



Division of Specialized Care for Children

Family Advisory Council
November 10, 2022 9:00 AM

Attendees:	Claire Cook	Haley Phelps	Adell Scott
	Amanda Simhauser	Amy Gorman	Erica Stearns
	Julie Martin	Byram Fager	Jamie Renth
	Maddie Hinkle	Marcela Flores	Mary Dixon
	Mary Herschelman	Molly Hofmann	Nancy Leman
	Nikki Goldwater	Patricia Perez	Robin Morgan
	Ruann Barack	Stephanie Leach	Joan Tam
	Violet Wiker	Cindy Smith	Kristin Lenover
	Pamela Marshall	Brooke Lovekamp	Kelly Currier-Brown
	Rosa Cole	Jodie Lindgren	Jaclyn Vasquez
	Jose Jimenez	Shayne Squires	Lauren Rivera
	Kelly Whistler	Aurea Garvin	Jennifer Meyers
	Shelly Roat	Nora Peters	Brittani Provost
	Kristin Grubb	Ally Chenoweth	Abby Huff
	Gail Koshgarian	Jasmine Deida	Monica Avolos

Communications Report - Amanda Simhauser (DSCC)

Amanda provided a presentation to the group. Regarding the Nursing Allocation Workgroup that Whitney Woodring is developing, a news story was put on the DSCC website on October 6th encouraging families to reach out to Whitney. An email was also sent to Home Care participants/families. Whitney is developing a Google document for feedback.

Amanda asked that council members share within their own pages or networks information on events, particularly for the downstate area. She also asked that the information be sent to her/her team so she can share it as well.

A mockup of a graphic to represent the Family Advisory Council was shared as well as graphics being used by other groups. Amanda noted feedback given from the group and asked that if anyone sees anything additional that may be helpful to send it to her. Contact is: arsimhau@uic.edu. Additional samples will be provided at the next meeting. It was suggested that there be merchandise created with whatever graphic is chosen (perhaps shirts that would help raise awareness).

Transition Tools checklists are being updated. DSCC is working on a transition related webinar to hopefully be held in the spring of 2023. More information to come.

Open Forum Participant Introductions

Erica stated that the Transition Conference reinforced how important in-person connection is to be around other families. She added that part of the reason open forum FAC meetings are done is so other families can see what is being worked on. She asked those visiting the

meeting from the public to give a brief introduction of themselves including their connection to DSC and where they are located. Monica Avolos, Maddie Hinkle, Abby Huff, Marcela Flores, Jennifer Meyers, Ally Chenoweth, Pamela Marshall, Amy Gorman, Jasmine Deida, Aurea Garvin, and Julie Martin introduced themselves.

Mary Dixon from The Arc of Illinois also introduced herself.

Quality Satisfaction - Ruann Barack (DSCC)

Ruann provided a presentation regarding survey response trends by years with DSCC as well as participant age for FY21 and FY22. In response to a question regarding why the participation number is so low, Ruann stated that by moving the surveys to being sent one time a year and informing families why it is important to give feedback, DSCC hopes to have higher numbers for next year. Regarding how the data has been used to change policy, Ruann stated that DSCC looks at the data to determine how teams are doing in the organization and at a leadership level. Most efforts have been looking to see how engagement can be improved. Molly added that the survey process was put in place in 2021 so it is still in its infancy stage. Around late 2019 DSCC implemented care coordination practice changes. The survey data breakdown by regional team helps to enforce practice changes that have been made to be more in line with best practices. The survey questions are related to all programs and care coordination services. Feedback from the families about their experiences is used to help inform Title V priorities and the information is shared with entities like HFS. Jose stated that a lot of times HFS uses information related to utilization and claims. Surveys will play a large role moving forward and participation is key. He added that he is extremely pleased with the amount of work DSCC is doing to bring additional perspectives to the attention of HFS. Molly stated that the survey that will go out to all DSCC families in February is for all three programs and is different from the survey that MFTD waiver families will receive.

Licensed LRA as a Waiver Service (Update) - Stephanie Leach (DSCC)

During the pandemic, flexibilities were added for the Home Care program. One of these was parents licensed as an RN or LPN getting paid for caring for their child. There are 90 participants in the Home Care program utilizing this. DSCC recently met with HFS and the Federal Centers for Medicare and Medicaid to discuss making this a permanent service for waiver and non-waiver participants. The next step is a confirmation email should be received by HFS from Federal CMS. After that, HFS will discuss with its administration and then this should be able to be implemented permanently. There is no exact date; however, the hope is that it will be in effect so there is not gap in services.

Unlicensed Family as Caregiver (Update) - Stephanie Leach (DSCC)

This initiative was started through the American Rescue Plan Act. CMS, HFS, IDPH, IDFPD are all working with DSCC to try to implement this. Stephanie hopes to have more information to share at the next meeting. At the next meeting, Erica would like to move forward with a subcommittee as caregivers need to be involved in the conversations. If interested, please connect with Erica via email. She added that she has heard from other families about a strong need and interest in having access to advocacy tools to work as a united front. In future meetings, she would like to discuss tolls so that a subcommittee can be formed and have projects/initiatives in addition to the above issue. In response to a question regarding why CNA parents can't be included, Stephanie stated that is due to licensing; however, CNAs would fit in the



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unlicensed family as caregiver initiative. Molly added that there is a challenge in Illinois regarding how the Nurse Practice Act creates limits on what a CNA can be paid to do. It was suggested that DSCC help tailor advocacy efforts; Erica would like the subcommittee to address this.

Interim Relief Program Overview – Haley Phelps (DSCC)

Haley stated that this is an HFS program for which DSCC is offering care coordination services. She provided a presentation giving an overview of the program. There will be a team of four DSCC staff for this separate program for which the population is not very large. For more information, please visit the following link: <https://dsc.uic.edu/interim-relief-program/>.

Open Forum Discussion

There was a question regarding mileage reimbursement being raised due to the price of gas. Molly stated she will share this feedback and see if there is anything in the works. There was a comment regarding being “surveyed out”. Erica stated that this echoes what several parents stated at the previous meeting. She thinks what Jose meant was that he hopes for more participation. Ruann stated that DSCC is looking at ways to make the survey process more efficient for families. It was suggested that surveys be completed during monthly calls with families.

Thomas Jerkovitz, DSCC Executive Director, stated that it is wonderful to hear the ideas and collaboration with other agencies to continuously improve programs. He thanked everyone for their time.

The next meeting will be on February 9, 2023 from 9:00 am to 11:00 am and will be a closed meeting.