



Best Practices for Children and Youth with Special Health Care Needs



Family To Family Health Information
and Education Center

Best Practices

"**Best Practice** asserts that there is a technique, method, process, activity, incentive or reward that is more effective at delivering a particular outcome than any other technique, method, process, etc. The idea is that with proper processes, checks, and testing, a desired outcome can be delivered with fewer problems and unforeseen complications. Best practices can also be defined as the most efficient (least amount of effort) and effective (best results) way of accomplishing a task, based on repeatable procedures that have proven themselves over time for large numbers of people.

In real-world application, Best Practice is a very useful concept. Despite the need to improve on processes as times change and things evolve, Best Practice is considered by some as a business 'buzzword' used to describe the process of developing and following a standard way of doing things that multiple organizations can use for management and policy."

Wikipedia®, 2008

NH Family Voices

New Hampshire Family Voices (NHFV) provides information and support to families of children and youth with special health care needs (CYSHCN) and the professionals who serve them via: individualized assistance, training, focus groups, conferences, resource guides, newsletter, lending library, website and surveys. NHFV provides and facilitates the voice of families through partnerships and collaboration. These activities are supported by funding from NHDHHS, Special Medical Services, USDHHS, Center for Medicare and Medicaid Services, CMS (F2F HIC grant), and The Hood Center for Children and Families.

This document was developed by NH Family Voices through a grant from the U.S. Department of Health and Human Services, Centers for Medicaid and Medicare (1LECMS300014)

Who Are Children and Youth with Special Health Care Needs?

"Children and youth with special health care needs are those who have, or are at risk for, a chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

The above definition was developed by the Maternal and Children Health Bureau, Division of Services for Children with Special Health Care Needs in collaboration with many experts in child health including parents, and has become widely accepted.

This definition includes children with a broad range of conditions or chronic illnesses such as cerebral palsy, developmental delay, ADHD, depression, asthma, sickle cell anemia or cystic fibrosis as well as children who develop a significant medical problem that is expected to last at least twelve months. The Maternal and Child Health Bureau definition helps to identify children based on the impact of their special health need and their need for health and related services, rather than only on their diagnosis. Many children have more than one special health need.

A recent national population based survey estimates that over 9 million (12.8 percent) children in the United States presently have a special health care need. One in five households include children with special health care needs. Some children with special health care needs require only an accurate diagnosis and routine treatment and monitoring. Other children will need life-sustaining technology, treatment, and medicines throughout their lives. Children with special health needs tend to receive their health care from a combination of private and public financing and delivery systems, and many depend on multiple providers. Almost all children with special health care needs, no matter the severity of their condition, live at home with their parents and brothers and sisters.

Children with special needs above all deserve a health, happy childhood and a chance to grow up to be productive adults. Like all children, they live with their families in towns, cities and rural areas of the United States , going to school, attending worship services, enjoying community events. However, unlike most children, they also have challenging health conditions that usually make their lives and their families' lives more complicated. Any child, at any time, could develop a disability or chronic health condition.

Best Practices

Family Centered Care

Definition of Family Centered Care

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

Principles of Family-Centered Care for Children

The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

Based on this partnership, family-centered care:

- Acknowledges the family as the constant in a child's life.
- Builds on family strengths.
- Supports the child in learning about and participating in his/her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes.

Sources: National Center for Family-Centered Care. *Family-Centered Care for Children with Special Health Care Needs*. (1989). Bethesda, MD: Association for the Care of Children's Health. Bishop, Woll and Arango (1993). *Family/Professional Collaboration for Children with Special Health Care Needs and their Families*. Burlington, VT: University of Vermont, Department of Social Work. Family-Centered Care Projects 1 and 2 (2002-2004). Bishop, Woll, Arango. Algodones, NM: Algodones Associates

Community Based Care

In order for families to value and benefit from services for Children and Youth with Special Health Care needs, the system of services must be organized so that families know how and where to get the services they need. It is equally important that the services are organized and delivered in culturally effective, family-centered, and accessible settings. Simplifying this process and avoiding duplication should be a goal of community-based systems of services.

Coordinated Care

Care coordination is a central, ongoing component of an effective system of care for children and youth with special health care needs and their families. Care coordination engages families in development of a care plan and links them to health and other services that address the full range of their needs and concerns. Principles of care coordination reflect the central role of families and the prioritization of child and family concerns, strengths and needs in effective care of children with special health care needs. Activities of care coordination may vary from family to family, but start with identification of an individual child and family needs, strengths and concerns, and aims simultaneously at meeting family needs, building family capacity and improving systems of care.

Principles of Care Coordination

- ♦ **Accessibility**
 - Universal source; available/accessible for all CYSHCN
 - Continuous across service systems and across transitions as important to family
 - Is housed within medical home but with family, rather than practice, as "client"
 - Integrated with community resources to assure access for all linguistic and cultural groups
- ♦ **Individualization** based on family circumstance, needs and strengths
 - Maximizes family care-giving capacity
 - Looks to family to define needs, rather than offering family what the system happens to provide
 - Builds, and builds on, family strengths
 - Provides anticipatory guidance to prepare family and child for future
 - Respects and engages with family culture and custom
- ♦ **Aligned with the family** in its interactions with the broader community
 - Promotes inclusion of child/youth in all settings
 - Promotes autonomy of child/youth towards and through transition
 - Serves as advocate for family when systems with challenging or unresponsive systems
 - Evaluates status of family and legitimizes family concerns to broader community

Principles of Care Coordination ... continued

- ♦ **Promotes solution of systematic problems** through network of Care Coordinators (CC's) guided by clear standards and ethics
 - Ties individual CC to broader network for quality assurance, accountability and support
 - Draws on knowledge base and resources of multiple disciplines, while not focused on providing any one specific therapeutic or curative service
 - Promotes appropriate use of services and resources (from family and system perspectives) based on needs of child, family and system
 - Reduces fragmentation and connects services across systems
 - Identifies and tracks systematic gaps and barriers

Source: *Care Coordination: Definitions & Principles*, Massachusetts Consortium for Children with Special Health Care Needs; June 2, 2005; revised October 6, 2005

Culturally Competent

What is Cultural Competence in Health Care?

Individual values, beliefs, and behaviors about health and well-being are shaped by various factors such as race, ethnicity, nationality, language, gender, socioeconomic status, physical and mental ability, sexual orientation, and occupation. Cultural competence in health care is broadly defined as the ability of providers and organizations to understand and integrate these factors into the delivery and structure of the health care system. The goal of culturally competent health care services is to provide the highest quality of care to every patient, regardless of race, ethnicity, cultural background, English proficiency or literacy. Some common strategies for improving the patient-provider interaction and institutionalizing changes in the health care system include:

- ♦ Provide interpreter services
- ♦ Recruit and retain minority staff
- ♦ Provide training to increase cultural awareness, knowledge, and skills
- ♦ Coordinate with traditional healers
- ♦ Use community health workers
- ♦ Incorporate culture-specific attitudes and values into health promotion tools
- ♦ Include family and community members in health care decision making
- ♦ Locate clinics in geographic areas that are easily accessible for certain populations
- ♦ Expand hours of operation
- ♦ Provide linguistic competency that extends beyond the clinical encounter to the appointment desk, advice lines, medical billing, and other written materials.

Brach, C. & Fraser, I. 2000. Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*, 57 (Supplement 1), 181-217.

Medical Home

What is a Medical Home?

By Tammy Mann, Texas Parent to Parent

A Medical Home (MH) is a model of care delivery that your family should already be receiving. It is the end result of parents and health care professionals acting as partners. After all, you both want the same thing, right? Healthy children and families who are able to achieve their maximum potential. Unfortunately, most parents are not aware of what "medical home" means, most professionals think they already provide it, and the ones that don't are trying to figure out how to bill for it!


Medical Home is not the "term of the month." The definition was introduced in 1992 by the American Academy of Pediatrics. Their belief is "that all children should have a medical home where care is **accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective.**"

To be fair, health care professionals are not taught about Medical Home in school. Doctors learned to fix what was broken or bleeding, take out what didn't belong in, add in what was missing... but nowhere in the "rule book" was anything that said "play nice with the patient," never mind be "**accessible,**" make sure that you take all forms of payment (yes, that means insurance, Medicaid, Medicare, etc.), provide care in the family's community (not the big city 150 miles away), and make yourself available to speak directly to the families (and not after the family has left 10 messages). The MH model gives "bedside manner" a whole new meaning!

The best thing that a medical professional has ever said to me was that I know my child better than anyone. Well, if you think about it, that's true. Who knows our children better than we do?

Family-centered care means just that - parents are the experts on their children, so why not be teammates with the health care professionals? In a true MH, recognizing that the family is the principal caregiver, the core, the one true constant in the child's life is just an extra tool for the provider. Nowhere else can you find a more reliable source for information.

Continuous means that you have the same health care professionals available from infancy through adolescence and young adulthood. AND, they assist with transitions including those to other pediatric providers or into adult health care systems.



Being able to access health care 24 hours a day, 7 days a week, 52 weeks a year should not be difficult if your health care provider has a **comprehensive** office. Hopefully, the preventive, primary, and tertiary (secondary) care needs are addressed in the office which should cut down on some of those "24 hour a day, 7 days a week, 52 weeks a year" emergency needs.

Providing resources falls into both **comprehensive and compassionate** services. Connecting families to support, educational, and community-based services only proves that the health care professionals understand and are working towards helping your family be the best they can be; it demonstrates concern for well-being, understanding and empathy.

The same can be said for being **culturally effective**. Professional translators or interpreters are great but truly understanding that a family's culture, beliefs, rituals, and customs are a part of the "whole" family, are the "frame work" of the family is critical and should be recognized, valued, and respected as families and physicians work together to develop a care plan.

Last, the family care plan should be **coordinated**. It should be developed by the health care provider, child/youth, and family, and shared with other providers, agencies, and organizations involved with the care of the patient. Families are linked to support, educational, and community-based services and a central record containing all pertinent medical information (including hospitalizations, and other specialty care like outside therapies, etc.) is kept and maintained in a central record by the primary provider. This can be your pediatrician, family practitioner, or as in one family I know, your dermatologist.

Hopefully, this gives you a better understanding of what it means when someone says "Medical Home."

References: The Medical Home Policy Statement. Pediatrics. Elk Grove Village, IL: American Academy of Pediatrics; 2002. <http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;110/1/184>.
Community Access to Child Health (CATCH) <http://www.aap.org/catch/index.html>

Family/Professional Collaboration

Parent-professional collaboration moves a step further than family involvement. To collaborate means to work together in an equally reciprocal relationship that is based on mutual trust and caring. The move toward collaboration is an effort to improve direct services for families and professionals, identify informal supports, and build communities for people with disabilities that are based on their culture, dreams, goals, priorities, and needs.

Principles of Family/Professional Collaborations

- promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family;
- recognizes and respects the knowledge, skills and experience that families and professionals bring to the relationship;
- acknowledges that the development of trust is an integral part of collaborative relationship;
- facilitates open communication so that families and professionals feel free to express themselves;
- creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored;
- recognizes that negotiation is essential in a collaborative relationship; and
- brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health needs and their families.

Source:

Bushop, K.K., Woll, J., & Arango, P. (1993). *Family/professional collaboration for children with special needs and their families*. Burlington, VT: University of Vermont, Department of Social Work, Family/Professional Collaboration Project.

Healthcare Transition for Youth with Special Health Care Needs

Youth with special health care needs are neither CHILDREN nor ADULTS. Their issues and concerns are similar, but different from both. This pivotal time called youth should be a time in which the total environment supports the child in becoming an adult. The support should encourage the aspirations and expectations that lead to productive adulthood - or - if supports are absent, it can be a time of actions that ingrain doubt, confusion and lack of initiative.

A major goal of the US Department of Health and Human Services, Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Needs (DSCSHCN) is to assure that all youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including adult health care, employment and independence. This concept of health and transition has become a prominent movement. The move to make health a part of transition planning for youth with special health needs and disabilities has become a national concept.

For young people with special needs, these issues are particularly important. Age-appropriate health care services are essential for reducing the risk of secondary disabling conditions. Teens who learn how to manage their own health care are able to live more independently. But teens with disabilities often face additional challenges in this step towards adulthood. They may find it hard to find an adult provider who is trained in pediatric or developmental conditions, and is willing to assume primary responsibility for their care. Or, teens who already receive care from a family physician may find it easy to continue in a child's role rather than take on an adult role. Either way, young people may be uncomfortable in the role of adult health care consumers, and families may have trouble letting go.

Children and teens, as developmentally able, need to understand their medical condition, medication, and health insurance. They need to learn how to communicate with their doctors, make appointments, and make informed health decisions. Parents and caregivers need to learn about changes in health care needs, services, and insurance coverage as youth transition into adulthood. Pediatricians and other service providers can play an important role in providing information and direction to youth and families on issues affecting health care and lifestyle choices. It is helpful to begin planning by writing down future goals and then identifying the things that need to be done in order to achieve those goals.

Successful transition requires that youth, family, doctors, and other providers all work together to plan for needed skills and services, ways to get the services, and methods of paying for them.

Web Resources to Learn More.....

Family Centered Care

Institute for Family-Centered Care

www.familycenteredcare.org

The Institute serves as a central resource for both family members and members of the health care field. This site shares information, facilitates problem-solving and promotes dialogue among individuals and organizations working toward family-centered care.

National Resource Center for Family Centered Practice

www.uiowa.edu/~nrcfcp

Provides technical assistance, staff training, research, and information about family-based programs and issues. Contains extensive bibliographies, numerous online links, online newsletter, other publications and resources.

Medical Homes

National Center of Medical Home Initiatives for Children with Special Needs

www.medicalhomeinfo.org

The National Center of Medical Home Initiatives for Children with Special Needs provides support to physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home. Center has in house expertise as well as national contacts for all areas of care in community setting.

Family-Professional Partnership

Family Voices

www.familyvoices.org

A national, grassroots clearinghouse, speaking on behalf of children with special needs. *The National Center for Parent-Professional Partnerships* resides within Family Voices. They offer resources and publications for families on healthcare issues for children with special health care needs, and relevant links.

Cultural Competence

National Center for Cultural Competence

www11.georgetown.edu/research/gucchd/nccc

The mission of the National Center for Cultural Competence (NCCC) is to increase the capacity of health and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems. Many resources on site.

Health Care Transition

Adolescent Health Transition Project

<http://depts.washington.edu/healthtr/index.html>

A resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities. This site is a resource for information, materials, and links to other people with an interest in health transition issues.

Healthy and Ready to Work

www.hrtw.org

Provides information and connections to health and transition expertise nationwide - from those in the know, doing the work and living it! This site focuses on understanding systems, access to quality health care, and increasing the involvement of youth.

New Hampshire Resources

Center for Medical Home Improvement

www.medicalhomeimprovement.org

The Center for Medical Home Improvement promotes the medical home as a family-centered "way of doing things" for Children and Youth with Special Health Care Needs; this includes how practices partner with, respond to, and care for CYSHCN.

Special Medical Services

www.dhhs.nh.gov/DHHS/SPECIALMEDSRVCS/default.htm

Special Medical Services provides NH families with health information and support services, care coordination services; support for child development and neuromotor clinics; nutritional and feeding/swallowing consultation; psychological and physical therapy services.

NH Family Voices

www.nhfv.org

A member of the National Family Voices organization speaking on behalf of NH's children with special needs. Assistance to families including resources and publications for families on health, developmental, physical and behavioral issues.

Hood Center for Children and Families

<http://hoodcenter.dartmouth.edu>

The Hood Center is dedicated to improving the well-being of children, adolescents, and families through health promotion research and family-centered support.

Institute on Disability, UCED

<http://iod.unh.edu>

The Institute on Disability/UCED (IOD) at the University of New Hampshire was established in 1987 to provide a coherent university-based focus for the improvement of knowledge, policies, and practices related to the lives of persons with disabilities and their families.

NH Minority Health Coalition

www.nhhealthequity.org

The mission of the NH Minority Health Coalition is to identify underserved populations in the state with barriers to accessing appropriate health care, to advocate for adequate and appropriate services and to educate and empower these populations to be active participants in their own health care.