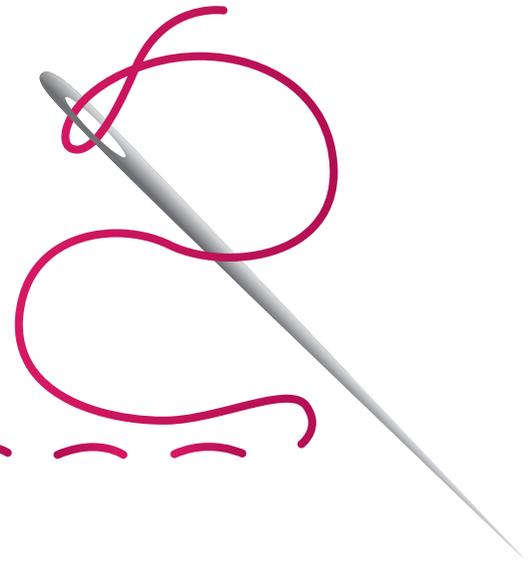


Chapter 6

FAMILY-CENTERED CARE & MEDICAL HOME



Family-Centered Care

Children's health is rooted in the family. Family-centered care recognizes the parents' role in their children's health and health care. Good family-centered care relies on a positive relationship between families and professionals caring for their child. A mutually respectful and collaborative partnership promotes good communication, goal setting, and problem-solving. This collaboration enables families to increase their health knowledge and skills as well as take responsibility for their children's health. When it works well, everyone benefits, especially the child.

FAMILY-CENTERED CARE

Family-centered care is grounded in a mutually respectful and collaborative partnership among children, patients, families, physicians, nurses and other professionals for the planning, delivery and evaluation of health care as well as in the education of health care professionals. These collaborative relationships are guided by the following principles:

- Respecting each child & his/her family
- Honoring racial, ethnic, cultural & socio-economic diversity and its effect on the family's experience & perception of care
- Recognizing & building on the strengths of each child & family, even in difficult & challenging situations
- Supporting & facilitating choice for the child & family about approaches to care & support
- Ensuring flexibility in organizational policies, procedures & provider practices so services can be tailored to the needs, beliefs & cultural values of each child & family
- Sharing honest & unbiased information with families on an on-going basis & in ways they find useful & affirming
- Providing and/or ensuring formal & informal support (i.e. parent to parent support) for the child & parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence & young adulthood)
- Collaborating with families at all levels in the care of the individual child
- Empowering each child & family to discover their own strengths, build confidence and make choices & decisions about their health

If you need help, don't be embarrassed.

Let professionals in your child's life know what your needs are – don't be afraid to ask for help.

FAMILY & PROFESSIONAL COLLABORATION

- Promotes a relationship in which family members & professionals work together to ensure the best services for the child & the family
- Recognizes & respects the knowledge, skills & experience that families & professionals bring to the relationship
- Acknowledges that the development of trust is an integral part of a collaborative relationship
- Recognizes that negotiation is essential in collaborative relationships
- Facilitates open communication so that families & professionals feel free to express themselves
- Creates an atmosphere in which the cultural traditions, values & diversity of families is acknowledged & honored
- Brings to the relationship the mutual commitment of families, professionals & communities to meet the needs of children with special health care needs & their families

Knowing how to interact with professionals can be critical to your success as an advocate for your child.

FOUR HABITS OF HIGHLY EFFECTIVE FAMILY & PROFESSIONAL PARTNERSHIPS:

- **BE PROACTIVE**
Adopt an attitude that is collaborative and responsible.
- **BEGIN WITH THE END IN MIND**
Be able to envision the future & the possibilities for your child.
- **PUT FIRST THINGS FIRST**
Prioritize what is most important or urgent in the coming year.
- **SEEK FIRST TO UNDERSTAND & THEN TO BE UNDERSTOOD**
Listen to professionals. You don't have to always agree but to understand their viewpoint.

Medical Home

Children and youth with special health care needs and disabilities deserve the same level of regular health care that other children receive. Often finding primary care providers where the family lives that are able to understand the child's chronic condition and how it affects their entire life can be difficult.

A Medical Home is not a building or a house. The Medical Home concept is a way for you and your child's doctor to work together. A Medical Home teams you with your doctor to plan for and meet your child and/or youth's special needs. When you have problems finding resources in your community or coordinating your child's specialist visits, the doctor and staff in your Medical Home are able to help you. Being family-centered, they know your family's needs and understand your child or youth.

A Medical Home:

- Has a caring attitude
- Is able to listen & welcomes your questions
- Knows your child & your family, including your names!
- Has a willingness to try things differently to meet your family's needs
- Allows for hope
- Helps your child to grow, learn, play, laugh & love

The relationship that the Medical Home has with your family is important in assisting the child as they meet challenges in life. The Medical Home doctor knows the child and can provide timely referrals to early intervention programs, school and childcare. By doing this, families are able to get support when they need it. For example, most children with special health care needs can go to community child care, but sometimes it helps to have the doctor work with the child care provider so they know how to care for the child's special needs. Or when the school does not understand your child's needs, it helps to have the doctor talk with the school to explain your child's special needs. Ideally, the medical home, schools, and community agencies work together to help families and their children reach their goals.

Medical practices in Virginia are actively working to improve care for children with special health care needs. The Virginia Chapter of the American Academy of Pediatrics, the Virginia Department of Health, the Virginia Community Healthcare Association, and Medical Home Plus, Inc. are working to improve access to care for children with special health care needs and disabilities. They are training doctors and other community providers about the Medical Home concept so children and youth are healthy and happy in their community.

For more information about Medical Home, contact the National Center for Medical Home Implementation (1-800-433-9016 or www.medicalhomeinfo.org) or Medical Home Plus, Inc. (1-877-264-8366 or www.medhomeplus.org).

A Medical Home has the Following Qualities:

ACCESSIBILITY

- Care is available 24 hours a day, 7 days a week through an “on-call” doctor
- Care is provided in the family’s community of choice
- The office space & equipment is accessible to the child

FAMILY-CENTERED MEDICAL HOME STAFF MEMBERS

- Know you & your child well
- Are able to make accommodations for your child’s special needs
- Show respect
- Ask your opinion

CONTINUITY

- Provides a primary health care provider who routinely sees the child at most visits
- Understands change & guides the family & child through the ages & stages of growing up

COMPASSION

- Understands & expresses concern for the child & the family

COMPREHENSIVE CARE

- Cares for your child as a whole person, not just a disability or diagnosis
- Makes sure that your child has their shots
- Understands your child’s special condition & how that makes a difference in their life

COORDINATION

- Collaborates with other providers & agencies to ensure that your child’s needs are met
- Works with your insurance company to make sure your child gets what he or she needs
- Works with the family & child to develop a plan with goals to help plan the way

CULTURAL COMPETENCY

- Provides information to you that is understandable both verbally & written
- Gets interpretation & translation services if needed
- Values & respects differing cultural backgrounds

