

DIVISION OF SPECIALIZED CARE FOR CHILDREN



2017 FISCAL YEAR ANNUAL REPORT

UIC

PARTNER - HELP - CONNECT

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

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**SPECIALIZED CARE
FOR CHILDREN**



LETTER FROM THE EXECUTIVE DIRECTOR



Thomas Jerkovitz
Executive Director

Fiscal year 2017 marked a milestone for the University of Illinois at Chicago's Division of Specialized Care for Children (DSCC). We celebrated 80 years as the state's designated organization to serve children and youth with special healthcare needs. We are proud to be a leader in providing care coordination as part of our overall mission to partner, help and connect children and families to the proper services.

Care coordination is fundamental and a primary focus of our activities. It's a process that involves working with doctors, schools, community groups and others to develop a plan of care that addresses a child's medical, social, behavioral, educational and financial needs. Our care coordination can include explaining insurance benefits, helping families understand and follow their child's medical treatment plan, putting a family in touch with the right specialist for their child's condition and arranging transportation to the appointments. These activities are all focused on the individual child's and family's needs.

We updated our vision statement to reaffirm our focus on the child and family. We believe that children and youth with special healthcare needs should be at the center of a seamless support system that improves the quality of their lives. As you read through this report, you'll learn more about how we are working to achieve that vision and the progress we've made over the last fiscal year. DSCC also continues to fulfill the University's education mission by providing excellent internship and educational opportunities for students. In addition, we value our collaborations and partnerships with other University departments and systems to increase access to and improve the quality of health care and related services to families.

Thank you for your interest and support of DSCC.

Thomas F. Jerkovitz
Executive Director

OUR 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.



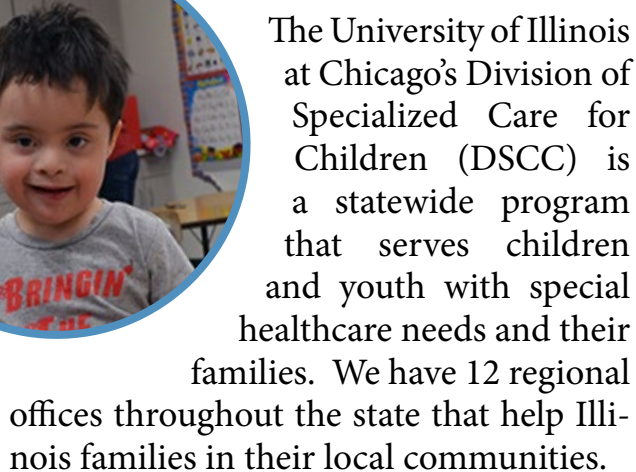
We *partner* with families, doctors, specialists, schools, community organizations, insurance companies and state agencies to help all of these supports work together in the best interest of the child and family.



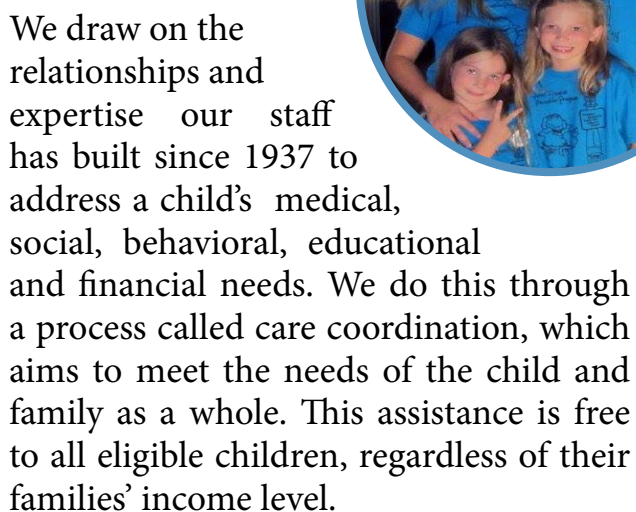
We *help* by using our knowledge of children with complex medical needs to evaluate each family's situation so we can identify gaps and plan solutions to meet their needs.



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.

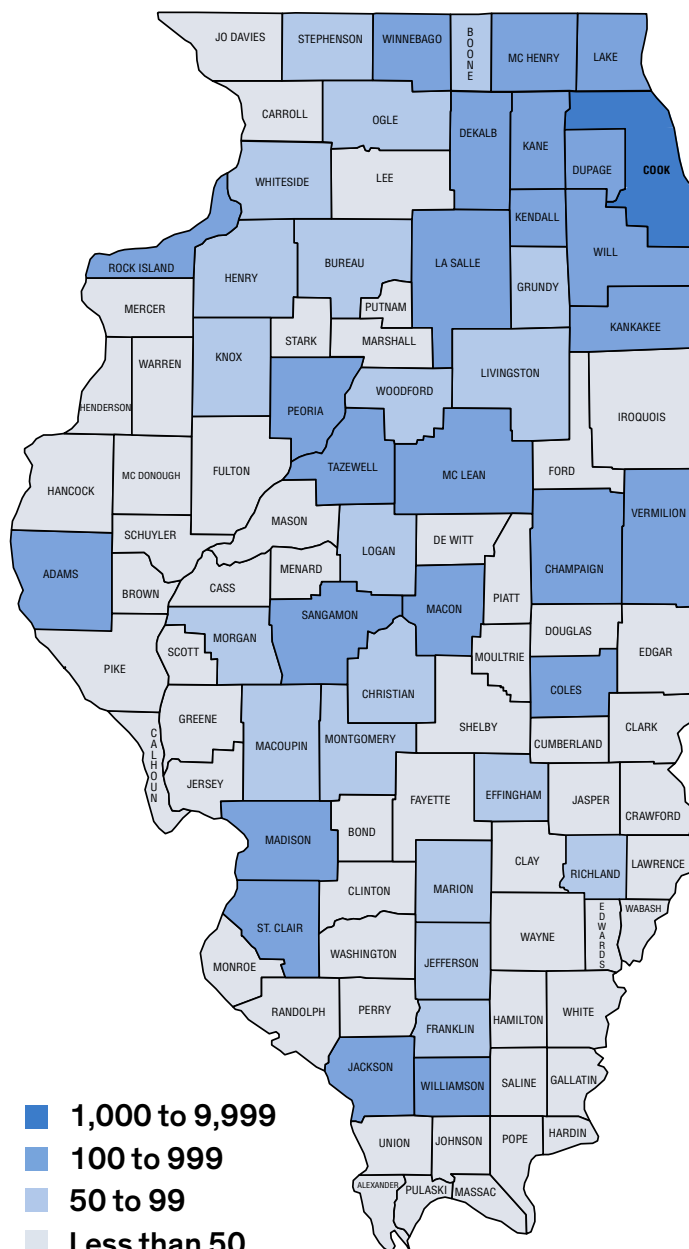


Our staff includes social workers, nurses, speech pathologists, audiologists and other team members who are trained to help families find the specialty care and resources they need for their child to reach their full potential.



In fiscal year 2017, we served more than 18,300 families throughout Illinois (see map).

FY 2017 Active Cases by County



***All cases by county that were actively enrolled or in intake between July 1, 2016, and June 30, 2017.**

PARTNER



One of our strategic goals is to strengthen our partnerships with families in care coordination services through regular contact between our staff and the parents/caretakers, joint decision-making with family members, more frequent use of family surveys and input from our Family Advisory Council (FAC). In fiscal year 2017, our family liaisons traveled across the state to meet with families and community members. They also reinvigorated the FAC. The FAC currently has 13 members. The group has helped with the development of the Maternal and Child Health Services Block Grant application, review of DSCC's marketing and outreach messaging and facilitated peer-to-peer support among DSCC families.



"I never realized how exhausted and depressed I was before the help of DSCC. Now I am able to not only take care of Fallon, but I'm able to take some time for myself and also my husband."

— Katie Schlautman,
mother of Fallon in the
Home Care Program &
Family Advisory Council Member

WHO WE ARE



DSCC's Referral Sources for FY 2017

Referral Source	Total
Adverse Pregnancy Outcomes Reporting System (APORS)	3,999
Supplemental Security Income (SSI)	2,288
Newborn Genetic Screening (NBGS)	726
Family	587
Early Intervention	524
Newborn Hearing Screening (NBHS)	520
Hospital	500
DSCC Staff	194
Illinois Department of Public Health	152
Providers	110
School	78
Website - DSCC	48
Other sources, including county health departments, Illinois Department of Children and Family Services, nursing agencies, rehabilitative services and outreach programs	208
TOTAL	9,934



OUR CARE COORDINATION

Our care coordination is free and tailored to each child and family's situation. It may include:

- Accessing diagnostic testing
- Finding specialized medical care
- Coordinating services among different providers
- Helping families maximize their insurance & understand their coverage/benefits
- Communicating with doctors, specialists & schools
- Assisting with transportation for appointments
- Connecting families for parent-to-parent support
- Paying for eligible medical expenses, such as equipment, therapies, supplies & medical services, when families meet income guidelines
- Attending educational meetings & working with schools to develop Individualized Education Programs (IEPs)
- Locating community funding opportunities & resources, such as food pantries, utility assistance, grants, etc.
- Preparing for the transition to adulthood

"(Our Care Coordinator) and others have gone to bat for us in dealing with the intricacies of all the bills that go along with taking care of (Abby)... Abby has a baclofen pump... and for a while (my wife) had to take her to Peoria every three or four weeks to get it refilled, and DSCC helped us with the mileage reimbursement with all of the trips. That was at a time when money was really tight in our house."

— Mike Burdick, father of Abby in the Home Care Program



— Care Coordinator Courtney Kerfoot with Payton Webb in the Home Care Program



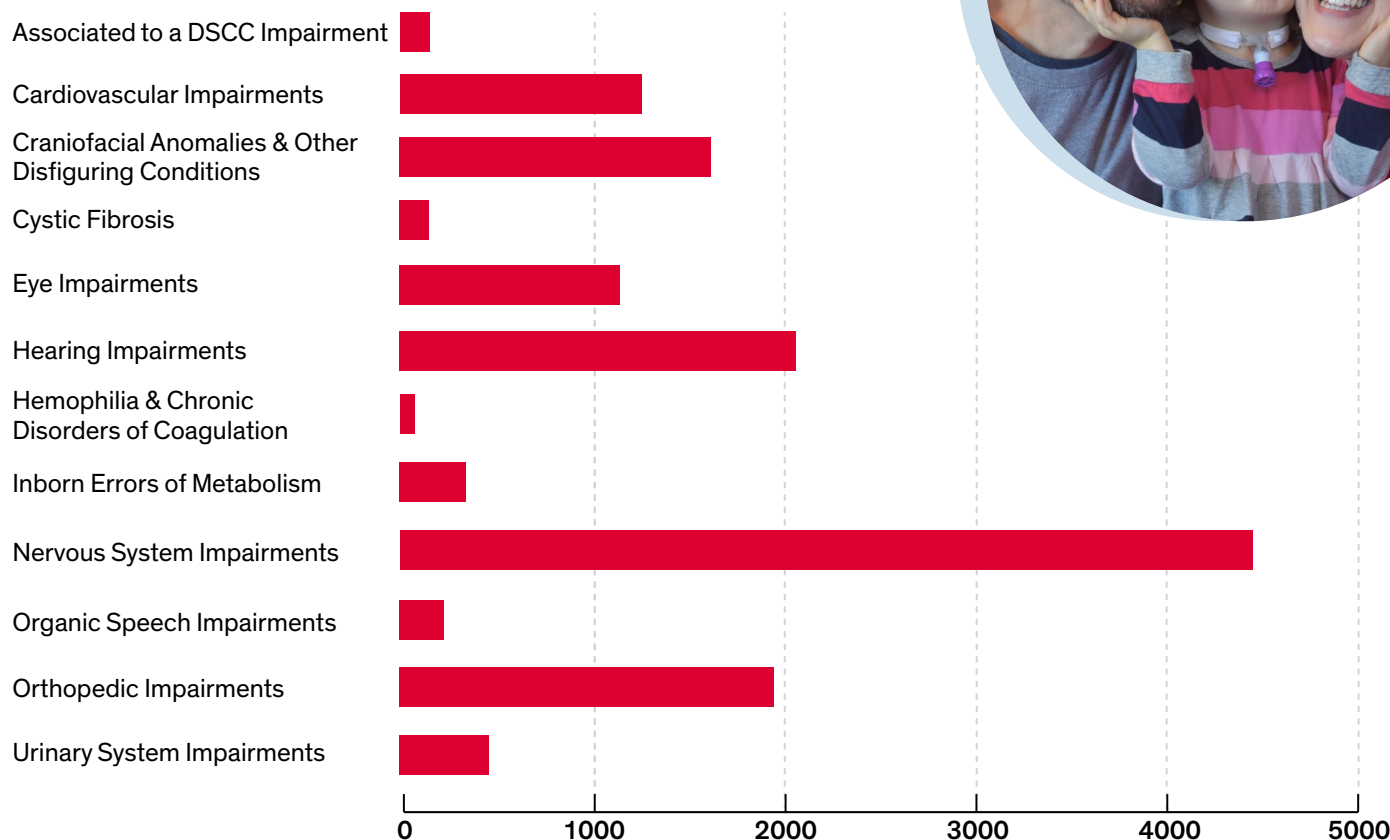
WHO WE SERVE

DSCC serves Illinois families with children up to age 21 who have or are suspected of having an eligible medical condition through our Core Program. The condition must be chronic, treatable and fall in one of our 11 eligible impairment categories. Eligible conditions include, but are not limited to:

- Cardiac impairments
- Cystic fibrosis
- Eye impairments (cataract, glaucoma, strabismus)
- External body impairments (cleft lip and palate, craniofacial anomalies)
- Hearing impairments
- Hemophilia
- Inborn errors of metabolism (phenylketonuria or PKU)
- Nervous system impairments (cerebral palsy, seizures, etc.)
- Orthopedic impairments
- Speech impairments (dysarthria, vocal cord paralysis)
- Urinary system impairment



Impairment Category for Active Core Cases in FY 2017



WHO WE SERVE

DSCC also 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. The program makes it possible for infants, children and young adults to stay in their own home with the help of DSCC.

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.

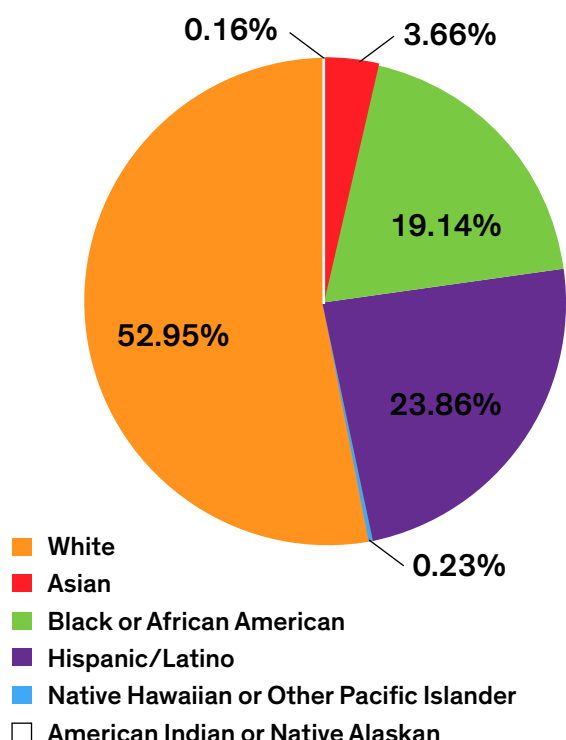
Children eligible for the waiver must meet medical criteria determined by their health condition and technology needs and be less than 21 years of age. Youth may qualify regardless of their family's income.

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



WHO WE SERVE

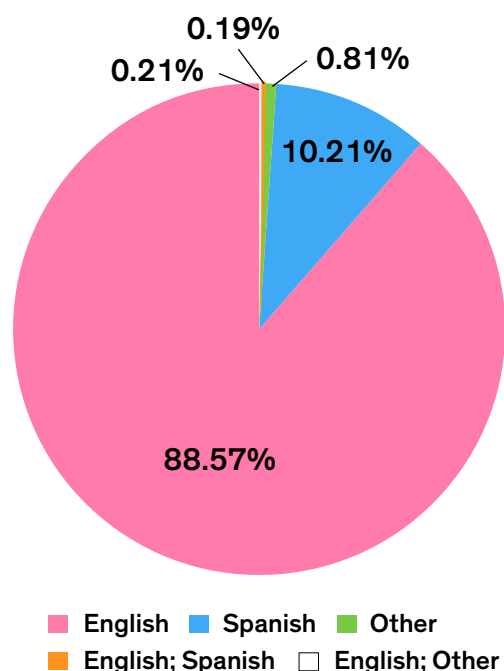
Known Ethnicity of Active Participants in FY 2017



enrolled in the waiver program 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.

Preferred Language of Active Participants in FY 2017



Age of FY 2017 Active Participants

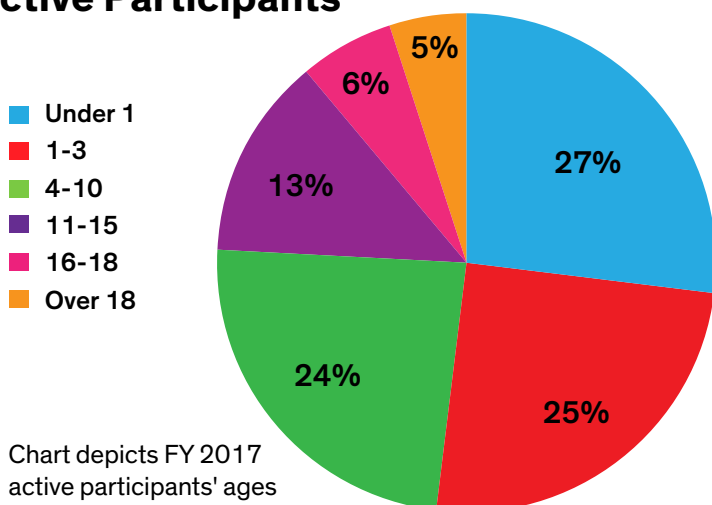


Chart depicts FY 2017 active participants' ages as of June 30, 2017.

HELP



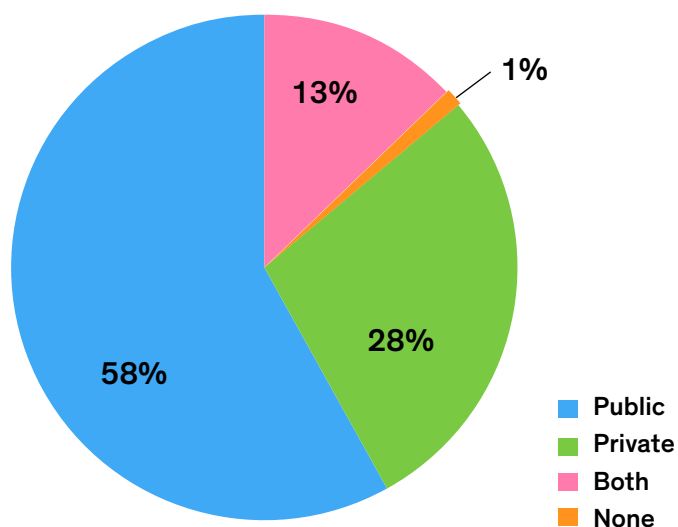
One of DSCC's major strategic goals is to update our eligibility categories. This change will streamline and simplify our eligibility requirements so we can provide care coordination services in a timelier manner. We will also be able to serve more children with special healthcare needs, within the parameters of our funding from the federal Maternal and Child Health Services Block Grant. The DSCC Medical Advisory Board was instrumental in developing the proposed rules. We are hopeful these rules will be approved through the process required by the Joint Committee on Administrative Rules and implemented in 2018.



WHO WE SERVE



Insurance Type for FY 2017 Core and Home Care Participants



OUR IMPACT



“DSCC gave us the confidence to bring Radhika home... Staying at home is the most important part. It made us a family again... The challenges are still there, but you feel like you are a family.”

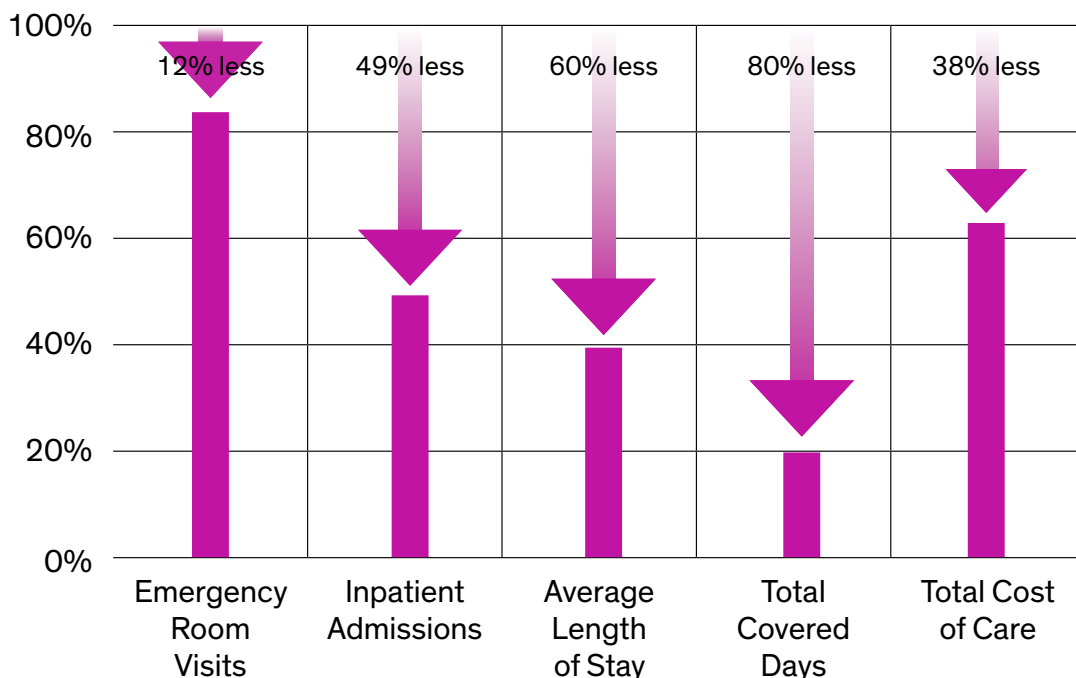
— Saurabh Agarwal, father of Radhika in the Home Care program

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.

We compared a group of 297 Core children 12 months prior to enrolling and looked at key metrics for both 12 and 24 months after enrollment. We identified improvements in:



OUR IMPACT

CONNECT



As part of our efforts to connect families to much-needed services and resources, DSCC staff presented at or participated in 90 events across the state in FY 2017. These events included local health fairs, special needs conferences, workshops and functions for physicians and healthcare professionals. DSCC staff also participated in parent support groups and other community agency meetings to develop relationships and build their network of resources and referrals.



“(DSCC has) been an emotional shoulder to lean on... They’ve helped connect us to various grants for funding and have taken pressure off of myself and my husband when it comes to contacting medical facilities and practitioners regarding services and approvals and payments.”

— Jessica Lance, mother of twin boys in the Core Program



“We’ve been working with DSCC (since her son Alex’s diagnosis with cystic fibrosis) and have had a very positive experience. We have typically qualified for copay assistance and over the years, that has been a huge help with prescriptions as Alex takes several medications and even the copays become rather costly.”

— Andrea Killian, mother of Alex in the Core Program

OUR FUNDING

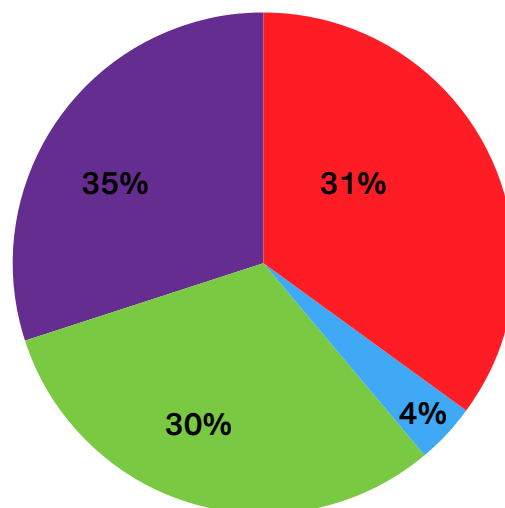
DSCC is funded through a combination of state and federal revenue sources.

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.

Source of FY 2017 Spending



- Educational Administration & Allowance
- State/University
- Federal
- Healthcare and Family Services Reimbursement (Federal and State)

Chart depicts operational and administrative program costs. It does not reflect spending on direct services.



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 2017, DSCC hosted eight University student interns in our offices across the state. These interns included five master's degree candidates and one completing her bachelor's degree from the School of Social Work. These six interns worked in the Core or Home Care programs. Additionally, Home Care hosted one master's candidate from the College of Nursing. DSCC's Information Technology Department also employed an intern from the Graduate Public Service Internship Program at the University of Illinois Springfield.



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 all facets of their child’s care are 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 2017. 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 2017 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.

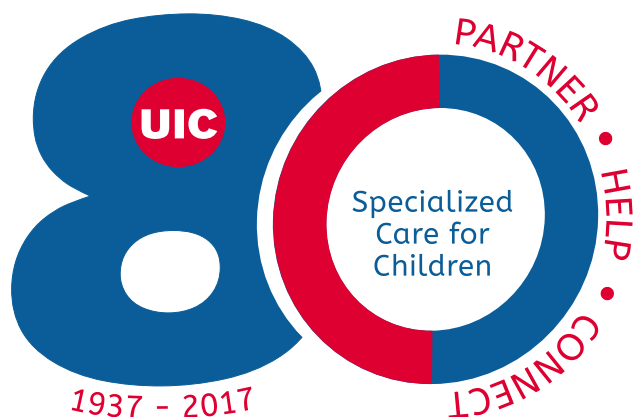
University of Illinois Administration

Administrative Information Technology Services

DSCC partners with families to help their children with special healthcare needs connect to services and resources. A part of this partnership includes securely and confidentially gathering information about our families so we can identify their needs and effectively develop a plan to meet them.

In FY 2017, DSCC worked with the Administrative Information Technology Services (AITS) office in the University of Illinois System to combine information gathered from our care coordination and our claims system and use this data to provide better outcomes for children and their families. We can now easily compare and link our care coordination activities to other services that DSCC provides to families. The project also allows us to create trending reports to see how things change over time and ultimately measure our effectiveness.

CELEBRATING 80 YEARS



In 1935, Title V of the Social Security Act enabled states to "extend and improve services for crippled children."

Two years later, Illinois Governor Henry Horner issued an executive order to create the Division of Physically Handicapped Children in the Department of Public Welfare to receive federal funds and administer services to the state's children with special needs as part of Title V of the Social Security Act.

In 1941, the division was transferred to the University of Illinois and underwent a name change the following year. By the division's 10th anniversary in 1947, more than 50,000 children had been registered and helped.

In 1991, the division's name was officially changed to the Division of Specialized Care for Children (DSCC). Through 80 years of growth and change, DSCC has remained Illinois' Title V program for children and youth with special healthcare needs.

