

Annual Report

FISCAL YEAR 2020



**SPECIALIZED CARE
FOR CHILDREN**



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.



**SPECIALIZED CARE
FOR CHILDREN**

(800) 322-3722 | dsccl.uic.edu



Executive Director Greeting

The University of Illinois Chicago's Division of Specialized Care for Children (DSCC) has served Illinois children with special healthcare needs and their families since 1937.

Throughout our 83-year history, we've adapted and evolved to meet the changing needs of the families we serve. But no single year brought more change and challenges to date than fiscal year 2020 (July 1, 2019, through June 30, 2020).

The COVID-19 pandemic abruptly altered life as we know it. Schools and workplaces shut down. Social distancing physically separated families from loved ones, friends and other valuable support systems. Parents and caregivers juggled childcare and work responsibilities simultaneously at home.

We recognize the profound stress these changes put on our participant families, especially those whose children are high-risk and medically complex. From the start of the stay-at-home order, our team united remotely to provide much-needed support to our families.

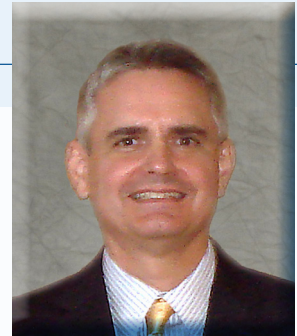
We checked in with our participants, compiled resources, provided education and partnered with state agencies to ensure Illinois included all children and youth with special healthcare needs in its disaster planning and response. These efforts are ongoing.

Though uncertainty remains, the dedication of our team and the strength and resilience of our families continue to encourage and inspire us. We look forward to brighter times ahead and another 80 years of partnering, helping and connecting with children with special healthcare needs and their families.

Thank you for supporting our mission.



Thomas F. Jerkovitz



Who We Are

The University of Illinois 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.

We partner with Illinois families and communities to help these children and youth connect to the services and resources necessary to reach their full potential.

DSCC has an eight-decade history of serving Illinois families. We guide families through their child's journey with a medical condition and work with doctors, schools and community groups to create a seamless support system.

Our staff partners with families to develop a plan of care that addresses a child's medical, social, behavioral, educational and financial needs. This process is called care coordination.

We provide care coordination services through three programs:

- The Core Program serves youth from birth to age 21 with medically eligible conditions.
- The Connect Care Program serves youth from birth to age 21 with special healthcare needs who are enrolled in a Medicaid HealthChoice Illinois plan that has contracted with DSCC for care coordination.
- The Home Care Program serves children and youth in need of in-home shift nursing.

In fiscal year 2020, we served more than 18,600 families in all 102 counties in Illinois. Additionally, our staff provided resource information and referrals to more than 500 children and youth who were not eligible for DSCC services.

Our Team

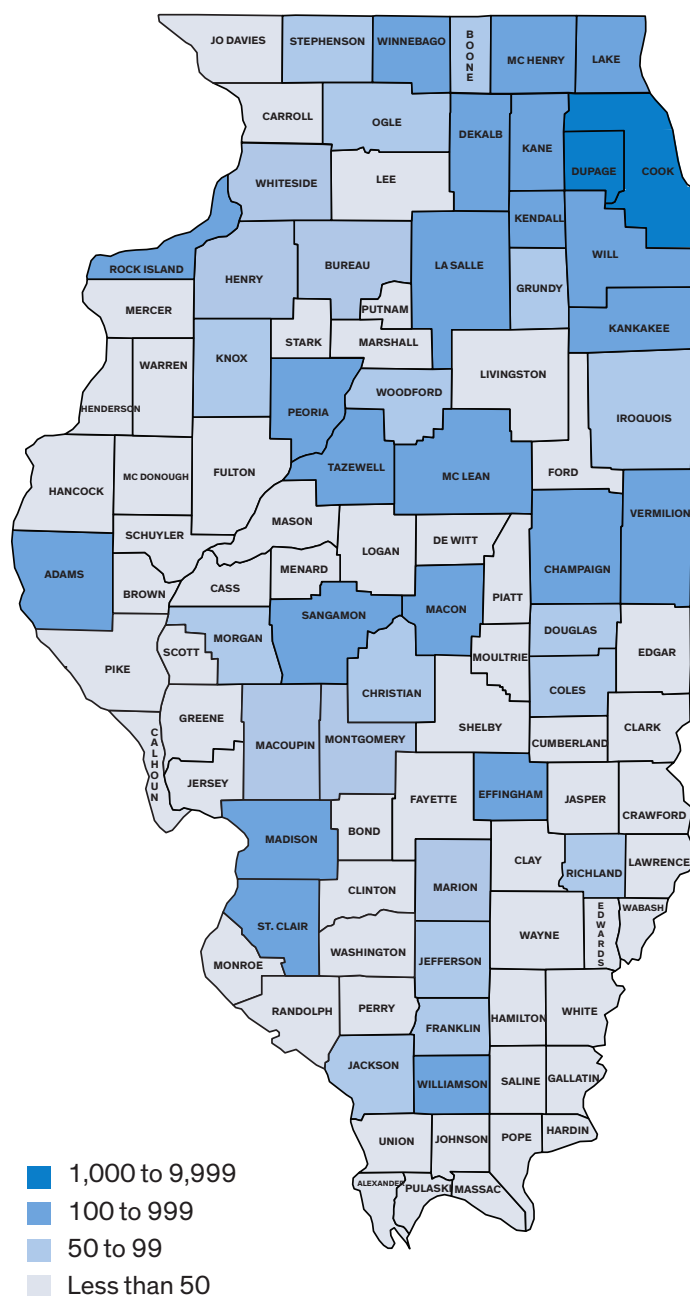
Our staff works out of 11 regional offices throughout the state to help families in their local communities.

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

These professionals are trained to help families find the specialty care and resources necessary to meet their unique needs. Dedicated staff also work with families to help them better understand their insurance benefits and how to maximize available coverage.

FY 2020 Active Cases by County



Map of all DSCC cases by county that were actively enrolled or in intake between July 1, 2019, and June 30, 2020.

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.

Title V programs exist in all 50 states and nine territories. At least 30 percent of the Title V funds that states and territories receive must 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 all children and youth with special healthcare need and their families.

DSCC staff who work directly with families keep us up-to-date on the different systemic issues affecting children and special healthcare needs in Illinois. Through our Title V role, we can find solutions for these issues and address any inequities.

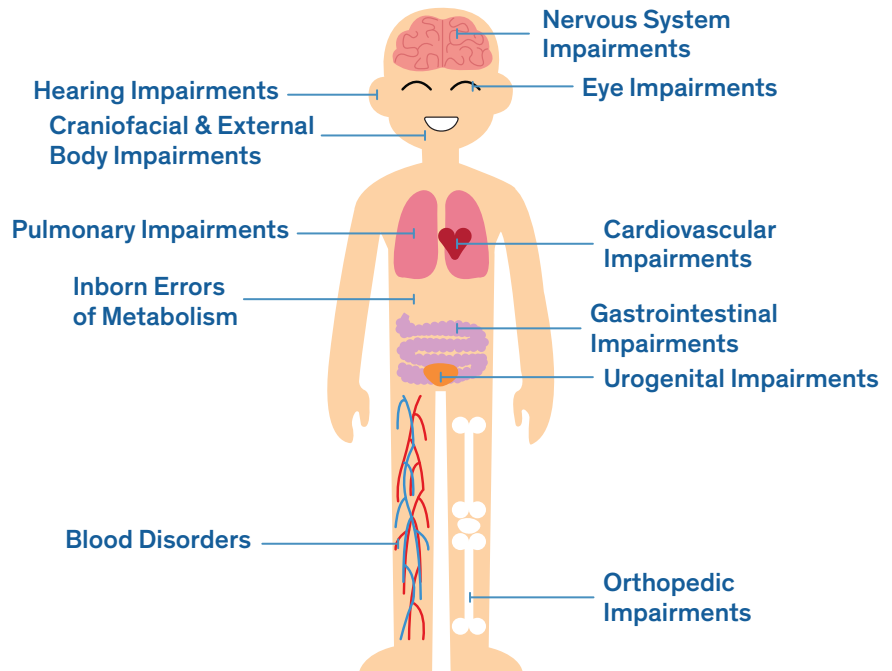
We have targeted priorities for the block grant that guide our work. This work includes:

- 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

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. The condition must be chronic and fall in one of our 11 eligible impairment categories.



Core Enrollment and Resource Team

We launched our new Core Enrollment and Resource Team in the summer of 2020. This team is dedicated to helping families who are not enrolled in our care coordination programs find the right resources and services.

This team also handles Core Program referrals for our Chicago, Lombard and Springfield offices to help expedite the intake process for eligible families. This team will continue to expand across the state to become a central access point for families to enroll in DSCC's Core Program.

Connect Care

Our Connect Care Program is a new program for children and youth with special healthcare needs enrolled in Medicaid managed care.

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

The Illinois Department of Healthcare and Family Services (HFS) moved children with special healthcare needs into a HealthChoice Illinois health plan on Feb. 1, 2020.

Our staff worked with HFS to prepare for this transition. This effort resulted in the development of our Connect Care Program.



Who We Serve

Connect Care is initially serving the approximately 2,300 children and youth who were enrolled in our Core Program and transitioned from Medicaid fee-for-service insurance coverage to HealthChoice Illinois.

New enrollments in this program are being considered on a case-by-case basis.

DSCC developed contracts with the HealthChoice Illinois managed care organizations to continue our care coordination services for these participants and families.

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 healthcare needs in Illinois.

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 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 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, tracheostomy tubes 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.

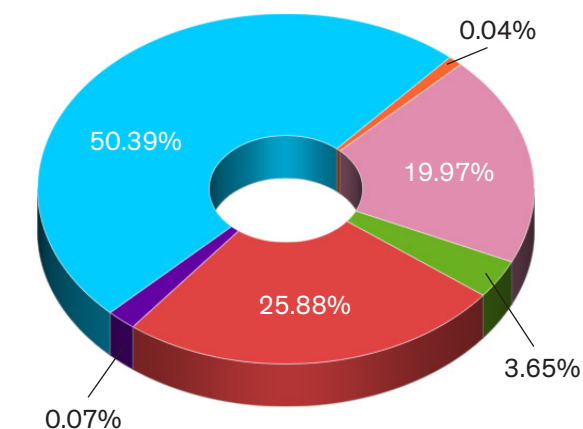
Youth may qualify regardless of their family's income. Originally, the waiver only covered participants less than 21 years of age. As of May 1, 2017, the waiver covers participants of all ages if the participant was enrolled in the waiver prior to the day before his or her 21st birthday. This amendment 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.



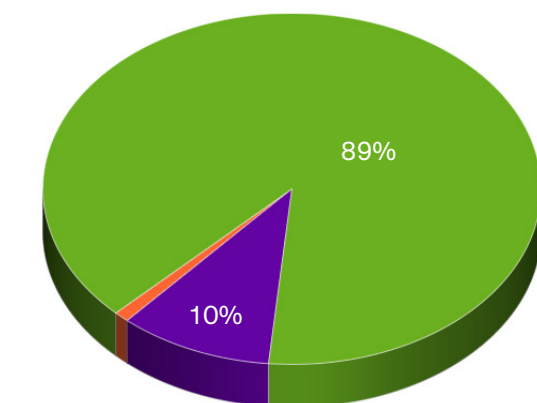
Who We Serve

Known Ethnicity of Active Participants in FY 2020



- White
- Hispanic/Latino
- Black or African American
- Asian
- American Indian or Native Alaskan
- Native Hawaiian or Other Pacific Islander

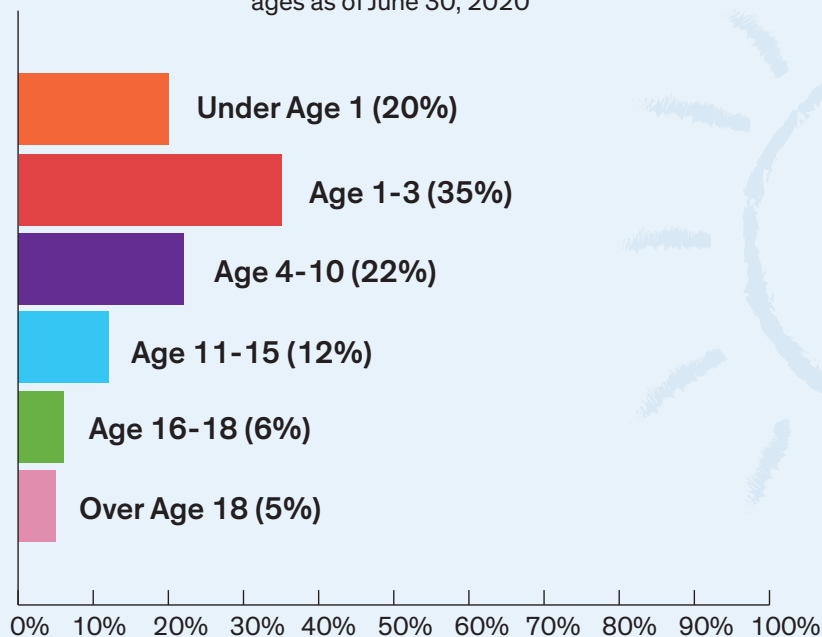
Preferred Language of All Active Participants in FY 2020



- English
- Spanish
- Other

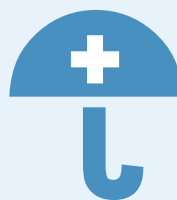
Age of All Active FY 2020 Participants

Chart depicts FY 2020 active participants' ages as of June 30, 2020



Insurance Type for FY 2020 Active Participants

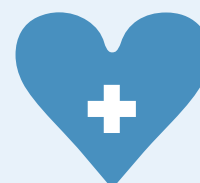
Public
57%



Private
27%



Dual
16%



Our Care Coordination

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

We define 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.

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 both the child and their entire family.

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 individualized education program (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

Financial assistance is available to eligible participants to cover expenses not covered by Medicaid or other insurance.



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.

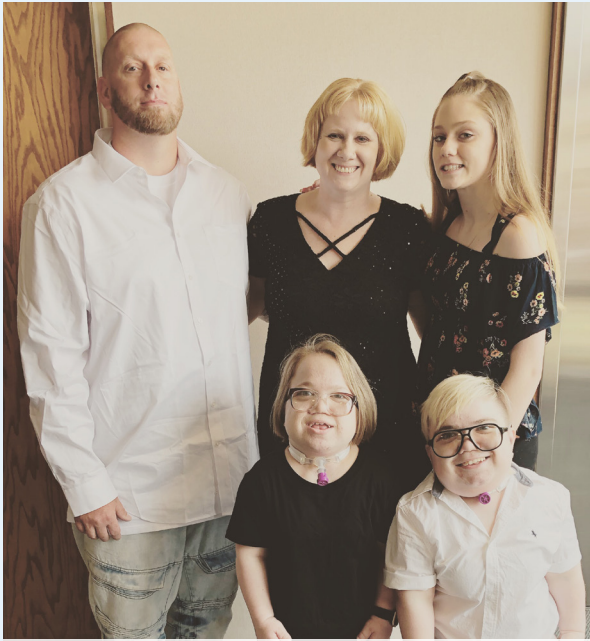
During FY 2020, our staff used a comprehensive and holistic assessment to help our care coordination teams develop a person-centered plan for each of our families.

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
- Education
- Transition
- Social/emotional
- Financial

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.

Our Care Coordination



Family Impact

Our care coordination helps families:

- Feel more confident and organized in the care of their child
- Understand and stay at the center of decisions about their child's care
- Develop a stronger partnership with their child's doctors and specialists
- Express their worries and concerns and address them productively
- Effectively navigate the maze of resources and insurance coverage/benefits
- Support and achieve their child's educational and vocational goals
- 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 providers' treatment plans
- Communicate more effectively with everyone involved in their child's care

DSCC staff has also developed an extensive network of pediatric specialists for children with special healthcare needs and can facilitate referrals for other providers and resources.

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. DSCC care coordination teams work with families to develop a plan that focuses on what matters most to them.

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

Care Coordination Documentation System

We implemented a new electronic care coordination system called ClientTrack in March 2020.

ClientTrack helps our care coordination teams work more efficiently and effectively as they partner with families.

The platform provides for care tracking, monitoring, data sharing, reporting and advanced analytics. It also integrates healthcare data sources and allows families to connect with their child's providers.

Moving to ClientTrack as the COVID-19 pandemic hit our communities was very challenging. Thanks to our team's hard work, adaptability and perseverance, we now have a more reliable system with the features and tools to better meet the needs of our participants and our care coordination teams.

We continue to develop our use of ClientTrack and plan to include a parent and provider portal in the future.

Care Coordination Leadership

In 2020, Molly Hofmann was promoted to DSCC's Director of Care Coordination, Systems Development and Education.

Molly has been the Associate Director of Care Coordination for the past four years and has consistently demonstrated her superb clinical, managerial and leadership skills. Her passion to improve systems of care for children and youth with special healthcare needs and their families is displayed daily by her innovative approaches to program development and quality improvement.

In addition to her leadership of DSCC's care coordination programs, Molly now oversees the various projects and initiatives for DSCC's Title V strategies.

Our COVID-19 Response

The COVID-19 pandemic affected every aspect of life for our participants, their families and our staff.

When the shutdowns started in March 2020, our workforce and operations became fully remote in less than two weeks' time. Our technology upgrades and dedicated Information Technology staff helped us achieve this enormous undertaking.

Our team remained available to support families and help meet their needs through each phase of the ongoing public health emergency.

In the beginning, we prioritized checking in with our participant families above all other care coordination activities. During these check-ins, we placed a special emphasis on families with increased medical and social risks.

We also instructed Care Coordinators to provide additional education on the importance of social distancing, good respiratory hygiene and ways families must prepare for any changes in the child's or caregiver's needs, including backup caregiver support.

Our staff continues to work with our participant families to understand their challenges and provide the appropriate support and resources.

Our team members also continue to support and assist one another as logistics change in the office and at home. In spring 2020, we began sending self-care strategies and tips to practice mindfulness to all staff on a regular basis. We also put together a library of self-care resources for staff to reference when they need help with stress management.

Resources and Guides

Our staff put together a comprehensive list of resources and supports to help our participants and all families of children with special healthcare needs in Illinois navigate the challenges of the pandemic.

Our COVID-19 Resource Directory is available on our website. Our staff continually updates it with the latest information about financial assistance, free meals, health and condition-specific information, tools to support remote learning, mental health tips for caregivers and more. We also shared these resources on our social media channels.

Our COVID-19 Resource Directory was the third-highest viewed page on our website with more than 3,900 page views in calendar year 2020.

We shared tips on our website and social media to help our participants and their families plan and take the proper precautions with their medical supplies at the start of the pandemic. We also compiled guidance and instructions for families of children with medical complexity to help them safely clean and re-use supplies in case of a shortage.

Through our Resource Directory and social media, we also shared the latest guidance and resources for families regarding remote learning and preparing for a possible return to the classroom. Our staff also put together a list of virtual summer camps and learning opportunities to help all Illinois families keep their children engaged and learning during social distancing.

Appendix K

We partnered with the Illinois Department of Healthcare and Family Services (HFS) and the Illinois Department of Public Health to ensure children with special needs were included in the state's disaster planning for COVID-19.

We also worked with HFS to develop and implement the items in Illinois' Appendix K. Appendix K is a standalone document that states may use in emergency situations to request changes to home and community-based services waivers. In Illinois, it applies to individuals receiving Home Care services.

Illinois' Appendix K items include additional respite hours for each participant in the medically fragile, technology-dependent waiver and approving skilled nursing services by parents or legally responsible relatives.

We continue to support families and nursing agencies with information and reminders about the Appendix K provisions.

The Family Voice

A major strategic goal at DSCC is to strengthen our partnerships with families in care coordination services.

Feedback from our participants and families is the most valuable tool we possess to achieve this goal and make the best use of DSCC's resources.

Throughout FY 2020, we worked to strengthen the ways families can share their input and have a direct role in shaping our policies and strategic goals.

Family Surveys

We formed a Family Survey Committee to develop surveys for our participant families to fill out at specific intervals of their child's enrollment with DSCC. In August of 2019, we implemented the following surveys electronically to Core, Connect Care and Home Care participants:

- An initial survey following registration
- A survey for participants enrolled at the one-year, three-year and five-year marks
- An exit survey when a participant dis-enrolls from the program

We received 455 completed surveys from August 2019 to March 2020. Across all programs, participants agreed that DSCC staff and their care coordination efforts have a positive impact on their child and family.

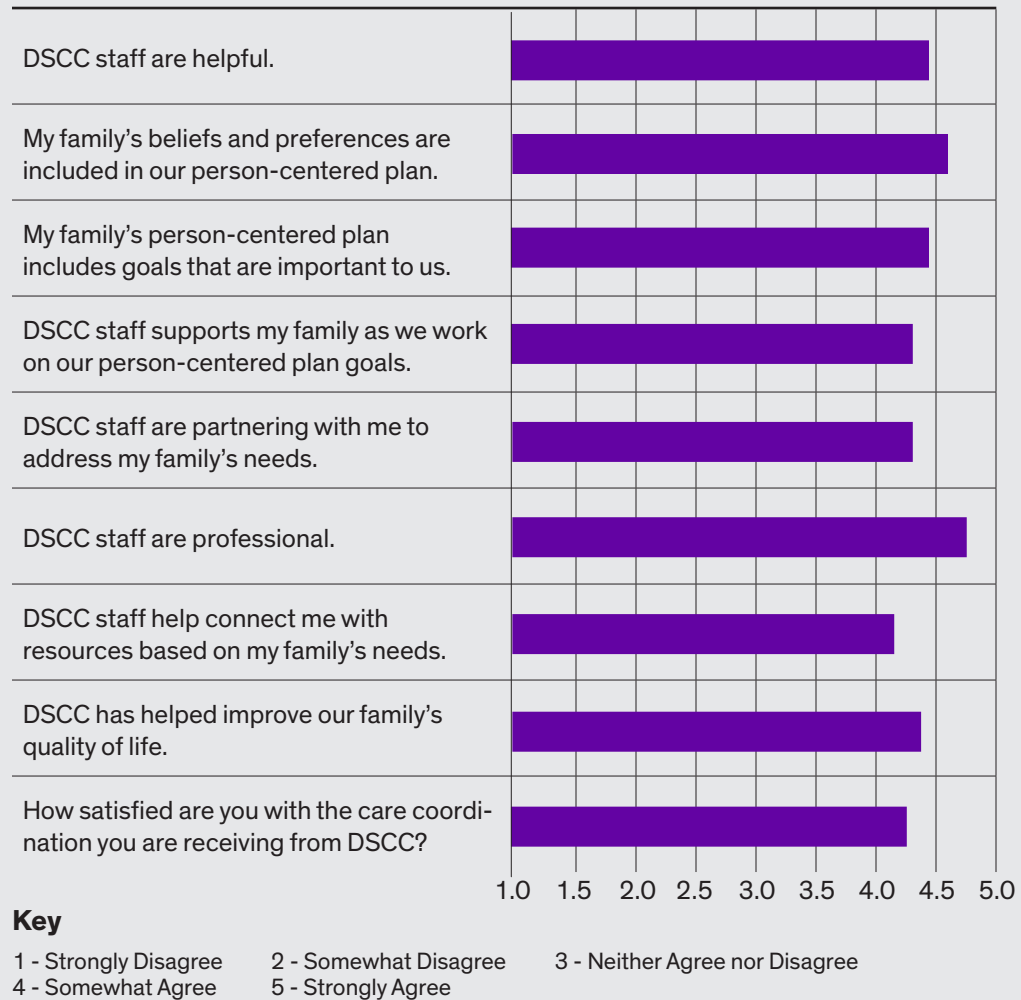
Next Steps

Our Quality Improvement and Information Technology teams are now working to survey families who do not have email. They are also working to implement these additional surveys:

- A survey to a random sample of families after DSCC staff complete a home visit
- 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 for when the participant is ages 14, 16, 18 and 20

The responses from our family surveys 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.

Family Survey Results - August 2019 - March 2020



The Family Voice

Family Advisory Council

We are updating our Family Advisory Council (FAC) setup to make it easier for families to participate and share their input.

A team of our staff formed a Family Advisory Workgroup to help strengthen the council's family engagement and ability to keep family-centered values at the forefront of discussions.

The FAC's mission is to bring together families and our staff and leadership to promote the delivery of participant and family-centered services.

Our updated council will connect families to resources and provide guidance to strengthen our teamwork, improve communication and empower families to have a voice in their child's care.

We began seeking new FAC members during the summer of 2020. Future meetings will start in February 2021.

The new meeting structure will allow opportunities for family members of children with special needs who are not enrolled in DSCC's programs to participate.



Our Title V Priorities

Needs Assessment

One of our Title V responsibilities includes conducting a needs assessment every five years. This assessment helps us identify concerns, set priorities and develop strategies. We submitted our latest needs assessment in the summer of 2020.

We partnered with several state programs and agencies to complete our latest needs assessment. This process included:

- A DSCC family survey
- Interviews with key informants, including DSCC care coordination team members who work directly with families
- A public input survey on the health challenges facing Illinois communities, led by the Illinois Department of Public Health (IDPH)
- A series of listening sessions coordinated by EverThrive
- A data workbook produced by the UIC School of Public Health
- Expert panel webinars, led by IDPH

Through this process, we identified the following areas of need:

- Continued improvement in supporting adolescents with special healthcare needs through the transition to adulthood.
- Providing care for children and youth with special healthcare needs in a well-functioning system.
- Insurance adequacy for families of children and youth with special healthcare needs.
- More inclusivity, integration and adaptation of services for children and youth with special healthcare needs and their caregivers.
- More partnership across communities pertaining to services for children and youth with special healthcare needs as well as improved partnerships between entities that serve children and youth with special healthcare needs.

Updated Priorities

DSCC staff worked through the needs assessment results throughout FY 2020 and used the information to help set priorities for Illinois children with special healthcare needs through the block grant. The two updated priorities are:

1. Strengthen transition planning and services for children and youth with special healthcare needs.
2. Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special healthcare needs.

Title V gave states additional time to work through their block grant submission due to the COVID-19 pandemic.

We are developing an action plan to achieve these priority goals and will report our progress along the way.



Our Outreach

Our community outreach focuses on both in-person events and our digital communication channels. We provided education and information to more than 260,000 people through outreach events, our website and social media during FY 2020.

DSCC staff presented at or participated in 72 outreach events throughout Illinois in FY 2020 before the COVID-19 shutdown. 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.

"We have learned so much, to the point where I don't know what I want to do first. It's been so informative, and we are well taken care of... I was free to just learn and not have to worry about how I was going to pay for it."

– Lily Dining, mother of a DSCC participant and 2019 Transition Conference attendee



Statewide Transition Conference

DSCC served on the steering committee to plan the 15th annual Illinois Statewide Transition Conference on Oct. 17-18, 2019, in Collinsville. The event targeted adolescents, parents, caretakers, vocational professionals, healthcare professionals, educators and others involved with improving outcomes for transition-age youth with special needs.

The conference highlights the opportunities and resources available for youth as they, their families and support teams plan and prepare for the future. We covered the conference-related expenses for 23 of our participant families across the state.

Parent Institute Lectures

The COVID-19 pandemic led us to cancel our 2020 Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing. The one-week program for parents of young children with a significant hearing loss typically takes place each June at the Illinois School for the Deaf in Jacksonville.

The Institute includes daily lectures by experts in the field on how to raise a child with hearing loss.

To help more families benefit from the Institute lectures, we made the presentations available online in early 2020. Videos on each topic are posted on the Illinois Sound Beginnings website.

Lecture topics include the Individuals with Disabilities in Education Act (IDEA), advocacy, communication options, assistive listening devices and more.

Parents and caregivers can watch each presentation at their own pace in the comfort of their own home.



Our Outreach

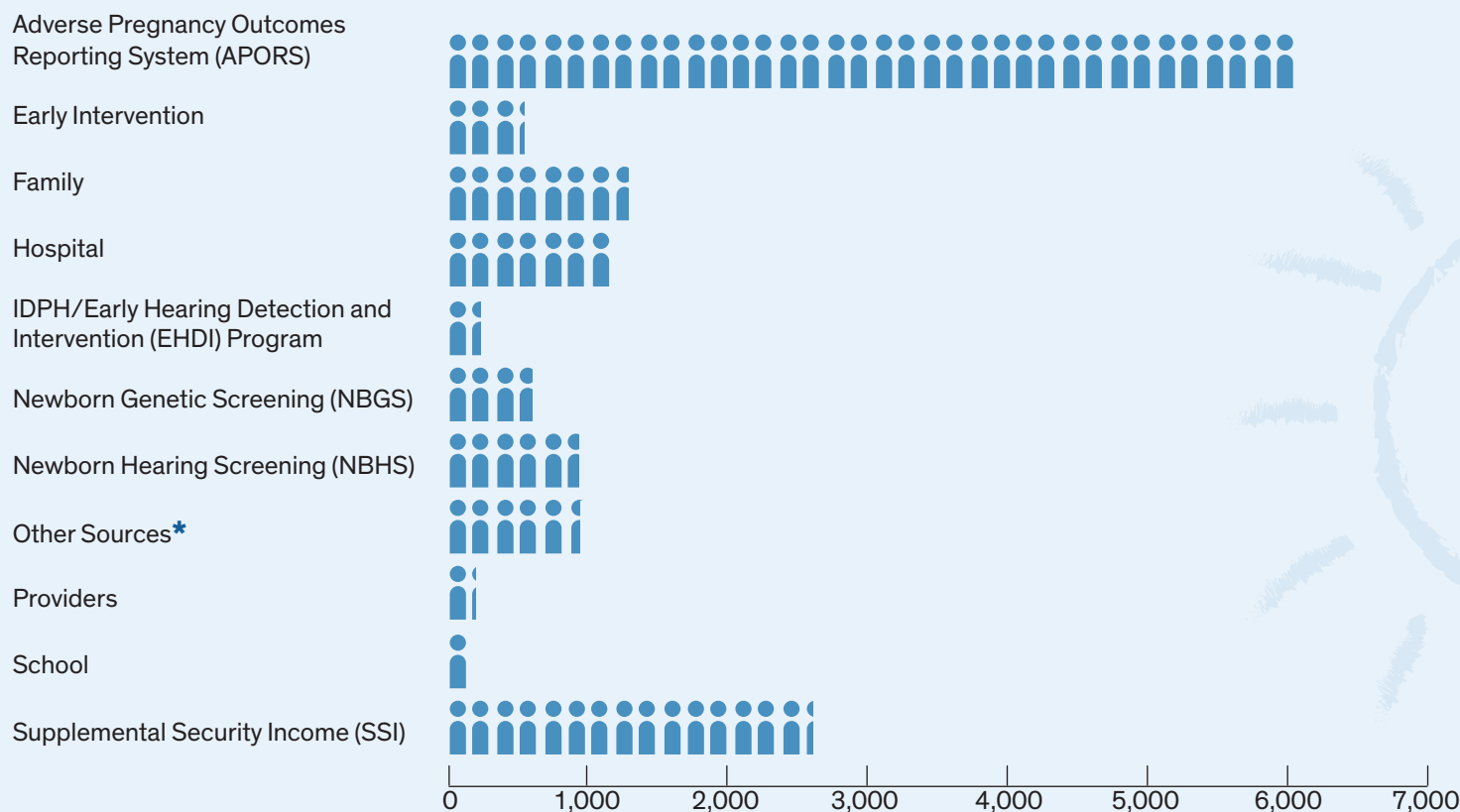
Referral Sources

DSCC partners with numerous state agencies, healthcare facilities, community organizations, schools and others to find children and families eligible for our programs.

Many of our regional staff routinely participate in rounds held by the specialty services in Illinois' children's hospitals and clinics. This is an important referral source and provides a regular opportunity for our staff to interact with families of children and youth with special healthcare needs. It's also a great opportunity for staff to meet with pediatric care providers as well as to inform them of community resources that may be able to help families, regardless of their eligibility for DSCC services.

Illinois Department of Public Health (IDPH) screening programs for metabolic diseases and hearing loss and the Adverse Pregnancy Outcomes Reporting System are also important referral sources for us. Here's a more detailed look at our top referral sources for FY 2020:

DSCC's Referral Sources for FY 2020



* Other sources include nursing agencies, social service agencies, Illinois Department of Children and Family Services (DCFS), rehabilitative services and DSCC outreach

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 and future employers about our services. Our internships also cultivate potential future employees and provide extra staffing to improve our level of assistance.

Our FY 2020 internship opportunities included University students from the School of Social Work. These interns worked in our regional offices across the state. Our Home Care Region 4 team later hired one of these interns to join our staff full-time.

Clinical Rotations and Experience

Our regional offices also provided valuable clinical experience for multiple nursing and social work students to complete their advanced degrees.

Our Chicago Core, Connect Care and Home Care teams served as a clinical rotation site for UIC undergraduate nursing students during their Community Health course.

DSCC is a clinical partner in Almost Home Kids' fellowship program for Advanced Practice Registered Nurses (APRNs) in the subspecialties of developmental behavioral pediatrics, mental health and complex care. Our Chicago Core and Home Care offices hosted four of these APRN scholars in January and February 2020.

During the fall 2019 semester, one of our Home Care Program Hospital Liaisons hosted two master's generalist students from UIC College of Nursing. Their project was to conduct a survey with Home Care and Core staff on their learning needs in the areas of hospital discharge, transitional care and respite.

The students attended an initial home visit with a Home Care Enrollment Specialist and observed the family's assessment. They toured all the respite/transitional facilities in Chicago and attended rounds at several Chicago-area hospitals.

The students learned about the medical, nursing, care coordination, and home and community needs of children who are medically fragile and technology dependent.

Based on their findings, our Home Care Hospital Liaisons developed a staff training module on care coordination activities related to hospital discharge, respite care and transitional facility care.

Our Chicago Home Care Hospital Liaison also meets with UIC College of Medicine Pediatrics residents each month during their development rotation. She explains DSCC's services, who is eligible and how to make a referral. These meetings were in-person until March 2020.

This liaison also serves as the co-chair of the Education Committee for the American Case Management Association, Illinois Chapter. In this role, she aims to bring educational content that reflects the populations we serve.

Our Chicago Home Care Hospital Liaison also partnered with a UIC College of Nursing faculty member to present at all five sites for the 2019 School Health Days Conference from the Illinois Department of Public Health. The presentation discussed the role of the school nurse and private duty nurses.



Our University Collaboration

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 FY 2020. 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.

UIC Disability and Human Development Department - Illinois Leadership Education in Neurodevelopmental and related Disabilities (IL LEND) Program

Youth with special healthcare needs must have better access to systemic support and resources.

Research also shows that youth want to be actively engaged in their health but do not always know how or where to start.

We are working to create a Youth Transition Council (YTC) to help our staff develop youth-focused solutions to these issues.

This council will incorporate the youth voice into the planning, design, implementation and evaluation of our transition services. It will also help DSCC better support youth in their transition to adulthood as they move to adult health care, work and independence.

Our staff partnered with IL Lend throughout FY 2020 to develop, record and report the established framework of DSCC’s Youth Transition Council in a formal guidebook. The guidebook gives an overview of the purpose and benefits of a YTC and how it should be designed and implemented. It also includes insights from interviews with leadership from other diverse youth councils across the country.

We will use this guidebook to implement the YTC as part of our strategic goals in the years ahead.



Our Funding

DSCC receives 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.

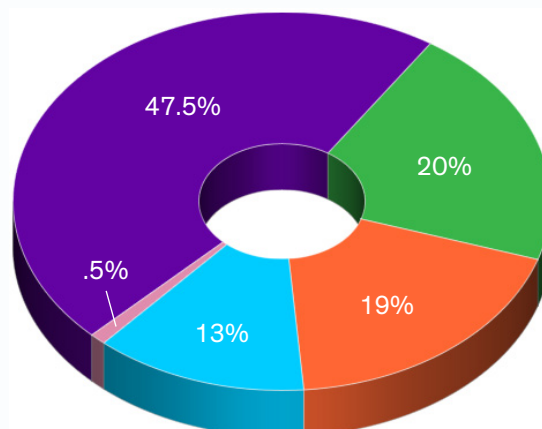
Since 1937, DSCC has managed Illinois' Title V program for children and youth with special healthcare needs. Block grant funds require a state match of \$3 for every \$4 of federal money spent. DSCC's state match is funded through the University of Illinois.

DSCC has entered into contracts for the provision of its care coordination services.

The contracts are with managed care organizations (MCOs), which participate in Illinois' Medicaid Managed Care Program.

Children who received services through the Core Program and were Medicaid-eligible were transitioned to managed care in February 2020. The result of this transition and DSCC's continued involvement created the Connect Care Program. DSCC is compensated by the MCOs for its work with Connect Care participants.

Sources of FY 2020 Spending



- State/University
- Healthcare & Family Services (HFS) Reimbursement
- Education Administration & Allowance
- Federal
- Connect Care





SPECIALIZED CARE FOR CHILDREN

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