



Illinois Family-to-Family Health Information Center

2024

Susan Agrawal, PhD

Today's Presentation



About Me



About Family-
to-Family



Other Arc of
IL Programs

About Me – Lived Experience

Parent of a child who was medically complex

Diagnoses

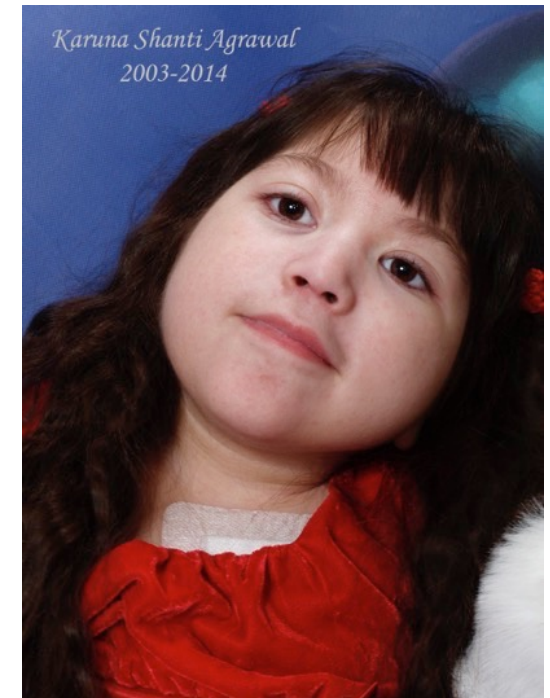
- Cerebral Palsy
- Autoimmune Disease

Technology

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

Needed Services

- Home Nursing
- Palliative Care
- Education
- Care Coordination



About Me – Professional Experience

Current Position

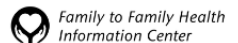
- Director, Family-to-Family Health Information Center at the Arc of IL

Advocacy

- MFTD Waiver Families, Founder
- Kids' Waivers Website

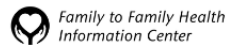
Writer and Editor

- Complex Child Magazine
- Feeding Tube Awareness Foundation
- Freelance Projects





*Family to Family Health
Information Center*



Family to Family Health
Information Center

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

Federal Grant Program funded through HRSA

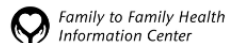
One in every state, some territories, some targeted for Native Americans and Alaskan Natives

State-affiliated organization for Family Voices

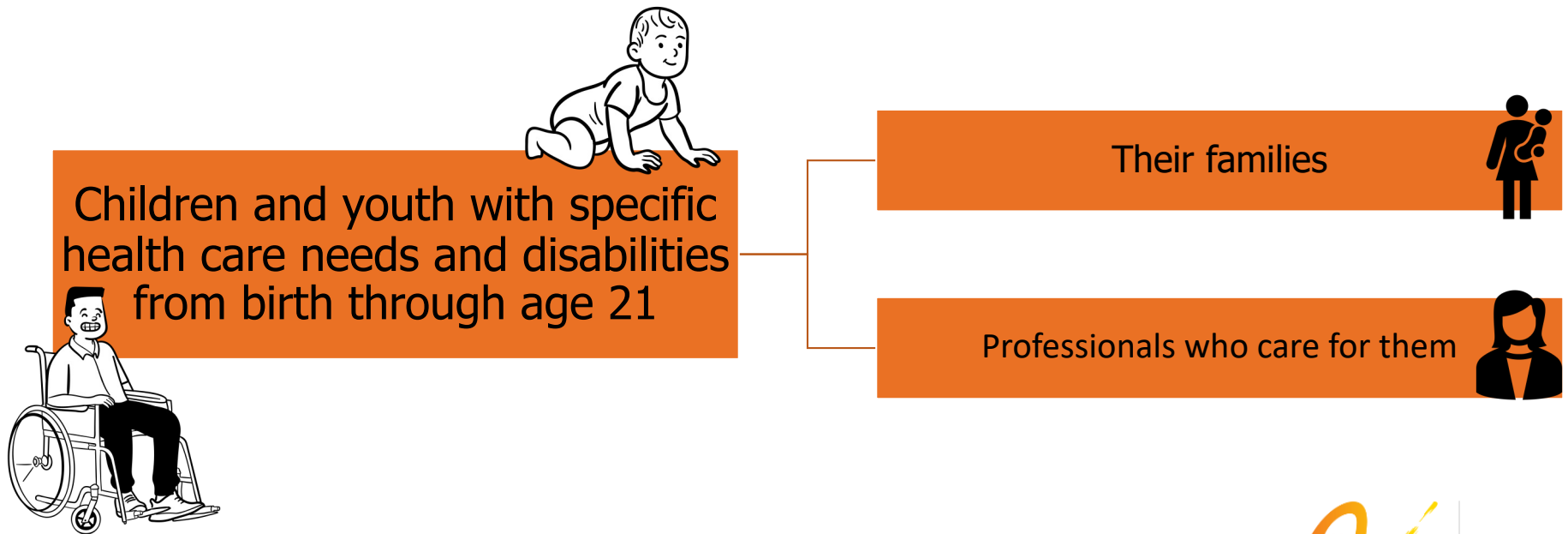
In Illinois, F2F is a program of the Arc of IL



Family Voices is a national organization and grassroots network of families and friends of children and youth with special health care needs and disabilities that **promotes partnership with families** — including those of cultural, linguistic and geographic diversity — **in order to improve healthcare services and policies for children.**



Who Does Family-to-Family Serve?



Who are These Children?

Physical disabilities

Developmental or intellectual disabilities

Behavioral, emotional, mental health, or sensory issues

Autism spectrum disorders

Medical technology like a feeding tube or tracheostomy

Genetic, chromosomal, or congenital conditions

Vision or hearing impairments, or who are deaf or blind

Complex conditions or multiple disabilities

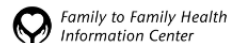
Cerebral palsy, epilepsy, or other neurological conditions

Chronic conditions like asthma, diabetes, or sickle cell anemia

Learning disabilities

Cancer or other blood disorders

Other health conditions or disabilities that affect a child's development or function



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

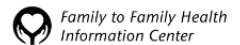


Outreach trainings on program or topics

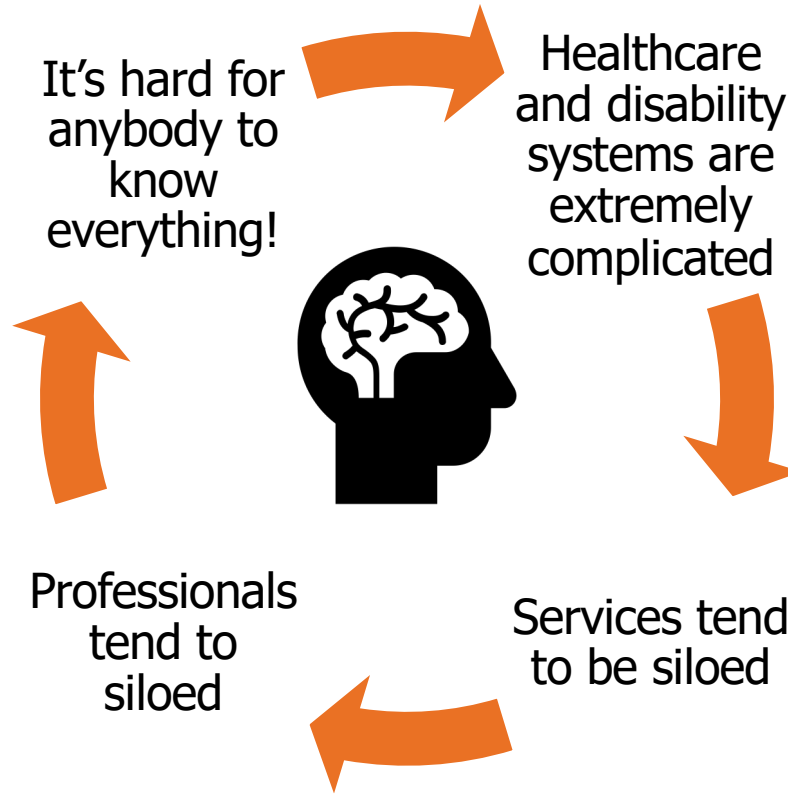
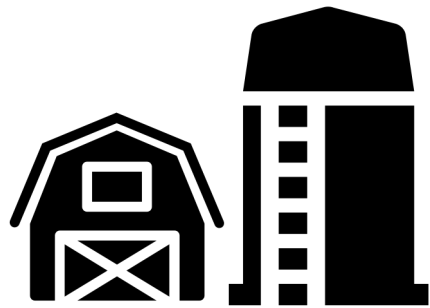


Collaboration with organizations, agencies, providers

All regular services are free!



Why is Family-to-Family Needed?



What We Do: Help Families Navigate the Healthcare System

Information to sign up for and understand insurance and Medicaid benefits

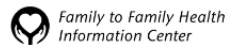
Find services for specific conditions such as autism or diabetes

Assist with finding services for behavioral health

Figure out what insurance/Medicaid covers and find ways to meet needs that aren't covered

Help families find healthcare services

Figure out how to respond to changes in state and federal policies



What We Do: Help Families Navigate Disability Systems

Find peer support
and emotional
support

Learn about Medicaid
waivers, who is
eligible, and how to
apply

Assist with special
education questions,
including Section 504
plans and IEPs

Learn about PUNS
waiting list and how
to get on it

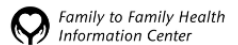
Help families build
their own leadership
and advocacy skills

Assist with questions
about other benefits
like SSI, Title V
(DSCC), SNAP, WIC



Help find respite care

Assist with
coordinating care
providers



Common Questions



- How can I get an autism diagnostic screening for my child?
- Can you help me find a therapist (especially ABA)?
- How do I get diapers covered by Medicaid?
- What Medicaid Waiver(s) is my child eligible for?
- What is PUNS and how long is the waiting list?
- What resources are there for families who don't qualify for any waivers?
- What help can I get while I am on a waiting list?
- Can you help me appeal my cut in home nursing hours?
- What is SSI and how do I get it?
- Can I get paid to take care of my child with a disability?
- Can you help me get better school services for my child?

What We Do: Advocacy and Training



Advocate for programs to improve the lives of children with disabilities and chronic medical conditions

Increase awareness about disabilities

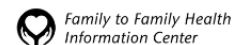
Work with professionals, legislators, and lawyers

Keep up-to-date on state and federal policies that affect children with disabilities

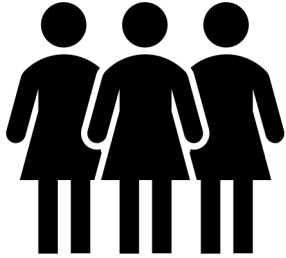
Partner with Title V (DSCC) and other agencies

Outreach events at schools, for organizations, etc.

Webinars and conferences for families and professionals



What We Do: Helping Professionals



Provide information on topics outside their area of expertise

Assist with specific cases that require targeted help

Take referrals for cases from professionals

Provide new or recently updated/changed policy information

Provide trainings and webinars

Collaborate on advocacy or other projects

Professionals also teach us about their areas of expertise!

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

How to Reach Family-to-Family



779-254-9158
815-464-1832 ext. 1017
866-931-1110
Spanish: 800.588.7002
Language Line for other languages



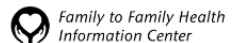
susan@thearcofil.org



<https://www.familyvoicesillinois.org>



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

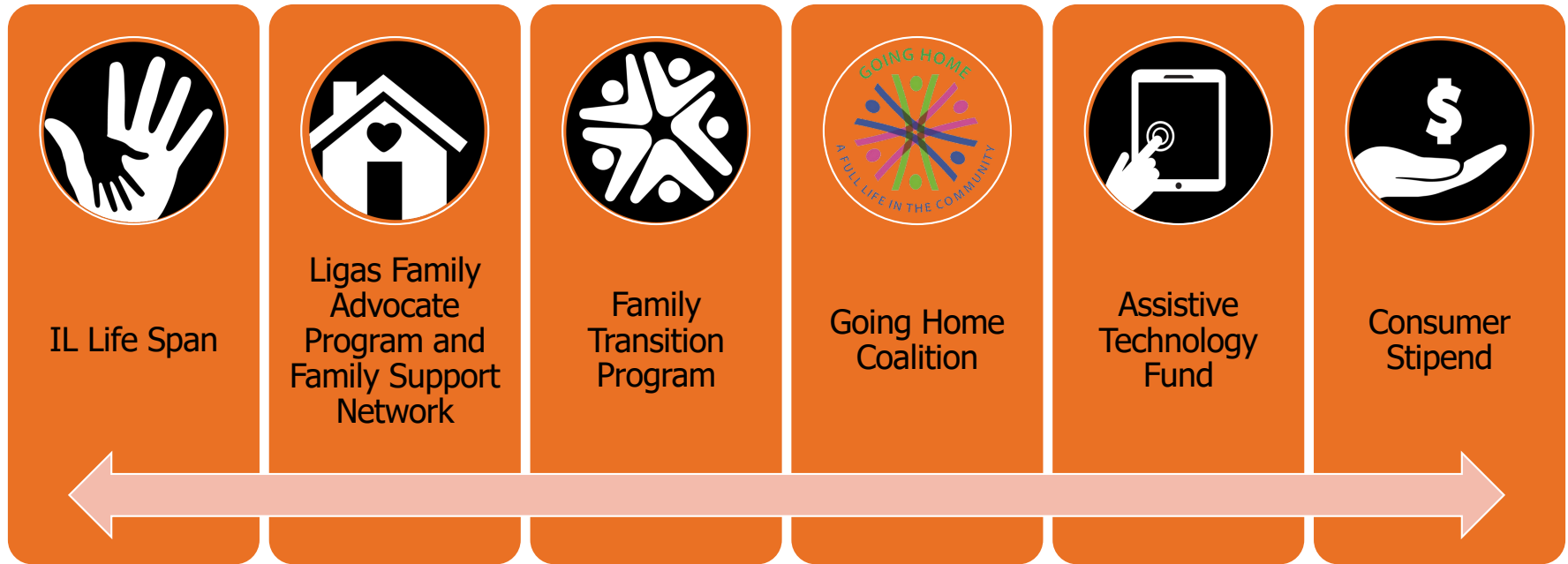




The Arc®

Illinois

Other Arc of IL Programs





IL Life Span

- Assistance to those with Intellectual and Developmental Disabilities
- From birth through the entire life span
- Questions about adults
- Questions about children when they are ID/DD focused

Ligas Family Advocate Program and Family Support Network



Ligas Family Advocate Program

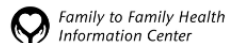
Assistance to those who have been selected from the PUNS list who are Ligas Class Members



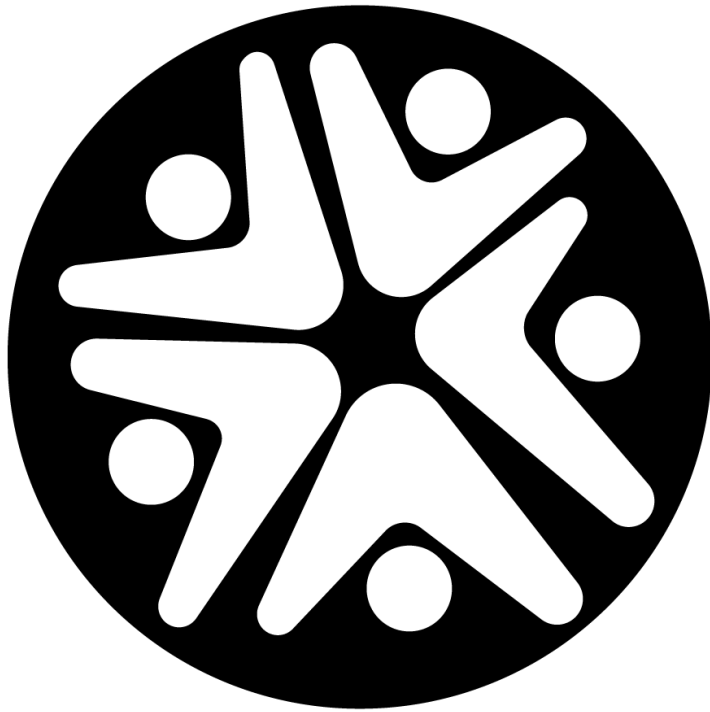
Family Support Network

Help for those with ID/DD to live and thrive in their own homes

Monthly webinars on basic topics in English and Spanish



Family Transition Program



Assisting individuals living in institutions to transition home

Mentorship

Operation Welcome Home

Going Home Coalition



Advocacy for community living

Transition away from institutional living

Systems change to make community living possible

Questions?



779-254-9158



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