



Division of Specialized Care for Children

**Family Advisory Council
Open Meeting
November 14, 2024, 9:00 AM**

Attendees –

| | | | | |
|-----------------------|------------------|----------------------|----------------|------------------|
| Jaleesha Allen | Claire Cook | Dr. Ebonie Zielinski | Adell Scott | Amanda Simhauser |
| Brittani Provost | Erica Stearns | Violet Wiker | Jaclyn Vasquez | Aurea Garvin |
| Mary Herschelman | Marshae Young | Gail Koshgarian | Jasmine Deida | Kelly Whistler |
| Ally Chenoweth | Jessica Brafford | Mattanah Israel | Lindsay Ross | Haley Phelps |
| Isaias Vega | Lisa Washington | Dr. Molly Hofmann | Ruann Barack | Stephanie Leach |
| Terri-Lynn Jones-Wood | Jamie Renth | Jose Jimenez | Joy Martinez | Joyce Clay |
| Kendra Irby | Maritza Rivera | Robin Morgan | Shelly Roat | Susan Agrawal |
| Tim Kirschner | Tulha Mansoor | Miriam Orta-Frautso | Dena Chapman | |

Welcome, Erica Stearns & Jaclyn Vasquez –

The meeting began with a warm welcome from **Erica Stearns**, Division of Specialized Care for Children (DSCC) Home Care Family Outreach Associate and Family Advisory Council (FAC) co-chair, and **Jaclyn Vasquez**, Family Advisory Council co-chair, who emphasized the critical importance of fostering an inclusive and accessible environment for all participants. They reiterated DSCC’s commitment to ensuring meaningful engagement through bilingual access. Erica acknowledged the indispensable role of Isaias, the session’s interpreter, who has consistently provided high-quality interpretation services for [Family Advisory Council](#) meetings. Participants were given a quick tutorial on Zoom’s interpretation features to ensure smooth communication. Erica reviewed essential meeting protocols, including maintaining muted microphones to reduce background noise, using the chat for submitting questions, and properly identifying participants in the meeting chat for seamless interaction. The agenda was presented, and attendees were encouraged to contribute and collaborate during the discussions actively.

Needs Assessment Update, Dr. Ebonie Zielinski –

Dr. Ebonie Zielinski, Assistant Director of Operations for Research and Practice Initiatives at DSCC, presented key findings from the recent DSCC needs assessment, which provided valuable insights into the persistent challenges families face across Illinois. The assessment highlighted

significant barriers, including inadequate access to care, fragmented healthcare services, and a lack of support for smooth transitions between care systems. Families, particularly those in rural regions or relying on Medicaid, reported heightened isolation, systemic discrimination, and difficulty navigating healthcare systems. Dr. Zielinski shared strategies to address these challenges, focusing on building strong coalitions among providers, enhancing family engagement through targeted outreach, and training healthcare professionals to mitigate implicit bias and address anti-ableism practices. The presentation sparked a meaningful discussion among attendees about actionable strategies for implementing these solutions and improving care delivery for underserved populations.

Claire Cook, the Title V Transition Specialist for DSCC, outlined the organization's transition goals for the coming years, rooted in findings from a recent needs assessment. The primary objective is to empower Illinois teens and young adults with the tools and skills to successfully navigate adulthood. This includes improving access to healthcare, mental health support, substance use services, and sexual and reproductive healthcare. Additionally, a focus is placed on fostering self-advocacy skills and confidence so these young individuals can take charge of their futures. Claire emphasized the importance of addressing the gaps in support systems that leave many adolescents, with and without special healthcare needs, unprepared for the transition into adult life. Key areas include life skills, insurance navigation, and the shift from pediatric to adult healthcare providers.

To achieve these goals, DSCC plans to expand its outreach through educational opportunities, social media engagement, and community partnerships. Efforts will include collaboration with the [Youth Advisory Council \(YAC\)](#) to develop and review resources, ensuring youth voices are integrated into the process. DSCC also remains committed to providing person-centered care coordination for eligible children and their families, supporting a smooth transition to adult systems. Lastly, broadening partnerships across Illinois is critical to ensuring that resources reach the communities that need them most. Claire concluded with an invitation for further input and collaboration to refine these initiatives and ensure their success.

Dena Chapman, FAC meeting guest, provided feedback emphasizing the challenges parents face during the transition process for adult children with medically complex needs. Reflecting on her personal experience, she highlighted the lack of a structured process and the need for better education and preparation for parents. Dina suggested that transition planning should mirror the strong support provided for IEP and school transitions, offering clear guidance and resources for families. She noted widespread confusion about the appropriate age for transition and urged improved communication to clarify this aspect. Dina expressed her willingness to contribute to information sharing and discussions to enhance the transition experience for families.



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Family Training Update, Brittani Provost –

Brittani Provost, Manager of DSCC’s Benefits Management and Research Unit, provided updates on their health insurance education initiatives. Her team supports care coordination by addressing complex insurance issues and offering virtual health insurance webinars for families and community members each spring. Based on participant feedback from surveys, the webinars are scheduled for Tuesday evenings to ensure accessibility. For 2025, the series will focus on Home and Community-Based Waivers, featuring presentations from external organizations, including the Department of Rehabilitation Services and Developmental Disabilities. Materials and sessions will continue to be offered in Spanish, and resources, including recorded webinars from previous years, remain available on DSCC’s website.

The DSCC website, dsc.ue.edu, hosts recordings, slides, and materials for all past webinars under the “Family Education Webinars” section in the “Browse Resources” tab. This platform ensures ongoing access to educational content while noting that recorded information reflects its accuracy at the time of creation. Brittani concluded by welcoming questions and inviting attendees to explore these resources.

YAC & Transitional Conference Update, Claire Cook –

Claire Cook, Title V Transition Specialist, provided inspiring updates on the [Youth Advisory Council \(YAC\)](#) detailing its progress and initiatives. With seven active members, the YAC continues to make strides in empowering youth with special healthcare needs and incorporating their voices into DSCC’s strategic initiatives. Claire outlined recent projects, including the development of college readiness guides and transition planning resources. Recruitment efforts for expanding YAC membership were also highlighted, and attendees were encouraged to share this opportunity with eligible youth. Claire mentioned that participants are compensated with \$30 gift cards for each meeting as a token of appreciation for their time and input. The council’s work was commended for its focus on amplifying youth perspectives and shaping DSCC’s future direction in a meaningful way.

Interim Relief Overview, Haley Phelps –

Haley Phelps, Interim Relief Program Manager at DSCC, provided an overview of the Interim Relief Program, which addresses the shortage of psychiatric residential treatment options for youth enrolled in Medicaid. Haley described challenges such as long wait times and the lack of in-state treatment facilities, which often leave families in distress. To support caregivers in

navigating these difficulties, Haley unveiled a Caregiver Mental Health Toolkit, which is set to launch in November, coinciding with National Family Caregivers Month. The toolkit includes resources such as stress management strategies, access to crisis hotline numbers, and practical tools for self-care. Haley emphasized DSCC's commitment to supporting caregivers in managing their mental health while caring for children with complex needs.

FAC Accomplishments, Erica Stearns –

Erica Stearns, reflected on the achievements over the past year, celebrating its growing membership and influence within DSCC's organizational framework. Key accomplishments included increased language accessibility for non-English-speaking families, which has enhanced participation and representation, and the successful integration of family voices into major planning and decision-making processes. Erica acknowledged the dedication of FAC members, attributing the council's success to their invaluable contributions. She encouraged continued collaboration to further DSCC's mission of improving care and resources for families across Illinois.

Discussion, FAC members –

The Family Advisory Council (FAC) meeting discussion centered on lived experiences and perspectives shared by caregivers, DSCC staff, and FAC members about home care challenges and coordination.

Lindsay Ross, a FAC member, highlighted the transformative value of DSCC home visits, sharing her personal story of managing extensive medical equipment for her child and emphasizing the importance of understanding caregivers' realities.

Shelly Roat, Assistant Director, and former care coordinator, reflected on how firsthand home visits revealed the profound challenges families face beyond clinical descriptions.

Jessica Bradford, a FAC member, shared her appreciation for care coordinators' empathy and her pride in showing her child's organized medical setup, noting its positive impact on mental health.

Erica Stearns, DSCC Home Care Family Outreach Associate and Family Advisory Council co-chair, humorously described managing medical supplies as "medical equipment Tetris," underlining how caregivers' homes often double as field hospitals, affecting privacy and mental health.

The discussion also addressed resource challenges. ***Lindsay*** inquired about systems to redistribute unused medical supplies. ***Dr. Molly Hofmann***, Director of Care Coordination, Systems Development, and Education at DSCC, clarified that while DSCC does not currently have formal redistribution channels, it benefits from robust informal sharing mechanisms, such



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as engagement within community groups. *Erica* reinforced the importance of leveraging existing networks and improving care coordination transparency.

Aurea, a FAC member, raised questions about the scope of care coordinators' responsibilities, prompting *Lisa Washington*, DSCC's Associate Director, to detail the processes, including assessments, personalized care plans, and goal setting tailored to family needs. The interdisciplinary collaboration required for effective care, such as during hospital discharges or accessing local resources was communicated.

Concerns about caregiving and policy changes were discussed. FAC members debated the implications of **parents becoming CNAs** for their children, including potential long-term impacts on care authorization and insurance.

Suggestions included creating separate classifications for parent CNAs to protect families. DSCC representatives pledged to escalate these concerns to the administration and explore clarifications before policy implementation deadlines.

The session concluded with updates on early intervention advocacy, the importance of sharing caregiver stories, and reminders for upcoming meetings, emphasizing the collaborative approach to addressing families' needs.

Closing, Dr. Molly Hofmann –

Dr. Molly Hofmann concluded the meeting with heartfelt thanks to all attendees for their engagement and thoughtful contributions. She reiterated the critical role of the FAC in driving meaningful changes across DSCC's programs and services. Molly encouraged members to stay connected through DSCC's communication platforms and reminded them of the next scheduled meeting. Her remarks underscored the importance of continued collaboration to achieve shared goals and improve outcomes for families statewide.