

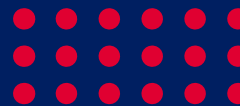
Fiscal Year 2023

ANNUAL REPORT



**Division of Specialized
Care for Children**

Executive Director Greeting



Fiscal year 2023 was a year of meaningful change and growth for the University of Illinois Chicago's Division of Specialized Care for Children (DSCC).

One of the most noteworthy events was the end of the public health emergency due to the COVID-19 pandemic. This declaration in May 2023 prompted our return to in-home visits with our participants and their families. These face-to-face visits are an important way to establish and deepen our connection with families. Though many families chose to meet with their Care Coordinator during the pandemic, we are thrilled to now meet in person with all families. We continue to accommodate families' preferences to make our face-to-face visits as safe as possible for both our participant families and team members.

We also partnered with the Illinois Department of Healthcare and Family Services (HFS) to make two pandemic-related benefits permanent for Home Care Program families. Parents or legally responsible adults (LRAs) can now provide skilled nursing services to their children if they hold an active registered nurse (RN) or licensed practical nurse (LPN) license. Nursing agencies can also now permanently receive payment for overtime hours to Home Care participants. These are among several ongoing initiatives to improve in-home nursing options for families of children and adults with complex medical needs.

Our partnership with HFS also grew as we began to operate the Interim Relief Program on its behalf in the fall of 2022. The Interim Relief Program serves children who have eligible mental health or behavioral disorders. We offer Interim Relief participants our care coordination services and other areas of support.

Family feedback remained a major guidepost for our work throughout FY 2023. We used participant input and feedback from our Family Advisory Council to streamline and simplify our annual family survey process. These efforts saw our survey response rate grow from 6 percent in 2022 to 23 percent in 2023. Family input also led to the development of a new Family Portal to help our participant families more easily connect with their care coordination teams. We also offered a virtual Health Insurance Education Series to help families navigate the health insurance maze and understand their benefits and coverage.

These highlights offer a snapshot of the many ways we continue to evolve and tackle new projects in response to our participant families' needs, goals and preferences. You can learn more about these efforts and find a variety of information and resources on our website at dsc.uic.edu.

I am proud of our many partnerships and the ongoing dedication and professionalism of our DSCC team. It is an honor to work together to put Illinois children and families at the center of a seamless support system that improves the quality of their lives.

Thank you for supporting our mission.

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

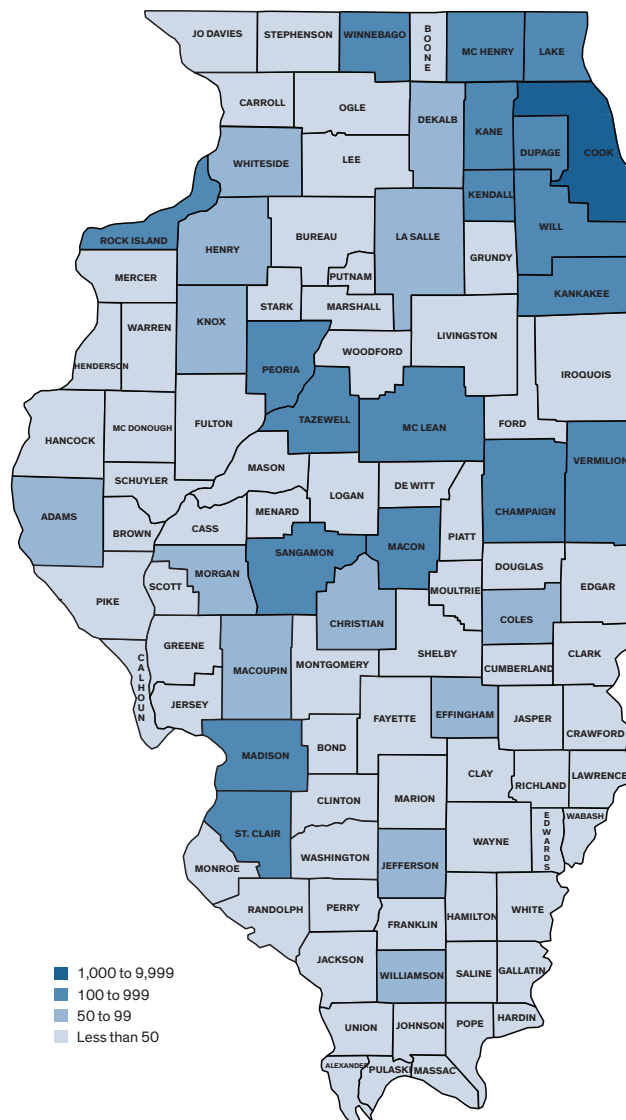
The University of Illinois Chicago's Division of Specialized Care for Children (DSCC) is a statewide program that serves children and youth with special healthcare needs and their families.

Throughout our 86-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.

FY 2023 Active Cases by County



Map of all cases by county that were actively enrolled or in intake between July 1, 2022, and June 30, 2023.



In fiscal year 2023, we served more than 13,400 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 work with families to help them better understand their insurance benefits and how to maximize available coverage.

Our care coordination teams from across the state came together at two different locations for our Together Towards Tomorrow Conferences.

The north conference took place in Chicago on April 19-21, 2023. The conference for our southern teams took place in Springfield on May 17-19, 2023.

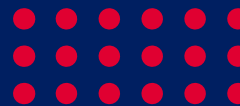
It was a wonderful opportunity to see many of our team members in-person and learn how to best care for ourselves and the children and families we serve.

The conferences included sessions on:

- Personal safety
- Planning, problem-solving and decision-making
- Secondary traumatic stress
- Self-care



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.

Since 1937, DSCC has managed Illinois' Title V program for children and youth with special healthcare needs. Therefore, our role goes 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 systems of care 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.

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:

Strengthen transition planning and services for children and youth with special healthcare needs.

Our Title V transition initiatives include:

- 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:
 - The update of more than 90 transition-related tips and tool sheets and an [updated Transition Toolkit](#).
 - The development of a [“Guide to Adult Benefits, Services and Resources”](#).
 - 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 operations of the Interim Relief Program, where we provide 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.
- We have updated our Family Advisory Council structure to include participation from families who are not enrolled in our care coordination programs.
- We continue to promote educational resources available through our online Resource Directory to parents and caregivers of children and youth with special healthcare needs.
- We successfully partnered with the Illinois Department of Public Health (IDPH) to support the opening of a new transition/respite facility and to improve multi-county licensure for Home Care Program nursing agencies.
- We partnered with the HFS to make several improved changes for the Home Care Program.

These changes include:

- Making overtime pay permanent for nurses
- Enabling parents who are licensed nurses to be paid caregivers for their children
- Setting permanent rate increases for nurse training and respite services

We have also worked with HFS to discuss how to enable parents to receive payment as paid caregivers for their children with medical complexity.

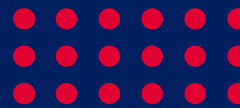
- We began partnerships with Almost Home Kids and other educators to fund training to improve the skill and comfort level of home nurses and family caregivers of individuals with medical complexity across Illinois.

In partnership with IDPH, we also started planning for 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.

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).

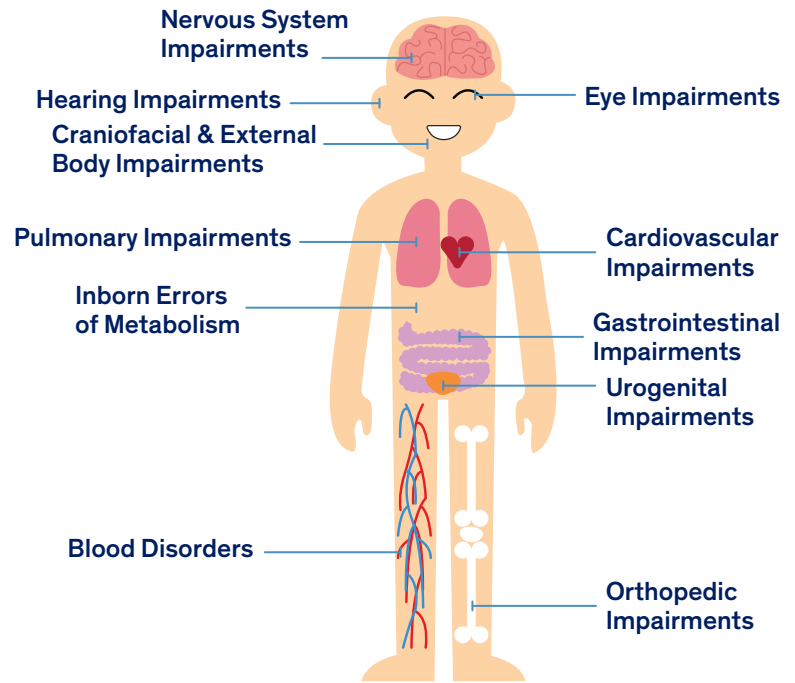
The Core Program supports needs such as therapy, specialized equipment and transportation related to medical appointments and treatment.

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. We partner with the HealthChoice Illinois MCOs through contracts to provide care coordination services for their members. These services include support, resources and guidance to families.

Eligible Conditions for the Core Program



DSCC Quality Specialist Honored for Service to Families in Crisis

Tess Rhodes is a registered nurse on our Quality Improvement Team. She collaborates with her DSCC teammates and partner organizations across Illinois to make sure children in crisis have the right support.

CountyCare's Health, Safety and Welfare Team **awarded Tess its Certificate of Excellence** in July 2023. The certificate recognizes her "tremendous commitment and dedication" to keeping County Care participants safe and meeting their families' needs.

DSCC has a contract with CountyCare to provide care coordination to the children and youth with special healthcare needs in its Medicaid managed care health plan.

As a Core/Connect Care Quality Improvement Specialist, Tess helps DSCC's care coordination teams when a participant enrolled in CountyCare has a critical incident.

DSCC works with CountyCare to report these incidents and make sure our teams respond to reduce any risks for our participants and help them get the right resources and services they need.

“Tess has received accolades by email from their team multiple times, so this Certificate of Excellence proves not only have they valued her efforts in the past but her continued support for our participants, Care Coordinators, and relationship with CountyCare is truly making an impact,” said Tess’ supervisor, Quality Improvement Manager Brandon Bartels.

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 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 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 skilled nursing facility.

Individuals eligible for the waiver must meet medical criteria determined by their health

Home Care Family Outreach Associate

We have created a new Home Care Family Outreach Associate (HCFOA) role to strengthen our support for Home Care Program participants and their families.

Our HCFOA understands the challenges that families face when caring for loved ones with complex medical conditions and has lived experiences as a caregiver and parent.

This role provides support to Home Care families by acknowledging shared experiences and helping to guide families through the complexities of multiple systems of care.

This person also works to create a sense of community for caregivers within DSCC where families feel supported and empowered to navigate caregiving confidently. Home Care families can contact their Care Coordinator for a referral to speak with our HCFOA.

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, such as environmental modifications, vehicle modifications, extermination services and nurse training. Youth may qualify regardless of their family’s income. Originally, the waiver only covered participants less than 21 years of age.

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 are seeing a growing number of adults who receive services. In FY 2023, we had 156 Home Care participants over the age of 21.

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

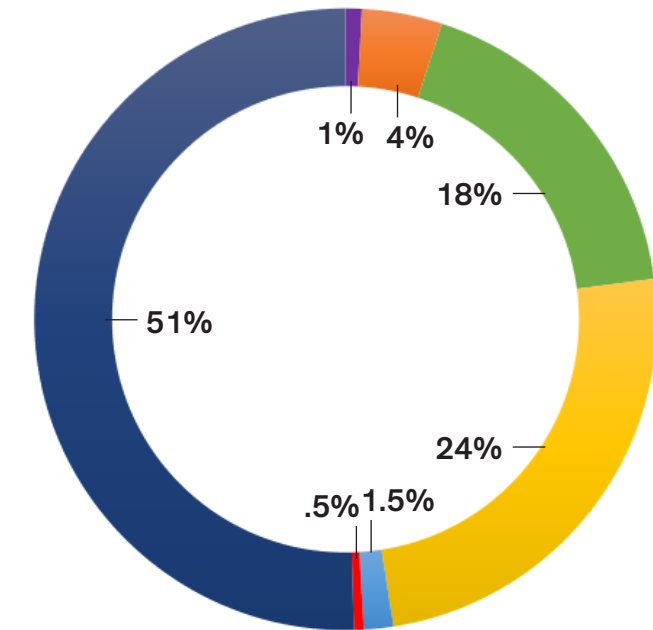
Interim Relief was an existing program under HFS. We began operating this program on behalf of HFS in late fall 2022. We offer Interim Relief participants our care coordination services and other areas of support through our person-centered planning and family-centered care.

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

Program Leadership

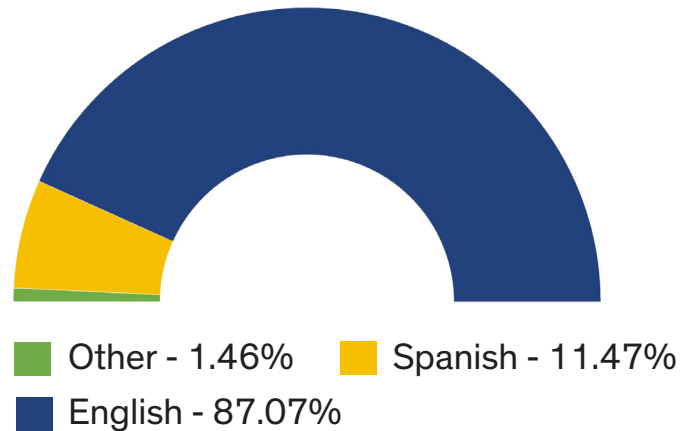


Known Race/Ethnicity of Active Participants in FY 2023

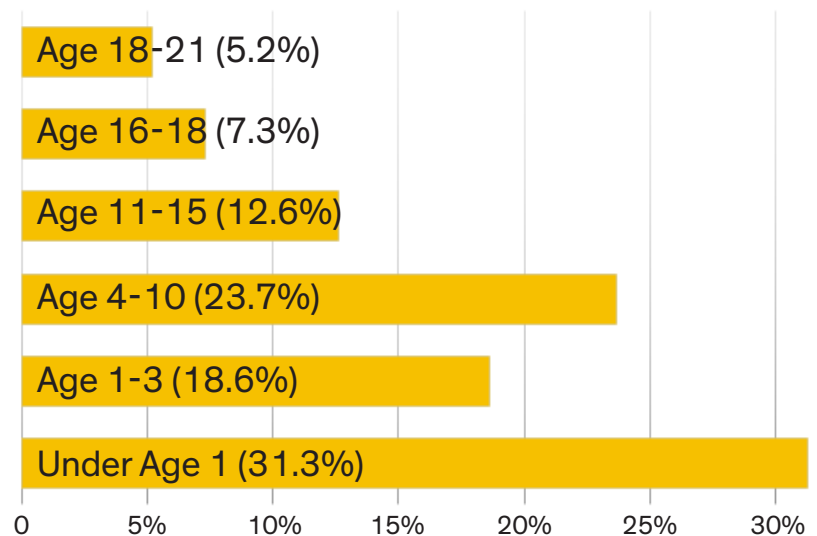


- White/European American
- Hispanic/Latina/e/o
- Black/African American/African
- Asian/Asian American
- Native Hawaiian or Other Pacific Islander
- American Indian, Alaska Native or Indigenous
- Other

Preferred Language of All Active Participants in FY 2023



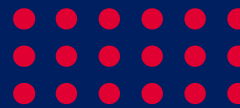
Age of All Active Participants in FY 2023



Insurance Type for All Active Participants in FY 2023



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 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 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.

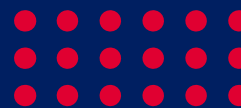


"We connected with DSCC at the hospital and really appreciate all that they do. DSCC has helped us track down nursing services and medical equipment. They're always there to help and are another go-to when you need help filling in the gaps."

- Tim Reynolds, father of Home Care Program participant Isabella



End of Public Health Emergency



The public health emergency due to the COVID-19 pandemic ended on May 11, 2023.

This ending led to a variety of changes for our participant families, including a return to in-person visits and the end of continuous Medicaid coverage.

Return to In-Person Visits

Meeting in person with our participants and families is an important part of our care coordination. We paused these visits for several years during the public health emergency (though many families continued to meet with their Care Coordinator during the pandemic).

The public health emergency allowed face-to-face visits to occur virtually. After the public health emergency ended, we returned to face-to-face meetings with our participants.

Seeing our participants in person helps us get to know them and their family better. It can also help improve a family's connection with their DSCC Care Coordinator. Our partnership with Medicaid and Medicaid managed care plans also requires us to meet with participants in person.

Face-to-face visits provide valuable opportunities for our teams to:

- Broaden their perspective and understanding of our participants' situations and needs
- Build trusting relationships
- Increase engagement
- Discuss issues that are best handled in person

Our care coordination teams have worked with individual families to accommodate their preferences and make the home visits as safe and comfortable for them as possible. We also share important personal safety tips and reminders for our team members in our policies and procedures.

End of Continuous Medicaid Coverage

When the public health emergency began in 2020, the federal government allowed for continuous Medicaid coverage. This flexibility meant no one would lose Medicaid coverage during this time.

The federal government ended continuous Medicaid coverage on March 31, 2023.

On April 1, Illinois Medicaid began reviewing eligibility for all Medicaid cases. This process is called redetermination. Redetermination is when Medicaid looks to see if a participant is still eligible.

We shared information and reminders from the Illinois Department of Healthcare and Family Services to help families understand the redetermination process and take the steps necessary to keep their coverage.

More details about the end of [*the public health emergency and its impact on our DSCC participants*](#) are available on our website.



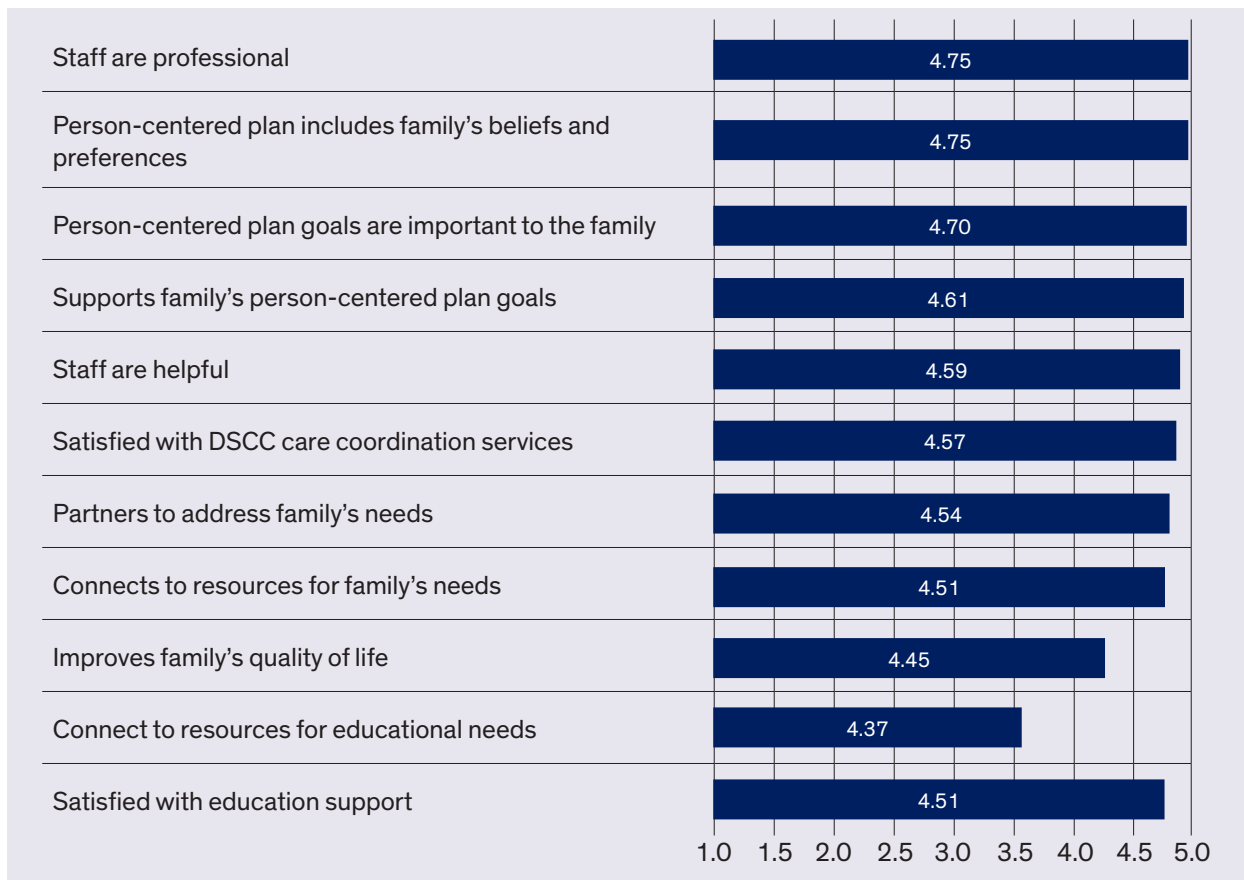
The Family Survey

We value the opinions, thoughts and experiences of the families we serve through our care coordination services. During FY 2023, we made several efforts to improve the family survey process to increase family engagement. We enlisted the help of our Family Advisory Council to offer ideas about how we could improve. This feedback led to the following updates:

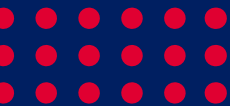
- We now distribute the annual family survey at the same time each year in February.
- We shared information about the new survey process with our participant families through social media, email messages and their care coordination teams.
- We stopped the separate series of surveys on education. Instead, we added several education-related questions to the annual family survey. This change reduced the number of surveys our families receive.
- We provided friendly reminders at certain points after the initial survey distribution to continue to encourage participation.

We are excited to announce that our initial efforts have improved our response rate from 6 percent in 2022 to 23 percent in 2023.

We will continue to think of ways we can improve the survey process to encourage more participation. Below is the average response by question from the 2023 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 truly appreciate our families taking time to inform us about what is working and what needs improvement with our care coordination practices. We take their feedback seriously and work to make improvements in policy, procedures and processes that impact their lives.

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

Care Coordination:

Our care coordination teams resumed face-to-face visits with families after the public health emergency ended on May 11, 2023. We believe these visits will further improve our connection and engagement with families.

In late October 2023, DSCC introduced a [new Family Portal](#) that gives participant families one central place to communicate with their care coordination teams, sign documents and have access to information.

DSCC developed [“All About Me” page templates](#) that families can personalize for their child and share with all members of their treatment team. This page will help all team members know more about the child and their strengths before meeting them. Families can share this “About Me” page with their child’s school, therapists, other caregivers and more.

In fiscal year 2024, our care coordination education will focus on emphasizing the best practices of care coordination, such as collaboration, communication, follow through, partnership, etc.

DSCC is in the process of making improvements to the resources we share on our website by making our online Resource Directory searchable and better organized. These improvements will hopefully help all Illinois families of children and youth with special healthcare needs find and share resources more easily.

DSCC implemented a grievance process in which families can inform us of concerns about their care coordination. [The grievance form is on our website](#). This form is an opportunity for families to inform us of their experience so we can work together to find resolutions and make improvements.

DSCC updated our authorization form so families now sign only one form to allow the sharing of information with several providers. This update reduced the number of forms our families must sign. Additionally, we updated the signature pages to better clarify which signatures are necessary and improve our families’ understanding of the form.

Nursing:

DSCC increased our outreach to nursing agencies that have the required license. We have provided information about DSCC’s programs to recruit more nurses.

In collaboration with the Division of Health Care Facilities and Programs within the Illinois Department of Public Health, nursing agencies that work with DSCC are now able to receive a license to work across the state. This change provides more opportunities for nursing coverage for families of children and adults with complex medical needs.

DSCC is providing education and training to nursing agencies to continually improve the quality of care.

DSCC is developing an interactive website that will allow families looking for nursing to connect with nursing agencies. This website will be called NurseNet, and it should be available in 2024.

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 through improving our survey process. Our care coordination services continue to improve 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 a key part of strengthening our partnership with families.

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.

Our FAC played an important role in developing:

- Our new [DSCC Family Portal](#) to help families more easily communicate and share information with their care coordination team.
- Improvements to our family survey process, including reducing the number of surveys that families receive.
- A free, three-part virtual [Health Insurance Education Series](#) to help families navigate the health insurance maze and understand their coverage and benefits.



- New ***“All About Me” page templates*** to help providers, care coordination teams, schools and other caregivers understand the likes, strengths and needs of each child beyond their medical diagnosis.
- New and updated tip sheets and resources available to families on our website.
- Changes to education and training for our care coordination teams and more.

The FAC also added its first Spanish-speaking member to broaden its representation of DSCC’s diverse families.

We are grateful to all our FAC members and appreciate the unique perspectives and experiences each brings to the council.



“I saw the FAC as a platform specifically for our population to continue to elevate our voice and understand what’s going on in the state, where we can continue to advocate and promote policy changes and also as another way to build community,” Jaclyn said. “Especially during COVID when the girls were born. I didn’t get to meet other families who were experiencing something similar or had older children who went through it who I could learn from. I just felt it was a good place to be.”

FAC Member Spotlight

In April of 2020, Jaclyn Vasquez was a busy mom of two little boys in her 40s. She soon found out she was pregnant with identical twin girls.

It was a hard, high-risk pregnancy made even more difficult by the isolation, health risks and unknowns of the COVID-19 pandemic.

With an extensive professional background in early childhood development, Jaclyn successfully advocated for her own health and for her twins to stay in the womb as long as possible.

Jaclyn delivered Ava and Olivia at 27 weeks and five days. She suddenly became the mother of “micro-preemies” fighting for their lives. It was the beginning of a rollercoaster journey that led her to DSCC and our Family Advisory Council.

Jaclyn and her husband juggled caring for their two boys at home and being in the neonatal intensive care unit (NICU) with their daughters.

Olivia spent 100 days in the NICU. Ava struggled more with severe lung damage due to her prematurity.

Ava transitioned to Ann and Robert H. Lurie Children’s Hospital in Chicago. She received a tracheostomy tube (trach) and gastrostomy tube (g-tube) just before she turned 4 months old.

She spent a total of 586 days – 19 months – in the hospital before she was stable and strong enough to come home.

Ava immediately enrolled in the Home Care Program, which DSCC runs on behalf of the Illinois Department of Healthcare and Family Services.

Jaclyn and her family then began to experience the systems and challenges involved with caring for a child who is medically complex at home. These challenges include a shortage of qualified nurses to provide in-home care and a lack of community awareness across the board about what children like Ava need.

“This is a population where we’re so overwhelmed and there’s so much going on and there’s so much

scary, and not many people know about us or how to support us, even society in general,” Jaclyn said.

Jaclyn soon found DSCC’s Family Advisory Council (FAC) and wanted to learn more.

She joined the council and is now able to share both her experience as a parent and caregiver as well as her professional expertise. She is a former early childhood special education bilingual educator and administrator for the Child Parent Centers across Chicago Public Schools. She also served as the co-director of Policy and Leadership at the [*Erikson Institute*](#).

Jaclyn now cares for Ava, 3, full-time and runs her own consulting company focused on early childhood development, community systems and policy.

“I understand where these are possibilities of intersection to create space for information, awareness, center family voices in the conversation but also raise those voices to other tables and where we need to have our voices heard,” she said.

Jaclyn says she also appreciates how the FAC is a committee that is responsive to its members.

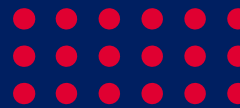
In the fall of 2023, she volunteered to join Erica Stearns as the FAC’s co-chair. In her new leadership role, she hopes to look at ways to use both data and family voices to make meaningful differences in real time.

“It really is a great space for us to connect with others and not feel so alone on our path to support our own children,” Jaclyn said. “I also think it’s a great place to learn about what else is happening across our state that could be a., either a possible resource, or b., where we can continue to elevate our voice to create changes not just for our own children but for other children as this population is growing.”



“We talk about the typically developing child and there’s so much conversation about the village that raises the child. If you need a whole village to raise a typically developing child, what are we doing for those that need additional support, especially in children like ours that are technologically dependent?”

Our Outreach



Our community outreach in FY 2023 focused on both in-person and virtual activities as well as our digital communication channels. We provided education and information to more than 182,000 people through outreach events, our website and social media.

Our team participated in 507 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 children and youth with special healthcare needs in Illinois. We encourage interested entities to [contact us through our website](#).

Statewide Transition Conference

The 17th annual Illinois Statewide Transition Conference, titled “Stepping Stones of Transition,” took place in East Peoria on Nov. 3-4, 2022.

Nearly 450 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 34 of our participant family members across the state.

“I am so thankful to DSCC for the fact they covered the cost to be here. That made a big difference in us being able to attend,” Anita said.



“As a parent, we can feel so overwhelmed. Even if help is right there, that reach can be hard to do... These types of resources educate me on how to best provide for my children’s needs and for their future.”

Thirty DSCC team members also attended the conference to network, learn from others and strengthen their skillsets and tools to serve participant 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.



DSCC participant Ayla Etheridge, then 16, said the conference helped her think more about how her interests and skills can shape her future and career goals.

“I’m very independent and would like to do more things myself,”

Ayla said. “This conference has kind of helped me visualize and think about my next steps.”

Anita Barraza attended the conference with her husband, mother-in-law, and two of her children – Daniel, then 17, and Diana, then 22. Daniel is a DSCC participant, and Diana had recently aged out of the program.

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 took place June 11-16 at the Illinois School for the Deaf in Jacksonville.

This free one-week program was for Illinois parents of children from birth to age 7 who have a significant hearing loss. DSCC supports the Institute, along with other sponsors.



The 2023 Institute served 22 families from across Illinois. 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
- Assistive communication devices
- Deaf culture
- School programming

Other activities include meeting in small groups to discuss specific concerns and connecting with other caregivers.

The children with hearing loss attend classrooms based on their age group. Experienced teachers and aides for children who are deaf or hard of hearing oversee these classrooms.

Attending children also can receive hearing, vision, psychological, speech, language and educational evaluations. They also get to play with other children who have a hearing loss.

Siblings also attend the Institute and take part in fun and educational activities, including art projects and learning to sign.



Kelly Lane and Crystal Harris said the Institute felt like home to their family. “We couldn’t have felt more welcome,” Kelly said.

Their son Casper, 4, has bilateral hearing loss, epilepsy and a developmental delay.

“This past week, I’ve felt a sense of comfort that I haven’t felt in a very long time,” Crystal said.

“And that’s saying a lot considering how much information overload has been happening,” Kelly added. “I feel like we should be feeling frazzled and overwhelmed with the amount of new information we’ve gotten,

but instead I just feel clarity. I feel clear on where my son’s at, where we need to go, and the options that we have and resources that we have at our disposal.”

Attending parent Eddi Fowler said she learned how to better communicate with her 2 ½-year-old daughter, Kacey.

In addition to learning American Sign Language (ASL) and cued speech, Eddi learned more about available resources and how to advocate for Kacey.

“I learned a lot, and I have a lot to take back home with me. I’ve got gigantic paperwork that’s going to help Kacey and my little family throughout the year with her education needs, her hearing loss, her autism, everything,” Eddi said.



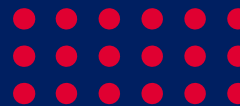
Referral Sources

Our top ten referral sources from highest to lowest for July 1, 2022, to June 30, 2023.

Referral Source	Count of Participants
Adverse Pregnancy Outcomes Reporting System (APORS)	4,032
Supplemental Security Income (SSI)	1,458
Hospital Referral	1,025
Friend/Family	783
Newborn Genetic Screening Diagnostic	737

Referral Source	Count of Participants
Newborn Hearing Screening Diagnostic	624
Early Intervention	411
IDPH/Early Hearing Detection and Intervention (EHDI) Program	279
Provider	193
DSCC Staff	111

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 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 Healthcare and Family Services

Rachel N. Caskey, MD, MAPP

Professor of Medicine and Pediatrics
Chief, Division of Academic Internal Medicine
University of Illinois Chicago

Laura Deon, MD

Pediatric Rehabilitation Medicine
Rush University Medical Center
La Rabida Children's Hospital

Carolyn C. Foster, MD, MS

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

Erin Hickey, MD

Assistant Professor of Clinical Medicine
University of Illinois Hospital at Chicago
Specialty: Pediatrics and Internal Medicine

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

Assistant Professor of Pediatrics, Section of Developmental and Behavioral Pediatrics
Department of Pediatrics
University of Chicago
Medical Director of Comer Outpatient Developmental and Behavioral Pediatric Programs, Department of Pediatrics, The University of Chicago & 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. Carolyn Foster is a physician and researcher who has dedicated her career to improving the care and quality of life for children with complex medical needs and their families.

Therefore, serving on DSCC's Medical Advisory Board (MAB) was a natural fit.

Foster joined the board in 2020. She brings her perspective as a provider as well as 15-plus years of research focused on home health care for children with complex medical needs.



"I was acutely aware from my own patients of the role DSCC played in helping them," Foster said. "I felt I could bring my experiences as a health services researcher and my understanding of how we evaluate healthcare services and what we know about kids with complex medical needs."

Foster is currently an attending physician at Ann and Robert H. Lurie Children's Hospital of Chicago in advanced general pediatrics and primary care. She is also an assistant professor of pediatrics at Northwestern University Feinberg School of Medicine.

Her research centers on developing and evaluating healthcare delivery interventions and healthcare policies for children with medical complexity and disability. The purpose is to maximize health outcomes for these children and improve how well their family members and caregivers navigate their systems of care.

Foster is particularly interested in improving both the access to and the quality of home and community-based health care for children to help them live safe, independent and full lives at home, school and beyond.

"I had a family member who had a health condition that impacted her experience in the day-to-day world, and it motivated me to be a physician. When I was in training, I appreciated this tool of using health services research to improve how we deliver care," she said.

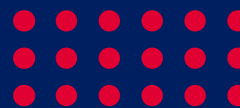
"I want to improve the delivery of care to kids and families who have the most significant medical needs. There is an ongoing gap in how we serve that population, so I want to put my effort there... This patient population deserves a voice, and I'm hoping to further emphasize that."

Foster said she appreciates DSCC's work to shed light on these issues statewide. She is happy to help advise and cheer on these efforts.

"Having a child who has a special healthcare need or disability or complex medical problem is really challenging because the health care, education and community resources are not always talking to one another," she said.

"DSCC is one of those key programs in the state of Illinois that really provides an important function in making it a little easier for families by helping with care coordination and getting what they need for their child."

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 2023 internship highlights include:

- Eight of our regional offices hosted at least one intern during the fiscal year.
 - One intern was earning a master's degree in social work from the University of Illinois Urbana-Champaign (UIUC).
 - One intern was earning a bachelor's degree in social work from UIUC.
 - Eight interns were earning their bachelor's degrees from UIUC's Interdisciplinary Health Sciences Program.
- Two interns from the Title V Maternal Child Health Internship Program were matched to work with our DSCC Title V team members and an epidemiologist from the Title V team at the Illinois Department of Public Health.
- Our Chicago Hospital Liaison hosted two graduate nursing students from UIC's Advanced Generalist master's program during the fall 2022 semester. These students worked on a project collating video education on the care of children with medical complexity for parent training purposes.

Our Chicago Hospital Liaison also serves as a board member and education committee co-chair 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 serves as a Medical Advisory Committee member for Almost Home Kids and Maryville Children's Health Center.

Intern Spotlights

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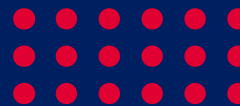
Emma Grassi – UIUC College of Applied Sciences, Master of Public Health



Before interning with DSCC, Emma had no experience working with children, let alone children with special healthcare needs. Emma says the internship with DSCC "opened a whole new world" for her.

The experience helped reshape her thinking and understanding about the need for a team to support children with special healthcare needs.

"The needs of the children and their families can easily get lost," Emma said. "The internship helped me understand that providing help isn't just a one-time thing, it's something that needs to happen throughout their life as they become adults."



As a Care Coordinator intern for the Mokena Regional Office during the fall 2022 semester, Emma learned alongside Regional Manager Deanna Deleshe, Care Coordinator Abby Moran and other care coordination team members.

“The internship was well structured, and everyone was open and willing to help you,” Emma said. “I was able to job shadow, speak with families, collect data, and learn about and better understand an area that I hadn’t been exposed to.”

Emma’s internship project focused on family engagement. She put together resource packets based on families’ feedback about what resources and information they wish they knew about sooner.

“I created resource packets focusing on cerebral palsy and hearing loss,” Emma said. “The packets will be used to remind and reengage families with DSCC about the services and supports available as their child continues to grow.”

Emma says DSCC was the perfect fit for her internship.

“I met some of the nicest, considerate, thoughtful people,” she said. “They even provided guidance and emphasized the importance of self-care on your mental health. You can’t just go all the time, you need a work-life balance. Taking time to reflect and recharge is key.”



Sandy Lu – UIUC School of Social Work, Master of Social Work

Sandy Lu is a graduate of UIUC’s hybrid iMSW Program. She interned with our Olney and Marion regional offices from May through December 2022.

One thing that impressed and surprised her was the technology and tools DSCC uses to keep everyone connected.

“I really appreciated the technology used by DSCC to connect with families, staff and others throughout the organization and state,” Sandy said. “The vast database of tools, resources, and people you could reach out to for more information or help was impressive. Seeing an organization use such a thorough, multi-faceted approach to addressing challenges was a new experience for me.”

For her internship project, Sandy created a Mental Health Toolbox to help families in southern Illinois access resources.

Her interest in mental health and a discussion with Olney and Marion Regional Office Manager Amy Jones led her to create the toolbox. Other factors for her focus included the mental health state of emergency for children and adolescents in 2021 and the ongoing struggle for racial justice.

“I learned that for families on Medicaid, there weren’t that many providers. Traveling long distances for care or long waiting lists were also barriers,” Sandy said. “I didn’t realize how different it can be accessing services in different parts of the state such as Chicago and southern Illinois.”

Sandy says she highly recommends interning with DSCC. “Everyone was so supportive. I was given a small caseload and able to job shadow, ask questions and experience how DSCC values partnering, helping and connecting, how the family is at the center of what DSCC does,” she said.

In February 2023, Sandy began working for DSCC fulltime as a Care Coordinator with the Home Care Program.

“Working as an intern really opened my eyes to what care coordination means. It helped set the foundation for the tasks and responsibilities I’m doing now. It helped me better develop so many important skills,” she said. “I’m glad I’m here.”



Selena Noriega Valdivia – UIUC College of Applied Health Sciences, Interdisciplinary Health Sciences Undergraduate

During her Peoria Regional Office internship, Selena shadowed Summer Puckett, Assistant Regional Manager for our Champaign and Peoria regional offices.

She learned about the day-to-day tasks and what coordinating services for our families looks like. She also joined family calls to learn about the information-gathering process, assessing their needs, and finding and connecting them to supports or resources to meet those needs.

Selena’s internship project focused on building connections with the Latin community and other ethnic communities to raise awareness about DSCC services and supports.

“I used existing flyers about DSCC and physically visited area sites such as ethnic markets, churches and events,” Serena said. “I posted flyers where I could and also made public announcements and answered questions after church services or other public events.”

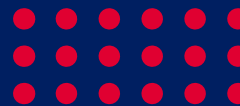
She met Spanish speakers but also met Indigenous people from Guatemala. Because they have their own dialect and don’t speak Spanish, it gave her more insight into the challenges for individuals experiencing a language barrier. She calls the internship with DSCC “a good wake-up call.”

“Instead of reading about it in a textbook, I was able to see and be a part of the interdisciplinary approach that I was learning about in college,” Selena said. “DSCC has nurses, social workers, therapists, and others working together to provide help not just to the families but to each other. The hands-on opportunities during the internship helped me see different perspectives and made me think about my degree differently, that there are lots of ways that I can use my skills to help others.”

The internship also helped her discover her passion for helping children and the ripple effect their challenges have on their entire family and community.

“This is a really great, hands-on internship for seeing the different ways healthcare providers, social workers, and others connect and why it’s important that they do...” Selena said. “It helped me build confidence, networking and public speaking skills, and a better understanding of what I want my career to look like.”

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.

We partnered with HFS to make two pandemic-related benefits permanent beyond the public health emergency in 2023.

These changes can provide continued flexibility and support beyond the public health emergency.

Licensed Parents/LRAs as Paid Caregivers

Parents or legally responsible adults (LRAs) can provide skilled nursing services to their children if they hold an active registered nurse (RN) or licensed practical nurse (LPN) license.

This approval includes participants enrolled in medically fragile, technology-dependent (MFTD) waiver services and non-waiver services. This approval is for all children approved for Home Care services, regardless of the child's age. Before the pandemic, this was only available when the participant was over the age of 21.

Overtime for Nurses

Nursing agencies now permanently receive payment for overtime hours to Home Care participants.

Overtime hours benefit the participant and family. They also allow nurse caregivers to provide more nursing coverage to participants.

The possibility of overtime also incentivizes the nurse caregiver to provide more coverage. Overtime allows nursing agencies to cover more authorized hours while stretching their staffing over fewer nurses. This is especially helpful to families during a time of increased demand for nurses.

Our FMAP Initiatives

We are also collaborating 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 have provided recommendations to the Department of Healthcare and Family Services regarding this important issue.

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

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



DSCC worked with our Information Technology Team and consultants to build the portal throughout 2023. We plan to roll it out in early 2024.

As part of our FMAP efforts, we worked to increase respite and nurse training rates. These rates were not initially included in the reimbursement rate increase that took effect in 2019. The public health emergency did allow for a temporary increase in respite and nurse training rates. We partnered with HFS to permanently increase these rates now that the public health emergency is over.

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.

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

Adolescence can be a challenging time for teens with intellectual and developmental disabilities (IDD).

It's not unusual to feel sad, stressed or overwhelmed.

We continue to partner on a research study to help teens with IDD learn how to manage these feelings and cope with times of change.

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 if 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. More than 250 DSCC participants have enrolled as of fall 2023.

Our participants in the study are receiving access to additional behavioral and mental health resources and support. The B.E.S.T. study also may help them 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.



DSCC participant Lily Kohtz, 19, says her mental health has improved since taking part in the B.E.S.T. study.

Lily has spina bifida, uses a wheelchair and has difficulty with anxiety and depression due to her disabilities.

“I think a lot of people don’t connect anxiety or depression to having a disability,” she said. “The B.E.S.T. study has helped me talk about these things. We all have bad days, but depression is worse. Understanding how disability and mental health are tied together and having strategies to use to help me cope has really helped me.”

Lily says she’s enjoyed the online group sessions, where she now meets monthly with four other teens and a group leader. All meetings are confidential.

“We go over coping strategies, such as controlling your thoughts and getting rid of the negative. I frequently use the skills we’ve learned and feel like my mental health has improved,” she said.

Lily’s mom, JoAnn Watkins, agrees that the study has benefitted Lily in many ways.

“I’ve seen a positive difference in Lily since she started with the B.E.S.T study. She’s using the skills she’s learned, and you can really see the improvement in her attitude and overall mental health,” she said.

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

Visit our website for more details about the [B.E.S.T study](#) and our involvement.

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 2023 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 Program

The UI Health Pediatric Neuropsychology Program serves infants, children, adolescents and young adults with a wide range of medical, neurodevelopmental, genetic, psychiatric and learning disorders.

DSCC provided \$400,000 in FY 2023 to support the clinic through Dec. 31, 2027. These funds made the following services possible during FY 2023:

- The Pediatric Neuropsychology Team led by Dr. Woojin Song, PhD., scheduled appointments with nearly 85 individuals.
- The team fully evaluated about 60 patients. They provided detailed reports that include the results from their testing, clinical diagnoses and recommendations for therapy, intervention, management and repeat testing, if indicated. The team uploads these reports into each patient's medical record and provides and reviews them with the patient's family and school. These reports are also shared with mental health providers as indicated.
- UI Health adult neuropsychology providers evaluated another 35 adolescents ages 16 to 18 to provide similar analysis, documentation and dissemination of the reports.

Many of the Pediatric Neuropsychology Program's patients are already struggling with serious chronic health conditions. Thanks to DSCC's financial support, the program is making a meaningful impact on these children and young adults' health and well-being.

“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, Assistant Professor of Pediatrics, Section of Developmental and Behavioral Pediatrics, at the University of Chicago is one of our Medical Advisory Board members. She has devoted her research efforts to the study of children with invasive home mechanical ventilation.

Sobotka has partnered with DSCC on a new 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.”

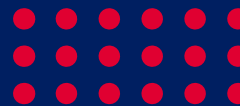
The study includes a one-year parent-to-parent coaching pilot program for families. This pilot program is for families who have a child on a ventilator in the hospital and are awaiting home nursing so their child can be discharged home.

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

The purpose of the parent coaching pilot is to help families gain tips and tricks to help find home health nurses.

Dr. Sobotka's team began partnering with DSCC's Staffing Support Specialist in May 2023 to find potential families to participate in the study.

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.



"DSCC has given us everything that we have right now when it has come to our son and his needs with his hearing loss. They were very comprehensive in the information that they gave me and really started giving me events that I could go to, to meet other people with hearing loss... I feel like there's a whole world of opportunities opening up for us."

– Sarah Berns, mother of Core Program participant Colsen



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