Location: Zoom
Date: February 02, 2022
Time: 9:00 am

Family Advisory Council Meeting

Attendees:

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

Minutes

Quality Report – Ruann Barack (DSCC)

Currently, DSCC surveys are sent out with the initial survey going out 60 days after enrollment, an annual survey is sent at one year, three years, and at five years, then every five years after the enrollment date. There is also a series of education surveys and a series of transition surveys that go out to specific age groups, and an exit survey that goes out 30 days after disenrollment. We also send surveys out via email daily at those timeframes and monthly for all other participants. These are always sent anonymously unless a family indicates they would like to be contacted by us on the survey. The manager then contacts the family once they are notified by the internal system. There is also a home visit survey that is based upon a random sample of visits that occurred the month before. The feedback is then used to see how we are performing and how we can improve.

Ruann requested everyone on the FAC forward their ideas and feedback so she can use the information to improve the survey and hopefully create ways to get families to engage in the survey. Feedback for the last survey was only at 6%.

In order the get families to engage with us, we are looking at letters and how to better communicate with families regarding the surveys, how to notify the care coordinator during the month the survey is sent so they can discuss it with the family and let them know how important it is to DSCC to receive feedback for improvement, and we are posting information about the survey on the website.

Thoughts and ideas from the group:

- Ally: Could you have the care coordinator (CC) do the survey during the monthly phone call/visit?
- Whitney: Loves Ally’s idea. She struggles with how many surveys she receives every time she takes her child to the doctor. She had three appointments in January and ends up with a survey

every time. It would be easier to answer a couple of questions instead of having to fill out an actual survey. Also, the parent may have constructive criticism regarding the care coordinator and that may make it awkward so Whitney suggested using a 3rd party that could be patched in during the call that could ask the survey questions so the answers could be more private/confidential. She did not want it to be a separate call.

  - Kelly Wyman (DSCC): Would it be beneficial for managers to occasionally check in with families directly? Managers would like to be approachable.
    Whitney: Indicated it would be a nice touch since she has worked with the manager in the past. Most of the time she has only had contact with the CC and doesn't know who to contact besides the CC, so that would be beneficial.
  - Please forward any other ideas to Ruann via the FAC email listed on the agenda.

Communications Report – Amanda Simhauser

- On September 02, 2021, mass emails were sent out to Home Care participant families. The emails included input on the state plan for children with medical complexity, our home nursing survey and a letter of medical necessity examples is available.
- January 07, 2022, we began the mass email to Core and Connect Care families. This included a welcome as well as a reminder that now that we are beginning another year in the pandemic our CCs are here to help guide them through challenges and help them with resources and services they may need.
- We have partnered with UIC's IL LEND Program to offer a new parent webinar series/support group for families.
- Amanda gave an overview of the news and participant stories featured on our social media and website over the past few months. You can go to DSCC.uic.edu to see stories about any of our families that are in the news or doing something to help other families or raise awareness we try to highlight them. Did a recap story about the Transition Conference held in November which was held both virtually and in person.
- Some initiatives Communications and Outreach are working on include improving our online resource directory by adding a search component and filtering, which will be added by the web vendor. Adding categories such as county will help refine the results of searching instead of just by regional office. In February we will be doing another Resource Roundup newsletter that will list what has been updated on the resource directory.
- Team is working on FY21 Annual Report which will be coming out in the next few weeks.
- A new Home Care Family Handbook is in the works. Previously the handbook was predominantly about the Core program.
- The Transition Tools Checklist tip sheets, which are located on our website, are being updated.
- All current brochures and handouts/printed materials are being updated with the new UIC logo.
- The 2022 Institute for Parents of Children Who are Deaf or Hard of Hearing is scheduled to return in person this year and we are working on getting the word out to families who qualify.

- February is Heart Awareness month, Congenital Heart Awareness, Feeding Tube Awareness week, post items on social media that pertain to those topics.
- The team is hoping to feature FAC families when updating the family stories. They are hoping someone is interested so please let them know if you are interested.
- They have also been working with the Quality Improvement team to update language used in the family survey and possibly add a section to our website to explain the purpose of the survey and what families can expect. If you have any feedback, please share via the FAC email and the workgroup will let Ruann and Amanda's team know what to include on the website.
- Profiles about the Medical Advisory Board members will be added to the website, as well.
- Please contact Amanda or her team regarding any questions or suggestions you may have.

The impacts of an ongoing pandemic on caregiver mental health and education – available resources and supportive initiatives – Erica Stearns (FAC Chair)

Erica explained that in her position at ARC, this past fall, they had received many concerns and calls from DMEs regarding the pandemic and how it has impacted our children's educational needs and therapy needs, etc. The issues vary drastically from one family to another. The specific child's needs, their location, and how different school districts handle things, all affect how things are handled and this is very stressful to families and affects everyone's mental health. Wanted to discuss experiences related to this and how others have troubleshooted through problems. Erica discussed how DSCC has worked with other agencies to navigate some of these issues.

In early January you may have received an email about partnering with the LEND program regarding a webinar series/parent support group. Erica requested Molly Hofmann (DSCC) explain more about this resource for parents.

Molly introduced herself and thanked everyone for participating in the meeting. DSCC recently started a partnership with the IL LEND committee to start a parent support group. This was implemented after receiving feedback from families. LEND stands for Leadership Education in Neurodevelopmental and related Disabilities. It is a training program/unpaid fellowship with members that are considered trainees made up of nurses, social workers, etc. and is open to people who are interested in leading more. The leadership of LEND is through UIC, College of Human Development and Disability. We have partnered with them in the past and currently have a Transition project with them which involves looking at the transition to adulthood in education and Latino youth. This past summer we discussed the concept of a parent support discussion group with their team of professionals. A couple of their trainees that had backgrounds in nursing and social work were interested in working on this project with us. They met and decided to request feedback to see what types of topics people were interested in and discussed how to set it up in an educational format.

There have been 2 sessions so far. The first one in November had issues with Zoom and only one parent was able to log in. It was held at 5:00 p.m. They decided to change things a bit for the next session which was held in January to include more than Home Care parents and include Core and Connect Care parents as well and move the event to 7:00 p.m. Molly did participate with the trainees, and they discussed how much time would be spent on education and how much time would be spent on support. LEND trainees and their leaders have been developing this and it's been a learning curve for DSCC. The title will be changed to indicate it is more of an educational than a support discussion. In January someone from Equipped for Equality talked about navigating IEP's during the pandemic. There were 17 parents that participated and Spanish translation was provided.

Molly wanted to share that emphasis was being placed on the educational piece more than the support piece. She would like to hear feedback/suggestions for future topics. The plan is to have a new one each month moving forward. If you participated in the January event, please send any feedback you would like to share.

Erica asked if these events will be recorded. Molly explained the presenter piece will be available/recorded but the questions and discussions will not be recorded to protect private information. Molly stated we have not received the recording back yet, but she will check on it and it will be put on the DSCC website once received.

Erica expressed there seems to be more educational opportunities than support and she is frustrated with doctors talking about parent's lives but not asking what support they actually need and want. She asked the parents in the FAC group how they felt about the emphasis being more on education instead of the support component and if they felt the same way as her.

Molly expressed concern about that as well. There were others at the event that expressed the training was not what they thought it was going to be. The title of the training was a little misleading. DSCC will have the opportunity to work with LEND in the spring to decide how to move forward using feedback from parents. If the support piece is what parents want in the future, Molly would like to make sure the correct people are working on this project to facilitate discussions and know how to follow up on concerning issues. It was expressed that both education and support are valuable topics and there could be valuable information from people with life experience that could help others, as well.

Jasmine would like to see something for Driver's Education for children with special needs who need modifications to drive.

Jasmine also stated that many schools do not know who DSCC is or what they do. Molly explained DSCC is aware and actively working to address that as DSCC just presented at the School Health Days conference held across the state including around 1600 attendees who heard about DSCC and our programs. Could a mass email go out to schools? (Shelly Roat: We previously sent information out to every school listed on the State Board of Education directory and maybe we can do this again.)

FAC members agreed that most parents are just treading water and anything scheduled or too long in time is difficult to attend, especially at dinner time (5:00 ish) or bed time (7:00 ish). They would appreciate the recorded version. It was also suggested doing the trainings as a recording so the parents could watch it whenever they could fit it in to their schedules, then have a short 15-minute scheduled discussion at a later time, possibly over lunch time/during the workday, or in the evening.

Please send any topics or feedback to Molly. Erica put together frequently asked questions and they are available on the website and meeting minutes.

HFS Nursing Allocation Recommendations for Home Care – Whitney Woodring (FAC)

Whitney put together a list of 3 suggestions that she hopes will help with communication and outreach to families:

1. Create a new program where the protocol is a DSCC care coordinator/manager contacts family and reviews the nursing allocation 6 to 8 weeks after a child comes home from the hospital. (It would be beneficial for parents to have some time to get home with their new child and begin to understand how the new normal will be on a daily basis and that will make the questions more useful at the 6 to 8 week time frame. Periodically checking on the family to see what they need in a more personal way would be helpful and appreciated.
2. Increase the use of website with HFS and create a better electronic way of communicating with families regarding appeals and rescheduling. (Receiving an email as soon as possible would be appreciated as opposed to waiting for mail to arrive when dealing with the appeals process. There are many legalities and back and forth communications so being aware of the situation ASAP via email would speed up the process.
3. Could some type of resource be created for navigating appeals? Could a workshop, recorded webinar, handbook, or resource guide be created? (How do parents know if the person reviewing the case knows anything about the child's condition?)

Any nursing allocations and recommendations can be emailed to Whitney (whitney.woodring@gmail.com) or Haley (dsccfac@uic.edu).

Appeal Tip Sheet Update (Home Care)– Stephanie Leach (DSCC) and Jose Jimenez (HFS)

Stephanie and Jose are working with the Bureau Chief at the Appeals Section of HFS to get guidance to distribute. Responsibilities of who does what gets confusing so many families go to their DSCC care coordinator to ask about the status of appeals. Our tip sheet will be framed out to explain who is responsible for what when it comes to the appeals process and will explain the responsibilities of the DSCC care coordinator, the family, and what HFS is responsible for and their expectations. Jose will be able to assist with the HFS section. When the draft is ready, they will distribute it so more notes or information can be added/adjusted and once it is completed, they will post it as a helpful guide to families on the website.

Jose explained the appeal process is the same for all waiver programs. Sometimes the structure process and appeal rights are fully vetted through legislation, administrative rules, or for federal guidance, to ensure it is all the same for the integrity of the appeal process. Sometimes they do not have flexibility even though it may not make sense for a specific program. Appeals go through the legal unit of HFS which is a separated branch from the program side to keep a firewall and to make sure they are an independent body to make decisions based on the facts presented.

Whitney: This sounds amazing and is there any way this tip sheet could be included in the letter/notice the family receives? How do we forward this new information to the families? Stephanie: Care coordinators need to be trained to send the information to the families when things change in services for the family. That may be the time they should send the appeals guide and contact the family. Stephanie will work with HFS and the team to improve this process so more information should be coming next meeting.

Amanda stated they would include the Appeals tip sheet in the Family Handbook, as well.

<u>Resource's Update – Amy Hrdlicka (DSCC) and Shelly Roat (DSCC)</u>

Amy explained that Amanda's team is working on edits to the templates that they will be using and getting the structure to the resource information. They are regrouping to get first steps kicked off shortly. Shelly: The group has some great ideas that they are working on, and they will update everyone at the next meeting.

<u>Emergency Disaster Plan – Kelly Wyman (DSCC)</u>

Kelly Wyman works with the Champaign and Peoria staff in central Illinois. She has been invited to work on strategic goals for emergency planning along with Jeanne Grady (DSCC). This was part of the strategic plan for this year since everyone is impacted by weather, especially our families who are vulnerable to having issues with medical technology and could be affected if the power goes out. We want to be able to assist families and help them connect with the correct resources as well as power our staff to know how to help families come up with emergency plans. We want to be able to partner with emergency planning organizations that respond around the state and advocate for our population. We are working on the section of our handbook that explains what to do in emergency situations. Kelly shared the Emergency Preparedness Resource with the team who want this to be useful to our families and wanted to get input from the FAC and what the team feels is necessary to have included in this resource. This document will be included with the minutes so everyone can review it and send feedback to Kelly's team via the FAC email.

Subjects included:

- Types of disasters to prepare For
- Considerations for things that may happen, i.e. (Battery backups, etc)
- Shelter in place
- Evacuation
- List of Contacts
- Resource Toolbox
- Creation of Family Emergency Planning guidance
- Information about Home Care program/Power outage

With Covid and other issues, the supply chain or getting service is challenging. It can be a major issue for families fiscally and handling situations like refrigeration of medications/special diet foods, etc.

<u>FAC Feature Story Volunteer – Adell Scott (DSCC)</u>

Adell would love to feature a FAC family or two on our website. Please email Adell if you are interested. DSCC may need a media release, then someone would schedule an interview which could be held over the phone or via email. The family would be able to view the interview prior to posting. Please contact the FAC workgroup via the FAC email if interested.

<u>Parking Tip Sheet Update – Adell Scott (DSCC)</u>

During the August meeting there was some discussion regarding transportation accessibility in rural areas and different parking and commuting costs. Adell shared a tip sheet that is being created which will be sent out with the meeting minutes for everyone to review and forward feedback. The tip sheet is broken down into sections:

- ○ Appointments and short stays (parking/shuttles/validation/etc.)
- ○ Extended stays (planned or unplanned)
- ○ Parking resources and financial assistance
- ○ Other helpful tips (grouped appointments, etc.)
- ○ Core financial assistance (what is covered)
- ○ First Transit (Medicaid need non-emergency transportation)
- ○ IMPACT (how to enroll as a provider)

Discussion and Ideas:

- Could St. Louis area information be added, i.e., meal cards, using Ronald McDonald house, restaurants on hospital campus do not take gift cards, how to get reimbursement, etc.
- Could a section be added for long trips, such as a 3-hour drive where things can happen?
- Add roadside assistance information
- what to do if you run out of oxygen
- what to do if you have medical emergencies
- where there are accessible restrooms along the route, etc.
- Possibly have care coordinators assist families with a travel plan for their trip. Can some of this information be added to the tip sheet?
- List of hospitals and places for assistance along the route.
- Sometimes can purchase multiple parking to save money which goes towards your cap, so do that whenever possible per Shelly Roat.

Will review at future meetings until resource is ready to release with all updates.

Shining Stars Recognition – Amy Hrdlicka (DSCC)

The Shining Star Program is a recognition program the regional office started in the Chicago area. Staff wanted to recognize their co-workers who have done something outstanding. A certificate and story are shared at their monthly staff meeting. This has been lifting morale and someone suggested a similar recognition program be implemented for families/parents to lift them up and show DSCC is supporting their everyday efforts. The leadership team liked the idea and wanted the FAC members to give them input on how they feel about this idea.

Discussion and Ideas:

- What would this look like and what is required of the family?
  A phone or email interview could be set up with the family. The family would be able to view the interview prior to it being posted to the website or Facebook.
- There was some concern that this could be viewed as condescending or patronizing.
- DSCC believes this is an opportunity to shine light on successes and positive outcomes through difficult situations and is a way to resonate with other parents that deal with difficult situations daily. It is more about being seen and understood and appreciated, not a pat on the back for what parents believe they do daily that is just necessary and a part of being a parent of a child with special needs. It can be educational and help show others what they did in similar situations that had a positive outcome.
- It could be a story about the care coordinator along with the parent as a team to work on and figure out problems together.
- The manager could be the person who contacts the family and acknowledges the family and/or care coordinator.

Any ideas or opinions regarding can be forwarded via email.

Advocacy Chair Position – Haley Bestudik (DSCC)

Currently the Advocacy Chair position is being held by Whitney. Haley and Whitney as well as the FAC need to discuss and come up with a plan for exactly what this position should entail. Whitney feels comfortable discussing the southern to central part of the state issues, but would like someone to share the position as partners who could help co-chair the northern part of the state. Please reach out to Whitney or the FAC workgroup if you are interested.

Letter of Medical Necessity Update – Nikki Goldwater (DSCC)

The Letter of Medical Necessity has been updated on the website in the Resource section. Since the last meeting/discussion, the letter has been sent out to Home Care families through email and went out to CC teams. Please browse Resources and send any feedback you think would be helpful.

Donation of Outgrown or Unused DME Equipment - Adell Scott (DSCC)

Recently a family had contacted a care coordinator wanting to donate DME that had been outgrown and they wanted to donate it to another family. DSCC does not have any avenues on ways to facilitate these situations because of liability concerns because there is no way to guarantee equipment is still safe and in working condition or meets current standards. A discussion regarding how to go about this in the future:

- Facebook may be a great way for parents to connect with others who may want used equipment.
- Erica stated that a sometimes therapists are aware a family is waiting for equipment and families can donate items to the therapist or a school that may forward the equipment to a family in need.
- It is difficult to find organizations that will accept products that are used. Any ideas or guidelines and a central location to donate items would be great.
- Are there Illinois technology programs where equipment can be picked up or you can donate to?

If anyone has an information regarding specific programs for donating, please forward to the FAC email.

***20-HOME MODIFICATION INFORMATION FOR FAMILIES TIP SHEET.pdf -Haley Bestudik (DSCC)**

This new tip sheet will be sent out and is linked here for access. Stephanie also mentioned there is a new tips sheet for vehicle modification available, as well.

Conclusion:

All listed agenda items concluded at 10:48, with a short discussion following which included:

- A request for Whitney to be the first to be interviewed for the family feature in 2022.
- Haley had set up a FAC distribution list and planned to send out a test email in the afternoon to make sure everything is working properly.
- Byram asked for some assistance with dental care near St. Louis and Molly and Shelly said they would be in contact with him to discuss.

The next meeting will be held on May 5, 2022 from 9 to 11 a.m. A reminder and email invite will be sent out.

Links and Resources:

- Family Resource Center on Disabilities (FRCD)
  Family Resource Center on Disabilities | Providing Parents of Children with Disabilities with Information, Training, and Assistance (frcd.org)
  312-939-3513

- Rest of the state:
  Family Matters Parent Training & Information Center
  Assistance for Families to Keep Children with Disabilities Living at Home | Family Matters Parent Training and Information Center (fmptic.org)
  1-866-436-7842

- Equip for Equality – Special Ed Help Line
  Contact our Helpline at 1-866-KIDS-046 (1-866-543-7046) or specialed@equipforequality.org

- Special Needs Alliance: https://www.specialneedsalliance.org/special-needs-101/special-education/

- Home Care Nursing Information for Families page on our website that has the Letter of Medical Necessity examples: https://dscc.uic.edu/home-care-nursing-information-for-families/

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