



Division of Specialized Care for Children

Family Advisory Council
August 24, 2023 9:00AM

Attendance

Ally Chenoweth	Jodie Lindgren	Adell Scott
Byram Fager	Erica Stearns	Ruann Barack
Gail Koshgarian	Claire Cook	Stephanie Leach
Jaclyn Vasquez	Haley Phelps	Amanda
Jessica Brafford	Tom Jerkovitz	Simhauser
Kelly Whistler	Molly Hofmann	Nikki Goldwater
Mary Herschelman	Violet Wiker	Jose Jimenez
Ekiko Aiken	Amy Hrdlicka	Mac Burks
Aida Estrella	Ebonie Zielinski	Mario Civito
Aurea Garvin	Terri-Lynn Jones-	Patricia Perez
Jasmine Deida	Wood	

Welcome & Meeting Structure Update | Erica Stearns (FAC Chair): Erica Stearns, FAC Chair, explained closed meetings are for DSCC staff, stakeholders invited by HFS, and official FAC members. These meetings are more detailed, and attendees are privileged to have more opportunities to interact with DSCC. In open meetings the public, participants, and their family members are invited, DSCC updates are brief to leave room for discussions with the public, DSCC, and FAC members.

FAC Member Introductions: Erica Stearns shared her story as an example for other FAC members to introduce themselves. She then asked FAC members to introduce themselves.

- **Jessica Brafford** is a southern Illinois parent with one child: a DSCC participant.
- **Jaclyn Vasquez** is an around-the-clock mom-nurse with a trach and vent-dependent child and DSCC participant. She is passionate about policy and advocacy. Supporting changes for all children with specialized care.
- **Ally Chenoweth**, is the mom of a 5-year-old DSCC participant who joined FAC to learn ways to help her son.
- **Mary Herschelman**, a member, and mother of a former DSCC participant. The participant passed away in 2021 but Mary continues to help in a way to honor her daughter and help other families.
- **Aurea Garvin** joined FAC to advocate as a mom who wants the best for her son.

- **Kelly Whistler** is a northwest suburb mom of a 14-year-old DSCC participant with multiple diagnoses. She brings information to help DSCC understand the needs of families with complex medical diagnoses with hospital-level care at home.
- **Byram Fager** is a grandfather with a grandson in the DSCC program. He became very active in his grandson's healthcare and was invited to join the group.
- **Jasmine Deida** has been an FAC member for 3 years. She has an 8-year-old DSCC participant and likes to advocate as a former DSCC participant herself.
- New member, **Ekiko Aiken** introduced herself and shared her story of having a medically fragile daughter and DSCC participant who passed away last year. Ekiko fought to the very end to advocate for her daughter, she became a FAC member to help families, with her experience, to not go through what her family went through and to continue learning.
- **Aida Estrella**, the new Spanish-speaking FAC member, is very happy to be a part of the FAC and feels very fortunate to be able to participate in giving support and opinions to other families and being able to share and be heard helping each other. Aida has a 6-year-old son who is a DSCC participant. Aida is a mom and a caregiver. She has learned so much since the nurse shortage and would like to help and learn from everyone.

Erica added that she previously met Aida and shared how Aida helped her realize the lack of bilingual nurses. She asked Aida to join the FAC to advocate for Spanish-speaking families.

- **Gail**, the mom of a 26-year-old DSCC participant, joined the FAC to advocate for other parents.

Quality Update / Ruann Barack (DSCC)

Ruann Barack, Associate Director of Quality Improvement and Education, shared a presentation on quality improvement activities. She noted that DSCC had been working on an improved authorization form. The new single-sign authorization form and signature part have been made clearer for families and was implemented in July 2023 with the goal to cut down the amount of time and number of forms to be signed.

NCQA Update: Ruann explained that DSCC continues to work towards NCQA accreditation. The survey date is scheduled for February 6, 2023, with a lookback period that started in August 2023.

2023 Family Survey Results: Ruann thanked the FAC members for their responses to the family survey and for their input and ideas on how DSCC can continue to engage with families. At the last meeting, there were recommendations to look at the data in multiple ways through demographics and categories. This was taken into consideration in this year's survey results. Ruann presented a response rate graph comparison between the years 2022 and 2023 responses. The year 2022 with 106 responses vs. the year 2023 with



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899 responses. Ruann showed a breakout by families per program and population. (See attached PowerPoint slides for more details)

A breakout of all DSCC program responses was measured with the 5-point metric scale with 5 being "strongly agree." All responses were above 4 points. Ruann shared a comparison of responses from 2021-2022 and 2023 and the results over time. She stated that DSCC was very grateful for survey comments because they helped DSCC adjust and know in which areas to focus to be better.

Ruann gave examples of how families have guided DSCC to improve care coordination, communication, connection, and engagement with families and added that DSCC is in the process of implementing a new family portal to connect with families, currently in the development process, and also developing an "About me" template for families to personalize for their child and to share with team members. For the current fiscal year 2024, DSCC is focusing on education and training for care coordination teams and best practice basics, such as collaboration, communication, follow-through, and partnership. DSCC is in the process of making improvements to tools on the DSCC website, making them more searchable and better organized. A grievance process was implemented earlier this year for families to share any concerns they have at any time; and in regard to the nursing area, DSCC has increased their outreach to nursing agencies that have the required license needed in order to recruit more nurses.

DSCC has been in collaboration with the Department of Healthcare and Family Services and Programs within the Illinois Department of Public Health so that nursing agencies that work with DSCC are able to receive a license to work across the state, in an effort to help with more nursing for families. DSCC is developing an interactive website for families to connect with nursing agencies which will be called Nurse Net. All these have been developed from feedback from family surveys.

Questions/ Comments:

- Jaclyn Vasquez shared her excitement to see new survey measures. She noted that only a quarter of the DSCC population responded and seeing that the majority were white, she asked how many languages the survey available.

Ruann noted that the survey was available in English and Spanish.

Jaclyn then asked, if care coordinators are reaching out to families that need additional support in completing the survey and if not, for this to be a subject to think about in the future. Because white individuals are the overwhelming majority being served by the waiver program and knowing the need for the help of black and brown families, maybe these families might not be getting the proper support and suggested this topic needs a bigger conversation for more research and a deeper dive to understand where the connect is, maybe looking at the area the majority of responses came from, to check lack of responses by areas. She suggested a third leg of research to identify root causes to address the needs of families that are under the radar and work with medical professionals to better identify families who need help.

Ruann thanked Jaclyn for all her feedback and stated she would take it back to research with Patricia Perez, who helped with the survey.

- Molly Hofmann explained that DSCC has 4 care coordination programs in operation, and also has the responsibility of being the state's Title V entity dedicated to serving children with special health care needs and that with this role, every 5 years DSCC goes through the needs assessments looking at root causes and understanding more about who might be under the radar and who needs help. She suggested that this should be addressed to the DSCC Title V, Ebonie Zielinski, Assistant Director of Research & Practice Initiatives, who is in charge of Title V needs assessment in partnership with the Illinois Department of Public Health and assistance from the University of Illinois Chicago School of Public Health.

As DSCC gets closer to the Needs Assessment, there will be opportunities for FAC members to participate in providing feedback about the broader system not just about DSCC services, such as challenges with services in schools, community resources, therapy providers, etc. and also opportunity to distribute amongst other individuals that would like to share their experience and have the opportunity to participate. DSCC is trying to hear from as many people as possible, especially looking at minority populations and making sure DSCC captures the voice that represents Illinois well.

Jaclyn Vasquez thanked Molly for the information and added that it would be interesting to be looked at by the FAC members and equally interesting to understand from the needs assessments how it would be implemented into the DSCC strategic planning process moving forward.

Molly added that the needs assessment will still be talked about around this time next year and every 5 years the Health Services Research Administration (where DSCC gets Title V grant money from), requires



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DSCC to have a system-building priorities action plan and explained that DSCC's current priority is preparation for transition to adulthood, and collaborating with other community partners and state entities to support and try to address system challenges. She is looking forward to additional discussion and feedback from this group regarding this matter.

Title V Needs Assessment | Ebonie Zielinski (DSCC)

Ebonie Zielinski, DSCC Assistant Director of Research and Practice, works in collaboration with Stephanie Leach, looking at statewide initiatives which are considered Title V for children with special healthcare needs.

Ebonie explained the Title V program is a part of the Social Security Act, known as the Maternal Child Health Program through all 59 states and jurisdictions, money that comes out to different state programs to improve the health and well-being of the nation's mothers, children, and their families. Throughout the state, there are maternal health, child health, and adolescent health, and DSCC is the grant holder for children and youth with special health care needs.

The definition for children and youth with special healthcare needs is children who have or are at risk for chronic medical, physical, developmental, and emotional conditions and who require healthcare or other services beyond what a child might normally need. Ebonie explained what a needs assessment means and that the process is done every five years. Advocacy and engagement are key. Families can help by sharing information. Ebonie stated if members are interested in participating and being a part of the needs assessment please reach out to DSCC.

Questions/Comments:

- Kelly suggested talking about outreach to families a lot of families, hospitals, and some health providers such as physical therapists, occupational therapists, etc., who are not familiar with the program. She asked if there was any outreach to other services/providers that might be able to spread information about DSCC to get resources for families/providers.

Ebonie asked Kelly if she knew specifically of hospitals or organizations needing information and explained that DSCC has hospital liaisons that can reach out to organizations that need information.

Molly added that DSCC has 11 different regional teams across the state, and they all have different outreach to communities and suggested if

Kelly is aware of a particular group, DSCC can have someone provide information and awareness about DSCC.

- Erika wanted to acknowledge that there are families that go unheard for different reasons but are still impacted by the changes and explained that FAC wants to partner with DSCC to help with outreach to families.
- Ekkiko shared that when she moved to Illinois 5 years ago, she found out about DSCC through a parent at school, and wondered how would she have known about DSCC if it wasn't for the school parent since the hospital they referred her family to, did not connect them with DSCC; and stated one of the resources given was SSI and asked if DSCC is a part of the SSI listing?

Molly explained that DSCC receives monthly lists of children enrolled with SSI, from adverse pregnancy outcome recording and newborn screening lists through IDPH. DSCC reaches out to families from those lists sending them information about DSCC. DSCC takes referrals from anyone, and this can be done through the website.

Kelly added that the majority who find DSCC are parent-to-parent and a big part of it is the community sharing those resources. Even when families are told about DSCC and programs there are families that are so overwhelmed that forget to ask for help. Kelly stated that care coordinators wait for families to ask for help rather than offering help with different resources.

Molly added that after this issue was shared last year, DSCC put together training for DSCC teams and webinars for families and participants to participate. There is a series of 3 recorded webinars on the DSCC website: <https://dsc.uic.edu/family-education-webinars/>

- Aurea Garvin asked as far as schools and daycares knowledge about services, does DSCC go out to them to share information?

Molly explained that DSCC does outreach and connects with different organizations that reach a large number of schools such as IDPH and suggested sending DSCC outreach material to the FAC members to have available to share.

Kelly suggested having some type of business cards for the FAC to hand out to families that are not aware/familiar with the program.

Erica read comments in the chat: Violet Wiker's comment said: "The Child Care Resource and Referral Programs were also visited, and staff were provided a brief in-service about DSCC. This was done pre-covid. Molly added these were done virtually as well. Nikki wrote that managers



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in the Chicago regions have attended large back-to-school fairs hosted by various groups that support children with special healthcare needs.

About Me Page Update | Stephanie Leach (DSCC)

Stephanie Leach talked about the "About Me" page and explained it is being created from feedback from family's frustrations and concerns about explaining over and over again about their children with different providers. DSCC is creating different templates for families to fill in for anybody that needs to know about their child, this could be given to doctors, therapists, extended family members, care coordinators, schools, etc., with the information families would want them to know about their child. She noted that Erica, Amanda Simhauser, Terri-Lynn Jones Wood, and herself are part of this committee and are trying to create optional fillable templates for all people who have children with special health care needs not only for DSCC participants but also for families who are not enrolled and might want it as a resource. These will come out as soon as possible and will be available on the DSCC website and sent out by email as well. If DSCC families fill them out, they will be uploaded into the care coordination software to be accessible to all providers. More to come.

Communications Update | Amanda Simhauser (DSCC)

Erica explained the communications update would follow in an email since presenter Amanda Simhauser was not available. Ebonie explained information will be sent to targeted groups, and also will be shared on DSCC social media sites. Ebonie suggested to start looking out for communications later this fall and offered her contact information in case anyone had any questions or further comments.

Mental Health First Aid Toolkit | Haley Phelps (DSCC)

Haley explained that the Mental Health First Aid Toolkit is still in the works, DSCC is trying to find more tangible training and resources to provide to families, including resources surrounding caregiver burnout. More updates will be available in future meetings and internal initiatives that the DSCC Learning support team has created to improve health literacy for care coordination teams and DSCC families.

Discussion | Erica Stearns (FAC Chair) and FAC members

- Erica shared that she has taken a position as a staff member with DSCC and explained her new role as the Home Care Family Outreach Associate. Erica stated how she became the FAC chair, and asked FAC members if anyone is interested in taking the FAC chair position, or co-Chair, since she will be working for DSCC, to let her and/or DSCC FAC

workgroup members know. Erika added that if anyone is not comfortable with her continuing to be part of the FAC please let them know as well.

- Jaclyn Vasquez asked if there are any updates on policies and/or legislation, regarding nursing shortage and paid caregivers.

Kelly added that specifically for a reimbursement rate increase, since she was told there was a 40% increase, and after that, she was told by someone from the legislation side that it was only a 20% increase. Kelly asked for clarification.

Molly stated that the most recent update from HFS was that they are still working on pulling together numbers on rates and a public notice will be coming soon, expected to take place in January. She is hoping to hear some additional information soon.

There have been discussions amongst parents in the home care program with their local legislators and HFS looking at who is able to be a paid caregiver and types of paid caregivers. But there isn't anything definitive yet as far as the next steps or what the legislation proposed. Jaclyn can follow up via email if she has additional questions.

- Kelly asked if there is a program for Chicagoland or Illinois hospitals where doctors or residents go to home visits and if this was something DSCC is involved in.

Molly explained that DSCC is aware of Almost Home Kids having a program in place in combination with the University of Chicago. Medical students and residents go and rotate through Almost Home Care facilities including home visits and accompany the family and child to provider's visits so they can understand the challenges with transportation and the multiple dynamics involved. Other medical residents and students from different hospitals are able to participate.

Jaclyn Vasquez added there are other hospitals with similar programs.

Kelly asked if that was something DSCC would benefit from being involved in. Having care coordinators spend half a day with participants at their homes so they can be involved and see what families need.

Molly explained that since the public health emergency is officially over, DSCC has resumed face-to-face visits, which means care coordinators should be contacting families to schedule these visits. Per guidelines and procedures in place, DSCC requires two face-to-face visits per year. She expects parents should be hearing soon from care coordinators and shared how nice it is to hear how helpful face-to-face visits are since there



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are families that feel face-to-face visits are a burden and refuse to schedule visits.

Kelly stated that care coordinators should be going to visits to understand the family's needs and provide resources they can offer to the family. She added that it becomes a burden when Care Coordinators go to visits just to get updates with a questionnaire rather than really checking on the well-being of the family.

Ekkiko noted that a potential partnership with medical students at home visits could serve the family in getting approval for their needs. Having a medical student coming and documenting that for families would be helpful. Instead of families documenting and trying to get approval, it would be helpful to have someone in the medical field make the letter of necessity and be able to submit that to insurance or provider, for approval.

- Kelly suggested that DSCC should be involved in the recruitment of nurses when graduating from school.
- Erica will gather all discussion points in an email for the FAC workgroup to discuss and will send updates.
- Erica stated that the FAC will be working on all topics sent in the background and thanked everyone for their attendance and engagement.

Next Meeting-Open Forum: **November 16, 2023, 9:00-11:00 am**