



## Division of Specialized Care for Children

### Family Advisory Council

#### Open Meeting

May 9, 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
Christina Kiesewetter	Gail Koshgarian	Jamie Renth	Mattanah Israel	Molly Hofmann
Robin Morgan	Rosa Cole	Ross Cole	Ruann Barack	Stephanie Leach
Terri-Lynn Wood-Jones	Thomas Jerkovitz	Mary Herschelman	Violet Wiker	Shelly Roat
Joyce Clay	Susan Agrawal	Abby Huff	Jennifer Meyers	Deb Oelker
Melanie Turenne	Lauren Schrero	Joy Martinez	Mary Rubenstein	Lashonda
Bryan Heine	Tamela Alexander			

#### **Welcome, Erica Stearns –**

**Erica Stearns**, DSCC Home Care Family Outreach Associate and co-chair of the Family Advisory Council, initiated the meeting with warmth and enthusiasm, emphasizing the importance of active participation and engagement.

#### **FAC Member Recruitment, Jaclyn Vasquez –**

**Jaclyn Vasquez**, DSCC family member and co-chair of the [Family Advisory Council](#), shared that two open recruitment positions are available, and new members from Southern Illinois are joining. Interested individuals are encouraged to join the Council by reaching out via email. She shared that meetings provide a platform to share stories and support others across the state, with open forums available for broader discussions with the community at large.

#### **NurseNet, Stephanie Leach –**

**Stephanie Leach**, DSCC Associate Director of Systems of Care, provided an update on [NurseNet](#), a new platform developed to support in-home, shift-based nursing for the home care program. NurseNet allows families to specify their nursing needs and matches them with available nurses from DSCC approved home health nursing agencies across the state. The platform was officially launched on April 9<sup>th</sup> after extensive testing and feedback. Currently, about 50 nursing agencies and 12 family users are registered, with ongoing efforts to assist with registration and gather

feedback for improvements. Additional information and a feedback form are available on the website.

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

***Ruann Barack***, DSCC Associate Director of Quality Improvement and Education, provided updates on the annual family survey, family webinars for 2024, and DSCC's recent accreditation. The family survey, which began on February 15 in English and Spanish, has a response rate of approximately 22.6%, comparable to last year. Initial survey results show that while some areas like satisfaction with care coordination have improved, others such as education support need further analysis. A deeper analysis of the survey results will be presented at the next Family Advisory Council meeting, where feedback will be solicited to develop an improvement plan. The [2024 DSCC Health Insurance Education](#) webinar series have started, with recordings of the March and April sessions available online, and the next webinar scheduled for May 14. Additionally, DSCC achieved NCQA accreditation on April 19 for three years, aligning their practices with best-case management standards and demonstrating a commitment to continuous quality improvement. This accreditation underscores DSCC's dedication to enhancing care coordination and program measures.

***Jaclyn Vasquez*** suggests that in the next meeting, they should dive into a deeper analysis of the data. She requests that the data be disaggregated by race and geographic location to see different opinions based on these factors. Additionally, she asks for a reminder of the recruitment strategies used, to help brainstorm for the next iteration. Jaclyn emphasizes the importance of thinking outside the box and mentions considering places like waiting rooms for conducting surveys.

### ***Communications Update, Amanda Simhauser –***

***Amanda Simhauser***, DSCC Manager of Communications, provided an update on communication efforts. She began by discussing the promotion of their health insurance education series, ensuring that both participant families and the wider community are aware of these sessions. This outreach has been conducted through newsletters, social media, and their website. Amanda highlighted that recordings from this year's and last year's sessions are available on their website. She also mentioned the upcoming session on May 14 and encouraged everyone to explore the resources and information available online.

Amanda then shifted to discussing their annual roundup of [inclusive summer camp](#) opportunities in Illinois, which are promoted through various channels to inform families about day, overnight, and virtual camps for all ages and abilities. She explained the improvements made to [DSCC Events page](#), including a new search component and filter tools to help users easily find specific camps or events. She encouraged attendees to contribute information about any local events that might benefit families and directed them to their news page for updates on DSCC initiatives. Lastly, Amanda promoted DSCC's social media presence, particularly on



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[Facebook](#), where they share information about events, resources, and staff highlights, especially during awareness months. She concluded by providing her contact information for further feedback and suggestions.

### ***Youth Advisory Council, Claire Cook –***

***Claire Cook***, Title V Transition Specialist, introduced the new [Youth Advisory Council \(YAC\)](#). The YAC is designed for youth and young adults aged 15 to 24 with special healthcare needs in Illinois, focusing on their transition to adulthood. The council aims to provide these individuals with a platform to share their perspectives on important issues and help improve communication strategies. Meetings will be held quarterly, and participants will receive gift cards. Information about the YAC, including a flyer, FAQs, and application forms in English and Spanish, is available on the DSCC website. Claire also provided her contact information for those needing additional details or application assistance.

***Stephanie Leach***, expressed excitement about the launch of the YAC, emphasizing its long-awaited need and the value of listening to youth voices. She reiterated that membership is open to all qualifying youth with special healthcare needs in Illinois, not just DSCC participants. This initiative underscores the importance of inclusive and representative feedback to shape the support and resources provided by the DSCC.

### ***EverThrive Presentation, Tamela Milan-Alexander –***

***Tamela Milan-Alexander***, Community Engagement Director at EverThrive Illinois, presented information about the Title V Maternal and Child Health Advisory Council, known as the MCH Family Council. She highlighted EverThrive Illinois's mission to achieve reproductive justice and health equity through policy action and systems change. Tamela explained that the MCH Family Council is a platform for participants of Title V programs or any MCH-related programs to provide feedback and shape women's health programming in Illinois. The council meets quarterly, and members receive a stipend for their participation. Tamela emphasized the importance of leveraging the voices of those with lived experiences to educate and inform state health initiatives, sharing resources like their maternal mortality campaign.

***Matannah Israel***, FAC member and ambassador on the MCH Family Council, shared her positive experiences with EverThrive Illinois. She highlighted the networking and advocacy opportunities provided by the council, including speaking to the governor about early childhood programs. Matannah appreciated the safe space offered by the council for sharing experiences and gaining valuable resources. The discussion underscored the importance of cross-

collaboration between advisory councils to enhance health equity and community engagement. The session concluded with encouragement for members to join the MCH Family Council and gratitude for Tamela's informative presentation.

### ***Discussion, FAC members and Guests –***

***Aurea Gavin***, FAC member and a current scholar of the Camden Coalition, shared about an opportunity through the [National Low Income Housing Coalition's \(NLIHC\) 2024 Collective Cohort](#), specifically for people who have used various federal assistance programs to participate in writing suggestions to congresspeople. She emphasized the importance of women being heard.

***Matannah Israel*** discussed parents getting compensated through [Division of Rehabilitative Services \(DRS\)](#) to care for their children is starting to become a trend, advising parents to contact their care coordinator for more information. Additionally, ***Thomas Jerkovitz*** mentioned legislation introduced in the House allowing licensed CNAs to care for their children for compensation. However, the bill is currently stuck in house rules, though it may resurface later. ***Erica Stearns*** acknowledged the updates and shared limited knowledge on the difference between DSCC and DRS regarding paid parent caregiving programs, emphasizing the differences in services and waiver types.

***Erica Stearns*** highlighted (from an anonymous FAC member) that unreliable transportation has caused many families to miss appointments or be unable to participate in community activities. The main problem seems to be a lack of reliable transportation providers.

***Joyce Clay***, community guest, shared her experience attempting to become her child's transportation provider through the [IMPACT](#) program, which was a complex and frustrating process filled with roadblocks, leading her to abandon it.

***Ekiko Aiken***, FAC member, shared her difficulties using PACE transportation for her child, describing a particularly bad experience where they were stuck on the bus for hours, causing them to be late for an appointment. She suggested that having a system to prioritize medically complex children would be beneficial.

***Bryan Heine***, Tri County Special Education Family Liaison from Southern Illinois, spoke about the frequent last-minute cancellations families face due to the unavailability of transportation providers, despite scheduling well in advance. Bryan addressed the transportation challenges for medical appointments, especially those in St. Louis. Locally, they've managed to use their transportation, but distant appointments require coordination with managed care plans like Meridian and Molina. Consistency with transportation services remains an issue, causing stress for families due to the potential for missed appointments. They've tried to mitigate this by recommending reliable companies and requesting the removal of unreliable ones from the



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service lists. A local transportation company goes to St. Louis once a week and attempts to schedule appointments around this availability.

**Mary Otts-Rubenstein**, community guest, highlighted the significant transportation issues in Chicago for families with medically fragile children. Despite using various services like Medicaid routes, PACE, and Uber, they face a shortage of wheelchair-accessible vehicles. The process for services like PACE is slow, and Chicago Public Schools' in-person requirements add to the complications. She suggested that purchasing wheelchair vans might be more efficient than constantly diverting donation dollars to transportation.

**Jessica Bradford**, FAC Member from southern Illinois, shared her experience of buying a van to transport her son's medical equipment due to the lack of transportation options to St. Louis hospitals. Without the van, attending appointments would have been extremely difficult. She sought additional local resources for transportation.

**Shelly Roat**, DSCC Assistant Director of Operations for Core Southern Region, provided information regarding TransDev (previously known First Transit), the HFS contracted company which approves and/or arranges transportation to and from medical appointments for participants with All Kids/Medicaid. Updated information and clarification on eligibility was shared regarding [IMPACT](#) provider enrollment. IMPACT is a Medicaid software program used to reimburse healthcare providers like doctors and HMOs. She stated IMPACT is not designed for parents seeking travel reimbursements, making it a complicated process. Providers need credentials such as Social Security numbers and tax IDs. Parents enrolling to get reimbursed for driving their child need car insurance, a driver's license, and a Social Security number. Shelly confirmed that non-family members, including grandparents and aunts, are eligible to enroll in the IMPACT program for child transportation. Upon completing the required steps, they can receive approval and reimbursement. The system does not verify if the transporter is the child's parent.

For those interested in the [IMPACT](#) program and reimbursement options, Shelly suggested that DSCC participant families consult with their care coordinators for guidance, emphasizing the importance of continued collaboration and support. Shelly recommends families to contact their DSCC care coordinator for assistance if they are having difficulty getting travel for an appointment approved by Transdev or Transdev cannot locate a transportation provider.

**Melanie Turenne**, community guest, spoke about the nursing shortages exacerbated by COVID-19, which forced her to leave her job to care for her son. Despite hiring a private caregiver for respite care at personal expense, she inquired about using respite funds for non-medical

caregivers. It was clarified that the waiver allows 336 hours of respite per year, which can be used anytime but must involve an RN, LPN, or CNA paid by the agency.

The discussion concluded with a conversation between guests about personal care services for children with Medicaid. Additionally, DSCC staff members proposed the formation of a subcommittee to address transportation-related issues impacting DSCC participant families. Both community members and FAC members expressed interest in joining a future subcommittee. Erica Stearns will provide ongoing communication regarding future [Transportation Subcommittee](#) updates, with initial invitation to be included in the FAC Meeting Minutes follow-up email.

### ***Closing, Thomas Jerkovitz –***

***Tom Jerkovitz***, DSCC Executive Director, expressed gratitude to all participants and highlighted the importance of smaller groups within the larger assembly to effectively address and develop new ideas. He thanked Tamela for her presentation on EverThrive and others like Bryan and Susan for their contributions, especially in the context of complex and evolving programs. Jerkovitz emphasized the value of these meetings in facilitating collaboration and spreading awareness about various initiatives and waivers within the state, acknowledging the complexity and the need for collective effort and knowledge sharing.

### ***Resources Shared:***

[DSCC's NurseNet](#)

[DSCC's Family Education Webinars](#)

[Inclusive Summer Camp Programs](#)

[Youth Advisory Council \(YAC\)](#)

[EverThrive](#)

[National Low Income Housing Coalition's 2024 Collective Cohort](#)

[Transportation Subcommittee](#)

[About IMPACT](#)

[IMPACT Guide for Families](#)

[Illinois Medicaid Managed Care Transportation Toolkit](#)

[Family-to-Family Health Information Center](#)

[Personal Care Services \(PCS\)](#)