Division of Specialized Care for Children
Partner, Help, Connect

How DSCC Supports Youth with Special Healthcare Needs and their Families
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 nearly 16,000 Illinois families in FY 2018.
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.
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
Care Coordination Practices

DSCC care coordination teams use a comprehensive assessment to develop a person-centered plan for each family.

The assessment focuses on five domains:
- Medical
- Social/emotional
- Education
- Financial
- Transition
Care Coordination Practices

The person-centered plan is guided by the participant's family’s needs, wants, dreams & desires.

The plan includes:
- Desired outcomes/goals
- Strengths
- Needs (clinical & social support)
- Steps to achieve goals
- Barriers & risk factors
DSCC provides care coordination services to two populations.

- Core Program – Youth from birth to age 21 with medically eligible conditions.
- 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
- Craniofacial & External Body Impairments
- Pulmonary Impairments
- Cardiovascular Impairments
- Inborn Errors of Metabolism
- Gastrointestinal Impairments
- Urogenital Impairments
- Blood Disorders
- Orthopedic Impairments
Home Care Program

- Provides care coordination to children & youth who require skilled in-home nursing.


- In 2014, DSCC became the single point of entry for Illinois children in need of in-home shift nursing (through MFTD waiver or NPCS).

- DSCC has operated the MFTD waiver since 1983.
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.
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
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
Every state receives Title V funding through the Maternal and Child Health Block Grant.

30 percent must be allocated to children and youth with special healthcare needs.

DSCC is Illinois’ designated organization to serve children and youth with special healthcare needs.
Ways DSCC Serves CYSHCN in Illinois

Comprehensive care coordination through Core or Home Care Program.

Contributions to systems of care serving CYSHCN:
- Transition
- Early Hearing Detection and Intervention
- Relationships with healthcare providers & community resources statewide
- Collaboration with Title XIX
Population-based health strategies.

- DSCC serves as a resource throughout the state to help non-eligible children & families find services or other resources to assist them.

Administrative operation of the Medically Fragile, Technology-Dependent Waiver and Non-Waiver Program for state’s Medicaid Program.
DSCC works with youth & their families to address the transition to adulthood.

Aspects of transition:

- Health care
- Independence
- School & work
Transition

- Person-centered planning for transition.
  - Brainstorm ways to increase opportunities
  - Promote maximum self-sufficiency & independence
  - Identify supports needed for a successful transition
IEP Supports for Transition

• Sam will refill her own prescriptions before running out for three consecutive months.

• Christopher will describe his conditions with 90 percent accuracy.

• Jessica will be able to explain how her condition affects her job choices & will be able to identify, from a list of job descriptions, which opportunities would be most suitable by 12/1/17.

Take Medications As Directed

Things to Know About Your Medicine

• Make sure you know the exact name of the medicine(s) you take (brand and generic).
• Some medications have brand and generic forms. Ask your doctor if it is alright to substitute with generic forms.
• Learn why you need to take each medicine (how it treats your condition).
• Take your medicine at the same time every day. Taking your medicine at a specific time such as 10:00 p.m. might be better than bedtime if your bedtime changes. Work with your doctor to set a schedule that works for you.
• Ask your doctor or pharmacist if you have questions about taking your medicine.
• Let your doctor know if you have trouble taking your medicines (hard to swallow, forget to take, upset stomach, other problems).
• Side effects can be bothersome and dangerous - make sure you know what to look for.
• Don’t take too much or too little medication. Know how much to take, when you can take them, and which medications can be taken together.
• Whenever you go to a doctor or to the hospital, always bring your medications or a list of your medications, including non-prescription medications.
• Keep track of when you need to refill your medicines and call the pharmacy for your refills.
• Keep your list of medicines with you.
Connect with Us

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JIC Specialized Care for Children
Questions?