



2023 YEAR IN REVIEW

Child Health Specialty Clinics
Division of Child and Community Health
www.chsciowa.org

The Division of Child and Community Health and Child Health Specialty Clinics (CHSC) are part of the University of Iowa Carver College of Medicine and the Stead Family Department of Pediatrics. CHSC provides gap-filling clinical care, health assessments, care coordination, and family to family support for Iowa's Children and Youth with Special Health Care Needs and their families. CHSC has a network of regional centers and satellite locations in mainly rural areas across Iowa, employing over 85 clinical providers, public health professionals, and Family Navigators.

Partnering with Iowa Families

The foundation of CHSC's funding comes from the Title V Maternal and Child Block Grant, part of the 1935 Social Security Act. Each state receives a "block" of funding to improve the health, safety, and well-being of all mothers and children. In Iowa, the Title V Program for Children and Youth with Special Health Care Needs is guided by three priorities:

1. **Access** to community-based services and supports, pediatric specialty providers, and coordination of care.
2. Support for families of youth and youth adults making the **transition** to adulthood.
3. Support for **parenting** children and youth with special health care needs.



Approximately 143,000 Iowa children and youth have special health care needs, these include:

- Chronic conditions
- Mental or behavioral health diagnoses
- Development disorders
- Intellectual disability
- Genetic disorders

Director Vanessa Curtis, MD



Dr. Vanessa Curtis has been named the new Director of the Division of Child and Community Health and Child Health Specialty Clinics as of January 1, 2024.

Dr. Curtis is also a Clinical Associate Professor in the Division and Endocrinology and Diabetes and has been with the University of Iowa Stead Family Department of Pediatrics since 2010. Her clinical and research interests include pediatric fitness and obesity, bone health, and endocrine aspects of sports medicine.

Dr. Curtis takes over from Dr. Thomas Scholz, who has led the Division since 2015. Dr. Scholz will continue to see patients at the Pediatric Cardiology Outreach Clinic in Dubuque and participate in several research studies.



Programs, Training, and Outreach Activities

Family Navigators

CHSC Family Navigators are staff members who are also the parent or primary caregiver of a child with special health care needs. They work with families to provide emotional support, systems navigation, and connections to community resources. Many families raising children and youth with special health care needs find that talking with someone who has “been there” can help.

Iowa Family Leadership Training Institute

The Iowa Family Leadership Training Institute teaches parents and caregivers of children with special health care needs to develop their leadership and advocacy skills. Held annually, this training includes the development of a Community Service Project and pairs each participant with an experienced family leader.

Storytelling for Families

Digital Storytelling is an in-person training based on The StoryCenter model that helps parents produce a three-minute video about their child and family’s journey. Examples can be found on the Iowa Family Leadership Training Institute YouTube Channel. Storytelling for Family Leaders is a virtual training that includes online modules and Zoom sessions for peer coaching to help families develop a 10-minute story to be used as part of their advocacy efforts.

Waiver Services

CHSC supports families and organizes services for children and youth who are eligible for the Health and Disability Waiver or the Children’s Mental Health Waiver.

Autism and Other Developmental Disabilities

The Iowa Regional Autism Assistance Program (RAP) provides consultation and care planning for children with autism and their families. CHSC staff utilize standardized tools to help children at risk for autism and help families find diagnostic services in their community. RAP also provides technical assistance and training to medical home providers, educators, and other early intervention community providers.

Nutrition Services

CHSC Registered Dietitians provide families with a nutrition assessment at a provider’s request and follow-up care coordination through telemedicine. Staff also facilitate nutrition-focused system building activities such as training and education on topics specific to children and youth with special health care needs.

Early ACCESS

Early ACCESS is Iowa’s system of early intervention for infants and toddlers with or at risk of a developmental delay. CHSC provides service coordination, nutrition services, and health assessments for children 0-3 years old enrolled in this program.

Workforce Development and Provider Training

CHSC provides training and resources to help primary care providers treat children with mild to moderate mental health needs within their medical home and screen for autism and other developmental disabilities through the Iowa Pediatric Mental Health Collaborative and the Iowa Autism Learning Community.

2023 Highlights



The CHSC Family Advisory Council completed its 10th year.

The CHSC Youth and Young Adult Council completed its 2nd year.

CHSC provided services and supports to 8,138 children, youth, and families from all 99 Iowa counties.

Celebrating 87 Years!

CHSC has been serving Iowa families since 1936

Family Stories

Liam's Family

When our daughter Liam was diagnosed with a rare disease called Dup15q, our life underwent a radical change and we didn't know where to go or what to do. When she was 8 months old, we were referred to Early ACCESS. They connected us with physical therapy, speech therapy, occupational therapy, and a dietitian to address Liam's feeding difficulties.

Liam began walking at 2 1/2 years old, but she still does not speak. Throughout this process our family has received many supports from the Early ACCESS team and CHSC. They listened to our concerns, helped resolve our doubts and guided us through the Medicaid application process. We feel grateful to live in a place where there are special programs and people with so much dedication to guide and help us.



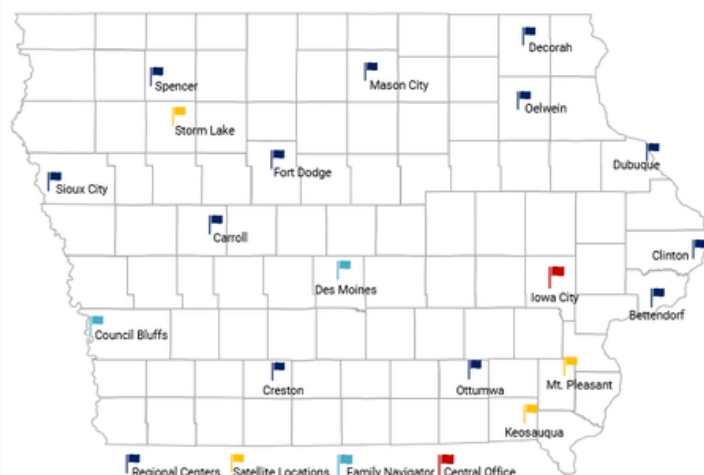
The Damman Family

Our son Lex, the youngest of three, was diagnosed with Autism when he was three years old. This was at the beginning of the COVID pandemic and we as a family felt lost and extremely overwhelmed. Then we contacted CHSC and met Allison, our Family Navigator. She was quick to provide me with a listening ear and help us find resources for Lex. Allison was there when we learned that Lex also has 3P duplication, a chromosome abnormality. She was also there when we found out our middle child, who had been struggling since she was a toddler, was also on the spectrum and had ADHD.

In the fall of 2022 Allison recommended that I apply for the Iowa Family Leadership Training Institute. I was hesitant to participate at first, but I'm so very glad I did. I met a network of people who had similar stories and had faced similar obstacles. I learned that we as parents are the best resource and advocate for our children. I am so very thankful for the opportunity to have been part of this program. Even though we have all moved on in different ways I will always be cheering on the parents and families I met along the way.



CHSC Regional Center and Satellite Locations



CHSC includes 12 permanent Regional Centers that are open either four or five days a week depending on community needs and available resources.

All Regional Centers have registered nurses, family navigators, and clerical staff. Most have an advanced registered nurse practitioner (ARNP), and some have dietitians and other program staff.

Services are also provided through satellite locations that are staffed once or twice a month, and locations with family navigators who provide family to family support.

Clinical Services

Gap-filling direct services are provided to families through Regional Centers, primarily in rural areas of the state. ARNPs provide developmental and behavioral screenings and assessments, mental health care, medication management, and other medical supports.

In 2023, ARNPs completed 4,746 in-person visits with 2,117 children and youth.

Family Navigators

All families who receive services through CHSC have access to support from Family Navigators, staff members who are also the parent or primary caregiver of a child with special health care needs. They work with families to provide emotional support, systems navigation, and connections to community resources.

In 2023, Family Navigators provided over 31,000 contacts on behalf of over 5,000 children and their families.

Telehealth

CHSC has been providing telehealth services since 2005 and all Regional Centers are equipped with modern telehealth equipment. Instead of driving across the state, families can travel to their local Regional Centers and connect with specialty providers from psychiatry, psychology, nutrition, nephrology, neurology, genetics, and endocrinology.

In 2023, 3,560 telehealth appointments were completed between Iowa children and specialty providers.

Visit www.chsciowa.org for more information

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