



Division of Specialized Care for Children

Family Advisory Council
August 11, 2022 9:00 AM

Attendees:	Haley Bestudik	Adell Scott	Amy Hrdlicka
	Chelsea Hacker	Jaclyn Vasquez	Lisa Washington
	Molly Hofmann	Lauren Rivera	Nancy Lemman
	Nikki Goldwater	Ruann Barack	Joan Tam
	Erica Stearns	Whitney Woodring	Rosa Cole
	Ally Chenoweth	Amanda Simhauser	Gail Koshgarian
	Jasmine Deida	Robin Morgan	Jose Jimenez
	Stephanie Leach	Kristin Grubb	

Contract Renewal Update/Reminder for FY23

Contract renewals are in for current members. Contracts are also being worked on for new members. New member Jaclyn Vasquez introduced herself.

Home Visits/Contact Survey – Molly Hofmann (DSCC)

Molly stated that DSCC needs feedback from families regarding their preferred times of contact as well as on the family surveys. Regarding home visits, while a Public Health Emergency (PHE) is still in effect, over the last year DSCC has given guidance to staff that conducting home visits are at the discretion of staff and the family. Some home visits are occurring while others are still being conducted virtually. Medicaid has indicated that at the end of the PHE home that they will require entities working with Medicaid programs should be prepared to resume home visits. Responses to a survey conducted last year showed 40% of families were not yet comfortable with home visits resuming. That information was shared with Medicaid. Molly asked if it would be helpful for DSCC to collect a survey from a broader group of individuals. She also asked if information regarding safety precautions being taken should be put out to perhaps provide reassurance to families. Lauren shared that she likes the idea of safety and would prefer to not have people in her home. She added that the survey could be good to have data to present to Medicaid. She asked if in person visits would resume in business hours. Zoom is a nice option so families don't have to take time off from work for a meeting. Molly stated that this goes hand in hand with the home visits topic. It has been some time since DSCC conducted a survey regarding communication/time of contact preferences. There were a large number of responses that indicated 3:00 – 7:00 pm was the preferred time for contact. DSCC has supported team members being able to flex their time with what works for them and their families. DSCC is still operating fairly remote so the need for office space being used needs to be looked at. Families used to come in to fill out paperwork, etc. so this also needs to be looked at for families' preferences. Having staff work more flexible hours also includes ancillary supports that would need to be in place as well (benefits, claims, IT, etc.). Whitney agreed with Lauren and added that she works from home so it is a struggle to accommodate what the care coordinator requests. She added that trying to coordinate with someone who works the same hours can get tricky and that she understands DSCC employees also have families. She suggested perhaps having some flex schedule to work with families who need that and normal business hours



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for some staff to work with those who are available during the day. Jaclyn added that she also works from home and is the primary caregiver. She would like her husband to be present for visits and he leaves the house for work in the morning. She has noticed that more organizations that support families are not flexible; not having flexibility makes it easy on the organizations versus the ease of support for families. Erica agreed with previously made statements and asked if weekends are an option as it would be helpful to have the family unit together though each family has different schedules. She asked if DSCC has had concerns for kids receiving care coordination services and that home visits are necessary for the wellbeing of the child. Molly stated that when things went remote in the beginning of the pandemic, there was a lot of pause about how DSCC would make sure that some of the kids that have different dynamics in their situations were safe. There hasn't been much seen as a result that has led to unsafe situations. If DSCC does become aware of concerns, those calls are still being made. Supervisory visits were paused but have resumed. Stephanie stated that there was one specific situation where over the phone things seemed ok and then when an in-home visit occurred it was not as portrayed over the phone. The care coordinator took immediate action to make sure the child was safe at that time.

Molly asked if the group thinks families are getting survey fatigued and if an electronic version is the most helpful method or perhaps a phone call. Jaclyn asked if the survey would serve a general population but not those that need it most. Molly stated that the annual home visit is completed whether the participant is in Home Care, Core, or Connect Care. The survey would go to all DSCC families to find out a preferred time of day to be in contact, concern regarding home visits and if so, what might help families feel more comfortable. Some of that is outside DSCC's ability to control but feedback can be shared with Medicaid if there is an overwhelming response of families not feeling comfortable with home visits resuming. Jaclyn stated she is more likely to talk about it versus an extra survey. Whitney asked if there can be two distribution lists so those who prefer a phone call can be contacted that way and those who prefer a survey can receive one. Molly stated that perhaps DSCC should go about this in multiple ways. DSCC does have preferred communication but not preferred time so perhaps that needs to be captured as well. The goal is to understand families DSCC serves and how to align that and how to better prepare the workforce of the future. The care coordination teams have a lot more flexibility now and it is much easier to get on a Zoom call at night rather than driving an hour to meet with a family and then drive home. Molly will put questions together and methods to collect feedback and share that information with the FAC.

Communications Report/Website Demo – Amanda Simhauser (DSCC)

Amanda showed the Home Care Information Hub on the DSCC website. Please provide Amanda with feedback and any events/information to be shared. It was pointed out that most events are for the northern part of the state. The question of how to get more visibility for events in the southern part of the state was asked. Amanda stated that she makes an effort for events to be as balanced as possible. She also pointed out that the event information shared in the presentation were from the top performing posts. She encouraged members to send her information on events in other parts of the state outside of the Chicago area. It was also shared that information in the southern part of the state is dispersed differently and not as well as in the northern part. There needs to be a collective goal to improve the information that is disseminated; however, it's



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not only the responsibility of DSCC to do so. Molly encouraged members to send information to Amanda so she can share it through DSCC's social media channels as this is one area of commitment for being the Title V organization across the state. It may be beneficial for DSCC to remind staff to share information with all DSCC rather than only among their teams. In response to the question of if information can be shared about events in other states, Amanda stated that if there is something in a neighboring state, she shares it. She tried to determine if the event is accessible to a large group of families and also looks at the source of information to make sure it is reputable as well as the cost. Amanda added that she is also working on participant family photos and additional participant stories.

Quality Report – Ruann Barack (DSCC)

Ruann provided a presentation to the group. DSCC is looking at using the phone and text for family surveys. Scores have gone down slightly and DSCC wants to address this as soon as possible to get feedback. Erica asked the group if lower scores in care coordination services and quality of life are related. Could it be overall quality of life? What are factors and is that related to not feeling as happy with services? Are the issues separate? An email was sent a few weeks ago but she didn't get any feedback from members. Erica also wants to know how the FAC can better communicate what topics members want to discuss. It is clear DSCC is taking information and using it to be beneficial for families.

Nancy stated she feels the survey process is good and is not having difficulty with it. She has been really happy with how care coordination has gone as well as quality of life; however, she knows that is not the case for everyone. Regarding when surveys are sent out, Molly stated that they are sent at different intervals of a child's care and there are different topics for the surveys (annual, transition to adulthood, school support, following home visits). The annual survey will be moved to being sent out once a year to all participants. Surveys are also sent 60 days after enrollment and 30 days after a participant leaves DSCC services. It was stated that there may be more responses on the extreme ends and sometimes when things are calm and stable, people may not be as quick to respond. Questions asked included if the lack of responses is tied to people who have been in the programs longer and if satisfaction is higher with families who are newer. Ruann stated that responses are anonymous; however, she may be able to see on the back end how long participants have been with DSCC. This information may also be part of what the family completes. Ally shared that something that impacts her satisfaction with care coordination is when she finds out that there was a resource that would be helpful that she wasn't notified about. There have been great strides made toward this. She shared that last week she found out about the Affordable Connectivity Program, which saved her family \$60 per month on internet. If this is not on the tip sheets, it should be added. Information such as this is helpful to receive. Rosa stated her care coordinator checks in; however, the check ins seem vague so she doesn't feel anything needed is provided. She wishes her care coordinator could be more helpful as she feels like she does everything on her own. Molly stated she will connect with Rosa offline to try to get her the help she needs. In response to a question regarding what a family should do when they encounter challenges with their care coordinator, Molly stated that DSCC wants every family to have a positive experience. All care coordinators report to regional managers who have assistant directors who work with associate directors. If a family feels like something is not being addressed, one option is to contact the office and ask to speak with the regional manager. Another option is to contact Molly or Lisa Washington. DSCC is also working to put a form on the website so families can enter online whatever the issue is that they feel



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dissatisfied about. This form will get routed through until it is resolved. Molly stated that DSCC doesn't want its involvement in a child's care to feel burdensome. Resources come and go very quickly so it is challenging, but there are people trying to stay on top of this and teams are being trained on how to be aware of resources and share them. DSCC wants families to speak up and know that they can do so. Ruann will provide an update on the online form, which is not ready yet, at the next meeting. Procedures are being developed around what will be called a grievance. Materials on the website can be translated into a selected language and hard copies of the form will also be available in English and Spanish.

Procedure for Change in Care Coordinator – Adell Scott (DSCC)

Adell took the questions raised at the last meeting regarding when there is a change in care coordinators. She developed a rough draft of what to expect when that occurs.

- New care coordinator should reach out within 30 days. If the change is from one office to another this should be done within 7 days. This can be a joint call with the current care coordinator, new care coordinator and family or just between the new care coordinator and family.
- Follow up letter mailed to home to include contact information for new care coordinator.
- Care coordinator/program coordinator assistant names are updated in Client Track participant record.
- Family is informed – who is primary contact, preferred method and time/day of contact.
- Providers informed – especially those with home nurse, HME.
- Waiver/Non-waiver – if waiver, what services are being used.
- Renewals/authorizations/person-centered plans – new care coordinator reviews and also checks due dates.
- Reviews additional needs in progress (community resources being worked on, guardianship, POA, DRS services, etc.).
- LOC review/review of medical needs.
- Review assessment, person-centered plan and most recent monthly contacts made with family.
- DSCC financial supports.

Adell stated she could build on this list to take to management teams and incorporate into formal procedure; it could also be a tip sheet once finalized. The question of how a family can request a change in care coordinators was asked. Stephanie stated that there are internal procedures and then on family side there can be tip sheets. Adell will circle back when she has something more formal.

Nursing Allocation Workgroup – Whitney Woodring/Haley Bestudik

There is a tip sheet in terms of what to do if families want to file an appeal. Whitney has not received any feedback/others' experiences. Haley and Whitney have discussed reaching out to other parents on the FAC to get their thoughts. Whitney shared that her experience with nursing allocations has not been great; this is the reason she is passionate about making the process better. She would like to hear from someone who hasn't had issues or who has and how their process has gone. Haley is going to give email addresses to Whitney so she can send a few questions to the other parents on the FAC. Whitney shared how limited she is in getting



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information out due to HIPAA. Regarding the issue of not being able to get a nurse and how to get a policy change to increase pay to increase the workforce, Stephanie stated that the MFTD waiver updates were up for public comment. Some comments were given to HFS and DSCC about the level of care tool used for assessment being put under review again. DSCC has been partnering with HFS and surveys have been sent to agencies and families; comparisons with other states for in home shift nursing are being done as well. All of this is being worked on to try to make a recommendation on a change. Molly added that families' recommendations would be strong piece of the tool being evaluated. There are additional projects being done with looking at who are paid caregivers. Recommendations have been made that family and others be able to be paid for a child's care. This would require a major shift and a great deal of policy change. Updates will be shared. Another issue is the rate being paid to agencies compared to what the rate of pay is for the nurse and if there need to be requirements in place for that. If there are things DSCC can do to help promote Whitney's efforts, Amanda can send something out to Home Care program families to let them know of the subcommittee and try to help recruit. Molly suggested setting a date for a meeting, which would allow people to try to schedule around making it. This may help people think they can make it rather than an unknown of when it might be held. Erica shared that when agencies were opened up to serve the entire state, her personal family experience/quality of life were immensely impacted and improved. They are now able to work with a better agency that has stricter recruitment and requirements and a sharper training process. The nurse also gets benefits. She sees a huge difference in the nurses with this agency versus the ones from the old agency, who made \$10 per hour less and received no benefits. It was suggested that nursing issues in general be incorporated and not just focus on allocation rates. How can DSCC collaborate to have more unity and better experience for families and nurses? Whitney stated she is not opposed to expanding the scope but would rely heavily on Haley for her knowledge.

Next meeting is open forum. When minutes are sent, hopefully a date will be provided. Send topics to Erica, Haley or bring to the next meeting.