Fiscal Year 2022

# ANNUAL REPORT

UNIVERSITY OF
ILLINOIS CHICAGO

**Division of Specialized Care for Children**

# Executive Director Greeting

The University of Illinois Chicago's Division of Specialized Care for Children (DSCC) is a leader in providing care coordination to children and youth with special healthcare needs. Throughout fiscal year 2022, we prepared for continued program growth and support for families in a post-pandemic world.

We planned for the expansion of our Connect Care Program to serve more families in 2023. This program serves children and youth with special healthcare needs enrolled in a Medicaid managed care plan. We also began to operate the Interim Relief Program for children with eligible mental health or behavioral disorders on behalf of the Department of Healthcare and Family Services (HFS).

Our team continued to operate the Home Care Program for HFS and remained the single point of entry for all Illinois youth under age 21 who need in-home nursing. We worked with our state and federal partners to improve in-home nursing options for families and strengthen the systems that support them. These initiatives included changing the license process for nursing agencies to make it easier to offer nursing care throughout the state. We listened to our participant families and partnered with HFS to try to make helpful pandemic-related benefits permanent for Home Care families. This work progressed in FY 2022 and should result in long-term improvements to the Home Care Program.

We also made strides in how we collect family feedback and use that input to improve our service and support. We listened to our Family Advisory Council (FAC)'s suggestions to simplify our family survey process. Their feedback helped us plan changes to make the survey process easier and more convenient for families in 2023. We also used the FAC's recommendations to provide new educational materials for families. All Illinois families can find this information and more helpful resources on our website at dscc.uic.edu.

I am proud of our team's work to improve the lives of our participants and all children and youth with special healthcare needs across the state. We look forward to finding new ways to empower families and strengthen their role in their child's care.

Thank you for supporting our mission.

Thomas F. Jerkovitz

Thomas F. Jerkovitz

# 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.

# 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.

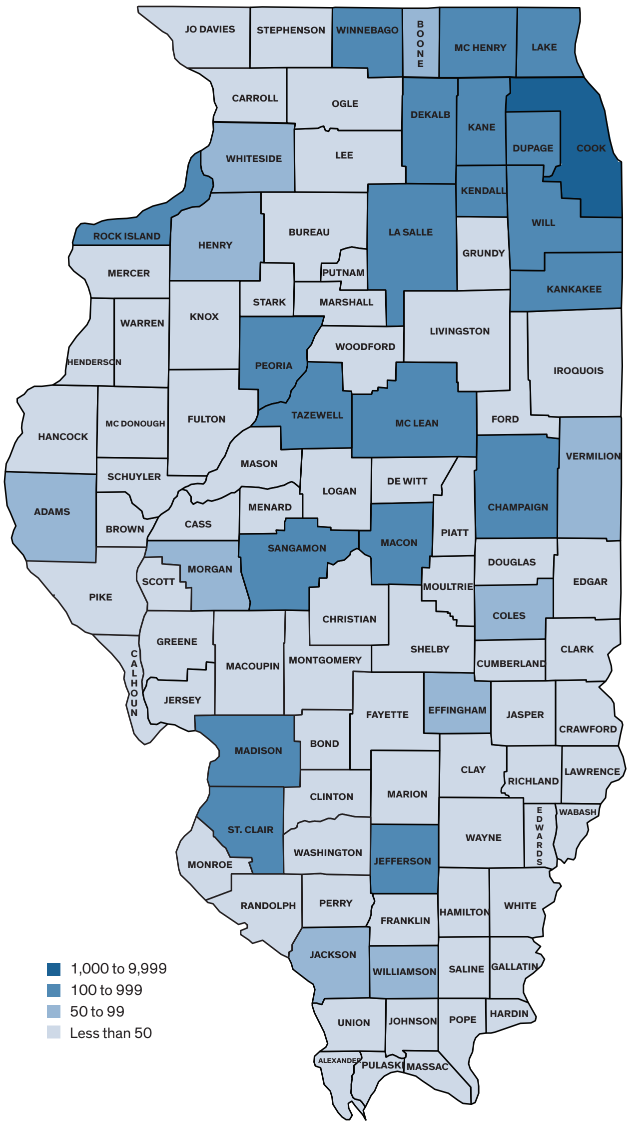
Throughout our 85-year history, we have guided Illinois families through their child's journey with a medical condition. We do this through care coordination services. Our care coordination connects families to the services and resources their children need to reach their full potential. We also partner with doctors, schools and community groups to put families at the center of a seamless support system.

Our team provides 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 a contract with DSCC for care coordination.
- **The Home Care Program** serves children and adults in need of in-home shift nursing.

In fiscal year 2022, we served more than 13,100 families across Illinois through care coordination, resource information and/or referrals.

## FY 2022 Active Cases by County



**Map of all cases by county that were actively enrolled or in intake between July 1, 2021, and June 30, 2022.**

## Our Team

Our team 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
- Other human service-related professionals

We train our team 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.

# 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 needs and their families. DSCC team members who work directly with families share details about the systemic issues affecting children and youth with 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
- Newborn screening for genetic and metabolic diseases
- Developing relationships with healthcare providers and community resources statewide
- Access to national resources for children

## Our Title V Priorities

One of our Title V responsibilities is to identify concerns, set priorities and develop strategies to better serve all Illinois children and youth with special healthcare needs and their families.

We continue to work on the two main priorities that guide our Title V work:

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.

We currently have an action plan outlining strategies to work toward these priority goals.

# Our Title V Role

## A Legacy Supporting the Transition to Adulthood

Our Title V Transition Specialist Darcy Contri is stepping down at the end of 2022 after 26 years with DSCC.

Preparing youth and their families for the transition to adulthood is a key part of our mission. Darcy's expertise in transition has been vital in strengthening DSCC's transition support services.

Over the years, Darcy became the go-to source for all questions and resources about transition. She's led DSCC's transition team for the last several years. The team helps to identify and address staff training materials and develop resources to support the successful transition of DSCC participants. These resources include DSCC's extensive Transition Tools. These tools consist of checklists, tip sheets and other helpful information in the areas of health, education, work and play.

Darcy built relationships and collaborated with outside entities, organizations, schools, medical systems and provider practices to expand transition efforts outside of DSCC and across the state. She's represented DSCC at many outreach events and ensured DSCC is represented on the state's network of Transition Planning Councils.

Darcy has also been vital to the ongoing success of the annual Illinois Statewide Transition Conference. This conference gives families and professionals valuable information about the resources and opportunities available for youth with disabilities as they prepare for adulthood. (More details about the 2021 transition conference are on page 15 of this report.)

Darcy has helped plan the conference since it began in 2005, serving on its steering committee each year since and devoting countless hours to make it a valuable experience for as many families and professionals as possible.

She also partnered with DSCC Medical Advisory Board Member Dr. Shubhra Mukherjee to increase medical professionals' participation at the conference. They developed the conference's first healthcare track in 2006, with the goal of building more clinical engagement and increasing awareness and support for patients with complex healthcare needs and their families. The conference's healthcare track continues to help providers build youth's capacity and healthcare skills to prepare for adulthood.

Darcy is also the published co-author of two transition-related articles: "Transition Planning for Youth with Special Health Care Needs (YSHCN) in Illinois Schools" in the Journal of School Nursing in 2014 and "Transitioning Youth to Adult Healthcare: New tools from the Illinois Transition Care Project" in the Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach in 2015.

We will always value Darcy's contributions and are grateful for her expertise and dedication to youth and families.

# Our Programs

## Core Program

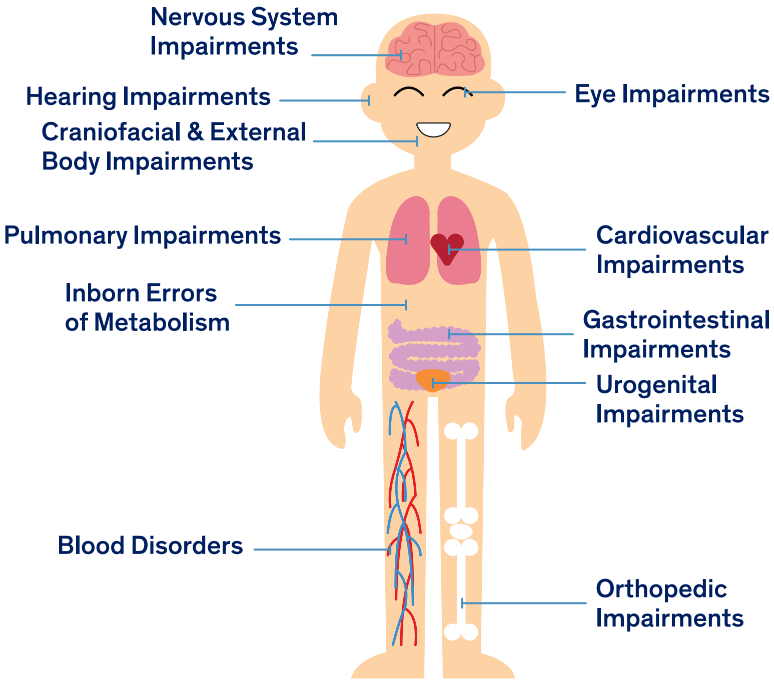
Our Core Program serves Illinois families with children up to age 21 who have or are suspected of having an eligible medical condition. The condition must be chronic and fall in one of our 11 eligible impairment categories. (See the diagram on the right.)

## Connect Care

Children and youth up to age 21 who have eligible chronic health issues and are a member of an Illinois Medicaid managed care organization (MCO) are enrolled in the Connect Care Program.

HealthChoice Illinois is the Medicaid managed care program that is required statewide. Connect Care serves the children and youth who were enrolled in our Core Program and transitioned from Medicaid fee-for-service insurance coverage to HealthChoice Illinois.

### Eligible Conditions for the Core Program



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

We consider new enrollments into this program on a case-by-case basis. We hope to expand this program to more children and families in the next fiscal year and have started planning for this growth.

## 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 live safely at home.

The Home Care Program has grown over the last three decades. It currently 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 Those Who are Medically Fragile Technology Dependent (MFTD). The waiver serves individuals who depend on technology – such as ventilators, tracheostomy tubes and gastrostomy tubes – and need in-home shift nursing to stay in their own home rather than a hospital or a skilled nursing facility.

Individuals eligible for the waiver must meet medical criteria determined by their health condition and technology needs. They also must 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. These services include 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.

Individuals of all ages may receive MFTD waiver services but only if they were enrolled in the waiver before their 21st birthday. This waiver amendment allows participants to stay with the Home Care Program for life.

- **Non-Waiver:** DSCC is also 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. However, they are less dependent on technology and do not qualify for the MFTD waiver. Non-waiver Home Care participants must be eligible for Medicaid.

Since our Home Care waiver participants may stay in the program beyond the age of 21, we see a growing number of adults who receive services. In FY 2022, we had 143 Home Care participants over the age of 21.

Dominic was born with a rare condition that affected his abdominal wall and prevented his lungs and chest wall from fully developing. He required surgery and spent many months in the hospital during his first years of life. Through the highs and lows, DSCC has helped Dominic's family navigate his changing needs over the last seven years.

“It's been a pretty easy program to work with. All of my case managers have been extremely helpful,” his mother, Aurea, said. “It's nice to have someone follow up with me consistently.”

## Interim Relief Program

In February 2022, DSCC started work to provide Interim Relief Program services.

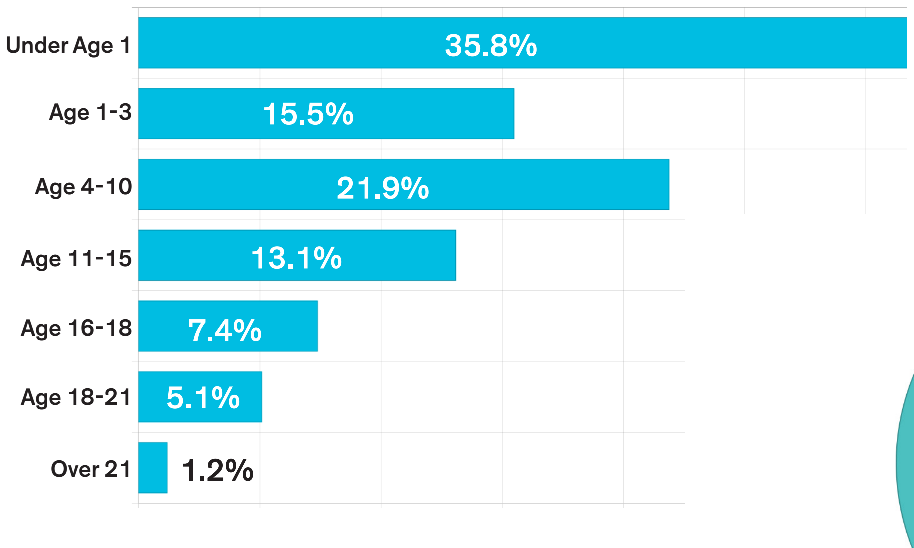
Interim Relief is an existing program under the Illinois Department of Healthcare and Family Services (HFS). It supports the need for children with eligible mental health or behavioral disorders to receive Psychiatric Residential Treatment Facility level of care.

DSCC will operate the program on behalf of HFS. A dedicated group of DSCC staff will provide care coordination and other areas of support for Interim Relief Program participants and their families.

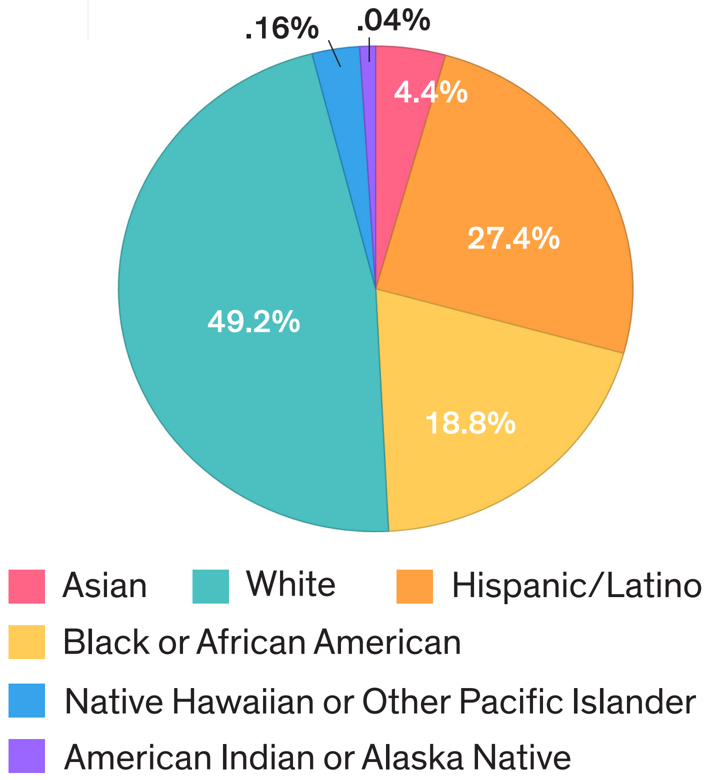
We look forward to sharing our expertise on person-centered planning and family-centered care with this group of children and families. DSCC will begin providing Interim Relief services to participants in late fall 2022.

# Our Programs

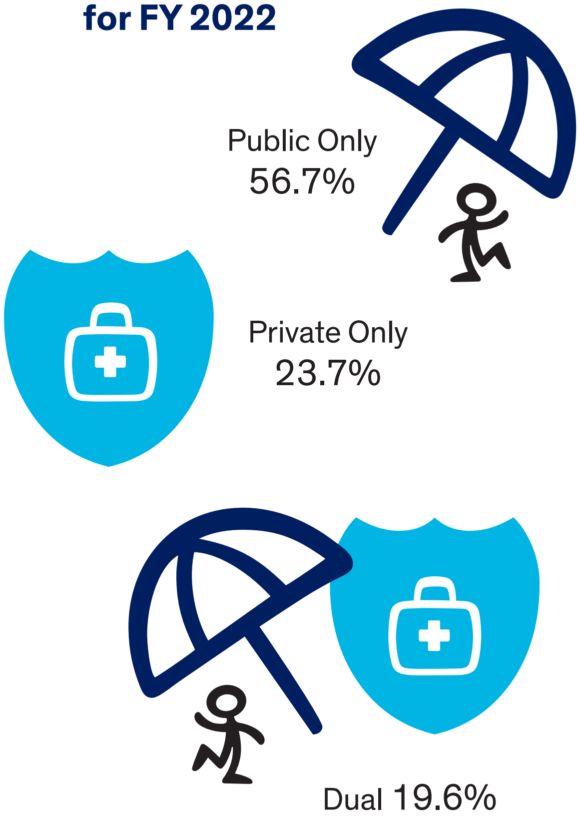
### Age of FY 2022 Active Participants



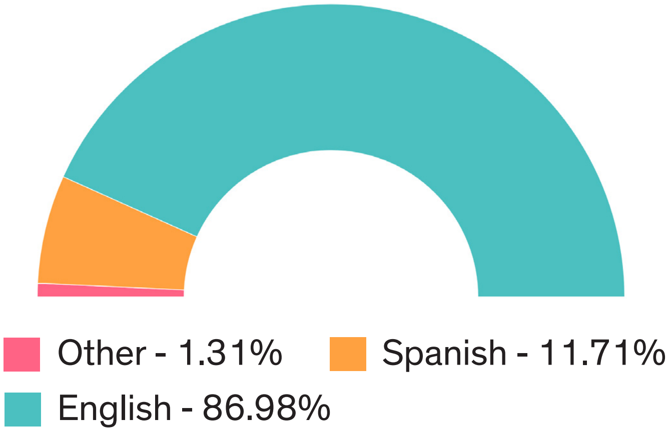
### Known Ethnicity of Active Participants in FY 2022



### Insurance Type for FY 2022



### Preferred Language of All Active Participants in FY 2022



# Our Care Coordination

Our care coordination is 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 team'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 can help families:

- Access diagnostic testing
- Develop a care plan focused on their strengths and goals
- Find specialized medical care
- Maximize their insurance and understand their coverage/benefits
- Communicate with doctors and specialists
- Receive support at school meetings and have help with their child's Individualized Education Program (IEP) or 504 Plan process
- Coordinate transportation for appointments
- Apply for grants to fund therapies, equipment or other needs
- Connect with local charities, programs and resources
- Meet other families for parent-to-parent support
- Prepare for the transition to adulthood

We can also provide financial assistance to participants who meet our income eligibility guidelines. This assistance can help cover expenses or "fill the gap" for costs not covered by Medicaid or other insurance.

## Comprehensive Assessment

Our care coordination teams use a comprehensive and holistic assessment to develop a person-centered plan for each of our families. The assessment focuses on five domains:

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

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

## Person-Centered Planning

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

The person-centered plan focuses on the participant and family's needs, wants, dreams and desires. It includes their desired outcomes/goals, strengths, needs (both clinical and social support) and the steps to achieve these goals. The plan also identifies possible barriers and risk factors and how to minimize them.

# Our Care Coordination

Our care coordination teams use 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.

## Family Impact

Our care coordination benefits and empowers families in many ways. It helps them:

- 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 employment 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

Our team has also developed an extensive network of pediatric specialists for children with special healthcare needs. We can facilitate referrals for other providers and share resources.

Petra, 17, says DSCC has helped her family with insurance coverage issues and how to navigate the healthcare system as a whole. As Petra has grown, she gets to speak with her DSCC Care Coordinator herself during regular check-ins.

"I really love talking to her and having someone to ask questions to and who I can also relate to," Petra said of her current Care Coordinator Sarah Kelly. Sarah also has a disability and uses a wheelchair.

"It helps a lot," Petra said.

# The Family Voice

Throughout fiscal year 2022, we continued to focus on improving opportunities to gather feedback from the families we serve. We also looked at how we can better use that input to make improvements.

Our participant families regularly share feedback with their care coordination teams. We also have a Family Advisory Council and a series of surveys that we send to each participant family.

We truly appreciate our families taking time to share what is working and what needs improvement with our care coordination practices.  We value their feedback and are committed to incorporating it into all DSCC policy, procedure and process decisions that affect their lives.

## Family Advisory Council

Our partnership with families is a key part of our support for all Illinois children and youth with special healthcare needs.

Our Family Advisory Council (FAC) is made up of participant family members from throughout the state. Its mission is to bring our families, team members and leadership together to promote the delivery of participant-centered and family-centered services.

The FAC connects families to resources and provides guidance to strengthen our teamwork, improve communication and empower families to have a voice in their child's care.

The council meets four times a year. Every other meeting is an open forum for all Illinois families of children with special healthcare needs.

The schedule and meeting minutes are posted on our website's ***Family Advisory Council page***.

FAC members have provided valuable feedback to improve our team's communications and resource sharing, quality improvement efforts and collaboration to support children with complex medical needs.

We used the FAC's recommendations to create new tip sheets that explain available services and supports for Home Care Program participants. The tip sheets focus on topics including home and vehicle modifications, energy reimbursement, the appeal process and more. They are available in the new ***Home Care Information Hub*** section of our website.

FAC members also shared helpful feedback on how we can improve our financial assistance process for families.

We also asked the FAC for ideas and input to help increase our family survey participation. Their feedback on the number of surveys and different ways to reach families have helped us update the survey process.

FAC Advocacy Chair Whitney Woodring also began an effort to help improve the home nursing allocation and appeal process for Home Care families through the Illinois Department of Healthcare and Family Services (HFS). She started seeking feedback from families across Illinois to learn about their experiences, both positive and negative.

She plans to bring this feedback to the FAC to make recommendations for changes and help HFS understand families' unique needs and circumstances when deciding nursing allocations.

# The Family Voice

## FAC Member Spotlight – Advocacy Chair Whitney Woodring

Whitney Woodring says the in-home nursing support her family receives through the Home Care Program is invaluable.

Her daughter Willa (pictured on the left) was born with Congenital Central Hypoventilation Syndrome (CCHS), a lifelong and life-threatening genetic disorder that affects her breathing and nervous system. She says there are only about 1,400 to 1,500 people in the world with a CCHS diagnosis.

"No single person with CCHS presents the same way," she said. "So, it's really hard to come up with a plan of care."

Willa received a tracheostomy at 2 months old. She arrived home more than two months later and has received in-home nursing through the Home Care Program ever since.

Willa's nervous system can't regulate, so if she's playing hard or gets overexcited, her body won't tell her to breathe. Therefore, Willa needs constant monitoring.

"But if you didn't know about her condition, you'd have no idea that there's anything going on with her except for the fact she has a trach," Whitney said. "She is just your normal, crazy 4-and-a-half-year-old. She is a tiny tornado who loves to terrorize her older sister."

As Willa grows, Whitney remains a strong advocate not only for her daughter but also for other families of children with special healthcare needs.

She joined DSCC's Family Advisory Council in 2021 and soon volunteered to serve as its advocacy chair. Whitney appreciates the opportunity to connect with other families and share what she's learned.

"It's been an incredibly positive experience working with (DSCC), and I've gained even more of an understanding that I'm not alone. Being a medical mom and a medical parent is often very isolating. My husband and I know what each other is going through and what we face on a daily basis (with their daughters) but our friends or outside people don't really get it," she said. "(The council) has opened my circle."

See more of Whitney and Willa's story at dscc.uic.edu/family-story/willas-family-story/.

# The Family Voice

## Family Surveys

We sent a series of surveys to our participant families at specific intervals in their child's enrollment with DSCC during FY 2022. These surveys went to Core, Connect Care and Home Care participants:

- An initial survey following enrollment
- A survey for active participants at the one-year, three-year and five-year and every subsequent five-year enrollment mark
- A series of surveys focused on education for when the participant turns the following ages: 3.5, 6, 8, 10 and 12
- A series of surveys focused on transition for when the participant turns the following ages: 14, 16, 18 and 20
- An exit survey when a participant leaves the program

Due to low response rates, we have primarily focused on trying to increase participation.

Our efforts included asking the Family Advisory Council for feedback and considering their concerns about the number of surveys that families receive. We also asked our care coordination teams to encourage their participant families to complete the surveys during their monthly contacts. Additionally, we expanded our internal Family Survey Committee to include more care coordination team members and administrative staff.

These steps have led to the following changes and improvements to the survey process for 2023:

- Starting in February 2023, all participant families will receive an annual family survey in February, regardless of their enrollment date. This update will reduce the number of surveys families receive throughout the year. The single timeframe for annual surveys will also improve our external communication efforts about the importance of family feedback.
- We will incorporate an education support survey question into the annual family survey, eliminating the need for a separate series of surveys on education. This change further reduces the number of surveys we send to our families.
- We are researching the ability to send surveys through text messages.
- We plan to pilot calling families for the initial, exit and transition surveys. This update will allow us to hear directly from families during these important milestones.

We look forward to continuing our efforts to hear as many family voices as possible. This feedback is crucial to improving our partnership with families and our ability to meet their unique needs.

Eloise, 3,  has a rare brain malformation called alobar holoprosencephaly. Her parents say DSCC has helped them get through the many unknowns.

Eloise's mom, Rachel, said Care Coordinator Haley Shropshire is "the first person I go to, and I can count on her to look into something," whether it's glasses for Eloise, new equipment or an insurance question.

"Haley is a jack-of-all-trades, and we're so thankful for all that she does."

# Our Outreach

Our community outreach in FY 2022 focused on both in-person and virtual activities as well as our digital communication channels. We provided education and information to more than 236,500 people through outreach events, our website and social media.

Our team participated in 387 virtual and in-person events, including rounds at healthcare facilities, presentations to providers and community groups, parent and family support groups, resource fairs and more.

We are eager to present to interested organizations and community partners about our services and the unique needs of children and youth with special healthcare needs in Illinois. We encourage interested entities to ***contact us through our website***.

## Statewide Transition Conference

The Illinois Statewide Transition Conference, titled “Stepping Stones of Transition,” returned for its 16th year in November 2021 in East Peoria after a one-year absence due to the COVID-19 pandemic.

More than 660 families and professionals gathered in-person and virtually to gain skills, resources and information to help youth with disabilities prepare for adulthood.

DSCC is a conference sponsor and served on its steering committee. We covered the conference-related expenses for 33 of our participant family members across the state.

Kristen Fisher, mother of DSCC participant Connor Fisher, called the conference “phenomenal.”

“Seeing everyone at the conference and meeting other parents, it helps confirm that I’m not alone,” she said.

Nearly 40 of our team members also attended to network, learn from others and strengthen their skillsets and tools to serve our families. We also sponsored the conference’s health care track for providers who play a role in the transition from the pediatric to adult healthcare system and those who build youth’s capacity and healthcare skills to prepare for adulthood.

# Our Outreach

## Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing

Our annual Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing returned to its in-person format. The weeklong, free program took place in June at the Illinois School for the Deaf in Jacksonville.

DSCC supports the Institute, along with other sponsors.

The 2022 Institute served 22 families, including 24 children with hearing loss.

Participating parents and caregivers attended daily lectures by experts in the field to learn about raising a child with hearing loss. Lecture topics included:

- Child development
- Types of hearing loss
- Language development
- Communication choices
- Hearing aids and cochlear implants
- Deaf culture
- Parent rights
- School programming

Children spent each day in classrooms with experienced teachers of children who are deaf or hard of hearing. They were able to play with other children with hearing loss and receive hearing, vision, psychological, speech, language and educational evaluations.

Samantha Elliott called the Institute a wonderful experience. Her 5-year-old son, Jaxon, has hearing loss and no friends with similar needs in their hometown.

She said she loved seeing Jaxon “dive head first into the Deaf community” at the Institute and watching how sign language clicked for him as he communicated with the other children and staff at Institute.

“The staff and administrators have all been very welcoming and very informative and answered all of our questions,” she said.

“There is a lot of information and a lot of us don’t have access to it all,” Samantha added. “(The Institute) has really taken our kids to a different level.”

Kim Rhoades attended the Institute with her daughters, Chelsey, 8, and Cassidey, 5. Both daughters received a hearing loss diagnosis the year before. Kim said she is still learning about her daughters’ needs and what services and supports are available.

“I’ve learned a lot in every single class so far,” Kim said. “And it’s amazing to see how (Chelsey and Cassidey) can actually relate to the other kids.” Kim also appreciated the connections she made with other parents.

“Hearing their stories, you don’t feel alone. They’re going through the exact same thing I am,” she said. “It has really opened my eyes on several things, and I’d recommend coming next year. You will be constantly learning things you didn’t know and meeting people who can back you up and support you.”

# Our Education Opportunities

Through internship opportunities and special projects, DSCC fulfills the University's commitment to improve lives through education.

We 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 educate students about DSCC's mission so they can share information about our programs with their networks.

Additionally, our internships cultivate potential future employees and provide extra staffing to improve our level of service.

Our FY 2022 internship highlights include:

- Six of our regional offices hosted at least one intern during the fiscal year.
- Five interns were earning their master's degree in social work.
  - Four from the University of Illinois Urbana-Champaign (UIUC) School of Social Work
  - One from Aurora University
- Five interns were earning their bachelor's degree from UIUC's Interdisciplinary Health Sciences Program.
- Two interns from the Illinois Department of Public Health worked with our Director of Care Coordination, Systems Development and Education.

Our Chicago Home Care Hospital Liaison also met with UIC College of Medicine Pediatrics residents each month during their development rotation. She explained DSCC's services, who is eligible and how to make a referral.

This liaison also is an at-large member of the board of directors for the American Case Management Association, Illinois Chapter. In this role, she aims to bring educational content that reflects the populations we serve. She also participated in a panel presentation at the Case Management Society of America, Illinois Chapter, conference entitled, "Partnering to Safely Transition Medically Fragile, Technology Dependent Children Home from the Hospital."

## Intern Spotlight – Shruthi Mekala

Shruthi Mekala graduated from the UIUC College of Applied Health Sciences with a degree in interdisciplinary health sciences. She interned with our Champaign Regional Office from January to May 2022.

"DSCC gave me  the perfect opportunity to observe and practice an interdisciplinary approach to providing services to children and their families."

Her internship also included a research project on medical foods for individuals born with inborn errors of metabolism, such as Phenylketonuria (PKU) and Maple Syrup Urine Disease. PKU is a rare inherited disorder that can cause brain damage and other serious health problems if left untreated or poorly treated.

Shruthi said learning more about the condition and its impact on our families was a real “eye-opener.”

“Learning about PKU in biology class doesn’t give you a deep dive into what these children face or a family’s perspective,” Shruthi said. “It was incredibly impactful to speak with our families about their experiences, fears and the barriers they face trying to provide the special diet and medical foods their kids need.”

Shruthi is currently a medical student at the University of Illinois College of Medicine in Rockford.

“DSCC was great training for pre-med. The social conversations with families about school, how they’re doing and what they might need are so important as a doctor. It can be hard but so worth it.”

## Regional Manager Amy Jones Earns Outstanding Field Instructor Award

Amy Jones received the Outstanding Master of Social Work (MSW) Field Instructor Award for the summer 2021 semester. The honor is from the University of Illinois Champaign-Urbana’s (UIUC) School of Social Work.

Amy is the Regional Manager of DSCC’s Olney and Marion regional offices.

The School of Social Work gives the award during each internship rotation to a field instructor who has provided exceptional teaching/ mentoring for their MSW intern.

Sruthi Thinakkal nominated Amy for the award after spending two semesters as an intern in 2021.

“Based on Sruthi’s nomination letter, it is apparent that (Amy is) dedicated to providing an excellent learning experience for the students, and the School of Social Work is very appreciative,” MSW Field Director Lindsey Trout said.

# Our Medical Advisory Board

Our Medical Advisory Board (MAB) is a diverse group of physicians from across the state who represent a variety of pediatric health needs. Each offers a unique perspective and expert advice that guides how we serve families.

The MAB meets three times per year. Members offer recommendations for DSCC's clinical services and provides input on relevant policies, procedures and administrative rules.

The University of Illinois Board of Trustees appoints board members for a three-year term.

The 12 current Medical Advisory Board members are:

**Stephen E. Bash, MD**
Retired Pediatric Cardiologist
OSF Children's Hospital Teaching Staff

**Patricia R. Bellock**
Retired State Representative
Retired Deputy Minority Leader of Illinois House of Representatives
Retired Director of Illinois State Medicaid and Child Support Agency Illinois Health Care and Family Services

**Rachel N. Caskey, MD**
Professor of Medicine and Pediatrics
Chief, Division of Academic Internal Medicine
University of Illinois Chicago

**Laura Deon, MD**
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# Our Medical Advisory Board

## Medical Advisory Board Member Spotlight – Dr. Shubhra (Sue) Mukherjee

Dr. Shubhra Mukherjee, also known as Dr. Sue, is the medical director of pediatric and adolescent rehabilitation medicine at Shriners Children's Chicago.

Mukherjee currently cares for patients up to age 22. Her background includes working with young adults with complex healthcare needs and collaborating across medical specialties to help these patients and their families connect with the care they need.

She has served on the Medical Advisory Board (MAB) for more than 16 years. Her expertise in physical medicine and rehabilitation combined with a deep interest in transition of care for children with complex healthcare needs has been a great fit.

"DSCC understands the importance of supporting families and coordinating care. I appreciate their statewide focus and how the MAB serves as an avenue for clinician input on what changes are needed, sharing feedback about the struggles we encounter helping patients get what they need, and working together to find solutions," Mukherjee said.

"It's very rewarding to grow my knowledge and connect with like-minded professionals across so many different specialties. We're able to share, provide feedback and exchange ideas around removing barriers and supporting patients with complex health care needs at all stages," she added.

"DSCC helps me keep track of program changes and learn about new services or programs that are available. DSCC plays a vital role in sharing information and connecting the many different entities that individuals with complex needs depend on for their care."

# Our Collaborations

## System Improvements for In-Home Nursing in Illinois

Our DSCC team has worked in partnership with the Illinois Department of Healthcare and Family Services (HFS) and the federal Centers for Medicare and Medicaid Services (CMS) to expand and improve in-home nursing options and the systems that support them.

All the initiatives below must be done with approval from and in partnership with Medicaid. Here's a look at our major accomplishments and ongoing work for FY 2022.

### Licensed Legally Responsible Adults as a Waiver Service

The COVID-19 public health emergency has given families more flexibility to help care for their children with complex medical needs. One helpful way is allowing parents and legally responsible adults (LRAs) who are licensed registered nurses (RNs) and licensed practical nurses (LPNs) to be paid caregivers.

DSCC continues to work with HFS and CMS to make this much-needed benefit a permanent option for our Home Care Program participants.

### Unlicensed Family Members as Caregivers and Nursing Portal

DSCC is also working to expand paid caregiving options for the Home Care Program as part of Illinois' plans for an increased federal match (FMAP) from the American Rescue Plan Act.

One of the FMAP initiatives is to allow unlicensed family caregivers to be paid caregivers.

We are partnering with many agencies on this much-needed initiative that could provide relief to many Home Care families.

Our FMAP work also includes developing a nursing portal where nursing agencies and families can post open nursing shifts that are available.

The intent is to try to improve nursing coverage for open shifts across the state.

DSCC continues to work with our Information Technology team and consultants to build the portal.

We plan to hold a series of webinars explaining our FMAP initiatives during FY 2023.

### New License Process for Nursing Agencies

The nationwide nursing shortage has affected many Illinois families in need of in-home shift nursing for their children with complex medical needs.

There is a constant demand for more in-home nursing care options in all parts of the state, both rural and urban.

DSCC partnered with IDPH to help meet this need and give families more nursing care options. DSCC worked with IDPH in FY 2022 to change how our enrolled nursing agencies are licensed to serve Illinois counties. Before the change, nursing agencies could not be licensed to serve all of Illinois. They could only be licensed for individual counties.

This process made it difficult for nursing agencies to expand coverage to areas in need. Our participants who receive in-home shift nursing through the Home Care Program could only receive services from nursing agencies licensed for their specific county.

Now, all nursing agencies who are licensed and enrolled with DSCC in good standing may serve all

Home Care participants in any part of the state. This broader statewide approach to nursing agency licenses will offer more available nursing options to our participants and families.

## Staffing Support Team

Finding nurses can be an ongoing and difficult challenge for our Home Care Program participant families.

As part of our partnership to strengthen in-home nursing services, DSCC has a Staffing Support Team. This team includes a Staffing Support Specialist. This position reviews DSCC's care coordination efforts related to nurse staffing and recommends solutions to staffing issues to the care coordination team.

DSCC staff also regularly collect information on the status of in-home nursing staffing for all Home Care Program participants. The purpose is to help as many families as possible receive in-home shift nursing at their approved level.

## Patient-Centered Outcomes Research Institute (PCORI)

### Behavioral Health Stratified Treatment (B.E.S.T.) to Optimize Transition to Adulthood for Youth with Intellectual and Developmental Disabilities (IDD) Study

Research shows nearly one in five teens with intellectual and developmental disabilities (IDD) experiences depression or anxiety. Untreated depression and anxiety in teens with IDD can negatively affect their health, complicate their transition to adulthood and limit future possibilities.

These facts show the need to develop care coordination models that include mental health care and prevention. In FY 2022, DSCC continued our work with a research study exploring how care coordination that includes mental health supports can benefit youth with IDD.

The study is called the Patient-Centered Outcomes Research Institute (PCORI) Behavioral Health Stratified Treatment (B.E.S.T.) to Optimize Transition to Adulthood for Youth with IDD. It is a partnership with the University of Illinois Hospital and Health Sciences System (UI Health), the University of Illinois Chicago's (UIC) Department of Disability and Human Development and UIC Department of Pediatrics.

The goal of the B.E.S.T. study is to look at how a care coordination program that treats depression and anxiety is effective in making teens feel healthier, happier and able to handle future challenges. We worked with our study partners to develop a Youth and Family Advisory Committee to help develop the study.

We partnered with UIC throughout FY 2022 to develop this free and voluntary virtual program.

To take part in the study, a DSCC participant must:

- Be 13 to 20 years old
- Have an intellectual or developmental disability
- Comprehend at a fourth-grade or similar level
- Read and speak English (as well as their parents/caregivers)
- Have a computer, tablet or smartphone they can use to access the internet
- Be able to use Zoom

- Be enrolled in DSCC's Core or Connect Care programs (DSCC teens enrolled in the Home Care Program are not eligible to participate.)

Our participants who join the study will receive access to additional behavioral and mental health resources and support. The B.E.S.T. study also may help participating teens with IDD learn coping skills to manage feeling sad or having a down mood.

Recruitment for the B.E.S.T. study began in 2022. Study participation will last for two years.

## University of Illinois Chicago College of Medicine

### S.T.A.R. Clinic

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 for FY 2022 to fund the center's Sickle Cell Transition Adolescent-Adult Readiness (S.T.A.R.) Clinic. 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.

### Pediatric Neuropsychology Clinic

UIC College of Medicine's Pediatric Neuropsychology Clinic serves infants, children, adolescents and young adults with a wide range of medical, neurodevelopmental, genetic, psychiatric and learning disorders.

DSCC provided $400,000 in calendar year 2022 to support the clinic through 2026.

Our funds cover costs that include the salary for the neuropsychologist and the technician, supplies and educational materials.

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

### Advancing Equity for Hispanic Transition-Age Youth With Disabilities in Illinois

DSCC partnered with the IL LEND Program to advance equity for Hispanic transition-age youth with disabilities. The transition to adulthood can be a challenging time for both Hispanic adolescents and their parents. These challenges can be more difficult when the adolescent has a disability.

Our team worked with LEND trainees to identify the unique challenges Hispanic families can face during the transition to adulthood. In the spring of 2022, we created videos explaining the transition process, how to make the process easier, available resources and more for Hispanic families in the Chicago area. One video *speaks directly to teens* while the other *video is for parents and guardians*.

We also created *a tip sheet that lists individual transition resources* available for Hispanic teens.

The tip sheet is available in English and Spanish.

In the fall of 2022, DSCC partnered with various organizations to share these resources with Hispanic youth and families and provide training for professionals. These organizations included:

- Family Resource Center on Disabilities
- Illinois Life Span Program at The Arc of Illinois
- Ann and Robert H. Lurie Children's Hospital's Bilingual Information Specialists
- Resource Center for Autism and Developmental Delays (RCADD) at the UIC Center for Literacy
- El Valor
- Transition Program Manager for the Western Suburbs
- Whitney M. Young Magnet High School and Jones College Prep High School in Chicago

## Parent Education Virtual Workshop Series

We partnered with IL LEND to offer an educational workshop series for families enrolled in our programs. The free series provided an online space for DSCC parents and caregivers to access education, learn about resources and discuss strategies and support needs.

The workshop series first began in the fall of 2021 for Home Care Program participant families. In the winter of 2022, we opened the opportunity to families in all three of DSCC's programs.

The free virtual workshops took place on Zoom through April 2022. The workshop topics included navigating the COVID-19 pandemic, Early Intervention services and the transition to adult services.

IL LEND trainees and faculty organized the workshops for DSCC as part of our shared missions to expand resources and improve services for Illinois children with disabilities and special healthcare needs and their families.

## "Lessons Learned from Caregivers of Children with Medical Complexity"

Dr. Molly Hofmann, our Director of Care Coordination, Systems Development and Education, earned her Doctor of Nursing Practice (DNP) degree from UIC College of Nursing in 2021.

Dr. Hofmann's doctoral research included a policy analysis evaluating the support available for Illinois caregivers of children with medical complexity. She summarized her key findings in the article "Lessons Learned from Caregivers of Children with Medical Complexity: Implications for Policy and Providers," published in the July/August 2022 issue of "Home Healthcare Now."

Dr. Hofmann co-authored the article with Dr. Catherine Yonkaitis, Director of the Advanced Population Health Program at UIC College of Nursing. The article explains how Dr. Hofmann coordinated focus groups with caregivers and used a qualitative study approach to better understand the challenges facing parents and guardians. Three main themes emerged from the focus group discussions:

- Navigating the system is confusing.
- The quality of care in the home needs improvement.
- Caregivers need more help with providing care.

Dr. Hofmann also reviewed all Illinois policies, administrative rules and legislation related to children with medical complexity.

Her research found the need for improvements in the home healthcare system, including existing systems in place for support and providing care in the home. Such findings help guide our work to improve systems of care and strengthen Title V programs and services for all Illinois children with special healthcare needs.

## University of Chicago Study of Children with Home Mechanical Ventilation Assistance

Since 2018, DSCC has partnered with Dr. Sarah Sobotka on a research study of parents' and families' experiences caring for a child with a ventilator.

The study's main goal is to get a better sense of the challenges families face to help address possible gaps in care and services. Dr. Sobotka and her team are studying how to best support families of children who are dependent on technology to continue living in the community and avoid returning to the hospital, when possible.

Our Home Care Enrollment team worked with Dr. Sobotka to identify eligible and interested families. Dr. Sobotka and her research team then contacted eligible families for study visits, which included an interview and developmental testing of the child. This study involves four total study visits - a visit one-month post-discharge from the hospital and follow-up visits at six months, one year and two years.

The study was planned for a recruitment period of two years and with a total of 20 families.
Dr. Sobotka and her team completed recruitment in January 2022 and continue to do follow up.

The study recruited a total of 23 families to account for three children with injury or illness in childhood/adolescence and 20 children who had ventilators placed in the neonatal period. Research study highlights during FY 2022 include:

- Nine families completed the study. A total of 13 families have now completed the study through the two-year follow-up since it began.
- The research team completed 16 home visits for follow-up over Zoom or in person.
- The research team currently has nine families in follow-up.

Dr. Sobotka and her team are also excited to announce that their first publication on this work, titled "Early Childhood Developmental Skills of Children with Tracheostomies and Ventilators Recently Discharged Home," has been published in the Pediatric Pulmonology journal.

## University of Chicago Study of Home Care Nurses Working with Children with Home Mechanical Ventilation Assistance

Along with her study of families of children with home mechanical ventilation, Dr. Sobotka has also interviewed nurses who work in family homes caring for children with home mechanical ventilation.

Through her family study and partnership with DSCC, she has interviewed 20 home care nurses. Dr. Sobotka presented an abstract including results from both studies to the Pediatric Academic Society's annual meeting in the spring of 2022 entitled, "Parent and Nurse Perspectives on Promoting Successful Partnerships for Children with Ventilator Dependence." She later presented a synopsis of the study at the American Academy of Cerebral Palsy and Developmental Medicine's annual meeting in September 2022 by the same title.

In 2022, Dr. Sobotka also presented an abstract to both the Pediatric Academic Society's annual meeting as well as the American Academy of Cerebral Palsy and Developmental Medicine's annual meeting entitled, "Home Health Nurses' Perspectives on Gaps and Opportunities for Recruiting into the Workforce to Care for Children with Invasive Mechanical Ventilation (IMV)."

# Our Funding

DSCC's operations are paid through a combination of state and federal funds.

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.

DSCC has managed Illinois' Title V program for children and youth with special healthcare needs since 1937. Block grant funds require a state match of $3 for every $4 of federal money spent. State appropriations provide DSCC's required match.

DSCC maintains contracts with managed care organizations (MCOs) to provide care coordination services for eligible participants enrolled in Illinois' Medicaid Managed Care Program.  Fees charged to the MCOs partially fund the program that is known as Connect Care.

## Referral Sources

Our top ten referral sources from highest to lowest for July 1, 2021, to June 30, 2022.

| Referral Source | Count of Participants |
|---|---|
| Adverse Pregnancy Outcomes Reporting System (APORS) | 3,941 |
| Hospital | 1,030 |
| Newborn Genetic Screening Diagnostic | 1,003 |
| Supplemental Security Income (SSI) | 930 |
| Friend/Family | 904 |
| Newborn Hearing Screening | 536 |
| Early Intervention | 466 |
| IDPH/Early Hearing Detection and Intervention (EHDI) Program | 235 |
| Provider | 208 |
| DSCC Staff | 115 |

(Source, DSCC Annual Report in Power BI)

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