

WHO are Children and Youth with Special Health Care Needs?

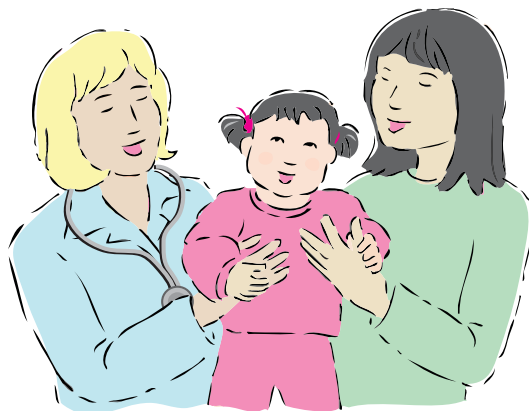


The special needs population includes children and youth from birth to adulthood with chronic childhood-onset medical conditions and/or developmental disabilities which are expected to last 12 months or longer. These chronic medical conditions require more frequent encounters with the health care system and related services than would be expected for most children of the same age.

Examples of such **chronic conditions** include: congenital heart disease, asthma, diabetes, childhood cancer, severe congenital anomalies, hemoglobinopathies and cystic fibrosis. **Physical disabilities** such as spina bifida, cerebral palsy and muscular dystrophy are included. **Developmental disabilities** include conditions such as intellectual disability, autism spectrum disorders, vision or hearing disorders, ADHD, epilepsy and mental health disorders.



What is a Pediatric Medical Home?



Building a Medical Home Partnership—Families and Providers Working Together

The medical home approach values and supports families in their role as primary caregiver and expert on their child. Primary health care providers bring their experience with many children and conditions and use their medical expertise to help families understand and integrate recommendations from a variety of sources.

“Medical Home” is not a destination, but a journey with collaboration among family, community and health care providers.

The Medical Home

A Medical Home is a source of high-quality health care in partnership with a child and his/her parents. Families, health care providers and their office staff work together to set priorities and plan a child’s care, to find and coordinate needed services in the community, and to provide supports in the home. A medical home is an information resource and a central location of a child’s personal health records built with:

- Respect, mutual trust and collaborative decision-making in health care encounters
- Identification of medical and non-medical services needed to optimize outcomes
- Connections to supports and services to meet child and family needs
- Coordination of specialty care and community services in a setting of acute and preventive primary health care
- Respect for cultural and religious beliefs and personal preferences

WHY Become a Medical Home?

“Medical homeness” reflects provision of high-quality health care. *All children and families benefit from the principles of care practiced in a medical home.*

Collaborative relationships with families optimize compliance and patient outcomes. Parents and patients are better able to understand their medical condition, set goals, communicate with their health care providers, get prescriptions filled and access resources.

Family and Health-Care Practice Benefits

- Opportunities for outcomes-based clinical improvement
- Increased wellness resulting from comprehensive care
- Improved coordination of care
- Decreased caregiver strain
- Increased patient and family satisfaction
- Increased professional satisfaction

Quality and Cost Benefits*

- Decreased parental work absences
- Avoided health care visits
- Reduced hospitalizations
- Reduced emergency department utilization

*Especially for the Special Needs Population

Top Strategies for Becoming a Medical Home

From the Center for Medical Home Improvement

1. Engage parents as partners at the practice level.
2. Identify children and youth with special health care needs (CYSHCN)—Build and use a registry; use a chart coding system; stratify by levels of complexity.
3. Use planned visit encounters.
4. Develop care coordination and communication at the practice level.

Methods:

- ◆ Determine levels of complexity for CYSHCN.
- ◆ Establish a family advisory group.
- ◆ Institute care coordination and designate a care coordinator.
- ◆ Co-manage care with specialists and determine information exchange method.
- ◆ Identify and share evidence-based practices.
- ◆ Implement a care planning process.
- ◆ Catalogue local resources & contact persons.
- ◆ Meet community partners - do “Lunch & Learns.”

For more information: www.medicalhome.org
Go to “Physicians” tab → “Learning Collaborative”

Anticipate and Prepare

- ◆ Orient families to your practice:
 - Identify staff roles
 - Outline after hours access.
- ◆ Use pre-visit contacts to determine child and family concerns, needs and goals —e.g. waiting room visit forms or a phone call a day ahead from care coordinator.
- ◆ Fit the visit to the child and family—e.g. schedule at their best time.
- ◆ Offer assistance or alternatives for waiting room challenges, e.g. infection exposures or medical equipment use.
- ◆ Determine cultural or personal preferences. Ask about literacy, translation needs and spiritual beliefs. Document these in the patient record.
- ◆ Add visit time as needed.



Maximize the Encounter

- ◆ Provide preventive services including immunizations, developmental surveillance and screening.
- ◆ Integrate evidence-based medicine.
- ◆ Collaborate with family to determine:
 - Timing of exam elements
 - Treatment approach
 - Method for measuring growth.
- ◆ Develop care plan indicating time frame & responsible person(s).
- ◆ Schedule non-acute visits for care coordination for CYSHCN.

Steps to Take

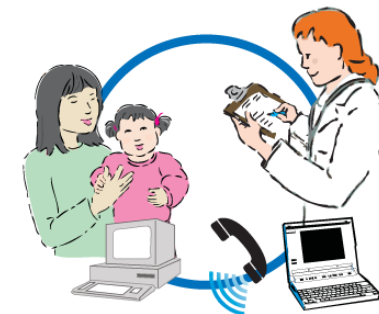
After the Visit—Help Coordinate Care

- ◆ Determine the best methods and times to communicate with families. Consider email, telephone communication and fax.
- ◆ Incorporate care reminders for families.
- ◆ Offer educational resources to child and family.
- ◆ Share community resource information with families—consider a family resource room, bulletin board, notebook, brochures highlighting local classes and resources, such as parenting classes, support groups and advocacy organizations.
- ◆ Assist in transitioning to adult health care.
- ◆ Make CYSHCN care plans available to on-call clinicians.
- ◆ Communicate with sub-specialists.
- ◆ Provide diagnosis-specific information and resources.
- ◆ Remember an Emergency Care Plan.

www.cshcn.org/resources/emergencypreparedness.cfm
www.aap.org/advocacy/blankform.pdf

Work Collaboratively with Families and Your Community

- Establish family feedback—e.g. practice surveys, parent advisory groups.
- Link families to other families for information and support.
- Research and catalogue community resources.
- Establish and maintain relationships with key community and state resource contacts.
- Advocate for improved community resources and collaboration.



Information and resources can be found at www.medicalhome.org or email info@medicalhome.org This brochure funded by the WA State Children with Special Health Care Needs Program and developed by the Washington State Medical Home Leadership Network.