



Division of Specialized Care for Children

Family Advisory Council

Open Meeting

Nov. 6, 2025, 9 a.m.

Attendees

FAC Members: Jasmine Deida, Byram Fager, Chelsie Hacker, Jaclyn Vasquez, Kelly Whistler, Yesenia Aiken, Aurea Garvin, Mattanah Israel, Ally Chenoweth, Dena Chapman, Theresia Davis, Margie Markevicius, Joyce Clay

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

DSCC Team Members: Tom Jerkovitz, Molly Hofmann, Ruann Barack Jamie Renth, Shelly Roat, Patricia Perez, Lisa Washington, Amanda Simhauser, Ruann Barack, Shelly Roat, Terri-Lynn Woods-Edwards, Britanni Provost, Jeremy Roberts, Jaleesha Allen

Community Members: 19 members of the community representing family members, advocates, and professionals

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 and introductions led by *Jaclyn Vasquez*, Co-Chair of the Family Advisory Council. Jaclyn opened the meeting by welcoming FAC members, families, DSCC staff, community partners, and representatives from the Illinois Department of Healthcare and Family Services. She reminded attendees that the FAC serves as a family-centered space to elevate lived experience, identify gaps, and influence statewide policy and practice. Participants were encouraged to introduce

themselves in the chat by name, affiliation, and region, and were reminded of the standard Zoom expectations, including staying muted when not speaking, using the chat for questions or comments, and keeping cameras on when possible to help foster connection.

DSCC Updates

Erica Stearns, Home Care Family Outreach Associate and Co-Chair of the FAC, provided a series of DSCC program and communication updates designed to strengthen family engagement and timely information-sharing.

- **DSCC Website “News” Page:** Erica highlighted the growing list of updates on the DSCC website, which includes information about program and policy changes that directly impact DSCC participant families. A recent post was shared regarding disruptions to SNAP benefits and access to statewide food and meal resources.
 - **DSCC Instagram Launch:** A new [DSCC Instagram page](#) has been launched to expand outreach and share resources in more accessible, family-friendly ways.
 - **New Respite Resource:** [Reliance Children’s Health Center Illinois](#), has been approved as an additional respite and transitional care option for medically fragile children and youth, located in Plainfield, IL.
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FAC Accomplishments

Erica reviewed key accomplishments from 2025 that were initiated through FAC member feedback and collaboration, emphasizing that each achievement began with a family or caregiver raising a concern or idea.

- **Caregiver Mental Health Toolkit:** Developed following a caregiver request at a previous meeting, this resource is now widely used and appears as a top search result for “caregiver mental health.”

- **Family-Led Training for DSCC Staff:** A new internal training series, Family Perspective on Care Coordination, was launched in July and featured a live family panel with FAC members. Staff participants reported that hearing directly from families had a meaningful impact. Erica encouraged interested FAC members to contact her for future sessions.
- [CNA Tip Sheet](#): Created to provide clear, family-friendly guidance on how parents can become certified nursing assistants (CNAs) for their own children.

Ongoing initiatives include the **FAC Member Bio webpage** (pending final layout), the **Transportation Subcommittee's research and recommendations** addressing Medicaid transportation barriers, and the development of the **Caregiver Toolbox**, which currently includes fifteen family-created resources covering topics such as hospital discharge, home nursing, support networks, and documentation systems. Erica reaffirmed that these milestones reflect the direct influence and persistence of families who spoke up about their experiences.

DME Liaison Introduction & Presentation

Jeremy Roberts, Home Care Respiratory Therapist & DME Liaison, introduced his role supporting families with Durable Medical Equipment (DME) needs. His focus includes troubleshooting delays, approvals, technical concerns, and communication breakdowns between vendors, families, and care coordinators. He encouraged families to first reach out to their care coordinators and to request his involvement if progress is stalled. Jeremy emphasized that families should not feel burdened with hours of follow-up calls when DSCC can often assist more efficiently through internal channels.

2026 Family Education Webinar Planning

Brittani Provost, Manager of Benefits Management and Research Team, shared updates on the Family Education Webinar Series, which continues to grow in attendance and

engagement. These webinars are typically held late spring through early summer, hosted in the evening, recorded, and posted online for ongoing access, with captioning and Spanish interpretation provided for all sessions. Survey feedback shows that families find the topics valuable, appreciate the accessibility, and prefer evening scheduling.

Families suggested topics for the 2026 series, including:

- Disaster and emergency preparedness for medically complex families
- Trauma-informed care and caregiver mental health
- Home and vehicle modification processes and funding opportunities
- Medicaid waiver deep-dives with lived family perspectives
- Out-of-state medical travel and transportation
- Transition to adulthood and guardianship alternatives

Several participants encouraged DSCC to expand partnerships with outside organizations to avoid duplication and broaden available expertise. Attendees also voiced a strong interest in webinars that address emotional well-being, mental health, and emergency response for individuals with complex needs.

Discussion

The open discussion portion of the meeting provided families with the opportunity to share issues, ideas, and personal experiences that would guide DSCC's continued mission to support families and children with special health care needs. Families shared several key areas of concern, including the lack of emergency preparedness procedures in schools for students with disabilities, particularly during fire, weather, and active threat drills. Participants also discussed ongoing challenges with power outages and noted difficulty securing priority power restoration or support from utility companies, even when enrolled in medical priority programs. Families emphasized the need for clearer, more practical guidance on home

accessibility modifications and expressed a desire for information regarding mental health services for nonverbal children with complex needs.

Families raised additional concerns about transportation barriers faced by medically fragile children who must travel out of state for specialty care, especially when no nurse accompanies the family. Several members expressed interest in DSCC developing and publishing a statewide resource list of real-life emergency preparedness lessons submitted by families. Erica confirmed that all feedback would be documented, shared with relevant DSCC teams, and revisited during future meetings to provide updates on progress and next steps.

Closing

Tom Jerkovitz, DSCC Executive Director, concluded the meeting by thanking presenters, FAC members, and community guests for their time and contributions. He emphasized that many of DSCC's most impactful improvements begin with the issues and ideas raised during this open discussion period. Tom encouraged continued participation and collaboration, noting that the next Closed FAC Meeting will take place in February 2026, with more details to follow by email.

Action Items

DSCC will evaluate the development of statewide emergency preparedness guidance, including school-based response plans. An update on the Parent CNA service will be shared with families once federal approval is received. The Family Education Webinar Team will work to incorporate topics related to mental health, disaster preparedness, and home modification into the 2026 schedule. DSCC staff will follow up directly with families who raised individual support needs related to home modifications or mental health resources. Additionally, DSCC

will explore options for compiling region-specific power outage and medical equipment backup resources to better support families during power-related emergencies.

Resources Share in the Chat

Protected Tomorrows (financial planning for families/caregivers):

<https://protectedtomorrows.com/>

The Arc of Illinois Upcoming Webinars and Events:

<https://www.thearcofil.org/events/category/arc-events/>

Family Matters Parent Training and Information Center (educational and IEP support):

<https://fmptic.org/>

Equip for Equality (a protection and support organization for people with disabilities):

<https://www.equipforequality.org/issues/special-education/>

GAC Special Education Initiative (Illinois Guardianship & Advocacy Commission):

<https://gac.illinois.gov/sped.html>

Tellin Tales Theatre (inclusive non-profit theatre performances for kids & adults)

<https://tellintales.org/>