Location: Zoom
Date: August 25, 2021
Time: 10:00 am

Family Advisory Council Meeting

Attendees:

Claire Richardson
Haley Bestudik
Adell Scott
Amanda Simhauser
Gail Koshgarian
Kristin Grubb
Lisa Washington
Robert Laib
Shelly Roat
Thomas Jerkovitz
Rebecca Anthony
Sean Kirby
Molly Hofmann
Ruann Barack
Amy Hrdlicka
Nancy Leman
Robin Morgan
Joan Tam
Violet Wiker
Becky Helmink
Mary Galer Herschelman
Shayne Squires
Lynne Riley
Jose Jimenez
Stephanie Leach
Ally Chenoweth
Byram Fager
Erica Stearns
Jasmine Deida
Nikki Goldwater
Rosa Cole
Whitney Woodring
Jim Eddings
Ursula Christian
Patricia Ocampo

Minutes

Thank You and Introduction to New Family Advisory Council Chair (Erica Stearns)

Erica introduced herself, stating she is a proud mom of two medically fragile and complex children who both receive Home Care waiver services. She was introduced to DSCC five years ago. DSCC became one of the most prominent helpful members of the team of people that helps her family. Erica added that she has medical conditions herself and has also worked in health care management so she has a multidimensional perspective. She stated she is honored to be the Chair of the Family Advisory Council and is excited to work collaboratively with her peers and DSCC to hopefully cultivate needed changes for children.

Resource List Update (Shelly Roat and Amy Hrdlicka)

Amy stated that a part of DSCC's Strategic Plan is to increase the amount of educational resources available to families. She and Shelly are working with Amanda Simhauser, Communications Manager, who has a resource database on DSCC's website. Shelly and Amy are working with Amanda to increase and enhance that database to meet the needs of families and assist care coordinators to point families to resources. Workgroups will be formed consisting of subject matter expert staff. Once the project is further along, Shelly and Amy will come back to the Family Advisory Council with an update. Members are asked to provide feedback on resources they would like to see DSCC list to Shelly (sgroat@uic.edu) or Amy (aeedders@uic.edu).

Communications Report (Amanda Simhauser)

Amanda provided a PowerPoint presentation (attached) and reviewed the Resource Directory on DSCC's website. Resources can be searched by category and region. Amanda has a "wish list" of ways she would like to improve the resources page and asked for feedback from the members regarding what they would like to see.

In response to a question regarding if there is a way for families to connect with other families with similar medical needs or conditions within their area, Erica expressed interest in finding a way to create a virtual community to meet each other and share experiences. Amanda stated that she has asked staff to share information with her on virtual parent support groups so she can post to the website. She asked members to let her know of these as well so can disseminate information.

Quality Report (Ruann Barack)
Ruann provided a PowerPoint presentation (attached) regarding DSCC's Family Surveys. She stated this is one way to hear from families about DSCC's work. The information received from the surveys is used to improve services across DSCC; care coordination teams like to see the results. Ruann stated that DSCC is always looking for ways to improve the process.

In response to a question regarding DSCC's plan for addressing items that have lower cumulative ratings, Ruann stated that an action plan is put into place to address how DSCC can serve participants/families better. There are times when families are not happy and indicate on their survey response that they would like to be contacted. Managers are involved in those instances. Ruann asked members to let her know if there are items that should be asked on the survey. Molly added that the areas where the response scores are consistently lower have to do with supporting the family/participating with needs in school system and school support. These are the only responses with scores below 3.5. Ruann stated that the education surveys were just implemented this summer and she can bring more information on those surveys/responses back to the group at the next meeting.

It was suggested that for the graphs giving the percentage of response by age, it might be helpful to know how many were sent out for that age (the ages 1-2 were very low but knowing that only 10 of the 322 surveys sent out were for that age group, that might be helpful as well). Erica stated that during the time when her children were in this age group, she did not fill out surveys due to how chaotic life was. She suggested it may be helpful for this group to discuss how to reach families with participants in that age group; it could be as simple as DSCC staff letting families know they will receive a survey. Ruann stated this is a good reminder to continue educating care coordination teams on when surveys are sent to families. Becky shared that she received a survey from a hospital that asked how the family was doing on a scale of 1-5 and asked with what they needed help. After sending the survey back, she was contacted by the hospital within a week.

Care Coordination Leadership Report (Molly Hofmann & Stephanie Leach)
Stephanie discussed the enhanced Federal Medical Assistance Percentage (FMAP) from the American Rescue Plan. This additional funding, in the form of more matching funds from federal CMS, will be used for the Home Care Program, mainly for participants with the Medically Fragile Technology Dependent (MFTD) waiver. DSCC submitted five initiatives to HFS, who reviewed and submitted the initiatives to federal CMS. While the official approval has not been received, DSCC is taking steps to implement the following initiatives:

1. Expanding consumer direction – DSCC proposed caregivers have the opportunity to be paid for their participants' care. Caregivers could be called personal assistants. There is much to do for infrastructure to ensure health, safety, and welfare of participants. This initiative would require a MFTD waiver amendment, which would be submitted to CMS. There would be a public comment period on for the proposed amendment.
2. Increase home respite rates – In home respite rates were not increased in 2019 when nursing rates were increased. During the pandemic, the rates were increased to match in home nursing rates and the request is for this to continue after the pandemic.
3. Child specific training for nurses – every child in the waiver has an opportunity for their nurse to be trained specifically on their care needs for 4 hours per waiver year. These rates were not increased in 2019; would like to increase these rates as well.

4. Portal – would allow communication between nursing agencies and families for open shifts where services are needed. Nursing agencies could see what is needed and families could see when nurses are available.
5. Training Initiatives – set aside funding to be used for training for nurses and family caregivers. Looking at expanding accessibility for training in areas of the state. Trainings would be ongoing to improve quality of care in the home setting. In response to a question regarding examples of training that have been requested/DSCC has in mind, Molly stated that information and proposals are being collected from providers who have expressed interest. One program has developed a simulation-based training to be used by caregivers and home nurses. There are also internet-based tools for refresher type training. Another initiative supports providers who don't get training on working with medically complex children and improving on medical rotations.

In response to a question regarding if the paid family caregiver initiative is approved, where does that leave the paid parent RN program/is that something that is still being considered as a continued services post COVID as well, Stephanie stated that DSCC fully intends to keep options for if a parent is an LPN or RN and employed by the nursing agency. Currently, there is an exception due to the public health emergency; that exception will extend six months after the public health emergency ends. Rule amendments will be required to keep this option available and DSCC and HFS are working on that. This is expected to be a smooth transition and will be included in the wavier renewal. Public comment on this will be in January or February; information will be communicated to the group. It is important for support to be expressed in public comments as those go to federal CMS. The paid caregiver opportunity would be ongoing/no end date.

Home Care Nursing Allocation/Approval/Appeal Decision

Whitney shared that she has brought this issue up a few times, but has a hard time finding others willing to share their experiences. She stated she struggles to see how people not interacting with families are making decisions on the level of support given to medically fragile children. She submitted an appeal months and go and has received nothing so she feels in limbo. The interpretation seems to be that her child is getting better. Whitney expressed concern regarding doctors not seeing the child. In her case, her child is one of 13 or 14 in the world with her condition, which can present differently depending on the mutation. If her appeal does not go in her favor, Whitney stated she will have to decide where to pull hours from. In response to how thorough her provider is with documentation, Whitney stated that they go to Cardinal Glennon and have additional specialists and a social worker who helped highlight the nuances in the letter. She asked about the quality control check on reviewers. Molly suggested Whitney and other families discuss challenges and make recommendations to share with HFS. The Family Advisory Council is in a good position to formalize recommendations. Whitney stated she has reached out to a few other people and has run into HIPAA challenges in terms of getting in touch with other families. It was shared that DSCC has sample letters on the website; Erica suggested making these more accessible in the resource directory. Letters can be found at: https://dscc.uic.edu/home-care-nursing-information-for-families/ and https://dscc.uic.edu/for-providers/home-care-information-and-resources/. She also supports forming an open parent group to discuss these issues. Erica shared that her family didn't quality for nursing because her children don't have enough technology dependent needs. This leads to difficult decisions since the children cannot be put in daycare. Another issue Erica raised is when kids transition from early intervention to school and the focus is on what the kids can do while some look towards a future of having to battel with Medicaid regarding what their children can't do.

Molly stated that Amanda is working on the ability for DSCC to send more specific emails to participants ad families. An example of this would be the physician letters of medical need. It would be great to send an email to families that these are available.

Whitney stated that once the appeal is submitted, there is a black out period. Her understanding was that DSCC was supposed to be a partner through the process; however, she has to update the care coordinator on the process of the appeal and that seems backwards to her. Molly thanked her for sharing her comments and added that DSCC team can help facilitate information for an appeal and that information comes from a specific department in HFS. Whitney added that there seems to be a communication breakdown since DSCC is also not notified if a hearing is scheduled. Stephanie suggested that Erica and Whitney work with Amanda to put something on the DSCC website/social media requesting help with trying to address these issues; their contact information can be provided. Regarding if HFS would be willing to receive feedback, Stephanie stated that DSCC works with a great group of people at HFS who want the best for participants. DSCC has a great relationship with HFS and she thinks parent feedback is wanted and expected out of the Family Advisory Council. Molly added that this is a great opportunity for the newly revamped council to say here's a topic that we see as an issue and here are our recommendations.

Jose Jimenez, Bureau Chief of Professional and Ancillary Services for HFS, introduced himself. He stated that the appeal process is applied to all nine waivers and the medical aspect is tricky. He stated he is happy to continue participating in these meetings as there is a need to connect with families. In response to Erica's question regarding any advice Jose may have in terms of communicating more effective and giving clear examples of what children need, Jose stated that community involvement is key and public comment time is required. Any recommendations with supporting data are extremely helpful. He added that HFS services close to 3.5 million Illinoisans so anything that is done has an impact on the budget and how services are paid for. If there is anything HFS can do to help create the picture of needs, they are willing to do it.

Discussion: Vision Toward Positive Health Outcomes (*Please come prepared with ideas regarding policies, programs, or procedures that you believe would contribute to your family's positive health outcomes. What would enhance the quality of care you received, the quality of life you experience or maximize your ability to utilize services? In other words, if you had a magic wand, what would the world look like so that it your child and family had more positive health outcomes?)*

Erica stated that DSCC wants to hear about ideas regarding policies, programs, procedures that would contribute to positive health outcomes for families. She mentioned:

- mental health should be included in this; connecting to others with shared experiences
- competitive nursing benefits and wages to attract quality nurses
- transportation challenges due to living in a rural area/accessible health care for children's hospitals – there was discussion regarding challenges of having multiple appointments in a day, week, month; parking rates. Telehealth visits were done during COVID, but now providers are pushing for in person appointments. Physicians want imaging done at their facilities when it could be done somewhere else that is more convenient for the families.

- Excuse heard frequently is that physicians are not as experience with pediatric patients. Rural hospitals need to be trained and become familiar with medically complex children. COVID restriction of only one adult accompanying the child caused issues as well.
- Therapy services have been limited during COVID.
- Accessibility for those who have English as a second language
- School districts prioritizing medically fragile children go back to school so healthier children were required to stay at home.
- Addressing issues in early childhood system would improve health outcomes.
- Transition – five is appropriate age to start having conversations about the future.

Haley thanked Erica for leading the discussion and everyone for participating. The next meeting, November 9th, will be closed and will be used to discuss next steps to move forward.

Links/Contacts/Additional Information
Joan shared that she is in Chicago and uses paratransit service from PACE for her son's appointments. It's a paid transportation service for the disabled. She also shared that her sone changed from in-person therapy to virtual therapy since the pandemic started and they receive therapies from Shirley Ryan Ability Lab.

Links to letter templates:
https://dscc.uic.edu/home-care-nursing-information-for-families/
https://dscc.uic.edu/for-providers/home-care-information-and-resources/

Contact information:
Shelly Roat sgroat@uic.edu
Amy Hrdlicka aeedders@uic.edu
Amanda Simhauser arsimhau@uic.edu