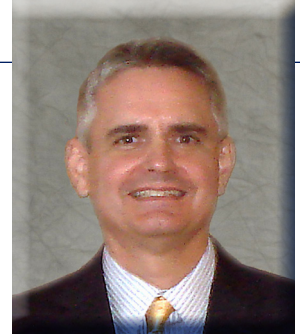


# Division of Specialized Care for Children



## Annual **REPORT**

# Executive Director Greeting



Fiscal year 2021 (July 1, 2020, through June 30, 2021) was our first full year of operating during a global pandemic.

The University of Illinois Chicago's Division of Specialized Care for Children (DSCC) team continued to persevere and collaborate to support Illinois children with special healthcare needs and their families through new and ongoing challenges.

Our staff found ways to stay connected to one another and to the families we serve as we worked almost entirely remotely. We partnered with state agencies and organizations to make sure the needs of the state's most medically complex children and adults are at the forefront of pandemic planning and response efforts. We shared the latest health guidance and resources about testing, vaccines, assistance programs and more to help all Illinois families. We also continued to improve the strength of our programs and the quality of services for participants.

During FY 2021, we finalized our contracts with the state's five Medicaid managed care organizations (MCOs). These contracts allow us to continue serving our participants who now receive insurance coverage through the state's Medicaid managed care program, called HealthChoice Illinois. We developed our Connect Care Program to serve these families and are pleased with its successful implementation.

We also developed a new strategic plan based on guiding principles to help us achieve our goals. These goals reflect our commitment to equitable systems for both children and youth with special healthcare needs in Illinois and our DSCC team. Equity is the common thread that unites each theme and motivates the thoughts and actions of our team.

Steps to achieve these goals include working with our state partners to simplify processes to meet our families' needs faster, leveraging technology to support families and their children's unique needs, and developing a process to better define and address health disparities facing children and youth with special healthcare needs in Illinois.

Though many of the challenges and uncertainty of the last year persist, we continue to adapt and strengthen the quality of our services and support. We are proud of our team's collective resilience, problem-solving and dedication to our participants. I have no doubt it will only grow stronger through the pandemic and beyond.

Thank you for supporting our mission.

A handwritten signature in black ink that reads "Thomas F. Jerkovitz". The signature is fluid and cursive, with a long horizontal line extending from the end of the name.

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.

We partner with Illinois families and communities to help these children and youth connect to the services and resources necessary to reach their full potential.

DSCC has an eight-decade history of serving Illinois families. We guide families through their child's journey with a medical condition and work with doctors, schools and community groups to create a seamless support system.

Our staff partners with families to develop a plan of care that addresses a child's medical, social, behavioral, educational and financial needs. This process is called care coordination.

We provide care coordination services through three programs:

- The Core Program serves youth from birth to age 21 with medically eligible conditions.
- The Connect Care Program serves youth from birth to age 21 with special healthcare needs who are enrolled in a Medicaid HealthChoice Illinois plan that has a contract with DSCC for care coordination.
- The Home Care Program serves children and youth in need of in-home shift nursing.

In fiscal year 2021, we served more than 17,400 families throughout the state through care coordination, resource information and/or referrals.

## Our Team

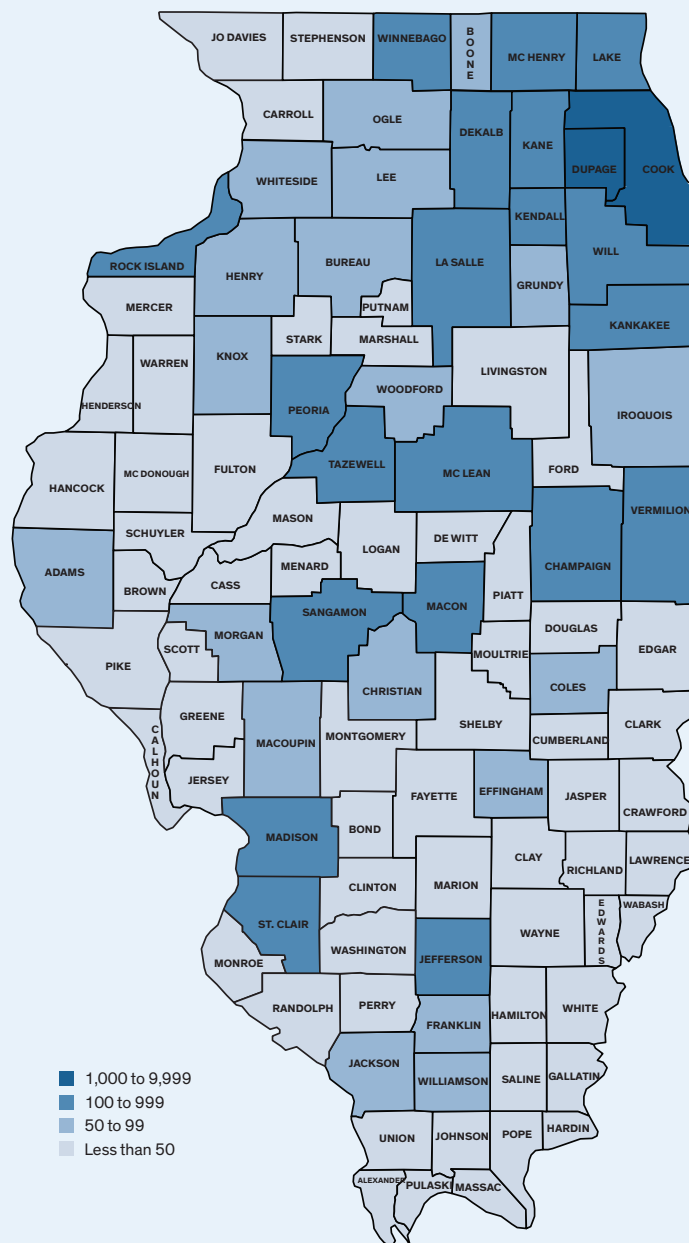
Our staff works out of 11 regional offices throughout the state to help families in their local communities.

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

These professionals are trained 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.

## FY 2021 Active Cases by County



**Map of all cases by county that were actively enrolled or in intake between July 1, 2020, and June 30, 2021.**

# Our Title V Role

The Maternal and Child Health Services Block Grant, authorized by Title V of the Social Security Act, is a federal program that aims to improve the health of all women, children and families.

Title V programs exist in all 50 states and nine territories. At least 30 percent of the Title V funds that states and territories receive must support services for children and youth with special healthcare needs.

Since 1937, DSCC has managed Illinois' Title V program for children and youth with special healthcare needs.

We are involved in various tasks and projects across the state to develop and strengthen the systems of care for all children and youth with special healthcare need and their families. DSCC staff who work directly with families keep us up-to-date on the different systemic issues affecting children and 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
- Early Hearing Detection and Intervention
- Newborn screens for genetic and metabolic diseases
- Developing relationships with healthcare providers and community resources statewide
- Access to national resources for children



## Title V Lifetime Achievement Award

Our former Associate Director for Title V Programs Ralph Schubert received the **2020 Title V Lifetime Achievement Award from the federal Maternal and Child Health Bureau.**

The award recognizes outstanding contributions to the field of maternal and child health over time.

Ralph retired from DSCC in August 2020.

"He's been a tireless and lifelong advocate for children," said Dr. Michael Warren, the Associate Administrator of the Maternal and Child Health Bureau.

Ralph has 40 years of public health experience in various local, state and federal positions in Illinois.

Before joining DSCC, Ralph spent a combined 30 years at the Illinois Department of Public Health and Illinois Department of Human Services.

His leadership positions at these agencies included Manager of Maternal and Child Health Grants and Program Development Unit. Ralph also served as the acting Associate Director for Family Health and the Associate Director for Program Planning and Development, where he was responsible for developing and implementing a new community health and prevention program.

He later became the Director of Public Policy for the Illinois Public Health Association before joining DSCC in August 2016.

## Our Title V Priorities

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

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

1. Strengthen transition planning and services for children and youth with special healthcare needs.
2. Convene and collaborate with community-based organizations to improve and expand services and supports serving children and youth with special healthcare needs.

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

# Who We Serve

## 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 under one of our 11 eligible impairment categories. The diagram to the right shows our Core-eligible conditions.

## Connect Care

Our Connect Care Program serves children and youth with special healthcare needs enrolled in Medicaid managed care. HealthChoice Illinois is the Medicaid managed care program that is required statewide.

Connect Care serves the children and youth who were enrolled in our Core Program and transitioned from Medicaid fee-for-service insurance coverage to HealthChoice Illinois.

We consider new enrollments into this program on a case-by-case basis.

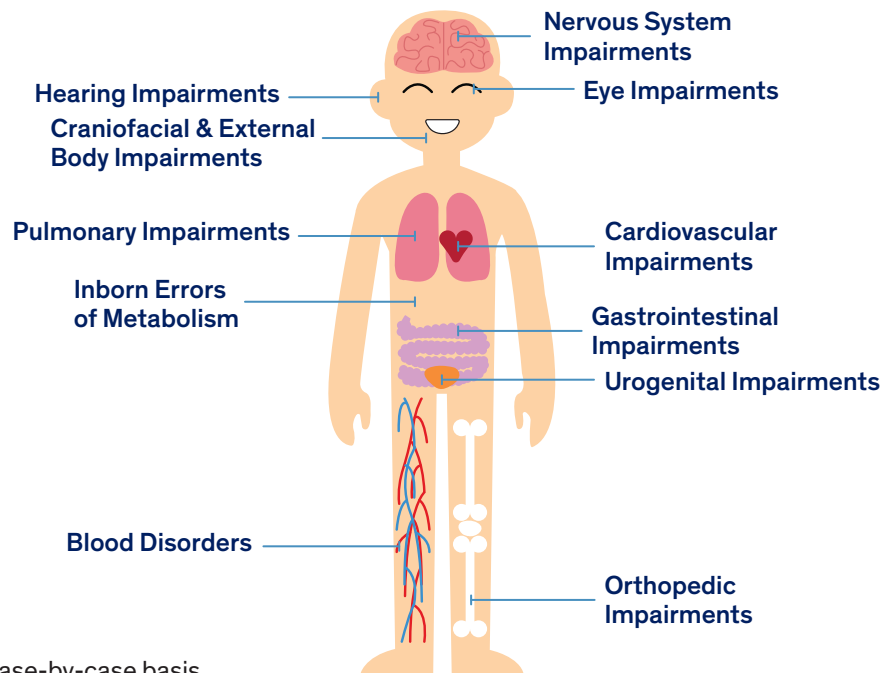
DSCC has contracts with the HealthChoice Illinois managed care organizations to continue our care coordination services for these participants and families.

Through the Connect Care Program, we can continue to serve children while they are enrolled in managed care. We also have greater opportunities to expand the number of privately insured children through our Core Program and to increase our involvement with more system-building initiatives related to the care of children with special healthcare needs in Illinois.

## Home Care

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

The program supports families who care for loved ones who are medically fragile and require skilled in-home shift nursing. With the help of DSCC's care coordination and resources from HFS, the program makes it possible for infants, children and adults to stay in their own home.



The Home Care Program has grown over the last three decades and now 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 Medically Fragile Technology Dependent Children (commonly called the MFTD waiver). Individuals served by the waiver depend on technology – such as ventilators, tracheostomy tubes and gastrostomy tubes – and require in-home shift nursing to stay in their own home rather than a hospital or a skilled nursing facility. Children eligible for the waiver must meet medical criteria determined by their health condition and technology needs and 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.

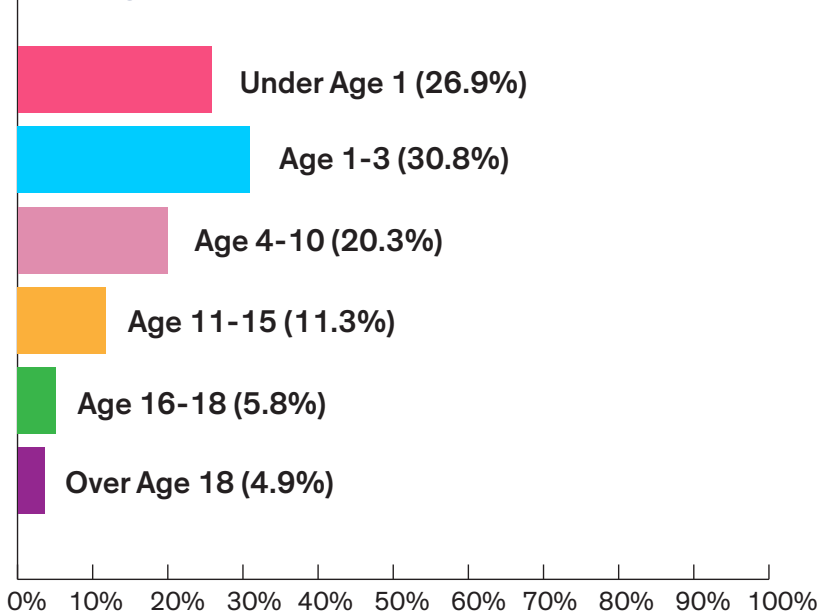
Youth may qualify regardless of their family's income. Originally, the waiver only covered participants less than 21 years of age. As of May 1, 2017, the waiver covers participants of all ages if the participant was enrolled in the waiver prior to the day before his or her 21st birthday. This amendment to the waiver allows participants to stay with the Home Care Program for life.

# Who We Serve

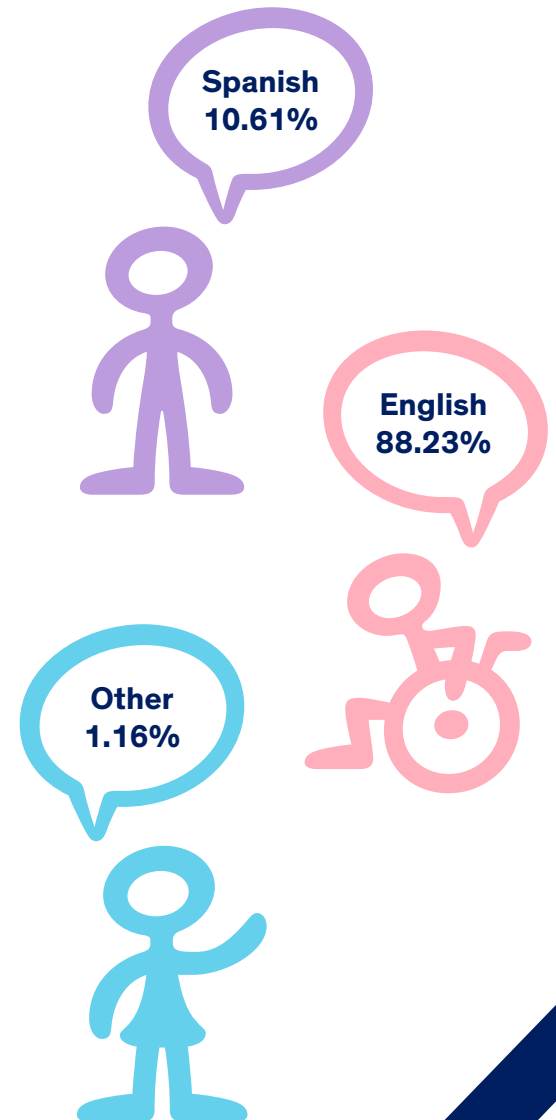
**Non-Waiver:** In January 2014, DSCC became the single point of entry for all individuals under age 21 who require in-home shift nursing services. These youth have an identifiable need for in-home shift nursing and personal care services but are less dependent on technology. The child or family must 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 2021, we had 141 Home Care participants over the age of 21.

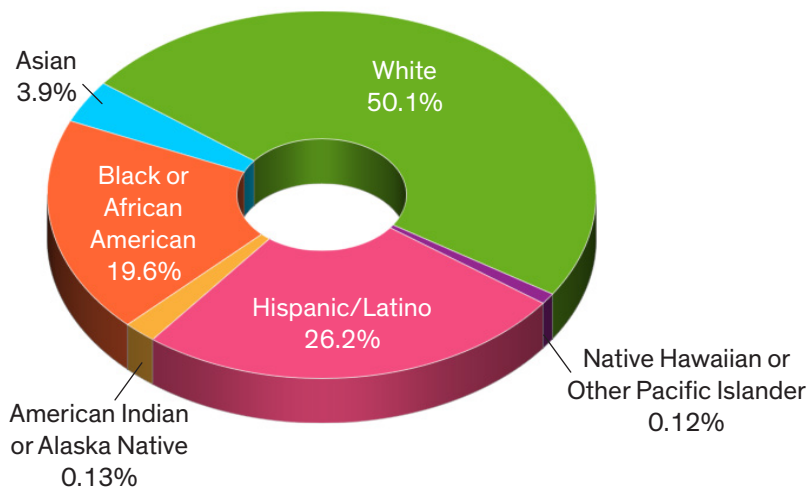
### Age of FY 2021 Active Participants



### Preferred Language of All Active Participants in FY 2021



### Known Ethnicity of Active Participants in FY 2021



# 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 staff'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 may include:

- Accessing diagnostic testing
- Developing a care plan focused on a family's strengths and goals
- Finding specialized medical care
- Helping families maximize their insurance and understand their coverage/benefits
- Communicating with doctors and specialists
- Attending school meetings and assisting with the Individualized Education Program (IEP) or 504 Plan process
- Coordinating transportation for appointments
- Applying for grants to fund therapies, equipment or other needs
- Linking families with local charities, programs and resources
- Connecting families for parent-to-parent support
- Preparing for the transition to adulthood

Financial assistance is available to eligible participants to cover expenses not covered by Medicaid or other insurance.

## Comprehensive Assessment

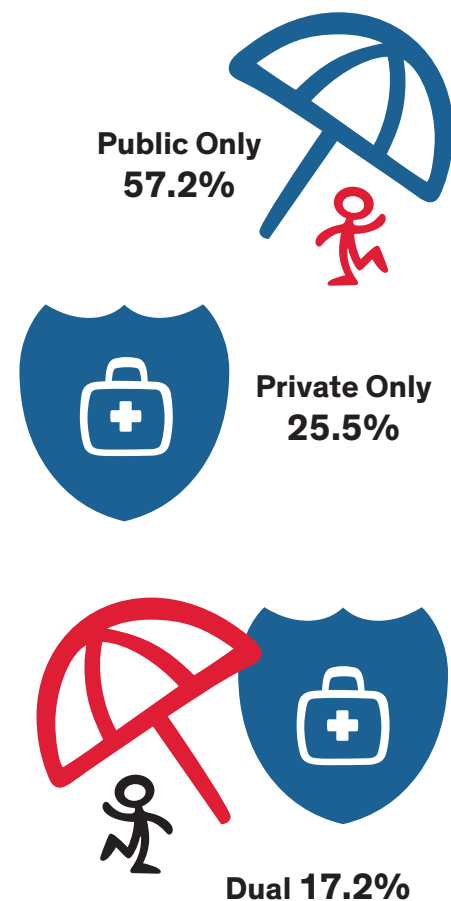
Our care coordination efforts focus on partnering with families and communities to help children and youth with special healthcare needs connect to the services and resources needed to reach their full potential.

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
- Education
- Financial
- Social/emotional
- Transition

The comprehensive assessment is an ongoing learning process for our staff and 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.

## Insurance Type for FY 2021





# Our Care Coordination

## 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 is guided by the participant and family's needs, wants, dreams and desires. It includes their desired outcomes/goals, strengths, needs (both clinical and social support), the steps to achieve these goals and the barriers and risk factors with plans to minimize them.

Our care coordination staff uses motivational interviewing to help complete their assessment and develop the person-centered plan. 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.

## Care Coordination Documentation System

FY 2021 was our first full year using a new electronic care coordination system.

ClientTrack helps our care coordination teams work more efficiently and effectively as they partner with families. The platform provides for care tracking, monitoring, data sharing, reporting and advanced analytics. It also integrates healthcare data sources and allows families to connect with their child's care team.

We implemented ClientTrack in March 2020. We are proud of our team's resiliency in learning a care coordination system in our newly remote working environment during the pandemic. We also appreciate our team's time, effort and talents to continue developing ClientTrack to better meet our staff and participants' needs throughout FY 2021. Future improvements include the introduction of a new family portal for our participant families to have easy access to their child's records.

## Family Impact

Our care coordination helps families:

- 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 vocational 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

DSCC staff has also developed an extensive network of pediatric specialists for children with special healthcare needs and can facilitate referrals for other providers and resources.



# Our COVID-19 Response

FY 2021 was the first full fiscal year affected by the COVID-19 pandemic.

Most of our team continued to work remotely throughout the fiscal year. They adapted to the new working environment while remaining flexible and ready to support our families' evolving needs and questions.

## Resources and Guides

Our care coordination staff regularly checked in with families and shared valuable resource and health education information.

We continued to build and update our online [COVID-19 Directory](#), a comprehensive list of resources and supports in the areas of financial assistance, free meals, health and condition-specific information, education guides and goals, mental health tips and more. In September 2020, we started periodic "Resource Roundup" newsletters via email to notify our participant families, community partners, team members and others of recent additions and updates to the directory.

We partnered with two physicians from Ann and Robert H. Lurie Children's Hospital to provide [tips on advanced preparations necessary for all parents and caregivers of children with medical complexity](#). The website article explained how advanced preparations can help parents and caregivers reduce stress, lighten their mental load and protect their children's health and safety during a family illness, including those related to the pandemic, and other emergencies.

Once vaccines became available, we developed a ["What to Expect During and After Your COVID-19 Vaccine"](#) fact sheet as well as a [frequently-asked-questions handout about the vaccine](#). Our staff directly shared these materials with families. We also posted them on our website and social media channels.

## Solutions for Pandemic-Related Challenges

Throughout the pandemic, Home Care Program families have notified us of concerns affecting their children and families. We have worked close with the Illinois Department of Healthcare and Family Services (HFS) to address these concerns.

As families struggled with decisions regarding their children's schooling during fall 2020, our Care Coordinators attended school meetings and worked with participants' Individualized Education Program (IEP) teams to make sure their needs were met.

We also created a dedicated email address for families to contact us with any concerns about their home nurses' access to personal protective equipment (PPE) while working in their home. Our team then followed up on reported issues to make sure nursing agencies were providing adequate PPE supplies for their nurses.

Our team also worked to notify Home Care families of additional elements available for their children as part of Appendix K. Appendix K is an emergency coverage document for individuals receiving services through a Medicaid waiver.

These elements include approval of nurse overtime for nurses working in the home setting, allowing parents who are licensed nurses to be paid caregivers and an increase in respite hours for participants on the medically fragile technology dependent (MFTD) waiver.

## Federal Medical Assistance Percentage (FMAP)

We worked closely with our state partners to develop a plan to use the increased federal funding to improve support and services for children and youth with complex medical needs during the pandemic and beyond.

In March 2021, President Joe Biden signed the American Rescue Plan Act of 2021 in response to the COVID-19 pandemic. Under this act, states' Medicaid Home and Community-Based Services (HCBS) qualified for a temporary 10 percent increase. This 10 percent increase is called the Federal Medical Assistance Percentage or FMAP.

Each state then had to determine initiatives to expand or strengthen their HCBS.

In Illinois, Medicaid reached out to the various waiver-operating agencies for feedback and suggestions.

DSCC is the Illinois program that operates the MFTD waiver on behalf of HFS. HCBS includes the MFTD waiver.

# Our COVID-19 Response

Therefore, the FMAP can provide extra funds to help support children and youth in the Home Care Program and their caregivers. FMAP improvements will also affect individuals who receive in-home, shift-based nursing as a non-waiver benefit.

In late May, DSCC asked our participant families, staff and community partners for input on how to use the FMAP funds. We also sought feedback on DSCC's ideas for improving HCBS for Home Care participants.

We shared the input we received with HFS and worked with the agency to develop Illinois' proposal for using the FMAP funds.

Ideas included in the proposal were:

1. Expand consumer direction (the ability for consumers to make choices about the services they receive) to allow unlicensed family caregivers to be paid caregivers. DSCC would then work to develop health and safety monitoring, assist with training and more. This change could provide caregiver relief to many Home Care families.
2. Develop a nursing portal where open shifts could be posted by nursing agencies and families. This portal would be visible to home nurses and families. The intent is to try to improve nursing coverage for open shifts across the state.
3. Improve training and access to training to help improve the quality of nursing care in the home. This initiative would include developing training that builds on and complements existing training for caregivers in the home.
4. Increase the in-home respite nursing rates to match the rates from the 2019 nursing rate increase.
5. Increase the child-specific training rates to match the rates from the 2019 nursing rate increase.

HFS submitted Illinois' proposal to the federal Centers for Medicare and Medicaid Services in July 2021. We anticipate its approval and have planned for the necessary next steps.

It is important to note that though the FMAP funding increase is temporary, we hope to make many of these changes permanent. We are discussing how to handle any relevant long-term costs with HFS.

We are excited about this opportunity to improve care for our Home Care Program participants. We expect numerous updates in the year ahead.

# The Family Voice

A major strategic goal at DSCC is to strengthen our partnerships with families receiving our care coordination services.

Feedback from our participants and families is the most valuable tool we have available to help us achieve this goal and make the best use of DSCC resources.

Throughout FY 2021, we strengthened and expanded the ways families share their input and have a direct role in shaping our policies and strategic goals.

## Family Surveys

Our Family Survey Committee develops and distributes a series of surveys to our participant families at specific intervals of their child's enrollment with DSCC.

In 2020, we began sending surveys by email to participants' legally responsible adult (LRA). If the LRA does not have an email address on file, we send the survey by mail.

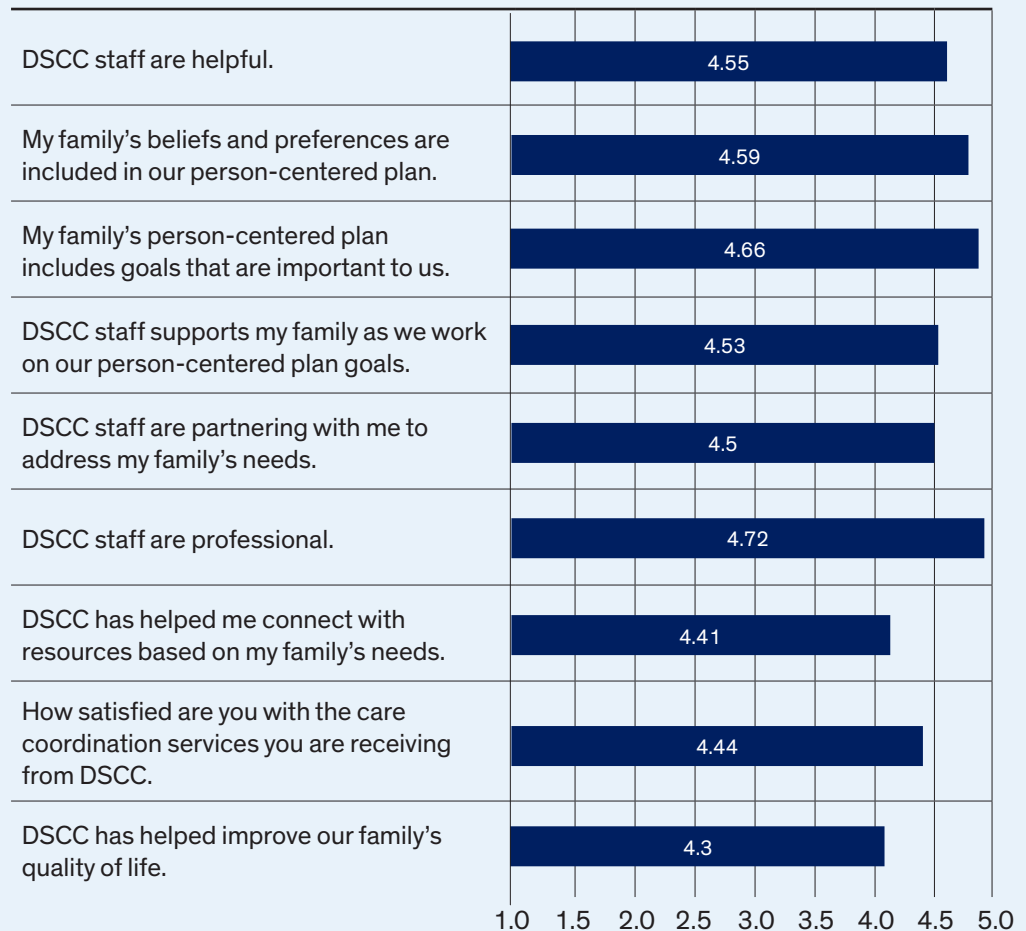
We sent the following surveys to our Core, Connect Care and Home Care participants in FY 2021:

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

We received 474 completed surveys from Aug. 24, 2020, to June 30, 2021.

## Family Survey Result Highlights - August 2020 to June 2021

We score our survey results on a five-point Likert scale with 5 being Strongly Agree and 1 being Strongly Disagree.



### Key

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



# The Family Voice

## Family Advisory Council

We have updated our Family Advisory Council (FAC) setup to make it easier for families to participate and share their input.

A team of our staff formed a FAC Workgroup to help strengthen the council's family engagement and ability to keep family-centered values at the forefront of discussions.

The FAC's mission is to bring together families and our staff and leadership to promote the delivery of participant and family-centered services. Our updated council 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.

New FAC members were selected in fall 2020 to ensure we have adequate representation throughout the state and across all our programs. We held our first meeting with the updated council in February 2021.

We also updated the FAC's meeting structure to allow opportunities for family members of children with special needs who are not enrolled in DSCC's programs to participate in public forums. The first public forum took place in August 2021.

With the new FAC structure, every other meeting is an open forum available for anyone interested in children with special healthcare needs to attend. Meeting information is posted on our website's [Family Advisory Council page](#).

Erica Stearns, the mother of two Home Care Program participants, volunteered to chair the FAC. Erica will work to ensure the FAC meets its goals, encourage active participation from her fellow members and ensure the council effectively communicates its outcomes and objectives.



**FAC Chair Erica Stearns and her daughter Margot, DSCC Home Care participant**

## Family Advisory Council Chair Erica Stearns

"I am the proud mother of two children who receive the medically fragile and technology-dependent waiver. I was introduced to the Division of Specialized Care for Children Family Advisory Council and began serving as chair in 2021.

What I love most about being involved in the DSCC FAC is the unique opportunity it has provided me to learn about and be involved in the conversations surrounding current initiatives related to supporting families of children with special healthcare needs.

All too often, families like our own feel as though many decisions are made without our knowledge or input, which ultimately impacts our children and our family as a whole. The DSCC Family Advisory Council is a safe space where our concerns and our input are not only valued and requested but also received with respect and genuine consideration.

It brings me immense comfort to know that (and be a part of) a team of people who place the family perspective at the center of their discussions and decisions.

Additionally, the FAC presents awesome opportunities for members to network with other families from across the state. Not only do members have the opportunity to connect with each other, we also have the chance to partner with professional stakeholders as well. Together, we work collaboratively to create supportive solutions for families throughout the state of Illinois."



**The Stearns family**

# Our Outreach

Our community outreach in FY 2021 focused on both in-person and virtual activities as well as our digital communication channels. We provided education and information to more than 163,800 people through outreach events, our website and social media.

Staff participated in 350 virtual and in-person events, including rounds at healthcare facilities, presentations to providers and community groups, parent and family support groups, resource and health fairs, and more. The COVID-19 pandemic led to the cancelation or reformatting of several outreach events that we either participate in, help plan or sponsor.

We were able to continue our annual Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing in a new virtual format from June 6-11, 2021.

The free program provided support and information for families of children with hearing loss. Experts in the field gave lectures via Zoom on topics including:

- Types of hearing loss
- Language development
- Communication choices
- Hearing aids and cochlear implants
- Deaf culture

- Parent rights
- School programming

We had 42 participant family members and professionals who registered to participate.

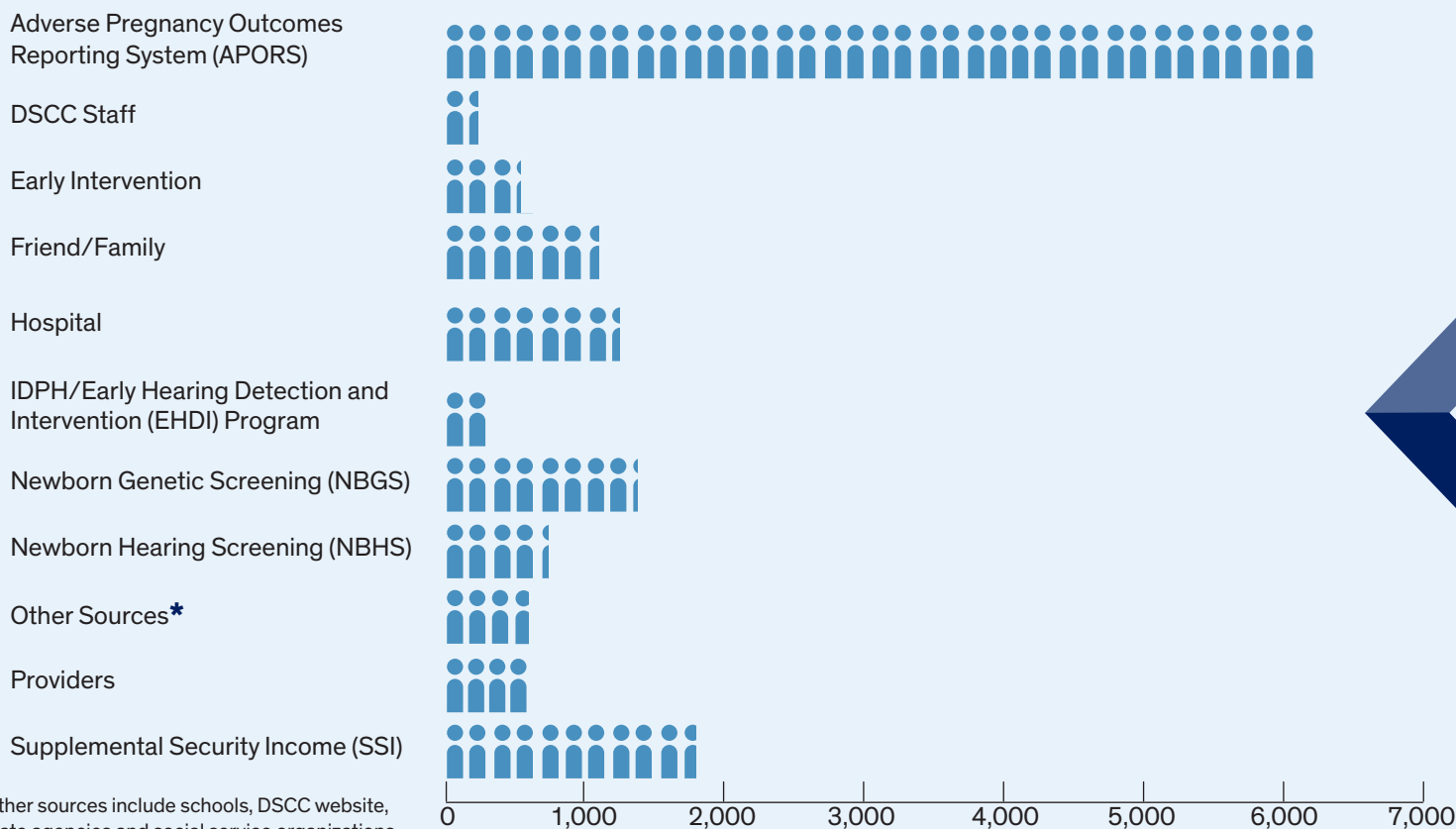
Executive Director Thomas Jerkovitz and Director of Care Coordination, System Development and Education Molly Hofmann were the keynote speakers at the 2021 Autism Behavior and Complex Needs (ABC) Conference on March 26, 2021.

The theme of the 2021 virtual conference was “Caring for Children with Special Healthcare Needs in the COVID Landscape.”

Their presentation included an overview of our organization, the importance of care coordination for children with special needs and an update on how the COVID-19 pandemic has affected our participants and operations.

Our team is 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](#).

## DSCC's Referral Sources for FY 2021



# Our Medical Advisory Board

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

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

The 13 current Medical Advisory Board members are:

## **Stephen E. Bash, MD**

Retired Pediatric Cardiologist  
OSF Children's Hospital Teaching Staff

## **Patricia R. Bellock**

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

## **Rachel N. Caskey, MD**

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

## **Laura Deon, MD**

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

## **Eric T. Elwood, MD, FACS**

Chief, Division of Plastic & Reconstructive Surgery  
Chief, Pediatric Plastic Surgery  
Associate Professor University of Illinois College of Medicine

## **Carolyn C. Foster, MD, MSHS**

Assistant Professor of Pediatrics - Ann and Robert H. Lurie Children's Hospital of Chicago

## **Paul M. Kent, MD, FAAP**

Associate Professor Department of Pediatrics  
Advocacy Role Leader Rush University Medical Center  
Medical Director Fibrolamellar Carcinoma Program  
Rush University Medical Center, Department of Pediatrics, Division of Hematology and Oncology

## **Julian J. Lin, MD**

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

## **Kenya McRae, JD, PhD**

Maternal Child Health Title V Director  
Illinois Department of Public Health

## **Shubhra (Sue) Mukherjee, MD**

Shriners Hospitals for Children – Chicago  
Medical Director of Rehabilitation  
Pediatric and Adolescent Rehabilitation Medicine

## **Sarah A. Sobotka, MD, MSCP**

Section of Developmental and Behavioral Pediatrics  
Department of Pediatrics  
University of Chicago

## **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  
Board Certified Child Abuse Pediatrician  
General Pediatrician at Swafford Pediatrics

# Our Medical Advisory Board

## Partnership to Develop Letters of Medical Necessity Examples

Physicians must provide current medical reports and other important details to support the need for in-home nursing and services for Home Care Program participants.

Our Home Care Enrollment Team worked with Medical Advisory Board Member Dr. Rachel Caskey to develop sample letters of medical necessity for home nursing to help physicians in this process.

These letter examples aim to help providers write more comprehensive letters that ensure Home Care participants receive the services they need. The sample letters are included in our medial report requests to physicians as part of our Home Care enrollment process.

The sample letters can also help participant families' efforts to make sure the Illinois Department of Healthcare and Family Services receives all the relevant information about their children's care needs.

We posted these sample letters on our website for families to easily access on our new [Home Care Nursing Information for Families page](#).



"Over the years I've worked with all kinds of sub-specialists. I've also seen what the families have to go through. DSCC is the only one that coordinates care statewide and helps steer these families through a confusing maze of insurance changes, seeing all kinds of specialists and understanding their treatment options. The help DSCC provides is more important now than it's ever been," Dr. Stephen Bash said.

**Dr. Bash is currently serving his seventh term on the Medical Advisory Board and is the current Chair.**

"I am so impressed by our members and all that they do," Dr. Bash said. "The amazing parent, specialist and staff presentations to the board continue to help us learn about and better understand the different specialties, the many pieces involved in getting and providing care and the ways we can help impact making the services these families need available. We volunteer because we love what we do, and the need is so great."



# Our Education Opportunities

Through internship opportunities and special projects, DSCC embodies the University's mission of transforming lives and serving society by educating, creating knowledge and putting knowledge to work on a large scale and with excellence. We strive to partner with University programs to host interns and build relationships that provide real-world learning experiences and job training. These experiences help students go on to rewarding, successful careers serving children and families.

These valuable mentoring opportunities also expose students to DSCC services so they can educate their peers and future employers about our services. Our internships also cultivate potential future employees and provide extra staffing to improve our level of assistance.

Our FY 2021 internship opportunities included University students from the School of Social Work. These interns worked in our regional offices across the state. DSCC is also a clinical partner in Almost Home Kids' fellowship program for Advanced Practice Registered Nurses (APRNs) in the sub-specialties of developmental behavioral pediatrics, mental health and complex care. Our Chicago Home Care Hospital Liaison met virtually with these APRN fellows and provided an overview of DSCC as well as an introduction to Medicaid waiver programs in their respective states.

Our Chicago Home Care Hospital Liaison serves on the medical advisory committees for Almost Home Kids and Maryville transitional care facilities. She also meets with UIC College of Medicine Pediatrics residents each month during their development rotation. She explains DSCC's services, who is eligible and how to make a referral.

This liaison also is an at-large member of the board of directors for the American Case Management Association, Illinois Chapter. In this role, she aims to bring educational content that reflects the populations we serve.



## Intern Spotlight: Sruthi Thinakkal

Sruthi Thinakkal interned with DSCC's Marion and Olney regional offices from May to December 2021.

She recently graduated with her master's degree in social work through the BHWELL Scholars Program at the University of Illinois at Urbana-Champaign.

"I'm so grateful for my internship at DSCC," Sruthi said. "My time with DSCC has not only shaped me as a social worker but also shaped my idea of the perfect team."

Sruthi shadowed DSCC Care Coordinators during their comprehensive assessments and person-centered planning conversations with families. She also helped Care Coordinators with data entry, scheduling and making calls to families.

One of Sruthi's major accomplishments during her internship was a guardianship project for DSCC families and staff members in southern Illinois. Sruthi created an extensive, easy to click through tool kit that includes definitions for the various guardianship processes, step-by-step instructions, courthouse contacts, blank copies of needed forms and legal resources. She presented the toolkit to a group of more than 50 DSCC staff members in the southern region of Illinois.

"It's hard leaving a fantastic team but the lessons I've learned will be with me always," Sruthi said.

"One of the biggest takeaways for me is the importance of just being there and listening. Chatting about every aspect of a kiddo, providing space to vent, helping to arrange something for a family that has so much going on every moment and obstacles no one expected, getting to know parents who are so worried about their kiddos that they forget about their own health, and hearing how they feel alone, not lonely. These conversations with families each month create an everlasting relationship and lessons that I will carry with me for a lifetime."

# Our Collaboration

## University of Illinois Hospital Health & Science System - Sickle Cell Center

Sickle cell disease is an inherited blood disorder that causes severe episodic pain and strokes. Children with sickle cell disease can also suffer from “silent strokes” that have no outward symptoms but can damage intellectual and academic abilities, attention and long-term memory.

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

DSCC provided \$200,000 to fund the center’s Sickle Cell Transition Adolescent-Adult Readiness (S.T.A.R.) Clinic in FY 2021. 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.

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

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

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

Dr. Sobotka and her research team accompany the DSCC Home Care care coordination teams on home visits with newly enrolled Home Care families and conduct an interview and developmental testing of the child.

Dr. Sobotka and her research team connect with the DSCC Home Care care coordination teams to identify newly enrolled Home Care families who may be interested in participating in the study. Dr. Sobotka and her research team then contact eligible families for study visits, which include an interview and developmental testing of the child. This study involves four study visits (a visit 30 days post-discharge from the hospital and follow-up visits at six months, one year and two years).

DSCC is responsible for identifying eligible families for the study and asking if they would like to participate. Eligibility requirements include:

- Having a child that uses a ventilator
- Having a child with a tracheostomy
- Being new to the Home Care Program
- Having a child under 18 years old
- Living at home with the child

The study was written for a recruitment period of two years and a total of 20 families.

In November 2018, DSCC Home Care Enrollment Specialists began recruiting participant families. All visits were in-person at the family home until the start of the COVID-19 pandemic. Since then, Dr. Sobotka and her research team have conducted visits via Zoom, over the phone and some in-person, depending on the stage of the pandemic and family preference. All persons are masked during family visits and screening for symptoms of research team members and family members are conducted 24 hours in advance of visits.

Recruitment was completed in January 2022 and follow-up is ongoing. The study recruited a total of 23 families to account for three children with injury or illness in childhood/adolescence; 20 children had ventilators placed in the neonatal period.



**Dr. Sobotka is an assistant professor of pediatrics at the University of Chicago. She is a member of DSCC’s Medical Advisory Board and passionate about helping children with complex disabilities.**

# Our Collaboration

Research study highlights during FY 2021 include:

- Eight Home Care participant families enrolled in the study. To date, a total of 23 families are enrolled.
- Two families completed the study in FY 2021. A total of seven families have now completed the study through the two-year follow-up since it began.
- In FY 2021, the research team completed 25 home visits for both enrollment and follow-up over Zoom or in-person.
- The research team currently has 16 families in follow-up and is seeking to enroll one more family.

Dr. Sobotka presented a synopsis of the study to the Pediatric Academic Society's annual meeting in the spring of 2021 titled Early Childhood Developmental Skills of Children with Tracheostomies and Ventilators Recently Discharged Home. She later presented an abstract of the study at the American Academy of Cerebral Palsy and Developmental Medicine's annual meeting in October 2021 by the same title.

This year she has submitted the following abstracts to both the Pediatric Academic Society's annual meeting as well as the American Academy of Cerebral Palsy and Developmental Medicine's annual meeting; *Parent and Nurse Perspectives on Promoting Successful Partnerships for Children with Ventilator Dependence and Home Health Nurses' Perspectives on Gaps and Opportunities for Recruiting into the Workforce to Care for Children with Invasive Mechanical Ventilation (IMV).*

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

Along with her study of families of children with home mechanical ventilation, Dr. Sobotka is conducting a congruent study in which she interviews nurses that work in family homes caring for children with home mechanical ventilation.

Recruitment is conducted through purposeful snowball sampling methodology with the nurses primarily being recruited from the family study. DSCC leadership has also passed along the recruitment information, which has resulted in a current total of 19 interviews with home care nurses.

We anticipate additional recruitment to reach theme saturation.

## Advancing Equity for Hispanic Transition-Age Youth With and Without Disabilities in Illinois: Collaboration with UIC Disability and Human Development Department - Illinois Leadership Education in Neurodevelopmental and related Disabilities (IL LEND) Program

DSCC is collaborating with the UIC's Illinois Leadership Education in Neurodevelopmental and related Disabilities (IL LEND) Program to advance equity for Hispanic transition-age youth.

Research demonstrates Hispanic students with disabilities are less likely to graduate high school, seek post-secondary schooling or training, apply and get accepted into programs/training in their interest areas, or gain meaningful employment.

There are many systemic factors and barriers working collectively against this population of community members. These include service shortages in areas heavily populated by Hispanic people, the Hispanic community's fears of policing and governmental repercussions concerning citizenship, and a lack of experience with and education on disabilities.

Our staff worked with the LEND Program's 2020 cohort of trainees in the disciplines of self-advocate, family and special education.

We learned there are no quick or one-size-fits-all solutions to improve outcomes for Hispanic transition-age youth with and without disabilities. Our team continued to work with the 2021 cohort of LEND trainees in the disciplines of family, special education and physical therapy.

We've completed a literature review and developed proposed interventions. We found a major systemic structural change is necessary to make significant change on a large scale. The need to explore and put in place multiple community interventions simultaneously has never been greater. We would like to see a multifaceted set of interventions introduced into the community at the same time with the same person in mind, to refocus the lens of education and parenting back to the child/student/youth.

# Our Collaboration

Youth in the United States, specifically Hispanic youth, continue to grow at a quick rate both in size of populous and economic disparity. We seek to promote and support strategies of cultural brokering - the act of bridging or mediating between groups or persons of differing cultural backgrounds – to reduce conflicts or produce change.

We are currently developing educational materials around these strategies with the LEND trainees. These include a video on peer-to-peer advice about transition and a parent/caregiver informational video outlining challenges and information about their rights under the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) along with resources for help.

Our project's next steps involve identifying community members to support cultural brokering and mediating between groups to improve acceptance of transition-related information and access to needed resources.

## **Patient-Centered Outcomes Research Institute (PCORI) Behavioral Health Stratified Treatment (BEST) to Optimize Transition to Adulthood for Youth with Intellectual and Developmental Disabilities (IDD) Study**

Teenagers with disabilities are more likely to be anxious and depressed. For teens with disabilities, untreated depression and anxiety can negatively affect their health, complicate their transition to adulthood and limit future possibilities.

DSCC is part of a new research study to help support the mental health of teenagers and young adults with intellectual and developmental disabilities (IDD).

The study is called the Patient-Centered Outcomes Research Institute (PCORI) Behavioral Health Stratified Treatment (BEST) 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) and the University of Illinois Chicago's Department of Disability and Human Development.

The goal of the PCORI BEST study is to look at how a care coordination program that treats depression and anxiety is effective in making teens feel healthier, happier and able to handle future challenges.

We are partnering with UIC to recruit our eligible participants in the study. To take part in the study, a DSCC participant must:

- Be 13 to 20 years old
- Have an intellectual or developmental disability

Our participants who join the study will receive access to additional behavioral and mental health resources and support.

The PCORI BEST study received approval in fiscal year 2021. We will work with the study partners to develop a Youth and Family Advisory Committee for the study.

Study participation will begin in 2022 and last for two years.

## **Illinois Children's Healthcare Foundation Pediatric Dentistry Outpatient Care Center**

The University of Illinois Chicago College of Dentistry recently opened the Illinois Children's Healthcare Foundation Pediatric Dentistry Outpatient Care Center (ILCHF PD-OCC) in October 2020.

The center provides much-needed dental care to children in need of dental support in Illinois.

ILCHF PD-OCC has two general anesthesia suites that serve children from 3 to 17 years old who need oral health care under general anesthesia.

Prior to the center opening, children in need of general anesthesia often had to endure long wait times before treatment.

We're proud to be among the supporters who helped fund this important initiative to improve oral health and overall quality of life for these pediatric patients and their families.



# Our Funding

DSCC receives a combination of state and federal revenue sources.

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.

Since 1937, DSCC has managed Illinois' Title V program for children and youth with special healthcare needs. Block grant funds require a state match of \$3 for every \$4 of federal money spent. DSCC's state match is funded through the University of Illinois.

DSCC has entered into contracts for the provision of its care coordination services. The contracts are with managed care organizations (MCOs), which participate in Illinois' Medicaid Managed Care Program .

Children who received services through the Core Program and were Medicaid-eligible were transitioned to managed care in February 2020. The result of this transition and DSCC's continued involvement created the Connect Care Program. DSCC is compensated by the MCOs for its work with Connect Care participants.

The revenue we receive from the Connect Care Program replaces the Medicaid Administrative funds for DSCC's Core participants who were Medicaid-eligible.





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