

FALL 2023



THE CONNECTION

OFFICIAL NEWSLETTER OF THE ARC TENNESSEE



CHAPTER EXCELLENCE AWARD WINNER SPOTLIGHT

by Ashley Coulter

We were proud to celebrate The Arc of the Great Smokies as this year's recipient of the Chapter Excellence Award. Leslie Zimmerman, The Arc of the Great Smokies' Membership Chair, and Kathy McGee, Executive Director of The Arc of the Great Smokies, are pictured at a booth at an event in September showing off their award. The Arc of the Great Smokies was selected as this year's winner because of their hard work and dedication to ensuring an accessible playground in their community reached completion. They also won the membership drive hosted by The Arc Tennessee - they increased membership by 220% during a three month period in Fall 2022! The Arc of the Great Smokies has remained resilient and committed to

overcoming challenges presented during and post-COVID. We are proud of all they have accomplished and excited to see their hard work recognized! Congratulations to The Arc of the Great Smokies as the 2023 recipient of the Chapter Excellence Award!



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SIBLING CONNECTION

A MESSAGE FROM BOARD PRESIDENT, KAREN DOWNER

I am often asked by parents raising a child with an Intellectual or Developmental Disability (IDD) how they should approach ensuring that siblings remain actively involved throughout the individual's life and most importantly, after the parents are gone. Well, I am not an expert on that topic. I can only look back at my own experience as a sibling and that of my peers and friends who are also siblings and point out a few things that seemed to be defining factors.

My sister, Mindy, is not quite 2 years younger than I am. She was physically VERY robust but severely intellectually and developmentally disabled and non-verbal. Most types of IDD were not well understood or addressed in the 1960's. As small children, we were joined at the hip and Mindy quickly adapted me to the role of her unofficial communicator and enabler. If she wanted out, she took me to the door and put my hand on the doorknob. If she wanted food, she took me to the refrigerator or cabinet for whatever she wanted. You get the picture. When anyone spoke to Mindy, she looked at me to answer. As we were together 24/7, it was easy and normal to assume the role Mindy developed for me. It was all we knew. As a 5-year-old sibling, I felt important and needed.

As a result of my sister's IDD, my mother acquired a master's degree (Special Education) while Mindy was still a toddler and then worked in the public-school classroom for decades. There was this constant "figuring things out as we go" adventure theme in our household. My brother and I were involved in the day-to-day adaptations made to best protect and support Mindy in our home. A Dutch-door was installed to her bedroom so she could not wander while everyone else was sleeping and would not feel imprisoned. We could certainly hear her. Hardware was installed up high inside exterior doors for the same reason. Seating at the dinner table required distancing Mindy's place as she was happy to eat everything within reach. My brother and I did not experience what is now referred to as "well sibling syndrome". We were always part of the ongoing challenge to keep Mindy safe because she was dangerously fearless. I must admit there was not ONE adaptation that went undefeated in true Houdini fashion. Not one.

CONTINUED ON PAGE 3



Sibling Connection continued

I believe that in those early years my parents fostered that very important close sibling relationship between the three of us. As we progressed through the early primary school years, options became fewer to non-existent for Mindy. Ultimately, the decision was made to send Mindy to the brand-new Greene Valley Developmental Center. Our parents were trying to establish a “normal” existence for my brother and I as well as ensure Mindy would have a home after they were gone. They were adamant that we as her siblings would not take on her full-time care when that time came. As 14 and 11-year-olds, we were well informed of this decision but not able to impact it. My parents then had to deal with a confused and grieving 11-year-old and a very stoic 14-year-old who acted out in other ways. For years, my mother had a very hard time not setting the table for 5. What I remember most is the house became very quiet after Mindy was gone.

Time passed and I remember asking my dad when I was headed off to college (that ever-present guilt kicking in), “What should I be doing about taking care of Mindy later; you know when you are gone?” His answer was, “You go get the best education and job you can. We think she’s good, but we never know what the future holds.”

Our parents stayed very much on top of and involved with Mindy’s residency at Greene Valley over time. I went along on the monthly visits until I left home for college. It was a 5 hour drive each way and my parents continued to go monthly until they simply could not make the trip anymore. My brother took our mom to Green Valley for those continuing visits until her dementia intervened.

The point I try to make to parents of children and adults with IDD is that my parents didn’t state an expectation or imply a responsibility regarding Mindy’s care. **Instead, they modeled it by keeping her care always front and center in our lives while giving us as her siblings the room to grow into our own full lives with education, marriages, children etc.** The difficult decisions involving Mindy’s care were always part of kitchen table discussions throughout our lives. We knew both short- and long-term decisions were hard and imperfect.

Fast forward from that 9-year-old in 1966 to the 57-year-old in 2015. In Tennessee, a 20-year-old lawsuit finally settles, and we siblings are notified that institutions including Greene Valley are closing. We are directed to find a suitable residence for Mindy. The decades worth of benefit systems and philosophical changes outside of institutional care were complicated and unfamiliar. There was very little time in this final exit round and even fewer choices of homes and care. There was a detailed and lengthy transition process as the state handed over the care of an individual. A sibling who has developed a natural familial connection to their sibling with IDD does not have to be summoned twice to take on support. It is that connection formed very early and respect for family that drives siblings to maintain and ensure ongoing support even when its hard.

CONTINUED ON PAGE 7

RIGHT: KAREN DOWNER PICTURED WITH HER SISTER, MINDY. ALSO PICTURED IS THEIR BROTHER, KIM MCDOWELL.





Special Education Community Conversations

BY JEN FISHER

The Family Engagement in Special Education team was busy in August heading out and about around the state to get your input. We held eight Special Education Community Conversations to gather feedback from our families and community members including parents, students, teachers, and representatives from community disability agencies. These conversations help the Family Engagement team and the Tennessee Department of Education to learn what is working well for families in the special education system. They also help us to identify effective ways to work together to address the challenges sometimes faced in special education by families.

In addition to gathering this important information, Community Conversations also provide a way for families and community members to learn about ideas, resources, or opportunities in the community that they previously did not know about. Families say that they have been able to identify specific ideas or steps either their school or their family could use to improve family engagement in special education.

These conversations are invaluable in finding ways for the Tennessee Department of Education, schools, families, and community to partner to provide the best possible outcomes for students in special education. To find future events or to sign up for news and updates, visit the Family Engagement website at www.familyengagementtn.com.



ERICA KONYAK, CAROLLYNN YOUNG, MICHELLE GROSS, AND CLAIRE MARR PICTURED AT A COMMUNITY CONVERSATIONS EVENT IN EAST TN

Donor Appreciation!

Donations are greatly appreciated and help The Arc Tennessee continue to deliver advocacy, information and support to people with disabilities and their families. Many thanks to our donors who contributed between June 28 through September 25, 2023.

KIM ADKINS
WORDSCRAFTS
CHARLES HOBBS
JEN FISHER

SHEILA MOORE
NICOLE JETT
DORIA PANVINI
BEN SCHWARTZMAN

With your support The Arc Tennessee is leading the fight for equality and inclusion, empowering people to live the lives they want, and inspiring a nationwide movement of advocates. With your help, we grow stronger. To donate on our website, scan the QR code shown here.





Chapter News

Activities and information from our local chapters

THE ARC OF THE GREAT SMOKIES

It's here! The John Sevier Inclusive Playground, where EVERYBODY PLAYS! The Arc of the Great Smokies initiated the idea with Blount County Parks & Recreation to build an Inclusive Playground. We partnered with Maryville Lions Club, City of Maryville, The Gate, Volunteer Action Civitans, a generous retired teacher, Tuckaleechee Chapel Missionary Baptist Church, and several other donors. It's a sight to behold and the children are loving it! It has ramps and rubberized surfacing as well as many other adaptations. They tell their parents, grandparents, and caregivers that they don't want to go to any other playground! We are very proud to have the first one in Blount County and it's fenced for safety and parental sanity.



The Grand Opening of the John Sevier Inclusive Playground was hosted on Friday, September 15, 2023. Channel 8 WVLT reported on the celebration! Mayor Andy White, donors, and community members were all present. And to top it off, there were free snow cones for all who came!



THE ARC CUMBERLAND COUNTY

On July 6, 2023, 134 members, family and guests attended The Arc Cumberland County Family Picnic, Annual Meeting and Awards Presentation. Mary Lampugnano received the Best Sib Award. Mary is pictured with her brother Jim Dwyer (left). The board received a check from Kind Charities of TN for use in our Special Olympics and Structured Athletics activities (below). The Arc Cumberland County also has members that are going to the Cumberland County Playhouse for dance instructions preparing for the holiday recital.



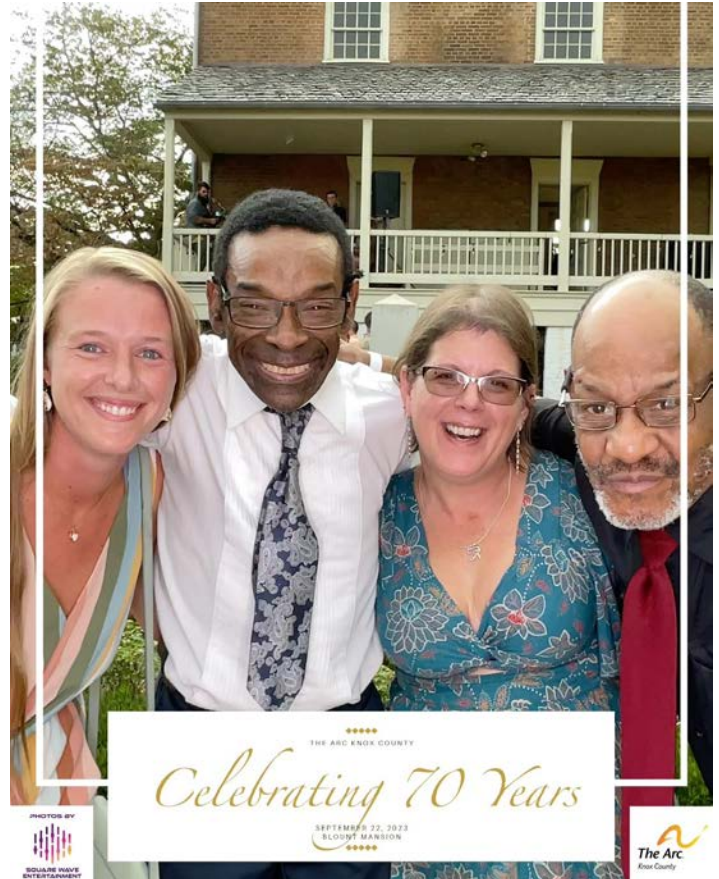


Chapter News continued

THE ARC OF THE MIDSOUTH

The Arc Mid-South attended “Access Awards Benefit “Claiming Our Space” hosted by Disability Connection Midsouth on July 28th, 2023.

Sandra Hawkins (pictured), The Arc Mid-South’s Community Advocate, was recognized for her hard work supporting disability inclusion and independence with the Advocate of the Year award.



THE ARC KNOX COUNTY

The Arc Knox County members and supporters gathered at the Blount Mansion to honor 70 years of providing programs and services to individuals with intellectual and developmental disabilities in Knox County. We danced to bluegrass music, ate delicious pasta and placed bids at our silent auction. It was a lovely evening with friends, family and loved ones. After a difficult search, Mindy took up residence at a group home in Chattanooga. It has been a journey for her coming back home. She deeply grieved the loss of her home at Greene Valley, but she has established herself in her new home and community over time. She immediately returns me to my prior role of enabler when I visit her home, as if we were not apart at all these last 50 years. It feels right.



Sibling Connection continued

There was a detailed and lengthy transition process as the state handed over the care of an individual. A sibling who has developed a natural familial connection to their sibling with IDD does not have to be summoned twice to take on support. It is that connection formed very early and respect for family that drives siblings to maintain and ensure ongoing support even when it is hard.

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It is exciting to see that the overall shift away from institutional care allows the connection among siblings to be even stronger and better defined. Our brothers and sisters can become members of the overall community in the same way they are members of our respective families. Siblings are now considered to have a unique role in the lives of their siblings with IDD instead of being separated from them. I think parents can have confidence in the siblings they raise and focus energy on improving services and support capacity and delivery.

There are now many resources available from The Arc for future planning that can involve siblings. These resources reduce the overall uncertainty in longer term planning. You can build a plan on www.futureplanning.thearc.org. In addition, The Arc Tennessee Advocacy Program often works with siblings of individuals who need support to identify available resources. You can check this program out at www.thearctn.org.

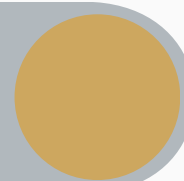
For depth and breadth of information related to siblings of individuals with IDD check out the Sibling Leadership Network at www.siblingleadership.org. Another great place to investigate is publications.ici.umn/impact/32-2/siblings-of-people-with-idd. Look for Impact Feature Issue on Siblings of People with IDD.

-Karen Downer



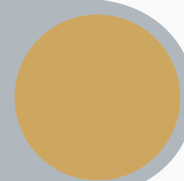
Tennessee Adult Brothers and Sisters (TABS)

Tennessee's statewide organization for adults with siblings with disabilities



Sibling Leadership Network (SLN)

Nationwide organization for adults with siblings with disabilities





Shining the Light on The Arc Tennessee Advocates: Middle TN

BY HEATHER HENDERSON

Last newsletter we highlighted our advocates from The Arc TN serving East Tennessee. This time we are taking a look at our advocates in Middle Tennessee! Cat Freeze is one of the adult advocates and a PATH facilitator here in Middle Tennessee. Her first job was as a People Talking To People interviewer with The Arc TN! Since that time, she has worked in different positions with other chapters of The Arc. Cat's passion and commitment to those she works with are appreciated and admired by all who come into contact with her.

Heather: How long have you worked at The Arc TN?

Cat: A little over two years.

Heather: What do you love most about your job?

Cat: The people I get to advocate for. I love hearing their stories and advocating for the changes they want to see in their lives. Standing up for others has always been in my DNA.

Heather: Do you have any strategies for dealing with stress at work?

Cat: Taking a step back and looking at the big picture. Music and reading are also ways that I deal with stress. Talking to my other team members as well.

Heather: What do you think our future looks like as a team?

Cat: The sky is the limit. What is so great about the Advocacy Team is that we all bring something different to the table. We all have different approaches and come from different backgrounds, which really makes us a well-rounded team.

Heather: What is something surprising that not many people know about you?

Cat: My background is in fashion design and sewing. I own my own clothing brand, Cat-land Forever Couture.

Lamont Tucker is another one of the advocates here in Middle Tennessee. Lamont's calm demeanor and straight talk are some of his best traits. Lamont's willingness to fill in where he can and be flexible in his role make him an asset to the team.

Heather: How long have you worked at The Arc TN?

Lamont: I've worked at The Arc TN for 16 years.

Heather: What do you love most about your job?

Lamont: I love being able to help people and seeing the change in their lives.

Heather: Do you have any strategies for dealing with stress at work?

Lamont: I deal with stress by not taking things personal and also short weekend trips.

Heather: What do you think our future looks like as a team?

Lamont: I like to think the team will become closer and more collaborative.

Heather: What is something surprising that not many people know about you?

Lamont: You may not know that I love the Ballet.

Emily Whitson is our Exceptional Education Mentor/SPED Advocate here in the Middle region. Emily is extremely knowledgeable in her work and very dedicated to assuring families feel supported and informed while navigating the IEP process with their children. Emily and her daughter even starred in a video for The Arc Tennessee's 9/11 Day of Service efforts!

Heather: How long have you worked at The Arc TN?

Emily: 4 years – since 2019.

Heather: What do you love most about your job?

Emily: I love when I can help a family feel empowered to advocate for their child or help a student feel empowered to advocate for themselves.

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Chapter News continued

DEVELOPMENTAL SERVICES OF DICKSON COUNTY

Following six weeks of practice, the Dream With Me performers held their recitals and skit productions at the White Bluff Bibb Center.



DSDC hosted a celebration at Montgomery Bell State Park, recognizing the organization's 50 years of serving individuals with a disability in middle Tennessee. The event was well-attended by current and prior staff and board members, people served, and local supporters of the organization and its mission.

Find Your Local Chapter

Scan the QR code to find a list of local chapters across the state



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Shining the Light continued

Heather: Do you have any strategies for dealing with stress at work?

Emily: Listening to crime podcasts are my stress relief.

Heather: What do you think our future looks like as a team?

Emily: I would like to grow our special education advocacy team to be able to serve more areas across the state.

Heather: What is something surprising that not many people know about you?

Emily: I love to cook. As a kid, I would watch cooking shows on Saturday mornings instead of cartoons.



TRAVIS SAINE, REPRESENTATIVE MARY LITTLETON, ROBYN LAMPLEY, DSDC EXECUTIVE DIRECTOR, DONALD REDDEN, PICTURED AT DSDC 50TH ANNIVERSARY CELEBRATION

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Being included in the **Internet** is more important than ever for people with disabilities. Don't be left behind. The Training starts **Tuesday, October 10th (9am-10:30am CT)**. Each week will cover a different topic.

Come to the training to:

- ✓ **Meet new people**
- ✓ **Learn new things to do for fun, work, and school**
- ✓ **Stay in touch with friends and family**
- ✓ **Share information about things that are important to you**
- ✓ **Learn How to Stay Safe Online**

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for People with
Disabilities**

Each weeks topics:

- ✓ **10/10 Using Zoom and Videoconferencing**
- ✓ **10/17 Staying Safe on the Internet**
- ✓ **10/24 Email, Facebook, and Texting**
- ✓ **10/31 Having Fun and Recreation on the Internet**
- ✓ **11/7 How to Look for a Job or Volunteering online**
- ✓ **11/14 Building Friendships and Relationships**



Register at:

[https://bit.ly/
my_tech_for_all_training_TN](https://bit.ly/my_tech_for_all_training_TN)



This project is funded under a Grant Contract with the State of Tennessee, Department of Intellectual and Developmental Disabilities.

Coaching sessions are provided.

See the full schedule at:

🌐 www.facebook.com/mytechforall
🌐 [webpage: www.mytechforall.com](http://wwwpage: www.mytechforall.com)

For more information
email: mytechforall99@gmail.com



The Name of the Game!

BY FRANK MEEUWIS

People First is the name of our game.

What the name “People First” means to us: the real importance of relating and interacting with each other as people, persons, as fellow-humans—individuals—with joy and sorrow, with friends and families, and also experiencing the miracle of life! Naming the group People First is to educate non-members that we are not disabled, handicapped, crippled or ill—gosh darn we are YOUR brothers and sisters, daughters and sons, we are your family, and share so much more in common than differences from any diagnosis!

What we do: empower people with disabilities to have voices to address issues of equality that affect them. To empower people is to give them the skills and the access to the “stuff” to bring about change. We were founded in Tennessee in 1982, and our movement—our cause—has grown up now, just like the rest of the Millennial generation! In 1999 we scored a major victory with the US Supreme Court deciding in Olmstead that people with disabilities have a right to receive supports and services in the community rather than institutions! That victory led to TN Institution closure... and then another... but it still took nearly 17 years for Tennessee to close its last segregating-institution for disabled-people in 2016!

Now, People First TN is a little older and the world just keeps changing quicker and quicker. Trying to keep-up means changing with the times—staying flexible! But what is in our hearts stays the same! At People First TN we make sure to raise our hearts’ song, hold our heads high, and move confidently into our shared future of a better society with all people integrated, included and involved! People First TN supports members to raise each group’s involvement within their community, to bring their voices to the larger community, and to be an ambassador to promote inclusion, participation and—what I’ll call—persistent presence!

People First members don’t have to have a disability diagnosis—members just must believe in the dignity and equality of every person! Agree with that? Then please join us! Parents and teachers, aunts and uncles, police and firefighters, businesswomen and men, doctors, nurses, politicians and lawyers—People First welcomes and wants members who recognize the beauty in each individual, and who want to model the kindness, civility and mutual-respect that we all deserve! To become a member, scan this QR code - memberships start at just \$5!



Fall 2023



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Nashville, TN 37228-1213

Visit www.thearctn.org or scan the QR code to see if there is a local chapter in your area. You can join through your local chapter or as an at-large member of The Arc TN! If you have questions, please email membership@thearctn.org.



You can also complete the form below and mail to:
The Arc Tennessee, 545 Mainstream Drive, Suite 100, Nashville, TN 37228

Name _____

Address _____

City, State & Zip Code _____

Phone Number _____ Email _____

Check all that apply:

Enroll me as a member (please circle: \$5 Self-Advocate, \$15 Individual, \$25 Family)

Please accept this donation (in honor of _____)

**Make check payable to The Arc Tennessee or call
615-248-5878 ext: 317 to process membership dues or make a donation by phone.**