

2017

TENNESSEE KINDRED STORIES OF DISABILITY

Special Supporting Families Edition: Connections to Communities



VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES



Council on
Developmental Disabilities

A Letter of Thanks

We thank you for taking the time to read this issue of Kindred Stories. Because of the work we do at the Vanderbilt Kennedy Center and the Tennessee Council on Developmental Disabilities, we felt it was important to highlight the experiences of families and their efforts to support those family members to become meaningfully engaged in their communities. We know the experience of disability adds a layer of challenge to community participation, and we are interested in learning from families.

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.

Students interviewed 15 different families in Tennessee who have members with disabilities to get their perspectives, and then summarized those experiences in their own narratives and voices. We made an effort to honor the families' experiences (both positive and negative), respect the work of the students, and, at the same time, offer some additional comments about resources and policies that relate to the challenges and successes in becoming valued, participating members of their communities. These stories include families' experiences with formal supports and services and accounts of how some families have found or created informal supports in their communities to help their son or daughter with a disability lead quality lives.

We thank the families who shared their stories. By reading them, you will receive snapshots in time of a diverse group, across a spectrum of disability, geographic location, socioeconomic status, and race. By sharing these stories, the students and families hope to demonstrate how individuals with disabilities and their families find support in their communities and how they address the barriers to full community inclusion and meaningful engagement that many of them still face on a daily basis.

To view additional stories on a variety of topics from Tennesseans with disabilities, please visit: kc.vanderbilt.edu/kindredstories.



Elise McMillan

*Co-Director, Vanderbilt Kennedy Center for
Excellence in Developmental Disabilities;
Senior Lecturer, Psychiatry & Behavioral Sciences*



Wanda Willis

*Executive Director, Tennessee Council on
Developmental Disabilities*

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Introduction

The national **Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities (I/DD)**, led in Tennessee by the **Council on Developmental Disabilities** and the **Department of Intellectual and Developmental Disabilities**, aims to identify and develop supports that assist individuals with disabilities and their family members in living meaningful, satisfying lives and that ensure they are not isolated, but significantly engaged with their communities throughout their lives.

The Supporting Families Community of Practice holds the core belief that all people, including those with disabilities, have the right to live, love, work, play, and pursue their life aspirations in their communities. Across the country, our culture is embracing this belief. It is necessary to change not only our conversations, but the way we think about people with I/DD and their families and the supports they need to live a good life. Our efforts to improve supports to families must take into consideration the significant percentage of families not currently connected to the formal disability service system and the needs of individuals with I/DD across the lifespan.

In an effort to discover more about the needs of families with members with I/DD and strategies they have used to overcome various barriers they've faced, interviews were conducted using the **Tennessee Kindred Stories of Disability** model. Partnering with the **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities**, families were interviewed by Vanderbilt University students to determine their challenges and accomplishments with forging connections to their communities. Common themes surfaced during the family interviews and we have outlined some of those themes throughout this booklet, grouped by the "challenges" and "successes" mentioned by families.

The Kindred Stories project gives individuals with disabilities and their families an opportunity to share their voices and stories. We hope these stories help other families feel less alone and offer examples of how some families have worked to develop supports for a good life and future for and with their loved one with a disability. By sharing these stories, we continue to promote understanding and awareness among professionals, policymakers and the general public about common challenges families may face and how our state can offer better supports to Tennesseans with I/DD and their families.

Continued on the next page

Introduction

In addition to the stories, the families have shared family photos with us and we have sprinkled them throughout the booklet and in no particular order. We appreciate their contributions to making this booklet both informational and personal.

Along with the family stories, we have provided commentary, guidance and information on resources to address some of the barriers outlined. We offer some explanations about how the public policy landscape is attempting to address barriers that individuals with I/DD and families face in their efforts to find support and inclusion in their communities. We also offer suggestions of specific local, state and national resources and organizations that can support families who may be experiencing similar challenges.

Our hope is that the content will spark new ideas and provide road signs for families to get on, and stay on, a positive trajectory throughout the lifespan of their family member with a disability.

Contact Tennessee Disability Pathfinder for more information on the ideas and resources included in this booklet.

(800) 640-4636
tnpathfinder@vanderbilt.edu
familypathfinder.org

Common Challenges and Successes



The most commonly noted challenges that appeared in the family stories are:

The lack of public transportation options, accessible or otherwise, in many communities severely inhibits the ability of individuals with disabilities to go to work, attend classes or training, or participate in community and social activities.

Most parents, and in some cases siblings, have some level of fear or anxiety about the future, in terms of who will care for or support their family member with a disability when they are no longer around or able to.

To help address this need, a law was enacted in 2015 by the Tennessee General Assembly to give people with intellectual disabilities who have “aging caregivers” priority enrollment into long-term services and supports funded by Medicaid. While this policy change is encouraging, it will take time and a concerted effort to raise awareness among Tennessee families who could take advantage of it. Furthermore, the law does not address the needs of families caring for loved ones with other types of disabilities—other than intellectual disabilities—who have aging caregivers.

There seems to be a pervasive need for, and lack of, qualified, dependable respite providers and funding, for people who are not in a Medicaid long-term services and supports program, which does offer respite as a covered service.

Some parents feel like they are the only ones who are able to, or care enough to, provide supports for or advocate on behalf of their loved one with a disability. This is often because they have been unable to find quality help in these areas. Although several advocacy organizations exist to serve this purpose, challenges remain in connecting families who need those resources.

Many individuals with disabilities, as well as their family members, frequently feel isolated.

Common Challenges

- Lack of Services
- Lack of Social and Community Engagement
- Isolation
- Transportation
- Low Expectations
- Family as Sole “Provider”
- Lack of Respite Options
- Future Concerns

There are too few services for those with developmental disabilities other than intellectual disabilities.

Recognizing this particular gap in services, the state’s first Medicaid-funded program for people with developmental disabilities (DD) other than intellectual disabilities (ID) was implemented, called “Employment and Community First CHOICES,” in July 2016. Raising awareness about the new program and ensuring sufficient capacity to meet the pent up demand for services will be continuing challenges.

Many families and individuals lack a social network, even those who are successfully employed.

These common challenges reflected in the experiences of families who were interviewed are not unique to the families who shared them, or even to families in Tennessee. Many are deeply entrenched barriers that will require concerted efforts by all stakeholders, policymakers and communities to systematically resolve. However, some families we talked to have found their own solutions or discovered strategies to address these challenges.

The most commonly noted successes that appeared in the family stories are:

Some families have been able to access natural community supports, instead of waiting for disability services to provide or develop supports.

Several families have recognized the need to thoughtfully prepare for life's later stages.

Some families do enjoy a supportive network of close friends and nearby, extended family members.

A number of parents have risen to the levels of leaders in their communities by making efforts to improve outcomes for all families who have members with disabilities, not just their own family.

Families feel empowered by having access to information which enables them to make their own informed choices and decisions.

Some have discovered that minor supports and accommodations can make a huge difference in a successful employment placement.

Families have found community integration opportunities for their sons and daughters through volunteering.

Community engagement, in all its forms, seems exponentially easier when the individual with a disability is personally driven to work or is socially engaged.

Among many parents there is a strong desire to respect their child's autonomy to make his or her own decisions.

We keep learning important lessons about what families face on a daily basis, and about what families need as they navigate their lives and support the meaningful community engagement of their loved ones with disabilities.

Common Successes

- Supportive Faith Communities
- Parents as Advocates
- Employment
- Community Engagement
- Informal Supports
- Focus on Gifts and Strengths
- Access to Information
- Preparation for the Future

Family Stories and Experiences



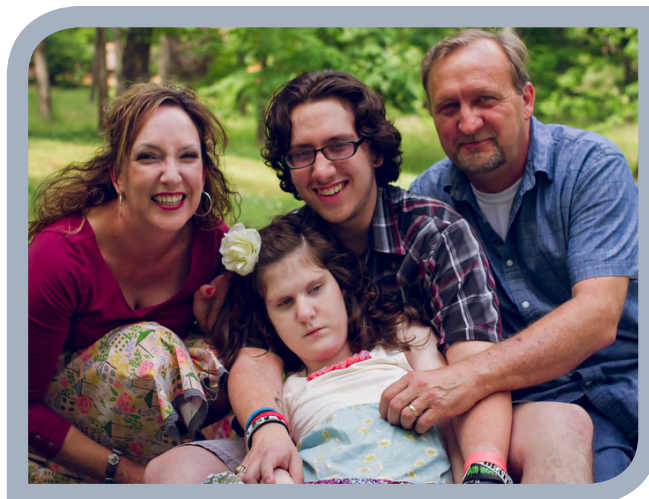
Challenges

On the lack of services

“When we moved to Tennessee, we were told that our son’s diagnosis was ‘not severe enough’ to receive supports,” said **Cynthia**. “Communication has always been a huge challenge for **Isaiah**. His speech patterns and articulation make it difficult for him to be understood. That affects his ability to form and maintain relationships, express his wants and needs, and even his ability to obtain a job.”

“We do have challenges,” **Karen** said. “For four years, **Tabby** had a private duty nurse who would go to school with her every day. Her last nurse had been with her for a little over three years, until she had to leave suddenly with health issues. We got a phone call that she couldn’t come back for eight weeks, which put the Home Health Agency and us in a bind. They didn’t have anyone to fill her position, and I wouldn’t send her to school without a nurse, so Tabitha didn’t go to school for a couple of weeks.”¹

“We’ve probably been on the waiting list for 10 or 15 years,” said **Kathy**. “We signed **Jonathan** up that long ago, because that would give us the extra funding to be able to hire somebody on a regular basis instead of just here and there when I need a little help. Right now we are receiving a little bit of funding from Family Support, which can be used for respite but it’s very minimal. Other programs either tell you that you’re making too much money or your son “isn’t disabled enough.”²



¹ While most programs that provide private duty nursing have rules that require staffing adequacy to prevent situations like the one Karen’s family faced, the reality is that many providers across the state are facing severe shortages in direct care staff, including nurses.

² Indeed, many existing programs have eligibility criteria that include functional assessments and other measures to determine the severity of a person’s support needs. These criteria are intended to ensure the programs’ scarce resources are directed to people with the greatest needs. However, reports like these have spurred advocates to call for review of the existing criteria to ensure services are reaching people who need them.

The Family Support program, established and funded by the Tennessee State Legislature, is hailed as one of the most important programs for people who do not qualify for long-term services and supports programs. Family Support provides funding directly to families who can use it to purchase services like respite care, day care services, home modifications, equipment, supplies, personal assistance, transportation, homemaker services, housing costs, health-related needs, nursing and counseling. Families who receive it seem to appreciate its flexibility. Still, due to budget constraints and program rules, a person still must meet qualifying criteria to receive Family Support funding, and not all qualifying families can be served. For more information on Family Support, visit www.tn.gov/didd/topic/family-support-faq

Tiffany mentioned that unlike other families of children with disabilities, they are in a unique category: since Joshua was not born with disabilities but diagnosed later in life, their family was not “plugged into services at a very young age”. Moreover, **Joshua** has been homeschooled all his life, so they are separated from the school system where educational information, resources and services are mostly allocated. As a result, Tiffany has often felt “disconnected from the disability world”

“**Kathleen** enrolled in a University and was able to find scholarships for her first year,” explained **Patti**. “However, she found out very soon that the school campus was not accessible for people with physical disabilities. Utilizing supports for students also were a challenge. The tutoring center wouldn’t help her, because they said she couldn’t physically carry the books. I took her books and cut them up so that she could carry whatever section she needed to study. They actually got really mad about that even though it was her own book, and they still wouldn’t tutor her.

“Eventually, Kathleen got into the honors program and guess what they offered in the honors program? Tutoring. And they didn’t care that she couldn’t carry the books. She finished her degree and is now earning her Master’s in Library Science.”

Kathie describes her son **William** as a strong and determined individual who does not like to be described as having a disability. He loves sports and was really good, but ultimately lacked options. She highlighted that her son was not provided with opportunities to play sports whilst he was in school due to his participation in Special Education (instead of the general curriculum). He quit school a week before 12th grade and did not want a Special Education diploma. William initially worked at a grocery

store and was good at arranging items on shelves. He now works at UPS and has been there for 14 years. He works 20 hours a week and pays his own rent.³

Natalie spends 3-4 days a week at an adult care center, where she is grouped with a number of other adults with disabilities under the supervision of a leader, and spends the day doing excursions into the community and, essentially, “being kept safe.” Her mother, **Lucy**, remains dissatisfied with the services Natalie receives during the day, but struggles with the reality of needing some time during which she is not solely responsible for her daughter. The additional pain of knowing that the care her daughter is receiving is not up to her personal standards is an added stressor for Lucy, not just presently, but also in the past and for the future.⁴

Before Natalie moved back home, she lived for a time in a family-based home. This allowed Lucy

³ *Special education laws protect students’ rights to have equal access to opportunities at school. Reports like these highlight the need to ensure that students’ experiences align with those intentions.*

⁴ *Recently, there has been a national movement toward “meaningful day” services in long-term services and support programs that fund such day centers, driven by experiences like Natalie’s. This movement is part of a broader recognition that services for people with disabilities should not solely focus on supervision, but instead on engaging in activities and relationships that are meaningful to the person. The federal government passed rules to require Medicaid programs to ensure services are provided this way from now on. Hearing from families and their experiences will continue to be critically important to ensure this challenge is addressed through program changes and other solutions.*

to keep her job. However, Natalie was taken advantage of financially and emotionally during her time there. Lucy's careful food planning and financial management efforts were mismanaged, ignored, or squandered. Described as "a nightmare", Lucy retired in order to move Natalie back into her home.⁵

Although **Grace** has been fortunate enough to gain valuable work experience, her mother is concerned for her future employment opportunities. According to **Leisa**, Grace would need 24/7 assistance when working at any job placement. Leisa is concerned that when Grace's services begin to dwindle, she will be unable to find work because employers are unlikely to be willing to provide the accommodations necessary to hire Grace.⁶

Grace currently lives at home with her mother. Leisa is trying to find some sort of living situation for Grace that will prepare her for what life will be like when she is no longer around.



⁵ This model, known as "Family Model Residential Support", is offered in long-term services and supports programs funded by Medicaid as an alternative that works well for some people who prefer not to, or cannot, live on their own. It offers an opportunity for people to live with a host family rather live in a group home or institutional environment.

⁶ Leisa is not alone in these fears; they are among the most commonly reported by parents and friends of people with disabilities. Recognizing this, Tennessee has joined a national movement by becoming an "Employment First" state thanks to Executive Order No. 28 signed by Governor Haslam. The order creates a Task Force of several state departments to focus on raising awareness among employers and the community at large about the benefits of hiring people with disabilities, and on removing barriers to employment like the ones Leisa identifies. Leisa's experience highlights the need to continue efforts in this area and increase support directly to families like hers.



Addressing the lack of services

Tennessee Disability Pathfinder's staff and online database can help individuals and families to identify, connect, and begin building a priority "go-to" list of disability-related agencies. It is very common to find that the professionals in the disability-related organizations are themselves family members of persons with disabilities. Many of them have personal experiences they are willing to share, which can be comforting when navigating unfamiliar territory. Below are some suggestions Pathfinder staff might point to in addressing the lack of services. For more information, visit familypathfinder.org.

- Advocacy organizations like The Arc Tennessee and its local chapters
- Disability-specific and/or health-specific organizations, such as Muscular Dystrophy Association of Knoxville, and the Down Syndrome Association of Memphis and the Mid-South, and the Arthritis Foundation
- Consumer and parent support groups
- Mentoring program, such as Family Voices "P2P"
- Tennessee Respite Coalition
- Family Support Program
- Employment and Community First (ECF) Choices Waiver

~TENNESSEE DISABILITY PATHFINDER

Challenges

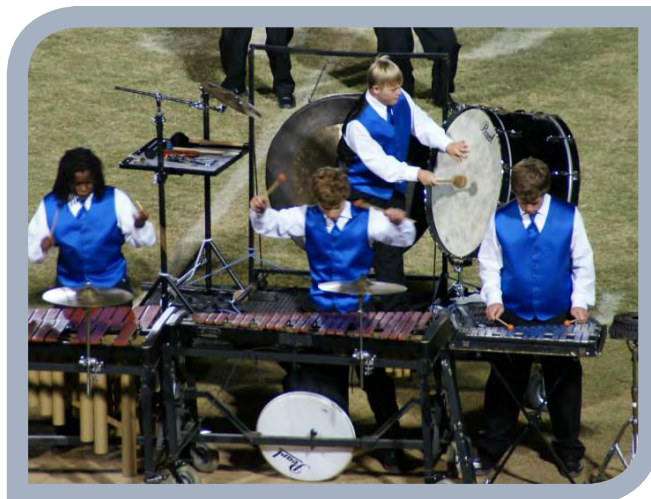
On barriers to social/community engagement

"We haven't been able to connect with many recreational and community activities in Sumner County," said **Karen**. "We can't find opportunities that are well-suited for **Tabby's** age. That's something that needs to change. I'm trying to talk with the mayor and our senator about this issue."

"For kids like Tabby, it's pretty much school and that's it. Unfortunately, we don't get invited to a lot of birthday parties and we can't do sleepovers. It would be nice to have something, just something."

"I wish there were more community activities for **Aimee**, said her father, **Roger**. "Chattanooga has wonderful therapeutic recreation programs with everything from hiking to wheelchair basketball to peer groups. There is also an autism center that has activities, but Aimee gets anxious and isn't really interested in participating for very long if at all."

"I wish that more people were willing to be patient and give people with disabilities a chance to be part of their lives. And that's, I guess, not just the parent, that's the advocate speaking. I think that many times our society just writes people off at first glance. I wish there was a way for people to take a few minutes and look past the differences and give people with disabilities a chance. Whether it's to include them in a golfing game, to include them in a reading club, or to have dinner with them. Just include them and not automatically write them off because they speak a little slower or act a little different."



"**Jonathan's** happy with all the activities he does, but he does long for a relationship," **Kathy** said. "We've tried to help him in that regard by arranging 'family dates' with other families with same-age daughters. Though a couple of families have accepted, most say 'no'. I will continue in my efforts to be a matchmaker. My son wants to find someone to love just like anybody else."



Addressing Isolation and Community Engagement

Many parents make a conscious decision to get their family member with a disability out into the community. They search for accessible events and make it happen. Schools are often the center of community engagement when a person is younger, but Tennessee Disability Pathfinder can work with a caller to identify other desired options for adults. For example, volunteering at the right place can go a long way towards helping someone have lasting relationships, purpose, and fun. Below are some suggestions that Pathfinder staff might point to in addressing community engagement. For more information, visit familypathfinder.org.

- Tennessee Disability Pathfinder's Events Calendar
- Accessible, local school programs such as sports, music, and theater and art events
- TRIAD's Community Engagement Partners for family and sensory friendly events
- Camps, summer programs, and recreation resources
- Natural supports from participation and/or volunteering in nearby organizations
- Rural public transportation
- Educational and training programs such as Partners in Policymaking and Tennessee Disability MegaConference
- Best Buddies of Tennessee

~TENNESSEE DISABILITY PATHFINDER

Challenges

On struggles with transportation

“**Terrell** wants a paid job, but is grateful for his time volunteering with Thrift Smart,” said **Linda**. “He is very meticulous with the clothing. He will help customers and knows the store inside and out. He loves that thrift store, and just has a strong desire to work.”

“A big challenge for our family, and one that impacts where he could work, is transportation. Everyone in our home works, so we can’t always take him places he might want to go. A reliable transportation system would be a great resource in helping him to obtain employment and gain independence.”



Struggles with Transportation

Transportation is consistently named as a top barrier to community inclusion and independence for people with disabilities, not only in Tennessee but nationally. Some additional barriers that have been identified by individuals and families across Tennessee:

- Limited transportation options in some areas of the state.
- Services provided by community action agencies, which prioritize transportation to medical appointments, can be unreliable.
- Geographic restrictions, service hours, eligibility processes, and fixed routes of local transit options may rule out many job opportunities for individuals with disabilities.
- Costs may be too high for a regular commute for individuals living near or below the poverty line.

Challenges

On battling low expectations

Though **Robert** has had many successes, he also faces challenges in his life. One of the biggest challenges is the attitude of other people. Throughout his education, Robert has had to deal with these attitudes. When he was younger, teachers in his school thought he would not be able to do homework and wanted to include that on his IEP. His mother, **Cynthia**, did not agree to that. Robert loves school and doing schoolwork. In fact, he used to ask for extra just for fun! Cynthia says the negative views and low expectations could have been detrimental to Robert's growth and independence in school.



Battling Low Expectations

“We must catch and communicate a collective vision. Parent aspirations are powerful, but so are the expectations of educators, employers, service providers, members of faith-based organizations, community leaders, and youth themselves. Indeed, every child with a significant disability in every state should hear the message from multiple sources—that they have something of value to contribute within the classroom and workplace and something essential they bring to their community.” Read more at: www.tennesseeworks.org/getting-to-work/raising-expectations/

~ERIK CARTER, PROFESSOR OF SPECIAL EDUCATION, VANDERBILT UNIVERSITY

Challenges

On being the sole “provider”

“Besides my husband, and myself, we don’t have anyone who can take care of **Tabby**,” said **Karen**. “My mom is probably the biggest help we have. She lives in Shelbyville and that’s two hours away. She’s older and can’t lift Tabitha. Tabitha is 80 pounds, so it can be a real challenge.

“My husband and I don’t get to go out on dates. Mother will watch her one night out of the year so we can go out. We can also hire a nurse, but haven’t always had great luck with that. Just because someone has a title doesn’t mean we are going to leave our kid with her. It can be difficult sometimes.”



Natalie’s mother, **Lucy**, is her sole care provider. Lucy chose to retire in order to care full-time for Natalie. Together, they have created a meaningful life, but Lucy is always concerned for her daughter’s ongoing, long-term care.

The Need for Respite

Although life can be challenging for anyone, families impacted by disability sometimes encounter additional stressors that over time can impact their well-being. At the same time, parents of children with disabilities may be unable to take time for themselves due to financial costs, difficulties finding a trustworthy “sitter,” or even feelings of guilt. Providing respite care means coming alongside a family to offer a brief break from the routine demands of everyday life. This respite could be as short as an hour or two, or as long as a week or more. It can involve going into a family’s home or providing space at a facility where family members with developmental disabilities can be cared for and/or participate in enjoyable activities. Either way, parents and/or siblings can get a much-needed break and time to focus on themselves, their marriage, or other family needs. Learn more: *Welcoming People with Developmental Disabilities and Their Families: A Practical Guide for Congregations* <http://vkc.mc.vanderbilt.edu/assets/files/resources/CongregationPracticeGuide.pdf>

To date, there have been limited options for caregivers to access respite services unless the person with disabilities is enrolled in a long-term services and supports program (which cover respite services, although those too are subject to benefit limits). While Family Support Program funding can assist with respite care, most families cannot afford to pay for respite and have trouble finding qualified caregivers that they feel comfortable leaving their loved one with.

Challenges

On fear of the future

Isaiah will graduate from high school at the age of 19. Because he attends a private school, he does not have the option of staying until age 22. Students in Tennessee public schools in special education can stay until age 22, under the federal Individuals with Disabilities Education Act (IDEA). The transition from school will open up a whole new set of challenges for Isaiah and his family. Isaiah's greatest fear is not having a job after graduation. "We're concerned about what happens after high school," said **Cynthia**. "The scarcity of supports makes it scary. The lack of opportunities for young adults with intellectual and developmental disabilities after school is appalling. Thankfully, college programs are being developed to help address this issue, but of course college will not be an option for everyone."



Lucy and **Natalie** have no family in Tennessee. So, for Lucy, the thought of Natalie's care and management after Lucy is no longer able to fill that role is terrifying. "My heart cries, just to think about my daughter in the future. I am getting older. I worry that when I'm going to be in the hospital when I get sick, I won't have somebody to come and see me or Natalie won't have somebody else. It makes me feel sad that I can't count on friends."

At this point, there are no set plans for what Natalie will do when Lucy can no longer serve as her care provider. Their network here in Nashville is small and, despite Lucy's deep dedication to her daughter's well-being and care, the future is uncertain. Lucy has found most of the opportunities for Natalie on her own and fears that once she herself is no longer available as an advocate and resource, that Natalie's future will be bleak.



Addressing a fear of the future

Tennessee Disability Pathfinder frequently looks up future planning resources and discusses options with family members. No matter where you live or how old the person with a disability is, it is never too late to make a plan. Below are some suggestions that Pathfinder staff might point to in addressing future concerns. For more information, visit familypathfinder.org.

- Employment and Community First (ECF) Choices Waiver
- Secondary transition resources
- ABLETN savings program
- Social Security information
- Conservatorship and Special Needs Trust resources
- Employment resources
- Supported and independent living resources
- Parent support groups
- Educational and training seminars and workshops
- Tennessee Parent-to-Parent
- Tennessee Adult Brothers and Sisters

~TENNESSEE DISABILITY PATHFINDER

Successes

On the support of a faith community

“In addition to **Jonathan’s** friends, his community at church is very helpful to him,” said **Vilma**. “I took him to church growing up, and to this day he is very religious. He knows that God is there for him and will never leave him, which really helped him when he had difficulties with bullying as a kid. Much as he knew that his friends and God would always support him, Jonathan also knew that he would always have us, his family. We have taught him that he will always have three people in his life: his father, me, and God.”

“**Terrell** volunteers at church on Sundays,” said **Linda**. “We have a special needs ministry called Connection Crew, which he enjoys. For a short while, Terrell volunteered as a greeter at church. He has since moved on from needing a peer tutor to volunteering independently in the preschool classroom. He loves to come home each Sunday and talk about what the children did and what he did to help.”

“When it comes to friends, I would say Terrell’s closet friend is his brother Myles. He will wait for Myles to come home every Friday so he can spend the weekend with him. Terrell loves socializing and gets along with everyone. He does not meet a stranger.”

Natalie enjoys listening to music, visiting and praying with patients at a hospital, and carrying the gifts to the altar during the Mass. She and her mother are involved in the Catholic Church, where, according to **Lucy**, people respect Natalie. “She’s a very big part of the church. That is a big support for us. They cherish her where we go.”



Successes

On the role of parents as advocates

"I have a huge role in **Jonathan's** life," said **Kathy**. "I've said from the beginning the parent is the best advocate, but in most cases the parent is the only advocate. Mom or dad has to be out there stirring the soup all the time. Mom or dad has to try to find activities, talk to employers, talk to different program directors to see if they'll allow your child into their camp or program. Parents have to keep knocking on doors and trying to make things happen."

Cynthia is the former president of the Down Syndrome Society in Chattanooga and is vocal about the disparities in services available in different counties and areas of Tennessee. She is an active advocate for the rights and abilities of individuals with Down syndrome in her community and is a graduate of the Council's Partners in Policymaking program.

"I was instrumental in making sure that the school system did what they were supposed to do," said **Roger**. "I have been an advocate for people with disabilities since we found out that **Aimee** had autism. I was the official mover, if you will, but the most credit goes to my wife because she is the one who does everything for Aimee. The school helped, of course, but my wife is the one who did the brunt of the work."

Even though **Robert** does face challenges, he still has a great support system of family and friends. Robert's parents are very supportive of him, and have always held high expectations. Robert's mom, **Cynthia** is his biggest advocate. She hopes Robert can live on his own one day in their home. In order for this to happen they're trying to make the house fully accessible for Robert by redoing his bathroom and adding ramps.



"As **Kathleen** got older she was adamant that she wanted to be a librarian," said **Patti**. "When she was in 5th grade, she was diagnosed with dyslexia. That made her really upset because we had to work twice as hard. I quit my job and developed a homeschool program for her to get her back up to speed. We also got involved with the Dyslexia Foundation of Memphis. It helped her to improve her reading and memory using specialized strategies, and it built her up socially because it's a small group where she could be like any other little girl. She loved it."

"By the time she was ready for 9th grade, she wanted to go back to school. I went back to work so I could pay for school. She went to a program at the Concord Academy, a high school where you had to do volunteer work. She got involved with the United Cerebral Palsy programs where she volunteered to be a mentor for young kids. Then she started working at the library."

Addressing the role of parents as advocates

Generally, parents are the first advocates for their sons and daughters. Become informed about your family's rights and make an effort to align with other parents who are experienced advocates. Set an example for your son or daughter so they also will feel confident self-advocating. Below are some suggestions that Pathfinder staff might point to in addressing parent and self-advocacy. For more information, visit familypathfinder.org.

- Support and Training of Exceptional Parents (STEP)
- Volunteer Advocacy Program
- Partners in Policy Making
- Disability and health-specific organizations
- Advocacy organizations
- Parent support groups
- Natural supports

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Successes

On employment

"**Jonathan**'s most recent job was being a porter, which means he cleans the tables in a dining hall," said **Kathy**. "He recently lost this job through no fault of his own. He's also in Special Growers, which is a gardening group of people with disabilities and their parents who grow herbs and then sell them to local restaurants. He is paid minimum wage and works mainly on Saturdays."

Nancy describes her son **Leo** as creative, funny, and very opinionated. Leo has been working at Harris Teeter for almost three years. He found the job through a friend at church. "We are very happy that Leo has this job," said Nancy. "Having Leo hold on to and excel in a job is a top priority. He can get a little angry and upset sometimes, but his current supervisor understands him and likes him. When he started the job, it was difficult. He couldn't stock the shelves as quickly as they expected. However, they were patient and tried him in different positions until they found a good fit. He is very reliable and does a good job. Parents and schools should really focus more on preparing kids for work."

"**Aimee** now works at the Chattanooga Housing Authority for three days a week, four hours each day," said **Roger**. "She takes the paper Section 8 applications and types them into spreadsheets to enter into their system. She loves her job. She thinks making money is great. We love it. We think it's great. She looks forward to it and she's always excited to do her work. I think she has a sense of accomplishment and pride in that she has a job and is earning money and that is a big step."



Leisa pushed her daughter, **Grace**, to explore interests beyond standard school activities. It was because of this that Leisa discovered Grace's inclination for art, music, and dance. Since then, Grace has turned her brilliant artistic ability into a business and has been featured on TV for her art. Grace has been lucky enough to turn her passion for art into a business. She has been extremely successful in showing and selling her work.



Addressing employment

Parent expectations play an essential role in the employment success of young people. Employment can offer more than a paycheck. It can offer a way to contribute one's strengths and skills, thus leading to a greater sense of purpose. Employment also can lead to lasting friendships, community involvement, and overall independence and higher quality of life. Below are some suggestions that Pathfinder staff might point to in addressing employment. For more information, visit familypathfinder.org.

- Employment resources in or near your county
- Natural supports and networking
- Vocational Rehabilitation
- Inclusive Higher Education programs such as Next Steps at Vanderbilt University, IDEAL at Lipscomb University, FUTURE at University of TN-Knoxville, EDGE at Union University, TigerLIFE at University of Memphis
- Benefits to Work Program
- Employment and Community First (ECF) Choices waiver
- TennesseeWorks online TN employment resource

~TENNESSEE DISABILITY PATHFINDER

Successes

On community engagement

“We really do try to get involved with as many activities as possible,” said **Kathy**. “If we hear of something new or interesting, we’re the first ones to jump on it! I’m also the director of the Tennessee Best Buddies, so Jonathan has opportunities to socialize with other adults his own age. I want him to have fun and enjoy life just like every other person. This especially means participating in as many community activities as we can. Not only is the exposure good for **Jonathan**, it’s also good for the people in the community who interact with him.”

“Currently **Kathleen** has adapted to a very busy schedule,” **Patti** said. “She’s involved with a program of AmeriCorps, which helps people with disabilities gain employment. She does that probably about 10-15 hours a week. She takes classes probably 10-12 hours a week. She also volunteers at the animal shelter down in Hattiesburg and that’s probably another five hours a week. And then she also does a lot with her church on campus. She’s also at different friends’ places three or four times a week. She’s built herself a very strong support network in Hattiesburg.”



Successes

On informal supports

Isaiah's family is a huge source of support to him. The large, close-knit family always has someone in the home. All of his seven siblings have helped out with Isaiah's care in some capacity, and several have approached their parents about their willingness to take Isaiah into their homes at some point in the future if needed.

"During her time off, I began to think about how I would feel having a nurse with me all the time in school," said **Karen**. "I talked with the teachers and they were concerned that **Tabby's** social interactions were being limited due to the presence of the nurse, who helped her to do most things.

"So, we sent her back without a nurse. It's been going pretty well. The teacher has done a really good job and Tabby has been spending a lot more time in the general classroom. And guess what? The other students have been helping her a lot more because the nurse isn't there."

Kevin attends public high school in his hometown of Medina. The community is very helpful and caring towards Kevin, which gives him many natural supports. They work hard to include Kevin in everyday activities.

Robert has made great friendships throughout his life. He has friends from college who he has met through clubs and in class. He has one friend who comes over and spends many days at his house. Robert's friends are a great source of support.



Grace is involved in the community at school, participates in Best Buddies, and recently made a friend in her neighborhood. **Leisa's** neighbor has just "adopted" Grace. She took her out to dinner a few Fridays ago, which is something Leisa has always dreamed about. People know Grace in the community and they are kind to her.

Successes

On the importance of sharing gifts

Apart from sports, **Joshua** is also quite interested in music. He assists with music every week with his faith community. According to **Tiffany**, "Church has been a great way to allow him to participate in the community."

"**Tabby** has many strengths and talents," said **Karen**. "She is a very good painter and her artwork has been displayed around the country. In fact, we were able to make a down payment on an accessible van for her with the money collected from her art sales. Tabitha also likes to play music, go to school, and hang out with her friends. She has a warm personality and a beautiful smile."

Robert has never had any trouble making friends and is very outgoing. He enjoys writing and performing his own songs, web design, animation, and horseback riding. In school, he was asked to perform his songs at his graduation ceremony.

Kevin's passion is music and he learned to play the recorder with the rest of his class in fifth grade. At the end-of-the-year concert, the high school band teacher approached his mother, **Debbie**, and told her that Kevin had learned all the music on his recorder with help from his peers.

Debbie explained that the teachers' willingness to try new things and to work around obstacles allows Kevin to be limitless when it comes to participating in desired activities. With Kevin's determination, he was able to become a member of the high school marching band as well as the concert band. "I did have concerns about marching band," said Debbie. "But why shouldn't he have the same opportunities as his sister? As much as he loves band, how could I explain that to him? All of his friends are in marching band and he's not in marching band? So I just felt like



we had to try it. And he has thrived."

Mary Ellen and **Will** are the parents of **John**. They talk about John's gifts. John has a great memory and great musical gifts; he has perfect pitch and can read music. He is very involved with the choir at church and loves to sing.

John currently works with archives at the college he graduated from, Visible Music College. He's working on putting together what they hope will one day be a gospel music archive. "The people at the college saw John's faith and his gift of music and were willing to take whatever steps necessary to make the experience work for him," said Mary Ellen.

Mary Ellen and Will recommend that parents of children with disabilities never say never, and that they continue to ask questions. They would also recommend that parents encourage their sons and daughters in their gifts and strengths and that they assist in making connections in the community that help them to share those gifts. That John can share his gifts and talents has made all the difference.

Successes

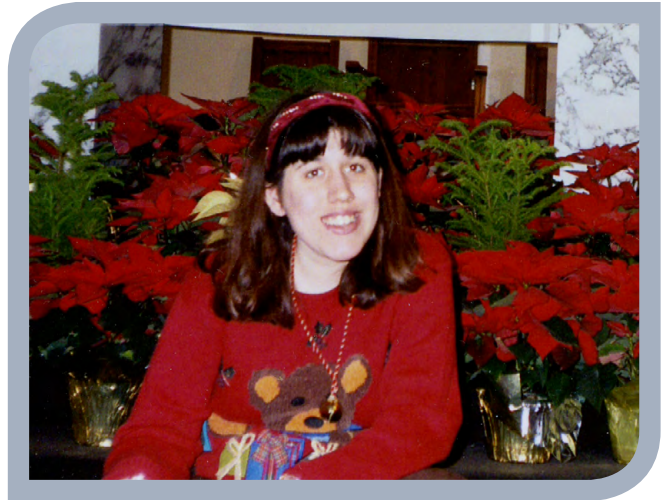
On the benefits of being informed

"If I were to give advice to adults with disabilities and their families, I would say to be involved in everything that they can," said **Kathie**. "Be aware of what's out there and ask other parents. Watch the newspapers and get in contact with parks and recreation. Connect with Tennessee Disability Pathfinder, attend disability conferences, and go through Partners in Policymaking at the Tennessee Council on Developmental Disabilities."

At present, most of the supports **Joshua** receives come from his own family and their social networks. They have been reaching out to as many people as possible to share their situation, to get information, and hopefully to draw on others' "funds of knowledge." **Tiffany** highly encouraged parents of children with disabilities to "talk to people outside of their comfort zone."

"Tennessee Disability Pathfinder also has been such an important resource for our family," said **Nancy**. "I totally applaud them for taking a person-to-person approach in connecting people with resources. We also have found that networking with other parents of children with Autism Spectrum Disorder is extremely beneficial. Like anything else, once you get one little 'in' then you spread your web. Autism Tennessee has been a huge help to us in meeting other families."

Grace is lucky to have a mother who actively searches for opportunities for her. **Leisa** describes herself by saying, "I'm a resourceful person and a networker. I just keep beating the bushes until I find them."



Leisa says parents need to connect with agencies, like the local autism society. She encourages others to find support groups, the activists and the parents. "Ask them what services they're using and what else they're doing," said Leisa. "Go online, read, and go to every seminar that you can go to. It's important to start looking towards the future at the time of the diagnoses so that you're not completely ignorant about all that's coming down the pike. There are resources out there and you just have to find where they are."



Addressing being informed

Families feel empowered by having access to information that enables them to make their own informed choices and decisions. By staying abreast of the latest additions and changes, Tennessee Disability Pathfinder can advise callers about programs they may not yet know about. For example, the Employment and Community First program, which started July 1, 2016, now serves persons with intellectual and developmental disabilities. Below are some suggestions that Pathfinder staff might point to that address staying informed. Many agencies also offer newsletters, so subscribing can be a great way to stay informed. For more information, visit familypathfinder.org.

- Tennessee Disability Pathfinder
- Local resources such as a Parks and Recreation Department
- Disability- and health-specific organizations
- Advocacy organizations such as Autism Tennessee
- Disability-related trainings and conferences such as Partners in Policy Making
- Networking with other parents and friends
- Support groups
- Online, print, and other informational resources-subscribe to newsletters!

~TENNESSEE DISABILITY PATHFINDER

Successes

On looking toward the future

“As parents, we try everything we can to help **Leo** be the best person he can be and have the most fulfilling life he can have,” said **Nancy**.

In the future, there is a possibility that **Kevin** may want to live on his own. If he chooses to do so and has the proper supports, **Debbie** will be okay with this option. As of right now, like most other 16-year-olds, Kevin hasn’t been thinking about his living arrangements after high school. However, he has recently expressed interest in finding a job. As a result, this job may be Kevin’s next step.

Whatever he chooses to do, Kevin will be successful because of his determination and willingness to try anything and because of his supportive family. “We just feel blessed beyond words that Kevin has not had too many limitations placed on him in school and in the community,” said Debbie. “We realize this is not always the case.”

“When **Tabitha** is older I just want to get her out somewhere, to do something,” **Karen** said. “Hopefully by the time she is older things will be different. Maybe there will be more opportunities. We have a lot of work to do.”



Resources

The **Vanderbilt Kennedy Center** and the **Tennessee Council on Developmental Disabilities** are part of the Tennessee Developmental Disabilities (DD) Network (www.tennddnetwork.org). The DD Network agencies partner with one another and with individuals with developmental disabilities and family members to ensure that they receive the services and supports they need—and jointly they take part in planning those services. Together we are working to promote principles of independence, productivity, inclusion, self-determination, and integration.

The DD Network and the Tennesseans it serves are supported by a statewide information and referral service, **Tennessee Disability Pathfinder**. Through a helpline and online database, Pathfinder connects individuals with disabilities, their families, caregivers, and service providers to appropriate community resources. Pathfinder's diverse staff includes professionals, family members, and/or individuals with disabilities that have many years of experience working in the disability-field. More information on all of these resources is included on the next page.

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.

vkc.mc.vanderbilt.edu, (615) 322-8240

Tennessee Council on Developmental Disabilities

Leads initiatives statewide to improve policies and practices that affect the everyday lives of Tennesseans with intellectual and developmental disabilities. The Council works with public and private groups to find innovative strategies that increase access to public education, employment, housing, health care, and all other aspects of community life. Council members are private citizens from across Tennessee who either have a disability or have a family member with a disability. They are appointed by the Governor. State agencies that oversee disability programs and representatives of the TN Developmental Disabilities Network also serve on the Council.

www.tn.gov/cdd, (615) 532-6615

Tennessee Disability Pathfinder

Provides free information, resources, support, and referrals to persons with disabilities, their families, friends, and professionals. Through individualized assistance, community engagement activities and trainings, and a multicultural program, they provide information and resources to individuals of all ages, all types of disabilities, and any language spoken.

familypathfinder.org, (800) 640-4636

Supporting Families

In 2013, Tennessee was selected to join a group of six states charged with identifying ways to better support and strengthen families that have members with intellectual and developmental disabilities. This "Supporting Families of Individuals with Disabilities" initiative, which is funded by the federal Administration on Intellectual and Developmental Disabilities, is led in Tennessee by the Tennessee Council on Developmental Disabilities and the Department of Intellectual and Developmental Disabilities.

www.supportstofamilies.org and www.lifecoursetools.org

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

Tennessee Council on Developmental Disabilities
www.tn.gov/cdd

Tennessee Disability Pathfinder
familypathfinder.org

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

This report was compiled, edited, and designed by Courtney Taylor and Kylie Muccilli (Vanderbilt Kennedy Center for Excellence in Developmental Disabilities) and Ned Solomon and Emma Shouse (Tennessee Council on Developmental Disabilities).