



Division of Specialized Care for Children

Family Advisory Council Closed Meeting August 8th, 2024, 9:00 AM

Attendees –

Jaclyn Vasquez	Aurea Garvin	Chelsie Hacker	Jasmine Deida
Ally Chenoweth	Byram Fager	Jessica Brafford	Aida Estrella
Ekiko Aiken	Mattanah Israel	Krystle Myers	Lindsay Ross
Jaleesha Allen	Claire Cook	Haley Phelps	Adell Scott
Jose Jimenez	Lisa Washington	Molly Hofmann	Ruann Barack
Stephanie Leach	Terri-Lynn Jones-Wood	Ebonie Zielinski	Erica Stearns

Welcome, Erica Stearns & Jaclyn Vasquez –

Erica Stearns, DSCC Home Care Family Outreach Associate and co-chair of the [Family Advisory Council \(FAC\)](#), highlighted the agenda and reviewed virtual meeting expectations. Participants were asked to introduce themselves in the chat. Everyone was reminded that the Family Advisory Council for the Division of Specialized Care for Children (DSCC) meeting was closed, for members only. **Erica Stearns and Jaclyn Vasquez**, co-chairs of the Family Advisory Council, introduced themselves, their roles, and experiences as mothers of medically complex children.

New Member Introductions, Erica Stearns –

Erica introduced two new members. She invited them to come on camera or use the chat to introduce themselves, encouraging a warm welcome from existing members.

Krystle Myers, a new FAC member, was the first to introduce herself, sharing her experience as a mother from Rockton, Illinois, whose daughter, Amelia, was diagnosed with a terminal disease. Krystle discussed her background in corporate coordination, which helped her navigate the complexities of the healthcare system. She expressed her passion for advocating for better care in Illinois, as her family had to seek medical treatment out of state due to inadequate care options locally.

Lindsay Ross, a new FAC member, introduced herself as the mother of 16-year-old identical twins, one of whom, Elena, has significant medical needs. Lindsay described her previous experience as a medical Spanish interpreter and how it influenced her advocacy for her

daughter. She spoke about the challenges of navigating the healthcare system and her commitment to making improvements.

Both new members emphasized their eagerness to contribute to the Family Advisory Council and help address systemic issues. Erica thanked them for sharing their stories and encouraged everyone to connect with the new members via chat.

Family Survey Overview, Ruann Barack –

Erica praised the Family Advisory Council (FAC) members for their hard work in improving the survey, which has helped capture valuable information from families. Erica acknowledged the challenges they had faced in getting people to fill out the survey in the past but highlighted the progress made. She then handed over the discussion to Ruann Barack.

Ruann Barack, the Associate Director of Quality Improvement in Education, expressed her gratitude to the families who participated in the 2024 family survey. She emphasized the importance of the feedback received, which helps DSCC continuously improve its services. Ruann provided an overview of the survey results, noting a slight increase in the response rate compared to the previous year. She discussed the strategies used to boost participation, such as sending reminder letters for mailed surveys, which led to a significant increase in responses.

Ruann managed to convey key points, including the breakdown of survey responses by program, gender, ethnicity, and urban vs. rural areas. She also highlighted the open-ended responses, which were categorized into appreciation and concerns, and discussed how these insights are used to make improvements.

After this segment of the meeting, Erica, Ruann, and Molly engaged with the attendees, addressing questions and comments. The discussion included the importance of follow-up on survey feedback, how the data informs strategic action plans, and the ongoing efforts to ensure that family voices are central to decision-making at DSCC. The conversation concluded with a commitment to using the survey results to guide improvements and a promise to keep the Family Advisory Council updated on the outcomes.

YAC & Transition Conference Update, Claire Cook –

Claire Cook, Title V Transition Specialist, provided updates on the [Youth Advisory Council \(YAC\)](#) and the upcoming Illinois Statewide Transition Conference. The Youth Advisory Council, which began accepting applications in April, now has eight confirmed members, with the first meeting scheduled for September. Meetings will be held quarterly, and applications are still being accepted via DSCC's website under the Youth Voice section. Claire also shared details about the [Illinois Statewide Transition Conference](#), which will be held in person on November 7th and 8th at the Crowne Plaza Conference Center in Springfield. The conference, designed for youth and young adults with disabilities, their families, caregivers, and professionals, will include three



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sessions presented in Spanish, with live interpretation available. The first session will be a family, caregiver, youth, and young adult meetup, led by Erica Stearns and Heather Long. DSCC will assist with booking and paying for hotel, travel, and meals for attendees. Claire encouraged those interested in attending, particularly FAC members with children approaching transition age, to connect with her for more information.

Family CNA Update, Molly Hofmann –

Molly Hofmann, DSCC Director of Care Coordination, Systems Development, and Education, provided an update on the progress of allowing legally responsible caregivers in the Home Care Program to be paid as Certified Nursing Assistants (CNAs) for their child's care. Previously, only parents who were Registered Nurses (RNs) or Licensed Practical Nurses (LPNs) could be paid for caregiving services, but recent legislation has expanded this to include CNAs. This expansion was part of a broader effort to support families during the COVID-19 pandemic and was made permanent in 2022-2023. The new legislation passed in the spring of 2023, allowing legally responsible caregivers to be paid as CNAs regardless of the child's age. However, the implementation requires updates to both the Medically Fragile Technology Dependent Waiver (MFTD) for those over 21 and a state plan amendment for those under 21, which must be approved by the Federal Centers for Medicare & Medicaid Services (CMS). These drafts are currently under review by the Health and Family Services (HFS) leadership team and will be open for public comment before being submitted for CMS approval.

Molly also discussed the logistical aspects of this initiative, including the CNA scope of practice in Illinois, which remains traditional without any expanded training programs. The update also covered a 7% rate increase for in-home care, including RN, LPN, and CNA care, expected to take effect on January 1st. Molly addressed questions from attendees, clarifying that CNA caregivers would not be paid for services outside their scope of practice, such as tracheostomy care or G-tube feeding unless performed off the clock. She also mentioned that a list of approximately 80 nursing agencies enrolled with DSCC is available on their website, which could assist parents like Lindsay, who inquired about preparing for the new CNA program. Molly recommended using resources like NurseNet to find nursing agencies and encouraged reaching out to DSCC for further assistance.

FAC Partnership in CC Training, Erica Stearns –

Erica shared her experience co-leading a training initiative with Jaclyn aimed at incorporating the family perspective into care coordination. This training is specifically designed for new care coordinators and occurs quarterly, providing an opportunity for Family Advisory Council (FAC)

members to share their caregiving experiences. The primary goal is to emphasize the importance of empathetic, personalized support in care coordination.

Training Goals:

1. **Highlight Family Experiences:** The training aims to provide care coordinators with insights into the daily challenges faced by caregivers, stressing the importance of understanding the family's perspective.
2. **Empathy and Personalization:** Emphasize the value of empathetic, personalized support over standardized care coordination.
3. **Collaboration with Families:** Encourage care coordinators to see families as partners in care, understanding that every family has unique challenges.

FAC Member Involvement:

- FAC members are invited to share their stories for 5-15 minutes during the training.
- Participation includes creating presentations with Erica, who supports them through the process. Compensation is provided for their time.
- The training allows care coordinators to ask questions and gain deeper insights into the real-life experiences of the families they will support.

Feedback and Impact:

- The training has received positive feedback from care coordinators, who found the stories moving and impactful.
- Erica noted that the training helps care coordinators better understand the complexities of the families' lives, ultimately leading to more effective and compassionate support.

Call to Action:

- Erica encouraged interested FAC members to participate in future sessions and expressed appreciation for the positive feedback and interest shown by the group.

Discussion, FAC members –

Krystle expressed her concerns about the coordination and expertise of care coordinators at DSCC. She highlighted the challenges in providing specialized support for children with complex medical conditions like cerebral palsy or leukodystrophy. ***Krystle*** suggested that care coordinators should receive specific training for different medical complexities to better assist families, particularly for children with progressive terminal diseases where time is critical.

- ✓ **Molly's Response-** She acknowledged the challenges mentioned by ***Krystle***. ***Molly*** then explained that DSCC provides care coordination for thousands of different diagnoses and



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emphasized their focus on a person-centered approach, where the family leads the care process. She also mentioned the importance of reliable resources, partnerships within the care team, and shared expertise among team members.

Krystle further elaborated on the urgency required for children with progressive terminal diseases. She emphasized the need for immediate access to the right specialists and resources, as delays could have severe consequences. She reiterated the importance of implementing specific guidance and support for children with fast-progressing conditions.

- ✓ **Erica's response-** appreciated Krystle's input and opened the floor for further discussion. Erica mentioned ongoing efforts at DSCC to address broader social, emotional, and mental health challenges that families face, beyond just the diagnosis-specific issues. She offered to share information on relevant training programs and welcomed input from other members.

Lindsay shared an emotional experience where her care coordinator, Rita Nesbitt, provided exceptional support during a difficult time. Lindsay was overwhelmed by the stress of scheduling an introduction with a new care coordinator, but Rita recognized her distress and offered to extend deadlines to alleviate the pressure. This compassionate gesture gave Lindsay peace of mind, as it was the first time anyone had been so understanding during a scheduled appointment. **Molly** responded by thanking Lindsay for sharing her story, emphasizing how such feedback motivates the team and helps improve their service to families.

Aida Estrella, FAC member, shared (in the chat) her experience with the challenges of being both a parent and a caregiver, especially when nursing companies are unable to provide consistent care. She highlighted the need for more resources to support parents who have to juggle multiple roles in caring for their children.

- ✓ **Erica** acknowledged Aida's challenges and recognized that many families in the home care program face similar issues. She invited further discussion and encouraged members to share any concerns, thoughts, or positive stories from their communities.

Closing, Erica Stearns –

The meeting concluded with gratitude and appreciation from **Erica**. Erica thanked everyone for attending, acknowledging the challenges of balancing busy summer schedules with the commitment to the Family Advisory Council. She expressed the DSCC team's appreciation for the participants' feedback, ideas, and ongoing partnership. Erica welcomed new members Krystle and Lindsay, encouraging everyone to continue sharing their experiences and

suggestions. She also mentioned that further discussion on the family survey and next steps would be addressed in future meetings. The meeting ended with well-wishes and an open invitation to reach out with any needs or ideas.