UNIVERSITY OF
ILLINOIS CHICAGO

Division of Specialized Care for Children

Family Advisory Council

November 16, 2023, 9:00 AM

Attendees –

Abby | Adell Scott | Ally Chenoweth | Amanda Simhauser| Aurea Garvin | Beth Albert | Byram Fager | Chelsie Hacker | Claire Cook | Ekiko Alken | Erica Stearns | Jodie Lindgren | Gail Koshgarian | Marshae Young | Erika Larkin | Haley Phelps | Jaclyn Vasquez | Jaleesha Allen | Jasmine Deida | Jessica Brafford | Joanna Grzegorczyk | Jose Jimenez | Joyce Clay | Kelly Whistler | Lynne Riley | Mattanah Israel | Dr. Molly Hofmann | Patrick Lindstrom| Ruann Barack | Shelly Roat | Stephanie Leach | Violet Wiker | Susan Agrawal

Welcome, Erica Stearns –

Erica Stearns co-chair of the Family Advisory Council, DSCC staff, and mom involved in the Core and Home Care waiver programs in Southern Illinois, excitedly introduced ***Jaclyn Vasquez*** as the new co-chair. Jaclyn, a medical waiver recipient from the western suburbs, expressed her enthusiasm for the role. The meeting continued with participants introducing themselves in the chat, specifying their roles and affiliations.

New Co-Chair Introduction, Jaclyn Vasquez –

Jaclyn Vasquez, a dedicated advocate, and mother of four, shared her personal and professional background. With one of her children on a medical waiver, Jaclyn emphasized the importance of elevating the voices of families with medically complex children in policy discussions. Drawing on her experience as a former early childhood special education educator, she highlighted the gaps in support and policy issues for this population. Jaclyn expressed her passion for bringing stories to the forefront of conversations and centering the voices of marginalized populations, advocating for equitable solutions. She discussed her journey navigating the challenges of having a child in the hospital for 19 months and the loneliness that came with it. Joining the Family Advisory Council, she found a supportive community to connect with and a platform to raise awareness, advocate for change, and influence policy. Jaclyn also addressed the transition from Early Intervention to the school district for her three-year-old twin with a medical waiver, seeking insights and guidance from others who have gone through similar experiences. Jaclyn's commitment to learning, sharing, and effecting positive change was evident in her heartfelt message to the council.

Communications Update, **Amanda Simhauser** –

Amanda Simhauser, Communications Manager for DSCC, provided updates on various projects and initiatives. Amanda first shared information about the new DSCC Family Portal, designed to streamline communication between participants and care coordination teams. She highlighted the rollout of the portal and the accompanying outreach efforts, including hardcopy letters, email blasts, and social media posts.

Amanda discussed the upcoming DSCC annual report for FY 2023, set to be published in January, featuring achievements, partnerships, and a member spotlight on Jaclyn Vasquez. She also touched on improvements to the online organization of the Resource Directory, introducing a search feature to enhance accessibility.

The Communications Team attended the Illinois Statewide Transition Conference, where 25 participant families were sponsored by DSCC. Amanda shared positive feedback from families and highlighted the connections made during the event. Additionally, she mentioned ongoing and upcoming projects, such as creating fillable "About Me" templates and updating lists of sensory-friendly holiday events. Amanda expressed excitement about the addition of a media content specialist, Margo DePorter, who has contributed to multimedia content, including videos covering events like the Institute for Parents of Preschool Children who are Deaf or Hard of Hearing.

About Me Pages, **Stephanie Leach** –

Chelsie Hacker, a FAC parent, expressed appreciation for the feedback received during this meeting, emphasizing its significant impact on helping families. She raised a concern about the repetitive paperwork required for medical appointments and suggested the creation of a template to streamline information sharing with doctors. Stephanie Leach, the Associate Director of Systems of Care at DSCC, revealed that they are already working on "About Me" templates, acknowledging the need for such resources. These templates, set to roll out in December, will cover various aspects, including social and medical information, providing a standardized and efficient way for families to share essential details about their child's needs. Stephanie highlighted the templates' versatility, applicable to caregivers, therapists, teachers, and care coordinators. The initiative aims to go beyond DSCC families and benefit others who may find these templates valuable. Additionally, there was discussion about the broader policy issue of streamlining paperwork through HIPAA to create a centralized database accessible to medical professionals, reducing the burden of repetitive paperwork for families.

Participants discussed the upcoming rollout of "About Me" templates. Chelsie and others expressed enthusiasm for templates that cater to non-medical personnel, making it easier to convey important details to teachers and social workers. ***Jessica*** and ***Byram,*** FAC parents, shared insights about the STARS program initiated by Cardinal Glennon Hospital, which offers a unique identification number for families to provide critical medical information during emergencies. Jessica discussed the program's national scope and its benefits, emphasizing the importance of local hospitals embracing this initiative.

***Home Care Family Outreach,* Erica Stearns** –

Erica Stearns, the Home Care Family Outreach Associate at DSCC, presented the newly established role designed to offer support and connection to families with medically complex children. Erica shared her personal experiences as a mother of two children on the MFTD waiver and emphasized her dual role as a patient with medically complex conditions. The program aims to meet caregivers at the beginning of their journey, providing reassurance and support from one caregiver to another. Erica also highlighted the role as a supplemental resource for care coordinators, offering assistance to families facing unique challenges or transitions in care. The program is in its early stages, having been rolled out to families new to DSCC and in two regions, with plans for a wider release in early 2024. Erica encouraged questions and feedback from the council, expressing the organization's commitment to evolving and meeting the needs of families. Potential collaboration with other parent ambassador roles and plans for a broader rollout in the coming months was also highlighted.

Chelsie, shared insights on managing overwhelming information, suggesting periodic check-ins with families after an initial meeting.

Also initiated was a discussion highlighting the challenge of families not knowing their available resources and difficulty connecting with care coordinators. The need for a liaison position to assist families and a comprehensive resource database was emphasized by several participants, including ***Kelly Whistler*** and Chelsie. Suggestions included regular resource checks, personalized assistance for families, and better questions from care coordinators to identify needs effectively. The importance of building trust and a supportive relationship between families and care coordinators was also highlighted. The proposed improvements aimed to enhance the overall support system for families within DSCC.

***Review of Accomplishments,* Erica Stearns** –

Accomplishments of the FAC were celebrated, including improved survey participation, a health insurance education series, enhanced accessibility for Spanish-speaking members, development of more accessible tools for families and caregivers (Family Portal, About Me pages, fact sheets, etc.), and the incredible work of FAC members outside and beyond this group. The discussion acknowledged the internal hub for staff resources and discussed making more information accessible to the public.

Discussion, Community Guests, and FAC members –

The DSCC Family Advisory Council meeting touched on a heartwarming and celebratory note as a member, ***Byram***, shared a personal triumph. He expressed his joy over receiving a school picture of his grandson, showcasing a more inclusive and thoughtful approach by the photographers who captured the essence of his grandson without emphasizing medical equipment. Byram highlighted the significance of advocating for such small yet meaningful aspects of life that often get overlooked for children with special needs. He suggested that the Family Advisory Council, with its collective strength, could potentially collaborate on creating a fact sheet or resource to promote awareness and encourage similar inclusive practices in schools and other settings. The emotional impact of this simple act resonated with the group, emphasizing the importance of advocating for the holistic well-being and recognition of children with special needs beyond their medical challenges.

Mattanah Israel, a family member from northwest Illinois, has been involved with DSCC for 16 years. She expressed she's had positive experiences, emphasizing the importance of trust and communication with care coordinators.

Ekiko Alken, a member for five years, stressed the need for a comprehensive database and suggested a newsletter for resource updates. Amanda Simhauser highlighted the online Resource Directory with over 1200 listings and quarterly Resource Roundup newsletters.

Care Team Discussion, Dr. Molly Hofmann –

Dr. Hofmann, Director of Care Coordination, Systems Development and Education at DSCC, led a discussion that aimed to create a balance between necessary documentation for contractual obligations and ensuring valuable, non-transactional interactions. Family members provided feedback, expressing the importance of flexibility in communication methods and the need for coordination meetings with various care team members, especially during significant transitions. The conversation acknowledged the challenges posed by care coordinator turnover and emphasized the reciprocal nature of the caregiver-care coordinator relationship.

Medicaid Denials, Brittani Provost –

DSCC Family Advisory Council participants discussed challenges faced by families with Medicaid denials, particularly regarding over-the-counter medications and equipment. ***Brittani Provost*** from the Benefits Management and Research Team at DSCC addressed the issue, acknowledging the complexity of individual cases. Families were advised to work closely with care coordinators and reach out to the benefits team for assistance. Brittani also offered ongoing dialogue and support for families navigating Medicaid challenges.

Concerns about over-the-counter (OTC) products and potential updates on reimbursement rates were further discussed. Jose from the Illinois Department of Healthcare and Family Services (HFS) provided insights into the challenges related to OTCs, explaining that when a product becomes OTC, it no longer requires a prescriber, making it non-matchable for Medicaid coverage. He acknowledged the balance between removing the prescriber barrier and introducing an out-of-pocket cost barrier. Additionally, an inquiry was made about reimbursement rate increases, and it was clarified that there was a potential increase effective January 1, 2024, pending CMS approval for a waiver amendment. The update is part of the ongoing process, and HFS will inform DSCC once CMS provides approval.

Closing, **Erica Stearns** –

Erica stated the presentation by EverThrive, will be rescheduled. Participants then discussed various committee updates, including the NICU-to-Home project focusing on post-hospital discharge support. Jaclyn shared her involvement in the National Research Network, aiming to influence research for system-level changes in pediatric healthcare. Jaclyn discussed her participation in the National Family Advisory Board and urged families to contribute their voices. Member ***Aurea Garvin*** shared their experience with the Camden Coalition program, emphasizing the importance of pediatric perspectives in national discussions about Medicaid changes. ***Joyce Clay*** (community guest) discussed her work with the National Rare Disease Commission and recommended that all caregivers doing advocacy work outside this council remember to include the population of aging medically complex participants who are over the age of 21 and facing many challenges.

Resource Contributions from Meeting Participants –

1. CYSHCNet (Children and Youth with Special Health Care Needs Network): https://www.cyshc.net/

2. Illinois Respite Coalition Respite Taskforce: http://www.illinoisrespitecoalition.org/

3. Camden Coalition Scholar Program: https://camdenhealth.org/work/national-consumer-scholars/

4. Rare Disease Commission: https://dph.illinois.gov/resource-center/advisory-boards/illinois-rare-diseases-commission.html

5. Family to Family Health Information Center and Family Voices (Illinois): https://www.thearcofil.org/about-us/programs/family-to-family-health-information-center-2/

6. Family Voices: https://familyvoices.org/felsc/whataref2fs/