

breaking ground

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**Accessible
Recreation:**
*Enjoying Life
Together*



Council on
Developmental Disabilities

Dear Readers,

After October's celebration of Disability Employment Awareness Month, this issue of *Breaking Ground* is focused on recreation – the things we do to for pure enjoyment when we are *not* working. In other words, it's what we do for fun.

Our culture, led by our younger generations, has started to place more value on enjoying life. Norms are shifting: we talk more about self-care and finding a balance between work and play. We think about things like exercise, being outside, and play as keys to wellness. Research now confirms these things are linked to physical and mental health. In short: we are realizing that recreation is a necessity, not a luxury.



Many of the stories you'll read in this issue are told by Tennesseans with disabilities. The disability community needs more than changing cultural norms. We need access.

I visited Pulaski, Tennessee last month to see the new adult-size changing table in the Pulaski Recreation Center.

That table means access to recreation – to fun, and joy, and wellness – for countless families. Both residents and visitors are using the rec center for the first time, thanks to that table.

Darlene Slinger with Pulaski Parks and Recreation shared several of those



stories in two videos. (She is joined by special guest Marshall the goose from our friends at the TN Disability Coalition!)



Our Council member Chrissy Hood pointed out the new splash pad and told me her

daughter was able to go last summer, with all of her peers, thanks to the new changing table. Their family attended the community-wide Fourth of July celebration. For the first time in almost 20 years, no one had to run home to change. No one had to risk the embarrassment of changing without a table. Adult-size changing tables change lives.



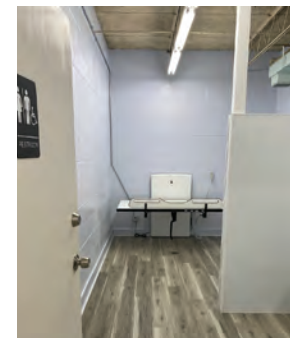
Darlene Slinger and TN Disability Coalition's mascot, Marshall

Adult-size changing tables are only one aspect of accessibility to recreation. You'll read about others in this issue of *Breaking Ground*. But we have a rare opportunity in Tennessee this year. Thanks to the generosity of our General Assembly and the Dept. of Intellectual and Developmental Disabilities, we have \$1 million worth of grants for businesses and local governments to install adult-size tables. We



need your help to take full advantage. As you read this issue, think about the places you find joy in your community. Think about the places you would not be able to go if you have, or ever acquire, the need for an adult-size changing table. Take a flyer about these grants to those locations. Let's find a way for everyone to enjoy life, together.

*Lauren Percy
Executive Director, TN Council on Developmental Disabilities*



Pulaski Parks and Recreation's new family restroom includes an adult-size changing table.

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On the cover: Council member Sarah Cripps fulfills her long-time dream of tandem skydiving. Experience the adrenaline on page 10.

Learn more about the Tennessee Council on Developmental Disabilities.

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ABLE Youth: Skills for Sports, Skills for Life

By Amy Saffell, Executive Director, ABLE Youth

ABLE Youth helps kids in Middle Tennessee with physical disabilities, ages 2 through high school graduation, learn to be independent through adaptive sports. Kids don't have to be full-time wheelchair users to join. So often, kids with varying physical disabilities focus on learning to walk through physical therapy. But even if they are able to walk in their everyday lives, they may not have the agility to play "able-bodied" or "typical" sports. They may believe sports are off-limits to them. They don't realize they can use a wheelchair just for sports and have a blast. ABLE Youth has sports wheelchairs for our kids to use, so they don't have to have a wheelchair of their own.

ABLE Youth is about fun and games, an important part of childhood that kids with disabilities may struggle to access due to accessibility or medical concerns. But ABLE Youth is about so much more: taking lessons that sports teach us out into the world.

The "ABLE" in ABLE Youth is an acronym with two important meanings. One is "Athletes Building Life Experiences," a fitting description of the ABLE Youth mission. The other is what ABLE Youth calls "The ABLE Way:"



Athletes from ABLE Youth's Music City Thunder wheelchair basketball team play in the Music City Madness Wheelchair Basketball Tournament in Murfreesboro.

- **Adapt** (to your surroundings)
- **Believe** (in yourself and your capabilities)
- **Love** (yourself and your life)
- **Enjoy** (all of the opportunities life brings)

These four qualities are ones that we've found to be critical to living life successfully with a disability and are principles we hope to instill in all our kids.

ABLE Youth offers lots of adaptive sports opportunities, both competitive and non-competitive. Super Sports Saturdays, held monthly, are our largest gathering of kids, where we play lots of different sports and games. Our Music City Thunder wheelchair basketball teams

compete through the National Wheelchair Basketball Association and travel to different states for tournaments. Competing in multi-sport adaptive athletic meets, also held outside of Tennessee, kids try out track, field events, and swimming, as well as other sports like archery. Closer to home, we participate in adaptive rock climbing, road races, and more. It doesn't matter if a child excels at any of the sports offered. We just want them to have the chance to try something new and to have fun first.

Being involved in adaptive sports and recreation provides many health benefits of being active, but the benefits go much further. Kids don't see people with disabilities in the media enough. If a kid is told



Wheelchair tennis is a popular activity for all ages at ABLE Youth's Super Sports Saturdays.

that they can't do something, they might not see that there are lots of people with disabilities out there doing the very thing that they were told that they couldn't do. They see it at ABLE Youth. Many of our kids don't see anyone else in a wheelchair at school, so it's often only at ABLE Youth when they see someone who looks like them. When they go to a tournament or meet, they see hundreds of kids with physical disabilities from across the country. At ABLE Youth, they're not alone.

They meet other kids who understand what it's like growing up with a disability. They learn from kids who are further along in the journey than they are. When they accomplish things that once seemed so far out of reach, they turn around and help the next kid coming along. As they start to learn what they can do through sports, they think, "If I can do this, then what else in life could I do?" It's a ripple effect throughout their whole lives. Through sports, they have something in common with their non-disabled peers. They have the power to change the whole world

as people without disabilities learn about their capabilities.

ABLE Youth's success stories are numerous and include very young participants. When a child joins us at a young age or when they are new to using a wheelchair, parents tell me the child immediately starts pushing their chair better at home. Studies show that kids who play adaptive sports are more likely to later be employed. Their ABLE Youth successes continue even into adulthood. ABLE Youth alumni are in the workforce in all kinds of industries. They're continuing their pursuit of wheelchair sports, too.

One of our alums plays wheelchair basketball at Auburn University. He joined ABLE Youth at 4 years old, full of energy and enthusiasm. Through ABLE Youth, he learned not only that he was a great athlete but also how to take care of his disability related everyday needs. He realized that living independently was possible. Through adaptive sports opportunities on college campuses, he built the courage to go to college away from home and put in the work to get there!



Kids in ABLE Youth have the opportunity to participate in local road races like the Hope & Possibility® Race.

We also currently have an alum playing wheelchair basketball professionally in Greece. Although it can be difficult traveling for our tournaments, getting to learn about travel as a wheelchair user at ABLE Youth planted the seed for the opportunity. Another alum is the head coach of the University of Texas at Arlington's women's wheelchair basketball team. No matter what our alumni are doing, we're proud of all the progress they've made, both in sports and in life.

You can find out more about ABLE Youth by visiting www.ableyouth.org or emailing info@ableyouth.org. ■

ABLE Youth is based in Nashville. Amy Saffell is ABLE Youth's Executive Director. Born in Atlanta with spina bifida, adaptive sports were an important part of her childhood. She previously worked at a record label.

STRIVE 4 You Inclusive Sports and Fitness

By Ricky Jones, STRIVE4You co-founder and 2011 Partners in Policymaking® graduate

Recreation and sports can be so empowering, bringing friends, family, and even couples together! Studies by the United States Association of Blind Athletes in 2014 showed that, compared to the general American population, less than 19% of blind and visually impaired K-12 students actively participate in physical education or after-school recreation activities. After high school, that number of blind and visually impaired adults getting regular moderate exercise drops to 14%. Only 9% of seniors and veterans are getting regular exercise.

My wife Christy and I were some of these very people, living sedentary, unhealthy, and truly unfulfilling lives. We knew we wanted more for ourselves, and most importantly,

more for our children. Christy and I both grew up visually impaired, dealing with society's negative stereotypes and desperately struggling against our own internal and external barriers. We knew there had to be more, and boy, were we right!

In our separate journey to find resources for ourselves and our children, we found each other. With the help of my younger brother, Dwaine, and others, I had re-started the TN Association of Blind Athletes (TNABA) in 2009. In 2011, Christy was looking for resources for her and for her sighted daughter, who was just starting kindergarten. When she called vocational rehabilitation services, the kind lady on the other end of the phone suggested Christy should come out to a TNABA picnic.

That is where she and I first met and began getting to know each other and our passion for life. Less than a year later, we realized there was so much more between us as we fell in love. Ten plus years later, we are married with three kids and have dedicated our lives to empowering others to live life to its fullest!

In late 2019, the TNABA and another nonprofit we participated in were both dissolving. But we wanted to continue the mission to provide confidence, resources, and, most importantly, opportunities for people with disabilities to get out of the house and live their lives on their terms. So, we decided to merge our passion for adaptive sports and recreation and self-defense into one national organization, called STRIVE4YOU.

STRIVE stands for "Strength, Training, & Recreation Inspiring Vitality & Empowerment." Our mission is to provide the education, resources, and opportunities for people with disabilities to live life to its fullest in a more inclusive society for all!

We use a peer-to-peer approach to mentor others to succeed through several programs.

- Our ARISE (Adaptive Recreation Inspiring Success & Empowerment) program provides recreational and sports opportunities.



Christy, Ricky and their three children lives in Madison, TN.



Veterans brush up on their archery skills at a sports day event.

- Our SEED (Safety Education Empowering Defense) program is the only one of its kind – created by the blind for the blind, taking a holistic approach to safety.
- Our BE REAL program we hope to launch soon. It will provide self-advocacy, communication, and disability awareness to help form positive interactions between everyone within the community.

Each program takes a two-prong approach:

1. First, providing services for a person with a disability.
2. Second, providing meaningful education and resources for those within the communities we live, work, and play in.

Our ARISE Program provides adaptive sports days to give folks the opportunity to try different adaptive sports to see what they like. We host three nationwide tournaments right here in Nashville. We host our annual “STRIVER Day,” an interactive conference which promotes health, wellness, safety, and self-defense, along with other disability-related topics. We also teach workshops and webinars for professionals on how to make their mainstream programming more inclusive for everyone!

Our SEED Program offers safety education and self-defense workshops throughout the country. These trainings teach students how to handle potentially dangerous contact with others. Students learn to assess the situation and respond appropriately until the situation is deescalated. The goal is to allow everyone to go home safely.

We are still forming the curriculum and program offerings for the BE REAL Program. We welcome all our fellow Partners in Policymaking® graduates to join the team and help us develop it!

If you want to get involved, you can check us out at <https://strive4you.org>. We have lots of ways you can join us.

Whether you are a person who has had a disability since birth or someone who has newly joined our community, we want you to know there is no reason that your challenges must dictate who you are. We are here to STRIVE for a better future for you, but first you must STRIVE for You! ■

Harvesting Inclusive Play: A Plan Takes Shape in Chattanooga

By Bliss Welch, Southeast development district, Tennessee Council on Developmental Disabilities

For me, one of the greatest joys of being a mom has been experiencing the world through my daughter's eyes. Over the years, I have accumulated countless memories of seeing Annabelle's wonder and amazement as she discovered the world around her.

Unfortunately, as a wheelchair mobile mom, I have also seen the sadness, disappointment, and frustration when Annabelle realizes the lack of accessibility in the world around her. It's heartbreaking for us both when the only option is for me to observe from the sidelines. I know that heartbreak is magnified for children who are wheelchair mobile and are forced to sit on the sidelines because of inaccessibility. Annabelle and I feel that accessibility and inclusion should be mandatory, not optional.



Heritage Park, from left to right: Skyler and Noah Phillips; Bliss and Annabelle Welch; Roddey and Ethan Coe

Several years ago, my friend Skyler Phillips asked me to join forces with him on his quest to build a universally inclusive playground in Chattanooga. Skyler is a captain and paramedic with the Chattanooga Fire Department and has devoted his entire adult life to public service. After his oldest son was diagnosed with autism, Skyler became a "dadvocate" (dad advocate) who is always seeking ways for the world to be more inclusive.

In 2017, the Phillips family traveled to Ohio to receive the necessary training to handle his son's new service dog. During the training class, Skyler met another "dadvocate" and they began discussing various advocacy projects they had worked on in the past.

One project mentioned by the other "dadvocate" was an inclusive playground. That conversation planted the seed for Skyler, and he began researching the need for a universally inclusive playground in Chattanooga. During his research, he was brought to tears from an old interview with Little Miss Wheelchair Tennessee, Liberty Barnum. Her story told of the inaccessibility of playgrounds. When Liberty said, "There's nothing I can really do, except sit," Skyler knew he had to do something.

From that moment on, it became Skyler's mission to ensure that no other child in the Chattanooga area would have to say those heartbreaking words again. While it was without a formal name on that day, Harvesting Inclusive Play was born.

I can still remember that phone call from Skyler five years ago when he asked me to help him figure out what to do and how to raise funds for a new playground. Skyler knew that during my year of reign as Ms. Wheelchair Tennessee 2013, I led several fundraising events. The money I raised that year wasn't a drop in the bucket compared to the funds needed for the children in our community to have a spectacular, fully inclusive playground. But I knew this was a project I wanted to be a part of. While neither of us were experts on



Nov. 2022 kick-off event for Harvesting Inclusive Play (pictured, from left to right: Bobby Dann, Kim Whitfield, Darrin Ledford, Shawn Whitfield, Skyler Phillips, Noah Phillips, Kris Holley, Asher Staton, Elliott Phillips, Anora Martin, Maverick Martin, Joel Westbrook, Annabelle Welch, Bliss Welch, Mandy Livingston, and Cyndi Leach)

fundraising, we were VERY passionate about inclusion and accessibility for ALL individuals.

Over the course of the next two years, the Harvesting Inclusive Play (HIP) Committee was born. Initially, the committee consisted of a wheelchair-mobile parent and parents of children with a disability. Fellow Council on Developmental Disabilities member Roddey Coe was also one of the founding members of the HIP committee. We selected Jack Benson Heritage Park in Chattanooga as the site we wanted for the future playground.

When Skyler pitched the playground idea to Councilman Darren Ledford, he was instantly on board and said he had been looking for something to add to Heritage Park. The City of Chattanooga is partnering with us on this project and will provide various site updates to the park. The HIP Committee chose a farm-themed playground design as a nod to the original farm property. We considered designs from three different playground companies and ultimately finalized a deal with Play and Park Structures, a playground company headquartered in Chattanooga.



Skylar Vaughn-Hisey and Bliss Welch with Harvesting Inclusive Play

The HIP Committee needed to partner with an existing 501(c)3 public charity to oversee incoming donations for this project. When we presented the universally inclusive playground concept to the Kiwanis Club of Chattanooga, it fit with their mission and aligned perfectly with the work they were already doing in their playground project committee.

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Little Miss Wheelchair Tennessee Anora Martin and Bliss Welch

Skydiving

My Unforgettable Adventure

By Sarah Cripps, Upper Cumberland development district, TN Council on Developmental Disabilities



In 1972, I was born with a bilateral cleft lip and palate and with bilateral anophthalmia (that is to say, without any globes in my eyes and without any vision). From an early age, I developed the philosophy that life is to be experienced fully with all of my intact senses.

In 1982, I saw a movie that changed my life. It was a biopic about the blind actor and musician, Tom Sullivan, entitled "If You Could See What I Hear." By watching this movie, I learned that Tom Sullivan had skydived despite his total blindness. I made a vow to myself that someday, I, too, would skydive.

On Saturday, November 28, 2020, I finally realized my long-held dream of skydiving when I took a tandem jump at the Tullahoma airfield. I purposely did not inform my parents or sisters in advance of my tandem jump because I feared that some of them would attempt to discourage me. They would learn about it once it was over, one way or the other, I decided. That morning, I telephoned my husband and informed him that I would be skydiving. Obviously, Mack, being the cautious and prudent sort, was apprehen-

sive and a bit nervous, but he wished me luck in my endeavor.

My research informed my decision to skydive only in Tullahoma. I knew that many of the instructors there had served as soldiers and jumpers in the United States Army's vaunted 101st Airborne Division at Fort Campbell.

The previous day, I had telephoned a close friend and cryptically asked her if she would be able to drive me to "an appointment in Tullahoma" on Saturday. She agreed to drive me and, fortunately, didn't ask me to elaborate.

Once my friend picked me up on Saturday morning and we were well underway, I disclosed my planned skydive.



Upon arrival at the airfield, I went inside and paid for my tandem jump. I also paid for a videographer to capture my tandem jump for posterity.

I decided not to inform the registration clerk of my blindness because I did not want this to be a roadblock for me. I had

come too far at this point and would not be denied.

I then met my instructor, and he satisfied all of my prerequisites: He was a former soldier with the 101st Airborne Division, and he had numerous successful jumps under his belt. When I revealed to my instructor that I was totally blind, he replied, "Okay, no worries. You'll be fine."

One of my primary concerns that day was to ensure that I did not lose my prosthetic eyes during the free fall. Therefore, after arriving at the airfield, I purchased some high-quality, sturdy goggles to ensure that my prostheses remained in place. After this, I was as prepared as I possibly could be.

I felt a pit in the bottom of my stomach as I boarded the aircraft. We began our ascent to our jumping altitude of 14,000 feet, nearly three miles up into the atmosphere. My instructor explained that due to the high speed of our descent during the free fall, and because of the rushing wind in our ears, we would not be able to communicate verbally until the parachute had been deployed and we were under canopy. He came up with a system of communication for the two



of us that involved him tapping me different numbers of times on my left and right shoulders. This is how he would direct me as to what actions I needed to take. My instructor also explained what I would need to do when exiting the aircraft.

Once we had ascended to 14,000 feet, I heard the call, "jumpers away!" It was time to leave the plane! My instructor and I sat on the floor of the plane in the threshold of the open door, with our legs dangling outside the plane into nothingness. Based upon my training and instruction, I knew that we would have to rock back and forth three times and then physically throw our bodies out of the airplane. This was the most harrowing part of the jump for me; I was terrified!



As I sat there waiting to jump, I wondered if I had the courage actually to throw my body out of the plane. I psyched myself up by reminding myself that I had wanted to skydive for thirty-eight years. This was no time for cold feet.

As I sat with my legs dangling outside the aircraft, I could feel the force of the wind on my legs and feet and also noted the cold. Then, we jumped!

Immediately upon exiting the airplane, my instructor and I began spinning violently while somersaulting backwards and forwards. The wind roared deafeningly in my ears, and this was the only sound of which I was conscious.

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Skydiving... *continued* from page 11

Once we were a good distance away from the airplane's propeller, my instructor began directing me through his series of taps. We soon were free falling at a speed of over 120 miles per hour, spread out in the prone position. During the free fall, I had only a few recurring thoughts:

"This is it!"

"I hope the parachute opens!"

"God, my ears are hurting!"

Although I had planned ahead and purchased goggles, I did not think to wear ear plugs to protect my ears from the speedy descent and loss of altitude and from the roaring wind. This was a mistake. My ears bothered me for the next few days. At the same time, I could not stop smiling because of the exhilaration I felt during the free fall.

After a minute and a half, my instructor deployed the parachute. Immediately, the soundscape of the world around me changed dramatically. We floated quietly above the earth, descended slowly, and spoke freely. Far below me, I could hear the sounds of traffic and of birdsong.

Once we were under canopy, my instructor asked me, "Do you want to do some turns?" Of course, I immediately said, "Yes!" Then, I began manipulating the parachute as he directed, and we turned and spun in the air! How wonderfully thrilling it was to control the parachute and perform these loops and turns! This was right down my alley.

Then, we landed softly on our backsides and immediately scrambled to our feet. I had done it! Relief, utter contentment, and pride at my accomplishment washed over me. I returned home with an electrifying experience and an exciting story to share. ■



Sarah Cripps practices family law in Smithville, with degrees from Vanderbilt University and Tennessee Tech. Sarah has been blind since birth, and is a recognized community leader personally and professionally. She has represented the Upper Cumberland development district on the Tennessee Council on Developmental Disabilities since her appointment by Gov. Bill Lee in 2019. She also serves as the chair of the public policy committee.



Harvesting Inclusive Play...

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During the first two months of 2020, the HIP committee was busy finalizing plans to kick off our fundraising efforts at The Great Kiwanis Duck Race, an annual event in Chattanooga. By spring, all of our efforts came to a screeching halt because of the worldwide COVID-19 pandemic. There was so much uncertainty during 2020 that we weren't sure when or if we would be able to resume our plans for the playground.

So many obstacles have arisen since 2017. There have been numerous times we were ready to give up. But our driving force continues to be the children in our community who need an accessible, inclusive playground so children of ALL abilities can play together. The HIP committee has continued to work behind the scenes since the pandemic to ensure the completion of this project. Everything has finally fallen into place. The only remaining hurdle is raising the funds necessary to make this dream playground a reality for the children in our community.

In the famous words of Dr. Seuss' *The Lorax*, "Unless someone like you cares a whole awful lot, nothing is going to get better. It's not."

If you would like more information about the Harvesting Inclusive Play project or to make a donation, please visit our website (<https://www.harvestinginclusiveplay.com/>) or our Facebook page (<https://www.facebook.com/HarvestingInclusivePlay>). ■



Want to learn more about designing inclusive and accessible playgrounds?

Check out this article, "Principles of Inclusive Playground Design," from the Sept. 2022 National Parks and Recreation Association magazine: <https://www.nrpa.org/parks-recreation-magazine/2022/september/principles-of-inclusive-playground-design/>



Bliss Welch was appointed by Gov. Bill Lee to represent the Southeast development district on the Council in 2022. Bliss became a self-advocate during her teen years when diagnosed with Limb Girdle Muscular Dystrophy 2B/R2. She and her 11-year-old daughter, Annabelle, live in Harrison, TN. Bliss works as an Accounts Specialist at Island Cove Marina & Resort. Two years ago, she launched "Inclusion is Bliss," a social media-based way to share her triumphs and tragedies of living with a progressive form of muscular dystrophy. Bliss is passionate about changing the general population's perception of individuals with disabilities. She believes awareness, education, and understanding are key elements that must be in place for change to continue. Bliss serves as the Chairwoman for the Harvesting Inclusive Play committee in Chattanooga.

We Rock The Spectrum

By Steven Komarnitsky, We Rock The Spectrum - Franklin

Welcome to Tennessee's first inclusive sensory gym and recreational destination for children of ALL abilities, We Rock The Spectrum Kid's Gym in Franklin.

We're located on Murfreesboro Road in the Williamson Square Shopping Center next to the 96 and 65 interstates. The 5,600+ sq. ft. facility is filled with a variety of the latest occupational therapy equipment and sensory-based activities designed for all kids to use and enjoy.

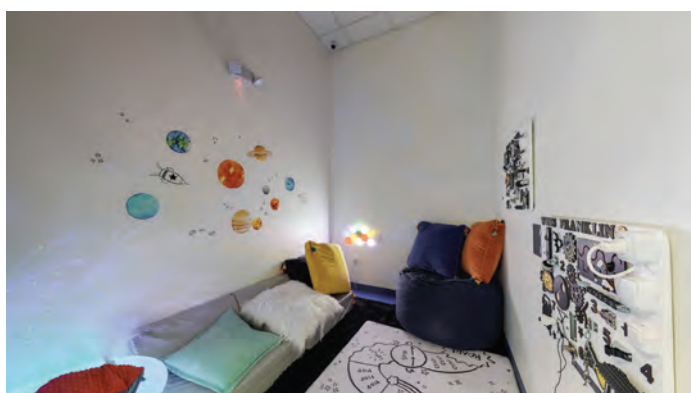
Our mission is to provide a safe, fun, and welcoming environment and provide a Play With A Purpose™ experience to each child and adult. The Play With A Purpose™ approach is exercising and stimulating any of the seven senses through positive physical, emotional, and social development. These seven senses include sight, smell, taste, hearing, touch, the vestibular system, and proprioception. Our sensory-safe equipment and the classes all work to encourage these! All children are able to benefit greatly from this equipment, and by allowing children of all ability levels to play together, they are able to learn a great deal from each



other and become the best motivation for success on every level.

My wife, Samantha Komarnitsky, and I are 2020 transplants from Los Angeles. We are dedicated parents to our son Nash (8) and daughter Colette "Coco" (6). At the age of 4, Nash was diagnosed with autism spectrum disorder. While researching resources for him, we discovered We Rock the Spectrum (WRTS). While WRTS was initially a place for Nash, once we introduced Coco to the gym, we soon realized how beneficial it is for ALL children to experience We Rock and help promote acceptance and inclusivity through play.





The We Rock the Spectrum – Franklin, TN staff is composed of the most caring, understanding, and energetic people around. We have a host of staffers and volunteers who come to us to assist our gym and its goal of aiding children with disabilities in growing beyond the expectations of doctors and therapists. Often, a therapist for a child with disabilities will attend the gym with the children in order to observe and provide their therapy while using the equipment in our gym. This allows kids the access they want to the amazing equipment while the therapist is able to take advantage of the support and availability of the staff and equipment, which might not be present in other settings. ■

Why do we rock? Our gym includes:

- Suspended equipment with swings – for balance and vestibular treatment
- Crash mats and crash pillows – for fun, motor planning, and strength
- Zip line – for stress release and joint and body relaxation
- Trampoline – for building leg and core strength
- Indoor play structure – for climbing and increasing playground skills
- Sensory-based toys and equipment- for improved auditory processing and fine motor skills
- Fine motor and arts and crafts area – for improved hand-eye coordination
- Calming room – for regulating emotions, and reducing negative sensory input
- Private 750 sq. ft. room for birthday parties, private events, and classes
- Universal, adjustable changing tables

For more information about our gym and our programs, visit our website at www.werockthespectrumfranklintn.com or follow us on social media!

Introducing A New Tool for Behavioral Health

By Jolene Sharp, Chief Information Officer

The checklist that follows has been reviewed by many professionals, self-advocates, and family members. But the first draft was banged out one morning after an experience with my daughter.

Those of us who support someone with a disability know that sometimes, the person we love doesn't have the language to tell us how they're feeling or what they need. For both of my children with disabilities, that sometimes looks like behavior that says all is not well. But WHAT is not well? As a parent, answering that question often involves a lot of detective work.

This checklist poured out of me a few months ago. My daughter is in 4th grade and has Down syndrome. I'd been emailing with her team about a new issue she was having at school. My husband suddenly had a lightbulb realization: we'd gotten behind on scheduling follow-up appointments with a specialist. That meant a medication dose might be out of date. I was kicking myself: How did I let this slip?

The answer, of course, is that every parent of a child with a disability is juggling dozens of pieces of the support puzzle. It's nearly impossible to track it all.

That's where this checklist comes in. Here at the Council, we want to make it just a little easier for people with disabilities to have their needs met. We want to make the detective work a little easier for supporters.

But here's the thing: This checklist is about universal human needs. While it's written for supporters of people with disabilities, it applies for all of us. It's easy for parents and supporters to forget to do this detective work for ourselves. When I am worn down or struggling with anxiety or stress, I am less able to stay calm and present for my kids (or spouse or anyone else in my orbit!). Taking time regularly to think about what I need to stay healthy is part of how I care for my loved ones.

The Council will be sharing this checklist across systems that provide support to people with disabilities. But we felt it was appropriate to share it first with you, our readers.



Jolene's husband Jon and daughter Lina on a recent hike

- Maybe you're a person with a disability who can use this list to help you think about your own needs. Maybe you want to share it with your parents or supporters.
- Maybe you're a parent of a child with a disability and you can use this list to help you understand your child's behavior.
- Maybe you're a teacher who can use this list to better understand a student's behavior support needs.
- Maybe you're a therapist or medical provider, and you can use this list to better serve clients or patients with disabilities.
- Maybe you work in a program that provides direct support to adults with disabilities and you can use this list to help you support the people you work with.

Whatever your role, we hope this list will make your life just a little bit easier. Most of all, we hope this list will help people with disabilities get the support they need to live healthy, happy lives. ■

Behavior Support Checklist

Supporting Well-being for People with Disabilities

It can be hard for people with disabilities to say when their needs aren't being met. Sometimes, unmet needs show up through behavior. Self-advocates and mental and behavioral health experts agree: behavior is always communication. Sometimes, behavior is a sign of a medical problem (like a seizure or a urinary tract infection). **Supporting well-being for a person with a disability means working to understand what the person's actions and non-verbal cues are telling us they need.**

A Checklist to Help

Key for all people:

- Independence/Autonomy
 - o Does the person have as much say as possible over their own life? Are they given meaningful choice whenever possible? Are they getting support to understand and make decisions?
 - o Are supporters and caregivers speaking directly TO the person? Are they paying attention to the person's responses (verbal or non-verbal) and wishes?
 - o Does the person have space to take reasonable risks and make mistakes?
 - o Does the person have time to be alone/do their own thing without direct supervision (as developmentally appropriate)?
 - o Need help in this area? Visit the TN Center for Decision-Making Support website www.tndecisionmaking.org for information and tools.

Medical needs:

- Mental Health
 - o Does the person have professional support for mental health? Do other family members?
 - o Are there mindfulness or other mental wellness tools that could be helpful?
 - o Are there signs that a more complete mental health evaluation is needed?
- Physical Health
 - o Is it possible the person is not feeling well?
 - o Are they experiencing pain they can't explain (for example, a urinary tract infection or dental pain)?

- o Are they getting recommended preventive, medical, and dental care?
- Medication
 - o Is medication being taken as prescribed?
 - o Have medication dosages been checked recently?
 - o Has a doctor checked for possible interactions between different medications the person is taking?
 - o Do any of the person's medications have possible negative side effects? Are there other alternatives to try?

General needs:

- Food/Water
 - o Is the person hungry/dehydrated? Do they have access to good nutrition?
- Rest
 - o Does the person need a physical or mental break? Is there a sensory-friendly space for a break?
 - o Are they sleeping well? Do they go to bed on time and seem rested in the mornings?
- Sensory input
 - o Is the person sensitive to noise, bright or flickering lights, textures, smells?
 - o Is the person seeking greater sensory input (pressure, repetitive motion, etc.)?
 - o How can the environment be made more comfortable for the person?

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- Communication
 - o Does the person have support to communicate their thoughts, feelings and desires? What tools could make this easier (for example, an assistive communication device)?
 - o Are supporters trained in the person's preferred communication methods?
 - o Is the person getting help to grow their communication skills?
- Physical Activity/Outdoor Time
 - o Does the person get regular physical activity that is accessible and enjoyable for them?
 - o Do they have regular access to fresh air, sunshine, and the outdoors?
- Routine/Structure/Predictability
 - o Does the person have an easy way to see plans for the moment/day/week?
 - o Are the person's preferences for routine honored as much as possible?
 - o Are changes to the schedule/routine discussed in advance with the person?
 - o Does the person have access to concrete information about what to expect for new/out of the routine experiences (e.g. visiting or looking at photos of a new place ahead of time, talking through what will happen at an event, etc.)?
 - o What other tools might help the person's schedule and routines feel predictable?
- Stress Management
 - o Have there been any significant changes in the person's life (including changes to aids/support staff)?
 - o Have there been any losses the person might be grieving?
- o Are there stressors in the person's family or close social circles (e.g. tense/turbulent relationships, divorce, arguments, job loss, financial strain)?
- o Is the person being included in discussions about family events or potentially stressful situations? Are changes being explained in accessible ways?
- Recreation/social engagement/connection
 - o Is the person participating in a range of activities they enjoy?
 - o Do they choose how they spend their free time?
 - o Do they have opportunities to learn new hobbies/skills? Do they have a regular creative outlet?
 - o Do they have regular, meaningful social opportunities? Do they have support to develop healthy relationships? (If local opportunities are limited, have they explored virtual groups or activities?)
- Purpose
 - o Is the person getting support for meaningful education or employment?
 - o Does the person have opportunities to volunteer/contribute to causes that are meaningful to them (church, nonprofit organizations, etc.)?
 - o Does the person have daily responsibilities to the full extent of their ability in the family or home?
- Safety
 - o Have there been any sudden changes in behavior or physical markers that could be signs of abuse? (Please seek immediate professional advice if you have any concerns on this point.)
 - o Are the person's boundaries about their own body or physical space being respected? Are they being taught how to respect others' boundaries?
 - o Are there technologies or other tools to help the person stay safe while maximizing independence?

Need More Help?

If someone you support needs more behavioral support, there are resources to help. TN Disability Pathfinder (www.tnpathfinder.org/) is our state's one-stop shop for finding disability-related information and services. Search their website or call 1-800-640-4636. **In case of a mental health crisis:** Call or text the [988 Crisis Hotline](https://www.tn.gov/2018/06/01/988-crisis-hotline/).

A First in Baseball History

A first in baseball history: players with disabilities and former professional players took the field together for a 9-inning exhibition game. The game was held at AT&T Field in Chattanooga on November 5, 2022. Players came from 12 states to participate in this historic classic.

Alternative Baseball provides empowerment, enrichment, and excitement for teens and adults (ages 15+) with autism and other disabilities through the authentic baseball experience. If you're interested in bringing Alternative Baseball to your community or joining a local program, visit www.alternativebaseball.org. Call 770-313-1762 with questions or for help filling out the online forms.

Want to watch the game? The organization hopes to publicly release an online recording in April for Autism Awareness Month.



Tennessee Council on Developmental Disabilities

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