Family Advisory Council Meeting

Attendees:
- Claire Richardson
- Haley Bestudik
- Adell Scott
- Amanda Simhauser
- Elizabeth Curry
- Gail Koshgarian
- Jodie Lindgren
- Kristin Grubb
- Lisa Washington
- Robert Laib
- Shelly Roat
- Thomas Jerkovitz
- Molly Hofmann
- Ruann Barack
- Amy Edders
- Amy Bussa
- Eric Nielsen
- Chelsie Hacker
- Jonathan Gauerke
- Laura Braucht
- Nancy Leman
- Robin Morgan
- Joan Tam
- Violet Wiker
- Courtney Wood
- Stephanie Leach
- Ally Chenoweth
- Byram Fager
- Erica Stearns
- Jasmine Sere Enzo Josh
- Kelly Whistler
- Lauren Rivera
- Nikki Goldwater
- Rosa Cole
- Thomas Gensler
- Whitney Woodring

Minutes

Welcome & DSCC/FAC Intros
An email has been set up for issues related to the Family Advisory Council. Members are encouraged to reach out using this email address.

New Family Advisory Council Member Introductions
Robin Morgan introduced herself. She is with the waiver management unit that oversees the MFTD waiver at Healthcare & Family Services. Robin will be participating in some of these meetings in case anyone has questions related to the waiver.

The following new members introduced themselves: Kelly Whistler, Amy Bussa, Whitney Woodring, Erica Stearns, Lauren Rivera, and Gail Koshgarian.

If members would like to share information related to their child’s diagnosis, they can send permission via the FAC email. DSCC staff will compile the information and share with the council members.

New contracts will need to be signed by members for the new fiscal year, which starts July 1, 2021. Members are encouraged to reach out to DSCC with any issues related to completing and returning the contracts.

About DSCC (Care Coordination Leadership)
Care Coordination Leadership presented information on the three programs at DSCC (PowerPoint is attached). Thomas Jerkovitz, Executive Director, stated that the poverty level table can be found on the DHHS website.

Molly Hofmann and Thomas Jerkovitz both stated they look forward to hearing feedback from the Council.

In response to a question regarding how DSCC addresses gaps in care coordinators’ knowledge (i.e. ensuring they understand that just because a kid is healthy, it doesn’t mean the child is getting better), Molly stated that the determination of resources (i.e. number of nursing hours) is decided by HFS who has a team of contracted physicians who look at documentation from the child’s physician so the better documentation from providers, the more that can help the reviewers understand that child’s needs. She added that during the
pandemic, there has been a concern that when appointments were being avoided that may have been taken to mean there is improvement. Regarding the care coordination piece, Molly stated that there are many different conditions with thousands of children participating in DSCC programs. DSCC tries to ensure the team is trained in understanding the unique needs of individuals and families and that they have resources to educate themselves on those conditions. If families observe areas that need improvement, Molly stated that DSCC wants to hear that information. Feedback from families as well as trends that are observed help determine training topics for the year. In response to a question regarding if there is a liaison with HFS and if an FAC family member could fill that sort of role, Molly stated that Robin from HFS will be participating in the FAC meetings again; this has not happened previously. Using this group for feedback to her might be one first step. Another step might be for this group to pull feedback together so discussion can be held with partners at Medicaid. Stephanie added that if Whitney could help gather some specifics from other families, this can be added to the next meeting agenda.

Stephanie will check to see if the tool used to determine qualifications for the MFTD waiver is available for parents and get back to group. The tool is based on points and relates to clinical aspects. There is no part of the tool that relates points to an amount of dollars. HFS would have to speak to how this is decided. HFS confirms eligibility and decides on resources then sends that information to DSCC. DSCC can let HFS know if this is something for which the Council would like more information.

Feedback was given regarding a lack of consistency among care coordinators in terms of available resources and qualifications. It was asked if a list exists that can be used and also shared with parents. Stephanie stated that DSCC tries to train staff across the board and if a care coordinator is not as seasoned, they are encouraged to go to their managers or ADO if the care coordinator is unaware of a resource about which a family is asking. Molly stated that DSCC is working on a procedure manual and resources information for staff. If families are having issues or hearing of issues from other families, DSCC wants that feedback so it can be addressed. Issues can only be addressed if brought to DSCC’s attention. The first step would be for families to talk to the care coordinator’s manager. ADOs can work with managers to follow up on feedback. Lisa added that families should be informed that by bringing issues to the manager, they are not getting the care coordinator in trouble; it’s about addressing the needs of a family who needs assistance.

After discussion regarding families being involved in making sure the resource list is up to date, it was suggested that a workgroup could be formed for this. Resource points that Council members would like to hear more about can be added to the agenda for the next meeting. Many suggestions being offered fit well with items that are already being worked on by DSCC. Erica stated she would like to be a part of this effort. Both parents and providers would like to have this information.

Molly stated that there is an opportunity to share feedback on waivers. HFS was made aware that the American Rescue Plan has additional money that will be made available for waiver programs. DSCC is putting together a recording with an email address for individuals to provide feedback. The recording will be on DSCC’s website and Facebook and will also be sent to this group. States have to submit their responses by June 12th so there is very little time to provide feedback. Members are asked to watch for this information and share it.

Communications Report (Amanda Simhauser)
Amanda presentation on communication efforts at DSCC (PowerPoint is attached).
Amanda would like to be part of work to improve the resource directory.
Quality Report (Ruann Barack)
Ruann presented information on DSCC’s culture of quality as well as initiatives being conducted by the Quality Improvement team (PowerPoint is attached).

Old Business
Family Advisory Council Officer Position Openings – please reach out if interested.

Paperwork Processing – Molly stated that DSCC is partnering with University legal and HIPAA teams to see if improvements can be made in the authorization process. She recently learned that there are changes being made around HIPAA with implementation expected to be in early 2022. Authorizations will not be needed for a majority of health and community resource providers. More information to come on this.

Molly thanked the FAC members for taking time out of their busy schedules to participate in the meeting. Stephanie stated DSCC wants this to be an engaged council and wants to hear from the members. DSCC welcomes agenda topics and presentations family members would like to give.

Courtney stated the next meeting will be August 25th at 10 am and will be an open forum with registration for public participation. Please reach out with suggestions, agenda items, and interest in officer positions.
Who We Are

We are a statewide program that’s served children and youth with special healthcare needs and their families since 1937.

We helped more than 19,600 Illinois families in FY 2019.
Our Vision and Mission

**Vision**
- Children and youth with special healthcare needs (CYSHCN) and their families will be the center of a seamless support system that improves the quality of their lives.

**Mission**
- We partner with Illinois families and communities to help CYSHCN connect to services and resources.
We define care coordination as a **person-and family-centered, strength-based, assessment-driven** approach of empowering families to achieve their goals, ultimately leading to positive health outcomes, improved quality of life and overall family satisfaction.

DSCC Care Coordination efforts focus on partnering with families and communities to help children with special healthcare needs connect to services and resources they need.
Care Coordination

Our care coordination is tailored to each child and family.

Care coordination teams can include:

- Registered nurses
- Social workers
- Speech-language pathologists
- Audiologists
- Respiratory therapists
- Health insurance specialists
Who We Serve

DSCC provides care coordination services through three programs:

- **Core Program** – Ages birth to 21 with medically eligible conditions.

- **Connect Care Program** – Ages birth to 21 with special healthcare needs who are enrolled in a Medicaid HealthChoice Illinois plan that has contracted with DSCC for care coordination.

- **Home Care Program** – Child or youth in need of in-home shift nursing.
Core Program

For youth up to age 21 who have/are suspected of having an eligible condition.

Condition must:

- Be chronic.
- Qualify as one of 11 eligible categories.
- Cause impairment or need for long-term care.
- Require a care plan.
- Benefit from care coordination.
Core Medically Eligible Conditions

- Nervous System Impairments
- Eye Impairments
- Hearing Impairments
- Craniofacial & External Body Impairments
- Cardiovascular Impairments
- Pulmonary Impairments
- Inborn Errors of Metabolism
- Gastrointestinal Impairments
- Urogenital Impairments
- Blood Disorders
- Orthopedic Impairments
A new program for children and youth with special healthcare needs (CYSHCN) enrolled in Medicaid managed care.


DSCC is serving CYSHCN through plans that DSCC has a contract with.

New referrals to this program are considered on a case-by-case basis.
Provides care coordination to children & youth who require skilled in-home nursing.


DSCC has operated the MFTD waiver since 1983.

In 2014, DSCC became the single point of entry for Illinois children in need of in-home shift nursing.
Medicaid Home and Community-Based Services Waiver (MFTD)

- Must have both medical & technology needs.
- Must be less than 21 years of age at the time of enrollment.
- May qualify regardless of parental income.
- Participants enrolled in the waiver prior to their 21st birthday, & still receiving services on their 21st birthday, may stay with Home Care for life.
Home Care Populations

Non-Waiver (NCPS)

- Must have an identifiable need for in-home shift nursing, although typically less dependent on technology.
- Must be less than 21 years of age.
- Must be eligible for Medicaid.
Care coordination is free for all DSCC participants, regardless of a family’s income.

If a child’s condition isn’t listed in our eligible categories, we still can help.

» Many children have associated conditions with their diagnosis that may be eligible.

» Our staff is always ready to assist with referrals and resources.
Our care coordination helps families:

- Feel more confident & organized in their child’s care.
- Understand & stay at the center of decisions about their child’s care.
- Develop a stronger partnership with their child’s doctors & specialists.
- Effectively navigate the maze of resources & insurance coverage.
Our Impact

Our care coordination benefits medical providers by helping families:

- Keep their appointments.
- Understand & follow providers’ treatment plans.
- Communicate more effectively with everyone involved in their child’s care.
In addition to care coordination services, DSCC serves as Illinois Title V Program for CYSHCN. This means DSCC helps to work to create improvements for the systems serving CYSHCN & their families.

5-year priorities include:

- Improved support for the transition to adulthood
- Convene & collaborate with community-based organization to improve & expand services & supports serving CYSHCN in IL

Title V work is in partnership with Illinois Department of Public Health
Sources of FY 2020 Spending

- 47.5% State/University
- 20% Healthcare & Family Services (HFS) Reimbursement
- 13% Education Administration & Allowance
- 19% Federal
- .5% Connect Care
Applications & Referrals

☞ Call us at (800) 322-3722
   » Caregiver’s name
   » Phone number
   » Child’s address
   » County or zip code

☞ Visit our website
   » Download PDF application
   » Fill out “Refer a Family” form

☞ Find a local regional office
   » https://dscc.uic.edu/find-an-office
Communications Update for FAC

May 25, 2021
Amanda Simhauser, Communications Manager

» Joined DSCC in October 2016
» Based in Springfield, IL
» Former newspaper journalist and public information specialist

» Manages a team of soon-to-be three
  » Graphic Designer – Amy Nixon
  » Editorial Writer – Shayne Squires
Website

» News posts
» Events
» Resource Directory
  » COVID-19 Resource Directory
» Inquiries and form submissions
» Brochures and program information
DSCC Communication Channels

- Social media
  - Facebook
  - LinkedIn
  - YouTube
- E-Newsletter
- Marketing and outreach materials
  - Brochures, fact sheets, guides, etc.
- Letters
Communications Projects

- Summer Camp roundup
- FY 2020 Annual Report
- Home Care Family Handbook
- Logo update
- Family Stories
  - Whitted family example
- FAC member spotlights
  - Family story, reason for joining the council, etc.
  - Highlight on website and social media
- Feedback on communications initiatives and projects
- Listen to your ideas and suggestions
Contact me

(217) 558-2350

arsimhau@uic.edu
Quality Improvement: Culture

- Create an atmosphere of learning, understanding and accountability.
- Identify, celebrate and build upon our strengths.
- Value the creative and analytic input of all staff members.
- Using evidence-based research to guide our practice serving children with special healthcare needs.
Quality Improvement: Culture

• Empower those who know best to lead quality improvement activities.
• Being transparent and approachable.
• Utilizing data to drive decisions.
• Meeting teams where they are.
Quality Improvement: Culture

- Value the protected time to focus, analyze and improve our work.
- Sharing ideas across the organization for improvement.
- Establishing goals that challenge us to grow.
- The belief that there is always room for improvement.
- Recognizing each step towards achievement.
Quality Improvement Initiatives

- Internal Record Reviews
- Family Surveys
- DSCC Policy and Procedure Manual
- Education/Training for Care Coordination Teams
- Quality Improvement Projects
- Key Performance Measures
- Data Analysis
- Critical Incidents
- External Audits
- Technical Assistance
- Quality Champions
Quality Improvement Initiatives

- **HCQI:**
  - Nursing Agency Collaboration
  - Home Care Eligibility – Level of Care Reviews
  - Respiratory Therapy/HME

- **CQI:**
  - Administrative Approval Reviews
  - Claims Support
Spirit of Quality Improvement

- Quality improvement is everyone’s responsibility
- Use of data to drive decisions
- All creative ideas are important
- Little improvements are celebrated
- Improvement is always possible
- Teamwork is center of improvement
- You can make it possible
Questions?