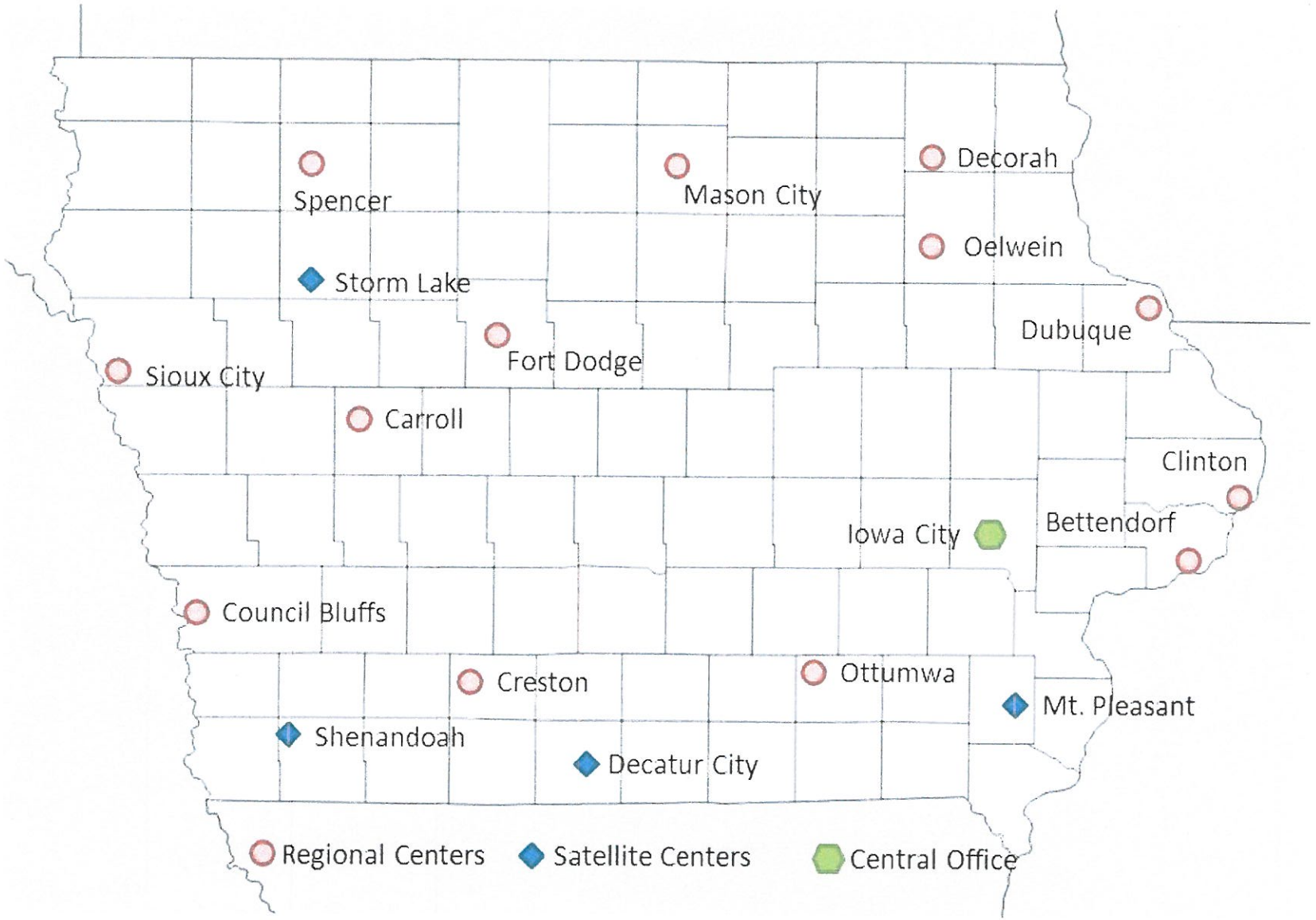
CHSC Regional and Satellite Centers



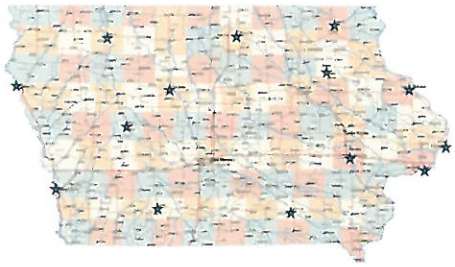
2011 Year in Review

Child Health Specialty Clinics

Assuring a System of Care for Iowa's Children and Youth with Special Health Care Needs

100 Hawkins Drive ~ Iowa City, IA 52242 ~ Tel: 319-356-1117 ~ Fax: 319-356-3715 ~ www.chsciowa.org

CHSC Regional Centers



Child Health Specialty Clinics (CHSC) is part of Iowa's statewide public health system. CHSC assures a family-centered, community-based, culturally-competent, coordinated system of care for children and youth with special health care needs (CYSHCN). CHSC supports community-based health homes and promotes best practice protocols. Staff from CHSC's regional centers work closely with local stakeholders to collaborate and coordinate their efforts to serve Iowa's CYSHCN and their families.

2011 - A Focus on Community Child Health Teams

The Community Child Health Team (CCHT) model combines primary care, care coordination, and family support. While parts of this model have already been implemented in CHSC's existing regional centers, in 2011 CHSC received a three-year grant from the Health Resources and Services Administration (HRSA). This grant will allow CHSC to disseminate CCHT practices to four community primary care sites: Adolescent Clinics at Blank Children's Hospital and the University of Iowa Hospitals and Clinics, and Federally Qualified Health Centers in Fort Dodge and Sioux City. Lessons learned from these four pilot sites will then be spread to additional sites.

Meet the Smiths *

Doris and Tony Smith reside in Waterloo, Iowa along with their seven children who range in age from three to twenty years old. Along with their three biological children, Steven, Susan, and Barbara, the Smiths opened their home and family to several foster children, eventually adopting Benjamin, Max, Tim, and Olivia.

After seven-year-old Benjamin came to live with them, Doris and Tony began noticing that he often had trouble concentrating and focusing on small tasks. After trying several different medications prescribed by their primary care provider, Benjamin's parents decided to look for someone who specialized in children with special behavioral needs, but were unable to find a psychiatrist in their area who was willing to see a child under the age of twelve. Still looking for a way to help their son, the Smiths turned to Child Health Specialty Clinics.

In September, 2008, Doris, Tony, and Benjamin had their first appointment at the CHSC Oelwein office where they received a comprehensive evaluation and were able to discuss care options with CHSC staff. Benjamin was subsequently able to see a child psychiatrist via CHSC's telehealth network and received a diagnosis of ADHD. CHSC staff worked with the Smiths, their primary care provider, and the child psychiatrist to find the most effective medication for Benjamin, whose care plan also includes play therapy and occupational therapy.

"The best part of CHSC is that they provide us with options that families can't find anywhere else," says Tony. "If we would have had to wait another five years to get Benjamin the medication and therapy he needs, I can't imagine what that would have been like."

CHSC staff across the state of Iowa help families get the care and services they need within their home communities while emphasizing early detection and intervention, putting Iowa's children and families on a pathway to health.

** Names have been changed*

Building Iowa's System of Care for CYSHCN - 2011 Progress

Members of CHSC's Community Child Health Teams (CCHT) live in the communities they serve. CCHTs work with families and partnering agencies to create a system that responds to the needs of the estimated 144,410 CYSHCN in Iowa and their families (*National Survey of Children's Health, 2007*). Highlights of activities from 2011 for each component of the System of Care for CYSHCN are featured below.

Direct Clinical Care

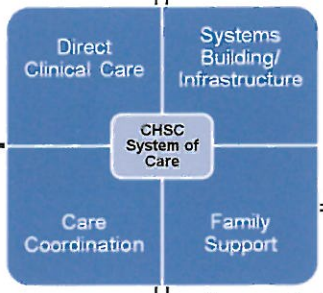
CHSC provided specialized direct clinical care when it was otherwise unavailable in a child's home community. In 2011 we...

* Provided specialized direct clinical care at 13 regional centers and three satellite clinics.
* Provided screening and comprehensive evaluations of children for developmental delay, autism spectrum disorder (ASD), feeding problems and poor growth, hearing, and other physical and behavioral problems.
* Fully implemented an electronic health record.
* Utilized telehealth to provide nutrition, behavioral, and ASD services.

Systems Building/Infrastructure

CHSC was dedicated to strengthening the public health system for CYSHCN. In 2011 we...

* Joined national quality improvement networks to lead, teach, and implement quality improvement methodology.
* Trained local providers in the use of appropriate child screening tools.
* Collaborated with state and national efforts to combat childhood obesity and bullying of CYSHCN.
* Represented the needs of CYSHCN to re-design the children's mental health system.
* Provided support for primary care providers treating CYSHCN through the Child & Youth Psychiatric Consult Project of Iowa (CYC-I)



Care Coordination

CHSC offered care coordination to every family we saw this past year. In 2011 we...

* Provided care coordination and follow-up services through Family Navigators, RNs, Social Workers, and ARNPs.
* Provided care coordination support to families of CYSHCH who were referred by local providers.
* Helped families locate and access needed resources.
* Coordinated referrals for specialized medical and psychiatric evaluations.
* Assisted CYSHCN and their families with the transition from the pediatric health care system to the adult health care system.
* Developed methodology to document the use of care coordination in electronic health record in order to track the costs and benefits of these services.

Family Support

CHSC employed a network of Family Navigators (FNs) who provided peer-to-peer support to families. Available at all regional centers, FNs are family members of CYSHCN and can speak from first-hand experience. In 2011 we...

* Coordinated the efforts of more than 25 family advocacy groups through the Family to Family Iowa network.
* Implemented training activities to assure Family Navigators have shared knowledge and skills.
* Developed social networking tools for families of children with certain genetic conditions.

Erin's Story * *(as told by her mother)*

When we first adopted Erin, it was difficult for our family to get answers or help for her complex behavioral and developmental concerns. Our adoption specialist at DHS suggested that we call Child Health Specialty Clinics. At CHSC, the Advanced Registered Nurse Practitioner and Staff Nurse conducted a complete developmental and health assessment. Along with the Family Navigator, they made recommendations, helped with paperwork, and coordinated support services.

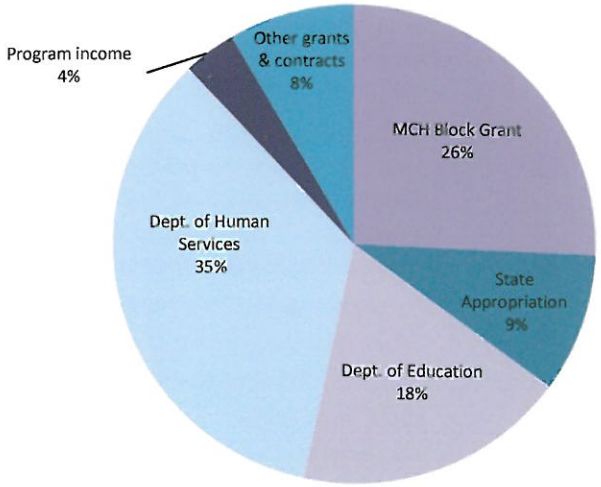
Through CHSC, our family utilized a variety of services including dietician services, physical therapy, occupational therapy, speech therapy, respite, and parenting classes, all of which have contributed to the growth and development of our daughter. CHSC has helped us become more understanding about Erin's developmental disabilities and special health care needs.

If I'm ever feeling overwhelmed or frustrated, I know I can call my Family Navigator, even if I don't have an appointment. We are now able to anticipate our daughter's needs and have become better equipped to deal with her behaviors at home and in public. Her overall development has progressed greatly and we hope that she continues to get the help she needs at school and in the community.

** Name has been changed*

CHSC Financial Support

CHSC is partially funded by the federal Title V Maternal and Child Health Block Grant and state appropriations via the Iowa Department of Public Health. In addition, CHSC receives funds from the Iowa Departments of Education and Human Services, other community partners, and program income. CHSC is administered through the University of Iowa, Department of Pediatrics. The chart below shows the breakdown of support received from each funding source in 2011.



Your Data ... Your Story

Data Resource Center for Child & Adolescent Health

Children with Special Health Care Needs (CSHCN) Indicator — National Survey CSHCN 2009-2010	CSHCN IOWA	CSHCN NATIONAL
Prevalence of CSHCN (Ages 0-17)	15.0%	15.1%
CSHCN who have more complex health needs * **i.e.** child has one or more ongoing health condition requring above-rourine amount or complexity of health services (Ages 0-17)	20.3%	19.2%
CHSCN who have more complex health needs * i.e. one or more current chronic conditions are rated moderate or severe	37.2%	42.9%
CSHCN who are uninsured (at some point in last yr)	7.7%	9.3%
CSHCN with private and/or public health insurance to pay for services they need	64.6%	60.6%
CSHCN with inadequate health insurance	31.3%	39.3%
CSHCN who received effective care coordination	16.0%	23.6%
CSHCN are served by systems of care that meet all age-relevant core outcomes (DRC suggests this item for health care that met federal min Q standards)	20.1%	17.6%
CSHCN who received coordinated, ongoing, comprehensive care within a medical home	47.0%	43.0%
CSHCN who had no difficulty getting referrals to specialty care	80.9%	76.6%
Youth with SHCN who receive services necessary to make appropriate transitions to adult health care, work, and independence	45.0%	40.0%
CSHCN whose families are partners in shared decision-making for child's optimal health	75.8%	70.3%
CSHCN whose conditions cause family members to cut back/stop work	17.6%	25.0%

Child Health Specialty Clinics
chsc Assuring a System of Care for Iowa's Children and Youth with Special Health Care Needs

Community Child Health Teams

Family Navigators provide family-to-family support. They are primary caregivers of a child or youth with special health care needs who have first-hand experience. Family Navigators receive a certificate of completion using a standardized training curriculum. Family Navigators:

- Connect emotionally with families of children and youth with special health care needs.
- Partner with families to identify and prioritize family needs.
- Identify existing formal and informal supports and resources.
- Provide assistance to complete service, financial or other applications as needed.
- Help families develop advocacy skills and reduce isolation.
- Accompany families to health, education and human services appointments as needed.
- Create and facilitate family-to-family support groups.
- Access community, state and national networks of Family Navigators familiar with resources and specific health conditions.
- Conduct trainings for families, health care providers, Family Navigators, and others.

Standardized data is collected to show the effectiveness of family-to-family support.

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(Family Navigator Working Definition.docx)