

# BREAKING

# GROUND

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**SPECIAL ISSUE:**

**SUPPORTING FAMILIES IN TENNESSEE**



**TENNESSEE COUNCIL**  
on developmental disabilities

## Supporting Families in Tennessee

The Volunteer State places substantial value on helping others. Communities across Tennessee are largely welcoming to fellow citizens with disabilities in neighborhood activities and establishments. State government programs provide important support to help Tennesseans with disabilities become independent and productive members of their communities. It would surprise most of us to learn that over 75% of Tennessee families receive no government assistance to support them in nurturing development in family members who have a developmental disability.

How can we better organize and coordinate government programs so that all Tennessee families have help in navigating the maze of services to find those most helpful to their needs? How can we encourage all parents to set high and attainable goals for their young children who have a developmental disability? How can we assist families in locating specialized professional services necessary for the health and growth of their family member? How can we support families discovering connections to other families who have experienced the joys and challenges of having a child, grandchild or sibling with a developmental disability?

This issue of Breaking Ground magazine is dedicated to an exciting new initiative in Tennessee that will explore these questions. The initiative is a national project called Supporting Families of Individuals with Intellectual & Developmental Disabilities: The National Community of

Practice. Tennessee was selected to participate in this national project that is charged with developing a new national agenda that will improve support to citizens who have a family member with a developmental disability. Our goal is to engage communities across Tennessee to better understand the needs and aspirations of citizens with developmental disabilities and their families, and to find more efficient and effective ways of meeting those needs throughout the lifespan. It's a large assignment, but one that is exciting to contemplate!



The Council is honored to join our partners at the Department of Intellectual and Developmental Disabilities in leading this initiative in Tennessee over the next five years. You can follow the progress of the initiative through updates in Breaking Ground magazine, the Department of Intellectual and Developmental Disabilities' Open Line newsletter and by signing up for the project's monthly electronic updates. More importantly, find out how you and your community can become involved in the Supporting Families initiative.

*Wanda Willis, Executive Director,  
Tennessee Council on Developmental Disabilities*



The Department of Intellectual and Developmental Disabilities (DIDD) is thrilled for the opportunity to be involved in the Supporting Families Community of Practice in partnership with the Tennessee Council on Developmental Disabilities. Being a part of a learning community with five

other states to learn about best practices that support families of people with intellectual and developmental disabilities is of critical importance to the future of the department. DIDD is working on future planning for the service delivery system, and wishes to include the

things that people with disabilities and their families need to obtain and maintain a good quality of life.

This Community of Practice will help guide DIDD and the Council through the next five years in strengthening the Tennessee interagency collaboration for people with intellectual and developmental disabilities, as well as provide a platform for learning from five other states about their experiences. I am looking forward to the fruits of this endeavor as it shapes the future of services and supports for Tennesseans with intellectual and developmental disabilities and their families.

*Debra K. Payne, Commissioner, Department of  
Intellectual and Developmental Disabilities*

# CONTENTS



- 2 **Changing the Culture: Moving From Providing Programs to Supporting Families**
- 4 **Meet the Bankstons**
- 5 **Being a Parent with a Disability**
- 6 **Promoting Good Mental Health**
- 7 **Maria's Story**
- 9 **Information and Resources for Parents with Disabilities**
- 10 **Project Enrich:  
Supporting Parents with Special Learning Needs**
- 12 **Parents Helping Parents**
- 13 **The Right to Parent**
- 15 **Our Journey**
- 17 **Council's Community Development Grant  
Can Help Families Explore Programs**

**The West Family.** Photo by Angela Crutcher



## Changing the Culture: Moving From Providing Programs to Supporting Families

by Emma Shouse, Director of Public Information, Tennessee Council on Developmental Disabilities



In 2013, the federal Administration on Intellectual and Developmental Disabilities funded a grant to identify ways that government programs can better support and strengthen families that have members with intellectual and developmental disabilities. Six states, including Tennessee,

are participating in a national 'Community of Practice' focused on sharing best policies and practices to support families in addressing the physical, social, emotional and material well-being of their entire family, including the member with a disability. In Tennessee, the Department of Intellectual and Developmental Disabilities and the Tennessee Council on Developmental Disabilities are the leaders of this project, with additional participation from other organizations, individuals and stakeholders. Tennessee will be investigating community supports of all types, both "disability-specific" and those available to all families in the community.

According to a national report called "Building a National Agenda for Supporting Families with a Member with Intellectual & Developmental Disabilities", there are more than 4.7 million citizens with intellectual and developmental disabilities in the United States. More than 75% of these individuals live in their communities without the aid of formal disability services and rely on their families and community resources for varying levels of support. Of the 25% who are receiving government-sponsored services (for example, Medicaid waiver services), over 50% of those individuals also live with their families.

There are important lessons we can learn from families who are "making it work" without currently accessing formal disability services. What can these families teach us about helping family members with disabilities build successful lives in the community?

Clearly, the family is a critical support system for the majority of Tennesseans with intellectual and developmental disabilities. This is especially the case given current budget cuts and long waiting lists for disability services. This crisis will only be intensified as the "baby boom" generation ages and more people with and without disabilities will need supports to remain in their communities. To maintain the family as the primary source of care, it is crucial for policymakers to recognize the types of ongoing supports that families need to effectively serve in this role. By strengthening families now, we prevent unnecessary crises and a possible breakdown in the family structure, and avoid the

need for out-of-home placement for individuals with disabilities.

Developing new and innovative policies, practices and strategies to support families of



individuals with intellectual and developmental disabilities, rather than simply expanding the traditional disability service system in our state, is a core goal of the Supporting Families Community of Practice. Strategies must target the entire family unit while benefiting the individual with a disability. Support must be provided to the family so they have the capacity to provide support to their member with disabilities when necessary over their lifespan. We must consider how we can reframe policies and systems that support the right of people with disabilities to live, love, work, play and pursue life aspirations just as others do in their community.

Continued on page 3

## Supporting Families of Individuals with Intellectual and Developmental Disabilities

Continued from page 2

### Families Teaching Families

One key concept in the “Supporting Families” framework is the importance of peer support. Connecting and networking a family with other families who have members with intellectual or developmental disabilities can be an invaluable system of support for all members of a family; this includes not just parents of children with disabilities, but also self-advocates of all ages, siblings, grandparents, other guardians and individuals with disabilities who become parents themselves. Developing high expectations early on for a child with disabilities is crucial for success later in the child’s life. One great way to support families who have young children with disabilities is connecting them with adult self-advocates and parents of adult children who are living successful, rewarding lives in their communities. This helps point families on a trajectory towards a fulfilling life from the very beginning.

### Looking at the Lifespan

Families and professionals in every area of the “service system” (pediatricians, teachers, therapists, case managers, etc.) should keep a “lifespan perspective” in mind when making decisions for and with a family member with disabilities. This means that from the moment a young child is diagnosed with an intellectual or developmental disability, families are supported by professionals in their child’s life, other families within the disability community, and their broader communities to begin planning for the future. How can families start at this moment building skills, relationships and natural supports within their community that can help lead to a successful, meaningful, self-determined life for their son or daughter with a disability?

### Surrounded by Services

When an individual with disabilities is fully immersed in the service system or “wrapped in

services” from birth through advanced age, we risk cutting them off from their communities and meaningful relationships that can support them. In all aspects, the service system and communities should remain focused on an overall quality of life for individuals with disabilities and their families who care for them. When disability services become a barrier to developing community connections, those services must be reevaluated. How can we support as many people as possible to live successfully without 24 hours of paid supports using relationship-based options like immediate family, extended family, friends, shared living, etc.?

**“ In all aspects, the service system and communities should remain focused on an overall quality of life for individuals with disabilities and their families who care for them. ”**

### Questions to Consider...

- How can the disability service system begin to transition from a primary focus on crisis intervention to a system that is focused on long-term planning and quality of life for families?
- How might the disability service system best serve families throughout the lifespan of their loved one with a disability, from birth through old age?
- What should the disability service system of the future look like? What supports should be offered?

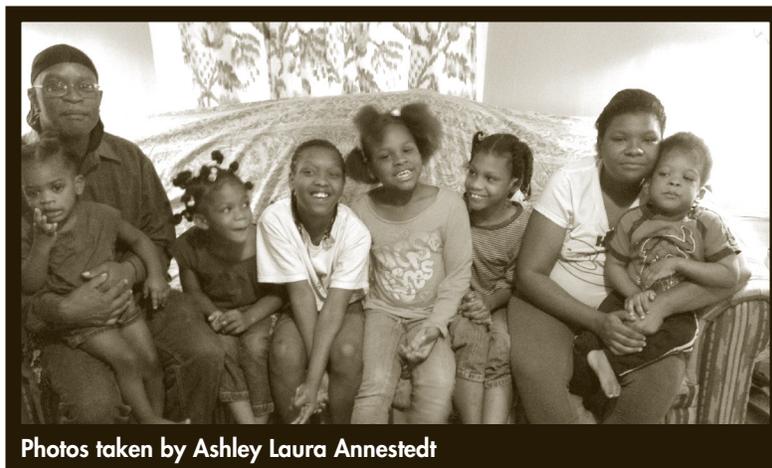
**To learn more about Tennessee’s Supporting Families Community of Practice initiative, contact Emma Shouse at [emma.shouse@tn.gov](mailto:emma.shouse@tn.gov) or 615-253-5368.**

<sup>1</sup> Building a National Agenda for Supporting Families with a Member with Intellectual & Developmental Disabilities, The Johnson Foundation at Wingspread and the Administration on Developmental Disabilities, [www.supportstofamilies.org](http://www.supportstofamilies.org), 2011.

# MEET *the* BANKSTONS

As told to Ashley Anstedt by Reginald Bankston

Lavona Smith and Reginald Bankston live in Memphis. They have been together since 2000 and have seven children. Reginald and Lavona both have intellectual disabilities, as do six of their seven children. They were referred to the UT Boling Center by their Blue Cross Blue Shield Field Care Manager, Jean Davis, and paired with the UT Project Enrich Supported Parenting Program. This family, with support from the community, is a true success story and testimony to the ongoing struggle for the rights of parents with disabilities.



Photos taken by Ashley Laura Anstedt

has some deafness in her left ear too. Because Lavona has a disability too, I feel like I'm out here on my own a lot. You know a lot of fathers would have already left this situation, because it's tough! But I know that I have to do right by my children. I put myself in their shoes and want them to have the best.

Lavona and I met in 2000 when I was DJing at a club. I already had my older daughter Felicia (age 21) then. I wished I had met



Jean Davis back then and she could have hooked me up with the Boling Center and all those other places, because Felicia had some special needs but I didn't know how to help her. She was in Special Education in school, but so was I so I didn't know what to do really!

Five of the kids I have with Lavona have special needs too; they all have a diagnosis of intellectual disability. Brianna is two, Antrone is three and he has Spina Bifida too; Sandra is six, Gloria is eight, Joyce is nine and Felicia is ten. We just got told that Felicia

Me and Lavona get along good, but sometimes I'm the momma AND the daddy. I do a lot of the cooking, washing, cleaning, carrying the kids to the doctor. I try to be the best husband and father I can. If I can't say something nice, I try to just not say it. Since Lavona has special needs too, sometimes it's hard to deal with but I try not to focus on it and just focus on the kids. I like to stay positive. My kids come first so I'll do whatever I need to do to help their mom. I actually thought for a long time that I couldn't have kids, and then God gave me seven, six with special needs! God must've thought I was really ready to be a dad, huh?

I think I've done good. I make sure the kids have what they need; I walk them to school every day, and make sure they are going to grow up and be good people. I do all that because that is how my momma raised me. She did all that stuff for me too. When I was coming up, my Momma taught all of my brothers and sisters right from wrong. I already knew what I had to do but she and my dad reminded me. My dad knew I was behind everyone else and told me that if I could not graduate high school then I needed to learn a trade. So I can do some mechanic work, I can do pipe work. Hey, I can do lots of things!

I hope my kids grow up the same way. I hope they get a good education, and meet someone they are real happy with and that treats them good. I want them to be happy.

# BEING A PARENT WITH A DISABILITY

by Frank Meeuwis

I am a person with a disability. I survived a traumatic brain injury following a car wreck when I was 18. My disability is visible in the partial paralysis of the right side of my body which affects the way I walk and do things with my one useful arm. My disability is not so visible in my sensitivity to emotions and a hundred other idiosyncrasies that are either part of my personality or part of my rehabilitated person.

In 2006, I completed a post-secondary degree in social work and soon after proposed marriage to my then-girlfriend (and former note-taker) Mary. Three years later we were married and soon became pregnant! Wow! What had I gotten myself into?

Before our child's birth (we did not want to know its sex), I was comfortable in that I had several years' experience in my current job, I had a reliable car, and I "owned" a home (really just the note to the bank!) But now I was going to be a father—the parent of another human being! Ordinarily, this is something that happens around the world to more than 237,000 new parents every day, but because of my experience, I felt—perhaps irrationally so—that statistics of accidents or disease etc. were more likely. After all, somebody, including myself, was behind each number in any one of the statistics that you read or hear about!

So, we participated in all the standard health pre-screenings available at Vanderbilt Hospital and learned that we had, to the best of their knowledge, a typical and healthy baby. That was good news! Nevertheless, Mary and I read numerous parenting books and did what was prescribed (and didn't do what was generally known to not be good for expectant mothers!) Well, May 23, 2011

Mary went into labor and early the next morning our 7 lb. 6 oz. boy was born! (Days later we chose his name: Jack.)

Jack is now two and a half years old. I still sometimes worry about the day—coming very soon—that Jack will realize that his father is not quite like other typical fathers, that "Papa" has a disability. That I cannot run or lift him in my arms over my head, or have Jack sit and ride on my shoulders, or do many of the things those fathers without physical disabilities can do. More importantly, however, I've realized that the most important and greatest part that I can and will play in Jack's life is—in one word—love. I am there for Jack. I play with him. We laugh when I tickle him. I hug and kiss him when he bumps his head. I read him a story at bedtime. I change his diapers, bathe him and prepare food for him. I teach him how to do things—everything from eating with a fork, to sipping from a cup, washing his hands, to saying 'please' and 'thank you'.

I know he will soon realize. I also know he will inevitably regret that his father maybe can't do things his friends' fathers do. (When I was a boy, I recall moments where I regretted my Dutch father wasn't like my friends' American dads!) I also know Jack will mature, and will gain appreciation for what it was—and will be—that I gave and did for him, just as I now appreciate my own parents. Additionally, he might grow up with enhanced empathy for, sensitivity to, and understanding of disability in the way that only a child of



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**I still sometimes worry about the day - coming very soon - that Jack will realize that his father is not quite like other typical fathers.**

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Continued on page 6

# PROMOTING Good Mental Health

by Elisabeth Dykens, PhD



Compared to parents of typically developing children, parents of children with developmental and intellectual disabilities experience substantially more stress. Stress drains our energy, like a car guzzling gas. Chronic stress can affect our health. Because how we feel affects those we interact with daily, generating positive emotions is an important effort. Feeling positive about one's self and one's life can be learned and practiced. Parents can feel less stressed and help their families to feel less stressed and more positive.

We can learn and practice ways to take better care of ourselves by living more attentively and finding things for which we can be grateful. We can focus on the joys and pleasures around us, which we often miss when we focus on our troubles.

Think of the nervous system as having an accelerator—the stress response—and a brake—the relaxation response. It's helpful to take our foot off the accelerator some of the time. Just three minutes of deep belly breathing turns on the relaxation response and turns off the stress response. Conscious breathing is our most important stress reduction tool. We can practice it anywhere, anytime. Our breath is our "go-to tool"

because we always have it with us.

We can reduce stress by learning to be open to whatever life brings without judging it as good or bad. This does not mean we have to like what happens, but we can manage even painful or difficult experiences one moment and one breath at a time.

The tips below can help you learn to live moment to moment. Don't try to do everything at once. Practice Tip 1 for Week 1. In Week 2, add Tip 2, and so forth. Practice these tips yourself and with your family. Practice with your family members with disabilities, adapting for their abilities. If it's difficult, be kind to yourself. There is no right or wrong way to practice these tips. Experiment and find what works for you.

**Tip 1:** Practice relaxation twice a day. Schedule a time twice daily for a 3- to 5-minute breathing period. Lie or sit comfortably. Breathe slowly and deeply. Count silently or softly aloud on the inhale, matching the same count on the exhale. Gradually extend the count to deepen the breath. Or use words like "breathing in, healing" on inhale, and "breathing out, release" on

Continued on page 8

## BEING A PARENT WITH A DISABILITY

Continued from page 5

a parent with a permanent disability can experience. In our time of rapidly aging populations and an increased likelihood of experiencing disability in our lives, either directly or indirectly, I hope Jack will benefit from his experience and turn all the 'lessons' into assets and strengths to become a better, more likeable person.

I am a very proud father of a very cute two-and-a-half-year-old little man! My disability is now part of me,

and also part of Jack's life for the rest of mine! My appreciation for life and my ability to love, though, are both incalculably greater because of my disability—and that is not something to lament or regret, but to embrace and celebrate! I am certain my disability will make my son someone he could never be had it not been for my disability!

*Frank Meeuwis is Project Director, People Talking to People, The Arc TN.*

# MARIA'S

# Story

by Elisheva Gralnik,  
Frances Otieno and  
Courtney Taylor

The Vanderbilt Kennedy Center's Multicultural Outreach Program (Tennessee Disability Pathfinder) and the Tennessee Kindred Stories of Disability Project teamed with the Tennessee Multicultural Alliance on Disability to collect stories from families with diverse cultural backgrounds now living in the United States. The aim was to highlight some of the unique barriers and challenges that these families face as they learn to navigate the disability service system in a new culture. Both the Multicultural Outreach Program and the Multicultural Alliance on Disability offer service provider cultural awareness training, information, and assistance to families with diverse backgrounds.

The following story was adapted from a collection of stories that were compiled from a series of interviews conducted by Vanderbilt University students enrolled in a course in the Department of Special Education, Peabody College.

It was 11 years ago that Maria and her husband left Mexico and came to the United States to work and save money with the hope of making a better life for their family. Because their plan was to stay in the United States for only two years, they left their four daughters to live with family in Mexico. However, after their son David was born and then received a diagnosis of autism, they made the difficult decision to stay in the U.S. indefinitely.

Maria says that disabilities are stigmatized in Mexico. She worried about taking her son back to an environment where he would face criticism and discrimination. She and her husband also worried about the lack of access to services.

"The closest school and services in Mexico are a day's drive from where we lived," said Maria. "We would not be able to get the services for David because of that and also because we could not afford it. It is very difficult to find work where we lived. It would be impossible to give David what he needs."

Maria's hometown community in Mexico is highly impoverished. There are no cars, electricity or places to work. She says though she faces a great deal of stress living as an undocumented immigrant in the United States, she feels she is doing the right thing for her family in the long run. Being separated from her daughters does take its toll. They often tell her that they



want to be with her, but Maria cannot leave the United States even to visit them because she does not have the appropriate documents to return.

Maria and her husband left Mexico when their youngest daughter was only two years old. The last time they spoke on the telephone,

her daughter told her that she wanted to meet her in person because she did not remember her. Maria often feels stuck and unsure of what to do. She receives no emotional support from her family or friends back home. They often shame her for leaving and do not understand why she stays.

"They do not understand David's condition," Maria said. "Yes, I am guilty for having left my kids. I live with that every day. But children with disabilities in Mexico are called crazy. They are bullied and laughed at. They are left to fend for themselves. I don't want that for David. I stay here so that David can have a chance at a better future."

Although their situation in the United States is better, Maria and her husband face many obstacles, often as the result of not having the appropriate documentation. Maria lives in constant fear when transporting David to and from school and services, which she does five days a week. She fears being stopped by the police, as she has no legal documentation, permit, or driver's license. Her biggest fear is that one day she will be stopped, receive an expensive ticket, or even be taken to jail.

Communication is another huge barrier. Maria speaks very little English, and because all of David's classes and services are conducted in English, she understands very little about what is taking place. David does have a teacher who speaks Spanish and who often acts as

Continued on page 8

**MARIA'S** *Story*

Continued from page 7

an “in-between” for Maria and the other teachers at David’s school. Maria also enlists the help of an English-speaking friend to communicate with David’s school and therapists. However, much of the time she must simply trust that David is receiving the appropriate services and care.

Financial barriers are also present. David often has to miss his therapy sessions when there is no money for gas. Maria’s husband was employed as a truck driver, but he recently became ill and had to have surgery that has kept him from going back to work. This has caused great financial stress. Maria is so busy with David that she has not had the time to look for a job. She does have an interest in working both to earn money and also to have the opportunity to connect with other adults. The only socializing Maria currently has is going to a parent support group for parents of children with disabilities.

Though the family faces many challenges, Maria remains grateful for all they have. Above all, Maria wishes she could change the situation with her daughters in Mexico.

“Sometimes I wish I had wings so I could fly between here and Mexico and be with everyone in my family when they need me,” she said. “I dream of getting a permit that would let me travel between Mexico and the U.S., or a permit that would allow my children to travel here and live with us. I struggle with this every day. There are many days when I feel like ‘closing up shop’ and going back to Mexico because my children need me there. Sometimes it feels like I’m wasting my time here, but I know I’m not. I’m here for David.”

For more information on the Multicultural Outreach Program and the Tennessee Multicultural Alliance on Disability, contact [alexander.santana@vanderbilt.edu](mailto:alexander.santana@vanderbilt.edu).

For more on Tennessee Kindred Stories of Disability, see [kc.vanderbilt.edu/kindredstories](http://kc.vanderbilt.edu/kindredstories).

## Promoting Good Mental Health

Continued from page 6

exhale. Again, choose the words that work best for you.

**Tip 2:** Be in the present moment. When we are fully in the present moment, we are not revisiting the past or worrying about the future. You can train your mind to be in the present moment. For example, try walking to where you’re going while being fully aware. Practice noticing the moment your foot hits the ground, or pay attention to sounds you hear while walking. Choose one routine in daily life and try to bring moment-to-moment awareness to that activity each time you do it. With practice, you will be present in the moment more often and for longer times. If you get lost in your thoughts, begin again.

**Tip 3:** Take hold of your mind. Our thoughts and feelings are like the weather. They come and go like clouds. We can’t control the weather, but we can choose how to meet it. Getting stuck in negative thoughts adds to stress. When you notice you’re stuck in negativity, name how you feel. Then try using your breath to move your attention from your thoughts to your breath. For example, breathing in:

“Frustrated” and breathing out: “Kindness”. Shifting your focus from your thoughts to your breath gives your mind a break. Like our bodies, our minds need rest.

**Tip 4:** Cultivate “lovingkindness”. Lovingkindness is our capacity to feel friendliness to ourselves and others without conditions. Sit comfortably. Bring attention to your breath and allow tension to flow out of your body. Breathing in: “May I feel peaceful” and breathing out: “May I be in a space of well-being”. In your mind, picture persons who have cared for you. Imagine them around you. Say to yourself, “May I be filled with lovingkindness. May I be peaceful.” Repeat these wishes for others.

**Tip 5:** Practice gratitude. At the end of each day, name one to three things for which you are grateful.

*Elisabeth Dykens, PhD is Director of the Vanderbilt Kennedy Center and Professor of Psychology and Psychiatry. She conducts research on stress intervention in families who have a member with a disability.*

# INFORMATION AND RESOURCES

## FOR PARENTS WITH DISABILITIES

by Lydia Wingo Kane

All parents face challenges and learn new things every day. Parents with disabilities are no different, though they sometimes encounter additional barriers. These can include issues involving how society and systems view their parenting skills and their rights to make choices about reproduction, health care or adoption. So how can parents with disabilities find the information they need to address tough issues like how to advocate for themselves and their children, and how to find the resources they need to be the best parents they can be?

Parents with disabilities can find information, including research and articles, or read about others who have shared personal experiences and stories online. They can also find online communities for support, specialized programs and services—like legal help and women’s services—and services focused on specific disabilities. Many websites offer products such as educational materials, adapted equipment, books and online training (webinars). The organizations highlighted in this article offer a range of information for parents with disabilities and provide a good starting place for getting connected to other resources.

If you’re a woman with a disability, what questions should you ask or information should you provide to your doctor to ensure that they consider your disability when making decisions about how to care for you? The Center for Research on Women with Disabilities (CROWD) has created a self-test women can take or professionals can use as well as a Reproductive Health Information module. The self-test highlights the basics of a well-woman exam and other issues related to women’s reproductive and sexual health. CROWD’s website is an excellent place to start learning about healthcare issues that affect women with disabilities.

If you want to know where to go to talk with other people and parents with disabilities about their experiences trying to conceive, or what other parents do to remain independent in parenting, go to Parents with Disabilities Online and join the Parent Empowerment Network. This



Photo by Simon Fulford

email community provides a place for parents to ask questions and share what has worked for them. The site also recommends books, articles and parenting products.

If you’re a parent with a disability in need of advocacy, TASP, The Association for Successful Parenting, aims to assist parents with learning and intellectual disabilities and their children. TASP also links to helpful resources like

the Raising Children Network, where parents can find a resource called Parenting in Pictures, a how-to guide on many parenting tasks using helpful photos. Parents can use the pictures to learn or be reminded how to change a diaper, do infant CPR and many other daily parenting tasks.

Another helpful organization to know about is the Center for Rights of Parents with Disabilities. Their goal is to combat discrimination affecting parents with disabilities. They can also assist with legal representation and provide information and referral.

Through the Looking Glass provides information and referral and also has specialized programs. Contact their Legal Program to find out where you can turn for help with your child custody case. Learn about their College Scholarship program for children whose parents have disabilities. Browse their list of resources for finding adapted parenting equipment.

Parents with mental health issues can find resources through the National Alliance on Mental Illness (NAMI). If you’d like to know how you can help your child or teenager understand mental illness, or how to connect with other parents in similar situations, NAMI is a good place to go.

To connect to these resources, go to Tennessee Disability Pathfinder’s Resources Library and look for Support for Parents with a Disability. The Library provides brief information and links to all of the websites mentioned above as well as other sources to learn more, including the National Council on Disability’s report “Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children” (2012), and an NPR “Talk of the Nation” discussion on this report.

# PROJECT ENRICH:

## SUPPORTING PARENTS WITH SPECIAL LEARNING NEEDS

by Ashley L. Annstedt, LCSW, UT Boling Center for Developmental Disabilities

Parenting is hard work! Ask any mom or dad who has suffered through the sleepless nights, never-ending diaper changes, and spit-ups. If you're reading this and smirking, then I guess you've been there.

Now, where did you learn to parent? Did you have excellent parents who were exceptional role models?

Did you read and Google endlessly to find the answers you were looking for? Or did it just come naturally?

A parent with an intellectual disability (ID) or other special learning need might answer no to one or all

of these questions. Adults with an ID have limited parenting resources in the Midsouth, which is why, 20 years ago, the University of Tennessee Boling Center for Developmental Disabilities (BCDD) Social Work department in collaboration with The Exchange Club of Memphis and Community Service Association (CSA) stepped in to fill that role with Project ENRICH. At present, the BCDD is the sole facilitator of the program and it is funded under a Tennessee Child Abuse Prevention grant.

Utilizing a program model first created by St. Louis University, Project ENRICH serves parents with varying degrees of ID as well as parents who are under-educated or with low or no literacy skills. Walk into room 206 at the BCDD on a Tuesday morning and

you'll find a group of parents along with Licensed Clinical Social Workers and trainees laughing, role playing, sharing stories of triumph and despair and, most importantly, learning. This group learns how to provide for the basic needs of every child, as well as how to care for their emotional and development needs.



The Bechtel Family.

Photo by Angela Bechtel

What you won't find are books, workbooks, worksheets and lengthy paperwork. As the coordinator of this program, I always get questions from folks in the community like, "THOSE kind of people have kids?!"

To which

my response is usually, "THOSE kind of people are parents just like you and me; they just need extra support in order to be successful." I find it funny that people outside the disability world think this is so odd. Especially when there are currently over 100,000 children in Special Education in the state of Tennessee alone, many of which have an intellectual disability and might be parents one day!

Project ENRICH utilizes Dr. Stephen Bavolek's evidence-based Nurturing Parenting curriculum which covers a wide range of topics from Alternatives to Spanking, Safety and Attachment, and Bonding. The BCDD Social Work department and Dr. Bavolek

Continued on page 11

# PROJECT ENRICH:

## SUPPORTING PARENTS WITH SPECIAL LEARNING NEEDS

Continued from page 10

are currently collaborating to adapt and validate this curriculum for parents with ID, and the BCDD is an official field site for this venture. The program is 12 weeks long and includes classes at the BCDD as well as visits from a Family Support Specialist who reinforces the curriculum topics in the home.

Parents are given a modified version of the Adult Adolescent Parenting Index and a Parent Skills Assessment in pictures at intake and graduation to measure their achievements in five competencies: Appropriate Expectations, Belief in/Use of Corporal Punishment, Appropriate Family Roles, Level of Empathy and Children’s Power and Independence.

Because the program is part of the BCDD, parents get face-to-face interaction and discussion with professionals practicing different disciplines at the Center, such as a presentation from the Clinical Nutrition department about healthy eating habits on a restricted budget, and information from the Developmental Pediatrics department about age appropriate expectations and development.

“ I like being around the other parents and learning to be a better momma. ”

Parents are referred to the program from various agencies in the community and come voluntarily or, in some cases, attend as a court-mandated requirement. “I wish all parents came to the program voluntarily, but that is just not the reality,” said Belinda Hardy, LCSW, and Chief of Social Work at BCDD. “Unfortunately, many parents are referred by DCS after their children have already been removed.”

There are no statistics to quote, but it has been the observation of those facilitating the program throughout the years that most referrals consist of neglect, medical neglect and lack of supervision; circumstances that could have been prevented by



The Daniel, Edwards Family. Photo by Mark Temple

proper support and education for this population of parents. “I like the class,” said Glenda Curtis, age 21, single mother to two children ages two years old and three months. “I like being around the other parents and learning to be a better momma.”

Glenda was referred by her DCS worker who recognized that she had some learning challenges and got her into the appropriate program prior to any discussion of the children’s removal. Now, the family is doing well. Glenda’s situation is similar to many other parents that come through here, who are faced not only with the challenge of functioning with an intellectual disability, but being unemployed, impoverished and living in unsafe neighborhoods.

In the abundant research and education on disability as a whole, there is very little pertaining to parents with intellectual disabilities. It is the goal of Project ENRICH to not only provide services to this population but to advocate throughout the state and nation for advancements in this area.

For further information about the program, contact Ashley Annestedt, LCSW, at [annestedt@uthsc.edu](mailto:annestedt@uthsc.edu) or 901.448.6670.

# PARENTS Helping PARENTS

by Belinda Hotchkiss,  
Executive Director, Family Voices of Tennessee

*As a parent, when we hear that something might be wrong with our children, fear immediately sets in. Your world stops and sometimes you feel incredibly alone.*

*When I was five months pregnant with my first child, my husband and I learned that our son was diagnosed with a rare and complex congenital heart defect called Taussig-Bing anomaly. He would require surgery right after birth. Our son Kael had his first open heart surgery at eight days old, his second at five months, and to date, a total of 15 surgeries or procedures. He had his third open heart surgery in January 2014.*

*So, needless to say, my family spends a lot of time in and out of hospitals. Although we have incredible support from our family and friends, there's a natural synergy that happens when you connect with another parent who has walked in your shoes. It wasn't until Kael was about a year old that I was connected with another mom whose son had the same diagnosis. Through this connection I was able to find support and comfort from someone who understood what I was feeling; a bond and relationship was formed.*

*Over the past nine years we have shared everything from worries about upcoming procedures, expectations of having a child with a chronic illness, general family life issues and the comical things nine-year-old boys do. – Kara Adams, mother of Kael Adams, Family Consultant/Project Coordinator at Family Voices of Tennessee.*

Tennessee Parent-to-Parent (TNP2P) started in 2013

and is a statewide program established to support and connect families of individuals with special health care needs. This provides families of children with special health care needs the opportunity to connect one-to-one with a parent/family with the same or similar special health care needs; in other words, someone who has "been there".

TNP2P program is based on a model program used across the country. Parent to Parent USA defines parent-to-parent support "as the intentional connection between a trained volunteer Support Parent and a parent seeking information, resources, guidance and support from an experienced parent." The "experienced parent" will be trained as a Mentor Parent.

"Mentors" are parents/family members who volunteer their time to share their personal experience, knowledge, and emotional support to other families who have children with a similar diagnosis or experiences. In order to become an effective mentor, parents/family members are

required to attend and participate in a training session involving communication/listening skills, confidentiality, story-telling and self-care debriefing techniques.

TNP2P also offers a training workshop on patient and family-centered care practices for all parents/family members who have children with special health care needs. These interactive workshops are provided to improve the overall relationship between the parent/



The Griffin Family.

Photo by Denise Tibbens

Continued on page 14

## THE RIGHT TO

## PARENT

by  
James Brown

Great things can happen when people and agencies come together to change the way the world works for people with disabilities. Earlier this year the National Federation of the Blind Tennessee Chapter (NFBTN) was hard at work pushing for legislation to ensure that parents with disabilities get a fair shake in custody hearings. As our custody bill was taking its steps to become a law, we met with staff from the Disability Law & Advocacy Center of Tennessee (DLAC), which promotes the rights of Tennesseans with disabilities to ensure they have an equal opportunity to be productive and respected members of society.

We became natural partners. DLAC worked with us to get organizations involved who advocate for people with many different disabilities, including The Arc Tennessee, the Tennessee Council on Developmental Disabilities and the Tennessee Disability Coalition. We especially appreciate DLAC's attorney, Elizabeth Setty Reeve, who found the solution to a concern raised in committee which allowed everyone to compromise, clearing the way for the custody bill to become law in July of 2013.

According to the 2012 National Council on Disability report, "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children", two thirds of all state child welfare laws allowed children to be taken away from a parent with a disability solely based on the condition of disability. Thanks to the new law, Tennessee is no longer counted as one of the states that openly practices this type of discrimination, and the state can no longer take children away from people exclusively based on a person's disability.

Since 1940, the National Federation of the Blind (NFB) has fought for security, opportunity, and equality for all blind people. In fact, its first president, Dr. tenBroek, penned the famous equal protection argument used in *Brown vs. Board of Education* that went on to shape the 14th Amendment and end racial segregation in the United States. Ironically, people with disabilities are still



Stephanie Jones and son, Kaleb

Photo by Cyndi Lou Griffin

fighting today for equal rights under the law. Even the basic equal right to have and keep a family is often not recognized.

As president of the NFBTN, I get weekly calls asking about different blindness-related topics. In August 2012, I received a call from a social worker here in Middle Tennessee. She began to describe a situation where a blind father had lost custody of his young child.

The social worker focused on one question: "As a blind person, how do you keep your children from sticking their fingers in electrical sockets?" I responded by asking her if she had a child, and then, how she kept her children from harm in that same situation. She responded, "I buy these little things at the store to put in the sockets." I told her that was amazing, because even though I'm blind, that was exactly what I did when my kids were younger. I didn't realize until later that she was most likely insinuating that a blind person couldn't put a plug in an electrical outlet—something that I have done automatically thousands of times in my life.

Continued on page 14

# THE RIGHT TO PARENT



Continued on from page 13

Unfortunately, blindness often becomes the overriding factor used by the courts and social service agencies in making decisions about the care of children. Just last year, the same blind parent was told by his social worker, "Everything is in order, but I do not know what to recommend to the judge because you are blind." In other words, she didn't want to recommend giving custody back to the parent only because of his blindness. If the circumstances were exactly the same and he was sighted, she would have recommended that the child be placed back with the parent without reservation.

Often sighted people who suddenly find themselves in a dark room or who wake up in the dark believe they understand blindness. However, they don't appreciate that the problems blindness present can be mitigated through proper training in alternative skills. The real problem of blindness is not the lack of sight, but the attitudes about blindness held by the public. In addition, most people don't realize that there are unique parenting techniques used by the blind. Because of the lack of knowledge in this area, the NFBTN and the new administration of the Tennessee Department

of Children's Services (DCS) agreed to a training where the NFBTN educates DCS employees on the extraordinary abilities of blind parents. Alternative techniques like using bells on the shoes of toddlers to keep up with the jingling feet of our little ones, talking thermometers, strap-on baby carriers, strollers with reversible handles, and simply reading our kids a bedtime story with a Braille book are all just a fraction of the different ways of parenting that will be covered during the training. Much credit is due to the new DCS administration who truly wants to understand the role of parents with disabilities within the family.

Parents come in different shapes and sizes. Parents who are blind are no different than the average sighted parent. Some of us blind folks are great at parenthood; others are not. The second president of the National Federation of the Blind, Dr. Kenneth Jernigan, said, "We who are blind are pretty much like you. We are, that is, if we have the chance to try. We have our share of both geniuses and jerks, but most of us are somewhere between; ordinary people living regular lives."

*James Brown is President, National Federation of the Blind of Tennessee*

## PARENTS *Helping* PARENTS

Continued from page 12

family member and the provider. The workshops are peer led; each facilitator is a parent of a child with special health care needs. Attendees will improve their knowledge on the following areas: Shared Decision-Making, Transition, Information and Community-Based Resources, Cultural Diversity, Peer Support and Parent-to-Parent Support.

We believe parents/families can be empowered by being connected with other families with similar life situations. It is our hope that through this program, parents/families can empower one another with strength, support and knowledge.

If you are a parent/family member of a child with

special health care needs and would like to learn more about Tennessee Parent-to-Parent, please contact Kara Adams at 615.515.8634 or email her at [kara\\_a@ndisability.org](mailto:kara_a@ndisability.org). Please visit our website and fill out the "Me and My Doctor Questionnaire" located at [http://ndisability.org/coalition\\_programs/family\\_voices](http://ndisability.org/coalition_programs/family_voices).

*Family Voices of Tennessee's Parent-to-Parent Program, a program of the Tennessee Disability Coalition, is supported by a grant from the Tennessee Department of Health, Family Health and Wellness Division/ Integrated Community Systems for CYSHCN through Project D70MC24125 from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.*

# Our JOURNEY



by Steven Sheegog, Sr.

It's a hot summer August day in Smyrna, Tennessee. I'm sitting on a bench outside the Tennessee Rehabilitation Center, one of eight of its kind in the United States. It provides job and life skills training for individuals with physical and developmental disabilities, including those with Traumatic Brain Injury. My son, Steven II, is preparing to participate in the graduation ceremony.

It's not his first graduation; actually it's his third. He had one for middle school, and one for high school. These are nice milestones for anyone and their families, but these are extra special to us because Steven has autism.

It has been a unique journey for us. It was at times very difficult; difficult for the individual with a disability, the siblings and the parents. My wife, Levon, and I were somewhat prepared by growing up in African American working class households in Memphis. We both came from rather large families—I'm the oldest of eight children and Levon is the oldest of six. Therefore we dealt with some challenges that others in typical middle class families did not.

I received extra preparation because one of my brothers, Shawn, has both autism and Down syndrome.

He was the fourth child and was by far our favorite brother. My parents' belief and value system was that we took care of our own. My mother was a stay-at-home-mom, and my dad was the provider. The only services they pursued were to get Shawn in school.

But there were no services available to him, or they weren't aware of any. He briefly attended Avon Lenox School in Memphis until my parents relocated to north Mississippi. They never worked toward Shawn's independence. He might have never been able to live on his own, but I think he and my parents could have lived fuller lives.

Even with this kind of preparation, one is never ready for the news that their child has a disability. We noticed Steven was nonverbal and he always pointed to what he wanted. We took him to the UT Boling Center in Memphis when he was four and were given the news. As young parents of two children—his sister Alisha was two at the time—we did not know what to do. They just told us that we had to be very supportive of him and it was not going to be easy.

As his father I wanted to find out what our options were to get Steven the help he needed. Levon wanted Steven to be independent, and that included treating him no differently than we did Alisha. He had to carry his weight both inside and outside our home. That has been the foundation that shaped our paths.

I became active in the disability community by first attending Partners in Policymaking classes and speaking at events. I learned so much about the plight of all citizens with disabilities, not just Steven's. To me it was very similar to African Americans during the civil rights era. My wife made sure Steven did his chores at home, groomed himself and ironed his clothes. Our biggest challenge was in education - learning how to prepare for an IEP, knowing Steven's rights and conducting a meeting. We were blessed to attend a STEP (Support and Training for Exceptional Parents) class which gave us the blueprint.

Continued on page 16

*Our* JOURNEY

Continued from page 15

Also, networking with other parents of children with disabilities proved extremely valuable. Education became even more challenging because Steven was transferred to a different school every two years, and we had to start the process over and over again.

Later, I was recommended to complete the term of a colleague and friend on the Tennessee Council on Developmental Disabilities. I was appointed by former Governor Don Sundquist in 2002. Serving on the Council has helped me mature as a person and an advocate. Additionally, it gave me the opportunity to help other people, as well as Steven.

However, because Steven has a developmental disability but not an intellectual disability, services for him are almost nonexistent in Tennessee. The limited services that were available didn't apply, because we had already addressed those needs on our own.

In spite of the obstacles, Steven has been very successful. He went on to become one of the most popular students at East High School, passed the state's standardized test, the Gateway exam, and earned a regular high school diploma. He obtained a driver's license and attended Mid South Community College in West Memphis. He's just nine hours short of an associate's degree.

Currently, the biggest challenge for Steven and our family has been the transition from high school to adult life. Like most young men, Steven wants a job and a family of his own. As a step in the employment direction, he's been receiving Vocational Rehabilitation services for almost three years which has led us to where we are today on this hot August afternoon.

I go inside and Steven and Levon are being interviewed by Dan Whittle, a freelance reporter, who has done work for the Murfreesboro Post. Watching them, I reflect back to these remarks I once gave to an incoming class for the Partners in Policymaking program:

"I, like most fathers, wanted my son to grow up to be just like me. When we were given the news about Steven's autism, that hope became greatly diminished.



But looking back at Steven's accomplishments something became very clear.

Steven had several birthday parties and many friends attended them. I never had a birthday party until later as an adult. Steven served as a manager for the East High girls' basketball team and was beloved. I was a statistician for the Fairley High boys' basketball team and no one cared. Steven ran track for the East boys' track team and helped them win the city championship in 2005. I played baseball for Fairley and we won the district championship but lost in the city championship game. Steven was voted, "Most Likely to be Remembered" and "Best School Spirit" by his East High classmates. I didn't receive a vote. Steven ran summer AAU track for the Blues City Runners and won 5 AAU gold medals and his 800-meter relay team finished 12th in the country in 2005 and 9th in 2006 at the AAU Summer Olympics. I played one year of American Legion baseball and we finished last.

I could go on but you get the picture. Steven did not grow up just like me. He turned out better than me."

# Council's Community Development Grant Can Help Families Explore Programs



by Alicia Cone, PhD, Director of Grant Program, Tennessee Council on Developmental Disabilities

In 2013, the Tennessee Council on Developmental Disabilities received an Education Travel Fund request to travel to another state and look into a promising community-based program that was having good outcomes in the areas of employment, relationship building and community connecting. Unfortunately, at that time, we did not have a mechanism in place to support such a request. However, the Council is always thinking about better ways to support Tennesseans and their families to do grassroots work in their local communities.

**“ The Council is always thinking about better ways to support Tennesseans and their families to do grassroots work in their local communities. ”**

As the Council's executive director and grant director brainstormed about what strategies could be used to support this kind of local program development, we realized two things: 1) we wanted to be able to see a tangible outcome from the investment of the Council's money, 2) and we wanted to be able to invest "seed" money without having to commit large amounts of grant dollars to the effort. We thought about other programs that invest small dollar amounts with people with disabilities and their families, but got big returns for that investment. Examples include Family

Support and the Tennessee Respite Coalition.

Where we ended up was a new fund that has two components. The first component pays for travel to the location of the program being visited and researched. In this regard, this component of the Community Development Grant is very much like the Education Travel Fund. The second component of the CDG provides seed money of no more than \$500 to implement a Plan of Action. This \$500 is used to take the first step or two in replicating the program back here in a local Tennessee community. This second component resembles our larger grants, by requiring a short narrative to describe the program being visited, what it offers, and how it would be useful to Tennessee. This component requires a short narrative to describe the program being visited, what it offers and how it would be useful to Tennessee. It requires a brief Plan of Action - think Work Plan - that will describe the activities to be completed upon return to Tennessee. And lastly, a brief budget that will outline how the \$500 will be spent to implement the Plan of Action.

We realize that \$500 may not go far, but we believe it's enough to hold the first organizing meetings, to disseminate information and to garner community support for further program development. The goal was never to pay for buildings, staff or equipment, but instead to help "seed" an idea and grow grassroots support in a local community under the leadership of Tennesseans with disabilities and their families.

For further information, visit [www.tn.gov/cdd](http://www.tn.gov/cdd) to read the full program description with requirements and to download an application.

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