

Uniting Healthcare, Advocacy, and Disability

Family-to-Family
Health Information Center
Symposium

September 17, 2024





Welcome!

You can access the slides for all the presentations on the Symposium page. A link will be provided in the chat.

The symposium is being recorded. You will be able to access the recordings in a few days on the Symposium page.

Closed Captioning is enabled and available in English or Spanish through StreamText. We will provide a link in the chat.

Please provide us your feedback on our survey that will be provided via email. Professionals who want to receive CEUs MUST fill out the survey.

Please be respectful of our speakers and moderators. We encourage the respectful exchange of ideas through the chat function. Harassment or other disruptive behavior will not be tolerated. If, after a private warning, an attendee continues to behave in a manner that is disruptive to this event, The Arc of Illinois reserves the right to remove the attendee.

Questions and Comments?

Participants are
muted

If you want to
speak, please
raise your hand

Please put
Questions in
the Q & A box

Please put
Comments in
the Chat box



Today's Schedule: Morning

9:30-10:00: Welcome and Introduction to Family-to-Family and The Arc of Illinois

10:00-11:00: Navigating the Caregiver Continuum: From Diagnosis to Advocacy

Break 11:00-11:15

11:15-12:15: An Overview of The Autism Program of Illinois (TAP)



Today's Schedule: Lunch

Lunch break from
12:15-1:00



Today's Schedule: Afternoon

1:00-2:00: Children's Medicaid Waivers and Paid Parent Caregiving

2:00-2:30: Advocacy in Action

Break 2:30-2:45

2:45-3:45: Effective Individualized Education Plans: Medical Support and Resources

3:45-4:00: Concluding Remarks with our new ED Samantha Alloway

Logistics

You may log in
and log out
during breaks

CEUs are
available for
those who
preregistered



AMPLIFYING Impact.

Individual, Family, and Organizational Memberships Become a Member!

There's Strength in Numbers

Together we are more **powerful**. Together we have more **resources**. Together our individual actions create **momentum** for change.

Since 1950, The Arc of Illinois has been committed to empowering persons with disabilities to have full participation in community life through informed choices and they're able to do so with dignity.

Membership ensures crucial programs and services remain available to the people who need them and that disability no longer means lack of opportunity. Let's achieve, **together**.

Your membership contributes to the work of The Arc of Illinois. Because of members like you, The Arc of Illinois is able to support others in the community, continue to offer free webinars and resources, and have a louder voice in legislative advocacy.

(815) 464-1832

Mon - Thurs: 9:00am - 5:00pm | Fri: 9:00am - 4:00pm



Select Language ▾

JOIN US



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Events ▾

Resources ▾



DONATE

The Arc of Illinois

Advocating with individuals with
intellectual and developmental disabilities

Sign Up For Advocacy Updates

<https://www.thearcofil.org/join-us/>

SPEAK UP AND SPEAK OUT summit

October 9 - 11, 2024



Registration Open!

**SUSO 2024 will
be Virtual Only**

**SUSO 2025 will be
hybrid**

Questions?

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**Funded by The Illinois Council on
Developmental Disabilities**

Family-to-Family Health Information Center

Susan Agrawal, Director





What is the Family-to-Family Health Information Center?

Family-led program that helps other families and professionals to navigate healthcare and disability systems for children and youth

What is Family-to-Family?

Federal Grant Program

Part of a National Network of Family-to-Family Programs

Program of The Arc of Illinois

Staffed by family members who are trained to help other families

State Affiliate of Family Voices, a national family-led organization of families and friends of children/youth with disabilities and chronic medical conditions

Lived Experience is Our Foundation

Parent of a child who was medically complex

Diagnoses

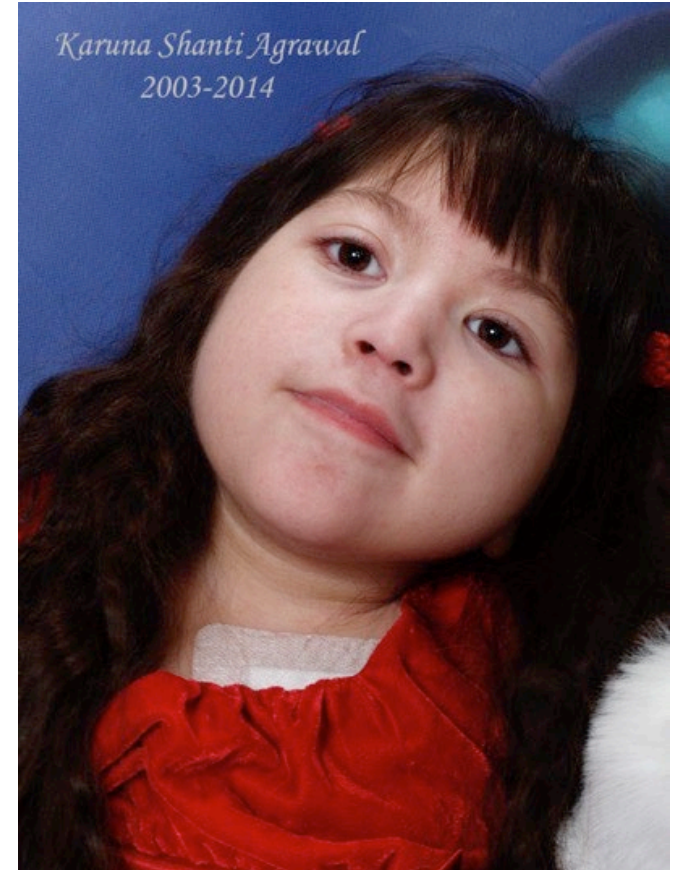
- Cerebral Palsy
- Autoimmune Disease

Technology

- Vent
- Central Line
- IV Nutrition
- Feeding Tube
- Oxygen
- Foley Catheter

Needed Services

- Home Nursing
- Palliative Care
- Education
- Care Coordination



Who Does Family-to-Family Serve?



Children and youth with specific health care needs and disabilities from birth through age 21



Their families



Professionals who care for them



Who Do We Serve?

Children with ANY specific health care need, disability, or chronic condition

- Physical disability
- Developmental delay or intellectual disability
- Behavioral condition or severe emotional disturbance
- Genetic or congenital condition
- Autism
- Technology dependent
- Chronic conditions like asthma, diabetes, sickle cell
- Deaf or blind

Some of the Things We Do



Individual
consultations
with families



Individual
consultations
with
professionals



Webinar
trainings and
virtual
conference



Outreach
visits to
schools,
programs,
hospitals



Outreach
trainings on
program or
topics

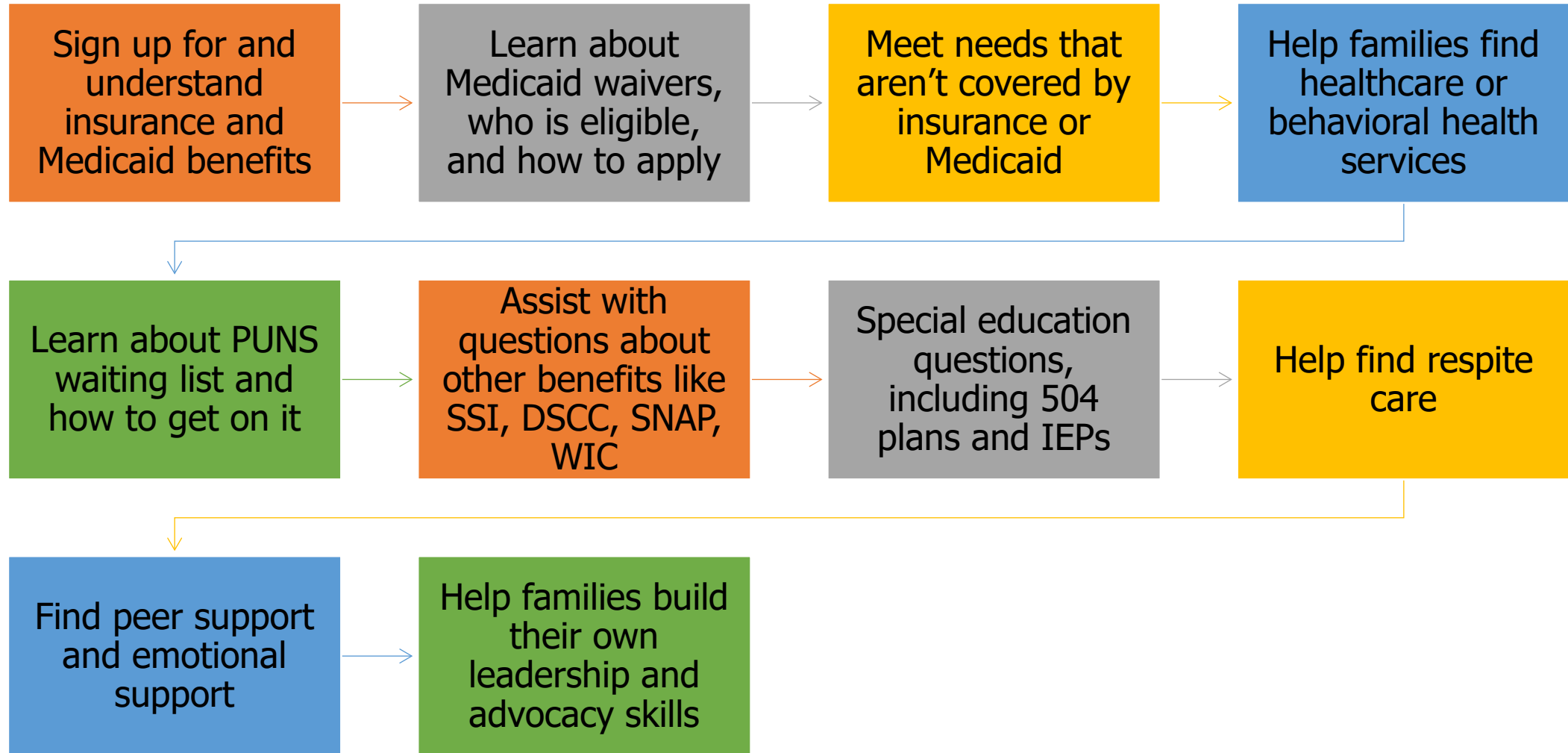


Collaboration
with
organizations,
agencies,
providers

All regular services are free!



Helping Families Navigate Healthcare and Disability Systems



When Should Professionals Call Us or Refer to Us?



Whenever you need information beyond your own expertise



Whenever you are not permitted to provide the type of help necessary



When the case is too complicated or large in scope



When a case does not require your specific expertise



When a family mostly needs a listening ear



When a family needs to talk to someone with lived experience

Other Arc of IL Programs



Illinois Life Span



Family Advocate
Program and
Family Support
Network



Family Transition
Program



Going Home
Coalition and REV
UP Illinois





Illinois Life Span

- Assistance to those with Intellectual and Developmental Disabilities
- From birth through the entire life span
- Questions when they focus on Intellectual and Developmental Disabilities



Family Advocate Program and Family Support Network



Family Advocate Program

Assistance to adults who have been selected from the PUNS list who are Ligas Class Members



Family Support Network

Help for those with ID/DD to live and thrive in the community



Family Transition Program

Assists individuals living in institutions to transition to the community

Mentorship from individuals who have transitioned to the community



Going Home Coalition and REV UP Illinois

Going Home Coalition

- Diverse statewide network of self-advocates, families, community service providers, and allies
- Advocate for Systems Change to transition away from institutional living
- Empower fair and equal choices and opportunities for people with intellectual and developmental disabilities
- Everyone, regardless of their challenges, has the right to live a full life in the community
- Community is strengthened by diversity, inclusion, and accessibility

REV UP Illinois

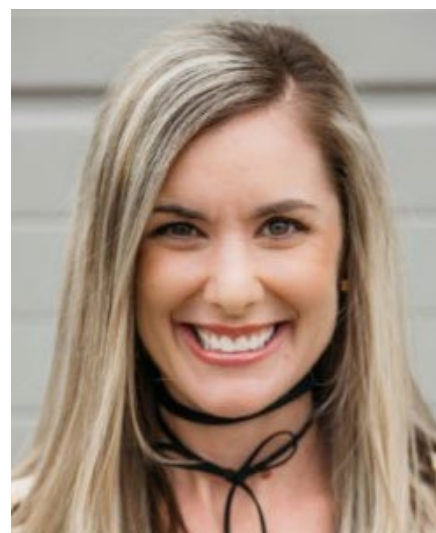
- REV UP stands for Register, Educate, Vote, Use Your Power
- Build the power of the disability vote through civic engagement coalition
- Improve the accessibility of elections for the disability community
- Provides voter education and registration presentations and accessible voting resources



Contact admin@thearcofil.org to get involved!



Thank you!
The Arc of Illinois





How to Reach Family-to-Family



779-254-9158 cell
815-464-1832 ext. 1017
866-931-1110
Spanish: 800-588-7002
Language Line for other languages



susan@thearcofil.org



<https://www.familyvoicesillinois.org>



<https://www.facebook.com/ilfamilyvoices>