



Division of Specialized Care for Children

Family Advisory Council
February 9, 2023 9:00AM

Attendees:

Claire Cook	Andrew Nichols	Erica Stearns
Ebonie Zielinski	Lauren Rivera	Brandon Bartels
Mary Herschelmann	Jaclyn Vasquez	Joan Tam
Nancy Lemman	Thomas Jerkovitz	Ally Chenoweth
Maria Civito	Stephanie Leach	Byram Fager
Molly Hofmann	Tiffany Kalka	Jasmine Deida
Haley Phelps	Chelsie Hacker	Robin Morgan
Amanda Simhauser	Adell Scott	Jose Jimenez
		Violet Wiker

Welcome from Erica Stearns (FAC): Introduction of new attendees.

Family Portal Update: Adell Scott / Tiffany Kalka (DSCC)

Adell announced sneak peak of the Family Portal that is designed to provide parents and caregivers closer communication with DSCC.

Tiffany Kalka presented the sneak peak of the DSCC Family Portal which is still in the works. Log in and registration process was reviewed. Families will be able to upload a picture for each participant, see their active care coordination team, find documents needed for signatures, and send and receive messages to/from care coordination team. All these features will be accessible from the landing page when first signed in. Menu Options were explained:

Communications: where families can compose, receive, and reply to messages from the care coordination team.

Participant information: view providers working with families, view diagnosis and current treatment plans.

Family Members: list of family members in household and relationship to participant(s).

Person Centered Plan: will be accessible in English and Spanish.

Referrals: place where families will find referrals the care team has sent to the families from providers.

Comprehensive Assessments: reports will be accessible through the portal.

Medication List: medications known to DSCC, active medications, name of medication, dosage and frequencies, reasons, and changes/concerns with medication.

Participant Photo: for families to upload a photo of the participant to be displayed in their portal home page.

Document History: where signed documents can be found. Accessible in English and Spanish.

Self-Attestation: can be printed in English or Spanish.

Letters: families will be able to see who created the letter, date and type of letter, letters can be printed and/or viewed.

Document upload: allows families to upload a document when documents are requested.

Signature Request: Families will be able to sign different forms, signature can be done with a stylus, finger, or mouse.

Assistance: travel cost logs for reimbursement, area to upload receipts and description of expenses.

Questions:

- Erica asked if portal is language accessible? Stephanie replied Google Translate will be used for translation to different languages and explained it would be the same as DSCC's website where there is an option to translate the webpage to desired language.
- Jaclyn Vasquez asked if this has been tested with families since google translate is not a great translating tool.
Amanda Simhauser shared that there haven't been any issues but will be working as part of the university's larger digital accessibility project and language translation tools will be part of that. Will check if Google translate is still the best tool or if there are any better ones. Amanda reinstated that there have not been any issues with Google translate and asked families to please share it with DSCC if any issues to be able resolve them.
- Erica asked if internal documents will also be provided in Spanish. Stephanie explained that for documents with signing abilities will have the option to be viewed in English and Spanish.

Stephanie Leach (DSCC) explained that the pilot with families will provide more feedback and check on glitches.

Adell requested 8 volunteers for the pilot, if interested to let her know by February 20th via the FAC email: dscfac@uic.edu.

Training will be with Tiffany, and it is scheduled for March 16th 11:00am-12:00pm, and testing will begin on March 20th. In need of bilingual families as volunteers. Tiffany and Adell will be sending an email to volunteers with dates and information. Meeting will be recorded if any volunteer is unable to attend.

Communications and Quality Update: Amanda Simhauser (DSCC)

Amanda gave an overview on communications.

Follow up on discussion of last meeting topic: FAC new logo to represent group and to be used on different communications, multiple samples have been put together and will be going for final review to be able to share for a final vote.

New Annual Family Survey process launching this month will be more convenient and streamlined for families, it will start on February 15th, and will go out every February regardless on when families are enrolled. Simpler process, fewer surveys, updated annual survey will include education questions rather



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than receiving a separate education survey. Changes were based on feedback received from families. Changes have been posted on DSCC website and FB page, also shared via email. Feedback welcome, please reach out to Amanda Simhauser.

Permanent Care Announcement: Will be sent via mail, email, shared on website and social media.

New initiative rolling out DSCC Health Insurance Education Series: virtual presentations to help families navigate insurance coverage, benefits, questions related to insurance. English and Spanish presentations. Series will start as a series of three, in March, April, and May respectively, and will be held in the evening.

Stephanie Leach (DSCC) explained this is in response to discussion from FAC meetings and families wanting to know more information about these topics. Working on promoting this initiative to families via fliers, emails, and FB posts. Working on putting together a new section on DSCC website where meeting recordings will be posted and for handouts to be shared- for families that are not able to attend meetings and/or for review.

Stephanie asked for family council feedback on any ideas/ ways to spread the word to reach families who would benefit from these presentations.

Jaclyn Vasquez (FAC) suggested to also add a space on DSCC website for people to add questions, like FAQ, ongoing questions. Stephanie will look into the best way to handle questions and see how they can be routed as opposed to a general DSCC email.

New Grievance Procedure explained, online and hard copy forms have been created for families to file grievance. If family is unhappy with any part of DSCC's operation or staff behavior or to notify administration of an issue. It will have a dedicated section in the DSCC website starting March 1st under the "How We Help" section. Stephanie showed how the page will look and procedures.

Erica expressed her excitement and asked if any language about confidentiality has been created to avoid creating tension between family and care coordination relationship. Stephanie explained that currently there is no language addressing confidentiality. Molly Hofmann (DSCC) explained that DSCC's goal is to ensure the best way to help families and how these grievances can be resolved. Do not want families to be concerned providing feedback. Molly asked the council to encourage families in these situations to reach out to any member of the DSCC administrative team, whom will be happy to work with them to resolve any issues.

Erica asked about the “request a callback area” and Stephanie explained it is not attached to grievances. It is a general call back for people needing more information about DSCC or need more explanation about our programs.

New Emergency Preparedness Tip sheet - New emergency work group have been working on a new emergency plan template. Posted on the Home Care information hub on the website and online resource. Link was provided. <https://dsc.uic.edu/wp-content/uploads/2022/12/163-EMERGENCY-PREPAREDNESS-TIP-SHEET.pdf>

News of DSCC participants stories have been uploaded to the website and FB page. Link was provided. <https://dsc.uic.edu/who-we-are/news/>

Contact Amanda Simhauser with any questions or suggestions communications related. arsimhau@uic.edu.

HC Nursing Services Overtime Policy and licensed (RN and LPN) parents/ LRA’s approved to provide care permanently: Stephanie Leach (DSCC)

Nursing Services Overtime Policy: during the Public Health Emergency (PHE), some exceptions were implemented for families and were successful. DSCC partnered with HFS and worked hard on implementing these exceptions to keep them permanent. Communications with families are being sent. Nursing Services overtime was approved and implemented.

Parents as caregivers: Prior to PHE, parents were not allowed to work as a caregiver but during PHE exceptions were made and now it has been implemented permanently.

Feel free to email Stephanie Leach if questions: sleach1@uic.edu.

Erica asked as far as the overtime policy how are families allowed to utilize that? Will information be shared with families about these changes?

Stephanie explained that letters will be going out to families with procedure, labor practices standards, etc. nursing agencies have also been notified. Information given to the nursing agencies can be found on the DSCC website under the Home Care hub: provider notices.

Erica asked if a family is met with denial or resistance from an agency and their resource allocation has not been fully utilized, will there be instructions for family members to follow? Or should it be taken as a grievance report?

Stephanie advised to let DSCC know when this happens, in any form of communication information is sent to DSCC, it is well received; and explained issues need to be known so that DSCC can contact the nursing agency and explain to them how it can successfully work.



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Jaclyn Vasquez asked for updates on ability to pay parents that don't have an RN and do not have an RN license? Stephanie explained that supporting family care givers is the goal, one of DSCC's initiatives is to provide some direction to pay parent care givers. DSCC has been working with HFS on this topic and with other partners within the state, trying to figure out the best way to maneuver and make system changes to get this done. Continue working on it on the back end.

Youth Transition Council (YTC)- Claire Cook (DSCC)

Claire explained Transition has been selected as one of the state of Illinois' top priorities for the Title V block grant. As a part of Title V, DSCC oversees children and youth with special healthcare needs. One of DSCC's priorities is help preparing children transition to adulthood and will be preparing and implementing a Youth Transition Council-similar to the FAC. Goals are to advocate, educate and empower. Expand accessibility to transition and resources. Claire explained there will be up to 15 young adults from across the state. There will be a youth chair, committees, and roles that the council will decide. Team will consist of Claire as transition specialist, a YTC adult navigator, and Courtney Kerfoot, transition team lead. Looking for all youth to be between ages 15-23 currently enrolled in a DSCC program. Claire explained council is still in an early stage and asked FAC to email any suggestions. clairer3@uic.edu

Erica asked nonverbal youth unable to participate will be represented. Claire explained that DSCC will make accommodations for youth who need them. Meetings will be via zoom and translator/ interpreter will be provided, as needed.

Erica asked how would the recruiting process start, or if there are participants in mind already?

Claire explained they are looking into the youth that participated in the Youth Transition Conference in November, but it will be open to everyone.

Erica suggested if there is an opportunity for former DSCC participants that will be part of the YTC to also become a member of the FAC as they transition. Topic to talk about with the FAC members to maybe present at a Youth Transition Council meeting.

Erica asked what inspired this development? Tom Jerkovitz explained that Title V is a Social Security act which grants money out to each state, which 30% must be used for children that need special health care. DSCC meets periodically with the Illinois Department of Public Health, whom the grant passes through. DSCC discusses priorities internally, and with IDPH, that's how transition was

identified as a point of emphasis for DSCC to continue to work as to emphasized targets.

Discussion - Erica Stearns (FAC) and FAC Members

- Ally: Making the pay for nurses more of a universal rule for all agencies since it fluctuates depending on the agencies and how much they keep. Molly Hoffman (DSCC) explained that the rate the nursing agencies receive for the nursing care is a rate determined by Medicaid. The current set up varies by nursing agency, and varies by operational costs, factor in what type of benefits are offered, cost of benefits which varies by the size of the company. Medicaid has had some discussion on whether a minimum of this amount must be paid directly to the nurse. No decisions have been made but something to be looked up potentially in the future. Requested something in writing to bring back to the team and discuss. Email address to send feedback: mollywh@uic.edu.
- Molly (DSCC) reviewed Family Survey going out to families on February 15th and encouraged families to ask their nursing agencies for feedback since it will be an opportunity to provide such feedback on the survey.
- Erica explained there is an intention to create subcommittee with the goal to have more conversations with parents. Asked parents that are interested to send her an email.
- Jaclyn, Chelsea, Erica, Byram, and Jasmine held a discussion about their interest in creating a group for families to communicate and support one another. Chelsea shared how helpful it would have been to have a connection with other parents when she started her journey of medical issues. Jaclyn and Byram shared ideas of possibly connecting families by age, needs, or area/location.
- Erica would like to connect with more members on ideas for FAC meetings and asked to please reach out with suggestions

Closing / Tom Jerkovitz (DSCC):

Tom Jerkovitz thanked everyone for attending the meeting, express his he was glad for progress made, he asked families to please take time to fill the family survey to continue shape the program as DSCC advocate with the university and the federal government. Looking forward to hearing the outcome of the three webcasts about health insurance and continue to work on that. Expressed appreciation on FAC's willingness to meet and create a networking group for DSCC families.

Next Meeting: May 11th - Open Forum