FAMILY VOICES
OF NORTH DAKOTA®

Health Information and Education Center

BEST PRACTICES
FOR
CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

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

Family Voices of North Dakota (FVND)

FVND 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. FVND provides and facilitates the voice of families though partnerships and collaboration.

Funding for this publication comes from Maternal and Child Health Bureau under Grant H84MC07992-01-01 and Department of Health Children's Special Health Services.

Who are Children with Special Health Care Needs

"Children and youth with special health care needs (CYSHCN) 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.

Source: Family Voices 2340 Alamo SE, Suite 102 Albuquerque, NM 87106 Tel: (888) 835-5669 or (505) 872-4774; www.familyvoices.org or kidshealth@familyvoices.org

Children and Youth with Special Health Care Needs Cont.

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 CYSHCN. 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. CYSHCN 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 CYSHCN, no matter the severity of their condition, live at home with their parents and brothers and sisters.

CYSHCN 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.

Source: Family Voices 2340 Alamo SE, Suite 102 Albuquerque, NM 87106 Tel: (888) 835-5669 or (505) 872-4774 www.familyvoices.org dshealth@familyvoices.org

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,

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. Activi-ties 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.

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Principles of Care Coordination

Accessibility-Universal source; available/accessible for all CYSHCN which is 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 which 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.

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), 181-21

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.

Cont.

Medical Home Cont.

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 cus-toms 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 Collaboration

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 fell 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 transi-tion to all aspects of adulthood, including adult health care, employment and independence. This concept of health and transition has became a prominent movement. The move to make health a part of transition planning for youth with special health needs and disabilities has became 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 familymembers 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 newslet-ter, 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 Partnerships

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.

Web Resources

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.

Family Voices of North Dakota has many resources to offer on their website, you may contact us: www.fvnd.org or call toll free to 888-522-9654

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Children and Youth with Special Health Care Needs (CYSHCN) in NORTH DAKOTA

What does the National Survey of Children with Special Health Care Needs[1] tell us:

About their health?

- **13%** of CYSHCN miss 11 or more days of school due to illness.

About their insurance coverage?

- **10%** of CYSHCN were without insurance at some point during the past year.
- **26%** of currently insured CYSHCN have coverage that is not adequate.

About their access to care?

- **11%** of CYSHCN have families that need but did not get all respite care, genetic counseling and/or mental health services.
- **16%** of CYSHCN who need specialty care have problems getting a referral.
- **6%** of CYSHCN do not have a usual source of care or rely on the emergency room.

About family-centered care?

- **31%** of CYSHCN do not have family-centered care.

About the impact of their care on their family?

- **22%** of families pay $1,000 or more in medical expenses per year.
- **18%** of families experience financial problems due to their child's health needs.
- **9%** of families spend 11 or more hours per week providing and/or coordinating health care for their child.

"Your advocacy work for families within North Dakota has been a blessing to the families you have direct contact with, as well as families who do not access services."

A Provider

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WHO ARE CYSHCN?

There are approximately **16,541 children** under the age of 18 in North Dakota who have special health care needs, **representing over 12% of all households**[1].

Children and youth with special health care needs (CYSHCN) are those who have or are at risk for 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[2]. Some CYSHCN require only an accurate diagnosis and routine treatment and monitoring. Other children and youth need life-sustaining technology, treatment, and medicines throughout their lives. CYSHCN tend to receive their health care from a combination of private and public financing and delivery systems, and many depend on multiple providers.

WHERE DO FAMILIES OF CYSHCN FIND HELP?

Because the health care needs of CYSHCN are chronic and complex, parents and caregivers often find it challenging to locate the information and resources needed to help their children. Experienced families are often the best source of assistance for parents of CYSHCN as they themselves have first hand knowledge of the maze of services and programs designed to help CYSHCN. In North Dakota, **Family Voices of ND** provides such family-to-family assistance.

FV ND is a parent-run organization that provides information and supports to families of children and youth with special healthcare needs (CYSHCN) and the professionals that serve them. FV of ND provides this assistance through direct contact (telephone, e-mail, in-person), publication development and dissemination, workshops, trainings, and presentations as well as partnership activities with state agencies and community-based organizations. FV of ND receives funding from Maternal and Child Health Bureau (Family-to-Family Health Information Center grant) and the ND CSHS/Department of Health (Rural Health Grant).

In 2007, FV of ND worked diligently with families to assist them in educating providers and policy makers regarding needed services for CYSHCN, resulting in a successful campaign to pass new legislation to increase Medicaid coverage - *The Children with Disabilities Program*. FV of ND also helped to ensure that this legislation also included funding for a medically fragile waiver.

FV of ND is now assisting ND Medical Services Division in outreach and information of this program, helping families to learn more about Medicaid benefits and how to apply for the Children with Disabilities Program.

Through topical calls, workshops, and 1-1 assistance, FV of ND helps families navigate health care systems. Working with Title V CSHCN Program, the Medical Home State Team, and other agencies and organizations, FV of ND promotes and assists families in working with professionals as partners and advisors, helping to shape health care policies to benefit more families now and in the future.

[1] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2005–2006. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.

[2] Maternal and Child Health Bureau. Definition of CSHCN. HRSA website. Retrieved 11/08/06 from http://mchb.hrsa.gov/programs/research/issues.htm #chscn