OUR VISION

Children and youth with special healthcare needs and their families are at the center of a seamless support system that improves the quality of their lives.

OUR MISSION

We partner with Illinois families and communities to help children and youth with special healthcare needs connect to services and resources.
Throughout our 82 years, the University of Illinois at Chicago’s Division of Specialized Care for Children (DSCC) has evolved to coincide with changes in the healthcare field. This evolution is ongoing.

This past fiscal year (July 1, 2018, through June 30, 2019) saw significant progress in how our organization views health care and best practices for children with special healthcare needs and their families.

We implemented new medical eligibility requirements for children in our Core Program. The updated requirements simplify our eligibility criteria and streamline impairment categories to cover body systems rather than specific conditions.

The new eligibility requirements became effective Oct. 1, 2018. These changes allow us to help families in a timelier manner.

Our care coordination teams are using a more comprehensive and holistic assessment to develop a person-centered plan for each of our families. The comprehensive assessment addresses a child and family’s needs in the areas of:

- Health
- Education
- Social
- Emotional
- Financial
- Transition

A multidisciplinary team of DSCC staff from across the state developed new assessment tools. The tools enhance these efforts and ensure our care coordination is consistent with best practices for children and youth with special healthcare needs.

During winter 2019, the Illinois Chapter of the American Academy of Pediatrics highlighted DSCC for our ongoing work to help families achieve critical goals, have their needs met and mitigate barriers and risks.

By implementing strategies for person-centered goals, we are driving positive change in the lives of our participants and families.

DSCC is also working closely with the Illinois Department of Healthcare and Family Services (HFS) to prepare for its expanded Medicaid managed care program. On Feb. 1, 2020, enrollment in a managed care organization will be mandatory for most DSCC families who receive Medicaid and do not have private health insurance.

During FY 2019, our staff worked with HFS and its partners to plan for continuing our care coordination services for DSCC families affected by this transition.

We also remain a key part of the University of Illinois’ public service mission. We continue to pursue new collaborations with other University departments and systems to improve health care and related services for all Illinois residents.

Through our internships and educational opportunities for graduate students, we’re helping to develop social workers, healthcare providers and technology professionals who will lead their fields with service and compassion.

It’s a time of great change and opportunities for growth at DSCC in how we serve children with special healthcare needs. We look forward to the future.

Thank you for supporting our mission.

Thomas F. Jerkovitz
Who We Are

The University of Illinois at Chicago’s Division of Specialized Care for Children (DSCC) is a statewide program that serves children and youth with special healthcare needs and their families.

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

Our Title V Role
The Maternal and Child Health Services Block Grant, authorized by Title V of the Social Security Act, is a federal program that aims to improve the health of all women, children and families, including children and youth with special healthcare needs and their families.

Title V programs exist in all 50 states and nine territories. States and territories are required to use at least 30 percent of these funds to support services for children and youth with special healthcare needs.

Since 1937, DSCC has managed Illinois’ Title V program for children and youth with special healthcare needs.

We are involved in various tasks and projects across the state to develop and strengthen the systems of care for children and youth with special healthcare needs and their families. This work includes:

- Planning for the transition to adulthood
- Supporting care coordination for medically eligible children and youth and their families
- Gap-filling financial assistance
- Early Hearing Detection and Intervention
- Newborn screens for genetic and metabolic diseases
- Developing relationships with healthcare providers and community resources statewide
- Working with the other “Big Five” states to develop and adopt population-based strategies to serve children with special healthcare needs
- Access to national resources for children with special healthcare needs through our Title V linkage

Five-Year Needs Assessment
DSCC conducts a needs assessment every five years. This assessment helps identify concerns and set priorities for the next five years. Our next needs assessment is due July 15, 2020.

Map of all DSCC cases by county that were actively enrolled or in intake between July 1, 2018, and June 30, 2019.
Who We Are

As part of our needs assessment, DSCC is looking at services for children with special healthcare needs regarding:

- Family-centered care
- Adequate health insurance
- Organization of service systems
- Provision of care through a medical home
- Screening for special health needs
- Transition

As part of our data gathering for the needs assessment, DSCC developed a Survey of Children’s Health. We sent the survey to 5,500 of our participant families in May 2019.

We received more than 1,000 responses, which represents roughly 20 percent of the families we help through care coordination.

The survey underlined the value of transition assistance, care coordination and gap-filling financial assistance for the families we serve.

DSCC staff will continue to work through the survey results during the coming year. We will use the results to help set priorities for Illinois children with special healthcare needs through the block grant.

Our Team

We have 11 regional offices throughout the state that help Illinois families in their local communities.

Our staff draws on the relationships and expertise we’ve built over 80-plus years to address a child's medical, social, behavioral, educational and financial needs. We do this through a process called care coordination.

The multidisciplinary nature of our team is one of our greatest strengths. Our care coordination teams can include:

- Registered nurses
- Social workers
- Speech-language pathologists
- Audiologists
- Respiratory therapists
- Health insurance specialists
Our staff is trained to help families find the specialty care and resources they need for their child to reach their full potential.

DSCC provides care coordination services to two populations. The Core Program serves youth from birth to age 21 with medically eligible conditions. The Home Care Program serves children and youth in need of in-home shift nursing.

In fiscal year 2019, we provided care coordination to more than 19,600 families in all 102 counties in Illinois.

DSCC connected with these families through a variety of referral sources, including the Adverse Pregnancy Outcomes Reporting System (APORS), hospitals, newborn hearing and genetic screening and other families (see the table below). Our staff also provided resource information and referrals to 273 youth who are not eligible for DSCC services and reached more than 320,000 people through outreach events, our website and social media.

**Who We Are**

DSCC’s Referral Sources for FY 2019 - Total 19,656

- Adverse Pregnancy Outcomes Reporting System (APORS)
- Early Intervention
- Family
- Hospital
- Illinois Department of Public Health
- Newborn Genetic Screening (NBGS)
- Newborn Hearing Screening (NBHS)
- Other Sources*
- Providers
- School
- Supplemental Security Income (SSI)

*Includes nursing agencies, social service agencies, Illinois Department of Children and Family Services (DCFS), rehabilitative services and DSCC outreach
Our Care Coordination

Care coordination is our primary service and at the heart of how we help families.

We tailor our care coordination to each child and family’s situation. Our care coordination considers the family’s experiences and values with our staff’s expertise and extensive network of relationships across the state. We then partner with parents/caregivers to identify the needs of the child and family as a whole.

Our Care Coordinators use this information to develop a plan of care for their long-term success.

This help is free to all eligible children, regardless of their family’s income level.

Our care coordination may include:

- Accessing diagnostic testing
- Developing a care plan focused on a family’s strengths and goals
- Finding specialized medical care
- Helping families maximize their insurance and understand their coverage/benefits
- Communicating with doctors and specialists
- Attending school meetings and assisting with the IEP or 504 Plan process
- Coordinating transportation for appointments
- Applying for grants to fund therapies, equipment or other needs
- Linking families with local charities, programs and resources
- Connecting families for parent-to-parent support
- Preparing for the transition to adulthood

Comprehensive Assessment

Our care coordination efforts focus on partnering with families and communities to help children and youth with special healthcare needs connect to the services and resources needed to reach their full potential.

Best practices in care coordination show us that we must be comprehensive in our approach, looking at both the medical and psychosocial needs of the participant and their family.

During FY 2019, our staff used a comprehensive and holistic assessment to help our care coordination teams develop a person-centered plan for each of our families.

We researched best practices in care coordination and applied DSCC’s lengthy experience working with children with special healthcare needs in Illinois to identify the critical characteristics of high-performing pediatric care coordination. We used this research to develop a structure for the comprehensive assessment. The assessment focuses on five domains:

- Medical
- Social/emotional
- Education
- Financial
- Transition

The comprehensive assessment is an ongoing learning process for our staff and families. It captures what the participant and their family want in their life, the supports needed and their perspective on how they want to live.
Person-Centered Planning

Our Care Coordinators and their participants develop a person-centered plan based on what is learned during the comprehensive assessment.

The person-centered plan is guided by the participant and family's needs, wants, dreams and desires. It includes their desired outcomes/goals, strengths, needs (both clinical and social support), the steps to achieve these goals and the barriers and risk factors with plans to minimize them.

Our care coordination staff uses motivational interviewing to help their assessment and plan development process. This technique helps people discover their interest in considering and making a change in their lives.

We understand that the participant and their family know their unique needs and values better than anyone. Our person-centered planning helps DSCC care coordination teams understand what is important to someone so they can then support what is important for them.

This information helps us improve the participant and family's experience with care, improve their overall health and reduce their healthcare costs.

Motivational Interviewing

DSCC continues to invest in our team to make us the most effective partners for families, doctors, specialists, schools, community groups and others who support children with special healthcare needs.

During winter 2019, our staff underwent motivational interview training. Motivational interviewing is a collaborative conversation to strengthen a person's own motivation for and commitment to change.

Our staff learned how to use the Spirit of Motivational Interviewing called CAPE: Compassion, Acceptance, Partnership and Evocation.

- Compassion: Actively promoting the other’s welfare and giving priority to the other’s needs
- Acceptance: Respect for the person and their right to not change
- Partnership: Active collaboration between experts
- Evocation: Calling forth the person's strengths and resources for change

Motivational interviewing is a helpful tool for our staff to better engage with families and make the assessment and person-centered plan development process more successful. Training in these techniques will be ongoing.
Quality Improvement Culture
Promoting a culture of continuous quality improvement within DSCC is a top priority. This culture creates an atmosphere of learning, understanding and accountability. It also allows us to identify, celebrate and build upon our strengths.

We want to use research to guide our practice of serving children with special healthcare needs and use data to drive our decisions. We believe improvement is always possible and aim to set goals that challenge us to grow.

It’s important that we recognize each step toward achievement and mentor our staff to reach these goals. We developed the DSCC Scorecard as a performance-improvement tool to show our progress in different aspects of our work. We introduced the Scorecard in spring 2019 after a nearly two-year effort.

The Scorecard measures progress in the following areas of our strategic plan:

- Care Coordination Quality
- Partnering for Success
- Staffing Excellence
- DSCC Connects

The Scorecard displays information for the organization as a whole, at the program level (Core or Home Care Program) and at the regional office level. Each Scorecard metric has a target percentage and a threshold percentage. If performance falls below the threshold, we know where to focus our improvement efforts. This information helps us celebrate our successes, share lessons learned and develop solutions for improvement.

DSCC leadership selected 16 Quality Champions throughout the state to facilitate the Scorecard analysis and discussion within their regions.

Our 16 Quality Champions gathered for their first training in May 2019.

The Quality Champions receive ongoing training for how to celebrate areas of success and develop action plans to improve areas that need more attention. They are responsible for leading Quality Improvement Huddles in their respective regional offices each quarter to review the Scorecard measures and develop action plans as needed.

By involving our entire DSCC team in performance improvement discussions, we have the opportunity to build off of one another’s ideas. We are excited to unite as a team to drive our performance forward to improve our care for the participants and families we serve.
Who We Serve

Core Program
Our Core Program serves Illinois families with children up to age 21 who have or are suspected of having an eligible medical condition.

On Oct. 1, 2018, DSCC introduced new eligibility categories and Core Program procedures. This significant change updated and streamlined our practices with advances in the healthcare field.

Our Medical Advisory Board generalized our eligible impairment categories to cover body systems rather than specific conditions. This change simplified our eligibility requirements so we can provide care coordination assistance to a broader population of children with special healthcare needs. We are also able to provide care coordination services more quickly to families in need.

Connect Care
HealthChoice Illinois is the new Medicaid managed care program that is now required statewide.


Our staff worked with HFS throughout FY 2019 to prepare for this transition. This effort resulted in the development of our Connect Care Program. This third program will initially serve the approximately 2,300 children currently enrolled in our Core Program who will transition from Medicaid fee-for-service insurance coverage to HealthChoice Illinois.

This program creates an opportunity for us to continue to serve children while they are enrolled in managed care. It also allows us greater opportunities to expand the number of privately insured children through our Core Program and to increase our involvement with more system-building initiatives related to the care of children with special health needs in Illinois.

Core Medically Eligible Conditions

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

DSCC operates the Home Care Program on behalf of the Illinois Department of Healthcare and Family Services (HFS).

The Home Care Program supports families who care for loved ones who are medically fragile and require skilled in-home shift nursing. With the help of DSCC’s care coordination and resources from HFS, the program makes it possible for infants, children and young adults to stay in their own home.

The Home Care Program has grown over the last three decades and now serves two populations of children and young adults with special healthcare needs:

- **Waiver:** DSCC started operating the Home Care Program in 1983 to serve children who qualify for the Medicaid Title XIX Home and Community-Based Services Waiver for Medically Fragile Technology Dependent Children. Individuals served by the waiver depend on technology – such as on ventilators, tracheotomies and gastrostomy tubes – and require in-home shift nursing to stay in their own home rather than a hospital or a skilled nursing facility. Children eligible for the waiver must meet medical criteria determined by their health condition and technology needs and be less than 21 years of age at the time of the eligibility determination. Waiver participants may receive additional services not covered by the Medicaid State Plan, such as environmental modifications, vehicle modifications, extermination services and nurse training.

  Youth may qualify regardless of their family’s income. Originally, the waiver only covered participants less than 21 years of age. As of May 1, 2017, the waiver covers participants of all ages as long as the participant was enrolled in the waiver prior to the day before his or her 21st birthday. This amendment to the waiver allows participants to stay with the Home Care Program for life.

- **Non-Waiver:** In January 2014, DSCC became the single point of entry for all individuals under age 21 who require in-home shift nursing services. These youth have an identifiable need for in-home shift nursing and personal care services but are less dependent on technology. The child or family must be eligible for Medicaid.

Having a team of staff dedicated to enrollment has helped the Home Care application process move quicker so families can receive support sooner. The enrollment team has also freed up more time for DSCC Care Coordinators to focus on care coordination activities. Once DSCC enrolls a participant, the case moves from the enrollment team to an ongoing Care Coordinator.
Who We Serve

Known Ethnicity of All Active Participants in FY 2019

- White: 52.50%
- Hispanic/Latino: 20.13%
- Black or African American: 23.65%
- Asian: 3.53%
- American Indian or Native Alaskan: 0.12%
- Native Hawaiian or Other Pacific Islander: 0.06%

Insurance Type for FY 2019 Core and Home Care Participants

- Public: 59%
- Private: 26%
- Both: 15%

Preferred Language of All Active Participants in FY 2019

- English: 87.96%
- Spanish: 10.25%
- Other: 1.07%
- English, Other: 0.37%
- English, Spanish: 0.36%

Age of All Active FY 2019 Participants

Chart depicts FY 2019 active participants' ages as of June 30, 2019

- Under 1: 31%
- Age 1-3: 25%
- Age 4-10: 12%
- Age 11-15: 23%
- Age 16-18: 20.13%
- Age 18+: 2.50%
Our Results

Families enrolled with DSCC have a consistent helping hand to guide and support them through their child’s journey. Our care coordination makes it possible for families to feel more confident, organized and involved in decisions about their child’s care. Our Care Coordinators also help families develop a stronger partnership with their child’s doctors and specialists and effectively navigate the maze of resources and insurance coverage/benefits.

Our families are also well-equipped to better support and achieve their child’s educational and vocational goals and plan accordingly for their child’s transition from pediatric services to adult services.

Our care coordination benefits medical providers by helping families keep their appointments, follow their providers’ treatment plans and communicate more effectively with everyone involved in their child’s care. DSCC staff has developed an extensive network of pediatric specialists for children with special healthcare needs and can facilitate referrals for other providers and resources.

Family Surveys
A major strategic goal at DSCC is to strengthen our partnerships with families in care coordination services. During FY 2019, we prepared to implement a series of surveys for participant families to fill out at specific intervals of their child’s journey with DSCC. These surveys will be phased in throughout FY 2020. The surveys include:

- An initial survey following registration
- A survey to a random sample of families after a DSCC home visit is completed
- A series of surveys focused on education for when the participant is 3.5 and 5 years old as well as when he/she completes first, third, fifth and seventh grade
- A series of surveys focused on transition to be given when the participant is age 14, 16, 18 and 20
- An exit survey when a participant dis-enrolls from the program

Feedback from our participants and families is the most valuable tool we have to help us make the best use of DSCC’s resources. This input will play a large role in our strategic planning and goal development to ensure our families’ best interests stay at the heart of what we do.

“(DSCC) has and continues to make being at home so much more manageable and has fought with us and for us. We really genuinely appreciate it.”

– Brittany Stineman, mother of Nash in the Home Core Program
Our Outreach

As part of our efforts to connect families to much-needed services and resources, DSCC staff presented at or participated in 127 outreach events throughout Illinois in FY 2019. These events included functions at community school districts, local health and social service fairs, special needs conferences and workshops for physicians and other healthcare providers.

DSCC served on the steering committee for the 14th annual Illinois Statewide Transition Conference on Oct. 25-26, 2018, in Itasca. More than 700 youth, parents, caretakers, vocational professionals, healthcare professionals, educators and others attended. Participants discussed the possibilities for students with disabilities in the areas of independent living, education and training, employment, community integration, health care and self-advocacy. DSCC covered the conference-related expenses for 39 of our participant family members across the state.

DSCC also supported the 2019 Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing, held June 9-14, 2019, on the Illinois School for the Deaf campus in Jacksonville. The 2019 Institute was the largest on record, with 34 participant children enrolled and a total of 119 people attending from 31 families.

The one-week program is provided at no cost to families. It includes daily lectures by experts in the field to learn about raising a child with hearing loss.

Associate Director Earns Nursing Honor

In summer 2019, our Associate Director Molly Hofmann was named one of the 40 Under 40 Emerging Nurse Leaders in Illinois.

The Illinois Nurses Foundation sponsors this award. It highlights and celebrates young nurse leaders who are influencing health care and the nursing profession today.

Molly is an advanced practice registered nurse (APRN) who serves as our Associate Director of Care Coordination. In this role, she oversees the development and implementation of all care coordination operations, policies and procedures for the Core and Home Care Programs. Molly is also working on her doctorate of nursing practice degree through UIC’s College of Nursing in Peoria.

The Illinois Nurses Foundation praised Molly’s focus on quality care and policy for children. They presented her award during a recognition even in Lisle on Sept. 12, 2019.
Our Education Opportunities

**Internships**
Through internship opportunities and special projects, DSCC embodies the University’s mission of transforming lives and serving society by educating, creating knowledge and putting knowledge to work on a large scale and with excellence. We strive to partner with University programs to host interns and build relationships that provide real-world learning experiences and job training. These experiences help students go on to rewarding, successful careers serving children and families.

These valuable mentoring opportunities also expose students to DSCC services so they can educate their peers, contacts and future employers about our services. Our internships also cultivate potential future employees and provide extra staffing to improve our level of assistance.

In FY 2019, DSCC hosted six University student interns in our offices across the state. These interns included one master’s degree candidate, two completing their bachelor’s degree from the School of Social Work, one intern completing her degree in Sociology, and two interns from the College of Nursing.

**Clinical Rotations**
Our Chicago Home Care and Core offices also partner with UIC’s College of Nursing to serve as a clinical rotation site for undergraduate students in a community nursing course. This rotation takes place every semester. These nursing students have the opportunity to learn more about the care of a child with special healthcare needs outside of the hospital setting.

During the fall 2018 semester, our Home Care Quality Improvement staff worked together with a clinical associate professor at the College of Nursing to develop a clinical rotation project for two master’s nursing students. These students conducted a learning needs assessment for our staff’s medication reconciliation process. They used this information to develop and present a training module on the basics of medication orders. This training is now available to new DSCC employees to help them understand the basics of medication orders. They also helped plan and staff a collaborative conference DSCC did with Ann and Robert H. Lurie Children’s Hospital for training Home Care nurses.

The master’s nursing students also attended a home visit with an enrollment specialist and visited hospitals throughout Chicago with DSCC’s hospital liaison to attend care conferences, staffings, rounds, and meetings with families. Finally, they attended two outreach events/in-services.

Through these activities, the students learned about conducting a needs assessment; developing and providing training; conference planning; data analysis; successful collaboration; outreach; comprehensive family assessment; resources; common diagnoses and needs of the population of children and youth with special healthcare needs; barriers to addressing those needs; and strategies to overcoming those needs.

Additionally, DSCC hired one of these master’s students as a Care Coordinator in Chicago Home Care.

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Lisette Ríos was born with a cleft lip and referred to DSCC shortly after. DSCC helped her family find medical specialists, discuss treatment options, coordinate surgeries and more. This support inspired Lisette to pursue a career in social work. She attended UIC and completed her internship at DSCC in fall 2018.
Our Collaborations

University of Illinois Hospital and Health Sciences System (UI Health)

Sickle Cell Center
Sickle cell disease is an inherited blood disorder that causes severe episodic pain and strokes. Children with sickle cell disease can also suffer from “silent strokes” that have no outward symptoms but can damage intellectual and academic abilities, attention and long-term memory.

Children with sickle cell disease who do not keep regular medical appointments are more likely to suffer from these silent strokes. DSCC partners with the UIC Sickle Cell Center to help families of children with sickle cell disease keep their child’s appointments and make sure their child’s care is running smoothly.

DSCC provided $200,000 to fund the center’s Sickle Cell Transition Adolescent-Adult Readiness (S.T.A.R.) Clinic in fiscal year 2019. The clinic prepares youth and their caregivers for managing sickle cell disease as an adult through education in five key areas of transition: medical, emotional/psychological, social domain, academic/education and vocation and career.

DSCC also provided another $200,000 in FY 2019 to pay for a neuropsychologist position. This position assesses sickle cell patients to detect strokes and silent cerebral infarcts (a localized area of dead tissue caused by a lack of blood supply). Having this expertise onsite helps patients avoid long waits and is crucial to early detection and preventing subsequent cognitive issues, which helps both the S.T.A.R. Clinic and DSCC’s efforts to serve children with sickle cell disease.

Nitty Gritty Nursing Conference
Based on feedback from our staff and partner agencies, we recognized a need for improved training for nurses working in the home setting. Two of our Home Care Program Liaisons worked with Ann and Robert H. Lurie Children’s Hospital of Chicago to produce a conference for nurses working in the home.

The “Nitty Gritty Nursing: Improve Your Community Nursing Skills for Children who are Medically Fragile, Technology Dependent (MFTD)” conference took place on Oct. 27, 2018.

Lurie provided the clinical expertise for training on ventilator care and management, tracheostomy care and management, infusion care and management, and enteral and skin care.

Our Home Care Program Liaisons covered common challenges for nurses in the home care setting, how to communicate with the families of MFTD children, best practices and tips for success. Continuing education credits were available for participants to help incentivize nurses to attend.

This conference provided valuable training for nurses who work with children in the Home Care Program and other children with special healthcare needs throughout the state. A June 2019 article in the journal Health Affairs titled, “Home Health Care for Children With Medical Complexity: Workforce Gaps, Policy, and Future Directions,” highlighted “Nitty Gritty Nursing” as a successful example of targeted nursing education.

The training also demonstrates how our care coordination and Title V work go hand in hand. Our Care Coordinators recognized a need for additional training for home nurses through their work with families. DSCC was able to address the need through our Title V role and relationships.

This project is one small way we can partner with the clinical teams that treat medically complex children to help ensure that nurses providing care in the home have access to high quality training.
Our Funding

DSCC is funded by a combination of state and federal revenue sources.

The federal Maternal and Child Health Services Block Grant, authorized by Title V of the Social Security Act, funds programs to improve the health of women, children and families in all 50 states. At least 30 percent of these funds must support children and youth with special healthcare needs. Since 1937, DSCC has managed Illinois’ Title V program for children and youth with special healthcare needs. Block grant funds require a state match of $3 for every $4 of federal money spent. DSCC’s state match is funded through the University of Illinois.

DSCC works to maximize its federal financial participation through an agreement with the Illinois Department of Healthcare and Family Services (HFS) to receive reimbursement for our Medicaid administration costs.

Sources of FY 2019 Spending

“*It’s not just a service that’s provided, it’s information on the diagnoses. It’s almost like a translator to the medical world... You realize how valuable it is to be able to speak with someone who knows about different programs and support groups.*”

- Nedra Whitted, grandmother to Stanton in the Core Program