



University of Iowa Child Health Specialty Clinics

Division of Health Promotion & Chronic Disease Prevention

Phone: (866) 219-9119

<https://chsciowa.org>

Protecting & Improving
the Health of Iowans



Assuring a System of Care for Children and Youth with Special Health Care Needs – Carver’s Story

When our son Carver was born, there were some complications. The umbilical cord was wrapped around him several times, and at one point, he was without oxygen and a heartbeat. The doctors didn’t know what the future held for Carver, but they also didn’t know what a fighter he was. After only 10 days in the NICU, we were able to take our healthy and beautiful baby boy home. Carver was a typical baby, but as time went on we noticed that his legs “looked funny” and he wasn’t reaching physical milestones. After several doctor visits, Carver was diagnosed with Spastic Diplegic Cerebral Palsy, a condition which makes his legs very stiff and walking difficult. The doctor said that this was caused from the lack of oxygen during Carver’s birth.

Despite all our medical visits, no one mentioned Early ACCESS. I had never heard of it either, until a co-worker gave me the name and number of an angel named Jan who worked at Child Health Specialty Clinics (CHSC). Jan is an Early ACCESS Service Coordinator and the parent of a child with special needs. She helped us set up in-home physical therapy, speech therapy, and consultations with a CHSC dietitian via Skype. Jan also helped us navigate the foreign worlds of Social Security Insurance/Disability and Medicaid for children with special health care needs. These are supports that we would not have been able to figure out on our own. Having a child with special needs can be scary and well...HARD! I am so thankful that I had another mother guiding me through those first critical years of my son’s life. My only regret it that we didn’t get referred to Early ACCESS the day he was born.



Did you know?

Child Health Specialty Clinics (CHSC) administers Iowa’s MCH Title V program for children and youth with special health care needs in partnership with the Iowa Department of Public Health. CHSC is part of the Division of Child and Community Health in the University of Iowa Stead Family Department of Pediatrics. CHSC’s mission is to assure a System of Care for all Iowa children and youth with special health care needs. Over 128,000 Iowa children and youth have special health care needs including chronic physical, developmental, behavioral and emotional concerns. In federal fiscal year 2017, CHSC served over 6,000 Iowa children and youth and their families, providing gap-filling clinical services, care coordination and support from Family Navigators.

Why is Child Health Specialty Clinics important to protecting and improving the health of Iowans?

- About 18% of all Iowa children and youth 0 to 18 years of age have a special health care need.
- Special health needs often impact the entire family and can require the involvement of multiple service systems.
- Federal rules require that at least 30% of each state’s Title V Maternal and Child Health Block Grant funds be used to focus on children and youth with special health care needs.

Which Iowa Public Health Goals are we working to achieve?

Strengthen the health infrastructure

Promote healthy living

Prevent injuries and violence

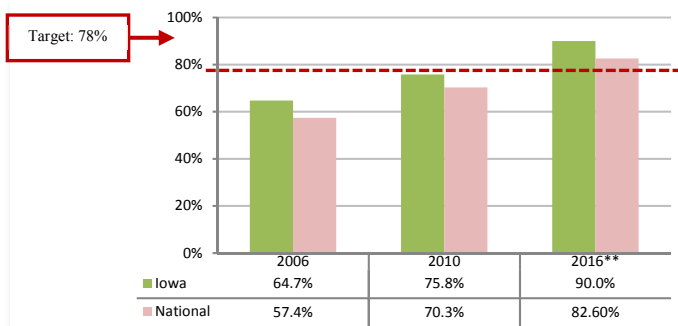
What do we do?

- CHSC provides gap-filling clinical services including assessments of child development, health conditions and behavioral concerns.
- CHSC has a network of 14 regional centers and four satellite locations across Iowa, providing access to pediatric specialty care through telehealth.
- CHSC employs over 100 public health professionals, clinical providers, and family members of children and youth with special health care needs who work with communities to build partnerships, improve coordination of services and promote optimal child health.
- CHSC’s Family Navigators provide families of children and youth with special health care needs with individual problem-solving and emotional support. They have firsthand experience as a parent or caregiver of a child with special needs. Family Navigators work with other CHSC staff including ARNPs, nurses, and social workers.

How do we measure our progress?

We employ a process of continuous quality improvement and report our metrics to the federal government every year using state and national performance measures.

1 Percent of children and youth with special health care needs (CYSHCN) ages 0-18 years whose families' partner in decision-making at all levels and are satisfied with the services they receive.



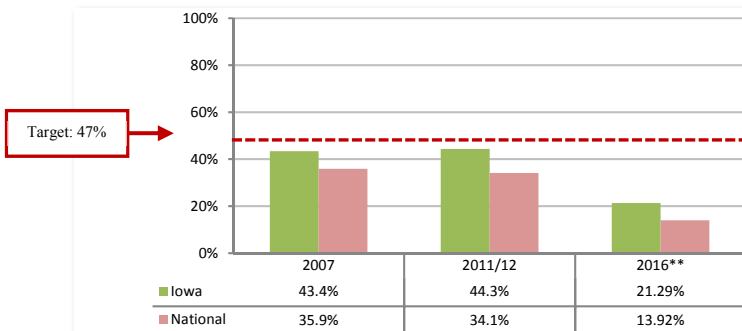
Data Source: 2006 & 2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). 2016 National Survey of Children's Health (NSCH). ** See note on change in data source and methodology.

2 Percent of CYSHCN ages 0-18 years who receive coordinated, ongoing, comprehensive care within a medical home.



Data Source: 2006 & 2010 NS-CSHCN. 2016 NSCH.**

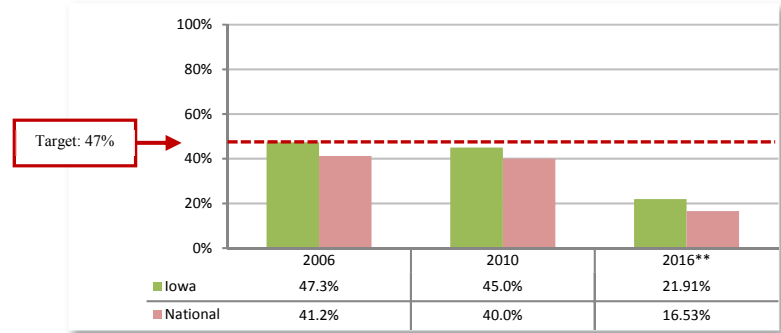
3 Percent of CYSHCN who met the criteria for each of three essential system measures: adequate insurance, receive ongoing and coordinated care within a medical home, and had at least one preventive health care visit in the past 12 months.



Data Source: 2006 & 2010 NS-CSHCN. 2016 NSCH.**

**Note that the data source and methodology changed in 2016. Therefore, making comparisons to data prior to 2016 is not recommended.

4 Percent of CYSHCN who received the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.



Data Source: 2006 & 2010 NS-CSHCN. 2016 NSCH.**

What can Iowans do to help?

1. Refer children or youth with special needs to CHSC by visiting <https://chsciowa.org/>.
2. Be inclusive of children with special health care needs and their families.
3. Discuss with policymakers the importance of a System of Care for children and youth with special health care needs and their families.

Expenditures

General fund & federal grant: K07-0703/0871; 0153-0706/0730/0732

	State Fiscal Year 2016 Actual	State Fiscal Year 2017 Actual	State Fiscal Year 2018 Estimate
State funds	\$1,184,157	\$1,139,345	\$745,163
Federal funds	\$2,785,084	\$2,788,146	\$2,230,364
Other funds	\$0	\$704,429	\$778,211
Total funds	\$3,969,241	\$4,631,920	\$3,753,738
FTEs	0.00	0.50	0.25

Note: Funding information is intended to provide an overview of funding related to the program area. It does not include all federal and state requirements and/or restrictions for the use of funds. Contact the program area for more detailed budget information.

Iowa Department of Public Health Division of Health Promotion & Chronic Disease Prevention Child Health Specialty Clinics

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