



## **Division of Specialized Care for Children**

### **Family Advisory Council**

#### **Open Meeting**

**May 8, 2025, 9:00 AM**

#### **Attendees**

**FAC Members:** Ally Chenoweth, Jasmine Deida, Chelsie Hacker, Gail Koshgarian, Jaclyn Vasquez, Jessica Brafford, Yesenia Aiken, Mattanah Israel, Christina Kiesewetter, Dena Chapman, Kassandra Santos, Theresia Davis

**FAC Workgroup:** Stephanie Leach, Haley Phelps, Adell Scott, Violet Wilker, Erica Stearns

**DSCC Team Members:** Tom Jerkovitz, Jamie Renth, Shelly Roat, Patricia Perez, Lisa Washington, Amanda Simhauser, Ruann Barack, Jaleesha Allen, Margo DePorter

**Community Members:** 18 members of the community representing family members, advocates, and professionals

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#### **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. She opened the session by acknowledging the value of the FAC as a space to share updates, elevate family voices, and foster meaningful dialogue around supporting children and youth with special healthcare needs across Illinois. Jaclyn reminded participants of the importance of maintaining a brave, safe, and respectful space and encouraged camera use for connection,

active participation in the chat, and including one's name and location to help foster a sense of community.

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## Communications Team Updates

**Margo DePorter**, DSCC Multimedia Content Specialist, joined by **Amanda Simhauser**, DSCC Communications Manager, provided a thorough update from the DSCC Communications and Outreach Team. The update included a curated list of inclusive summer camps now available on the [DSCC website](#) to help families identify suitable options for their children. The team also shared information about resources related to the 2025 Health Insurance Education Series and promoted an upcoming two-part webinar titled “Preparing for Adulthood: A Roadmap for the Future,” designed to support youth and families in planning for the transition to adulthood.

Margo highlighted DSCC's ongoing leadership role in the annual statewide transition conference, “Stepping Stones of Transition,” which is scheduled to take place October 30–31 in Springfield. Additionally, resources developed for Mental Health Awareness Month were spotlighted, including the [Caregiver Mental Health Toolkit](#) and a collection of online materials designed to promote caregiver wellness.

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## FAC & Subcommittee Updates

**Erica Stearns**, DSCC Home Care Family Outreach Associate and Co-Chair of the FAC, shared a comprehensive update on FAC activities. She emphasized the Council's commitment to amplifying family voices and creating space for impactful change. Erica reported that there are current vacancies on the Council, particularly in the Southern region, and encouraged interested families to apply. She also introduced the recently developed FAC Look Book, which highlights stories and photos of families to help advocate for the FAC's work. Erica noted that the FAC's model of engagement is gaining recognition from other states as a best practice.

Subcommittees and working groups also provided updates on their work:

- The [Youth Advisory Council](#) is currently developing materials related to college accommodations and service navigation for youth with special healthcare needs.
- The **Transportation Subcommittee** is finalizing a set of national best practice recommendations focused on improving transportation options for children with special healthcare needs.
- The **Caregiver Toolbox Group** is designing caregiver-created resources, such as emergency documents, care summaries, and guides to navigating medical crises.

During the discussion, families shared ideas for developing standardized medical summaries that could be used across emergency departments. Suggestions included QR-coded ID bracelets and customizable care coordination templates. Some participants volunteered tools they had created for their own use and expressed interest in collaborating to build a unified, accessible resource.

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## LRA/CNA Updates

**Stephanie Leach**, Associate Director of Systems of Care, provided an update on the Legal Responsible Adult (LRA) / Certified Nursing Assistant (CNA) initiative. This program would allow family caregivers to be paid for providing nursing care to their own children. Stephanie reported that the state has submitted a plan amendment to the Centers for Medicare and Medicaid Services (CMS) and is ready to move forward with implementation once federal approval is received. Erica Stearns and Stephanie also discussed how families may be eligible for Workforce Innovation and Opportunity Act (WIOA) grants to help offset the cost of CNA training. **Susan Agrawal**, Family Advocate and director at Family-to-Family Health Information Center through The Arc of Illinois, added insights about complementary legislative initiatives and encouraged continued family advocacy as discussions continue with the Governor's Office.

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## Discussion

During the open discussion portion of the meeting, Family Advisory Council (FAC) members voiced widespread concerns about ongoing problems with a specific Durable Medical Equipment (DME) provider. The central themes included delays or absence of critical medical supplies, poor customer service, lack of communication, and supply denials without formal documentation. These issues have had direct consequences on children's health and have placed emotional and logistical strain on families. Several members shared personal accounts illustrating the repeated need to follow up, unclear order processes, and staff miscommunication. Concerns were also raised about the provider's lack of empathy and knowledge when interacting with families managing complex care needs. Although a recent town hall with the DME company's leadership acknowledged some of these problems, families reported little to no improvement since then.

DSCC leadership acknowledged the severity of the issues and committed to taking the next steps, including follow-up with the DME provider through their respiratory team and exploring ways to make DME provider lists more accessible. Suggestions included organizing the lists by provider specialty to better support families seeking alternatives. Families were encouraged to continue reporting issues and to connect with their care coordinators for help navigating DME challenges.

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## Closing

***Erica Stearns*** concluded the meeting by expressing her deep appreciation for the honesty, engagement, and passion of all participants. ***Stephanie Leach*** emphasized the vital role that the Family Advisory Council plays in driving meaningful change across the state. ***Jaclyn Vasquez*** echoed these sentiments, reaffirming that family feedback is essential to systemic improvement and expressing gratitude for everyone's continued commitment, energy, and advocacy. The meeting closed with a collective recommitment from DSCC leadership to listen, act, and support families through an ongoing, collaborative partnership.

The Next **CLOSED** FAC meeting is scheduled for **August 7, 2025**.