddie provides on-the-job support to his client who weighs cookie dough at Sweet Jordon's Bakery in Paris, TN.

"This program isn't getting the funding that it used to, and they are limiting job coaching. The more lawmakers and legislators are aware of the value of programs that support individuals with disabilities, the better off we'll be."

Jennifer (Bell Buckle, TN)

My name is Jennifer. I have lived in Tennessee since I was 15 years old. I grew up in a line of generations of Special Education teachers. Supporting individuals with disabilities is in my blood. I knew that I was destined to work with people with disabilities, but I didn't want to be a classroom teacher like my mother and grandmother. I had grown up around individuals with disabilities and watched them age out of public schools without much continuing guidance or support in their adult lives. After they completed school, many individuals with disabilities were left on their own. That's why I made the decision to become a DSP, so I could

help individuals with special needs live fulfilling and active lives.

I work as a DSP in the family model version. We have two individuals that live in our home with us. Many of my duties are duties that parents would do for their children: making sure they are fed, clothed, and clean; making sure their bills are paid; getting

them to doctor appointments; helping them

shower and shave; ensuring they have the therapy and health care they need; and

many others. The individuals who live with

always on the job, but I would not trade it

for the world.

me participate in everything my family does, from church to vacations. In a sense, I am

One reason I do this job is because it allows my kids to be exposed to people who are different from them and grow up without prejudices. We have no immediate plans to retire until we become eligible for Social Security, but honestly, I am happy staying right where I am. I love my job, especially when I get to watch my individuals meet their goals. Even the tiniest goals mean a lot to me, it's a really good feeling.

DSPs should not be considered minimum wage workers. If DSPs are seen as minimum wage workers, individuals with disabilities will not get the care they need. I think lawmakers have started to recognize this in

> the past few years. We deserve a wage higher than minimum wage. Lawmakers should continue this trend of recognizing our efforts and our worth. In addition, the people making laws and regulations for this population need to have done this job to truly understand what the job entails on a day-to-day basis. If you have never walked

in my shoes, it is hard for me to say that your laws and regulations are going to be effective.

Those in charge really need to have some kind of notion of what we do.

On another note, my agency definitely makes me feel valued and supported.





Jennifer and her client play a board game together.

I have a coach I can call if I have any sort of issues, and she has her supervisor who she can talk to as well. I do think it is extremely important for DSPs to be valued and respected. I love my job, and it is something I value every single day. In order for individuals with disabilities to receive the care and support they need, elected officials and lawmakers need to ensure that people who provide this care, especially DSPs, receive the money and support they earn.

"The individuals who live with me participate in everything my family does, from church to vacations. In a sense, I am always on the job, but I would not trade it for the world."

Billy (Greenfield, TN)

I moved to Tennessee at the age of nine and have lived here for 46 years. I have an associate divinity degree and am married with three children. I've been a DSP for a little over two years.

I initially became a DSP to make a little extra money. It was a long process to get hired. I started out as a substitute, but now I'm full time and guaranteed 36 hours a week. I usually work in a house with three men. A typical day on the job for me starts at either 4:00 p.m. or 12:00 a.m. When I go in at 4:00, I check the individual support plans² and medications. Then I get to work cooking. After dinner, the three men will sometimes go outside or watch TV. Sometimes I watch football with one of them. I give them their meds, explain to them what they are, and log what I gave each of them because we must keep track of everything. After they go to bed, I clean up from dinner, wash dishes, and check on the men every hour as they're sleeping. I also log what they all ate and when I gave them their medicine.

- Describes an individual's goals
- Specifies which support services will be used to achieve these goals
- Identifies the individual's support team and their support roles
- Provides strategies on how to address identified risks

When I come in at 12:00 a.m., I set up everything to cook breakfast. This is when most of the cleaning gets done, so I sweep and mop the floors, clean the bathrooms, and take out the garbage. I check on the men every hour, but it's a good house and they usually sleep through the night. At 6:00 a.m., I wake them up and make breakfast while they get ready for the day. After breakfast, they get their meds and usually go outside while I clean up the dishes.

Before becoming a DSP, I went through two weeks of all-day training. The first part was about disability rights. I learned all about their individual rights in training. The next part of training was medical training. It included a lot of CPR training and how to administer different kinds of medicine. Once or twice a year we have additional training to keep us up to date. We also repeat the medical training every three years. The initial training was in person, but the rest are online so you can do them while you're in the house, like when the men are sleeping. The training is helpful, but I think other kinds of training would be useful too. For example, training on some of the housework like using the dishwasher and cleaning, or training on how to groom the men might be useful. I'm not really connected to a broader DSP or peer support network, but I receive a lot of support from my house manager.

I've gotten so close to my guys that my perspective has obviously changed a lot. I have a lot more empathy. I also just feel a significant attachment to them. Sometimes, to make their day more special, I'll bring

^{2.} An Individual Support Plan (ISP) is a document that typically:



Billy and his client enjoy watching Titan's football together.

some slice-and-bake cookies or some microwave popcorn. The simplest things can make such a big difference in their day and in their life. It takes almost no effort to do small things like this, but it creates the possibility of getting close with the clients. That's the most rewarding part about my job. It started off as just a way to get extra money, but it has since turned into a familial role.

I've helped these men learn to control their emotions. I've gotten to see their accomplishments, which in a way, is an accomplishment of my own. I've been there for their ups and downs. There is nothing better than seeing that you've made a difference in someone's life. I initially thought I wouldn't have done this job for all that long, but I love the time I spend with the men. My pride for my job is helped by the value that I feel that I have in my position. I feel that I'm very supported in my role, especially by the clients themselves. Though the COVID-19 pandemic has limited my interactions with the men, and with my supervisors, I still feel that they value us a lot. They really allow us to succeed in our job. At the end of the day, you have a lot of freedom to do what you want, so long as you are doing your job, and they give us that freedom. I also feel as safe as possible during this pandemic, with the supplies and resources that they provided us. With the pandemic, it's gotten a lot harder to make personal connections with the men and my bosses, but I still feel supported in such a period of transition.

Tina (Johnson City, TN)

My name is Tina. I have been working as a DSP for approximately 18 years. Prior to working as a DSP, I was educated in both health education and psychology, as well as working in a pediatric psychiatric hospital. This has helped prepare me for my careers in the health industry. At the psychiatric hospital I worked in a unit of six patients with organic brain damage. Operating in this role was very shocking and difficult initially, but the rigorous training I received from this job taught me many skills that carry over into my work as a DSP. meet but it is important to be able to adapt to different circumstances throughout the day. An example of adapting includes the current pandemic. Due to COVID-19, we have new restrictions, but have modified plans and activities so that there are still fun experiences. We go through drive thrus, spend one day a week at the park, and try to find activities, such as watching a parade from our cars, that are safe and fun. The agency I work for has helped by having movie nights and water gun fights with limited people.

I currently work in a residential behavioral home, supporting a group of men. I am

assisted in caretaking around two hours each day but am otherwise the sole person in charge. I work for 15 hours a day, four days a week. On Friday and Saturday, I work 10 hours and 8 hours respectively, and Sunday is my only day off.

My job responsibilities are very broad as I am responsible for the general health of these men. As a DSP, my role includes giving baths, transporting to doctor's appointments, and overall caretaking. I consider it a combination of being a nursing aide, special education teacher, and parent, all in one. Being a DSP, my duties change daily. There is a schedule I try to My training to be a DSP includes yearly training, including the CPI (Crisis Prevention

Institute) training, CPR training, and training on Title 6 and bloodborne pathogens. I am also trained to give medications. While some of these certifications can occur online, hands on programs such as CPR training are in person. One improvement I would suggest in this area is additional training in the behavioral arena.

Though this job is very difficult, I love working as a DSP. The connections with those I care for are very meaningful and they are very appreciative of my work. The challenges in this industry definitely include the pay. For the amount of work and effort this job





Tina organized a holiday cookie decorating activity for 3 of her clients who live together.

requires, the money is not a strong enough incentive to attract and keep good workers. With higher salaries there would be lower turnover rates, which is helpful to those being taken care of as they can become comfortable and connect with their DSP. Even with these challenges, being a DSP is something I enjoy very much and plan to continue until I retire. I feel like I am making an impact in their lives.

"With higher salaries there would be lower turnover rates, which is helpful to those being taken care of as they can become comfortable and connect with their DSP."

Carolyn (Johnson City, TN)

My name is Carolyn. I was born in Tennessee and I live here with my two boys. I have been working as a DSP for 18 years. I was in college when I first took a job as a DSP. I fell in love and it became my career.

I am also a job coach and I am on the crisis team for my agency. I do my job because I love it! I love seeing our guys happy and watching them learn. I love helping them when they are stuck, and need to get past whatever's bothering them.

Every day is different as a DSP. We work 12-hour shifts. I could work with one to 12 people in a single shift. I am trained with 90% of the people with disabilities that our agency works with. I have worked on and off with some of our guys for many years and we usually have new people as well. My job as a DSP is to make sure our guys are safe and happy. I help them with self-care such as cooking, showering, getting ready for the day, and doing laundry. We also take our guys out on outings into the community. Pretty much I can help them with whatever they need. The only time I would have to call in support would be if they needed a nurse for a specific medical need.

As a member of the crisis team, I could be called at any time to be with someone who needs extra help. Usually this happens in situations with verbal aggression that could turn into physical aggression or self-harm. Sometimes the people we work with just need another person to come in, alter the environment, and provide a calm setting. This is the most challenging part of my job. However, it is also so rewarding to be there in those moments. Sometimes the people we work with really have trouble getting past certain things. It is so special when you can help someone get past something.

To be a DSP, you need to be certified in first aid, CPR, and a certain level of medical certification. We also take a training course. However, this is not as comprehensive as it could be. I loved when the training was in person. For the past 12 years, it has been virtual. In person it is a lot easier to understand the content and ask questions. It is also so important to do site visits during training. You can read and watch videos about people with disabilities all day, but you won't really know how to support someone until you meet them in person.

There is also a continuing education course I could take through my agency, but I have not had the time. This can increase your rate of pay. Working as a job coach, on the crisis team, or in management also increases rate of pay. However, these positions only open up if someone leaves.

We have a DSP Facebook group for us to support each other. I often listen to how other DSP's days went and give them advice. The group has been helpful for organizing safe outings during COVID-19. The pandemic has made outings and going into the community very challenging. There is a lot less our guys can do right now. It shows in how they are feeling.



Carolyn provides support to her client who works at Food City in Gray, TN when he needs it.

As a DSP I feel well supported by my guys, their families, and my agency. One thing that the general community could do to further support DSPs and the people they work with is by knowing the benefit individuals with disabilities bring to the community and knowing that they can learn and contribute to the community. I also feel empowered to advocate for my guys and have done so on various occasions to make sure they have access to medical supports and opportunities to attend events and trips that interest them.

Although I work for an agency that has a low turnover rate, we have had seasons of shortages, which can make providing services more difficult. However, my "Although I work for an agency that has a low turnover rate, we have had seasons of shortages, which can make providing services more difficult."

agency works really well to support us and to help us through any difficulties. I love my job and being a part of the disability community.

Resources

National Alliance for Direct Support Professionals (NADSP) supports DSPs by improving practice standards, promoting system reform, and advancing knowledge, skills and values. <u>nadsp.org</u>

Institute on Community Integration DSP Workforce Development Program provides state-of-the-art resources to help people with disabilities and their families find and retain quality Direct Support Professionals (DSPs). <u>ici.umn.edu/projects/115</u>

Tennessee Disability Pathfinder helps people with disabilities, their families, educators, and other professionals find and access resources, support, and services available to meet their needs. <u>DisabilityPathfinder.org</u>

American Network of Community Options and Resources (ANCOR) is a national, nonprofit trade association representing more than 1,600 private community providers of services to people with disabilities. <u>ancor.org</u>

The Arc is a national community-based organization advocating for and with people with intellectual and developmental disabilities (I/DD) and serving them and their families. It has hundreds of state and local chapters across the country. <u>thearc.org</u>

About Us

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

Provides innovative leadership in education, research, and services to people with disabilities, the community, and families. All activities promote the independence, self-determination, productivity, integration, and inclusion of individuals with developmental disabilities and provide supports for families. <u>vkc.vumc.org/ucedd</u>, (615) 322-8240 or toll free (866) 936-8852

The Arc Tennessee

A statewide advocacy organization that empowers people with intellectual and developmental disabilities and their families to actively participate in the community throughout their lifetime. <u>thearctn.org</u>, (615) 248-5878 or toll free (800) 835-7077

About the Photographer

Jen Vogus is a photographer, educator, and parent advocate. She is also the founder of AbleVoices (<u>ablevoices.org</u>), a nonprofit organization that teaches photography to individuals with disabilities as a means for self-expression, empowerment, and advocacy. Jen is a graduate of the Tennessee Council on Developmental Disabilities' Partners in Policymaking Leadership Institute and a board member of The Arc Tennessee. Vogus was assisted during the virtual photo shoots and in the editing process by AbleVoices Photography Club members-Bryant, Sami, Will, Sam, Eric, Kyler, Eleanor, and Wilson.



"DSPs should not be considered minimum wage workers. If DSPs are seen as minimum wage workers, individuals with disabilities will not get the care they need."

> Tennessee Kindred Stories of Disability vkc.vumc.org/kindred