



Family-to-Family Health Information Center Symposium: Uniting Healthcare, Advocacy, and Disability VIRTUAL CONFERENCE | OCTOBER 7, 2025

AGENDA

9:15 – 9:30 AM Welcome and Introduction to Family-to-Family and The Arc of Illinois

Presented by Samantha Alloway, Executive Director; Susan Agrawal, Director of Family-to-Family; and staff members of The Arc of Illinois

9:30 – 10:30 AM From Hospital Rooms to Hashtags: Reimagining Caregiver Advocacy Through Social Media

Presented by Erica Stearns and Alyssa Nutile

In this session, Alyssa and Erica of Caffeinated Caregivers will share their journey into disability advocacy through social media as disabled caregivers of children who are medically complex. They'll discuss the gaps they noticed in online spaces, how their connection sparked a shared mission, and the creation of content rooted in humor, honesty, and the kinds of conversations they felt were missing. Grounded in the belief that caregivers are the lived experience, the connection, and the resources, they'll reflect on how storytelling, mutual support, and collaboration with allies can drive lasting change, and how digital platforms can amplify that advocacy like never before.

10:30 – 10:45 AM Break

10:45 – 11:45 AM Caring for Caregivers

Presented by Denice Rhodes, Caregivers Safe Space

This presentation will explore the emotional and physical impact of caregiving; the importance of safe spaces for caregivers; mindset, movement, and mental wellness; building a support system; and sustainable self-care without guilt.

11:45 AM – 12:30 PM: Lunch Break

12:30 – 1:30 PM Updates to Medicaid, Medicaid Waivers, and Family Caregiving

Presented by Susan Agrawal, PhD

We are all understandably concerned about cuts to Medicaid. In this presentation, participants will learn how Medicaid waivers work in Illinois, including which waivers offer paid family caregiving. Building on this foundation, this presentation provides an overview of how Medicaid changes may affect those in Illinois who are either enrolled in a waiver or waiting for a spot.

1:30 – 2:30 PM Charting the LifeCourse: The Basics

Presented by Megan Mutti, Director, Family Matters Parent Training and Information Center
Charting the LifeCourse (CtLC) framework and tools help you organize your ideas, vision, and goals, as well as problem-solve, navigate and advocate for supports. In many states, CtLC is used for person-centered planning in disability programs. In this presentation, participants will learn three key CtLC principles, how to complete a One-Page Description or Life Trajectory using a sample or personal example, and understand how to use a CtLC tool in their work.

2:30 – 2:45 PM Break

2:45 – 3:45 PM Appealing Illinois Department of Human Services Medicaid Decisions

Presented by Steve Scheuer, Legal Aid Chicago

The presentation will cover the process of filing a Medicaid administrative appeal with the Illinois Department of Human Services. Attendees will learn: 1) circumstances under which a Medicaid administrative appeal should be filed, 2) differences between a grievance and appeal with a Managed Care Organization, 3) methods to resolve the dispute prior to a Medicaid administrative hearing, 4) best practices in a Medicaid administrative hearing.

3:45 – 4:00 PM Closing Remarks

ABOUT THE PRESENTERS

Susan Agrawal, PhD

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.

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. She is the parent to an adult daughter, Annie, who lives with autism and intellectual disabilities.

Alyssa Nutile

Alyssa Nutile 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.

Denice Rhodes

Denice Rhodes is the CEO and Founder of Caregivers Safe Space, a community dedicated to supporting those who care for others. With over 37 years of caregiving experience, she brings compassion, wisdom, and advocacy to the forefront. Denice is passionate about promoting mental wellness, connection, and self-care for caregivers everywhere.

Steve Scheur

Steve Scheuer is a Supervisory Attorney in the Public Benefits Practice Group at Legal Aid Chicago. His practice focuses on access to public benefits, including Medicaid, SNAP, TANF, AABD Cash, and Social Security. He represents clients in administrative hearings before the Illinois Department of Human Services and the Social Security Administration.

Erica Stearns

Erica Stearns 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

October 7, 2025
9:15 AM to 4:00 PM

Registration Fees for Participants are:

The Arc of Illinois Members:

Professional.....\$80.00
Self-Advocate/Family Member.....\$10.00

Non Members of The Arc of Illinois:

Professional.....\$140.00
Self-Advocate/Family Member.....\$40.00

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
7550 183rd Street
Tinley Park, IL 60477

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
October 7, 2025

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:



Family to Family Health
Information Center

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October 7, 2025

**This event will be held
VIRTUALLY**

The Arc
Illinois

**CHECK OUT
OUR OTHER EVENTS!**

**REGISTER
TODAY!**

SCAN TO REGISTER

qr.link/5o4OjY

A large blue circle contains the text 'CHECK OUT OUR OTHER EVENTS!' in bold yellow and white. Below the text is a megaphone icon with yellow lightning bolts. To the right of the circle is a black speech bubble with 'REGISTER TODAY!' in white. Below the speech bubble is a QR code with 'SCAN TO REGISTER' written below it. At the bottom right of the graphic is the URL 'qr.link/5o4OjY' in orange.