



Quality Health Care for Children with Special Health Care Needs

Health Information and Education Center
Providing information to families and professionals through:
Workshops/trainings
Presentations
Toll-Free Number
Website/List-serv
Newsletter and Materials

Looking for information about a child's special health care needs? Family Voices of North Dakota a Health Information and Education Resource Center is run by parents having children with special health care needs, multiple disabilities and mental health conditions.

We maintain a free lending library of books, videos, and audio tapes on specific conditions and disabilities, sibling relationships, behavior, health care issues and social issues. We assist families & professionals with the following on a one-to-one basis as well as through workshops:

Health Care Financing, Health Care Delivery Systems, Educational System, Medical Home, Support Groups, Disease/Condition Specific Materials, Daily Living Needs and Advocacy Issues

Through information, support and education, families and professionals learn to optimize the lives of our children and others who share their lives.

Family Voices of North Dakota Health Information and Education Center offers the resources and assistance in obtaining these goals.



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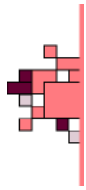
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Quality Health Care for Children with Special Health Care Needs

When we founded Family Voices in 1992, one of our first activities was to identify six principles that are the foundation for quality health care for children with special needs. As health care systems change, we find growing emphasis on measuring quality in order to assure good health care practices, systems, and outcomes. We find that our six principles have stood the test of time and provide a useful framework for discussions in public and private arenas about quality health care for our children.

In a Quality Health Care System...

Quality health care...is family-centered:

- s Health care services allow the child to live at home, attend local schools, be part of the community.
- s The health care team honors the family's culture, language, customs, and decision-making processes.
- s Families receive information about parent-to-parent support groups and other family organizations.
- s Health care is delivered in locations and at times convenient for families.
- s If necessary, families receive transportation assistance to get to medical appointments.
- s Coordination of the child's health care, related services, and payment is explained and provided.

Resources on Quality Health Care for Children with Special Health Care Needs

- s ***Quality of Health Care for Children and Adolescents; A Chartbook.***
The Commonwealth Fund
A comprehensive report on quality of children's care.
<http://www.cmf.org>
- s ***The Health Care Experience of Families of Children with Special Health Care Needs***
The Family Partners Project, Family Voices
Summary of findings and conclusions.
<http://www.familyvoices.org/YourVoiceCounts/sumfind-conc.htm>
- s ***Measuring Quality for Children with Special Health Care Needs. CAHPS (Consumer Assessment of Health Plans) Survey.***
Family Voices
<http://www.familyvoices.org/Information/cahps.htm>
- s ***Child Health Toolbox: Measuring Performance in Child Health Programs. Measuring Services for Children with Special Health Care Needs,*** March 2002. Agency for Healthcare Research and Quality, Rockville, MD.
<http://www.ahrq.gov/ctoolbx/cshcn.htm>
- s ***Developing and Analyzing Performance Measures - A Guide for Assessing Quality of Care for Children with Special Health Care Needs***
Quality Community Managed Care (QCMC) Project
<http://www.uic.edu/sph/cade/qcmc/qcmc3/frontmatter.pdf>

Quality health care...is cost-effective...continued

- § The insurance plan monitors overall costs to the family, including out-of-pocket expenses.
- § All payors communicate to make sure that payments are made on time.
 - § Family leaders help set capitation rates that cover real costs for children with special health care needs. §

Real costs are tracked to assure that our children receive necessary benefits.

- § Families serve on commissions reviewing expenditures for children with special health care needs.
- § When a family exceeds a lifetime cap, the insurance provider either offers a new plan with comparable benefits, or transfers the child to a new plan with comparable benefits, with no interruption in coverage, medical home, or access to specialists.

§ A more detailed paper on quality is available on Family Voices website www.familyvoices.org.

- § Care coordinators understand the range of services and communicate with one another and the family.
- § Health services are coordinated with other services important to the child and family.
- § Health care sites are accessible, providing translation services and family-friendly information.

Adapted with permission from NH Family Voices

Quality health care...supports families as caregivers:

- § Families receive information about their child's diagnosis, services, expected outcomes, ways to pay, and their rights and responsibilities.
- § Families can easily access medical records and other important information and documents.
- § Information is communicated in family-friendly language and formats.
- § Families are full members of health care teams, participating in all decisions.
- § The plan of care supports the direct care given by families and describes the child's role in self-care.
- § Providers and health systems give families and children opportunities to comment on care they receive.
- § The plan of care includes assistance in the transition from pediatric to adult health services.

Quality health care...gives every child access to primary and specialty care:

- § The child's medical home delivers well child and preventative care through guidelines from the American Academy of Pediatrics.
- § The primary provider knows about the child's special health condition and how to find resources.
- § The primary care provider communicates effectively with specialists and other providers.

- § The child receives appropriate care from pediatric specialists, based on efficient referrals.
- § The family can choose primary and specialty providers, including a specialist as the primary provider.
- § The child's care plan is developed by the family and providers, and is monitored often.

Quality health care...includes flexible, family-centered health benefits:

- § The health insurance plan identifies and follows children with special needs.
- § Covered benefits include the services that children with special health care needs require.
- § The plan of care allows and describes standing referrals, access to out of network providers, extension of benefits, exceptions to policy, and supports for a family to care for the child safely at home.
- § Families can easily find and use information about grievance and appeals processes.
- § Health systems regularly review and address gaps in coverage and services, based on family feedback.

Quality health care...builds on strong family-professional partnerships:

- § Families and providers make decisions together, with the child participating as much as possible.

- § Administrative policies and practices support long term relationships between families and providers.
- § Families help professionals develop and use tools that measure quality of care and family satisfaction. § Families participate in in-service trainings with providers, agencies and health plans.
- § Families serve on statewide and local public and private policymaking boards.

Quality health care...is cost-effective:

- § Public and private policies assure that families can afford their child's health care.
- § Families are assisted in understanding and utilizing all payment options.
- § Families have roles in making cost decisions, including vendor selection.
- § Payors compare hospitalizations or other expensive treatments to alternatives, such as out of network services that might cost less or produce a better outcome at almost the same price.