



# Care of Students with Complex Healthcare Needs

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# Objectives



Describe coordination of care between the student's home, primary care provider, specialists, and school.



Outline services available through the UIC Division of Specialized Care for Children (DSCC).



Identify indications for tracheostomy



Describe medical interventions for a child with tracheostomy



Discuss emergency interventions for children with tracheostomy

# DSCC Services for CYHSN in School Setting



- » Cynthia Booth, APRN, MSN, PCNS-BC
- » *Home Care Program Liaison*

# 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.



# Our Vision and Mission



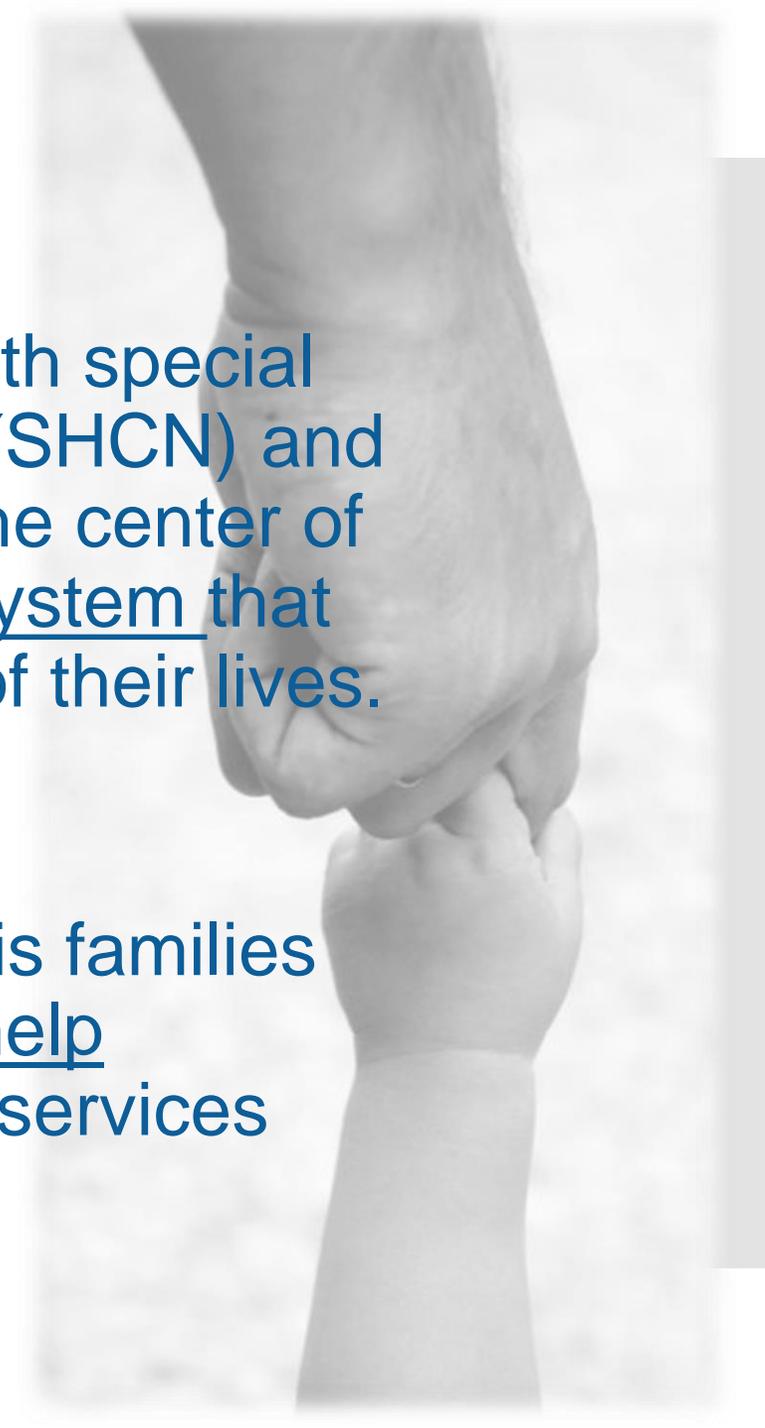
## Vision

- » 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.



# Our Families

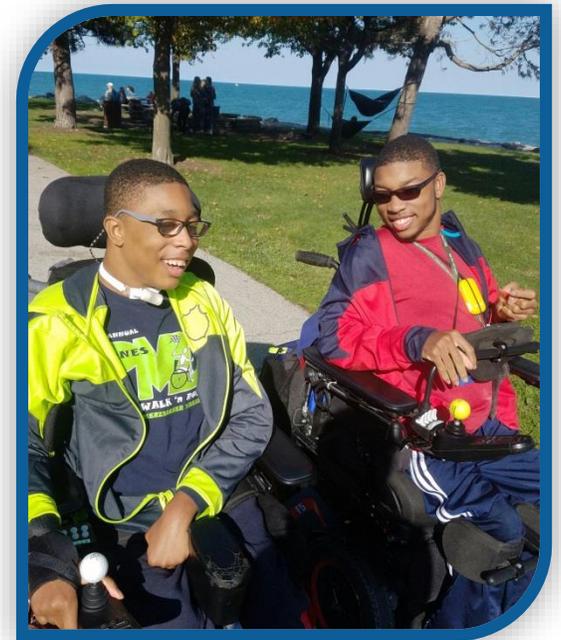


## The Jones Family

“We’ve been with DSCC for about 15 years, and I have to say we’ve had some very, very good care coordinators. We have our monthly conversations. They’re always able to give us resources accordingly, being proactive... Everyone needs a partner, especially in this situation.”

- » Gina Jones, mother of Garrett and Gavin in the Home Care Program

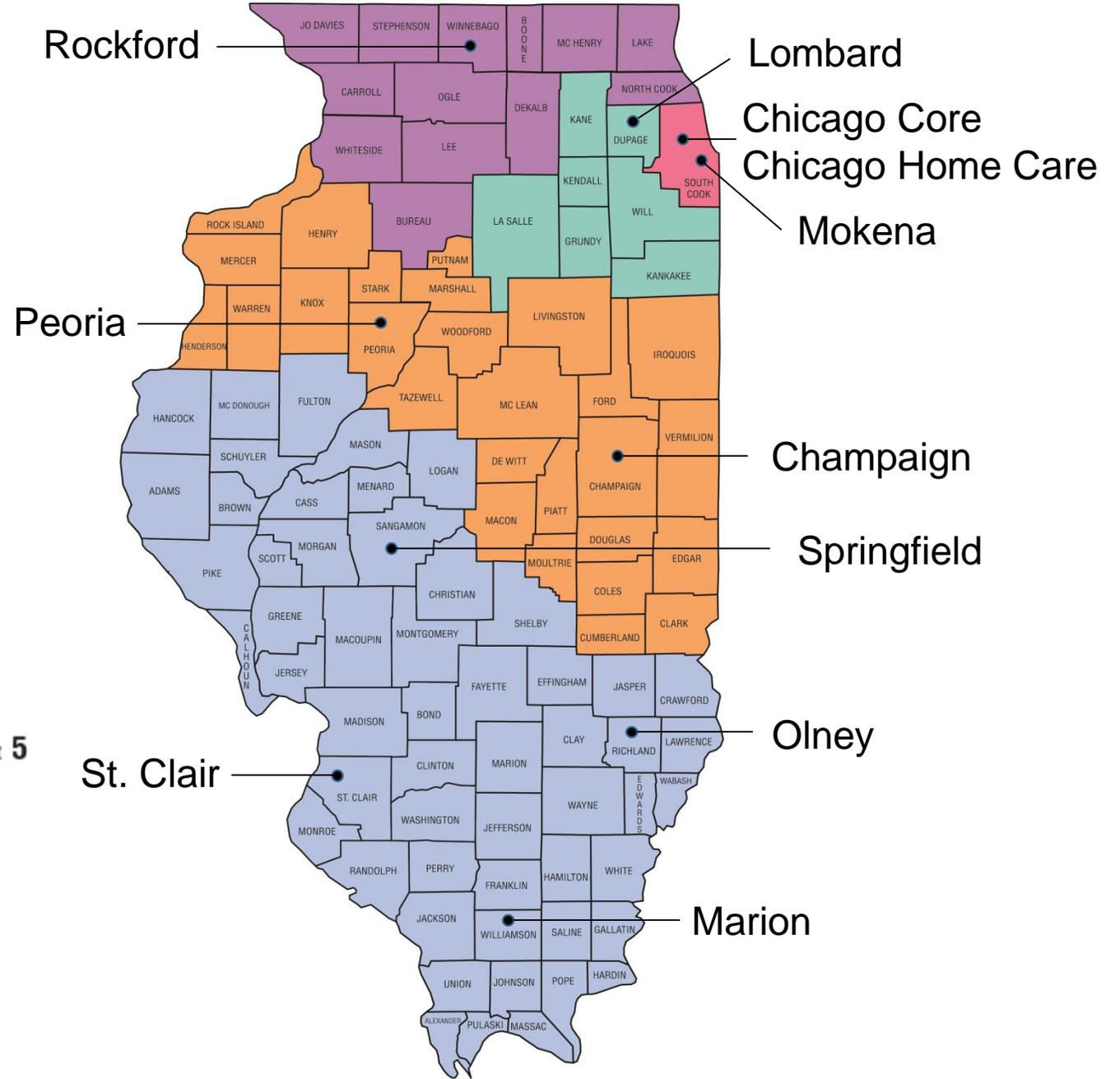
## Family Video



# Regional Office Map



- Region 1 & 5
- Region 2
- Region 3
- Region 4
- Region 6



# Care Coordination



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



# Person-Centered Planning and Link To Assessment



- ➡ Care coordinator engages in the assessment process with the participant and their family and completes person-centered plan together — following the assessment.
- ➡ The assessment process is an ongoing learning process, not a single event or annual meeting.

# Person-Centered Planning and Link To Assessment



- ➡ The assessment and planning process captures:
  - » What the person wants in their life
  - » The supports needed
  - » The person's perspective on how they want to live
- ➡ Care coordinator and participant/family develop the person-centered plan based on what is learned during the assessment.

# 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



# Who We Serve



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.



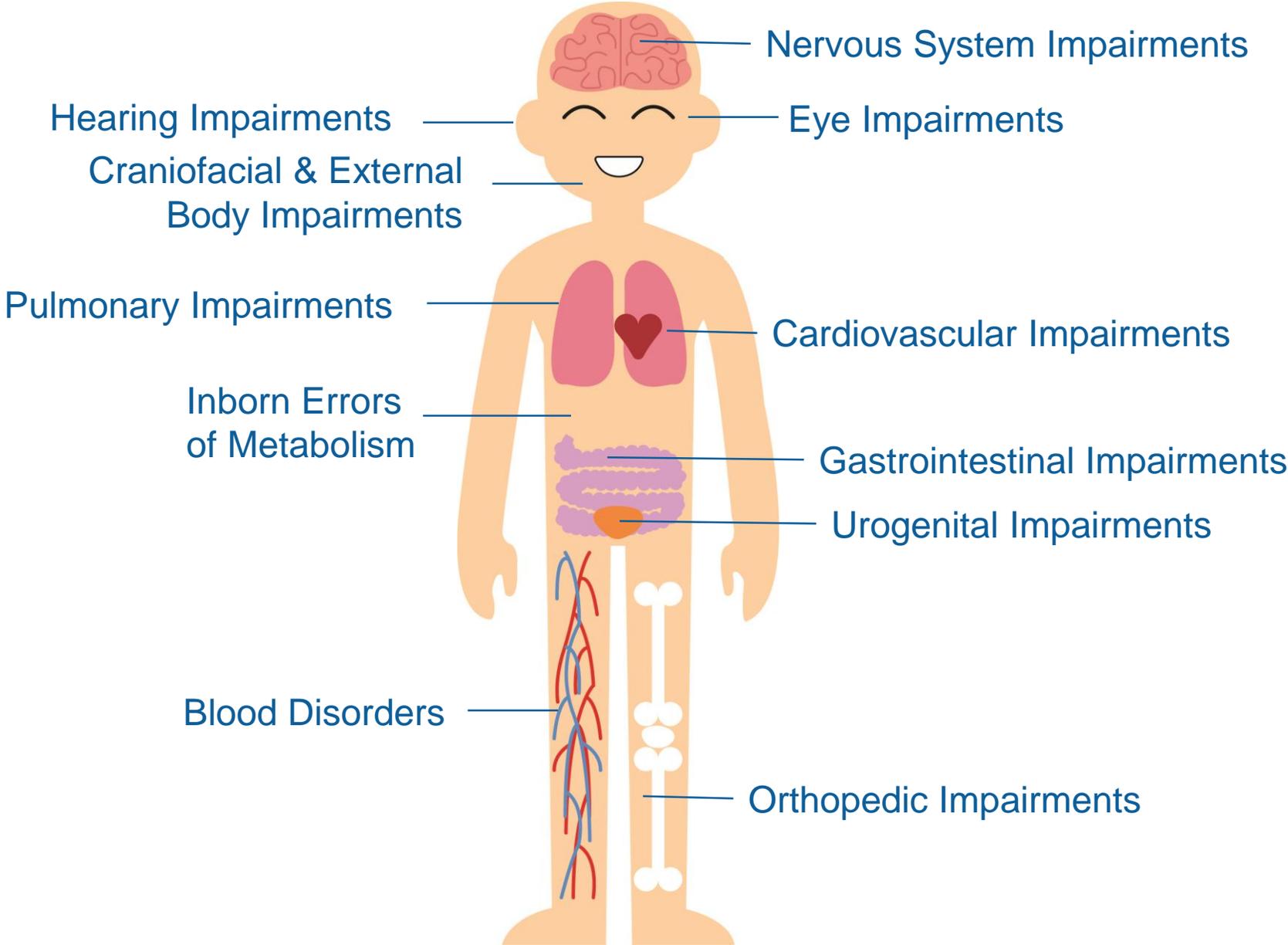
# Core Program



- ➔ 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

Hearing Impairments

Craniofacial & External  
Body Impairments

Pulmonary Impairments

Cardiovascular Impairments

Inborn Errors  
of Metabolism

Gastrointestinal Impairments

Urogenital Impairments

Blood Disorders

Orthopedic Impairments

# Core Case Example: Early Childhood



- ➔ Referral source: Early Intervention
- ➔ Child: “Anthony”, age 3
- ➔ Needs identified: Cerebral palsy with mobility impairment, hearing impairment, transitioning to early childhood education, need for care coordination
- ➔ Functional status: Orally fed, dependent wheelchair user, limited communication
- ➔ Family goals: home access modifications, assistance paying for hearing aids
- ➔ Plan: Enroll in core for care coordination
- ➔ Refer to local city offices and charitable organizations for assistance with home modifications
- ➔ Refer to charitable organizations for assistance paying for hearing aids.

# Home Care Program



- ➔ Provides care coordination to children & youth who require skilled in-home nursing.
- ➔ Operated on behalf of the Illinois Department of Healthcare & Family Services (HFS).
- ➔ 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.



# Home Care Populations



- ➔ 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 21<sup>st</sup> birthday, & still receiving services on their 21<sup>st</sup> 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.

# Home Care Example: Middle School



- ➔ Referral source: Acute care hospital case manager
- ➔ Child “Sarah” with dx Cerebral Palsy, Dysphagia, Obstructive sleep apnea
- ➔ Needs identified: care coordination, specialized equipment, family training, nursing assistance in home
- ➔ Care needs: Oxygen per NC at night, bolus tube feeding with reflux, 5 daily medications
- ➔ Family goal: Training in Sarah’s care, home nursing
- ➔ Plan: Apply for Non-waiver, assist in identifying nursing agency, provide ongoing care coordination support including re-integration to school setting, refer to core program for home access modifications

# Home Care Example: Teen Traumatic Injury



- ➔ Referral source: Inpatient Rehab Case Manager
- ➔ Youth: “Jonathan” 17 year old previously healthy sustained TBI and SCI
- ➔ Needs identified: Nursing care, home access modifications, family support, care coordination
- ➔ Care needs: Trach/Vent dependence, continuous g tube dependence, need for supervision, family training and support
- ➔ Family goals: Bring Jonathan home, appropriate nursing support, home modifications, care coordination
- ➔ Plan: Apply for MFTD waiver, select nursing agency, home access modification quotes, ongoing care coordination and support, reintegration

# Partnering with Schools



- ➔ Comprehensive Assessment includes Educational Domain
- ➔ Obtain and Review 504/IEP
- ➔ Attend school conferences with parents if requested
- ➔ Contact school at parent's request to help coordinate services and address needs of participant
- ➔ Facilitate attendance of PDN with student
- ➔ Assist in obtaining homebound services

# Personal Nurse at School- DSCC



- ➔ Family preference/District policy
- ➔ Must follow physician approved plan of care
- ➔ Potential school/agency conflicts
- ➔ DSCC nurses may have competing responsibilities
- ➔ 1:1 nurse at school deducted from participant's total allocation
- ➔ School nurse also responsible for participant while at school

# The Law and One on One Nursing in School



➡ **Note:** Per Federal Register, Vol. 71, No. 156, 300.34, the school district will be responsible for providing nursing services during school hours if the child's physician feels that a 1:1 nurse at school is medically indicated. This would ensure that the participant is able to attend school and receive therapies. If the school district needs further information about how they can claim for nursing services provided while at school, they can contact the School Based Health Services program at 217-782-3953 or by visiting the website

# We're Here to Help



- ➔ 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.



# 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>



<i>For Providers</i>
<i>Provider Application</i>
<i>Reimbursement Information</i>
<i>Explanation of Provider Payments</i>
<i>Provider Forms</i>
<i>Tools &amp; Resources</i>
<i>Provider Portal</i>
<i>Refer A Family</i>

# Connect with Us



(800) 322-3722



[dsc@uic.edu](mailto:dsc@uic.edu)



[dsc.uic.edu](http://dsc.uic.edu)



UIC Specialized Care for Children

Questions?

Thank you!



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