

Family-to-Family Health Information Center Symposium: Uniting Healthcare, Advocacy, and Disability

Virtual Conference | September 17, 2024

9:30 - 10:00 am **Welcome and Introduction to Family-to-Family and The Arc of Illinois**
presented by Susan Agrawal, PhD

10:00 - 11:00 am **Navigating the Caregiver Continuum: From Diagnosis to Advocacy**
Presented by Erica Stearns and Alyssa Nutile

This presentation introduces the "caregiver continuum," a framework that guides us through the various phases of caregiving, from the initial shock of diagnosis to the complexities of long-term care. We'll explore how caregivers' needs, challenges, and advocacy evolve, and advocacy and discuss strategies for maintaining mental resilience. You'll gain crucial insights into delivering personalized support that enhances the well-being of both caregivers and their families, fostering a healthier, better-informed caregiving community.

11:00 - 11:15 am **Break**

11:15 am - 12:15 pm **An Overview of The Autism Program of Illinois (TAP)**
Presented by Shannon Dyson, TAP Director, and Sarah Anderson, TAP Training Coordinator

This presentation will provide an overview of The Autism Program of Illinois (TAP), a grant funded by the Illinois Department of Human Services. TAP serves and supports persons with autism, their families and communities through a coordinated network of providers and university programs while developing, utilizing and sharing best and promising practices. The TAP network providers include 5 university programs and 9 organizations located throughout the state of Illinois.

12:15 - 1:00 pm **Lunch Break**

1:00 - 2:00 pm **Children's Medicaid Waivers and Paid Parent Caregiving**
Presented by Susan Agrawal, PhD

During the pandemic, paying parents for care became much more widespread. How is it working now in Illinois? First, I will outline the Medicaid programs and waivers available for children under age 22 in Illinois. Next, I will describe which Illinois programs pay parents for caring for children and adults with disabilities. I will conclude with a call to action for improving home and community based services and paid parent caregiving in Illinois.

2:00 - 2:30 pm **Advocacy in Action** **Presented by Stephanie Salinas and Mary Otts-Rubenstein**

Advocacy in Action will feature two parent advocates discussing how small actions in advocacy led to tremendous assistance to families. Stephanie Salinas describes how her idea to bring a program to pay parents for CNA-level care became a law. Mary Otts-Rubenstein will talk about how she became involved in helping migrant children with disabilities to access services and benefits they desperately need.

2:30 - 2:45 pm **Break**

2:45 - 3:45 pm **Effective Individualized Education Plans: Medical Support and Resources**
Presented by Megan Mutti, MA, Director, Family Matters

Navigating the IEP process can be challenging, and is made even more difficult when your child has medical complexities. Join Family Matters PTIC as we explore resources and supports that can assist you in ensuring that your child's needs are safely and effectively met within the school environment.

3:45 - 4:00 pm **Closing Remarks**

ABOUT THE PRESENTERS

Susan Agrawal

Susan is a parent, advocate, and writer who began serving as the Director of the Family-to-Family Health (F2F) Information Center in 2024, assisting families of children and young adults with disabilities and special healthcare needs to navigate the health care and disability systems in Illinois. She has lived experience through her daughter Karuna, who had multiple disabilities and complex health issues throughout her eleven years of life. Susan is the founder of MFTD Waiver Families and spent more than a decade advocating for children in the Medically Fragile Technology Dependent Waiver. In addition, she is an independent researcher on children's Medicaid waivers and programs, including the website Kids' Waivers.

Sarah Anderson

Sarah holds a bachelor's degree in communications, with a minor in psychology, from Southern Illinois University at Carbondale, as well as an associate's degree in applied science, occupational therapy assistant from Lincoln Land Community College. She has experience working with children with autism in school and therapy settings. For the past 6 years, Sarah has provided healthcare management and occupational therapy at rehabilitation clinics. In addition to her professional experience, Sarah has had a great depth of personal experience through advocating for her son, who was diagnosed with autism at age 8 and is now an adult.

Shannon Dyson

Shannon holds a bachelor's and master's degree in psychology from Southern Illinois University Edwardsville and a Doctorate degree in School Psychology from the University of Iowa. She completed her predoctoral internship at the Marcus Autism Center in Atlanta, Georgia. She also managed day treatment services for the Complex Behavior Program at the Center for Autism Spectrum Disorders at Nationwide Children's Hospital in Columbus, Ohio. She joined TAP in 2019 bringing with her extensive clinical experience and knowledge about children and adolescents diagnosed with severe behavior disorders, autism, and other developmental disabilities.

Megan Mutti

Megan is the Executive Director of Family Matters Parent Training Center. She was most recently a member of the Ligas Family Advocate Team at the Arc of Illinois. Megan is a 2023 graduate of the Illinois Partners in Policymaking Program and a 2020 graduate of the LEND Program at UIC, where she participated as a Family Fellow. Megan attended the University of Missouri-Columbia, where she completed both her BS and MA in Human Development and Family Studies. She spent many years as a member of the Pediatric Supportive Care Team at Children's Hospital of Illinois, where she focused on patient and family-centered care. Megan, who resides in Germantown Hills, IL, is the mom to two daughters, one of whom is a young adult with autism and an intellectual disability.

Alyssa Nutile

Alyssa is a writer, researcher, and media producer. She serves as the operations manager for Wild Home Podcasting, the media producer for The Rare Life podcast, and co-founder of Caffeinated Caregivers. Her introduction to the world of caregiving began with her daughter G's diagnosis in 2019. Alyssa balances family life, career, and the challenges of parenting two children, one of whom has a disability. Her personal experience navigating her own disability as well as those of her daughter inform her professional work and advocacy efforts.

Mary Otts-Rubenstein

Mary is a parent caregiver living in Chicago. She currently channels her past experience as a project manager and head of multiple award-winning nonprofit organizations into knocking down the obstacles in caring for a medically fragile and disabled child. Mary is passionate about peer-to-peer mentorship and graciously learns from Queer and/or disabled folks about the primacy of healthcare as a human right. Recently this has been channeled into orienting families arriving in Chicago from Central and South America in order to access basic healthcare and education for their disabled children in the midst of crises in their home countries

Stephanie Salinas

Erica Stearns

Erica is a researcher passionate about the power of personal narratives in disability advocacy. She is the creator and host of the Atypical Truth podcast and co-founder of Caffeinated Caregivers. As a mother of two children with a rare genetic disorder and having been born with rare birth defects herself, Erica brings a unique dual perspective to her work. Driven by her own personal experiences, she provides peer support to caregivers of children with medical complexities through the University of Illinois Chicago, Division of Specialized Care for Children.

COST & REGISTRATION

Virtual Conference
September 17, 2024
9:30 a.m. to 4 p.m.

Registration Fees for Participants are:

The Arc of Illinois Members:

Professional.....\$80.00
Self-Advocate/Family Member.....\$20.00

Non Members of The Arc of Illinois:

Professional.....\$140.00
Self-Advocate/Family Member.....\$55.00

Groups of more than 7 from one agency are entitled to a 10% discount. Please complete the attached registration form, fax it to 815-464-5292, then mail the hard copy along with your check to:

The Arc of Illinois
9980 190th St, Suite C
Mokena, IL 60448
815-464-1832

SPECIAL ACCOMODATIONS:

CEUs

CEUs will be offered for this training. Licensed Social Workers, Licensed Nursing Home Administrators and QIDP's signing in and out on the day of the event are entitled to five (5) credits.

CANCELLATIONS & REFUNDS

Participants canceling their registration 72 hours in advance will be entitled to a credit or refund, less a \$25.00 administrative cost. No refund or credit will be given for cancellation less than 72 hours before the seminar.

REGISTRATION FORM

**Family-to-Family Health Information
Center Symposium**
September 17, 2024

One form per person, please print legibly.

Name: _____

Job Title: _____

Agency: _____

Address: _____

City: _____

State: _____ **Zip:** _____

Phone: _____

E-mail: _____

ACCOUNT PAYABLE: _____

METHOD OF PAYMENT:

____ Fax form and mail check to The Arc of Illinois
(815-464-5292)

____ Check enclosed payable to The Arc of Illinois

____ P.O. or State Voucher #

____ Charge to my Credit Card

Name as it appears on credit card:

Credit Card Number: _____

Expiration Date: _____ **CVV Code:** _____

Billing Zip Code: _____

Card holder's signature:



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Register for the 2024
F2F Health Information
Center/ILS Monthly
Webinars for additional
topics!

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This event will be
held
VIRTUALLY