UNIVERSITY OF
ILLINOIS CHICAGO

Division of Specialized Care for Children

Family Advisory Council

Closed Meeting

Feb. 5, 2026, 9 A.M.

Attendees

FAC Members: Jaclyn Vasquez (Chairperson), Byram Fager, Aurea Garvin, Mary Herschelman, Gail Koshgarian, Jasmine Deida, Ally Chenoweth, Yesenia Ekiko Aiken, Mattanah Israel, Dena Chapman, Kassandra Santos, Margie Markevicius, Areli Flores, Savannah Watts, Esra Tasdelen, Joyce Clay

FAC Workgroup: Erica Stearns (Chairperson), Stephanie Leach, Haley Phelps, Adell Scott, Violet Wilker

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

---

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 reminded attendees that the Family Advisory Council (FAC) is a collaborative space intended to provide updates, encourage open dialogue, and support meaningful engagement between families, DSCC staff, and HFS representatives.

Housekeeping items were reviewed, including muting microphones when not speaking, utilizing the chat for questions and resource sharing, and maintaining a respectful and supportive environment. Members were encouraged to actively engage and share their lived experiences to help improve DSCC services statewide.

FAC members were also informed that FAC and Youth Advisory Council member bios had been published on the DSCC website, offering an opportunity for members to connect beyond meetings and highlight the diverse experiences represented within the Council.

Introductions

New FAC members were welcomed and provided introductions. ***Esra Tasdelen*** shared her experience as a parent of a child with complex medical needs enrolled in DSCC's waiver program and her background as an academic and writer focused on caregiving and disability advocacy. ***Savannah Watts*** shared her experience as a parent of a child with spina bifida, her professional background in graphic design, and her lived experience navigating rural healthcare access challenges. ***Margie Markevicius***, attending her first official closed meeting as a member, also introduced herself and shared her family's journey, including her son's rare genetic condition and her advocacy interest in supporting other families.

Acknowledgement

Erica Stearns, Co-Chair of the FAC, shared the heartbreaking news of the passing of FAC member ***Krystle Myers'*** daughter, Amelia. Crystal's advocacy work at the state and national level, including efforts to expand newborn screening, was acknowledged. Members were encouraged to keep the family in their thoughts and wear purple in solidarity.

DSCC Financial Assistance Update & Discussion

Thomas Jerkovitz, Executive Director of DSCC, provided a presentation regarding DSCC financial assistance expenditures and sustainability concerns. Key points included:

- The Title V block grant funding has remained largely flat for approximately 17 years.
- Financial assistance spending has significantly increased, particularly in ramps, lifts, mobility aids, and family reimbursement categories.
- Year-to-date expenditures exceed projected averages, creating budgetary strain.
- DSCC will enforce the existing $7,500 annual cap for the remainder of the fiscal year.
- DSCC remains committed to providing assistance but must balance sustainability with equitable distribution of limited funds.
- DSCC will continue operating as the payer of last resort and will keep pursuing charitable/community funding partners when needs exceed the cap.
- DSCC will brief internal staff on Tuesday and send a family letter next week explaining the cap enforcement, clarifying that DSCC's fiscal year runs July–June, and outlining plans to gather broader family feedback.
- DSCC is seeking input on what types of assistance families value most, what changes would have the least disruption, and what improvements are needed in communication, clarity, and processes (noting future changes are not necessarily permanent and could be revisited as data and feedback evolve).

Several FAC members provided detailed feedback and examples from lived experience:

Kassandra, FAC member, emphasized that family needs vary widely (single caregivers vs. partnered households, differing support networks, distance from care). She highlighted communication gaps that can lead to frustration and misplaced resentment toward care coordinators, especially when families get unclear answers about eligibility (e.g., "specific diagnosis" without a clear yes/no) and are left waiting without direction. Kassandra also stressed the realities of travel costs (gas, tolls, parking, hotels) and challenges like last-minute lodging availability (e.g., Ronald McDonald House timing), which can force families into expensive decisions. She shared financial strain openly (overdraft letters, maxed out cards) and noted that reimbursement delays can make support feel unusable in real time. Near the end, Kassandra asked about a DSCC "card" referenced in a letter. Molly, Director of Care Coordination, Systems Development, and Education for DSCC, acknowledged a generic card exists (not a guarantee of payment) and said DSCC would follow up on Kassandra's individual situation.

Mattanah, FAC member, raised concerns about uncertainty ahead, asking what DSCC will do as broader "cuts" hit families and whether the $7,500 cap could be lowered if funds deplete faster. Mattanah also shared personal experience with high-cost needs (e.g., vehicle modification far exceeding the cap in the past) and warned that stricter rules could make it harder for families already stretched thin. DSCC clarified that they have not made a decision about lowering the cap for future years and that feedback on what families value most will help guide any next steps.

Aurea, FAC member, focused heavily on practical process improvements. She asked for easy, self-serve access to documents (like mileage logs and reimbursement forms) through the DSCC portal so families can complete forms in real time (e.g., while waiting at appointments) rather than losing time tracking emails later. Aurea described "ambiguity fatigue," where unclear requirements and back-and-forth documentation requests lead families to give up, even when reimbursement would be meaningful. She proposed that DSCC develop simple checklists for each category (therapy, travel, etc.) with a clear disclaimer that submission does not guarantee approval. Aurea also suggested infographics that clearly outline what each program offers, and she volunteered her interest in a subcommittee to help build improved materials and resources.

Yesenia, FAC member, asked DSCC to dig deeper into the data behind the equipment spending spike, specifically the age, weight, and demographic patterns driving ramps, lifts, and equipment costs. She shared an example where a family pursued what they truly needed (a wheelchair van) but ended up with a different solution that was unsafe or ineffective, resulting in wasted resources. Yesenia encouraged DSCC to use this moment to better align approvals with what will actually work in families' day-to-day realities and to reduce avoidable spending on equipment that does not end up being usable.

Erica and ***Jaclyn***, Co-Chairs of the Family Advisory Council, reinforced themes from multiple families. Erica highlighted the systemic challenge that care coordinators often must ask others for answers, and that follow-up can lag too long. She emphasized that even when the coordinator does not have the answer immediately, timely updates matter. Erica also raised the idea of DSCC exploring stronger relationships with DME vendors to reduce markup and price inflation and improve outcomes, so families receive the right equipment the first time. Jaclyn emphasized that if FAC members, who are engaged and informed, still experience confusion, many more families outside the FAC likely feel it even more. She encouraged DSCC to solicit broad input and create accessible tools like FAQs, resource hubs, and digestible communications (including social media snippets that direct families back to the website), while also being mindful of tone and the reality that many families do not have the luxury of waiting long periods for answers or reimbursements.

Closing

The meeting concluded with appreciation for member honesty and engagement. ***Erica***, Co-Chair of the FAC, and ***Thomas***, Executive Director of DSCC, reiterated that this discussion marks the beginning of ongoing work to evaluate financial assistance processes, improve communication, and ensure the most meaningful support possible for families across Illinois.

Members were encouraged to continue providing feedback and to participate in future subcommittee efforts focused on improving documentation, communication, and transparency.