



2018 Fiscal Year **Annual Report**

We **partner** with Illinois families and communities to **help** children and youth with special healthcare needs **connect** to services and resources.



SPECIALIZED CARE FOR CHILDREN

July 1, 2017 — June 30, 2018

Executive Director Greeting



The University of Illinois at Chicago's Division of Specialized Care for Children (DSCC) has served children with special healthcare needs for more than 80 years. We're proud of our long-standing mission to partner with Illinois families and communities to help these children connect with services and resources.

Fiscal year 2018 was a year of preparation to strengthen these partnerships and further empower families to reach their full potential.

Our staff, administration and Medical Advisory Board worked together to update our medical eligibility requirements for children in our Core Program. The goal was to simplify our eligibility criteria and streamline impairment categories to cover body systems rather than specific conditions. These changes allow us to assist families in a timelier manner.

The new eligibility requirements are just one part of new Administrative Rules that govern our program. These rules went into effect Oct. 1, 2018. Most of the groundwork for this significant milestone took place throughout FY 2018.

We also continued to invest in our staff to improve our expertise and the skills and processes we use to help our families. We've redesigned our internal training and quality improvement initiatives to support our staff with the research and best practices necessary for high-quality care coordination.

Our care coordination teams are now using a more comprehensive and holistic assessment to develop a person-centered plan for each of our families. By focusing on their strengths and goals, we are giving families the tools and support they need to achieve what matters most to them.

We are also proud to be a part of the invaluable public services the University of Illinois provides all state residents. Our internship and educational opportunities help foster the next generation of social workers, healthcare providers and technology professionals.

We also continue to pursue new collaborations with other University departments and systems to improve health care and related services for all Illinois residents.

Thank you for supporting the mission of DSCC.

A handwritten signature in black ink that reads "Thomas F. Jerkovitz". The signature is fluid and cursive, with a long horizontal stroke extending from the end.

Thomas F. Jerkovitz

Mission and Vision

We believe children and youth with special healthcare needs should be at the center of a seamless support system that improves the quality of their lives.

To achieve that vision, we **partner** with Illinois families and communities to **help** children and youth with special healthcare needs **connect** to services and resources.



We **partner** with families, doctors, specialists, schools, community organizations, insurance companies and state agencies to help all of these supports work together in the best interest of the child and family.



We **help** by using our knowledge of children with complex medical needs to evaluate each family's situation so we can identify gaps and plan solutions to meet their needs.



We **connect** families to services and resources through the extensive relationships we've developed in local communities, and we follow up to make sure they continue to meet the family's needs.

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Who We Are

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

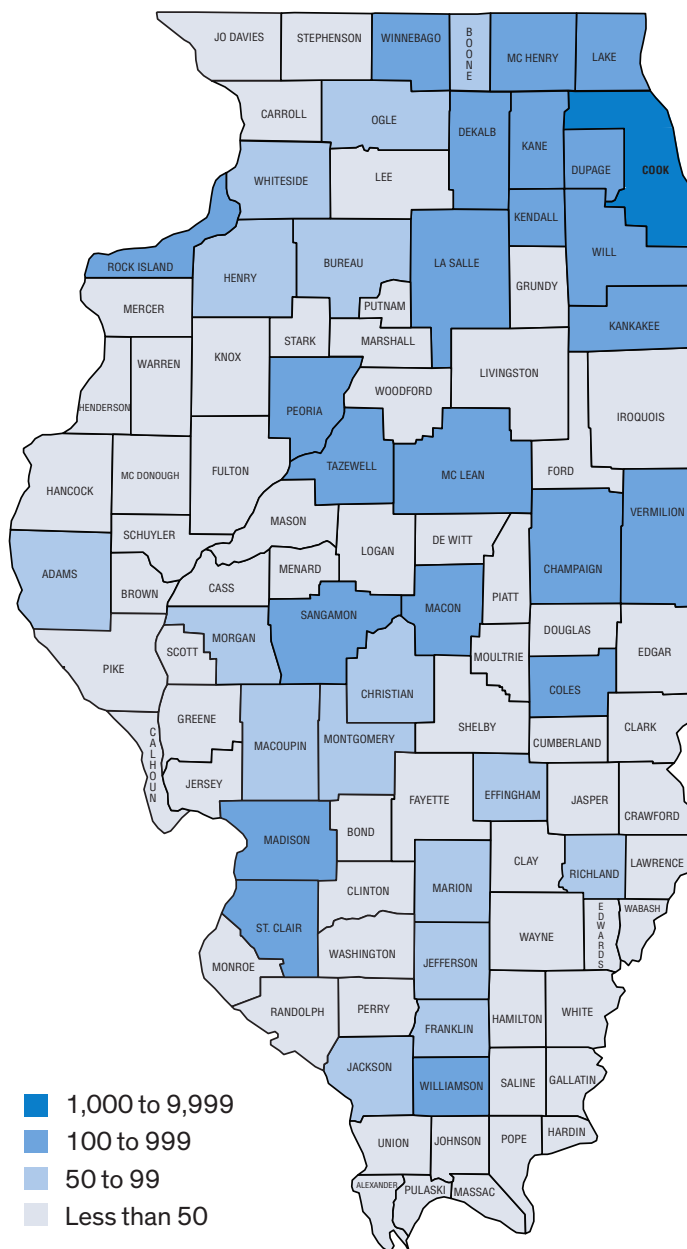
Each state receives federal funds to improve the health of children and youth with special healthcare needs. DSCC has been the designated program to receive these funds for Illinois since 1937.

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

Our staff includes social workers, nurses, speech pathologists, audiologists and other team members. These professionals are trained to help families find the specialty care and resources they need for their children to reach their full potential.

We do this through a process called care coordination, which is a partnership between our Care Coordinators and the parents/caregivers. This partnership combines the family's experiences and values with our staff's expertise and extensive network of relationships across the state. We then work together to address a child's medical, social, behavioral, educational and financial needs.

FY 2018 Active Cases by County



Map of all cases by county that were actively enrolled or in intake between July 1, 2017, and June 30, 2018.

Who We Are

DSCC's Referral Sources for FY 2018

REFERRAL SOURCE	TOTAL
Adverse Pregnancy Outcomes Reporting System (APORS)	3,213
Supplemental Security Income (SSI)	2,548
Family	2,313
Hospital	1,692
Early Intervention	1,182
Newborn Hearing Screening (NBHS)	859
Newborn Genetic Screening (NBGS)	856
Providers	478
School	255
Illinois Department of Public Health	215
County Health Department	199
Illinois Department of Healthcare and Family Services (HFS)	143
Nursing Personal Care Services (NPCS)	113
DSCC Staff	112
DSCC Website	112
Other sources, including nursing agencies, social service agencies, Illinois Department of Children and Family Services (DCFS), rehabilitative services and DSCC outreach	1,659
TOTAL	15,837

In fiscal year 2018, we provided care coordination to more than 15,800 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. Our staff also provided resource information and referrals to 340 youth who are not eligible for DSCC services and reached more than 260,000 people through outreach events, our website and social media.

Our care coordination identifies the needs of the child and family as a whole. Our Care Coordinators then work with each family to develop a plan of care for their long-term success. This assistance is free to all eligible children, regardless of their family's income level.

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.



Who We Are



PARTNER

A major strategic goal at DSCC is to strengthen our partnerships with families in care coordination services. We aim to accomplish this through regular contact between our staff and parents/ caretakers and joint decision-making with family members. We're also working toward more frequent use of family surveys and input from our Family Advisory Council (FAC).

During FY 2018, staff from across the state worked with our FAC to develop a series of surveys for participant families to fill out at specific intervals of their child's journey with DSCC. 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.

Families should expect to receive surveys starting in FY 2019. We look forward to a more uniform approach to collecting this valuable input. 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.



Who We Are

Investing in our Team

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

During FY 2018, we introduced a new Learning Management System to help staff stay on top of necessary training and professional development. We formed new quality improvement teams for the Core and Home Care programs. Their mission is to partner in excellence, connect research to practice and help those who serve. This support is essential to fulfill DSCC's overall mission to partner with Illinois families and communities to help children with special healthcare needs connect to services and resources.

In the spring 2018, our staff gathered for an intensive two-day training session on best practices in care coordination and how to partner with families to identify their strengths and needs in the areas of medical, social/emotional, education, financial and transition. Our team also learned about the importance of person-centered planning, which focuses on each participant's needs, wants, dreams and desires.

DSCC works with our team on ongoing education and training throughout the year on various topics related to care coordination. We are using these skills and knowledge to help our participants and their families live their best life possible.



DSCC Associate Director of Care Coordination Molly Hofmann, APRN, MSN, PCNS-BC, speaks to downstate staff during our spring training session in Springfield.

DSCC is also developing a scorecard to monitor performance of key areas related to our three mission pillars of partner, help and connect. The scorecard is a performance improvement tool that will allow current performance data to be readily available to staff throughout the state.

Our Care Coordination

DSCC defines care coordination as a person- and family-centered, strength-based, assessment-driven approach of empowering families to achieve their goals. This process ultimately leads to positive health outcomes, improved quality of life and overall family satisfaction.

Our care coordination is free and tailored to each child and family's situation. It 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. Our staff uses a more 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 80-plus years of experience working with children with special healthcare needs in Illinois to identify the critical characteristics of high-performing pediatric



"A thorough assessment is important because that kind of assessment not only looks at the healthcare piece but the family's whole life and what their concerns are or decisions they want to make – taking all that into consideration."

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

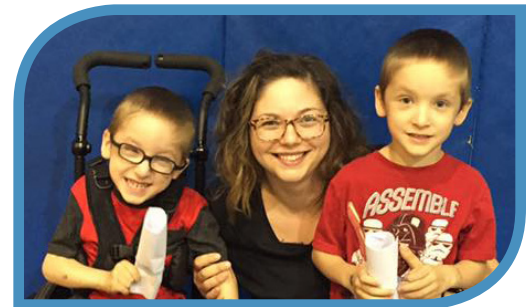
Our Care Coordination

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 and 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.

"I think it's important for your Care Coordinator to have a full view of your life and your lifestyle choices to provide accurate care. Some families have religious preferences, some families have socioeconomic challenges that it's nice for the Care Coordinator to be aware of so they aren't suggesting things out of the realm of feasibility for the family."

– Jessica Lance,
mother of
Gabe and
Gavin in
the Core
Program



"It's nice to have someone sort of guide me in the process- 'This is what we're looking at, this is what needs to happen, what are your desires and needs?' Then, I'm able to focus in and give it the attention I need."

– Christie Lyons, mother
of Natalie, a former Core
Program participant



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.

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.

Who We Serve

Core Program

We serve Illinois families with children up to age 21 who have or are suspected of having an eligible medical condition through the Core Program.

During FY 2018, we worked toward completing a major strategic goal to update and streamline our eligibility categories and procedures for the Core Program.

Our Medical Advisory Board generalized our eligible impairment categories to cover body systems rather than specific conditions. This change simplifies our eligibility requirements.

Below is a comparison of FY 2018's eligibility categories compared to the new:

Eligibility Prior to Oct. 1, 2018	Current Eligibility
Cardiovascular Impairments – heart, larger blood vessels of the heart	No change
Cystic Fibrosis	Pulmonary Impairments - disabling conditions affecting the lungs or breathing, such as cystic fibrosis or chronic lung disease
External Body Impairments - oral, nasal, major bronchi, esophageal; breathing-speech-eating; also, “beyond range of acceptable appearance”	Craniofacial and External Body Impairments -speech impairments may now be within this updated category
Eye Impairments	No change
	Gastrointestinal - disabling conditions affecting the esophagus, stomach or intestines
Hearing Impairments	No change
Hemophilia and Chronic Disorders of Coagulation	Blood Disorders - inherited and acquired hematologic conditions

Who We Serve

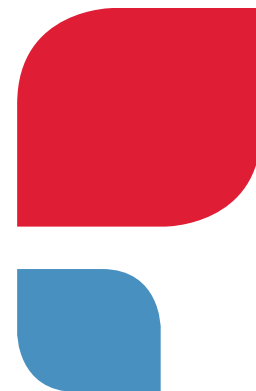


Eligibility Prior to Oct. 1, 2018	Current Eligibility
Inborn Errors of Metabolism - newborn conditions – leads to severe neurological, mental and physical deterioration	Inborn Errors of Metabolism - newborn conditions – leads to severe neurological, mental and/or physical deterioration
Nervous System Impairments - brain, spinal cord or peripheral nerves - resent recurring loss of consciousness, strength, etc.	Nervous System Impairments - speech apraxia (dyspraxia); dysarthria move to this category. Speech impairments may now be within this new category.
Orthopedic Impairments - Bones, joints, muscles	No change
Speech Impairments - impairment of intelligibility from structural defect of organs responsible for speech or neurological defects specific to orderly speech	The Speech Impairment category no longer exists. Speech impairments may be eligible under <u>Craniofacial and External Body Impairments</u> or <u>Nervous System Impairments</u> .
Urinary System Impairments - organic impairments affecting kidney, ureter, bladder and/or urethra – excludes isolated UTI	Urogenital Impairments - organic impairments affecting kidney, ureter, bladder, urethra and/or ano-genital structures

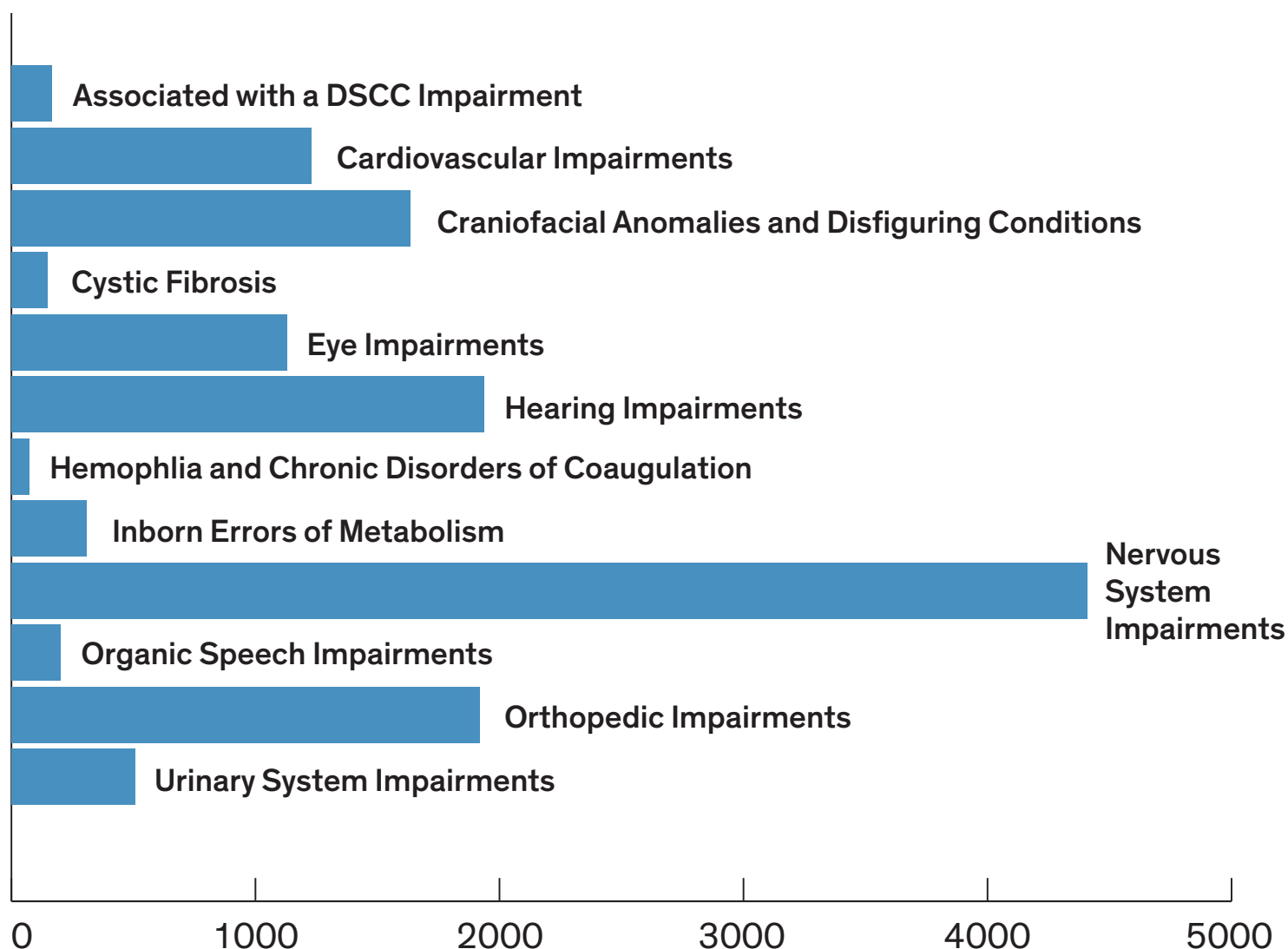
With these updates, we will be able to provide care coordination services more quickly to families in need. We also note that previously eligible medical conditions will remain eligible. No one will leave our program because of the new rules.

A team of our staff worked on reviewing and revising policies and procedures in preparation for the rule changes and to streamline our operations. The Joint Committee on Administrative Rules reviewed the rules over the summer and approved them for implementation on Oct. 1, 2018.

Who We Serve



Impairment Category for Active Core Cases in FY 2018



Who We Serve

Home Care

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

The 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.



HELP

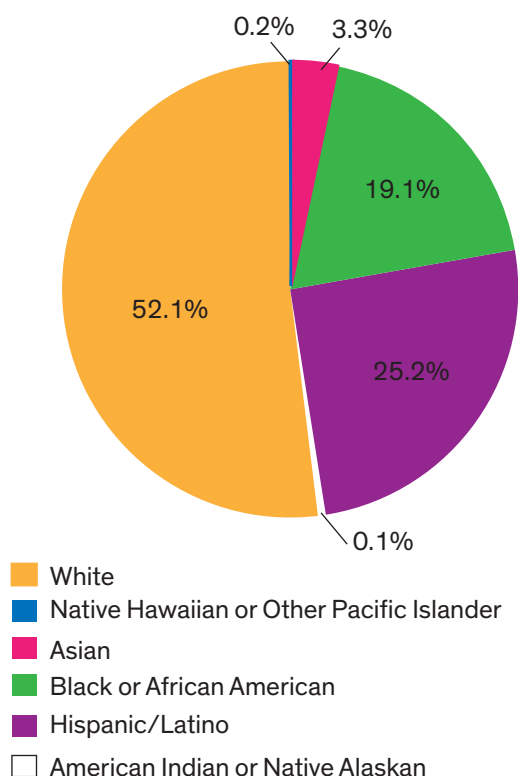
During FY 2018, DSCC created the new Home Care Enrollment Team as part of the Home Care

Quality Improvement and Enrollment unit. This statewide team will serve as a family's first introduction to DSCC and our care coordination. Team members will work closely with hospital liaisons to enroll a family in the Home Care program, conduct the initial home visit and home assessment and complete all of the necessary paperwork to submit the initial application to HFS for approval.

Having a team of staff dedicated to enrollment will help the Home Care application process move quicker so families can receive support sooner. The enrollment team will also free up more time for DSCC Care Coordinators to focus on care coordination activities. Once a participant is enrolled, their case will be transitioned from the enrollment team to an ongoing Care Coordinator.

The enrollment team was scheduled to take effect on Oct. 1, 2018.

Known Ethnicity of Active Participants in FY 2018



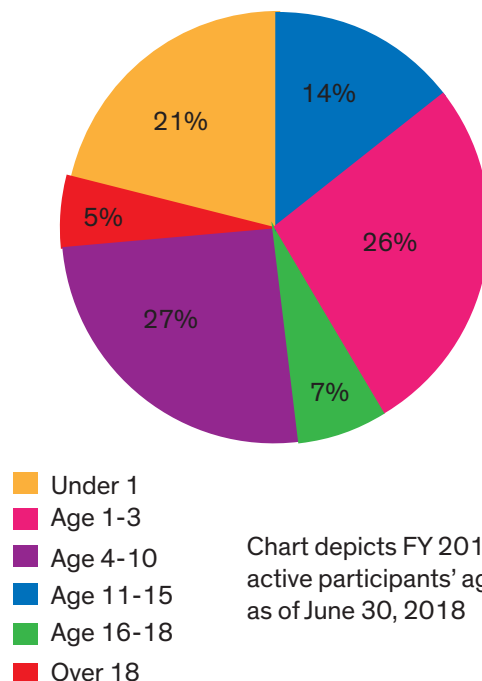
Who We Serve

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.

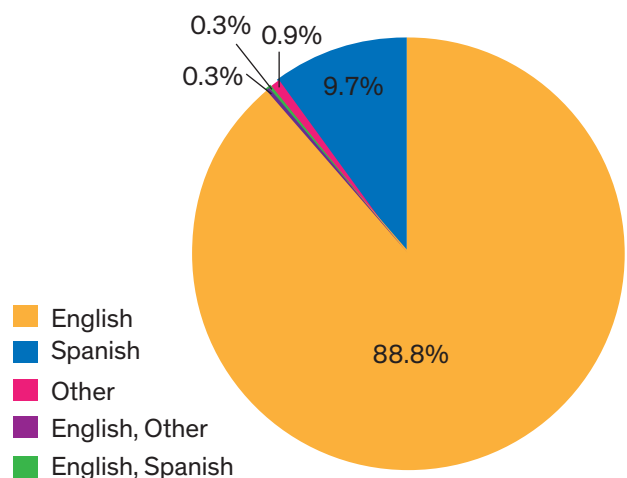
Waiver: DSCC started operating the Home Care Program in 1983 to serve children who qualify for the Medicaid Title XIX Home and Community-Based Services Waiver for Medically Fragile Technology Dependent Children. Individuals served by the waiver depend on technology – such as ventilators, tracheotomies 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.

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 child 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.

Age of FY 2018 Active Participants



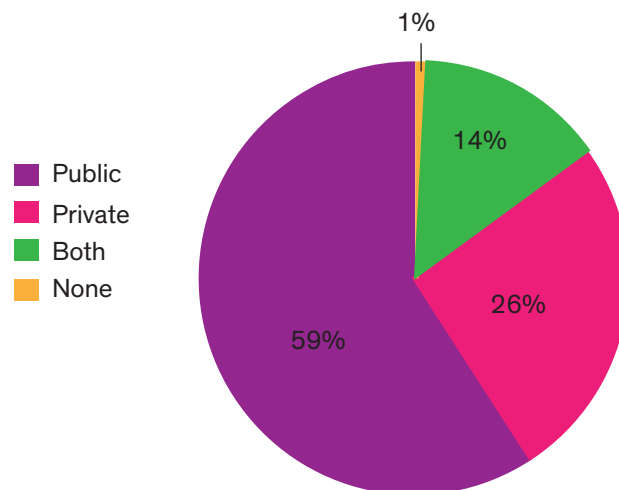
Preferred Language of Active Participants in FY 2018



Who We Serve

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.

Insurance Type for FY 2018 Core and Home Care Participants



"(DSCC Care Coordinators and staff) were a shoulder to lean on. They showed that they genuinely cared about my well-being as I was growing up and through school. They really showed a lot of love and support for all of the hard things that we were going through."

– Zayd Jawad, former participant in the Core Program

"I'm very impressed with the dedication of the Care Coordinators and think this is truly a service that benefits the state of Illinois."

– Dr. Keith Gabriel, a retiring orthopedic surgeon from HSHS Medical Group in Springfield. Dr. Gabriel provided free orthopedic assessment clinics to DSCC participants in east-central and southern Illinois for 16 years.



Our Impact



"DSCC came at a time when we really, really needed it... (Our Care Coordinator) Sarah Kelly has tried everything in her power just to make our life easier. She is extremely, extremely helpful, kind and caring."

– George Doueih, father of Sabrina in the Core Program

"(DSCC) gave me a guide... the reassurance you gave me that (my Care Coordinator) was here and he understood and if I needed anything, I could just call or come to the office and it was OK. There was nothing we couldn't handle, even though it might have seemed in that moment like I couldn't handle it."

– Brandy Santiago, mother of Trooper Orosco in the Core Program.



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 and organized in the care of their child and understand and stay at the center of decisions about their child's care. Our Care Coordinators 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 also 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.

Our Impact



As part of our efforts to connect families to much-needed services and resources, DSCC staff presented at or participated in 130 events throughout Illinois in FY 2018. 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 staff also participated in more than 60 different rounds or clinics throughout Illinois each month.

CONNECT

DSCC served on the steering committee for the 13th annual Illinois Statewide Transition Conference on Oct. 23-24, 2017, in Springfield. More than 500 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 20 participant families.

DSCC supported the 2018 Institute for Parents of Preschool Children who are Deaf or Hard of Hearing, held June 10-15 on the Illinois School for the Deaf campus in Jacksonville. Twenty-three DSCC families from across Illinois attended the 2018 Institute. 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. Lecture topics include child development, types of hearing loss, language development, communication choices, deaf culture and school programming. Other activities include meeting in small groups to discuss specific concerns and connecting with other caregivers.

During the Institute, children attend classrooms overseen by experienced teachers of children who are deaf or hard of hearing. They have the opportunity to receive hearing, vision, psychological, speech, language and educational evaluations as well as play with other children who have a hearing loss.



Our Funding

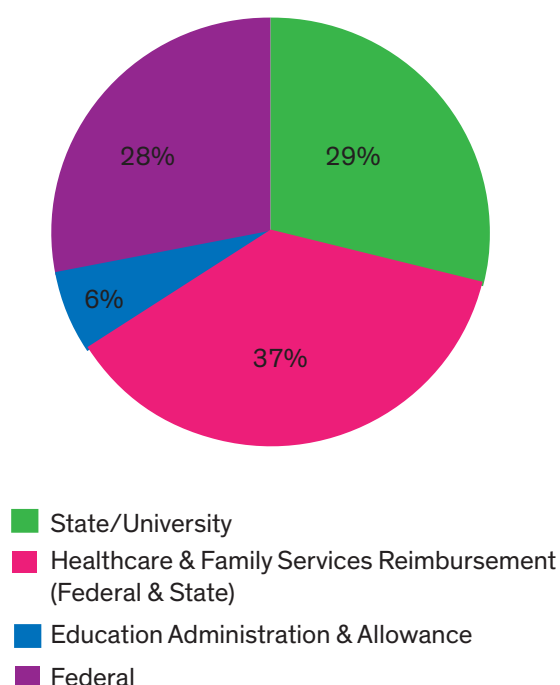
DSCC is funded through a combination of state and federal revenue sources.

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.

HFS provides funds to DSCC to operate the Home Care Program on its behalf for children who qualify under the Medicaid Title XIX Home and Community-Based Services Waiver for Children who are Medically Fragile, Technology Dependent as well as for Medicaid children who are eligible for in-home nursing services.

Sources of FY 2018 Spending



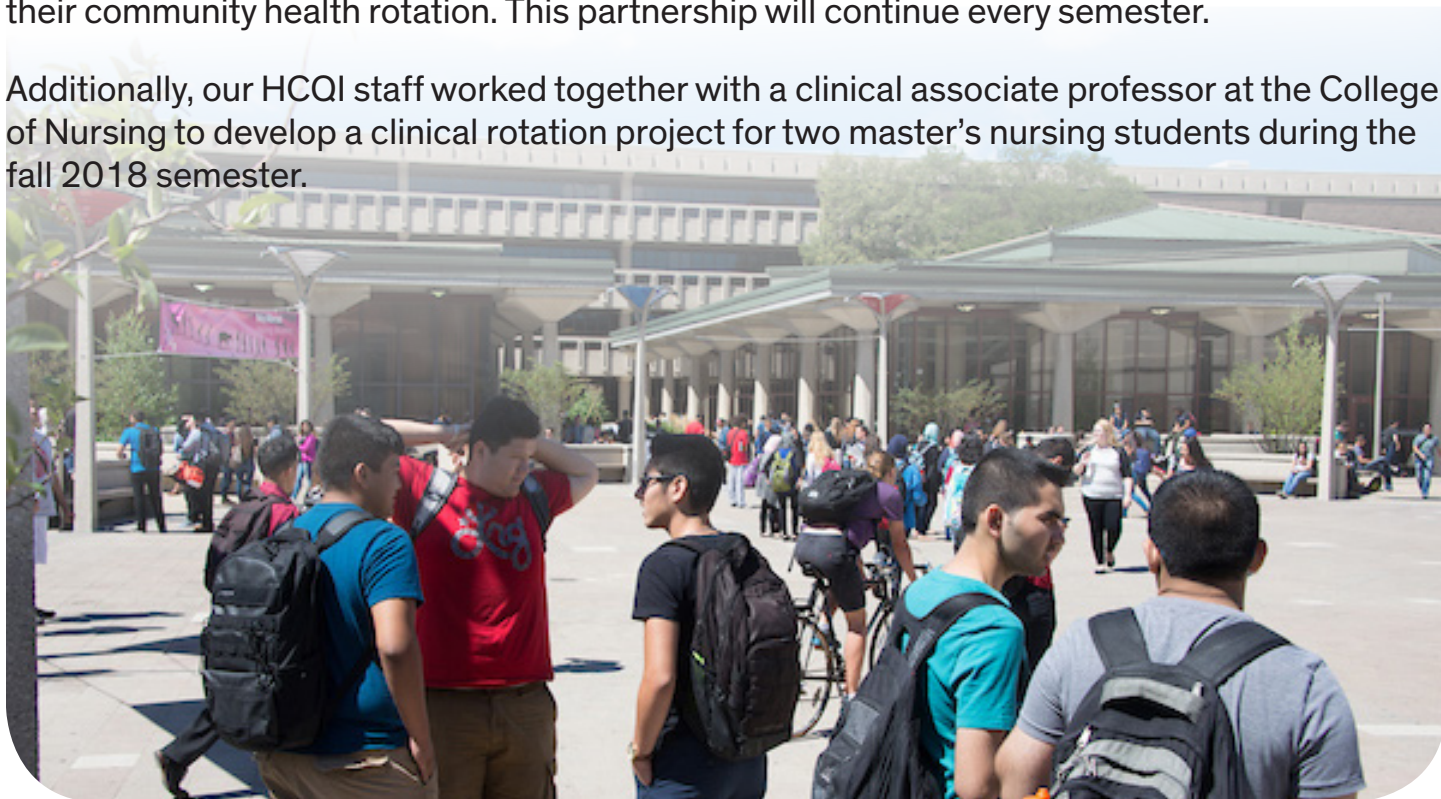
"The UIC-DSCC demonstrates strong commitment to improve the systems of care for children with chronic disease conditions and disabilities. It is to be recognized for its exemplary efforts to provide care coordination and financial assistance to eligible families, and to engage families in care coordination, outreach and education..." – Maternal and Child Health Bureau Summary for Illinois' Title V Program

Our Education Opportunities

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 for students to 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 2018, DSCC hosted five University student interns in our offices across the state. These interns included one master's degree candidate and three completing their bachelor's degrees from the School of Social Work. These four interns worked in the Core Program. Our Home Care Quality Improvement and Enrollment (HCQI) Unit also hosted one student from the College of Nursing. Our Chicago Home Care and Core offices also partnered with UIC's College of Nursing to serve as a clinical rotation site for undergraduate nurses enrolled in their community health rotation. This partnership will continue every semester.

Additionally, our HCQI 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 during the fall 2018 semester.



Our Collaborations



University of Illinois Hospital Health & Science System

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 2018. 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 an additional \$200,000 in FY 2018 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.

University of Illinois at Chicago

Division of Audiology, Department of Otolaryngology

DSCC continues to help improve outcomes for Illinois infants and children with suspected hearing loss through timely screening and follow-up services. DSCC’s Early Hearing Detection and Intervention (EHDI) program developed a partnership with UIC’s Department of Otolaryngology (Division of Audiology) to offer training sessions on Otoacoustic Emissions (OAE) screening and provide technical assistance when needed.

Research shows that newborns with hearing loss can, by the time they enter kindergarten, develop language skills that are similar to their peers without hearing loss when:

- Their hearing loss is identified through

Our Collaborations

- screening before 1 month of age,
- Their hearing loss is diagnosed before 3 months of age, and
- They start intervention services before 6 months of age.

To help Illinois newborns reach these “1-3-6” benchmarks, DSCC receives a grant from the federal Health Resources and Services Administration (HRSA). HRSA funds are used to promote screening of newborns to detect hearing loss, timely diagnostic evaluation and early intervention to lessen the effects of hearing loss on language acquisition among infants and young children. DSCC provided a part of these funds to the Division of Audiology to train public health nurses from the Chicago Department of Public Health and other county health departments and home visiting programs on the use of OAE screening devices.

In December 2017, DSCC provided eight OAE screening devices to the Chicago Department of Public Health to:

- Provide outpatient hearing screenings to children who did not pass their initial hearing screening at birth
- Reduce the number of newborns suspected of hearing loss who are lost to the state’s screening and follow-up system; and
- Ensure that more infants with hearing loss receive timely diagnostic evaluations and referral for intervention services



Five public health nurses from the Chicago Public Health Department pose with their hearing screening trainer.

DSCC arranged for the Division of Audiology to hold three training sessions in January, March and April 2018 to teach all 27 of the Chicago Department of Public Health’s public health nurses about newborn hearing screening and the proper use of OAE screening devices. In addition, the Division of Audiology continues to train staff from other local health departments or home visiting programs in Illinois that are in need of training for new employees or seeking refresher training.

This partnership with the Chicago Department of Public Health and the UIC Division of Audiology will help identify more families of newborns with hearing loss and encourage families of children with confirmed hearing loss to seek intervention services to help their children reach their full potential.

Our Collaborations

University of Chicago

Study of Children with Home Mechanical Ventilation Assistance

DSCC is working together with Dr. Sarah Sobotka on a research study of the parent and family experiences of caring for a child with a ventilator. Dr. Sobotka is an assistant professor of pediatrics at the University of Chicago. She is passionate about helping children with complex disabilities and has been interested in working with the Home Care Program for several years.

The study's main goal is to get a better sense of the challenges families face in order to help address possible gaps in care and services. We want to know how to best support families of children who are dependent on technology to continue living in the community.

Dr. Sobotka proposed a plan to accompany the DSCC Home Care care coordination teams on home visits with newly enrolled Home Care families and conduct an interview and developmental testing of the child. Dr. Sobotka's research team will join DSCC Care Coordinators on the 30-day home visit after a child comes home from the hospital. Dr. Sobotka and her research team will then contact participating families for a follow-up visit six months later.

DSCC is responsible for identifying eligible families for the study and asking if they would like to participate. Eligibility requirements include:

- Having a child that uses a ventilator
- Having a child with a tracheostomy
- Being new to the Home Care Program
- Having a child under 18 years old
- Living at home with the child

DSCC Home Care enrollment specialists plan to recruit participant families in November 2018. We are hopeful Dr. Sobotka's research will lead to advocacy and thoughtful consideration of how resources are provided to these families.