

SUMMER 2023



THE CONNECTION

OFFICIAL NEWSLETTER OF THE ARC TENNESSEE



Tennessee Disability MegaConference 2023 BACK IN PERSON IN NASHVILLE, TENNESSEE

by Ashley Coulter

On May 25, 2023, The Arc Tennessee welcomed over 260 attendees and 59 exhibitors to the 20th Tennessee Disability MegaConference. This year's event was held at the Loews Vanderbilt Hotel in Nashville, TN. The event was able to be in person for the first time since 2019, and it was so powerful to be back together. This year's theme was "Writing Your Own Story" and featured two superb keynote sessions supporting that theme! On Thursday, May 25th, Ivanova Smith shared her story that started in an orphanage in Latvia all the way to being a wife, mother, advocate, and speaker. On Friday, May 26th, a panel from the film, Truelove, joined us to share their stories and discuss the making of their documentary.

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IVANOVA SMITH SHARES HER STORY ON DAY ONE OF 2023'S MEGACONFERENCE

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TENNESSEE DISABILITY
MEGACONFERENCE 2023

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LEADERSHIP TEAM

ROBYN LAMPLEY
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HEATHER HENDERSON
ADVOCACY

ASHLEY COULTER
COMMUNICATIONS & PUBLIC
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Reflections On Mega

MESSAGE FROM BOARD PRESIDENT, KAREN DOWNER



Executive Committee members Karen Downer, Nikki Klumb, Robyn Lampley, & Linda Brown (not pictured, Jen Vogus)

Fiscal 23-24 year begins with new Leadership in the works as interviews for the Executive Director (ED) wind down in July. Heidi Haines transitions into her new role at the Rocky Mountain Down Syndrome Association – a great platform for her continued success in supporting the IDD community and close to her Colorado home. Meanwhile, the leadership team already in place at the Arc TN, continues their work uninterrupted under the direction of the Interim ED, Robyn Lampley. The Executive Committee expects that Robyn will ensure continued operations and provide a smooth transition for the new ED.

Mega Conference – Writing Your Own Story was the perfect transition into this new fiscal year. Keynote speaker Ivanova Smith began her life as an infant in an orphanage in Latvia. Notwithstanding her inability to speak and a later diagnosis of autism, she went on to prove by hard work and support from her adoptive American family, that she would write her own fantastic story. Ivanova is now a working parent of two - making huge contributions through her work as Self Advocate Faculty for the University of Washington Leadership Education in Neurodevelopmental and related Disabilities. She holds leadership roles on several state and national committees, Boards and Councils and through her speaking engagements across the country she is able to inform and influence so many of us. She was a LOT of exuberant inspiration!

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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 April 1 through June 27, 2023.

**KEVIN EDWARDS
ADELE DUNKIN
GLENDA BOND
SHONTIE BROWN**

**CHARLES HOBBS
WANDA REESE
MALEESA FLEENOR
SUSAN MCGRATH**

**KRISTIE IRVIN
DOWN SYNDROME ASSOCIATION
WORDCRAFTS**

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.



Reflections On Mega continued

Mega reminded me that we have come such a long way since the days of separation, seclusion, restraints, over-medication, and institutionalization. We are on a path of person centered thinking, self-advocacy, home and community based living as well as improving education and access to enabling technology. Are we there yet? Well NO, but because we ARE headed in the right direction, the possibilities as well as the work needed to achieve a better state will just continue to unfold in front of us.

My sister Mindy achieved the milestone age of 65 this year. She was deinstitutionalized only 7 years ago after 48 years of living at a state developmental center hundreds of miles from her childhood home. She now resides in an Intermediate Care Facility (ICF), which is a home near me in Chattanooga. She is very much in charge of her immediate household. Just ask her house manager. Her providers work very hard to support her life in her new home environment. Mega reminded me again of the critical role DSPs have in this community. It also reminded me that navigating benefit delivery systems while they are evolving is hard ...too hard. Lack of services, underpaid service providers, and inadequate medical supports continue to plague home and community based living. Culture change is a slow thing. Improving government policies, programs, regulations, rules and budgets is even slower. The leadership team at work at the Arc TN is very effectively executing the current system always with an emphasis on identifying and communicating improvements. Mega overall really slammed home for me that persistence continues to be our best weapon in this overall journey. Stay the course. Inform, influence and persist -- we are headed in the right direction. I look forward to being the Board President in the upcoming year.

-Karen Downey



The Arc Tennessee Awards 2023

BY ASHLEY COULTER

The Arc Tennessee annual awards event was held in Nashville on Wednesday, May 24th at the Loews Vanderbilt Hotel. More than 150 people gathered to recognize and celebrate all of our outstanding winners. Awards were given out by The Arc TN, TN Support & Training for Exceptional Parents (TNSTEP), and Employment & Community First CHOICES program.

TNSTEP Wayne Parker Advocate of the Year



Ericka Barrett

TNSTEP Wesley Rice Youth Advocate of the Year



Calyn Baldrige

TNSTEP Scott Finney Self-Advocate of the Year



Tabitha Lents

The Arc TN DSP Above & Beyond Award Winner



Katie Odom

The Arc TN Exemplary Educator of the Year



Sheila Carnes

The Arc TN Work Initiative Award Winner



D'Andre Crabtree

The Arc TN Public Awareness Award Winner



Marsh Naidoo

The Arc TN Inclusive Employer Award Winner



PriceLess Foods of Crossville - IGA



The Arc Tennessee Agency of Distinction Award winner, the Down Syndrome Association of Middle Tennessee

Awards *continued*

We had a record-breaking number of nominations this year! Public Awareness & Awards Committee members voted to select this year's winners and we were thrilled to celebrate. Senator Paul Bailey and Representative Kirk Haston were named winners of The Arc Tennessee's Legislative Award (not pictured). Bella Paul Hartwig was awarded The Arc Tennessee's Promising Young Leader award and The Ruth Roberts Sibling Award was given to Mary Lampugnano (not pictured). This year's winner for The Arc Tennessee Agency of Distinction was the Down Syndrome Association of Middle Tennessee (pictured above).

**The Arc TN
The Jake Award
Winner**



Linda Brown

**The Arc TN
Community Service
Award Winner**



Kaleena Smith

**The Arc TN
Self-Determination
Award Winner**



**Greyson Daniel
Jennings**

**The Arc TN
Medical Professional
of the Year**



Thomas Allingham, DO

**The Arc TN
Outstanding Therapist
of the Year**



Carol Matherly

**The Arc TN
Presidential Award
Winner**



Doria Panvini

**Roger Blue Award
Winner**



Carol Westlake



Awards continued

**Employment & Community First (ECF) CHOICES
Direct Support Professional (DSP) Award Winners**

Community Connector from East TN



Antonio Moore

Employment Champion from Middle TN



Amy Morris

Employment Champion from East TN



Shelby Shults

Other award winners (not pictured)

Community Connector from Middle TN & Rising Star Award Winner: Kelly Jackson

Community Connector from West TN: Alesha Gooch

Employment Champion from West TN: Crystal Dantzler

MegaConference continued

Attendees had a variety of breakout sessions to choose from including future planning, supported decision making, ECF CHOICES, and enabling technology. On Thursday night, attendees joined DJ Jackson for the highly anticipated dance! Our own Scott Finney got to help in the DJ booth! This year's conference offered opportunities to learn, network, and connect. We want to thank the sponsors for this year's MegaConference: Department of Human Services - Vocational Rehabilitation Services, The Arc Tennessee, Amerigroup Tennessee, TN Council on Developmental Disabilities, BlueCare of Tennessee, BNA - Nashville International Airport, TNCO, Pinnacle Bank, The Arc of Coffee & Moore Counties, Disability Rights TN, United Healthcare, Tennessee Relay, TNSTEP, Del Mar Medical, and ZenBusiness. More photos from this year's event can be found on page 11 of the newsletter!



TRUELOVE PANELISTS GLANCEY HOPPER, PHIL VIARDO, CHRIS KNIGHT, & CALLIE TRUELOVE



Chapter News

Activities and information from our local chapters

DEVELOPMENTAL SERVICES OF DICKSON COUNTY

Developmental Services partnered with the DCHS Lady Cougars to host a second annual basketball camp – fun was had by all! And People First hosted a table at MegaConference and enjoyed time with friends old and new.



THE ARC ANDERSON COUNTY

Will Johnson and his parents, Steve and Kelly, are the entrepreneurs behind Sweet Will’s Treats. The business is conducted from their boat where they deliver ice cream to summertime lake lovers in Norris, TN. The buoyant business was born from the idea of keeping Will connected with his community after he graduated from high school. Will was diagnosed with autism at an early age and his family was looking for opportunities to keep him engaged in meaningful social and recreational activities. What started as an avenue for Will to continue his involvement within the community soon grew into a way to aid other organizations in the area. The money raised through the Johnson family’s floating ice cream shop goes to support the non-profit they helped create called Open Doors Tennessee. This organization assists people with disabilities. They didn’t stop there though. The business has been so successful they have made donations to other area agencies that also support individuals with intellectual and developmental disabilities (I/DD). One of those agencies is The Arc Anderson County. Will and his family made a \$500 donation in support of The Arc’s Graduate Program. This program offers the tools and opportunities to foster personal growth to individuals with I/DD. Much like Will’s ice cream venture, the Graduate Program allows participants to develop their real-world skills through activities and volunteerism in the community.



Pictured top right: James Lampley goes in for a layup at basketball camp. Pictured bottom right: Christine Theofanopoulous and Richard Streck at the People First table at this year's MegaConference.

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FREE

Special Education Advocacy Training & Self-Determination Toolkits for Families and Students!



Free Special Education Advocacy Training

Learn about the special education system including early intervention services, individualized education programs (IEPs), Section 504, and more with:

- self-paced on-line learning modules,
- group Zoom meetings led by SPED professionals, and
- additional resources from our Family Engagement Specialists.



Free Self-Determination Toolkits

Self-determination allows students to make decisions that improve their quality of life. These toolkits teach your child how to:

- know and believe in themselves,
- know what they want for their future and make a plan to get there, and
- know what help they need to take control of their life.

**For more information about these free resources,
scan the QR code below or contact us!**



**FAMILY ENGAGEMENT
IN SPECIAL EDUCATION**



Shining the Light on The Arc Tennessee Advocates: East TN

BY HEATHER HENDERSON

Over the next couple of Connection Newsletters I want to recognize and show appreciation to our Advocacy Team here at The Arc Tennessee, who go above and beyond to assure those with I/DD living in Tennessee are respected and given the opportunity for their voices to be heard. Advocacy is at the heart of all we do at The Arc and I believe that our Advocates' dedication deserves to be celebrated. This article aims to introduce and spotlight each of the Advocates in each of our grand regions. First up we have Billy Worsham. Billy is a Community Resource Specialist in East TN. He works with both Special Education Advocacy and Adult Advocacy as well as chairs the Statewide Planning and Policy Committee. His calming manner, positivity, and wonderful facilitation skills are just a few of the traits that we all admire.

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

Billy: This will be 5 years.

Heather: What do you love most about your job?

Billy: Watching people speak for themselves and thrive in their lives.

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

Billy: Take a step or two back, and try to look at the whole picture. Try to understand people and their ways of thinking and doing, while listening and learning.

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

Billy: I believe as the times get more challenging that our future presents many diversified opportunities to support people to adjust to the times while at the same time being enabled to make change happen.

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

Billy: I wanted to be a locomotive engineer.

Serving the Chattanooga area, we have Hal Baker. Though Hal is retired, he has continued his work in this field as a part-time Community Resource Specialist with us at The Arc TN. Hal has a wealth of knowledge and expertise and is a tremendous resource for all of us. Hal is always up for any challenge we may throw his way and is always ready and eager to learn.

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

Hal: My tenure with Arc TN is five years to this point. I joined in the spring of 2018 and look forward to more meaningful years in Advocacy, which is what gives me the greatest pleasure in the position I fill for the Southeast region of the State

Heather: What do you love most about your job?

Hal: The direct contact with individuals and families, working with them to get the services and supports they need or sometimes just listening to their situations and giving small encouragements and suggestions is very fulfilling at this stage of my career. Being able to focus on making situations better is quite rewarding, especially without the distractions which seem to accompany so many jobs today.

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

Hal: The Arc TN is proficient at keeping a focus on what is important in Advocacy which leads to a fairly stressless work environment, there are always Advocacy matters which are difficult and frustrating, however working with the team, when necessary, alleviates most of those situations.

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The Arc TN Vaccine Grant

BY FRANK MEEUWIS

WHAT IS YOUR WHY?



#FVwhatisyourwhy



We are excited to launch a new, COVID-19 Easy to Read Hub with a suite of accessible and interactive materials for people with intellectual and developmental disabilities and their care providers. The risk of COVID-19 is not over and CDC is committed to providing up-to-date resources for people with intellectual and developmental disabilities so they can continue to stay safe. To access the materials online, please scan the provided QR code.



Chapter News continued from page 7

THE ARC ANDERSON COUNTY

Individuals with disabilities can contribute their time and talents to occupy valued roles within their communities and Will is on a mission to prove that one ice cream cone at a time. For more information on Will and his family business, please visit the Sweet Will's Treats "Make Life Sweet" Facebook page.



Pictured left to right: Ruth Brown, Zach Smiddy, D'Andre Crabtree, Andrew Ryan, Autumn Davis, Melanie Stanley, Will Johnson, Steve Johnson, Nikki Davis, Katie Odom

The Arc Anderson County will host our annual Dove Awards Banquet on Friday, July 28th at 6PM at Emory Valley Center located at 723 Emory Valley Road in Oak Ridge, TN. This event recognizes individuals that have exhibited exceptional support to those with intellectual and developmental disabilities (I/DD). Tickets are now on sale for \$20 each. Call 865-685-0159 or email arc@arcaid.org to reserve your tickets. There will be music, food, and fun!

Shining the Light continued from Page 9

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

Hal: The collegial atmosphere and experience within the group of Advocates lends itself to a resolution based system that is sure to have continual success for individuals and families.

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

Hal: I reflect on the years when I first worked for The Arc, (1969-70) as a part time recreation and employment specialist in Florida and count this as a wonderful bookend to a career.



People First Update

BY FRANK MEEUWIS

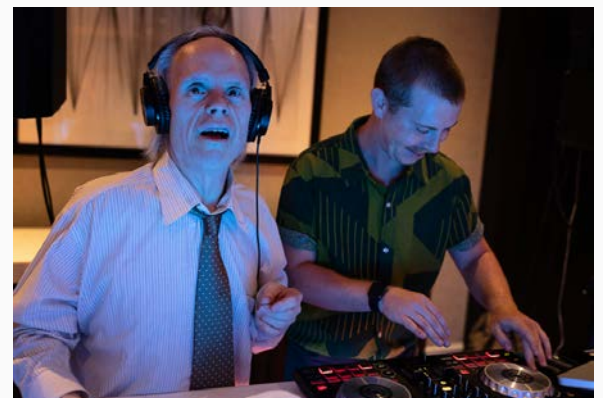
Summer is here, and people are lovin' it! People First kicked off the summer at May's Annual Tennessee Disability MegaConference in Nashville!

This was the first year back in person and face-to-face in the hotel... and what a hotel indeed! This was the first time at the iconic, award-winning Loews Vanderbilt Hotel. (Did I mention that a Rock-legend—Led Zeppelin's Jimmy Page—walked through the lobby while I first visited?)

We had an Exhibit Booth in the conference hall, right beside People First Davidson County's Joey Williams and Williamson County chapter member's Chris and mom Angela Braach. A PowerPoint slideshow highlighting the Dickson County Chapter scrolled through activities that People First has been doing in their local community. One example, they did a 9/11 project making tote bags with "Never Forgotten" on the bag and inside bottled water with Chapter info. The bags went to more than 20 places. For another project, they had established a relationship with their local Head-Start program and dressed up as Superheroes to give out goodie-bags to children at the program! These are just two examples of People First starting community involvement, and here is the formula:

1. Create and include a card with contact info for your group
2. Distribute favors or swag with your card. "Favors" or swag can be anything inexpensive because "It's the thought that counts."
3. Sit back and collect on the communal goodwill that you've started! (What happens is the psychological concept of reciprocity, which is that we are hard-wired to respond positively to a gift, even if we didn't ask for it, or even want it. We automatically feel indebted to the giver, regardless. Your group will have started a "giving loop" demonstrating the importance of giving back to your community!)

People First is developing plans to meet with groups across Tennessee this summer to see about implementing similar successful ideas in new areas with new groups of people across the state!



Summer 2023



The Arc[™]

Tennessee

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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.**