



Division of Specialized Care for Children

Family Advisory Council

Open Forum Meeting

May 7, 2026, 9 A.M.

Attendees

FAC Members: Ally Chenoweth, Areli Flores, Aurea Garvin, Byram Fager, Chelsie Hacker, Ekiko Aiken, Esra Tasdelen, Gail Koshgarian, Jaclyn Vasquez (Chair), Jasmine Deida, Joyce Clay, Kassandra Santos, Kelly Whistler, Krystle Myers, Margie Markevicius, Mattanah Israel, Savannah Watts, Theresia Davis

FAC Workgroup: Adell Scott, Erica Stearns, Claire Cook, Haley Phelps, Stephanie Leach

DSCC Team Members: Amanda Simhauser, Brittani Provost, Jamie Renth, Molly Hofmann

Community Guests & Statewide Partners: Ginna Larrotta, Janette Jones, Jose Jimenez, Lauren Schrero, Marcela Flores, Samantha Alloway, Scott Adair Cox, Stephanie Ramos, Susan Agrawal

Welcome

The University of Illinois Chicago's [Division of Specialized Care for Children](#) (DSCC) held its [Family Advisory Council](#) (FAC) Open Forum Meeting, beginning with a warm welcome from **Erica Stearns**, Home Care Family Outreach Associate and Staff Navigator for the FAC. Erica welcomed attendees, introduced herself and **Jaclyn Vasquez**, FAC Co-Chair, and thanked FAC members for their ongoing time, thoughtfulness, and behind-the-scenes contributions that support DSCC's work across the state.

Jaclyn Vasquez reviewed the FAC's commitment to making the space inclusive and accessible. She provided instructions on how to access language interpretation through Zoom and reviewed housekeeping reminders, including muting when not speaking, utilizing the chat for questions and resource sharing, and encouraging camera use when comfortable. Jaclyn also reviewed the day's agenda and invited participants to introduce themselves in the chat by sharing their name, role or affiliation, and where they were joining from in Illinois.

DSCC Updates

Care Coordination Internal Newsletters

Molly Hofman, DSCC Director of Care Coordination, Systems Development, and Education, shared information about monthly internal newsletters distributed to DSCC Care Coordination teams. These newsletters provide staff with updates and insights into DSCC programs, initiatives, and cross-team work.

Mission Possible Initiative and Family Panel Opportunity

Since July 2025, DSCC teams have been working on “Mission Possible,” an initiative focused on developing annual educational opportunities aligned with DSCC priorities. Molly Hofmann reflected positively on last year’s family panel, noting that it provided meaningful opportunities for families to share feedback and lived experiences directly with DSCC staff. The team plans to conclude this year’s initiative with a **Family Panel on July 30**, focused on families’ care ecosystems. Families interested in participating were encouraged to contact **Erica Stearns** (estearns@uic.edu).

Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing

Information was shared about the five-day [Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing](#), designed for parents of children ages six and under. The program will be held June 9–13, 2026, at the Illinois School for the Deaf in Jacksonville. Information flyers are available in English and Spanish on the DSCC website.

Illinois Statewide Transition Conference

The [Illinois Statewide Transition Conference](#) will take place November 5–6, 2026, at the Sheraton Lisle Naperville Hotel. The conference focuses on person-centered transition planning for youth with disabilities and includes sessions on education, employment, community living, and healthcare, with select sessions offered in Spanish.

Youth Advisory Council (YAC) Resource Development

Claire Cook shared that DSCC's [Youth Advisory Council](#) has developed three new resources, now available on the DSCC website, with additional updates forthcoming.

Community Connections

Erica Stearns paused the agenda to provide time for Community Connections, inviting FAC members, families, community partners, and guests to share updates, resources, or upcoming events related to children and youth with special healthcare needs via the chat. (**see Resources section below**)

Communications Team Presentation

Jaclyn Vasquez introduced **Amanda Simhauser**, DSCC Communications Manager, who provided an overview of the DSCC Communications Team, DSCC digital platforms, and how FAC feedback informs messaging, content development, and engagement strategies.

Amanda shared updates on DSCC's social media and digital communications. She highlighted May as Mental Health Awareness Month and shared that DSCC staff and FAC members collaborated on the [Caregiver Mental Health Toolkit](#), now available on the DSCC website.

Amanda also shared that new categories have been added to the [DSCC Resource Directory](#) to improve navigation among more than 1,100 resources. She noted that the DSCC website has also been refreshed with an updated design to enhance accessibility.

Upcoming programming was highlighted, including a [Caregiver Mental Health Webinar](#) taking place on May 12 from 6–7 p.m., focused on stress, burnout, and caregiver well-being.

Amanda shared that DSCC launched a new [eHome Care Training](#) webpage featuring virtual training resources for family caregivers and home nurses. She also highlighted [family stories](#) shared on the DSCC website and in the annual report, including a story from FAC member **Dena Chapman**. FAC members interested in sharing photos or stories were invited to reach out directly.

Amanda emphasized DSCC's commitment to using authentic family photos and stories to reflect the diversity of DSCC families and encouraged families to submit photos through the DSCC upload form. She also shared that DSCC strives to ensure email communications are helpful and manageable, and families were encouraged to complete the [Email Communication Preferences Survey](#).

Community Partner Spotlight

Jaclyn Vasquez introduced **Samantha Alloway**, Executive Director of [The Arc of Illinois](#), and shared appreciation for the organization's role in supporting families through advocacy, education, and connection.

Samantha Alloway introduced herself and shared that her passion for advocacy led her to her current role. She expressed interest in learning directly from DSCC families and provided an overview of several initiatives The Arc of Illinois is currently working on, including:

- Opposing proposed Medicaid cuts that could reduce services for people with intellectual and developmental disabilities (IDD)
- Expanding community living supports to reduce reliance on institutional care
- Supporting Kiki's Law to protect the right to use medical equipment such as masks
- Conducting listening sessions and surveys to gather family and individual input
- Advocating for fair wages for Direct Support Professionals (DSPs)
- Promoting the IDD Navigator to help families access services

- Supporting inclusive housing efforts and protecting SNAP benefits
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Discussion

Susan Agrawal, Director of [Family-to-Family Health Information Center](#) and [Family Voices](#) Illinois Affiliate, asked about proposed changes to the MFTD waiver. **Stephanie Leach**, Associate Director of Systems of Care at DSCC, shared that the team is seeking approval for a new service that would allow physical or occupational therapists to complete in-home assessments to identify needed home modifications.

Discussion also included inquiries about a future palliative care program, with **Scott Adair** from [The HAP Foundation](#) sharing that the Illinois Department of Healthcare and Family Services (HFS) is working closely with CMS and DSCC to move the program forward.

Erica Stearns and Samantha Alloway discussed The Arc of Illinois [Family Support Meetings](#), noting that they are open forums where families can ask questions and receive support in a safe, respectful environment.

Aurea Garvin, an FAC member, shared that she has not participated in many Arc of Illinois events or meetings because her child's needs are primarily related to medical complexity rather than developmental disability, which has made her hesitant to engage. Erica Stearns emphasized that developmental disabilities can include healthcare-related needs and that families caring for children with medical complexity are part of the broader IDD community. She noted positive movement under The Arc's new leadership and invited Susan Agrawal to share more about the Family-to-Family Health Information Center and Family Voices.

Susan Agrawal explained that Family-to-Family Health Information Centers help families understand healthcare systems, disability-related resources, and advocacy opportunities. She shared that Family Voices centers family voice in healthcare policy and practice and supports families in both state and federal advocacy efforts.

Stephanie Leach provided updates on parent CNA approval, noting that approval for caregivers of children under age 21 requires a State Plan Amendment that has not yet been approved. She shared that HFS may consider a phased rollout, potentially by age group.

Kassandra Santos, an FAC member, raised concerns about the challenges of maintaining CNA certification, particularly the difficulty of meeting recertification and continuing education requirements without backup caregiving support. Molly Hofman explained that while legislation allowing parent caregivers to work as CNAs passed approximately two years ago, implementation requires both waiver amendments and State Plan approval. She acknowledged ongoing delays and noted that advocacy efforts continue. Molly also recognized concerns about continuing education requirements and encouraged families to continue sharing barriers they experience. Kassandra elaborated that CNAs must complete eight hours of continuing education annually and suggested exploring solutions that better support caregivers who cannot easily leave their child. Molly Hofman shared that these concerns would be elevated to state partners and encouraged families experiencing similar challenges to connect with DSCC to explore potential solutions.

Closing

Erica Stearns thanked participants for their engagement and reminded attendees of upcoming meetings. Molly Hofman closed the meeting by expressing appreciation for the time, honesty, and dedication FAC members and community participants bring to the group.

Action Items

The following action items were identified during the meeting to support continued collaboration, follow-up, and system improvement:

- **Family Panel Recruitment:**

DSCC staff will continue outreach to identify family participants for the July 30 Mission

Possible Family Panel focused on care ecosystems. Interested families will contact Erica Stearns for additional information.

- **Communications and Resource Feedback:**

FAC members are encouraged to share ongoing feedback on DSCC communications, digital resources, and family-facing materials, as well as to participate in storytelling opportunities that reflect diverse lived experiences.

- **Parent CNA and Recertification Barriers:**

DSCC will elevate family concerns regarding CNA continuing education and recertification challenges to state partners at HFS. Families experiencing barriers are encouraged to share their experiences with DSCC for documentation and advocacy purposes.

- **MFTD Waiver and New Service Updates:**

DSCC will continue providing families with updates on proposed MFTD waiver changes, including progress on the potential in-home PT/OT assessment service and the development of a palliative care program in collaboration with HFS and CMS.

- **Community Connections:**

FAC members were encouraged to continue engaging with community partners, including The Arc of Illinois and Family Voices, through listening sessions, parent support meetings, and surveys to ensure a broad range of family perspectives are represented.

Resources

General Info & Social Media

- **Official DSCC Website:** The main hub for services, eligibility information, and family support in Illinois. dscclinktree.com
- **DSCC Linktree:** A quick-access menu for DSCC's current projects and popular links. linktr.ee/uicdscclinktree

- **DSCC Instagram:** Follow for updates, community stories, and event announcements. [@uicdsc](#)

Educational Resources & Toolkits

- **Caregiver Mental Health Toolkit:** Resources and strategies specifically designed to support the emotional well-being of parents and guardians. [Caregiver Toolkit Link](#)
- **eHome Care Training:** A specialized training guide for those caring for children with medical complexity at home. [eHomeCare Training Link](#)
- **Summer Camp List for All Abilities:** A directory of Illinois summer camps that accommodate children with various physical and developmental needs. [Explore Camp Opportunities](#)

Events & Engagement

- **2026 Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing:** A milestone program providing support and education for parents of preschool-aged children who are deaf or hard of hearing. [Institute for Parents Link](#)
- **DSCC Family Education Webinar: Caregiver Mental Health:** *Live Session: Tuesday, May 12th, 6:00 PM – 7:00 PM.* [Register for Webinar](#)
- **UIC-DSCC Youth Advisory Council:** A platform for youth with special healthcare needs to build leadership skills and influence programs. [Youth Advisory Council Link](#)

Family Stories & Media

- **DSCC Family Stories:** Read inspiring accounts from other families navigating the healthcare system in Illinois. [Read Family Stories](#)
- **SeizureSense Alert System: A Success Story:** Learn how DSCC helped one family secure a safer night's sleep through specialized alert technology. [Read the SeizureSense Story](#)
- **Media Upload & Surveys:**
 - **Upload Family Photos/Media:** [Secure Box Link](#)

- **Email Communication Survey:** [Take the Survey](#)
- **Contact:** Amanda (arsimhau@uic.edu)

The Arc of Illinois

- **The Arc of Illinois Main Site:** Information on advocacy, legislation, and community programs. thearcofil.org
- **Illinois LifeSpan Fact Sheets:** A library of clear, concise guides on topics ranging from guardianship to funding. [Fact Sheets Link](#)
- **Family-to-Family Health Center:** Connecting families to peer support and healthcare navigation assistance. [F2FHIC Website](#)
 - **Contact:** Susan (susan@thearcofil.org) | 779-254-9158
- [Family Support Group](#) is a place to gain clarity, ask questions, share experiences, or simply listen.

Additional Family Resources

- **Illinois Statewide Transition Conference:** An essential annual event for families of youth and young adults with disabilities transitioning into adulthood. illinoistransitionconference.org
- **Lucile Packard Foundation: Home Accessibility Webinar:** An archived session regarding the challenges and solutions for home accessibility for children with disabilities. [Watch Webinar Here](#)
- **Lynda P. Bollman Pediatric Hospice Program:** Offers pediatric hospice and palliative care support, including free CEUs for practitioners in the field. **Note** -- Please contact the program directly for current CEU registration links.

Camps & Community Support

- **Shady Oaks Camp (Homer Glen, IL):** Outdoor summer camp experiences for individuals with physical and developmental disabilities. shadyoakscamp.org | Contact

FAC guest Marcia Flores by email at Marcie.flores55@gmail.com or by phone 708-998-8977

- **Bounce Children's Foundation:** Peer support and community outings for families of children with chronic illnesses. bouncechildrensfoundation.org
- **Kohl Children's Museum:** Interactive, inclusive learning and play for young children. kohlchildrensmuseum.org
- **The Village Cares:** A local community network for family resources and support. [Facebook Group](#) | Contact FAC Member Theresia Davis at thevillagecares3@gmail.com