



DSCC Family Advisory Council

GUIDELINES



**Division of Specialized
Care for Children**

What Makes a Quality Advisor?

FAC members are individuals sought for their qualities such as:

- The ability to share insights and information about their experiences in a constructive manner
- A capacity to look beyond personal experiences
- Concern for multiple issues
- Good listening skills
- Respect for diverse perspectives
- Comfortable communication in group settings
- Effective interaction with various individuals
- Collaboration with others
- Meaningful storytelling
- A willingness to actively participate in meetings

Eligibility

1. Must be a family member of a current or former Core/Connect Care or Home Care participant or a current/former participant.
2. Must have knowledge of and interest in improving systems of care for children with special health care needs.
3. Must agree to a one-year commitment with the option to stay for a second. Once a term is completed, members can participate in Open Forum meetings that are open to the public.
4. Must have the time and technology available for use to attend quarterly virtual meetings. This includes a device that has Zoom capability, a working camera and microphone.

Member Application Process

DSCC staff, FAC members, or individual families can reach out to the FAC workgroup about prospective membership. The FAC workgroup will review the interested applicant, discuss the FAC guidelines with the interested applicant, and submit the applicant's name and contact information to the University Business Office to begin executing their contract. The University Business Office will contact the prospective FAC member with the additional steps required for member compensation.

Member Expectations

Our FAC members serve as a vital advisory resource to DSCC administration and staff. FAC members must demonstrate active engagement and provide input during our meetings for policy and program development necessary for statewide system improvements.

We encourage all FAC members to actively engage in the following ways:

- Attend each virtual meeting with your camera on and your mic ready.
- Review meeting agendas and provide discussion topic ideas in advance of meetings.
- Review recommendations from DSCC staff or administration.

Mission

The mission of the Family Advisory Council (FAC) is to foster a collaborative partnership among families, Division of Specialized Care for Children (DSCC) staff and administration, and external stakeholders. Our goal is to enhance the delivery of participant and family-centered services. We strive to connect families with resources, offer guidance to strengthen collaboration, improve communication, and empower families of children and youth with special healthcare needs (CYSHCN) to actively participate and have a meaningful voice in their child's care.

- Channel information, needs, and concerns of families of CYSHCN to staff and administration.
- Review, comment, and provide feedback on DSCC activities, programs, services, and strategies to improve family participation and access to services.
- Help DSCC engage families to ensure person and family centered values and priorities. Provide feedback on materials developed for families.
- Engage with your community and your peers about issues impacting caregivers and CYSHCN.

Size and Structure

The FAC will be comprised of both caregivers of DSCC participants (past or present), in addition to adult participants (past or present).

- 25 Family Advisory Council members
- 1 DSCC staff member: Navigator

Membership guidelines will ensure that neither Core/Connect Care nor Home Care exceeds 65% representation. Membership balance will be determined by geographical region and participant population size, as outlined below:

- Ten members from: Chicago Core/ Connect Care, Lombard Core/ Connect Care, Rockford Core/ Connect Care, Region 1, Region 2, Region 4, and Region 5.
- Six members from: Champaign Core/ Connect Care, Mokena Core/ Connect Care, Peoria Core/ Connect Care, Springfield Core/ Connect Care, and Region 6
- Six members from: Marion Core/ Connect Care, Olney Core/ Connect Care, St. Claire Core/ Connect Care, and Region 3.
- Three bereaved members: Bereaved caregivers/family members who no longer receive services from DSCC but would like to remain in the FAC.

Two meetings per year will be open to the public, specified as Open Forums, providing an opportunity for any interested parents, family members, and other CYSHCN stakeholders to participate and engage without a long-term commitment.

DSCC Navigator

One DSCC staff member will serve as navigator for the FAC. They will support the FAC and its members and help ensure that the activities of the FAC are integrated into system improvements. The navigator is the lead contact for other DSCC staff interested in involvement in the FAC.

FAC Officers

The appointed Chair/Co-Chairs serve as designated leaders responsible for overseeing meetings and planning. The appointed Chair(s) play a crucial role in maintaining the smooth operation of the Family Advisory Committee (FAC). This involves ensuring that the FAC stays focused on achieving its goals, promoting active participation among all members during meetings, and effectively communicating the council's activities and outcomes. Additionally, optional officers or subcommittees, aligned with FAC member interests, may be established to enhance the council's functionality.

FAC Meetings

There will be four virtual meetings held quarterly throughout the calendar year, providing regular opportunities for council members to convene and discuss matters. Additionally, face-to-face meetings may be arranged based on the needs of the FAC. Special meetings, beyond the regular quarterly schedule, may also occur during the year if deemed necessary. This flexible approach allows the council to adapt its meeting frequency and format to address specific requirements or urgent matters as they arise.

FAC Member Compensation

To be compensated for their time, FAC members must have a valid Social Security number. However, the FAC welcomes members who are interested in volunteering their time without compensation. FAC member payment cannot exceed \$600 per calendar year. Payments are available by check or direct deposit. Members with a valid Social Security number will be compensated as follows:

FAC Members = \$50 per virtual meeting

Chair/Co-Chairs = \$50 per hour, additional compensation provided for extra meetings and involvement

Meeting Agendas

The FAC navigator will collaborate with the Chair(s) to create and distribute an agenda before the meeting date. FAC members can submit any additional items for consideration ahead of the meeting. Any topic not addressed during a meeting will either be held for discussion in the next meeting or addressed and communicated between meetings.

Meeting Structure

Each meeting begins with updates from DSCC's Care Coordination, Quality, and Communications departments, covering relevant information for the programs and services offered to DSCC participants and families. Additionally, FAC members engaged in other CYSHCN committees or community organizations share updates and project-related details.

Care Coordination Report focuses on activities aimed at improving care coordination, offering insights into the team's strategies, initiatives, and developments within DSCC.

Quality Report focuses on assessing and ensuring quality standards within DSCC, outlining measures and initiatives taken to uphold or enhance the quality of services, processes, and outcomes.

Communications Report details outlines DSCC's communication strategies, both internally and externally, emphasizing transparency and clarity in all communication channels.

Community Report serves as a platform for FAC members to share their involvement in various activities, initiatives, or projects related to CYSHCN. It specifically focuses on their participation in other CYSHCN committees, councils, or community organizations. This report provides a platform for FAC members to update their peers on the broader work they are contributing to beyond the scope of the FAC, fostering transparency and collaboration within the community.

Discussion section is designated to provide an environment for open dialogue and the sharing of diverse perspectives within the council. We strongly encourage FAC members and Open Forum guests to actively contribute their own insights, information, and experiences related to the needs, concerns, or recommendations from families of CYSHCN.

Meeting Minutes

DSCC will publish the meeting minutes within two weeks of said meeting. DSCC will distribute the minutes to all FAC members and post them on the DSCC website. The FAC Meeting Minutes are available on the DSCC website for public access and review.

Guidelines & Authority

In situations of controversy, the DSCC staff navigator and the FAC Chair will assume primary responsibility for making decisions, guiding the resolution process, and providing leadership within the FAC.

Confidentiality Policy

The FAC meetings are a confidential space where the information discussed is not shared outside of the meetings without prior approval by an authorized DSCC staff member. FAC members will be trusted with information about DSCC, which may include anonymized information about the population that DSCC serves. While FAC members have the right to self-disclosure about their own child(ren), we request that they do not provide specific identifying information (name, birthdate, etc.).

If a FAC member is found to have inappropriately disclosed individual participant information revealed in a meeting to sources outside the FAC membership for purposes outside the Division's mission, DSCC has the right to remove said FAC member that violated the confidentiality policy.

Membership & Confidentiality Agreement

To abide by HIPAA requirements and to safeguard protected health information (PHI), FAC members are required to sign the following DSCC Membership & Confidentiality Agreement.

By signing below, I acknowledge and agree to follow the UIC Division of Specialized Care for Children Family Advisory Council Member Guideline terms, expectations, and confidentiality policy.

Print Full Name Here

Signature

Date