Family Handbook

Core Program
# Table of Contents

- Who We Are ........................................................................................................... 1
- How We Help ........................................................................................................... 2
- Is My Child Eligible? ................................................................................................. 3
- Care Coordination Tools ........................................................................................... 4
- ID Card ....................................................................................................................... 5
- When Should I Call My Care Coordination Team? ................................................ 6 - 7
- Financial Help ........................................................................................................... 8 - 10
- All Kids/Medicaid .................................................................................................... 11
- Words and Definitions ............................................................................................... 12 - 15
- How to Contact Us ................................................................................................... 16
- My Child’s Care Coordination Team ........................................................................ 17
The University of Illinois at Chicago’s Division of Specialized Care for Children (DSCC) provides free care coordination services to Illinois children with special healthcare needs.

Each state receives federal funds to improve the health of children and youth with special healthcare needs. DSCC has been the designated program for Illinois since 1937.

We have 11 regional offices throughout the state to help families in their local communities. Our staff includes social workers, nurses, speech pathologists, audiologists and other team members who are trained to help families find the specialty care and resources they need for their child to reach their full potential.

DSCC’s Care Coordination Teams use this knowledge to address a child’s medical, social, behavioral, educational and financial needs and develop a plan of care.

Our care coordination is tailored to each family and their specific goals. We will help you plan solutions that meet YOUR needs, strengths, dreams and desires for your child and family. In other words, your care plan will focus on what matters to you.

We want to empower you to make the best choices for the care, supports and resources you and your child need. As the parent or caregiver, you know your child and family’s unique needs and values better than anyone. We’re here to listen and partner with you to make the journey as smooth as possible.

Our families have told us:

“Part of the challenge of having a child with special health care needs is finding out what they need, where to get it, and then how to pay for it.”

We want to help . . .
How We Help

We have the experience, knowledge and networks to help guide you. How exactly we help you and your child depends on your specific preferences and needs. Care coordination services may include:

- Listening to your needs and developing a care coordination plan to help you set and track goals
- Accessing diagnostic testing to find out if your child has an eligible medical condition
- Finding specialized medical care providers who are experts in your child’s specific health issues
- Explaining insurance coverage to help you navigate your plan and maximize your benefits
- Locating community funding opportunities and resources, such as food pantries, utility assistance, grants, etc.
- Communicating with your child’s providers, school and other groups or individuals to make sure your wants and needs are heard
- Coordinating transportation for appointments
- Attending educational meetings and working with schools to develop Individualized Education Programs (IEPs)
- Providing transition support that helps you prepare for and manage the changes your child will go through as she or he enters the school system, adjusts from teen years to adult life and moves from pediatric to adult medical care
- Connecting you with other families for parent-to-parent support
- Paying for eligible medical expenses, such as equipment, therapies, supplies and medical services, if you meet income guidelines

“We know that if there’s something we need some help with, we can send an email or make a phone call and (DSCC has) been really responsive and helpful.”
Is My Child Eligible?

We are able to help children who are residents of Illinois and have certain chronic conditions that could benefit from care coordination. Eligible conditions include:

- Blood Disorders
- Cardiovascular Impairments
- Craniofacial and External Body Impairments
- Eye Impairments
- Gastrointestinal Impairments
- Hearing Impairments
- Inborn Errors of Metabolism
- Nervous System Impairments
- Orthopedic Impairments
- Pulmonary Impairments
- Urogenital Impairments

This is just a sample of the types of conditions that are eligible. The best way to determine if your child is eligible is to call us at (800) 322-3722. We’ll help you get a confirmed diagnosis and begin care coordination services. Even if your child is not eligible, we can connect you to programs and resources to meet your child’s needs.

“Our DSCC Care Coordinator helps make all special appointments, coordinates referrals, keeps doctors, schools, therapists . . . and all parties notified.”
Assessment of Need

Your Care Coordination Team will contact you to learn more about your child and family. These questions are part of a comprehensive assessment to help us understand and identify your child and family’s needs, strengths and goals. Our assessment focuses on five areas: medical, social/emotional, education, financial and transition.

You only have to answer those questions you feel might help us to help you. These questions include:

- Who are the healthcare providers your child sees?
- What preventive care has your child had?
- How does your child function?
- What equipment does he/she have or need?
- How do you get to medical appointments?
- What developmental or educational services is your child receiving or needing?
- How is the rest of the family doing?
- Is there a change or transition coming soon?
- What goals do you have for your child?

Care Coordination Plan

Your Care Coordination Team talks with you about your identified needs and what your goals and priorities are for your child and family. All of this information helps you and your Care Coordination Team develop a care coordination plan for your child that will be written and sent to you and other supports you identify, such as your child’s doctor. The plan is person-centered, meaning that it focuses on what is important to you and what is important for you. It’s designed to help you set and track goals, to make sure your child’s care is coordinated between various providers and to provide clear communication among everyone who helps care for your child.

Care Coordination Organizer

The Care Coordination Organizer is a tool we can give you to help you keep track of records and important paperwork. You can request it from your Care Coordination Team. They can also help you find other ways to stay organized.
If your child is eligible for financial help, you will receive an ID card in the mail. The card tells providers that your child is eligible for our financial assistance for approved medical services.

**How to use the card:**

- Present the ID card with an *additional* insurance card or All Kids card at appointments for DSCC-eligible conditions.

- Let the specialist know if there are questions regarding your coverage - they can call us at the phone number on the card.

Call us before you arrange care - we will find out if the service provider works with us (DSCC) so you will know if we can help pay for care. If you lose the card or have any questions, your Care Coordination Team can help.

---

**Sample Front**

**Sample Back**

**THIS IS NOT AN INSURANCE CARD.** DSCC pays for some medical services that require prior approval before the medical care can be provided. Please check with the DSCC Regional Office Care Coordinator prior to providing care by calling **1-800-322-3722**.

Providers should send claims and primary payer EOBs to:

Division of Specialized Care for Children (DSCC)
3135 Old Jacksonville Road
Springfield, IL 62704-6488

**1-877-791-5170**

The child’s DSCC Regional Office Care Coordinator must be notified prior to any medical care or the service may not be approved.

DSCC is a program operated through University of Illinois at Chicago (UIC). It is neither an entitlement nor welfare program. The child must meet certain criteria to be eligible and must continue to meet DSCC requirements for continued eligibility.

*Serving Children with Special Health Care Needs*
When Should I Call My Care Coordination Team?

If you are not sure if we can help, call us. We are here to support you. The more we know about your child’s needs, the better we will be able to help you meet those needs.

<table>
<thead>
<tr>
<th>When You Schedule, Change or Have:</th>
<th>Call and Tell Us:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appointments</strong> (with medical team, therapists or other providers)</td>
<td>• when and where the care will be provided</td>
</tr>
<tr>
<td><strong>Hospitalizations/Emergency Department</strong></td>
<td>• when, where and for what problem</td>
</tr>
<tr>
<td></td>
<td>• whether it is inpatient or outpatient</td>
</tr>
<tr>
<td><strong>Surgeries</strong></td>
<td>• who the surgeon is</td>
</tr>
<tr>
<td></td>
<td>• what kind of surgery is being done</td>
</tr>
<tr>
<td></td>
<td>• whether it is inpatient or outpatient</td>
</tr>
<tr>
<td></td>
<td>• whether lab work, x-rays or other care is needed before or after the surgery</td>
</tr>
<tr>
<td><strong>Referrals from your primary care doctor to a specialist</strong></td>
<td>• who, where, when and for what problem</td>
</tr>
<tr>
<td><strong>Recommendations from your primary care doctor or specialist for equipment, supplies, medications or services</strong></td>
<td>• what equipment, supplies, medications or services are needed</td>
</tr>
</tbody>
</table>
WHEN SHOULD I CALL MY CARE COORDINATION TEAM?

Our Care Coordination Team is prepared to work with you to find the help your child needs.

Always Call Us When You Have Any Change(s) In:

- Address or phone number
- Medical treatment or treatment plans
- Health insurance coverage or All Kids/Medicaid eligibility
- Doctors who care for your child

Other Reasons To Call:

- You have questions about bills, insurance statements or Explanations of Benefits (EOBs)
- To request assistance with travel expenses for medical care
- You have questions about community resources and services
- To learn about your child’s rights at school
- To link with other families with a child who has a condition like your child’s
- To start a plan to transition your child to independence and adulthood
- You want help with changes in your child’s life that concern you
- You have news to share about your child
- If you lose your DSCC ID Card
**FINANCIAL HELP**

We can help pay for some medical expenses associated with your child’s medically eligible condition if you meet our financial guidelines.

**How Do I Find Out If My Income Qualifies?**

**To Verify Your Income, We Need:**

- A completed Financial Application
- Your most recent federal income tax return OR All Kids/Medicaid eligibility (If your situation has changed since you filed your taxes, talk to your Care Coordination Team about using other income documentation.)
- Information about insurance
- Authorizations (consents) to give us permission to request and share information

If you meet the income guidelines, we’ll send you a letter with the dates your child is eligible for financial help. We will need new information each year to make sure you still qualify for financial help.

**What If I Don't Meet The Income Guidelines?**

If you do not meet financial guidelines, we can still help you through all of our other care coordination services. Our staff can help you find community funding opportunities and resources, such as food pantries and utility assistance programs. We can also help you apply for grants to fund therapies, equipment or other needs.
**FINANCIAL HELP**

**If My Income Qualifies, Do You Pay For All Of My Child’s Care?**

Your private or public insurance is billed first. Because we have to follow certain rules, you must contact us before your child receives care to see if we can help pay. We may be able to help pay:

- For certain medical services and supports
- When we approve the care prior to the service
- When the care is provided by an enrolled provider

**What Do I Do When My Child Needs A Service?**

- Call us before the service and tell us what your child needs.
- We understand emergencies happen. If you cannot tell us about the service before your child receives it, you need to tell us within 30 days of the service to find out if we can help pay.

**Prior Approval**

For certain services, we will send a Notice of Prior Approval form to you and the service provider. Take the Prior Approval form with you to your appointment. This form tells you and the provider:

- What service has been approved
- Who is approved to provide the service
- The date(s) the service takes place

We will process the bill for service after your insurance confirms what portion of the bill they will pay.
Summary Of Benefits
After we pay for care, you will receive a Summary of Benefits. The Summary of Benefits will list the services your child received and the payments made by us and other payers.

What Should I Do If I Receive A Bill For My Child’s Medical Care?

• Call your Care Coordination Team before sending payment.
• Send us the bill. The sooner we receive the bill, the quicker we see what we can help pay. Keep a copy of any bill you send.
• If you have an insurance Explanation of Benefits (EOB) for those bills, attach a copy of the EOB to the bill and send both.

What If My Child Needs Care On The Weekend Or After Hours And I Don’t Know If You Can Help Pay?

If you cannot call us during office hours:

• Leave a voice message at your Regional Office or email your Care Coordination Team.
• If your child sees a doctor in the emergency room, ask the ER doctor to call your child’s specialist, if necessary.
• Call your Care Coordination Team within 30 days of the date of your child’s care to see if we can help pay.
If your child does not have insurance, we’ll help you apply and enroll (if eligible) in All Kids or Medicaid.

The All Kids/Medicaid Program offers benefits for a wide range of medical, dental and vision services, including school physicals, immunizations, routine and preventive medical and dental care, mental health services and services for chronic health conditions.

If Your Child Has All Kids or Medicaid, We May be Able To:

- Help you find doctors and other providers that take All Kids/Medicaid
- Help your child link to other agencies or community resources not covered by All Kids/Medicaid
- Help you pay for some services not covered by All Kids/Medicaid
- Help with co-pays for children who have All Kids Share or Premium

“It is difficult to find a physician to fit (my youth’s) needs for the future as an adult. Lots of things will need planning as (he/she) moves from pediatrics to adult care.”
WORDS AND DEFINITIONS TO HELP YOU WORK WITH US

As you work with us, you may find some terms that are unfamiliar to you. This glossary explains these terms as they apply to our care coordination services. If you have questions regarding this information, call your Care Coordination Team.

**All Kids:** An Illinois Department of Healthcare and Family Services (HFS) insurance program that provides medical insurance for children ages birth through 18.

**Authorization to Release Health Information (Consent):** Special written permission from you to get or share your child’s medical information with those specific individuals you indicate.

**Care Coordination:** 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 Coordinator:** A DSCC staff person who is a nurse, social worker, speech pathologist or audiologist.

**Care Coordination Team:** The team includes you, your child, the Care Coordinator and Program Coordinator Assistant. Your Care Coordination Team will provide assistance to you and your child, answer your questions and talk with you about your concerns.
<table>
<thead>
<tr>
<th><strong>Words and Definitions to Help You Work with Us</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cost Log:</strong> A form that financially eligible families can complete for help with some “out-of-pocket” expenses, such as co-pays and deductibles.</td>
</tr>
<tr>
<td><strong>Diagnostic:</strong> The evaluation by an approved specialist that determines whether your child has a medically eligible condition.</td>
</tr>
<tr>
<td><strong>Eligibility Letter:</strong> A letter that states your child’s medically eligible condition(s) and the time period during which we may help pay bills for services related to the eligible condition(s).</td>
</tr>
<tr>
<td><strong>Explanation Of Benefits (EOB):</strong> A statement from your insurance company that explains what was paid on a specific bill and why the bill was processed in that way. We must have a copy of this paperwork in order to pay any cost for the service or equipment that was not covered by your insurance.</td>
</tr>
<tr>
<td><strong>Financial Period:</strong> If you meet the financial eligibility guidelines, a financial eligibility period is established. If you applied before Oct. 1, 2018, the period may be one or two years, depending on what documentation of income you provide. If you applied Oct. 1, 2018, or after, our financial eligibility period will be one year, regardless of documentation provided. Your financial period will be indicated on your eligibility letter.</td>
</tr>
</tbody>
</table>
WORDS AND DEFINITIONS TO HELP YOU WORK WITH US

HIPAA: Health Insurance Portability and Accountability Act of 1996. This Federal law protects the privacy of health information that can be linked to an individual. The law ensures your right to access your personal health information and to determine how that information may be shared with others.

ID Card: The card tells specialists that your child is eligible for our financial assistance for approved specialty care.

Insurance Referral: A formal request to your insurance company from your child’s primary care physician (PCP) for your child to see a specialist. Most insurance companies issue a referral number to the specialist to indicate the referral has been approved.

Legally Responsible Adult (LRA): For minor children, the parent or legal guardian is the LRA. Participants who are married, age 18 and over, or legally emancipated are their own LRA.

Maximize Benefits: We require that you maximize insurance benefits. When you follow all the rules of your insurance company, the insurance may pay for more services and at a higher rate.

Medicaid: An Illinois Department of Healthcare and Family Services (HFS) program that provides assistance with medical, dental and vision services for low-income families.
**Words and Definitions to Help You Work with Us**

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medically Eligible Condition:</strong></td>
<td>Medical eligibility is determined either through a diagnostic evaluation or through review of existing medical reports regarding your child’s condition.</td>
</tr>
<tr>
<td><strong>Network Provider:</strong></td>
<td>The providers that have agreements with your insurance company are considered “in-network” providers. Using “out-of-network” providers usually results in a lower payment by your insurance company or a penalty that you have to pay.</td>
</tr>
<tr>
<td><strong>Primary Care Physician (PCP):</strong></td>
<td>Your child’s regular pediatrician or family physician who gives routine child care. Many insurance companies require the child to have a PCP.</td>
</tr>
<tr>
<td><strong>Prior Approval:</strong></td>
<td>A written approval that is required for some services.</td>
</tr>
<tr>
<td><strong>Program Coordinator Assistant (PCA):</strong></td>
<td>A PCA will most likely be your first contact with us. The PCA will take your referral, discuss your child’s needs and send the application to you. The PCA will determine your financial eligibility and will update that financial eligibility periodically. The PCA and the Care Coordinator will work together as a team to meet your child’s needs.</td>
</tr>
<tr>
<td><strong>Regional Office:</strong></td>
<td>Illinois is divided into 102 counties. We have regional offices that cover all counties in the state.</td>
</tr>
<tr>
<td><strong>Specialty Care:</strong></td>
<td>Service from a physician or other provider who treats children with certain diagnoses.</td>
</tr>
<tr>
<td><strong>Transition:</strong></td>
<td>The process of preparing for adulthood and the changes that will bring in coordinating health care and other areas of your life.</td>
</tr>
</tbody>
</table>
**How to Contact Us**

**Call us Toll-Free:** (800) 322-3722 (DSCC)

**TTY:** (217) 785-4728

**Visit our Website:** dscc.uic.edu

**Facebook:** facebook.com/dscc.uic.edu

**Call the Regional Office nearest you:** List on back cover

**Can I Email My Care Coordination Team?**
If you want to email a member of your Care Coordination Team, we want you to know that we cannot promise that email is private. It is also important for you to know how we handle email. Please call us and ask us to send you our email guidelines.

**Can You Email Me?**
If you want us to email you, we need special written permission from you since we cannot promise email is private. Please call us and ask us to send you our email guidelines and a release form (authorization).

**What If I Need To Call You After Office Hours?**
If you are unable to call during office hours (8:00 a.m. - 4:30 p.m.), leave a voice message at your Regional Office.

**What Should I Tell You If I Call Or Email?**
- Your name
- Your child’s name
- The phone number where you can be reached
- The best time for us to call you back
Regional Office Information

Champaign
510 Devonshire, Suite A
Champaign, IL 61820-7306
(217) 333-6528 (Voice)
(217) 244-8390 (TTY)
(217) 244-4212 (Fax)
(800) 779-0889 (Toll Free)

Chicago
722 W. Maxwell Street, Suite 350
Chicago, IL 60607-5017
(312) 433-4114 (Voice)
(312) 433-4122 (TTY)
(312) 433-4121 (Fax)
(800) 425-1068 (Toll Free)

Chicago Home Care
1309 S. Halsted Street, Suite 307
Chicago, IL 60607-5021
(312) 433-4100 (Voice)
(312) 433-4108 (TTY)
(312) 433-4107 (Fax)
(800) 905-9995 (Toll Free)

Lombard
1919 S. Highland Avenue, Suite 320A
Lombard, IL 60148-6181
(630) 652-8900 (Voice)
(630) 424-0553 (TTY)
(630) 424-0669 (Fax)
(800) 924-0623 (Toll Free)

Marion
2309 W. Main Street, Suite 119
Marion, IL 62959-1196
(618) 997-4396 (Voice)
(618) 993-2481 (TTY)
(618) 993-8929 (Fax)
(800) 451-0464 (Toll Free)

Mokena
19065 Hickory Creek Drive, Suite 340
Mokena, IL 60448-8507
(708) 326-4400 (Voice)
(708) 478-3864 (TTY)
(708) 478-3850 (Fax)
(800) 425-5454 (Toll Free)

Olney
1102 S. West Street
Olney, IL 62450-1321
(618) 395-8461 (Voice)
(618) 392-3869 (TTY)
(618) 395-2902 (Fax)
(888) 841-3232 (Toll Free)

Peoria
7013 N. Stalworth Drive
Peoria, IL 61615-9465
(309) 693-5350 (Voice)
(309) 693-5345 (TTY)
(309) 693-5306 (Fax)
(800) 382-8569 (Toll Free)

Rockford
4302 N. Main Street, Room 106
Rockford, IL 61103-1209
(815) 987-7571 (Voice)
(815) 987-7995 (TTY)
(815) 987-7891 (Fax)
(800) 651-9319 (Toll Free)

St. Clair
1734 Corporate Crossing, Suite 1
O’Fallon, IL 62269-3734
(618) 624-0508 (Voice)
(618) 624-0544 (TTY)
(618) 624-0538 (Fax)
(800) 842-7204 (Toll Free)

Springfield
3135 Old Jacksonville Road
Springfield, IL 62704-6488
(217) 524-2000 (Voice)
(217) 524-2011 (TTY)
(217) 524-2020 (Fax)
(800) 946-8468 (Toll Free)