



2016  
FISCAL YEAR  
ANNUAL REPORT

**Partner • Help • Connect**

# *Executive Director's Greeting*



*Thomas F. Jerkovitz*

February 2017

The University of Illinois at Chicago's Division of Specialized Care for Children (DSCC) has provided vital support to families of children with special healthcare needs for nearly 80 years. We are continually evolving to partner with healthcare systems and searching for new ways to strengthen our relationship with families and communities to improve the lives of these children and those who care for them. I am pleased to introduce DSCC's first Annual Report to provide an overview of our efforts.

The Maternal and Child Health Services Block Grant, Title V of the Social Security Act, requires each state to have a program to serve Children and Youth with Special Healthcare Needs (CYSHCN). DSCC is the designated organization to serve CYSHCN in Illinois and has been since 1937. This relationship has transformed countless lives through:

- The Core Program to coordinate care for families of children with special healthcare needs.
- The Home Care Program to help families care for their loved ones who are medically fragile and require skilled nursing care at home.
- Outreach activities to develop partnerships in local communities and build our network of resources for families.
- Internships and other educational opportunities for University students to gain practical experience before graduation.

With 12 regional offices ranging from Rockford to Marion, DSCC assists children and families throughout the state. In fiscal year 2016, our staff provided care coordination and/or resources and information to more than 18,000 families.

The following pages will illustrate what this assistance looks like and the incredible effect it has on our families. They also showcase how our internships and special projects are helping shape the next generation of social workers and other professionals. And finally, we are excited to highlight our collaborations with University departments and systems to increase access to and improve the quality of health care and related services to families.

It's been an exciting year, and I thank you for your interest in DSCC.

Thomas F. Jerkovitz  
Executive Director

**We're Here  
to Help.**



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# OUR MISSION

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

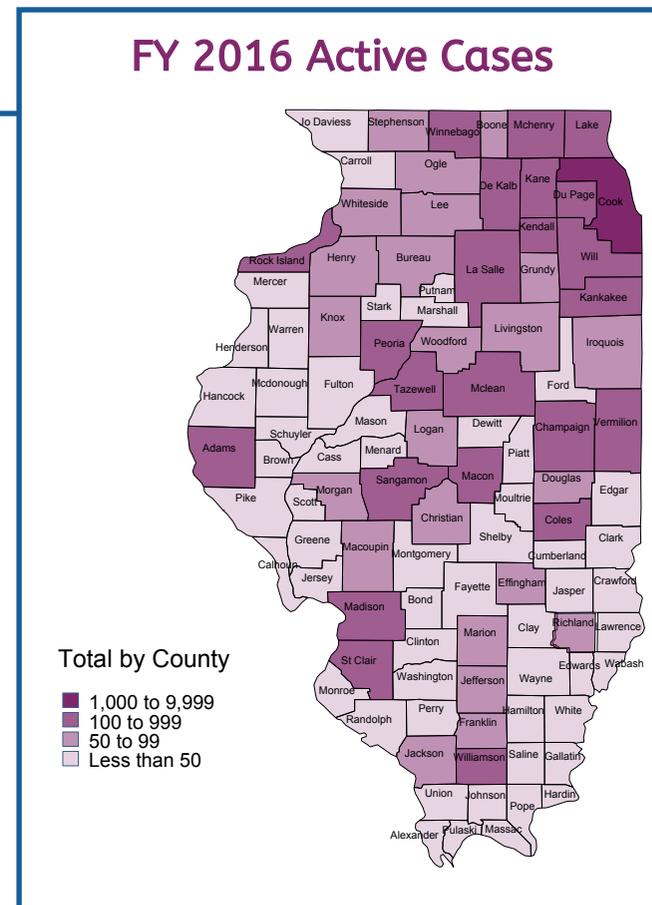


The birth of a child with special needs is one of the most challenging circumstances a family could ever face. Each diagnosis prompts its own flurry of questions and anxieties for parents. There's a flood of information and paperwork they must try to make sense of and absorb. Further, the healthcare system can often be fragmented, with families juggling visits among multiple providers. Families can easily feel overwhelmed, isolated and as if they are scrambling for help. The University of Illinois at Chicago's Division of Specialized Care for Children (DSCC) exists to give these families a consistent helping hand to guide and support them through their child's journey.

We help ensure children with special healthcare needs receive care that is family-centered, community-based and culturally competent. By partnering with families and communities, we put these children and their loved ones in contact with the services and resources they need to reach their full potential.

DSCC serves families with children and youth, from birth to age 21, who have eligible medical conditions. Families who care for youth and adults who are medically fragile, dependent on technology for their wellbeing and require in-home nursing receive support through the Home Care Program.

In fiscal year 2016, we served more than 18,000 families across Illinois (see Figure 1).



(Figure 1)

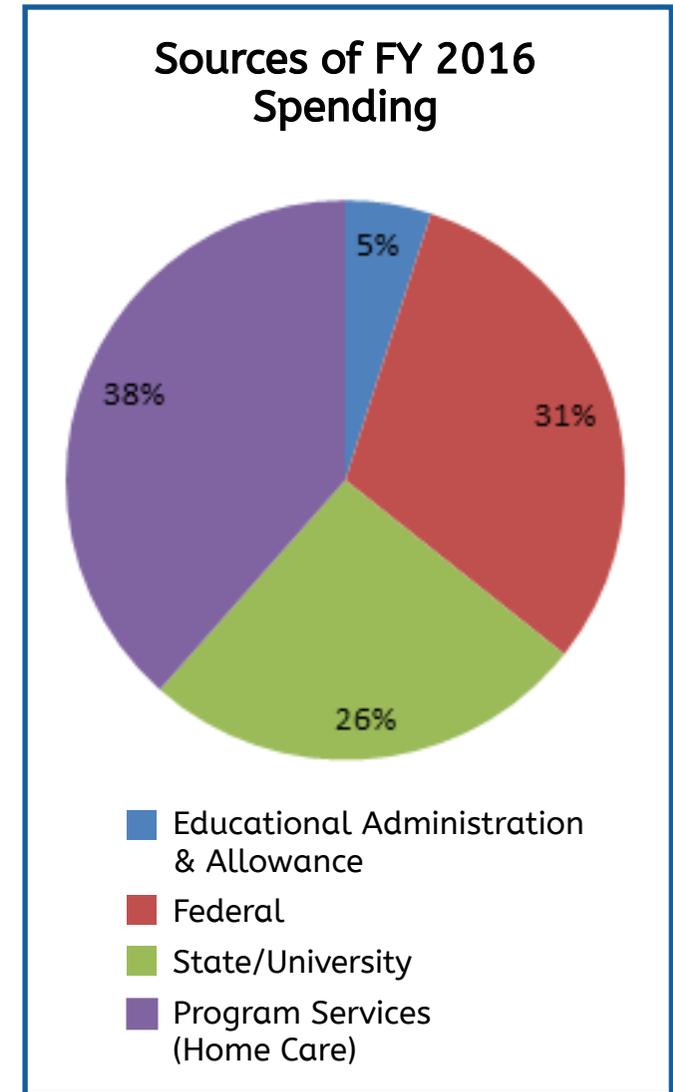
## *The Federal and State Partnership to Support Children and Youth with Special Healthcare Needs*

**D**SCC is funded through a combination of state and federal revenue sources (see Figure 2).

The Maternal and Child Health Services Block Grant, authorized by Title V of the Social Security Act, is a federal program devoted to improving the health of all women, children and families. It funds Title V programs in all 50 states and requires that at least 30 percent of these funds 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.



(Figure 2)

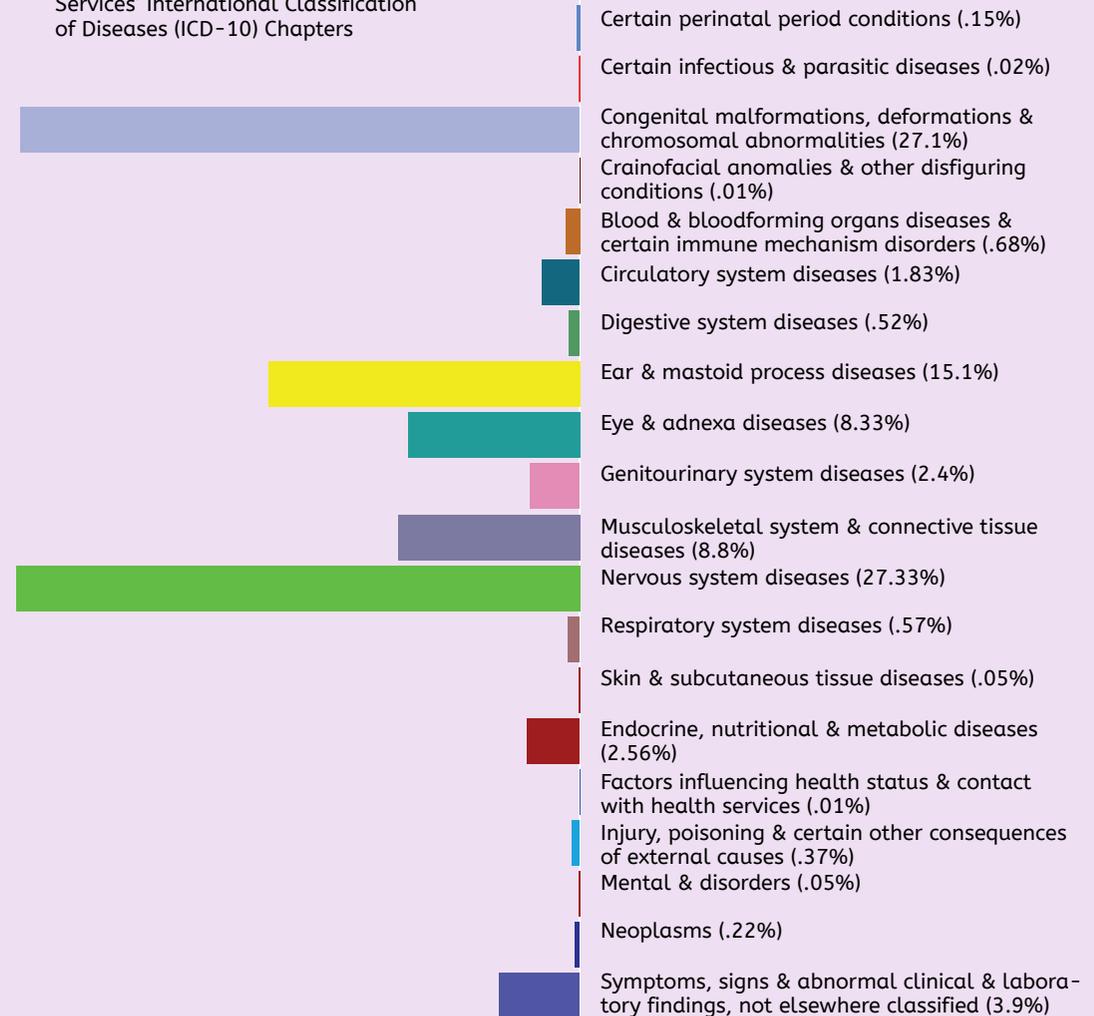
# CORE PROGRAM

Through our Core Program, we help organize care and services for Illinois families with children who have a treatable, chronic condition in one of **11 eligible impairment categories**. However, many of our children have multiple diagnoses (see Figure 3), and we try to help families meet all of their medical, health, educational and social needs. Core Program participants range in age from newborn to 21. Our staff includes nurses, social workers, audiologists, speech-language pathologists and other healthcare professionals in **regional offices** across the state who work directly with families in their geographic area.

Care coordination is free and tailored to each child and family’s situation to ensure all providers, services and resources are working together to promote the child’s health, happiness and long-term success. Care coordination looks different for each family, from accompanying mom or dad on a doctor’s visit, to helping parents understand and fully utilize their insurance coverage, to putting families in touch with a food pantry during difficult times. Our care coordinators are experts on the type of medical care, resources and social services available in the region they serve. With this expertise, they can develop a plan of care for each child, communicate with doctors and specialists, find specialized medical care, provide

## Diagnosis Category\* for Active Core Cases in FY 2016

\*Centers for Medicare and Medicaid Services’ International Classification of Diseases (ICD-10) Chapters



(Figure 3)

# CORE PROGRAM

# PARTNER

access to diagnostic testing and help families prepare for their child's transition to adulthood. Our care coordinators also work closely with schools regarding appropriate accommodations. We also provide financial assistance for families who meet certain income guidelines. This assistance covers specialty medical expenses – such as wheelchair ramps, lifts, orthotics, hearing aids, travel costs and insurance co-pays.

For nearly 80 years, our organization has built relationships with doctors and providers for children with special healthcare needs. These relationships help ensure families have access to specialists and experts in specific health issues who are available and accessible. We

## National Standards for Systems of Care for Children and Youth with Special Healthcare Needs

1. Screening, Assessment and Referral
2. Eligibility and Enrollment
3. Access to Care
4. Medical Home, including:
  - Pediatric Preventive and Primary Care
  - Care Coordination
  - Pediatric Specialty Care
5. Community-Based Services and Supports, including:
  - Respite Care
  - Palliative and Hospice Care
  - Home-Based Services
6. Family Professional Partnerships
7. Transition to Adulthood
8. Health Information Technology
9. Quality Assurance and Improvement
10. Insurance and Financing

(Figure 4)

have a **Medical Advisory Board** made up of a diverse group of healthcare professionals who regularly meet to discuss how DSCC can enhance our care coordination services. As part of the University, we also have unique access to resources, research and partnerships that help children with special health care needs thrive and support their families in the process.

We partner with major public and private agencies across the state to promote the 10 National Standards for Systems of Care for Children and Youth with Special Healthcare Needs (see Figure 4). DSCC places emphasis on three of these standards: medical home, transition and family involvement. Medical home is an approach to pediatric care that focuses on the family-physician partnership. The transition to adulthood ensures youth with special healthcare needs receive the services necessary to become as healthy, independent and successful as possible as adults. Our **Family Advisory Council** is vital to our success in responding to the needs of the families we serve.

# CORE PROGRAM

**O**ur care coordination staff is trained to help families make the most of their health insurance. We help families navigate the benefits available through the Affordable Care Act and, if applicable, help them enroll in All Kids, Medicaid or Get Covered Illinois. We also help financially eligible families with the cost of their private insurance co-pays and deductibles for specialty care and for certain services that are not covered by private or public insurance.

In addition, we promote and facilitate planning for youth to make the transition to adult services and resources. DSCC co-sponsors the annual Illinois Statewide Transition Conference, which draws approximately 500 participants. Our care coordination staff is trained on how to address transition issues and frequently make presentations and contact providers to help them better prepare families for issues and needs that arise as their children become adults.

We continue to collaborate with state agencies to promote medical home practices among providers. Our care coordinators, in turn, encourage the medical home partnership between families and providers and assist with locating resources in the community. We have published a newsletter explaining what makes a good medical home and hosted a webinar on family-professional partnerships. Further, we will continue to develop and promote materials that describe how a medical home benefits both families and providers.

HEEP



## Core Eligible Conditions

Children with eligible chronic health issues are enrolled in the Core Program.

These conditions are:

- ▶ 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 [PKU])
- ▶ Nervous System Impairments (Seizures, Nerve, Brain, Spinal Cord)
- ▶ Orthopedic Impairments
- ▶ Speech Impairments (Dysarthria, Vocal Cord Paralysis)
- ▶ Urinary System Impairments

# CORE PROGRAM

CONNECT

**M**ikey Lewinski is an outgoing 10-year-old who loves to play with his fifth-grade classmates. His mother, Michelle, credits DSCC with helping Mikey receive the orthotics and equipment he needs to keep up with his friends and stay active and happy.

When Michelle was 20 weeks pregnant, Mikey was diagnosed with spina bifida – a birth defect that caused an opening in his backbone and prevented his spinal cord from developing properly – and hydrocephalus, a buildup of cerebrospinal fluid inside the brain. Mikey required surgery immediately after birth to close his backbone. Less than two weeks later, he received a shunt to drain the excess fluid from his brain. His first year was subsequently filled with numerous doctor visits, a shunt revision surgery, and the start of physical and occupational therapy to strengthen his muscles.

Mikey is able to use his legs, but requires the use of orthotics and crutches to walk. Michelle said DSCC covered the cost of Mikey’s first set of orthotics at age 1 and has been a huge help to her family ever since.

“Our insurance does not cover a lot for Mikey - they don’t cover his catheters, they don’t cover his orthotics, and those are big things that could run thousands of dollars. To have DSCC be able to cover those costs for us has been a huge lifesaver,” Michelle said. “Our care coordinator, Sarah, is amazing. She is one of the easiest people I have ever worked with. She follows up with me on how Mikey is doing, how Mikey’s appointments are going and if there is anything we need.”

Sarah was also able to fix communication problems that arose when the Lewinskis recently moved to a new clinic for Mikey’s care.

“She took the reins and was the middleman, making the phone calls and getting stuff done,” Michelle said. “If I have a question about anything, I know that I can call her or just send her a quick email and she will answer my question as soon as she can. It absolutely makes a difference.”



# HOME CARE PROGRAM

PARTNER

The [Home Care Program](#) supports families who care for loved ones who are medically fragile and require skilled in-home nursing care. The program makes it possible for infants, children and young adults to stay in their own home with the help of our care coordinators. Care coordinators begin working with a family when their child is preparing to leave the hospital for the first time, and are there every step of the way to ensure they have the services and supports necessary to keep their child healthy and safe.

The Home Care Program provides care coordination services through a partnership between DSCC and the [Illinois Department of Healthcare and Family Services \(HFS\)](#). HFS has designated DSCC as the single point of entry for all Medicaid-funded, in-home shift nursing services and the single entity that provides care coordination for these services. The relationship with DSCC and HFS began in the mid-1980s when HFS chose DSCC as the operating entity for the Medicaid Title XIX Home and Community-Based Services Waiver for Children who are Medically Fragile, Technology Dependent. Such technology includes ventilators, tracheotomies and gastrostomy tubes.

The Home Care Program has grown over the last three decades and has expanded beyond the waiver program. Currently, Home Care serves two additional populations. These populations both require in-home shift nursing but have slightly different eligibility criteria. The first expansion occurred in January 2014 when DSCC became the single point of entry for all individuals under age 21 who require in-home shift nursing services. The second expansion took place in September 2014 when DSCC began providing Home Care services to adults over age 21 as a result of the [Hampe versus Hamos consent decree](#). The consent decree gives individuals who turn 21 (while enrolled in the waiver program) the choice to stay with the program instead of “aging out.” The consent decree also allows anyone who previously aged out of the waiver to return to the Home Care Program for services.



# HOME CARE PROGRAM

HELP

**T**he Home Care Program offers care coordination and connection to service providers, such as nursing agencies, durable medical equipment suppliers and other support services that are needed to safely care for children at home. It also aims to help family members stay as active in their loved ones' care as possible and develop a long-term care plan using community resources and services. Sometimes this help is in the form of holding a hand, attending a doctor's appointment or simply being a sounding board when life gets difficult.

As part of the Medicaid program, hospitalizations, doctor visits, medications and other care expenses may be covered by Medicaid after private health insurance has been applied to the cost. Individuals enrolled in the home and community-based services waiver program and Hampe class members may receive additional services through the Medicaid waiver program, including:

- ▶ Respite nursing care in the child's home or a designated community setting to periodically relieve the family of caregiving responsibilities.
- ▶ Family training on the child's treatment and equipment needs.
- ▶ Nurse training specific for the child's needs or to use new and unique equipment.
- ▶ Medical equipment and supplies ordered by the child's doctor and not covered by the Medicaid State Plan.
- ▶ Minor home modifications needed to provide access, accommodate medical equipment or secure the child's safe access and safety in the home.
- ▶ Vehicle modifications needed for the child to access care and community services.
- ▶ Extermination services needed to maintain a safe home environment.
- ▶ Assistance with electrical reimbursement for ventilator-dependent children.
- ▶ Short-term, issue-specific family or individual counseling.

These services are important as these individuals are at risk for institutionalization and may require these unique services to remain in the family home.

# HOME CARE PROGRAM

CONNECT

**K**imberly “Kimmy” Alvarez spent her first 23 months of life in a hospital. The toddler was born with congenital scoliosis so severe that it deformed her spine, chest and ribs and prevented her left lung from developing. Kimmy could not breathe on her own and her ribs threatened to crush her lungs.

Kimmy eventually underwent lifesaving surgery to receive a vertical expandable prosthetic titanium rib (VEPTR). The VEPTR device helps straighten Kimmy’s spine and separates her ribs so her lungs can grow. The VEPTR must be expanded regularly until Kimmy stops growing.

After the VEPTR was placed, Kimmy had to undergo a successful expansion surgery before doctors gave the OK for her to go home. It was welcome news, but also nerve-wracking to plan for Kimmy’s arrival and care at home, her mother, Mayra Pasillas, recalled.

“We were just lost. We had no clue. We just wanted to get her home, but we didn’t know what it was going to take to get her home safely,” Mayra said.

That’s when their DSCC care coordinator, Margaret, stepped in and began working with Kimmy’s family and doctors to prepare for Kimmy’s homecoming and help it go smoothly. She also worked with charities to help cover the cost of travel expenses for her arrival home and for subsequent surgeries.



*“If we didn’t have DSCC, I don’t know who would’ve helped us.”*

“She helped us out so much and would call every day,” Mayra said. “If we didn’t have DSCC, I don’t know who would’ve helped us.”

Later, when Kimmy’s family moved into a renovated older home, Margaret brought in an electrician to replace the power box and install new outlets to support Kimmy’s breathing machines. The house also had issues with ants and spiders, so Margaret set up regular exterminator visits. DSCC ensured all costs were covered under the Medicaid waiver program for children who are medically fragile and technology dependent.

Kimmy is now 3 ½ years old and thriving beyond her family’s highest hopes. Mayra says she’s seen a huge difference in her daughter’s progress and happiness since she has been home.

“She’s now standing, walking around and running, and she goes to school and is learning all of her little friends’ names,” Mayra said. “We all feel like she has her life back.”



# OUTREACH

As part of our efforts to connect families to much-needed services and resources, DSCC staff presented at or participated in 102 events across the state in FY 2016. These events included local health fairs, special needs conferences and functions for physicians and healthcare professionals and reached more than 6,800 people. Our staff also participated in parent support groups and other community agency meetings to develop relationships and build their network of resources and referrals. A few highlights include:

## Illinois Statewide Transition Conference



One of the major ways we help families is to prepare special needs children and their families for the many changes that occur during the transition to adulthood. DSCC was on the steering committee for the 11th annual Illinois Statewide Transition Conference in Chicago in late October 2015. The event is aimed at high school-aged students and young adults with disabilities and their family members, educators, vocational professionals, caregivers, healthcare professionals and community advocates. Our Statewide Transition Coordinator and Lombard Regional Office staff led a presentation on building skills to reach transition milestones in the areas of education, employment, health, living and social interactions.

## Dia del Niño

Bilingual staff from our Chicago Core and Home Care offices participated in the annual Dia del Niño Health Walk and Family Festival celebration on the UIC campus in April. We set up a coloring station, which was a huge hit with children as our staff spoke to their parents about how DSCC can help them find healthcare providers and local resources, understand insurance benefits, work with schools and create a plan to help their children transition into adulthood.



## T.O.U.C.H. Picnic

In September 2015, Peoria Regional Office staff attended their fourth annual T.O.U.C.H. (The Organization for Understanding Children's Hearts) Picnic at the Wildlife Prairie State Park near Peoria. T.O.U.C.H. is a parent support group for families of children that are diagnosed with congenital heart disease. It is affiliated with the Congenital Heart Center at the Children's Hospital of Illinois. Roughly 1,000 families and healthcare professionals attended this event, which provided a great opportunity for our care coordinators to socialize with current and potential Core Program families in a relaxed setting.

**T**hrough 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 2016, DSCC hosted 12 University student interns in our offices across the state. These interns included seven master’s degree candidates and three who are completing their bachelor’s degree from the School of Social Work. All 10 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 its fourth intern from the Graduate Public Service Internship Program at the University of Illinois Springfield.



**Melissa Croft, Intern**

“This internship has allowed me to utilize and hone my social work skills across a wide array of platforms – completing home visits and assessments, problem-solving with families and providers, working with multi-disciplinary teams, etc.”

Master of Social Work  
Home Care Program Region 3

One social work master’s candidate studied the Home Care Program to create a proposal to balance staff caseloads. Her research led to a proposed work study plan to evaluate various staff activities to find the relationship between their family caseload and workload and help us assign an intensity factor to cases. We’re now considering using this workload measurement tool to improve our business model and how caseloads are assigned.

# EDUCATION

DSCC also participates in the Human Development and Family Studies Program at the University of Illinois at Urbana-Champaign. This program prepares students for a variety of careers in human services, early childhood education and public service or advanced study in individual and family development. This supervised learning opportunity gives students experience working at DSCC that corresponds with their career interests to use and develop their skills in a professional setting.

The Division also recently became a partner in the University's new "Social Work HEALS: Social Work Healthcare Education and Leadership Scholars Program." This grant-funded, national scholarship and leadership program seeks to develop the next generation of healthcare social work leaders to improve quality and equitable access to healthcare in the United States.



**Dana Ulrich, Intern**

"My experience with the Core and Home Care programs has allowed me to apply and improve the skills I gained in the classroom, while also learning new aspects of the social work and medical field courtesy of the experienced supervisors and staff members."

Master of Social Work  
Rockford Regional Office



**Daquila Tate, Intern**

"Every person that works here at DSCC has inspired me to push myself beyond my limits. They have all shared their knowledge with me, and I enjoy being a part of a working environment in which people thoroughly enjoy making a difference in families' lives. I have gained so many essential skills that I will definitely utilize in my future practice as a social worker."

Master of Social Work  
Chicago Regional Office

# EDUCATION

## *StatCom Partnership*

Through the University of Illinois Community Learning Lab, DSCC has worked with the Department of Statistics' "Statistics in the Community" (StatCom) group. StatCom allows graduate students to apply their analytic skills to pro bono projects and gain practical experience. We asked StatCom to analyze the Home Care Program's Social Risk Assessment tool, which aims to identify any social factors that could affect the intensity of care coordination that a family needs.

The goal of the study was to evaluate the tool's validity, determine if assessment questions should be weighted differently, and determine if the tool could be used to balance caseloads. Students analyzed de-identified data, including Social Risk Assessment responses, demographics, number and types of contacts with and on behalf of the family, number of trained caregivers, number and type of incident reports, type of insurance and level of care and technology needs.

The analysis sought to find whether the Social Risk Assessment score of low, medium or high accurately predicted the level of intervention a case would require. StatCom's investigation resulted in five recommendations to improve predictive model accuracy. DSCC plans to partner with the School of Social Work to look at incorporating these recommendations into the Social Risk Assessment.



# COLLABORATION

DSCC is proud to be a part of the University of Illinois at Chicago. We are continually exploring opportunities to partner with UIC and the University system as a whole to build healthier communities and improve the quality of medical care, resources and training available in Illinois.



## 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 2016. 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. We recently amended our agreement with the College of Medicine to provide an additional \$200,000 in FY 2016 to pay for a neuropsychologist position. This position will assess 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 will help patients avoid long waits and is crucial to early detection and preventing subsequent cognitive issues.

# COLLABORATION

## University of Illinois at Chicago

### *CHECK Program*

[Coordination of Healthcare for Complex Kids \(CHECK\)](#) is a program operating within the UIC Department of Pediatrics under a grant awarded by the Centers for Medicare and Medicaid Services Health Care Innovation Awards. The program serves patients from birth to age 25 who live in Cook County and are enrolled in a Medicaid Managed Care Organization. The program specifically works with asthma, sickle cell disease, diabetes and prematurity conditions. It provides care coordination services similar to DSCC, but with different eligibility requirements and service models.

In April 2016, our administrative staff began meeting with CHECK leadership to discuss how our programs could collaborate. We set up a referral pipeline between the two programs to make sure patients receive the best care coordination possible for their needs.



## University of Illinois Administration

### *Administrative Information Technology Services*

DSCC has reached out to Administrative Information Technology Services to help us develop a data warehouse to merge information from our electronic care coordination system and our claims systems. Such combined data will help us better determine:

- Who are we serving?
- How do we get new participants?
- Who is leaving our program?
- What healthcare issues do our participants have?
- What level of support are we providing?

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