



## Division of Specialized Care for Children

# Annual Report

Fiscal Year 2025



# Executive Director Greeting

Each year, the Division of Specialized Care for Children (DSCC) has the privilege of working alongside families, providers and community partners to support children and youth with special healthcare needs across Illinois. Our FY 2025 Annual Report reflects our progress and the goals guiding our work ahead.

In FY 2025, we worked to address system gaps, uplift family voices and strengthen supports that help youth with disabilities transition to adulthood.

In response to feedback from families and home nurses, we sponsored the expanded eHomeCare training program on caring for children with complex medical needs at home. This free, virtual curriculum helps families and professionals refresh their skills and expand their knowledge. We are proud to support accessible training and safe, high-quality care.

We also deepened our engagement with families through our Family Advisory Council. With feedback from the FAC's dedicated parent leaders, we developed an online Caregiver Mental Health Toolkit. This resource offers practical tips, self-care strategies and mental health resources to help caregivers prioritize their well-being. The toolkit is available on our website for all Illinois families.

Keeping family feedback at the center of our work, we launched a new webinar series focused on planning for the transition to adulthood. The two-part series helps families navigate changing roles and challenges that come as their children enter adulthood. We also continued our annual Health Insurance Education Series for families, focusing on Medicaid Home and Community-Based Services Waiver Programs.

None of this work would be possible without the dedication of our staff, the trust of the families we serve and the strong partnerships we share across Illinois. We are especially grateful to the families who share their insights, experiences and leadership to improve services for children and youth statewide.

Thank you for your continued partnership and support.



A handwritten signature in black ink that reads "Thomas F. Jenkins". The signature is written in a cursive style with a long, sweeping underline that extends to the right.



## Our Vision

Children and youth with special healthcare needs should be 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.





# 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 (CYSHCN).

Title V programs exist in all 50 states and nine territories. Federal law requires that at least 30 percent of Title V funding support services for CYSHCN.

Since 1937, the Division of Specialized Care for Children (DSCC) has managed Illinois' Title V program for CYSHCN. Our role extends beyond the families enrolled in our care coordination programs. Through statewide partnerships and direct work with families, we help strengthen systems of care for all CYSHCN in Illinois.

This work allows us to identify system gaps, address inequities, and develop solutions that improve access to care.

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 core Title V responsibilities is identifying needs, setting priorities and implementing strategies to better serve all Illinois CYSHCN and their families. We continue to work on the two main priorities that guide our Title V work:

### **Priority 1: Strengthen Transition Planning and Services for CYSHCN**

DSCC advanced transition-related efforts that help youth and caregivers prepare for adulthood and support providers in guiding youth and families through the process. Key initiatives included:

- Educating youth and caregivers about transition planning
- Partnering with healthcare providers to strengthen transition practices
- Promoting transition-related resources within communities statewide

DSCC program initiatives included:

- Training care coordination teams on transition topics
- Launching DSCC's Youth Advisory Council
- Co-sponsoring the Illinois Statewide Transition Conference
- Expanding transition-focused tools and resources for care coordination teams

## **Priority 2: Support Early Screening and Connection to Family-Centered Care**

DSCC collaborated with families and community partners to promote early identification and connection to care within a medical home.

Key activities included:

- Partnering with the Illinois Department of Public Health (IDPH) and the UIC School of Epidemiology to analyze medical home and emergency department utilization data and report our research in a manuscript sent for journal publication
- Continuing research 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
- Expanding access to educational resources through DSCC's online Resource Directory

We partnered with other educators to fund training for home nurses and family caregivers of individuals with medical complexity.

Families also remained central to our Title V work through active partnership with the Family Advisory Council (FAC). Together, we:

- Developed an FAC sub-group to recommend improvements to the Medicaid transportation request and reimbursement processes
- Began developing a Caregiver Toolkit with practical tips and resources
- Published the online Caregiver Mental Health Toolkit
- Incorporated family perspectives into care coordination training

“DSCC has given us the information needed to advocate for our child and helped us with every resource they have to be able to keep her home, healthy, and thriving.”

## Needs Assessment and Future Direction

In 2025, we partnered with IDPH to complete a comprehensive statewide needs assessment for all maternal and child health populations. The assessment's findings are helping us set priorities and guide strategies for meaningful system improvement.

Families, caregivers and community partners played a central role throughout the 2025 needs assessment. Family leaders facilitated focus groups and partnered with us to analyze findings. They also highlighted inequities in access to care, care coordination and navigating the healthcare system.

Results from the assessment informed the new five-year action plan, launched in fall 2025. Through this plan, DSCC has prioritized system improvements in three key areas:

- Supporting the transition to adulthood for adolescents and youth with special healthcare needs.
- Improving access to care within a medical home for CYSHCN.
- Strengthening statewide disaster preparedness efforts for CYSHCN and their families.

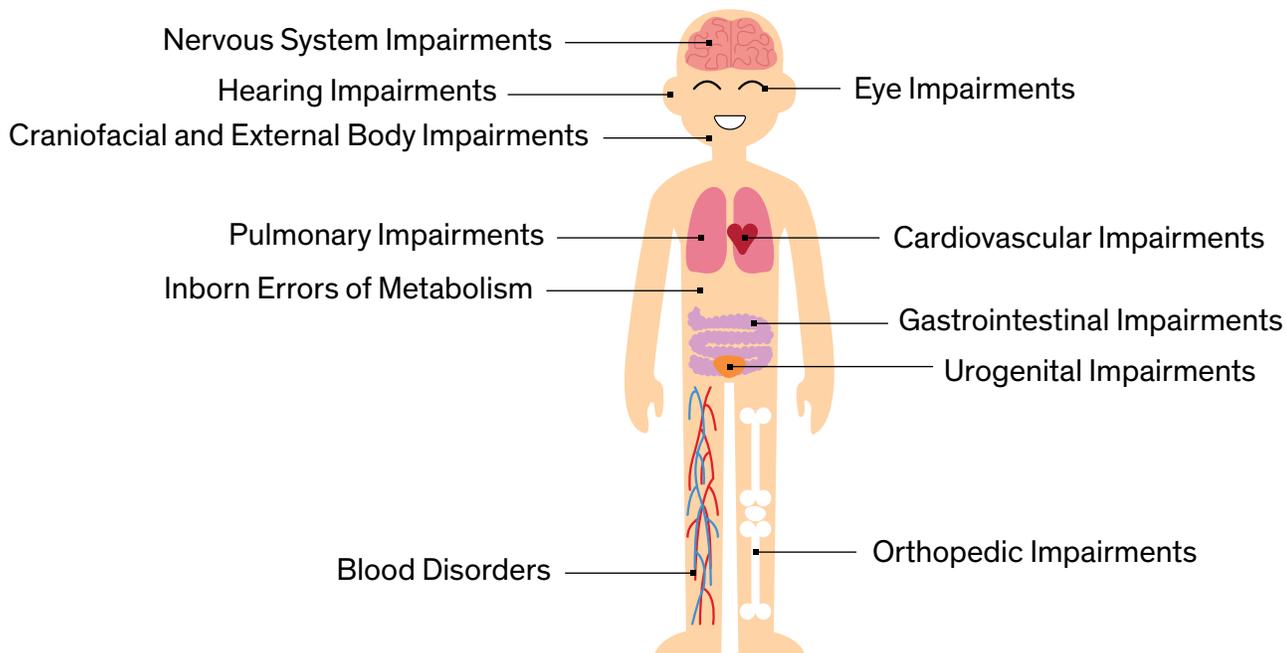


# Our Programs

DSCC provides care coordination services through four programs:

- **Core Program** – Serves youth from birth to age 21 with medical conditions in one of our 11 eligible impairment categories (see figure). Core Program services include developing a personalized care plan and providing support, resources and guidance to families. The program can also support needs such as therapy, specialized equipment and transportation for medical appointments and treatment.
- **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. Connect Care Program services include developing a personalized plan of care as well as support, resources and guidance to families.
- **Home Care Program** – Serves children and adults in need of skilled in-home shift nursing, including those who are medically fragile and technology-dependent. 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.
- **Interim Relief Program** – Serves children under age 21 with eligible mental health or behavioral disorders. This program supports the need for Psychiatric Residential Treatment Facility level of care.

## Eligible Impairment Categories for the Core Program

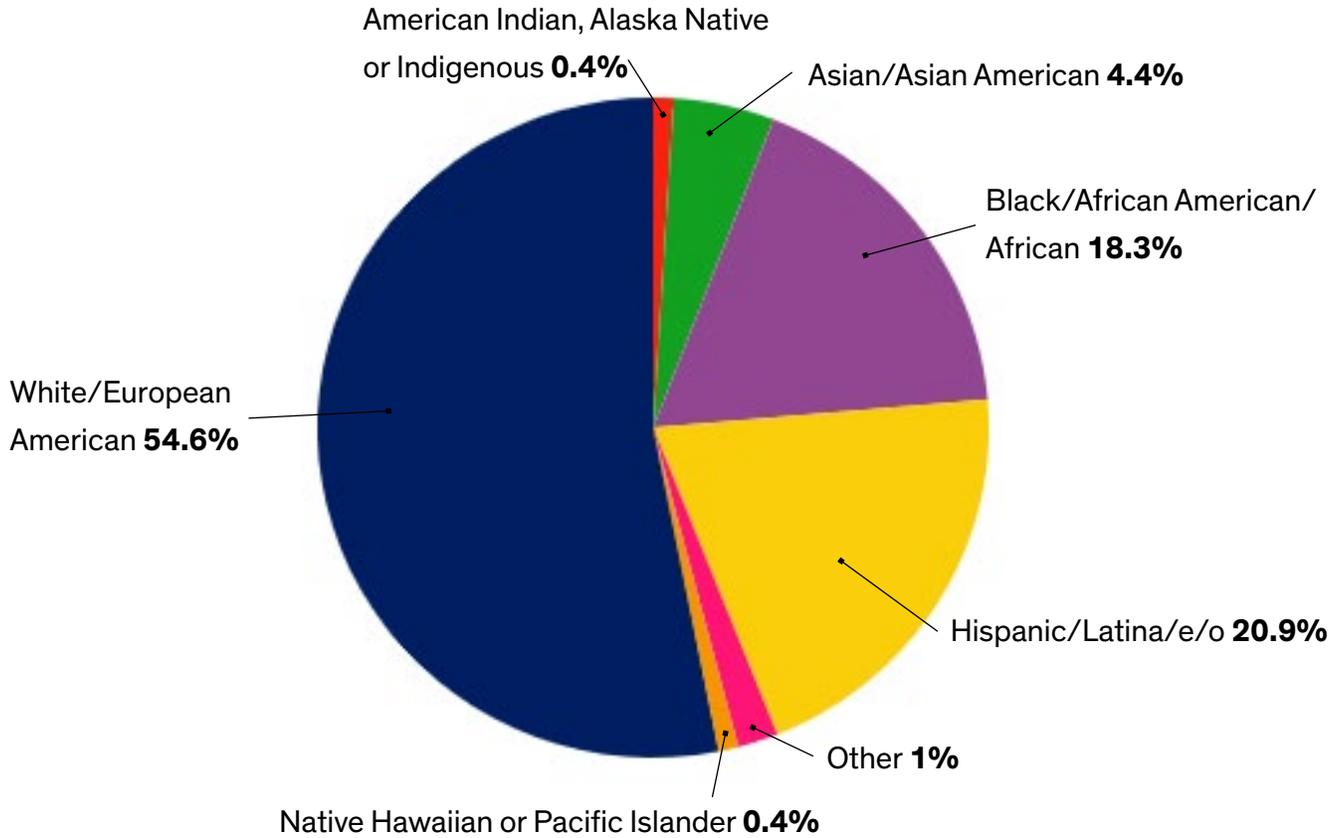


### For more information:

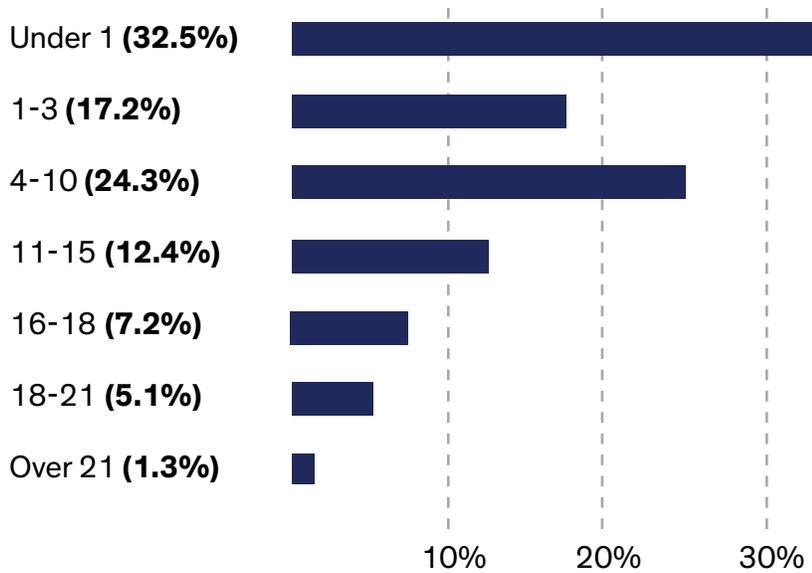
Visit <https://dsc.uic.edu/how-we-help/our-programs/> to learn about our care coordination programs.

# Our Participants

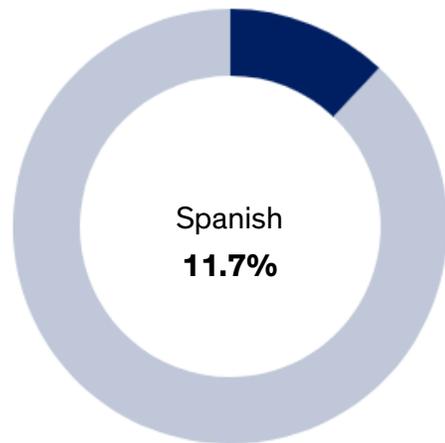
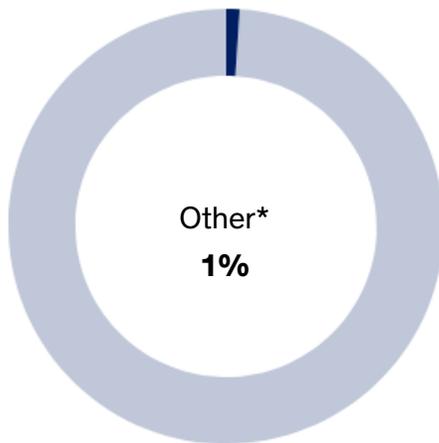
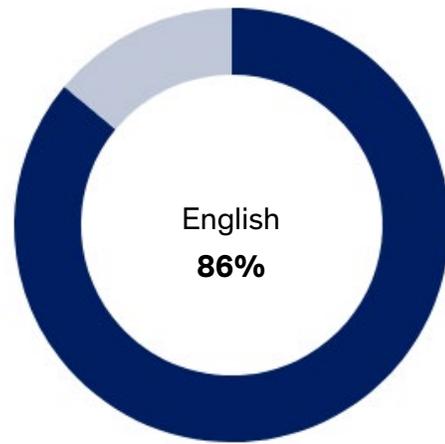
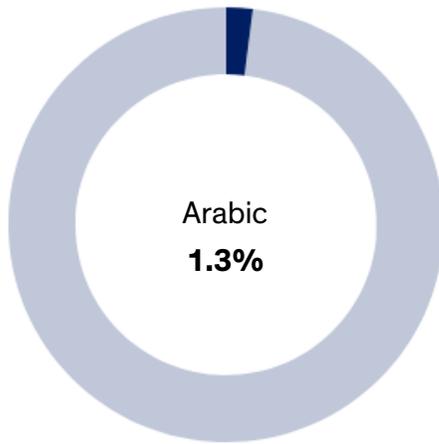
## Known Race/Ethnicity of Participants in FY 2025



## Age of FY 2025 Participants

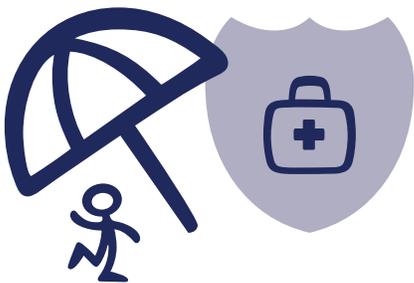


## Preferred Language of Participants in FY 2025



\*Other includes: Cantonese, Chinese, Hindi, Mandarin and Polish

## Insurance Type for FY 2025



Dual  
20%



Private Only  
20.4%



Public Only  
59.6%

# Our Care Coordination

Our Care Coordinators draw on the knowledge and expertise of our nearly 90-year history to serve families. Care Coordinators are the main point of contact for our participants, answering their questions and leading the team that's dedicated to their child's medical, social, behavioral, educational and financial needs.

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 not covered by Medicaid or other insurance.

## Care Coordination in Action



### Eli's Family

Beatrice Alvarez says DSCC is an essential partner in helping her son Eli, 19, navigate the crucial transition to adulthood.

Eli has Down syndrome and autism. He is also a musician and songwriter who is pursuing a career in the music industry.

As he enters adulthood, Eli is planning for his future and how to share his original music with the world. Beatrice wants to help him achieve his goals and the highest level of independence.

"It's scary," Beatrice said of the transition process. "Even the IEP (Individualized Education Program) is not the typical IEP anymore... it's also about, 'Oh, what do you want to do with your future?'"

Eli's Care Coordinator regularly checks in with his family, serving as a valuable sounding board. She's helped connect them with funding sources for Eli's hearing aids. She also helps troubleshoot gaps or issues with Eli's care and find appropriate resources.

"It's a really good relationship. I feel that I can reach out to her whenever I need to, and I'm grateful for that," Beatrice said.



### Quinn's Family

Quinn Brassard, 3, was diagnosed with Group B Streptococcus meningitis as an infant. The infection caused many complications, including mild cerebral palsy and mild to moderate hearing loss.

Her mom, Caitlyn, said DSCC ensured that Quinn's needs didn't "fall between the cracks" as she aged out of Early Intervention.

Caitlyn calls their Care Coordinator "amazing" and appreciates how she cares about their entire family.

"They really are like extended family, and just (asking), 'How's life going? Do you need any assistance? How can I make it a little easier on you through this process?'" she said.

Their Care Coordinator also helps with "the headache of insurance that we as special needs parents struggle with."

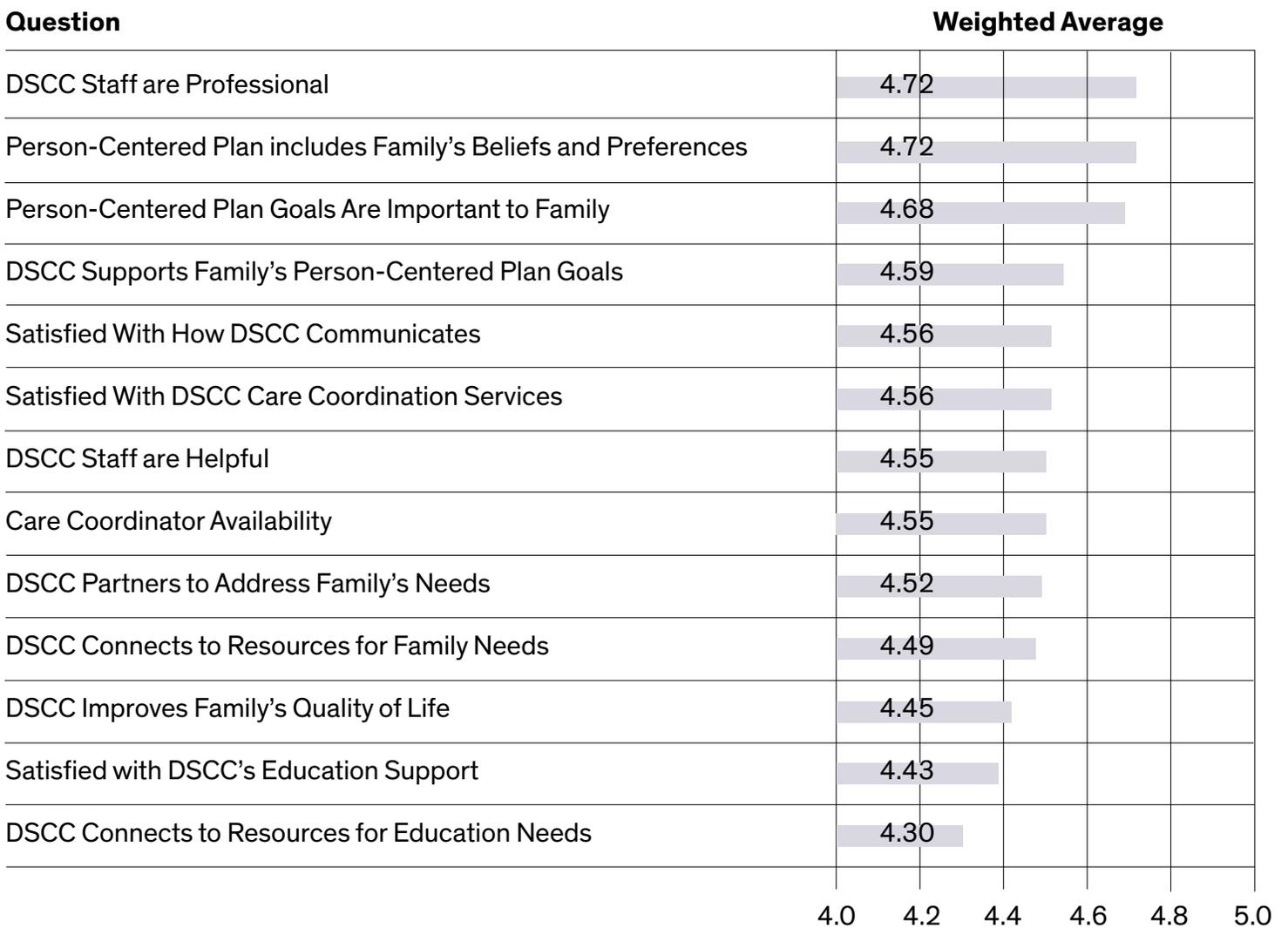
"As a special needs mom, you worry about, I'm not going to live forever. Is she going to have what she needs? Is she going to have resources she can reach out to if I'm not there," Caitlyn added. "DSCC has, in the short amount of time we've already had them, already proven that they're going to keep us going in having what we need."

# Family and Youth Engagement

Feedback from the families and young adults we serve shapes our work. We encourage our participants' input in several ways, including our annual family survey and our advisory councils.

## The Family Survey

Our annual family survey goes out to all participants in February of each year. It's an important and easy way for families to share how well we are meeting their needs.



**Five-point Likert scale:**

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

## Survey Results in Action

We've used input from our FY 2025 annual survey to develop customer service training for DSCC teams to strengthen our partnership with families. This training will eventually become part of our onboarding process for new staff and will also be incorporated into the 2027 organizational education initiative.

The training will focus on topics including:

- Communication
- Teamwork
- Sensitivity to the needs of children and youth with special healthcare needs
- Response times
- Follow-up times

We are also working on developing a 2027 organization-wide education and resource initiative that will focus on:

1. Engaging and connecting with families
2. Proactive care coordination
3. Connecting care coordination and health education

These are just a few examples of how we use the family voice to improve processes and procedures, ultimately enhancing our participants' quality of life and their families' ability to provide care. We will also continue partnering with our Family Advisory Council and Youth Advisory Council to explore ways to make the family survey more accessible and easier for our participants to complete.

## Family Advisory Council

Our Family Advisory Council (FAC) comprises participant family members from across 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.

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

Throughout FY 2025, our FAC provided crucial input and support for initiatives that include:

- **Caregiver Mental Health Toolkit** – Our FAC members shared the need for more mental health support and resources for caregivers. Their feedback helped us develop a new Caregiver Mental Health Toolkit. This comprehensive online resource can help caregivers navigate the unique challenges of their roles while prioritizing their mental health and well-being. The toolkit includes a diverse collection of tools and resources tailored to caregivers' needs. These resources can help manage stress, prioritize self-care and build resilience.

Our Caregiver Mental Health Toolkit includes:

- Stress management strategies and techniques to help you cope with tough times.
- Self-care tips and practical ways to nurture your own physical, emotional and mental health.
- Mental health support resources to connect you with professional help and support networks when needed.
- Apps, online tools, videos and podcasts you can access anytime.

The Caregiver Mental Health Toolkit is available on our website at <https://dsc.org/caregiver-mental-health-toolkit/>.

- **Family-Led Trainings and Panels for DSCC Team Members** – The FAC created the Family Perspective on Care Coordination training series for new DSCC team members. They also held their first family panel discussion that was open to the entire DSCC organization.

DSCC team members have shared how powerful it is to hear directly from families about what care coordination really feels like - what works, what doesn't and what truly makes a difference. These stories have helped new Care Coordinators understand families on a deeper level and have already strengthened those relationships in meaningful ways.

- **Transportation Subcommittee** – The FAC formed this subcommittee with family leaders and DSCC staff to address families' concerns. 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.

This group includes DSCC team members, FAC family leaders, and partners from organizations across Illinois. Together, they volunteered their time to complete a nationwide review of Medicaid's fee-for-service medical transportation programs. The group then used that information to create recommendations for how Illinois can improve access to transportation reimbursement for families.

- **Caregiver Toolbox Workgroup** - This group of FAC members is helping build resources for caregivers, by caregivers. The workgroup is developing tip sheets and information in four main categories to get started:

- From Hospital to Home: Helping families prepare for that big transition.
- Home Health Nursing 101: Tips and guides for navigating nursing care at home.
- Building Your Village: Practical advice on creating and maintaining your support network.
- Documentation and Organization: Strategies to help families stay on top of it all.

Learn more about the Family Advisory Council on our website at <https://dsc.uic.edu/who-we-are/family-advisory-council/>.

## FAC Member Spotlight – Dena Chapman

Dena Chapman believes deeply in the power of the parent voice, especially for parents navigating complex medical needs.

“The best resource for a parent of a child with medical complexities is another parent of a child with medical complexities,” she said.



Dena’s learned this lesson and continues to practice it, both as a parent and a longtime family advocate.

DSCC’s Family Advisory Council (FAC) is a valuable outlet for Dena to connect, share her hard-earned knowledge and gain insight from other families.

“What’s great about the FAC is the wealth of knowledge that exists within this group—it’s invaluable! Our lived experiences deem each one of us experts in knowing the needs of our kids/young adults; our collective experiences serve as a resource for new families and seasoned families as well—I’m constantly learning new information that helps me to make informed decisions for my son, and I know everyone else in the group feels the same way,” Dena said.

“The FAC is a phenomenal community of resourceful family advocates and I’m very proud to be a part of it.”

Dena’s son, Malachi, 26, has Spinal Muscular Atrophy, type 1. The condition affects his gross motor function, rendering him unable to walk, talk or breathe.

Dena says she enjoys continuing to learn from other families’ perspectives and sharing the lessons she’s learned during her 26 years of caregiving.

“We have to step up in our knowledge base so that we can provide the best care for our families and also to pay it forward for the families that are coming behind us,” she said.

She encourages all parents to take advantage of the FAC’s open forums, which occur twice a year.

“You can’t go wrong being a part of this group,” she said. “You’re going to learn, you’re going to grow, and you’re going to feel like you are contributing in a way that is both meaningful and impactful.”

To learn more about Dena and her family’s story, visit <https://dsc.uic.edu/who-we-are/family-stories/>.

## Youth Advisory Council

Our new Youth Advisory Council (YAC) gives teens and young adults an outlet to share what's important and helpful to them as they plan for the future.

The YAC is open to all Illinois youth with special healthcare needs ages 15 to 24. It 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 council held its first official meeting in October 2024 and now meets virtually four times a year.

The YAC's first project is to develop resources, tip sheets and a short video on college readiness, including how to advocate for yourself in Individualized Education Program (IEP) meetings and what accommodations are available.



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

# Our Outreach

Outreach is a vital part of DSCC's mission and an essential way we raise awareness of our programs and services. We connect with families and professionals through in-person community events, virtual opportunities and DSCC's digital communication channels.

In FY 2025, we provided education and information to more than **322,000 people** through our outreach events, website and social media.

Our team participated in **335 in-person and virtual events**, including hospital rounds, presentations for healthcare providers and community groups, family support groups, and resource and health fairs.



## Illinois State Fair

DSCC expanded our annual outreach at the Illinois State Fair to help support the fair's sensory-friendly initiatives. For the first four days of the 2024 state fair, DSCC team members staffed the fair's Sensory Station,

an air-conditioned, dedicated quiet zone with activities and resources to help visitors regroup and refocus.

Our team reached about 3,000 people and provided tools and resources to support children and adults with sensory sensitivities and other needs.



## Illinois Statewide Transition Conference

DSCC helped plan and sponsor the [19th annual Illinois Statewide Transition Conference](#) on Nov. 7-8, 2024, in Springfield.

The conference provides valuable resources and information to help youth with disabilities and their families navigate the transition to adulthood.

Nearly 450 people attended the 2024 event, including youth with disabilities, parents, caregivers, vocational professionals, healthcare professionals, educators and more.

DSCC covered the conference-related expenses for about 20 participant families to attend.

Participant Brenton Braxton attended with his parents and sister just before his 18th birthday. He said the resources and knowledge his family gained at the conference will help him achieve his goals.

“I think some things from here that I learned is that not only I’ll still have my independence, but I can also use my parents to help me in my journey and to living it to the fullest and doing all the things I want to do,” he said.

“The fact that we get to do it as a family is the most important part,” his mom, Veneise Braxton, added. “We’re a unit, and whatever comes our way, we get through it together.”

## Health Insurance Education Series for Families

DSCC hosted our third free virtual Health Education Series in the spring of 2025 to help Illinois families better navigate their health insurance coverage and benefits. In response to family input, our 2025 series explained Medicaid Home and Community-Based Services Waiver Programs for Illinois.

A total of 267 people attended the three-part series. All recordings, slides, and related materials are available on our [Family Education Webinars page](#).



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

June 10-14, 2025, marked [80 years of the Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing](#).

This free, annual program is for parents and caregivers of children aged 6 and under who have an identified hearing loss. It helps families learn, connect and find resources all in one place. DSCC helps support the Institute, along with other sponsors.

This year, 18 families from across the state found community and empowerment at this five-day program.



Parents Rogelio and Lizeth came to the Institute with their 10-year-old son, Roger, and their 2-year-old daughter, Aliah. Aliah was born with Microtia, a condition that affects the shape of the ear and causes hearing loss.

Their family came to the Institute to learn how to best support her development.

“We have learned a lot, how to help my daughter and how to make us stronger, how to defend her, how to prepare her for the future,” Lizeth said.

“My son Roger has been learning how to help his sister,” added Rogelio. Roger also formed a close bond with the other siblings at the Institute.

## Referral Sources

Our top ten referral sources from highest to lowest for July 1, 2024, to June 30, 2025.

Referral Source	Count of Participants
Adverse Pregnancy Outcomes Reporting System (APORS)	4,141
Supplemental Security Income (SSI) Referral	2,002
Hospital Referral	985
Newborn Genetic Screening Diagnostic	967
Friend/Family	759
Newborn Hearing Screening Diagnostic	554
Early Intervention	377
Illinois Department of Public Health (IDPH)/Early Hearing Detection and Intervention (EHDI) Program Referral	287
Provider	151
DSCC Staff	120



“From insurance to medical care and education, DSCC has been with me every step of the way.”

# Our Medical Advisory Board

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

The MAB meets twice a 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 2025 are:

## **Patricia R. Bellock**

Retired State Representative and Director  
Illinois State Medicaid and Child Support Agency  
Illinois Healthcare and Family Services  
Illinois Equal Justice Foundation Board Member  
Misericordia Western Auxiliary Board Member

## **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, MSHS**

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 Medicine  
and Pediatrics  
University of Illinois Hospital at Chicago

## **Matthew Mischler, MD, FAAP, FACP**

OSF St. Francis Medical Center  
University of Illinois College of Medicine at Peoria

## **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

## **Kathy D. Swafford, MD**

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. Matthew Mischler

As a physician and clinical professor of internal medicine-pediatrics, Dr. Matthew Mischler is passionate about providing high-quality care across the lifespan.

This continuity of care is especially important for youth with special healthcare needs as they transition to adulthood.

“How do we build safe landing spots on the other side for kids and families as they’re aging out of pediatric care?” Mischler said. “It’s such a needed space to be in. It’s so scary for families and caregivers. There’s so much fear and trepidation and absolutely, understandably so.”

As a member of DSCC’s Medical Advisory Board, Mischler enjoys collaborating with DSCC and healthcare professionals across Illinois to improve transition support for families and providers.

“One of the things that’s so huge that DSCC does is help families navigate in that space,” he said. “They meet patients and families where they are to try to help them through that time.”

Mischler currently practices at OSF St. Francis Medical Center and is a Clinical Professor of Internal Medicine and Pediatrics and Program Director of the Med-Peds Residency Program at the University of Illinois College of Medicine at Peoria.

Med-Peds physicians receive dual training in both pediatrics and adult medicine, making them uniquely qualified to provide seamless care from childhood through adulthood.

Mischler hopes his background and experience can help support DSCC’s ongoing efforts to strengthen providers’ knowledge, resources and skills to better support transition-age youth.

He also praises DSCC for guiding families during the crucial transition period and working to build safe landing spots for patients aging out of pediatric care.

“Having an organization that stretches across the state like DSCC is such a huge resource in Illinois,” he said.

As an MAB member, Mischler is focused on increasing awareness of DSCC and its wealth of transition resources across the state’s healthcare community.

“When there’s an organization that its mission and its goal is to support the most vulnerable and the most medically complex patients and families, that’s a really special thing to be a part of and that’s a huge thing for practicing physicians, nurse practitioners and PAs (physician assistants) to know is there for their patients,” he said.

“The more people who can be aware of what DSCC is and how many people they support and how much advocacy goes on behind the scenes for the most vulnerable patients, that’s really important.”

# 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.

The benefits of these valuable mentoring opportunities include:

- Expanding outreach by educating students about DSCC's programs and mission
- Cultivating potential future employees
- Providing extra staffing for DSCC to improve our level of service
- Sharing ideas to develop new resources and apply research to address participant families' needs and improve overall systems of care

Our FY 2025 internship highlights include:

- Seven DSCC regional offices hosted at least one intern to support care coordination and other projects (Champaign, Lombard, Marion, Olney, Springfield, St. Clair and Home Care Region 2).
- Six DSCC teams/departments hosted at least one intern to help with special projects and ongoing needs (Title V Research and Practice Initiatives; Benefits Management and Research; Home Care Quality Improvement; Hospital Liaisons; the Learning Support Team/Core Quality Improvement Team; and Transition of Care).
- Five interns were earning a master's in public health (MPH) from three universities: the University of Illinois Chicago (UIC), the University of California - Los Angeles and the University of Albany.
- Four interns were earning a master's degree in social work (MSW) from three universities: the University of Illinois Urbana-Champaign (UIUC), Dominican University and Southern Illinois University-Carbondale (SIUC).
- Three interns were earning their bachelor's degrees from UIUC's Interdisciplinary Health Sciences Program (B-IHS).
- One intern was earning a master's degree in health administration from Governors State University.
- One intern was earning a bachelor's degree in social work (BSW) from UIUC.
- One intern was earning a bachelor's degree in human services with a focus on communication disorders and sciences from Eastern Illinois University.

- One current DSCC employee earning her master’s in social work through UIUC completed her internship at DSCC from August 2024 to May 2025.
- During the fall 2024 semester, our Chicago Home Care Hospital Liaison hosted two students from UIUC’s Master of Science in Nursing for Non-RNs. The students job-shadowed and visited Ann and Robert H. Lurie Children’s Hospital of Chicago, La Rabida Children’s Hospital, Almost Home Kids and Maryville Children’s Healthcare Center to learn about care coordination and children and youth with special healthcare needs. They also developed a diagnosis-based resource guide for the Home Care Enrollment Team and completed a poster presentation with their cohort. One of the students secured a highly coveted nursing internship position at Lurie Children’s Hospital on the Cardiology Unit. After graduation, both students went on to work in pediatrics. The students expressed that the experience was enjoyable and eye-opening, providing insight into this population, their needs, and the numerous opportunities to serve them.

## LCSW Supervision

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

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

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

During FY 2025, one DSCC team member completed their 3,000 hours, while five additional staff members began their supervision cohort.

## Intern Spotlight – Erica Wild, UIUC School of Social Work

As the parent of two children with complex medical needs, Erica Wild understands how hard it can be for caregivers to show themselves kindness rather than self-judgment.

As part of her two-semester internship with DSCC, Erica developed the [“Self-Compassion for Caregivers of Children with Complex Medical Needs” training](#) for DSCC team members and families. It is available online in our [Caregiver Mental Health Toolkit](#).

Erica completed her internship in May 2025 and graduated with her bachelor’s degree in social work from the University of Illinois at Urbana-Champaign. She is now pursuing her master’s degree and credits DSCC with helping her realize her passion for the medical side of social work.

“Medical complexities can be so emotionally draining and overwhelming for everybody in the family,” Erica said. “This is what I want to do.”

# Our Collaborations

## Free Virtual Training Program on Caring for Children With Complex Medical Needs at Home

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 and care education for families.



Throughout FY 2025, we worked on several projects as part of Illinois' plans for an increased federal match (FMAP) from the American Rescue Plan Act.

Research shows that the number of children in need of medically complex care at home is steadily growing. With this growth, there is an urgent need for current and accessible educational resources to ensure the quality and safety of care for these children.

We've also heard from families and home nurses that they need a way to expand their knowledge about care in the home and refresh their skills.

We are proud to sponsor the expanded eHomeCare program, which helps meet this need by equipping caregivers with the necessary tools and knowledge to provide high-quality care.

The eHomeCare program provides comprehensive, evidence-based information on the care of children with complex medical needs at home. The training consists of eight on-demand courses to enhance the knowledge, skills and confidence of home care providers in areas including caring for a child with a tracheostomy, central line care and more.

Parents, extended family members, caregivers and others can use these modules to learn and refresh different skills for caring for their medically complex child in the home setting.

The eHomeCare Program originally started as one course focused on trach and vent care through a partnership of several Wisconsin-based nursing schools and hospitals.

DSCC provided funding and collaboration to expand the eHomeCare training program in response to family feedback on the need for more education and training on caring for children with complex medical needs at home.

We partnered with HFS and the federal Centers for Medicare and Medicaid Services to fund the project.

We hope the expanded eHomeCare training modules will be a valuable resource for families, caregivers and everyone involved in their children's complex care at home. You can learn more at <https://dsc.uic.edu/free-virtual-training-program-on-caring-for-children-with-complex-medical-needs-at-home/>.

## **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. Gaps in behavioral health services for these teens remain a significant challenge.

We continue to partner on the PCORI B.E.S.T. study to help bridge this gap and provide more comprehensive support to teens with IDD.

The study 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 examines whether care coordination that includes mental health programming can help teens with IDD improve their mood and manage stress. The virtual program is available for some teens and young adults enrolled in our Core or Connect Care programs.

As of fall 2025, 301 DSCC participants were enrolled in the study.

Study participants 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.

Youth and adults with IDD play an active role in shaping the study as members of the research team and advisory boards. This involvement ensures the study reflects their experiences and addresses real-world barriers to care.

Recruitment for the study will continue through at least May 2026.

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

Dr. Sarah Sobotka is funded by 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 is Associate Professor of Developmental and Behavioral Pediatrics at the University of Chicago Medicine. She also serves on our Medical Advisory Board.

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 a virtual feeding support group 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. Recently, they were able to expand their study to families who live farther from the University of Chicago and are willing to travel for their in-person assessment.

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



# Our Funding

A combination of state and federal funds finances DSCC's operations.

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 fund the direct costs of the Connect Care Program.



“DSCC has gone above and beyond to help meet our family’s needs. When we hit a roadblock, many members of DSCC took time out of their schedules to assist us. DSCC is the one organization that genuinely cares about the well-being of our family as a unit, not just a focus on the child. That is incredibly helpful as it helps us feel supported on this journey, which can frequently feel complicated and overwhelming.”