

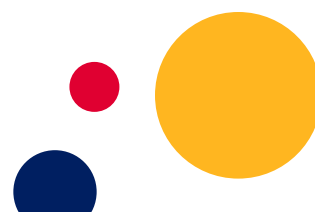


ANNUAL REPORT

Fiscal Year 2024



**Division of Specialized
Care for Children**



Executive Director Greeting

I am pleased to present the University of Illinois Chicago's Division of Specialized Care for Children's (DSCC) fiscal year 2024 Annual Report. Together, our team made remarkable achievements and milestones that reflect our ongoing commitment to supporting children with special healthcare needs and their families across Illinois.

A significant highlight of this year was DSCC earning Case Management Accreditation from the National Committee for Quality Assurance (NCQA). This prestigious recognition affirms our dedication to delivering high-quality, family-centered care coordination and continuous service improvement.

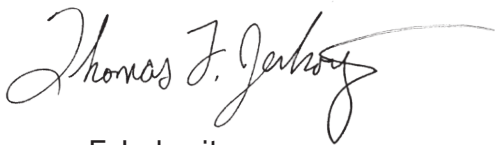
We also made significant strides in enhancing how families access resources and support. We developed a new DSCC Family Portal to give our participant families a convenient, secure and user-friendly platform to communicate with their care coordination team, manage important documents and more.

Additionally, we created and launched NurseNet, an online tool that helps families find in-home nursing care options more easily. We understand families' challenges in finding local home nurses available for their child's complex care. NurseNet helps address this critical need. We developed it with family feedback in mind and input from our Family Advisory Council.

Another major accomplishment was the rollout of our new Youth Advisory Council. This council provides young individuals with special healthcare needs a platform to share their experiences, insights and ideas, ensuring their voices shape programs and services for the transition to adulthood. The council's input will positively impact how we approach youth-centered care and help support a successful journey to adulthood for all Illinois youth.

These achievements are a testament to the collaboration, innovation and unwavering commitment of our team members, community partners and the families we serve. As we look ahead, we remain dedicated to empowering families, improving health outcomes and ensuring every child can reach their full potential.

Thank you for your continued support and partnership in making a difference for Illinois families.



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 nearly 90-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 four 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.
- **The Interim Relief Program** serves children with eligible mental health or behavioral disorders.

In fiscal year 2024, we served more than 13,900 families across Illinois through care coordination, resource information and/or referrals.

Our Team

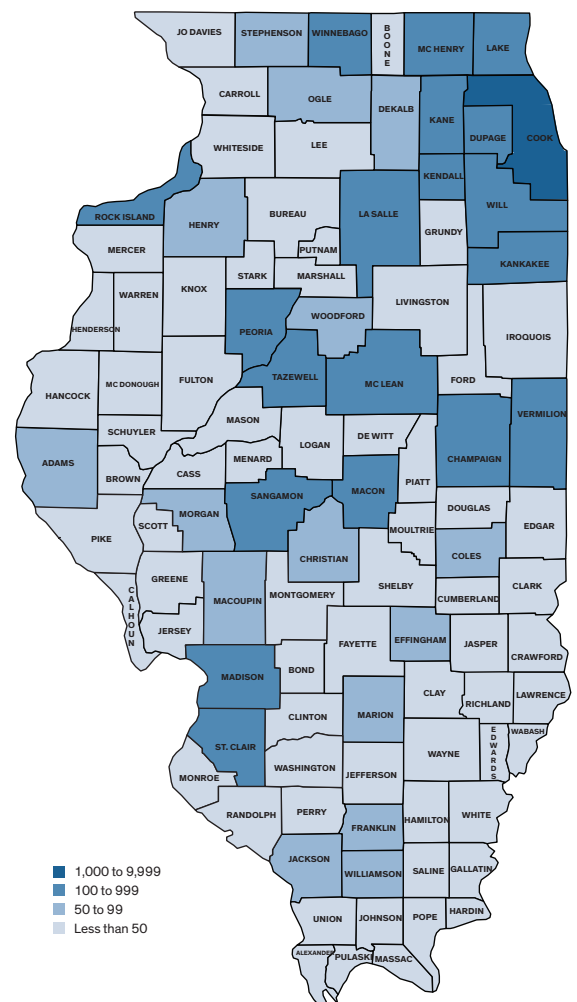
Our team works out of 11 regional offices throughout the state to help families in their local communities.

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 help families better understand their insurance benefits and how to maximize available coverage.

FY 2024 Active Cases by County



Map of all cases by county that were actively enrolled or in intake between July 1, 2023, and June 30, 2024.

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, including children and youth with special healthcare needs.

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.

DSCC has managed Illinois' Title V program for children and youth with special healthcare needs since 1937. Therefore, our role extends beyond the participants and families enrolled in our care coordination programs.

We are involved in various tasks and projects across the state to develop and strengthen the care systems for all children and youth with special healthcare needs and their families. Through collaborations with community partners and our DSCC team members who work directly with families, we continue to learn about the systemic issues affecting children and youth with special healthcare needs in Illinois.

We can find solutions for these issues and address any inequities through our Title V role. 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 screens 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 identifying concerns, setting priorities and developing 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:

Strengthen transition planning and services for children and youth with special healthcare needs. Our Title V transition initiatives include:

1

Helping youth and caregivers prepare for the transition to adulthood.

Partnering with providers to educate and support practice initiatives focused on preparation for the transition to adulthood.

Connecting within communities across the state to promote education and resources on transition.

DSCC program initiatives, which include:

- Development of an internal SharePoint site for DSCC care coordination teams to reference for all areas of the transition to adulthood.

1

- Development of DSCC’s new Youth Advisory Council.
- Our co-sponsorship of the Illinois Statewide Transition Conference.
- Enhanced training and resources for our care coordination teams.

Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special healthcare needs.

We began working with the Illinois Department of Healthcare and Family Services (HFS) on operation of the Interim Relief Program, providing care coordination for individuals enrolled in Medicaid with complex mental and behavioral healthcare needs.

We continued our research partnership with the UIC College of Medicine Department of Pediatrics and the Department of Human Disability on the Behavioral Health Stratified Treatment (B.E.S.T.) study (read more on page 34).

We continue to promote educational resources through our online Resource Directory to parents and caregivers of children and youth with special healthcare needs.

We partnered with HFS to make several improved changes for the Home Care Program. These changes include:

- The development of NurseNet, an online platform that connects families enrolled in the Home Care Program with nursing agencies with available nurses.
- Planning to enable parents who are certified nursing assistants (CNAs) to be paid caregivers for their children, once the update receives the appropriate state and federal approvals.

We continued partnerships with Almost Home Kids and other educators to fund training to improve the skill and comfort level of home nurses and family caregivers of individuals with medical complexity across Illinois.

We have updated our Family Advisory Council (FAC) structure to include participation from families not enrolled in our care coordination programs.

We continued our partnership with families through the FAC. The FAC has developed a new transportation subcommittee to problem-solve and find solutions for transportation issues and access.

We partnered with FAC members to incorporate the family perspective and insight into care coordination training.

2

In partnership with IDPH, we have worked on the next Title V Needs Assessment. Every five years, we must participate in a comprehensive needs assessment. This process includes:

- Gathering data and information from stakeholders and target populations on the needs of children and youth with special healthcare needs and the state’s capacity to meet those needs.
- Determining the priority needs for children and youth with special healthcare needs in Illinois.
- Identifying and implementing multidisciplinary strategies to address priorities.

The findings from the needs assessment will serve as a resource and the foundation for our work in the upcoming years of 2025 to 2030.

New Youth Advisory Council

Youth with special healthcare needs should have a significant role in shaping their future and helping improve support for others.

We developed our new Youth Advisory Council (YAC) to hear directly from teens and young adults about what's important and helpful to them as they plan for the future.

We began recruiting for the YAC in March 2024. The council is a diverse, youth-driven group that aims to develop more youth-focused ways to help individuals and families with transition planning, resources and services.

The YAC's goal is to support positive outcomes in adulthood for all Illinois youth with special healthcare needs in the areas of:

- Employment
- Health care
- Independence
- Quality of life

The YAC's role is to:

- Bring a different and personal perspective on issues important to youth.
- Partner with DSCC to help develop more youth-focused methods to enhance care coordination.
- Develop strategies to improve communication between youth/young adults and older adults.

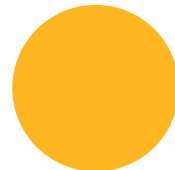
The YAC is open to youth with special healthcare needs who are:

- Ages 15 to 24
- Living in Illinois
- Planning for the transition to adulthood in the areas of education, health care, employment and home and community-based support

Youth do not have to be DSCC participants to join the council.

Members participate in four virtual meetings per year.

To learn more about the YAC and how to join, visit our Youth Advisory Council page at <https://dsc.c.uic.edu/youth-advisory-council/>.



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 figure).

The Core Program supports needs such as therapy, specialized equipment and transportation for medical appointments and treatment.

Connect Care Program

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) may be enrolled in the Connect Care Program.

HealthChoice Illinois is the Medicaid managed care program that is required statewide. We partner with the HealthChoice Illinois MCOs through contracts to provide care coordination services for their members. These services include developing a personalized plan of care as well as support, resources and guidance to families.

Home Care Program

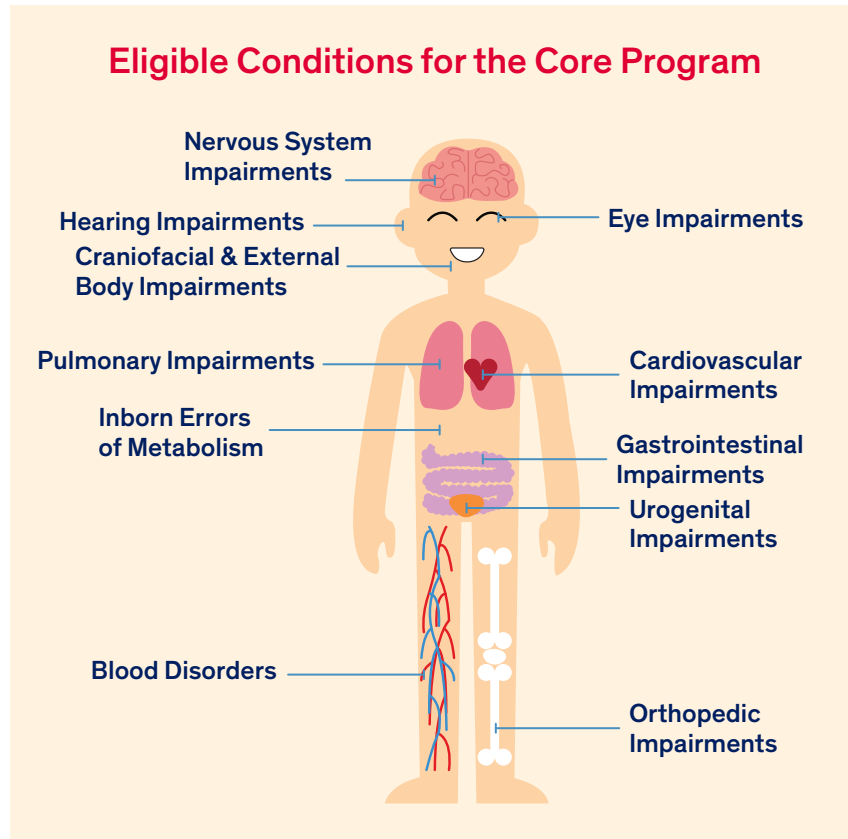
DSCC operates the Home Care Program on behalf of the Illinois Department of Healthcare and Family Services (HFS).

The program supports families who care for loved ones who are medically fragile and need 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 four 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 and be under 21 years of age at the time of the eligibility determination. Waiver participants may receive additional services not covered by the Medicaid State Plan, such as



environmental modifications, vehicle modifications, extermination services and nurse training. Youth may qualify regardless of their family's income. Initially, 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 entry point 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 age 21, we are seeing a growing number of adults who receive services. In FY 2024, we had 179 Home Care participants over 21.

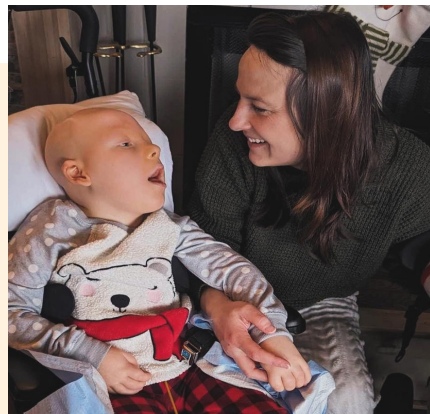
Home Care Family Outreach Associate

Families face unique and sometimes unexpected challenges when caring for a loved one with complex medical conditions.

We have a Home Care Family Outreach Associate (HCFOA) on our team who understands these challenges and can provide heartfelt support.

With lived experience as a patient, parent and caregiver, our HCFOA can recognize shared experiences and guide families through the complexities of multiple care systems.

Our HCFOA also works to create a sense of community for caregivers within DSCC. In this community, families can feel supported, empowered and more confident in their caregiving journey.



Our HCFOA works hand-in-hand with families and caregivers to:

- Create trusting partnerships
- Offer tailored support in addition to the care coordination services they receive from DSCC
- Provide essential caregiver resources

The HCFOA ensures that caregivers are equipped with the knowledge and skills they need to advocate for their children and navigate complex systems of care.



Interim Relief Program

The Interim Relief Program serves children who have eligible mental health or behavioral disorders. This program supports the need for Psychiatric Residential Treatment Facility level of care.

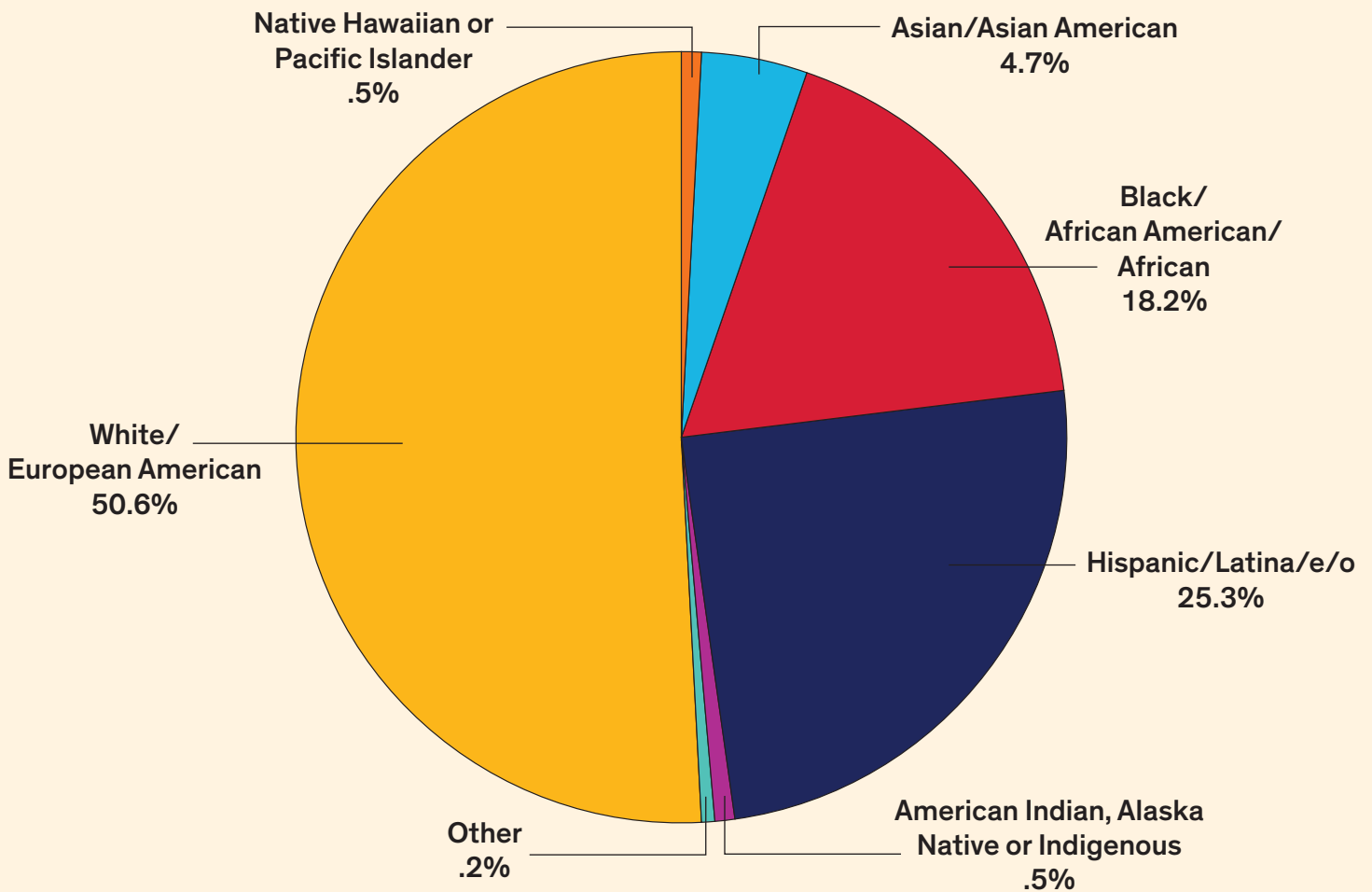
The criteria for Interim Relief services include:

- Under the age of 21
- Enrolled in Illinois Medicaid
- Not currently in the custody or guardianship of a state or federal agency
- Received a Letter of Medical Necessity from a physician detailing the need for Interim Relief services
- Completed the Interim Relief Services Application and Consent Form

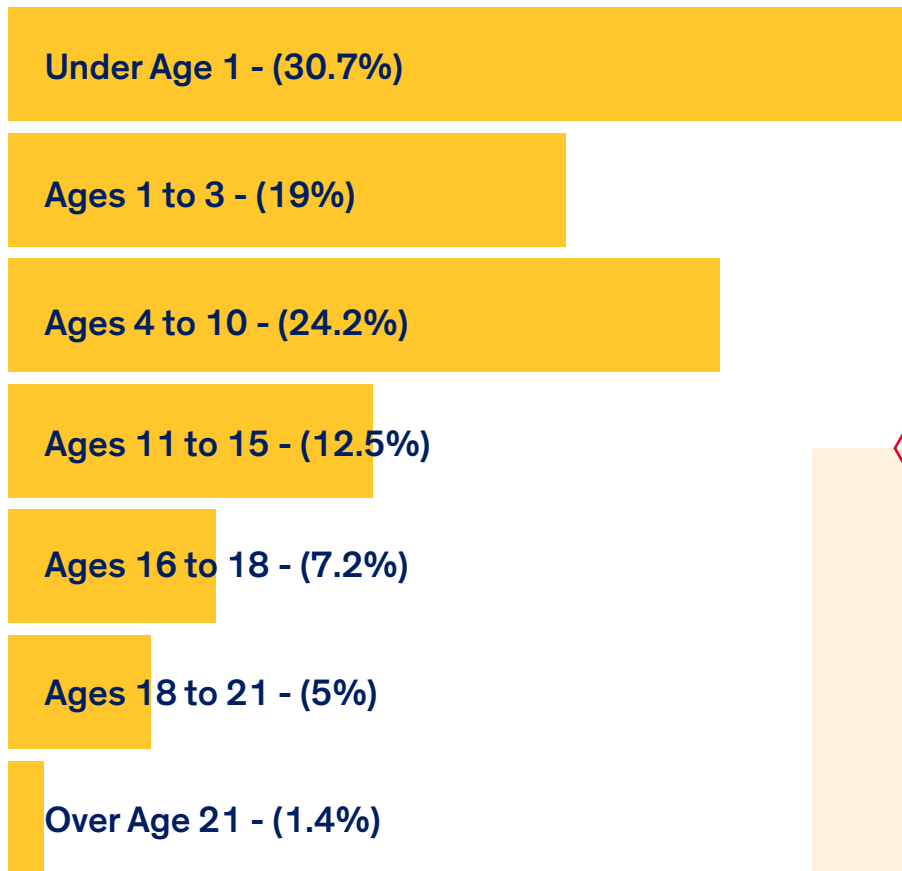
Interim Relief was an existing program under HFS. We began operating this program on behalf of HFS in late fall 2022. We offer Interim Relief participants our care coordination services and other areas of support through our person-centered planning and family-centered care.

The Interim Relief Program also partners with HFS' Pathways to Success to ensure families are properly supported and connected to their community's resources.

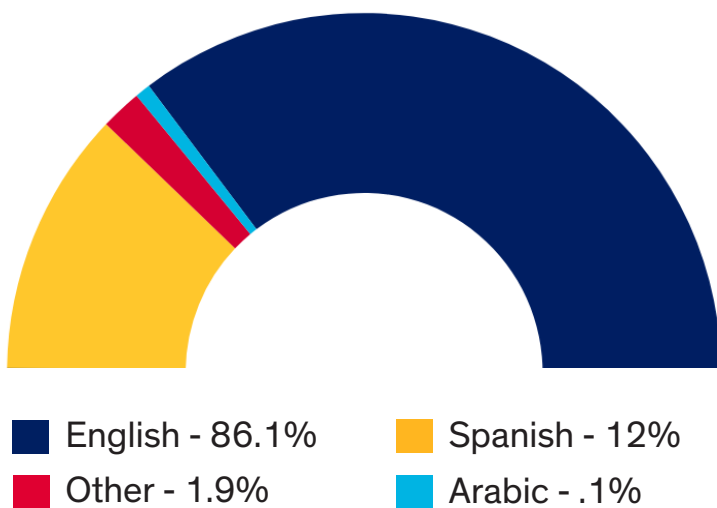
Known Race/Ethnicity of Active Participants in FY 2024



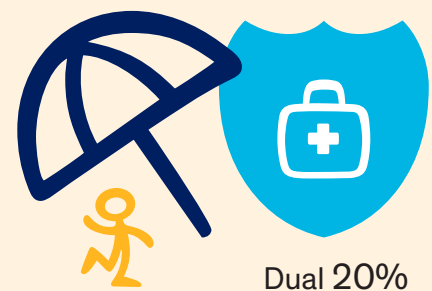
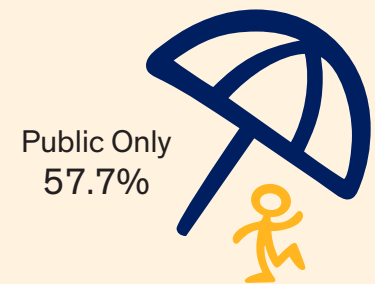
Age of All Active Participants in FY 2024



Preferred Language of All Active Participants in FY 2024



Insurance Type for All Active Participants in FY 2024



Our Care Coordination

Our care coordination focuses on empowering families and ensuring they have the necessary services, resources and knowledge to reach their goals.

Our care coordination teams are professionals who partner with families step-by-step, guiding them through the maze of medical jargon, paperwork and complex systems.

Most of all, our care coordination strives to create a seamless support system.

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. It 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 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 that Medicaid or other insurance do not cover.



Comprehensive Assessment

Our care coordination teams use a comprehensive and holistic assessment to develop a person-centered plan for each family. 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 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 teams use motivational interviewing in 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 focusing 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.



New DSCC Family Portal

It's essential for our participant families to be active partners in their child's care. In fall 2023, we introduced a new way for families to easily share information and communicate with their DSCC care coordination team.

Our new DSCC Family Portal aims to help families find the records they need all in one convenient place.

They can use the Family Portal to:

- Send messages
- Sign documents
- View important letters
- See a list of providers and much more

More details about the DSCC Family Portal are at <https://dsc.uic.edu/dsc-family-portal/>.



DSCC Earns Case Management Accreditation

In spring 2024, DSCC earned Case Management Accreditation from the National Committee for Quality Assurance (NCQA). This significant achievement recognizes our commitment to providing exceptional care coordination and related support to our participant families.

NCQA accreditation is widely known as a symbol of quality and shows an organization's dedication to meeting high-performance measures and continuous improvement.

This milestone highlights the strength and person-centered focus of our care coordination services. It also reflects the great work of our entire DSCC team to improve operations and strengthen how we partner, help and connect with families throughout the state.

In 2021, DSCC's leadership set a strategic goal to work toward NCQA accreditation. Our team members worked for more than three years to achieve this major recognition.

NCQA sets its accreditation standards high to encourage organizations to continuously enhance their quality. The standards aim to help organizations achieve the highest level of performance possible and create an environment of continuous improvement.

The NCQA Case Management Accreditation Program reviewed our care coordination and entire organization against the following standards:

1. Program Description: The organization uses up-to-date, evidence-based information to develop its case management program and regularly updates the program with relevant findings and information.
2. Patient Identification and Assessment: The organization systematically identifies patients who qualify for its programs.
3. Care Planning: The organization coordinates services for patients through the development of individualized care plans.



4. Care Monitoring: The organization has systems in place to support case management activities and monitors individualized care plans.
5. Care Transitions: The organization has a process to manage care transitions, identify problems that could cause care transitions and prevent unplanned transitions, when possible.
6. Measurement and Quality Improvement: At least annually, the organization measures patient satisfaction, program effectiveness and participation rates.
7. Staffing, Training and Verification: The organization defines staffing needs, provides staff with ongoing training and oversight, and verifies healthcare staff credentials.
8. Rights and Responsibilities: The organization communicates its commitment to the rights of patients and its expectations of patients' responsibilities.

Thank you to everyone who helped us reach this prestigious achievement!



“DSCC is a resource that if they don’t know the answer or they don’t know who has that answer, they will find out,” said Lauren O’Brien.

Her son, Josiah, 5, has a genetic deletion on chromosome 15, which causes global developmental delays, bilateral hearing loss and vision impairments.

“Having the Care Coordinator to at least bounce ideas off of and having him check in on our family and say, ‘How’s Josiah doing? Any great gains in therapy? What are you looking at? What are his short-term goals? What are his long-term goals?’ Just helping with any ideas of the special needs side that we don’t know – the resources that are out there for us that we wouldn’t know about without getting in contact with DSCC,” Lauren said.

“They’re a resource that can give you all the resources.”

Josiah’s dad, Jonathan, agrees.

“I think it’s all about having as many advocates in your corner, right? And I think DSCC will provide those, and we’re super grateful for them,” he said.

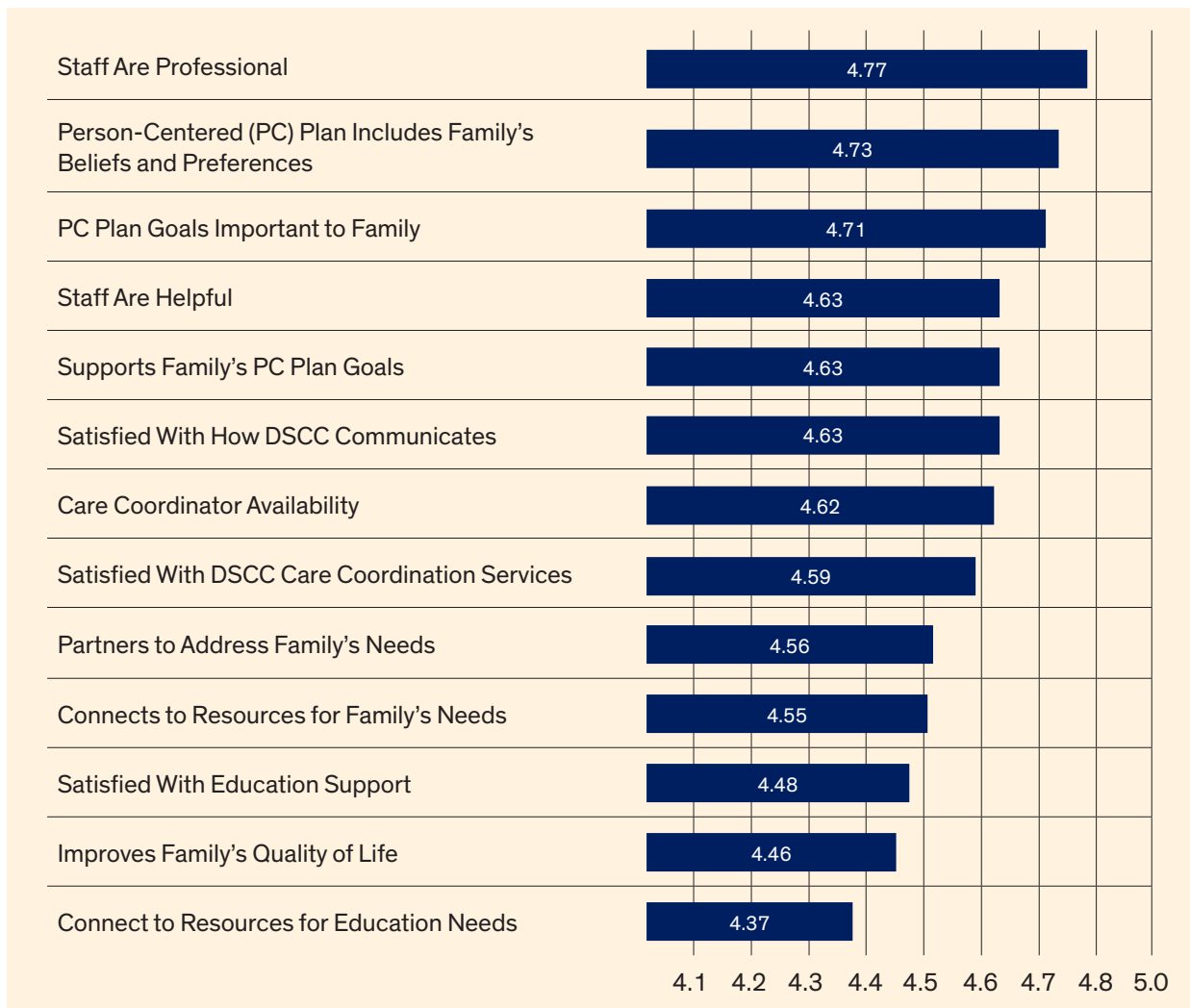
The Family Voice

We value the opinions, thoughts and experiences of the families we serve through our care coordination services. During FY 2024, we continued to improve the family survey process to increase family engagement and response rates.

We continue to seek the input of our Family Advisory Council for ideas about how we could improve. In addition, we conducted a detailed analysis of the responses, distribution information, response rates and all the survey comments our families provided. This analysis led us to make the following updates:

- Updated contact emails, reducing the number of invalid and bounced messages.
- Eliminated duplicate contact records for participants.
- Provided communication before we sent the survey through emails, social media and care coordination team contacts.
- Offered an incentive for survey participation, awarding a \$50 gift card to five random people who completed the 2024 Annual Family Survey.

Below are the average responses by question from the 2024 Annual Family Survey:



Five-point Likert scale:

1 - Strongly Disagree 2 - Somewhat Disagree 3 - Neither Agree nor Disagree 4 - Somewhat Agree 5 - Strongly Agree

We appreciate our families taking the time to tell us what is working and what needs improvement with our care coordination practices. We take their feedback seriously and use it to improve the policies, procedures and processes that impact their lives.

Here are a few examples of how family feedback has led to opportunities for improvement:

- DSCC will launch a new training initiative with our care coordination teams in 2025. This training will help re-educate on care coordination practices.
- DSCC will continue to promote our [Family Portal](#) to help support communication between families and DSCC care coordination teams. DSCC will educate and communicate with DSCC care coordination teams and families about the Family Portal.
- DSCC has re-evaluated the alignment of our Chicago regions for our Core and Connect Care programs. We have centralized the Chicago zip codes by combining two teams into one team under the leadership of two Assistant Regional Managers, one Regional Manager and a dedicated Assistant Director of Operations to better serve the Chicago community.
- DSCC will continue our [Family Education Webinars](#). The 2024 series focused on Social Security benefits, Medicaid denials and transitioning health insurance benefits to adulthood. The next series of webinars will begin in spring 2025 and focus on home and community-based Medicaid waivers for Illinois. These webinars will inform Illinois families about the services each waiver provides for children and young adults.
- DSCC is facilitating a communication plan around [NurseNet](#). We are ensuring that our team communicates to families that NurseNet is a tool to help find nursing. We are also educating DSCC staff to understand how to best use NurseNet. Additionally, we are working with nursing agencies on their role in the process.
- DSCC introduced a training session for current and new team members on the family perspective to help ensure we tailor our care coordination efforts to each specific family.
- DSCC added eight additional language options to our electronic care coordination record. In addition to English and Spanish, other choices now include Polish, Hindi, Arabic, Chinese, Mandarin, Cantonese, Tagalog and Filipino. These options help ensure we communicate with each family in their preferred language.

These are just a few examples of how we use the family voice to improve processes and/or procedures that ultimately help families in a positive way.

We want to thank everyone who took the time to complete the family survey this past year. We truly appreciate their time and feedback.

We will continue to work to engage more participation by improving our survey process. We continue to strengthen our care coordination services because of our families' ideas, thoughts and feedback.

Family Advisory Council

Our partnership with families is essential for everything we do. Our Family Advisory Council (FAC) is vital to maintaining and improving this collaboration.

The 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.

Throughout FY 2024, our FAC provided crucial input and support for these initiatives:

- [NurseNet](#) is a new digital platform that connects Illinois families needing nursing care with local home health agencies. Our FAC members played a key role in its development and testing, providing feedback to make the platform more responsive to both families and agencies.
- The FAC now includes statewide family representatives and a special role for bereaved family members, allowing them to stay involved and share their experiences to help drive meaningful change. Bereaved families had expressed a heartfelt desire to use their experiences to drive improvements and contribute to change in honor of their children.
- We've consistently seen increased attendance at the FAC's biannual open forum meetings. The attendance reflects strong community involvement and family engagement. Participants include community members, family members, educators, professionals focused on children and youth with special healthcare needs, family-led organizations, and other statewide stakeholders. This engagement showcases the FAC's significant impact and broad reach.
- In response to community concerns, the FAC has formed a transportation subcommittee with family leaders and DSCC staff. This collaborative workgroup is dedicated to examining the transportation issues families face and developing solutions. The subcommittee aims to submit actionable recommendations for these challenges to our state partners.
- The FAC has introduced live Spanish translation in meetings and materials, ensuring Spanish-speaking families can fully participate and contribute to our efforts. This step has helped make the FAC (and our organization as a whole) more inclusive and responsive to our diverse community.

We appreciate all our FAC members and greatly value their unique perspectives and lived experiences. We are grateful for the opportunity to learn from and strengthen our partnership with these diverse and dedicated families!



FAC Member Spotlight – Ekiko “Yesenia” Aiken

Ekiko “Yesenia” Aiken’s pregnancy with her daughter, Davina, was smooth and without complications. But when Davina had a seizure immediately after birth, a flurry of diagnostic tests followed.

As different diagnoses came back, Yesenia said she became a “fast advocate.”

“Her original prognosis was 30 days, and we took her home on a hospice plan... they were pretty much like, ‘Take her home, love on her and maximize the time you have with her,’” Yesenia recalled.

“From the moment she was born, everything that they gave me as far as diagnoses, I came back with, ‘Well, that’s not the final or definitive answer to what that means for her life.’ So, I advocated right away.”

Once home, Yesenia continued to relentlessly advocate for Davina and find a way to meet her medical needs while ensuring the best quality of life.

“It was just finding a way when no one was giving me any options – pressing them and finding a way. That became essentially the way we did things for the next 16 years. That’s how she made it to 16 years,” Yesenia said.

When Davina passed away at 16 in December 2022, Yesenia’s advocacy didn’t stop. She wanted to use what she learned to help other families.

One way Yesenia continues her advocacy is through our Family Advisory Council (FAC). Yesenia joined the council as a bereaved parent member in 2023.

“It really helped me to sort of pick that baton back up and feel connected to Davina and feel like that energy and drive and momentum could benefit someone else other than just our family,” Yesenia said.

Davina was born in Georgia and eventually diagnosed with Aicardi syndrome, a rare genetic disorder that affects the brain and eyes as well as other parts of the body. It caused seizures, vision problems, spinal defects and other developmental delays.

When Davina was young, Yesenia became a single parent. There were multiple hospitalizations and surgeries to repair Davina’s scoliosis. Yesenia also worked to find the proper medications to manage Davina’s seizures and a nutrition plan to help Davina gain weight.

She said she was never afraid to ask questions and consider all options. Ultimately, she would make decisions that fit Davina’s and her lifestyle.

“I would always inquire about everything and get as much information as I could get, but then I would narrow it down to what’s important to us, what maintains Davina’s quality of life, and what keeps her happy while maintaining my sanity, and not feeling guilty for that balance,” she said.

When Davina was 11, Yesenia decided to move back to her native Evanston so they could be closer to family and give Davina more educational opportunities.

After the move, Yesenia learned about DSCC from other families she met through their Aicardi syndrome connection.

Davina would thrive at school in Evanston, but finding available at-home nursing was challenging. Yesenia worked closely with her DSCC Care Coordinators to try to find the right services for Davina’s level of care.



After Davina passed away, her Care Coordinator asked Yesenia if she would consider joining DSCC's Family Advisory Council whenever she felt ready.

"Honestly, for me, (the FAC) was kind of like a lifeline. In that moment when you're going through so much and there's so much going on around and the grief has not quite settled in, it's kind of like a line that keeps you connected," Yesenia said.

When she attended her first meeting, Yesenia was immediately impressed by the other parents' passion, knowledge and diverse backgrounds.

"Everyone brings something different to the table, but the fact there are several parents who have taken on full-time jobs in respective organizations and brought what they get from those organizations to the table. It was really impressive to see parents being so involved," she said.

As an FAC member, Yesenia said she's excited to contribute to its newly formed transportation subcommittee, which is looking at the challenges families face in transporting their children to medical appointments, hospitals, therapies, etc., all over Illinois.

She also finds it refreshing to meet and know other families who are fighting just as hard for their kids. She also explained that her connection to other families and the world of caregiving is still vitally important to her identity after losing Davina.



Yesenia also wants to honor and continue sharing what Davina taught her throughout her 16 years.

"It wasn't for me to go through, get through and then leave it alone once it was done," Yesenia explained.

"She basically gave me a foundation for a future in advocacy, and she was essentially sort of the fuel to say, 'This is not where it stops. You've gained so much in this experience; move forward with what you have, and don't leave it alone.'

So that's what I'm trying to do now. I'm trying to make sense of the journey and all of the struggles and use those experiences to move me forward and to help others move forward."

To learn more about Yesenia and Davina's experiences, visit our Family Stories page at <https://dsc.uic.edu/who-we-are/family-stories/>.

Our Outreach

Outreach is integral to DSCC's mission and key to raising awareness about our programs and services. We focus on in-person community events, virtual opportunities and DSCC's digital communication channels to reach families and professionals.

In FY 2024, we provided education and information to more than 318,000 people through outreach events, our website and social media.

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

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

Here are a few outreach highlights and key events that DSCC helped support in FY 2024:



2023 Illinois State Fair

A team of DSCC staff from throughout central Illinois represented DSCC at the 2023 Illinois State Fair in Springfield.

Fair attendees visited our booth in Conservation World to color stickers, compete in the bean bag toss and learn about the services we provide to families across Illinois. Roughly 2,000 people visited us over three days from Aug. 11-13, 2023.

It was an excellent opportunity to speak with families from many parts of the state.



Illinois Statewide Transition Conference

The 18th annual Illinois Statewide Transition Conference occurred in Bloomington-Normal on November 2-3, 2023.

About 370 families and professionals gathered in person 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 25 participant family members across the state.

DSCC parent Luz Diaz said she struggled emotionally before attending the 2023 conference. She felt isolated and unsure of the future for her daughter, Ariana, now 20. Ariana has cerebral palsy and quadriplegia along with hearing loss and developmental delays.

The knowledge she gained and the connections she made with other families immediately lifted her spirits. Luz now feels more hopeful for what lies ahead.

“Before I came here, I was depressed. I felt so lonely. Now that I’ve seen everything here, my thoughts have changed. I don’t feel lonely. I feel like I belong, and I feel like this is my family,” she said. “Now I feel like I’m not alone.”



DSCC participant Vera Lynn Lindquist, 18, attended the transition conference in 2022 and 2023. She has autism, attention-deficit hyperactivity disorder, anxiety disorder from childhood, tinnitus and hearing loss.

Vera enjoyed exploring the transition conference’s booths and sharing about the goals she has worked on.

“I know a lot more about autism awareness and speaking up and speaking out...” Vera said. “I’ve self-advocated at school. I reached out to my teacher on my laptop, I emailed him. I was behind on a lesson and let him know. He came and helped (me). It made all my teachers very happy.”

Vera attended the conference both years with her grandmother and legal guardian, Cheryl Calcese.

“We’ve used many of the independence and decision-making strategies we learned about,” Cheryl said. “Vera got a debit card. She has a money limit on it when she goes out for pizza and other group social events. She has an app on her phone to figure out the tax and tip. She adjusts everything according to her budget. She’s doing well with that and hasn’t gone over her budget once!”

The transition conference also allowed Vera to build her self-esteem and self-advocacy skills.

“She feels very comfortable at this conference, and it shows. She’s visiting with vendors and participating in sessions. Here, her independence is shining. It’s very cool,” Cheryl said.

Cheryl also gained more resources and knowledge for herself.

“It’s always an amazing opportunity to learn and connect,” she said. “Thanks to the conference, I understand more about legal guardianship for adults and where to go for the paperwork for free or low-cost.”

Health Insurance Education Series for Families

DSCC offered our second free virtual Health Education Series in the spring of 2024 to help Illinois families better navigate their health insurance coverage and benefits.

Each month, DSCC team members and other presenters explained a different health insurance topic in English and Spanish.

The 2024 sessions focused on Social Security Benefits, Medicaid denials and transitioning health insurance benefits to adulthood.

Our Benefits Management and Research team developed this series in response to DSCC families’ questions and suggestions from our Family Advisory Council.

All the recordings, slides and related materials at <https://dsc.uic.edu/family-education-webinars/>.

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

Marcellus Weldon and his daughter, Mariana, were born with the same rare genetic disorder called Treacher Collins syndrome.

It affects the development of the head and face, including the ears.

“We don’t have any ear canal or any ear at all on both sides. So, we’re profound to moderate deaf. It just happens at birth,” Marcellus explained.

He uses the analogy of a car to describe living with their disabilities.

“Growing up, I was the passenger, and my mother was the driver because she also has the same condition as me,” he said.

“Now that I’m the parent, I’m the driver, and Mariana is the passenger. And we have to go through hills, valleys, twists and turns together. And there’s going to be things that I just can’t do with her.”

The desire to give Mariana, 6, the knowledge and tools necessary to be her own “driver” led the Weldon family to the 2024 Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing.

The Institute is a free, annual program for parents and caregivers of children ages 6 and under with an identified hearing loss. It focuses on helping families find answers, build connections and access resources all in one place.

During the four-day program, Marcellus watched Mariana bond with other children. He also learned more about his family’s type of hearing loss, education options and how to best support Mariana through school and beyond.

“It’s nice for me to see her thrive not only academically but socially, and she’s just been blossoming like no other. And that’s a beautiful thing to see,” he said.



“She has a community. She has somewhere to go,” Marcellus continued. “She has resources that I never had — someone to fill up her tank, using that analogy.”



The Weldons were among 27 families from all over Illinois who attended the 2024 Institute from June 13-16 on the Illinois School for the Deaf (ISD) campus in Jacksonville.

DSCC supports the Institute, along with other sponsors.

The Institute provides valuable education and networking for children with hearing loss, their parents/caregivers and their siblings.

Participating parents and caregivers attend daily lectures by experts in the field to learn about raising a child with hearing loss. They also meet in small groups with professionals to discuss specific concerns and connect with other caregivers.

The children with hearing loss attend classrooms with experienced teachers of children who are deaf or hard of hearing. They play with one another and often develop deep friendships.

Each child can also receive hearing, vision, psychological, speech, language and educational evaluations. DSCC parents Lauren and Jonathan O’Brien traveled to the Institute with their daughter, Alannah, 7, and son, Josiah, 4. Josiah has a genetic deletion on chromosome 15, which causes global delays with a bilateral hearing loss.

“I think the most important thing was for us to find a community because we are blessed to be in a really good school district with a deaf and hard-of-hearing community. But there’s not always kiddos that also have other diagnoses going on. And so here, you not only have the Deaf culture, but there were other kiddos that had similarities to him cognitively,” Lauren said.



“It’s just been amazing for us to have the parent side of it and then to know that (Josiah)’s being seen by all of these top specialists in the field. And then (Alannah)’s having the time of her life with other siblings. It’s so special for all of us to be here together and to get this experience.”

Learn more about the Institute at <https://dsc.uic.edu/families-gain-expert-guidance-and-support-network-for-raising-children-with-hearing-loss/>.

Referral Sources

Our top ten referral sources from highest to lowest for July 1, 2023, to June 30, 2024.

Referral Source	Count of Participants	Referral Source	Count of Participants
Adverse Pregnancy Outcomes Reporting System (APORS)	4,348	Newborn Hearing Screening Diagnostic	659
Supplemental Security Income (SSI) Referral	1,777	Early Intervention	396
Hospital Referral	1,001	Illinois Department of Public Health (IDPH)/Early Hearing Detection and Intervention (EHDI) Program Referral	256
Friend/Family	755	Provider	169
Newborn Genetic Screening Diagnostic	704	DSCC Staff	129

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 two times per year. Members offer recommendations for DSCC's clinical services and provide input on relevant policies, procedures and administrative rules.

The University of Illinois Board of Trustees appoints board members for a three-year term. The Medical Advisory Board members who served during FY 2024 are:

Stephen E. Bash, MD

Retired Pediatric Cardiologist
OSF Children's Hospital Teaching Staff

Patricia R. Bellock

Retired State Representative and Director
Illinois State Medicaid and Child Support Agency
Illinois Department of Healthcare and Family
Services

Rachel N. Caskey, MD, MAPP

Professor of Medicine and Pediatrics
Head of the Department of Medicine
University of Illinois Chicago

Laura Deon, MD

Pediatric Rehabilitation Medicine
Rush University Medical Center
La Rabida Children's Hospital
Health Equity Social Justice Leadership Program
Course Director
Rush University Medical Center

Carolyn C. Foster, MD, MS

Attending Physician and Assistant Professor
of Pediatrics
Ann and Robert H. Lurie Children's Hospital
of Chicago
Assistant Professor of Pediatrics
Northwestern University Feinberg School
of Medicine

Erin Hickey, MD

Assistant Professor of Clinical and Pediatrics
University of Illinois Hospital

Julian J. Lin, MD

Pediatric Neurosurgery
Department of Neurosurgery
University of Illinois – College of Medicine

Matthew Mischler, MD, FAAP, FACP

OSF St. Francis Medical Center
University of Illinois College of Medicine at Peoria
Specialty: Internal Medicine-Pediatrics

Shubhra (Sue) Mukherjee, MD

Shriners Children's Chicago
Medical Director of Rehabilitation
Pediatric and Adolescent Rehabilitation Medicine

Sarah A. Sobotka, MD, MSCP

Associate Professor of Pediatrics, Section of
Developmental and Behavioral Pediatrics
Ambulatory Medical Director of Comer Developmental
and Behavioral Pediatric Programs
Department of Pediatrics
The University of Chicago and Biological Sciences

Theodore R. Sunder, MD

Retired Professor
Pediatric Neurology
Southern Illinois University School of Medicine

Kathy D. Swafford, MD, FAAP

Medical Director
Children's Medical and Mental Health Network
General Pediatrics, SIU Family Medicine
Board Certified Child Abuse Pediatrician

Medical Advisory Board Member Spotlight – Dr. Sarah Sobotka

Dr. Sarah Sobotka first started working with DSCC through her research to improve support for children with mechanical ventilators and their families.

“I have been working with DSCC as a critical partner in my research program since 2017,” she said, noting how DSCC helped recruit eligible families for her research studies.

“I am so fortunate to have had the enthusiastic support from DSCC because our missions are so aligned and from a research standpoint, it allows me to work with a state agency that lacks the bias of a single hospital center or a single institution... it is a more balanced sample, working with the entire state.”

Sobotka and DSCC share the same goal to better understand the needs of children with medical complexity and connect their families with the right services and support to achieve their best quality of life.

In 2020, DSCC’s leadership invited her to join our Medical Advisory Board as an expert medical provider.

Her research and expertise provide valuable perspectives on how to best allocate resources and improve systems of care for all Illinois children and youth with special healthcare needs.

Sobotka is an Associate Professor of Pediatrics, Section of Developmental and Behavioral Pediatrics, and Ambulatory Medical Director of Comer Developmental and Behavioral Pediatric Programs in the Department of Pediatrics at the University of Chicago.

She became interested in children with medical complexity while completing her residency.

“I did my pediatric residency, and then I elected to do a developmental and behavioral pediatric fellowship in order to focus on the diagnosis and support of children with disabilities and their families,” Sobotka said.

She quickly saw how long children with medical complexity and undiagnosed disability spent in the hospital.

“I recognized early on that an impediment to their flourishing and to their families’ functioning was the length of time they were in the hospital,” she said. “So, some of my early work focused on that process of discharge and the many components that have to get together in order for a child with medical complexity, particularly kids with ventilators, to leave the hospital.”

As part of Dr. Sobotka’s training, she took an additional year between her third and fourth year of medical school to complete a Master of Science for Clinical Professionals. This advanced degree gave her training in epidemiology and research.

Sobotka’s research focus has explored what happens after children with complex medical needs leave the hospital, what the home nursing landscape looks like and what individual families’ experiences and needs are.

One of Dr. Sobotka’s first research studies involved interviewing DSCC Care Coordinators, skilled private duty nurses, and parents of children in the Home Care Program who came home with a ventilator.



“I interviewed those parents a couple of times after going home, so I really started to understand the complexity of home care challenges and what that looked like for families,” she said.

This research project identified gaps in therapy services for these children, and Sobotka developed interventions to support their diverse disabilities. She also learned more about how DSCC Care Coordinators support families and what motivates and challenges professionals in this important role.

Over the last seven years, Sobotka has continued to partner with DSCC on multiple studies. Recent projects include (more details are on pages 35 and 36 of this report):

- “Disparities in Home Nursing and Hospital Length of Stay for Children with Invasive Mechanical Ventilation: Identifying National Trends and Piloting a Parent-to-Parent Intervention”
- “Let’s E.A.T! (Eating with Assistive Technology)”

A major theme in her work is improving the healthcare system’s efficiency so that all children, especially those with medical complexity, spend more time in the least restrictive environment at home with their families.

“This ultimately has the greatest potential to improve their developmental trajectory, because although this is a population at high risk for complex disability, I still believe there are opportunities to mitigate the worst disability outcomes with the right interventions at the right times,” Sobotka said.

Sobotka says families’ experiences and feedback direct the course of her research.

As a Medical Advisory Board member, Sobotka enjoys the opportunity to collaborate with other members to advocate for parent caregivers. She also aims to keep families’ needs and priorities at the center of decisions and improvements in the healthcare system.

“My hope is that what I bring to DSCC and also to other investigators, clinicians, and families are the data points that help to drive advocacy and improvements in care,” she said.



Our Education Opportunities

DSCC fulfills the university's commitment to improving lives through education by providing internships and special project opportunities.

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 2024 internship highlights include:

- Nine regional offices hosted at least one intern during the fiscal year.
- One intern was earning a master's degree in social work from Dominican University.
- One intern was earning a master's degree in social work from the University of Illinois Urbana-Champaign (UIUC).
- Three interns were earning a master's in public health from three universities (University of California – Los Angeles (UCLA), Loyola University and the University of Albany) The students from UCLA and the University of Albany participated in the Title V Maternal Child Health (MCH) Internship Program. DSCC was a 2025 summer host site for the National MCH Workforce Development Center. The program aims to provide future MCH professionals with experience working in state and jurisdictional Title V agencies.
- Six interns were earning their bachelor's degrees from UIUC's Interdisciplinary Health Sciences Program.
- Our Chicago Home Care Hospital Liaison hosted two graduate nursing students from UIC's Advanced Generalist master's program during the fall 2023 semester. During the semester, they collaborated on a project to provide an orientation guide for families of children entering transitional care. Our Chicago Home Care Hospital Liaison is also a board member and education committee co-chair for the American Case Management Association, Illinois Chapter. In this role, she aims to provide educational content that reflects the populations we serve. She is also a member of the Medical Advisory Committee for Almost Home Kids and Maryville Children's Health Center.

LCSW Supervision

A licensed clinical social worker (LCSW) professional provides counseling, evaluation, intervention, and case management services to those who experience mental, social, familial and/or medical issues.

The designation is a huge achievement that requires earning a Master of Social Work (MSW), 3,000 hours of clinical supervision and passing a four-hour exam consisting of 170 questions.

DSCC's educational opportunities include a program to help our interested team members become LCSWs.

Associate Director of Care Coordination Lisa Washington, MSW, LCSW, has spearheaded our revamped clinical supervision program to support staff through the LCSW process. Lisa said earning an LCSW is hard work, but it's also an experience she wants to "pass on" and help others achieve.

“Giving back to our fellow social workers is part of our social worker ethos. Clinical supervision was new to me. I’m glad I didn’t say ‘no.’ It’s been very rewarding,” Lisa said. “Clinical supervision is an important way we can help our co-workers move forward, achieve and continue ‘passing it on.’”

Lisa has developed a framework that anyone interested in providing clinical supervision can use. At the close of FY 2024, nine DSCC employees successfully completed their 3,000 hours. Another ten people were on the waiting list.

Intern Spotlight - Michaela Kons - UIUC College of Applied Health Sciences, Interdisciplinary Health Sciences Undergraduate

When Michaela Kons began her internship with the Champaign Regional Office, she had no idea how much her project would affect her personally and professionally.

Michaela was nervous about having a hectic class schedule and a remote internship.

“I enjoy being around people and just wasn’t sure about being remote,” she explained. “From beginning to end, it turned out to be great!”

Champaign Regional Manager Rachel Gubbins and Care Coordinator Beth Niemerg helped guide her work and the project process. Michaela says they immediately put her at ease and provided important feedback.

“They were welcoming and treated me with respect every step of the way,” Michaela emphasized. “Their feedback helped me build confidence, prepare for the next steps and feel like part of the team.”



For her project, Michaela interviewed DSCC participants who were 20 years old and transitioning out of our program. She asked two main questions in each conversation:

- How has DSCC been helpful?
- How confident are you about moving forward?

Michaela said conducting the interviews was a new and interesting experience for her.

“I was nervous. I had never made random, person-to-person calls before,” Michaela said. “Thankfully, Beth walked me through my jitters and helped me prepare for those first calls.”

Trying to find a time to connect with DSCC participants was challenging, but Michaela persisted. She interviewed eight participants. Each had a different story and plan for the future.

“I’m 22, so I think some of the youth talked to me differently than they would their Care Coordinator,” Michaela said. “Their excitement was contagious. Along with the two questions, they frequently shared their goals, dreams and all the things they wanted to do.”

Michaela said an interview with a young woman living at home with her mother especially stood out. “She had short-term, attainable goals but big dreams as well,” Michaela said. “She wants to be a model and open a bakery. Her plans for the future were inspiring.”

Throughout the interview process, Michaela noted the appreciation participants expressed for DSCC. “A lot of them said they would miss their Care Coordinator,” Michaela said. “They also recognized DSCC’s positive impact on their family, how it helped reduce their parent’s stress.”

By the end of the internship, Michaela felt like she had also come full circle.

“My people, interviewing and phone skills got a big boost. I went from being nervous to enjoying speaking with so many different people,” Michaela said. “Researching so many things also helped me become more familiar with conditions, medical terms and reading doctors’ notes.”

Michaela plans to go into the medical field.

“I’m taking a gap year and working as a medical assistant,” Michaela said. “I’m using the skills I gained during my internship experience daily. The things I learned through that experience are helping me move forward no matter what specialty I choose to pursue in the future.”

Intern Spotlight - Mackenzie Wieggers - UIUC College of Applied Health Sciences, Interdisciplinary Health Sciences Undergraduate

Mackenzie Wieggers is passionate about ensuring everyone has equal access to health care.

As an Interdisciplinary Health Sciences undergraduate, Mackenzie has had internships with health organizations and senior facilities planning activities and monitoring health and wellness programs. This time, she wanted more hands-on opportunities and something more aligned with her passion for advocacy and inclusion.

Mackenzie says interning with the DSCC Interim Relief Program Team delivered everything on her “checklist” and much more.

“I worked remotely with Care Coordinators from all over the state. Everyone brought something different to the table,” Mackenzie said.

The Interim Relief Program serves children who have eligible mental health or behavioral disorders. Mackenzie says Interim Relief Program Manager Hailey Phelps was instrumental in her growth.

“I was worried about working remotely, but she provided great insight and tips for working online,” Mackenzie said. “She helped me learn how to be more concise and get my thoughts across. My skills improved so much thanks to all the great support.”

Mackenzie’s internship included job shadowing team members, improving and maintaining a nationwide spreadsheet of Psychiatric Residential Treatment Facility options for our participants, and helping develop a mental health toolkit.

“We talked a lot in my classes about hospital settings and care done in major facilities, but there are so many different ways to receive care,” Mackenzie said. “DSCC provided other perspectives and a broader view of all the moving pieces and partnerships that go into the health scape.”

Learning about DSCC’s extensive role in supporting participants and their families was “eye-opening.”

“I was surprised and truly impressed by the broad range of support DSCC offers families. Care coordination isn’t ‘just a job.’ Every case is unique and personal,” Mackenzie continued. “Seeing Care Coordinators embrace these families and provide advocacy, empathy and nurturing was amazing. The amount of heart they put into each case touched and inspired me.”

Mackenzie also enjoyed diving into the “nitty-gritty” of care behind the scenes.

“I learned so much about the process of placement, the business as a whole, and the important role our Care Coordinators play throughout in supporting families,” Mackenzie said. “Our Care Coordinators are navigating medical device companies, insurance, kids who are afraid to fly and more. They’re problem-solving at every step. They’re not just giving families another form to fill out, they’re connecting them to resources, nurturing them, helping them feel heard and not so alone.”

Mackenzie praises DSCC’s culture of helping.

“I’ve worked at other places where ‘sink or swim’ was the prevailing attitude,” Mackenzie stated. “Everyone I worked with at DSCC was so positive, helpful and focused on helping others succeed. If they didn’t know the answer, they would give me suggestions about who to contact. You just don’t get that everywhere.”

Mackenzie has a Bachelor of Science degree in Interdisciplinary Health Sciences. Her career goals include working for a pharmaceutical company overseeing quality assurance.

“Empathy is key. Seeing the patient behind each product is critical,” Mackenzie explained. “From helping people living in pain to developing new drugs, doing things the right way helps everyone benefit. For anyone working in pharmaceuticals, the patient has to be the main focus and drive. I want to be one of those people who is pushing for excellence and helping others.”



Our Collaborations

System Improvements for In-Home Nursing in Illinois

NurseNet Simplifies the Search for In-Home Nursing

Our DSCC team continues to partner 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 for families.

Throughout FY 2024, we worked on several projects as part of Illinois' plans for an increased federal match (FMAP) from the American Rescue Plan Act.

Our enhanced FMAP projects included the rollout of a new nursing portal we developed called NurseNet. DSCC worked with our Information Technology team and consultants to introduce the portal in April 2024. NurseNet aims to bridge the gap between Illinois families who need nursing and home health nursing agencies with available nurses.

Families of individuals enrolled in the Home Care Program can use NurseNet to share their nursing needs. Nursing agencies enrolled with DSCC can share information about where nurses are available.

This information can help families find suitable nursing care. It can also help nursing agencies identify opportunities to serve families.

Anyone can use NurseNet to search for general nursing opportunities across the state. You can learn more about NurseNet on our website at <https://dsc.uic.edu/nursenet/>.

The search for in-home nurses can be exhausting for many families of loved ones with complex medical needs.

Home Care Program parent Shekia Wright understands this challenge.

She tried NurseNet to find available nurses for her 1-year-old son, Kaharri Pittman. He has a tracheostomy and relies on a ventilator to breathe.

Shekia set up a NurseNet account and entered Kaharri's nursing needs.

She quickly found two available matches from two different nursing agencies. Overall, she was impressed with how easy NurseNet is to use.

"It was easy to set up the account and easy to find available nurses," Shekia said. "I would recommend NurseNet to any families looking for nursing."



In-Depth Training Opportunities for Caregivers and Nurses

Our FMAP work also includes funding projects to improve training and access to training to help improve the quality of nursing care in the home. This initiative includes developing training that builds on and complements existing training for caregivers in the home.

We partnered with Almost Home Kids to offer two in-depth, in-person training opportunities for families and caregivers of children with complex medical needs.

These free two-day training sessions took place at the University of Illinois Chicago Simulation and Integrative Learning (SAIL) Center in Chicago in July and September 2024.

The training was available to any parent or caregiver of a child in the Home and Community-Based Services Waiver for Those Who Are Medically Fragile Technology Dependent (MFTD) waiver.

The in-depth curriculum included:

- Daily care of the child with a tracheostomy and ventilator
- Equipment and alarms
- Gastrostomy care and feeding
- Tracheostomy basics
- Respiratory assessment and interventions
- Ventilator training with hands-on practice and much more

We also partnered with Almost Home Kids to offer simulation-based training sessions for pediatric home care nurses caring for children with medical complexities. No fees were charged to nurses attending the trainings as it was an HFS-approved FMAP initiative.

Additionally, we funded a project to expand eHomeCare. The eHomeCare program is a free online training program that provides training courses for caring for children who are medically complex.

As part of our FMAP work, we partnered with Dr. Kim Whitmore and her team at Ujima United. Dr. Whitmore previously developed eHomeCare and is working to expand the training to include seven additional courses.

The expanded eHomeCare training program will be completed in early 2025. The program offers free continuing education credits and is for:

- Nurses working in home-based environments
- Physicians
- Respiratory therapists
- Students from health professions
- Family members and caregivers of children with complex medical needs



Patient-Centered Outcomes Research Institute (PCORI) Behavioral Health Stratified Treatment (B.E.S.T.) to Optimize Transition to Adulthood for Youth Study

Teens with intellectual and developmental disabilities (IDD) face high rates of anxiety and depression. Although care coordination programs are available, significant gaps in behavioral health services for these teens persist.

We continue to partner on a research study to help bridge this gap and provide more comprehensive support to teens 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 B.E.S.T. study wants to understand if care coordination services that include mental health programming can help teens with IDD live happier and healthier lives. The study is available for some teens and young adults enrolled in our Core or Connect Care programs.

All DSCC participants receive care coordination services. The B.E.S.T. study looks at whether it's more beneficial for DSCC teens to receive care coordination that also includes programs to help with mood and stress.

We began to recruit participants in late 2022. About 250 DSCC participants remained enrolled in the study as of fall 2024.

Our participants in the study receive access to additional behavioral and mental health resources and support. They also learn coping skills to manage feeling sad or having a down mood.

Parents and caregivers can also gain information on how to support their teens.

The study is a virtual program that will continue recruiting through December 2025.

Youth and adults with IDD helped develop the study and play a core role in the B.E.S.T. research team and advisory boards. Their insights have shaped every aspect of the project, from developing engaging, accessible content to addressing key issues such as stigma and barriers to care.

This project not only improves the lives of youth with IDD but also empowers the IDD community to shape the services designed for them.



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 have “silent strokes” that have no outward symptoms but can damage intellectual and academic abilities, attention and long-term memory.

Silent strokes are more likely for children who do not keep regular medical appointments. DSCC partners with the UIC Sickle Cell Center to help families of children with sickle cell disease keep their appointments and make sure their child’s care is running smoothly.

DSCC provided \$200,000 for calendar year 2024 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 adults through education in five key transition areas: medical, emotional/psychological, social domain, academic/education, and vocation and career.

“Disparities in Home Nursing and Hospital Length of Stay for Children with Invasive Mechanical Ventilation: Identifying National Trends and Piloting a Parent-to-Parent Intervention”

Dr. Sarah Sobotka has devoted her research efforts to the study of children with invasive home mechanical ventilation (see pages 26 and 27 of this report).

Sobotka has partnered with DSCC on a research study called *“Disparities in Home Nursing and Hospital Length of Stay for Children with Invasive Mechanical Ventilation: Identifying National Trends and Piloting a Parent-to-Parent Intervention.”*

The study includes a parent-to-parent coaching pilot program for families. This pilot program is for families who have a child on a ventilator in the hospital and are awaiting home nursing so their child can be discharged home or have gone home and do not have enough home nursing support.

The parent coaching sessions take place in person or over Zoom. A parent coach discusses potential ways to address common challenges with finding and keeping home health nurses.

The parent coaching pilot aims to help families gain tips and tricks to maintain home health nursing teams.

Sobotka’s team began partnering with DSCC’s Staffing Support Specialist in May 2023 to find potential families to participate in the study and has enrolled ten families. Enrollment in this pilot study is now closed. Seven families have completed the program, and three are still actively receiving coaching.

“Let’s E.A.T! (Eating with Assistive Technology)”

Sobotka has received funding from the Gerber Foundation to conduct a randomized controlled trial (RCT) of an innovative interdisciplinary therapy intervention for children with tracheostomies and feeding tubes called “Let’s E.A.T! (Eating with Assistive Technology).”

Sobotka recognized the challenge of supporting eating by mouth for children with tracheostomies; many children do not receive community therapies because they are viewed as too medically complicated.

This RCT randomizes patients into a control group that receives virtual group therapy only or an intervention group that also receives biweekly virtual therapies and active management of their feeding tube by the study team.

The research team assesses each group every three months. The groups participate in the study for one year.

Dr. Sobotka and her team launched the study in the summer of 2024 and continue to recruit participants.

Interested families of children under 3 years of age with a tracheostomy and a feeding tube can email SobotkaLab@uchicago.edu to learn more about the study.

“The SafeCare@Home4Kids Learning Lab: Designing Safer Healthcare at Home for Children”

We are partnering on an ongoing research study to help improve home health care for children with complex medical needs.

The research team is led by [Dr. Carolyn Foster](#) of Ann and Robert H. Lurie Children’s Hospital of Chicago. Foster is one of our Medical Advisory Board Members and will be the board chair in FY 2025.

Foster and her research team received a [\\$2 million grant award](#) to fund the study, called “The SafeCare@Home4Kids Learning Lab: Designing Safer Healthcare at Home for Children.”

This study brings together experts and patient families to better understand how family caregivers and home nurses can help identify, communicate and prevent safety issues at home for children with complex medical needs. The study will use this input to create a digital safety toolkit to help support families.

DSCC is sharing our team’s experiences with families and home nurses who report safety challenges at home. Dr. Molly Hofmann, our Director of Care Coordination, Systems Development and Education, is one of the participating experts.

“SafeCare@Home4Kids” also wants to help improve communication when medical device and equipment malfunctions happen at home.

The study aims to create a better system where families can communicate safety problems at home and know who to notify when they occur. It will also host focus groups to hear directly from families about the safety issues that affect them.

The project kicked off in September 2023 and will continue through July 31, 2027.



Our Funding

DSCC's operations are financed 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.

“Care coordination is hard. I was overwhelmed trying to do it all,” said Mandy Nicolaides. Mandy's son Eldon, 9, has childhood apraxia of speech.

“When Eldon was a toddler, my Care Coordinator went to doctor appointments with me. She provided a ‘listening ear’ and another perspective to help me talk through things and better understand what was going on,” Mandy said.

The family's current Care Coordinator is usually the first person Mandy reaches out to when she has questions.

“If I need resources or want to explore an idea, I can go to her,” Mandy said. “Medical, financial, whatever I need to alleviate stress for all the things I'm trying to do. I trust and have faith in them (DSCC) to help me.”





Division of Specialized Care for Children

(800) 322-3722 | dsc.c.uic.edu