Division of Specialized Care for Children

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Objectives

- Provide an overview of DSCC and our work with CYSHCN in Illinois
- Share information on DSCC Programs of Care Coordination
- Explain the MFTD waiver and waiver services
- Review recent and upcoming changes impacting the Home Care Program at DSCC
DSCC

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

- Approximately 545,000 CYSHCN in Illinois
- Approximately 16,350 children in Illinois with medical complexity

**Figure 1. An Illustration of MCHB’s CYSHCN Definition**

1. **Prescription Medicine**
2. **Medical, Mental Health, or Educational Services**
3. **Specialized Therapies**
4. **Mental, Developmental, & Behavioral Treatment**
5. **Functional Limitations**

**CYSHCN**

“Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount **beyond that required by children generally.**”

**CYSHCN = Children & youth with special healthcare needs**
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
DSCC provides care coordination services through three programs:

- Core Program
- Connect Care Program
- Home Care Program

DSCC provides resource & referral information to thousands of Illinois children each year who are not enrolled in care coordination programs.
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.
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
How Care Coordination Helps

- Access diagnostic tests
- Find specialized medical care
- Help families maximize insurance & understand coverage/benefits
- Coordinate services among providers
- Develop a care plan focused on a family’s strengths & goals
- Attend school meetings
- Prepare for the transition to adulthood
How Care Coordination Helps

- Communicate with doctors & specialists
- Explain medical treatment plans
- Assist with transportation for medical appointments
- Connect families for parent-to-parent support
- Locate community resources
- Pay for eligible medical expenses when income guidelines are met
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.
DSCC Care Coordination Programs
Core Program

For youth up to age 21 who meet eligibility.

Eligibility criteria:

- Chronic condition.
- 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
- Pulmonary Impairments
- Cardiovascular Impairments
- Inborn Errors of Metabolism
- Gastrointestinal Impairments
- Urogenital Impairments
- Blood Disorders
- Orthopedic Impairments
Connect Care Program

- A program for children and youth with special healthcare needs (CYSHCN) enrolled in a Medicaid managed care plan that DSCC has a contract with.

- DSCC is performing care coordination on behalf of the MCO.

- Medical eligibility is identical to the Core Program.
Applications & Referrals for Core and Connect Care Programs

- 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
DSCC Home Care Program & the MFTD Waiver
Home Care Program

- 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.
Medically Fragile Technology Dependent 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.
Non-Waiver (NPCS) Nursing Services

- 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.
MFTD Waiver Benefits

- $25,000 every 5 years allotted to help with home modifications, vehicle modifications, or specialized medical equipment
- In home nursing is a waiver service for those over 21 – under 21 is an EPSDT benefit
- Respite 336 hours/year
- 4 hours of child specific training per nurse a year
- Placement maintenance counseling services
**New and Upcoming in Home Care**

- Generators can now be purchased with waiver funds
- Home modification and vehicle modification process improvements
- Agreement with IDPH for all state licensure of enrolled nursing agencies
- Licensed parent caregivers for all ages
- FMAP initiatives
- Family surveys!
Applications & Referrals to Home Care

- 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
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.
Family Advisory Council

Your voice is important to us!

We value our parents’ and patients’ feedback.

We’ve set up our Family Advisory Council (FAC) to make it easier for families to participate and share their input with us.

Our Family Advisory Council’s mission is to bring together our families and our staff and leadership to promote the delivery of participant- and family-centered services.

The FAC connects families to resources and provides guidance to strengthen our teamwork, improve communication and empower families to have a voice in their child’s care.

Our Family Advisory Council consists of 22 family members from across the state and two Division of Specialized Care for Children (DSCC) staff members.

The FAC meets four times a year: two meetings per year are open to all Illinois families of children with special healthcare needs. You do not have to be a DSCC participant to attend these open forums.

Please check the schedule below for the next public meeting. We will post meeting registration information once it is available.

If you would like more details on how you can participate in the Family Advisory Council, please email docfa@uic.edu.

We hope to hear from you!

FAC MEETING SCHEDULE

- Aug 11, 2022
  - 9 to 11 a.m.

FAC MEETING MINUTES

- May 3, 2022
- Feb 2, 2022
- Nov 9, 2021 (canceled)
Quarterly meeting with stakeholders from across the state:

- Caregivers & Past Participants
- DSCC Staff & Administrators
- HFS Staff & Administrators

Collaboration from all parties to improve the experience of those receiving services from DSCC.
Teamwork Makes the Dreamwork!

- Creating accessible resources:
  - Energy Reimbursement Tip Sheet
  - Health Insurance Premium Payment (HIPP) Program Tip Sheet
  - Home Care Appeal and Peer-to-Peer Review Tip Sheet
  - Home Generator Tip Sheet
  - Home Modification Tip Sheet
  - Nursing Services Tip Sheet
  - Transportation Tip Sheet
Home Care Information Hub

Important information and reminders for families of children and adults in the Home Care Program

The Home Care Program offers care coordination and support to help your
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<thead>
<tr>
<th>Advocating Together for a Better Future</th>
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<tr>
<td>Reducing the amount of paper authorizations.</td>
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<td>Improving the accessibility of family surveys.</td>
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<td>Creating an online grievance tool.</td>
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<td>Improving statewide event updates on social media.</td>
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<tr>
<td>Enhancing the dissemination of information &amp; resources.</td>
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<td>Empowering families to share and connect.</td>
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