



Division of Specialized Care for Children

Family Advisory Council
May 11, 2023, 9:00 AM

Attendees:

Claire Cook	Ruann Barack	Adell Scott
Violet Wiker	Nikki Goldwater	Amanda Simhauser
Molly Hofmann	Joan Tam	Thomas Jerkovitz
Stephanie Leach	Haley Phelps	Maria Civito
Shelly Roat	Erica Stearns	Byram Fager
Jaclyn Vasquez	Chelsie Hacker	Jessica Brafford
Mary Herschelman	Jamie Renth	Jose Jimenez
Aurea Garvin	Lisa Washington	Jasmine Deida
Gail Koshgarian	Jodi Lindgren	

Welcome from Erica Stearns (FAC): Erica Stearns, FAC Chair, reminded everyone of the meeting being an open forum and invited attendees to introduce themselves and share with who are they affiliated with.

Quality Update / Ruann Barack (DSCC): Ruann Barack, DSCC Associate Director of Quality Improvement and Education shared and explained a presentation on the following:

Family Survey Ruann thanked the FAC committee for their feedback and ideas for better engagement and proceeded to explain updates to the survey process:

- Reduced number of surveys sent to families: discontinued education survey and added support with education item to the annual survey.
- Survey schedule changed to one time per year, instead of based upon enrollment dates. This started on February 2023.
- Questions and electronic survey were reviewed to make sure they are user friendly and easier to complete.
- Improved communications with families.
- Improved overall response rate to 23% this year, which is almost double compared to last year.
- Currently in process of analyzing results to continue to improve services to our families.
- Results will be shared in the next meeting.

Authorization Improvements: The following have been approved and working on getting these updated in the DSCC system in the next couple of months:

- One authorization for all external providers.

- Making signatures more user friendly.

Education

- Family Webinars - Ruann explained that this is the first time DSCC held webinars around insurance and have received very positive feedback. These webinars started in March with "Understanding your Insurance", "Medicaid Availability and Coverage" in April, and last session being held in May with "Insurance Appeals." All webinars are recorded, and tip sheets have been created, both can be found in the DSCC website.
- First In Person Conference with DSCC Teams - Chicago Conference was held in April 2023 and the Springfield Conference is scheduled for May 2023. Focusing on Personal Safety, Person Centered Planning and Selfcare.
- Financial Assistance Project continues to move forward reviewing DSCC financial support looking to make it more user friendly, more to come.
- Working towards NCQA accreditation. Survey date is February 2024. Lookback period starts August 2023.

Questions/Comments:

Erica Stearns shared that resources and webinars provided by DSCC are very helpful to families and explained her experience with it. Erica shared the DSCC website link in the meeting chat for attendees to access.

Erica asked if the 23% return rate on survey responses are above average and if FAC recommendations have helped improve responses? Ruann explained the responses have doubled if not more, a step in the right direction and will continue to strive to do better. Ruann also shared that comments received in the survey from families are always helpful.

Family Advisory Logo Results (Erica Stearns FAC Chair): Erica shared the results for the new FAC logo and explained it will be used for different internal documents and guidelines to new members.

National Consumer Scholar in Complex Care Program (Evelyne Kane - Camden Coalition)

Evelyne Kane, Senior Program Manager at the Campton Coalition, introduced herself and explained the Campton Coalition is a multidisciplinary, community-based nonprofit working to improve care for people with complex health and social needs in the city of Camden, across New Jersey, and around the country. They develop and test care management models and redesign systems in partnership with consumers, community members, health systems, community-



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based organizations, government agencies, payers, and more, with the goal of achieving person-centered, equitable care. Evelyne shared that applications to their National Consumer Scholar Program application are currently open through the end of May for the 2023-2024 group and suggested to visit their website or send her an email if any questions.

<https://camdenhealth.org/event/apply-to-become-a-2023-2024-national-consumer-scholar/>

ekane@camdenhealth.org

Questions:

FAC members shared their experiences with policy making and efforts made since becoming a caregiver and shared their excitement about the program.

Grace Heimerdinger-Baake shared her experience with lack of help for children with complex care in her area (northwest Illinois between Rockford and Galena), she stated she had reached out to her local hospital inquiring about an advisory council and was told they did not have one, she was also told they did not have social workers specialized in pediatric care. Grace asked for suggestions on how to be heard and expressed she was very happy about the program.

Ekiko Aiken inquired about small and/or large victories that the group has been able to accomplish either in national or state level. Evelyne shared several achievements done by consumer scholars to explain the impact of the National Consumer Scholar Program.

Erica shared that as a state-based program it is difficult to get organizations to connect with and asked if the stakeholders that participate in annual conventions for the consumer scholar program would be interested in helping, having some of these medical providers collaborate with the cause. Evelyne shared they do have participation from providers all across the country, beyond the conference the coalition does all sorts of work across the country and asked to contact her with any questions.

Byram inquired about resources and guidelines for financial advisory to not lose benefits and/or not be counted away from future services and proceeded to ask Evelyne if there is a national guideline or resource page available.

Evelyne explained the need of policy change since there are not a lot of good work around options and shared the following link:

<https://camdenhealth.org/resources/compensating-consumers-and-considerations-for-public-benefit-recipients/>

Summer Activity Update & Discussion (Amanda Simhauser (DSCC) & Byram Fager (FAC member):

Amanda Simhauser shared her screen and explained how to navigate the DSCC website to locate the "2023 Summer Camp Opportunities Round Up" page, which includes summer camps, enrichment opportunities, college experience opportunities, dance programs, etc. anything inclusive and that caters to a specific health need or condition to keep children engaged over the summer. Posted and sent out to families at the end of March 2023. Camps list can be searched chronologically and by locations. It is constantly shared in social media with reminders to visit the page for summer camps. DSCC tries to capture as much of the state as possible, some camps are free and some cost. Amanda asked the FAC members to share with DSCC if they know of any camps available to be added to the website.

Questions/Comments

FAC member asked if DSCC provides out of state camps information. Amanda explained that there are some out of state camps included in the list, DSCC tries not to limit to just in state opportunities and includes some out of state camps. Adams Camp in Colorado was recommended. Amanda suggested to always check back with DSCC website since the list gets updated with new opportunities periodically.

Byram Fager asked if there is a way to sort the list by location. Amanda shared and explained the calendar view by month. Also, recommended to search through our website by regional office under "additional information". Amanda added that DSCC will work on getting links created by regional offices to lessen navigation for families to find information needed.

Byram Fager shared his concerns regarding the lack of daycares for children with special needs, especially during the summertime, around his area (Marion, IL) and questioned if it is the same in other parts of the state. Byram also shared that he has heard of groups getting together to form a non-profit to build daycares specifically focused on children with specialized needs and suggested that this could maybe qualify for grant funding from the state.

Jessica from Waterloo, IL, member of her region B-5 family council, shared that the same issue was discussed at their forum, and were questions inquiring about grants for daycares for special needs children and stated she is willing to become an advocate for the cause.

Jaclyn Vasquez (FAC member) shared that this is a topic across the state and added the need of policy changes, better support locally, and reaching out to local legislators to continue to elevate this in different ways. Jaclyn suggested for everyone to unite and approach it from multiple angles to ensure it's pushed as a united force across the state to make differences.



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Erica shared that there are different Facebook groups specific to different complex care, ages, waiver services, local groups, etc. and added that DSCC provides resource lists on their website such as the ARC Center of Illinois. Signing up for a Palliative Care team was suggested for parents new to the state.

Discussions and suggestions about summer camps were shared and questioned if waiver benefits qualify to cover for costs.

Shelly Roat, Assistant Director of Operations for the Core Program for the southern regions, explained DSCC supports camp costs from gift funds available for qualifying Home Care and Core participants, if camps are related to their eligible condition can be supported out of Core funds, and suggested to always ask your care coordinator.

Thomas Jerkovitz, DSCC Executive Director, emphasized gift funds availability for special purposes such as camps, and suggested parents to always ask their care coordinator if any doubt.

Erica suggested that if the care coordinator does not have the answer to reach out to someone above the care coordinator such as the regional manager.

FAC will share suggestions with DSCC to better navigate the summer camps list. Amanda shared suggestions are always welcome and will work on better filter information by location/ condition/ age group, etc. for next year, if possible, this year.

Discussion

Care Giver Opportunities

Erica asked for feedback and if that something about families would like to see more of in future meetings.

FAC member shared her approval to caregiver opportunity presentations and added to include resources for specific issues such as who to contact to advocate for caregivers of the MFTD waiver getting paid.

Molly explained that some families are having discussions with their state legislators by telling their personal stories and experiences and explaining the importance and need for unlicensed family members to be paid as caregivers in Illinois.

Byram Fager asked about organizations who lobby that will help with information for families in regards of health care for children with special needs, to make families aware which bills are out there to support.

Tom Jerkovitz explained DSCC is part of the University of Illinois system and do not lobby as everything goes through the University of Illinois legislative branch and suggested to visiting the Illinois General Assembly website to view bills pertaining to the Department of Public Health. Mr. Jerkovitz added that it may also be helpful to seek out resources such as The Arc of Illinois to guide families in the right direction for advocacy.

Erica added that pediatrics is often overlooked, especially pediatrics developmental disability (DD) and shared a list of organization who lobby (The Arc of Illinois, They Deserve More, and Caring Across Generations) for caregivers to contact about the need for partners in advocating for paid caregiving. Erica offered to share some type of universal language for families to use when contacting legislators.

For other future FAC topics, Byram Fager suggested resources for mental health and compassion fatigue to be added to the DSCC website. Byram shared his experience with an online mental health first aid training and how it helped him recognize and understand signs for mental health.

Erica searched through the DSCC website and found mental health support for the Home Care program.

Stephanie Leach, DSCC Associate Director of System of Care, explained that under the MFTD waiver, there is a service called "Placement Maintenance Counseling", support given to participants and their family to do whatever it takes to keep the child at home with the counseling offered under the Medicaid state plan. It is an option offered for families in the MFTD waiver.

Erica shared a resource called Give An Hour <https://giveanhour.org> for caregivers of patients with rare diseases, offering peer to peer support groups, help with pairing families with local mental health support for parents of pediatric care givers. Erica shared her struggle with finding local mental health support that can relate to what it is to be a pediatric care giver and having a mental health section in the DSCC website with free resources is a great idea.

Thomas Jerkovitz, DSCC Executive Director, shared that he is looking forward to seeing the results of the family survey as DSCC takes this very seriously and want to continuously improve the services provided to the families. He is very pleased with the 23% responses compared to single digits with past methods. Mr. Jerkovitz encouraged families to review the insurance webinars and to contact DSCC for summer camps since there are gift funds available. He thanked everyone for their time and input.

The next meeting will be on August 24, 2023, from 9:00am to 11:00am and will be a closed meeting.



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Resources shared in the chat:

DSCC summer camp listing: <https://dsccl.uic.edu/2023-summer-camp-opportunities-for-all-ages-and-abilities/>

Other camps:

The painted turtle sponsored by Paul Newman overnight camp in California offers camp for different conditions & families & siblings.

https://www.thepaintedturtle.org/?gclid=Cj0KCQjwslejBhDOARIsANYqkD2ECDTJoLoNW3fig8i7Etxn_9S9K72KuT6-G9eyGWkRMxKFMH2N-XEaAiGtEALw_wcB

Fresh air camp in Ohio <https://www.freshaircamp.org/>

Camp Little Giant - Dynamic Duos Overnight Camp Session 1 in Makanda - Sunday, June 25, 2023 - All Day <https://dsccl.uic.edu/events/camp-little-giant-dynamic-duos-overnight-camp-session-1-in-makanda/>

Family Support section of the DSCC online Resource Directory - <https://dsccl.uic.edu/resources/family/>

These two family support organizations offer great resources, programs, and support group opportunities:

The Family Resource Center on Disabilities -

https://dsccl.uic.edu/dsccl_resource/family-resource-center-on-disabilities-frcd/

Family Matters Parent Training and Information Center -

https://dsccl.uic.edu/dsccl_resource/family-matters-parent-training-information-center/

IPADDUnite on Facebook is a large group of parents of children aged 14+ with IDD/DD.

Byram contact info: byram@sicf.org

National Consumer Scholar in Complex Care Program (Evelyne Kane - Camden Coalition)

For more information and to apply: <https://camdenhealth.org/event/apply-to-become-a-2023-2024-national-consumer-scholar/>

Feel free to check out the webpage linked above and welcome folks to reach out to me if you have questions - ekane@camdenhealth.org

<https://camdenhealth.org/resources/addressing-the-benefits-cliff-to-enable-equitable-compensation-for-consumers/>

<https://camdenhealth.org/resources/compensating-consumers-and-considerations-for-public-benefit-recipients/>

Other Fellowships:

Here is a great state-based option: Caring Across Generations - Illinois Cohort Care Fellowship <https://caringacross.org>

Other organizations to contact (email) about the need for partners in advocating for paid caregiving: The Arc of Illinois, They Deserve More, and Caring Across Generations

Mental Health First Responder training from Byram:

<https://www.thenationalcouncil.org/>

From Amanda S.: A lot of our mental health resources on the website are listed in the Family Support or Medical/Health section of our website. A Self-Care/Mental Health section is on our list to add as a new category, and we'd love the FAC's input on what content and resources to add there. Here are a couple quick existing ones I pulled out -

https://dsc.uic.edu/dsc_resource/mental-health-and-developmental-disabilities-training-modules/

https://dsc.uic.edu/dsc_resource/self-care-for-caregivers/

https://dsc.uic.edu/dsc_resource/the-mightys-digital-toolkit-for-caregivers/

https://dsc.uic.edu/dsc_resource/mental-health-resources/