

What your family has done for us is hard to put into words. Here's a shot. You put air back into our lungs, hope into our hearts, most important the fight back into our spirit. Not only that, you gave us the key to unlock any lock. You gave us information, educated us, and brought families together. You should be so proud of what your family has done for families in need of help.

-Parent Participant



For 10 years, families of young children with autism spectrum disorder have taken part in free monthly Saturday morning workshops that provide them with practical information to help them support their child's development and learning. Families find these workshops so worthwhile that many drive long distances to take part—and more recently, these workshops also are being livestreamed to other sites in Tennessee and other states to reach more families. Families First is a core program of the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorder (TRIAD). TRIAD is committed to providing exemplary autism-specific research, direct service, and training to individuals with autism spectrum disorders (ASD), their families, and service providers.



# WHAT IS AUTISM SPECTRUM DISORDER?

Autism spectrum disorder (ASD) is a complex brain-based disorder that affects multiple areas of development, including social interaction, verbal and nonverbal communication, play, behavior, and interests. Its symptoms show up early in life, sometimes in infancy, but generally before 3 years of age.

### WHY EARLY HELP MATTERS

We know from research that early intervention is key—and training parents and other caregivers is an essential component. When a child is diagnosed with ASD, caregivers often report feeling overwhelmed and frustrated at the task of securing services. These feelings often stem from lack of funding or insurance coverage for these services, an insufficient number of specialized providers, a waitlist for available services, and intervention models that often do not incorporate caregivers in meaningful ways. Caregivers' search for these services often results in feelings of isolation from parents of typically developing children who may not be experiencing similar obstacles.

Seeing that families of young children with ASD needed information and support, in 2008, TRIAD launched a high-quality workshop program committed to training caregivers of young children with ASD in a way that removes traditional barriers to service access. Philanthropists Ann and Monroe Carell, Jr. provided a founding gift.

## WHAT FAMILIES LEARN

Families First focuses on equipping caregivers with practical tools to support their child, to provide resources to more easily apply strategy and planning ideas, and to give caregivers an opportunity to meet other caregivers with similar questions or concerns.

Families First's purpose is two-fold:

- to empower caregivers with strategies that enable them to capitalize on their child's strengths in helping their child meet the child's full potential, and
- to provide a network of support.

I have felt (and sometimes still feel) like I am drowning in a sea of information about how to help my son. Even supermom could not do it all. Your course helped me learn to set small, attainable goals. It gave me hope that this is something I can do at home to help my child succeed. It gave me many of the tools I'll need to get started helping now! With all the expensive therapies we are investigating, I can hardly believe this is free. Thank, thank, thank you–so grateful!

# -Parent Participant

Families First began through a base model of free live monthly workshops focused on providing caregivers with practical tools to address common goal areas for their child following diagnosis. This base model has been continually refined to meet the needs of the caregivers served by presenting the information in an engaging and interactive way, which results in caregivers leaving the workshop with a clear action plan and supporting materials to implement their individualized plan.

Workshops cover topics of practical value to families, including addressing challenges with behavior, toilet training, sleep, mealtime, and community outings; and developing communication, social, play, self-help, and safety skills.

Families First provides families with free child care by staff and student volunteers in a preschool setting. This allows families to attend who may not feel comfortable with or cannot afford to leave their children with others.

# EXPANDING THE REACH OF FAMILIES FIRST

As the use of telehealth, telemedicine, and online learning has increased, Families First sought to use these strategies to increase the reach of the base program while still maintaining the overall goal and quality of the programming. Initially, the two most popular topic areas were packaged into two series of 12 brief online training modules. These are available to caregivers who are unable to or who are uncomfortable with attending a live workshop. Caregivers who attend a live workshop also can use the online modules as a refresher and/or to share this information with others in their child's life.



Families First has meant a lot to me because when my oldest grandson was diagnosed with autism, we didn't know where to turn. So, we heard about Families First and we said, let's go see what it's all about, and we have been coming ever since. I have gotten to meet others. We have become friends. I see what they go through, and I go 'maybe this will help me.' So, I don't feel quite so alone as I did when I first started coming to Families First. I don't feel like I'm the only one and I'm not alone.

-Grandparent of 3- and 4-year-olds with ASD



I have read so many articles, and talked with other 'Autism Moms' over the last few years regarding potty training. I have learned so much more than I expected today. I am excited to use my new plan.

-Parent

In addition to the live workshop model and online training modules, TRIAD created a livestream model. The high-quality live model is livestreamed to remote sites at places where caregivers are able to interact with other caregivers in their local areas with

similar questions and needs. They have access to a professional contact at those livestream sites to help individualize the information for their communities and individual participants. They also receive the same hands-on, make-ittake-it materials.







TRIAD initially created the livestream model to provide access for parents across Tennessee and the region who historically had to travel long distances to attend the live workshops, particularly families in rural, low-resource, and traditionally underserved communities. This model now has been extended nationally to partners in other areas of the country who have identified the need for this type of programming. Families First currently has 9 livestream sites. TRIAD also has initiated train-the-trainer programming with selected partners, e.g., providers with the Tennessee Early Intervention System, leaders of Tennessee Disability Pathfinder support groups for families, and even providers in Trinidad.

Over its 10-year history Families First has had over 4,000 caregivers attend live workshops and livestream sites. Participants have come from 109 counties and 9 states.

## THE VISION OF FAMILIES FIRST

The goals of Families First are rooted in an effort to achieve inclusive communities, both for young children with autism spectrum disorder and their families, by providing practical strategies to promote successful home routines and community outings. By promoting such routines and activities at a young



age, the ultimate goal is to help set young children with ASD on a trajectory of meaningful inclusion throughout their childhood and adulthood. We are excited to continue to see where this program will go. We are so thankful for all who have been a part of it!

### ABOUT US

Founded in 1965, the mission of the Vanderbilt Kennedy Center for Research on Human Development is to facilitate discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families. The Center brings together scientists and practitioners in behavior, education, genetics, and neuroscience to work together to solve the mysteries of development and learning. For information, see vkc.vumc.org.

Founded in 1998, TRIAD's mission is to improve assessment and treatment services for children with autism spectrum disorder and their families while advancing knowledge and training. TRIAD clinical and outreach teams offer diagnostic assessment, parent workshops, and other services to families with children who have or are suspected of having ASD.TRIAD provides training and consultation in behavioral and educational assessment and intervention strategies for school personnel, community professionals, and pediatric care providers. TRIAD partners with community organizations to build capacity for the inclusion of individuals with ASD or related disorders. For information, see triad.vumc.org.

#### **GEOGRAPHIC DISTRIBUTION OF PARTICIPATING FAMILIES IN TENNESSEE**



#### FAMILIES FIRST PROGRAM FAMILY PARTICIPANT SUMMARY

States and Number of Counties Served		
Alabama = 14	Mississippi = 2	South Carolina = 1
Georgia = 8	New Mexico = 7	Tennessee = 109
Kentucky = 15	Ohio = 1	Texas = 4

# PARTICIPANT COMMENTS

I think this was beneficial to me because I rarely get time to talk to a therapist about how and why things work.

Practical materials I can use right away! To go get materials and prep is incredibly hard. What a gift to have this done for me, this will help my family so much.

It was exactly what I needed. It showed real life problems and gave/showed real life examples of how to start changing them.

> Ideas of how to look at things from my son's point of view.



Being in the presence of a provider who exhibits joy and enthusiasm-a person who expresses optimism for our children's futuremeans the world.

Extremely informative-feel like I can start this with success now that I have a foundation for the tools to do it.

What I loved most about today's training was how applicable it was. The information provided will impact our families in a very tangible way. Those are the types of trainings that are needed!

I love meeting other parents and professionals that have that understanding of what both myself and my child are going through.