



## Division of Specialized Care for Children

### Family Advisory Council Closed Meeting February 8, 2024, 9:00 AM

#### **Attendees –**

Adell Scott	Ally Chenoweth	Amanda Simhauser	Aurea Garvin	Byram Fager
Chelsie Hacker	Claire Cook	Ekiko Aiken	Erica Stearns	Ebonie Zielinski
Haley Phelps	Jaclyn Vasquez	Jasmine Deida	Jessica Brafford	Jose Jimenez
Kelly Whistler	Lauren Rivera	Lisa Washington	Mattanah Israel	Molly Hofmann
Robin Morgan	Rosa Cole	Aida Estrella	Ruann Barack	Stephanie Leach
Terri-Lynn Wood-Jones	Thomas Jerkowitz			

#### **Welcome, Erica Stearns & Jaclyn Vasquez –**

**Erica Stearns & Jaclyn Vasquez**, co-chairs of the Family Advisory Council, initiated the meeting with warmth and enthusiasm, emphasizing the importance of active participation and engagement. They introduced themselves as facilitators of the meeting and highlighted the significance of the gathering for the first time in the new year for the Family Advisory Council of the Division of Specialized Care for Children (DSCC). **Erica** shared an anecdote about meeting a fellow member, **Byram Fager**, underscoring the unique connections within the group. The facilitators addressed language accessibility, provided instructions for participation, and encouraged members to keep their cameras on during the meeting for enhanced engagement. They also highlighted the importance of following meeting protocols, including muting when not speaking and using the raise hand feature for engagement. Erica and Jaclyn concluded the welcome by expressing appreciation for the member's attendance and participation.

#### **New Member Introductions, Mattanah Israel –**

**Erica** welcomed **Mattanah Israel**, a new member with over 16 years of involvement with DSCC programs. Mattanah attended the previous open meeting but had not formally joined the Family Advisory Council (FAC) until now. Mattanah has been involved with DSCC programs for over 16 years as a parent in Region 4. She has also served as an ambassador for Every Mother, Illinois, a maternal and child health family council. Erica expressed her honor in having Mattanah join the council.

**Mattanah** expressed her interest in joining the FAC as a parent of a DSCC child. Mattanah shared her enthusiasm for sharing and receiving information about the programs.

**Jaclyn** shared her experience as a parent of a child with medical complexities during COVID-19 and the importance of connecting with other families.

**Aurea Garvin**, a FAC parent, joined the council at the suggestion of her care coordinator and found the experience valuable in advocating for her child.

**Jose Jimenez**, HFS staff, emphasized HFS's role in supporting families and policymaking, expressing willingness to assist with concerns.

**Robin Morgan**, HFS staff, shared her role in overseeing compliance with federal regulations and admiration for the caregivers' dedication.

Other FAC parents: **Jasmine Deida, Ekiko Aiken & Chelsea Hacker** also shared their experiences, challenges, and motivations for joining the FAC. Members expressed gratitude for the support and resources provided by DSCC and FAC in navigating complex medical needs.

**Byram Fager**, a FAC parent, shared his advocacy experience during COVID-19 and the importance of sharing information and resources with other families.

**Rosa Cole**, a FAC parent, who joined the FAC to gather information and connect with other families, expressed appreciation for the shared experiences and support within the group.

### **Member Engagement, Jaclyn Vasquez–**

**Jaclyn**, FAC Co-Chair, initiated the discussion by introducing the topic of ideal member engagement within the group. She highlighted the importance of adhering to best practices during virtual meetings, such as being on camera, when possible, and muting mics to minimize background noise. She emphasized the significance of active engagement from all members and encouraged various forms of participation, including reviewing meeting agendas in advance, and submitting topics for discussion to Erica. Members were encouraged to provide input on recommendations from staff or administration and to raise any new needs or concerns that may arise within the group. Jaclyn highlighted the importance of fostering a supportive environment where members can share experiences and collaborate to effect change. Jaclyn also emphasized the value of peer support and encouraged members to connect outside meetings to share insights and offer assistance.

The group discussed the importance of sharing feedback and ensuring that family-centered values and priorities remain central to the group's discussions and decisions. Jaclyn acknowledged recent initiatives, such as the trial of an online platform or portal and encouraged members to provide feedback on such initiatives to help improve services and resources for families.

Members were reminded to review and return the member guidelines with their signatures by February 15th, as requested by Jaclyn. She assured everyone that reminders would be sent out



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

accordingly. Jaclyn encouraged members to email any further questions or concerns and assured them that their input would be addressed and considered.

### ***CNA/LHA Home Care Update, Thomas Jerkovitz –***

**Thomas Jerkovitz**, the Executive Director at DSCC, led the discussion on the CNA/LHA Homecare Update, highlighting the progress of House Bill 4178 and its recent movement out of committee. Attendees engaged in a detailed discussion regarding House Bill 4178, seeking clarification on its provisions, impact on caregivers, and potential implications for family members providing care. Thomas provided insights into the legislative process, emphasizing the importance of understanding the terminology and the various stages a bill undergoes before enactment. Thomas discussed the significance of the online filing of witness slips and encouraged active participation in supporting or opposing bills electronically. **Stephanie Leach**, the Associate Director of Systems of Care at DSCC, offered clarification on the specifics of House Bill 4178, highlighting its focus on expanding support for family members providing care under the Medicaid program. Attendees discussed the potential inclusion of House Bill 4178 in the Medicaid omnibus bill and its implications for budget allocations and legislative timelines.

### ***Quality Update, Ruann Barack –***

**Ruann Barack**, Associate Director of Quality Improvement at DSCC, expressed gratitude for the opportunity to address the council. She provided updates on behalf of the council, focusing on the upcoming family survey and the continuation of initiatives from 2023 based on council feedback.

**Family Survey:** Ruann emphasized the importance of family voices in the annual survey. Highlighted enhancements made in 2023 based on council suggestions. She stated that the survey from 2023 will be used again for continuity, allowing for long-term analysis. Efforts to encourage survey participation have begun, including announcements and reminder notices.

**Survey Timeline:** Initial communications in January, survey distribution in February and March, with plans to close in mid-April. Ruann indicated that results will be analyzed, and feedback from the council will be sought for further insights.

**Family Webinars:** Ruann announced the continuation of family webinars in 2024, following positive feedback from the previous year. She stated the topics for the webinars including Social Security benefits, Medicaid denials, and transitioning health insurance benefits to adulthood, all derived from council suggestions.

## ***Communication Update, Amanda Simhauser –***

**Amanda Simhauser**, DSCC Communications Manager, reported on recent updates to the organization's website, highlighting the implementation of a searchable online resource directory containing over 1300 listings. She emphasized the improved user experience with the addition of search functionalities and display options for events on the website. Amanda provided insights into the decision to enhance the website based on feedback from the council, especially regarding the difficulty in navigating through extensive event listings.

Future Website Improvements: Amanda discussed ongoing efforts to refine the website's taxonomy to better organize resource directories and enhance user accessibility. She introduced new content additions to the website, including a social determinants of health information page and customizable "All About Me" templates for parents to share vital information with care providers.

Annual Report and Messaging: Amanda informed the council about the publication of the organization's annual report for FY 2023, highlighting program descriptions, outreach efforts, and partnerships. She acknowledged the contributions of Jaclyn, who was featured in the report's spotlight section.

Social Media and Outreach: Amanda highlighted the organization's social media efforts, including awareness campaigns for specific events such as Feeding Tube Awareness Week and Rare Disease Day. She encouraged council members to share resources and personal stories relevant to these events to increase awareness and engagement.

Updates on the Family Portal: Amanda provided updates on the implementation of the DSCC online portal, including initial announcements to participants and ongoing promotion efforts. She directed council members to the organization's website for more information and resources related to the family portal.

## ***Discussion, FAC members –***

**Lauren Rivera**, FAC parent, initiated the discussion by expressing concerns about the default settings for annual DSCC authorizations. She emphasized the need for families to have control over sharing sensitive information. Lauren shared her own experience with the default settings, highlighting the emotional burden it places on families and the administrative hassle for care coordinators to change them. She proposed allowing families to choose what information to share or making the process more flexible, such as through DocuSign or paper forms. **Stephanie Leach** acknowledged Lauren's concerns and expressed gratitude for bringing up the issue. She assured the group that the matter would be taken to the DSCC for further discussion.

**Aurea Garvin** shared her experience of being selected for the Camden Coalition Scholar Program. She discussed the conference she attended, highlighting the emphasis on social



## Division of Specialized Care for Children

services and changes in healthcare policies, particularly regarding Medicaid. Aurea also expressed disappointment at the lack of focus on pediatrics in some discussions and shared insights into medically fragile daycare services.

Thomas provided updates on the impact of cyber-attacks on healthcare systems, particularly the disruption caused by the attack on Lurie Children's Hospital of Chicago. The discussion highlighted the challenges faced by families and care coordinators due to the cyber-attack, including the shift back to paper records. UIC/DSCC has taken the necessary steps to secure safety to the best of its ability.

The discussion also touched on training options for Certified Nursing Assistants (CNAs). Participants explored the possibility of online training courses for CNAs, but it was noted that current requirements necessitate hands-on training and licensure. The conversation underscored the importance of staying informed about training opportunities and policy changes in the healthcare sector.

### ***Closing, Thomas Jerkovitz –***

***Thomas*** thanked participants for their engagement and emphasized the importance of continued collaboration in advancing the council's objectives. Erica commended council members for their active participation and encouraged ongoing engagement in future discussions and activities. Thomas expressed appreciation for the contributions of council members and reiterated the council's commitment to promoting family-centered care. He encouraged members to watch for follow-up emails containing additional information and resources.