

***EVERY CHILD DESERVES A MEDICAL HOME***

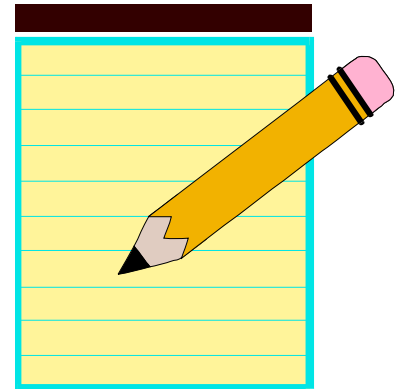
# **Component One: Common Elements**

***Facilitator Manual***



**In Collaboration With  
American Academy of Pediatrics  
Family Voices  
Maternal and Child Health Bureau  
National Association of Children's Hospitals and Related Institutions  
Shriners Hospitals for Children**

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## Component One: Common Elements

**Time Frame** – Please note that the sections' content is customizable and the state time allocation might not fit your presentational needs. Feel free to use appropriate amounts of time to meet your educational scope.

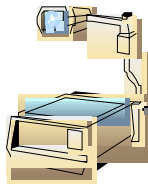
**Section One:** Defining Children and Youth with Special Health Care Needs and Medical Home 15 minutes

**Section Two:** Common Elements of the Medical Home 30 minutes

**Section Three:** Wrap-up 5 minutes

**Total Time:** 50 minutes

### Equipment Needed





- LCD and laptop
- Screen
- Flip chart/chart paper
- Marking pens
- Microphone if large group

### Learning Objectives



- Define the medical home concept.
- Define *children and youth with special health care needs (CYSHCN)*.
- Understand the reality of providing care for CYSHCN from all provider perspectives: physicians, allied health care professionals, and family members.
- Define the common elements of medical home, and assess whether they have been incorporated into personal practices.
- Understand the personal importance of providing a medical home.


## Component One: Common Elements



	<p>Time to conduct this component of the Medical Home Workshop is <b>50 minutes</b>.</p>
<p><b>Teaching Point</b></p> 	<p><b>Teaching Point Boxes</b></p> <p>Shaded boxes outlined in bold indicate teaching points or discussion questions for the facilitators and are only present in the facilitator’s manual. The teaching points do not appear in the participant’s manual. All other information appears in both manuals.</p> <p>This component focuses on 7 elements: accessibility, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective care. The elements are integral to the medical home concept and are applicable to any discussions about the concept. Throughout this presentation, it is important to reinforce the importance of providing a medical home. The first section of this component provides statistics indicating the prevalence of CYSHCN and the reality it presents to their families. These statistics are offered to assist you in creating an argument depicting the need for medical homes for CYSHCN. Creating this argument early in your presentation immediately answers the question “why should I do this?” which may be in participants’ minds.</p> <p><b>Component Flexibility</b></p> <p>The curriculum is written in a flexible format, allowing for great adaptation in organization or content to meet local needs and issues. Feel free to condense the following slides or add local information to meet the needs of your audience. Also, take into consideration the participants’ level of knowledge about this area and time considerations when planning your presentation.</p>
	<p><b>Appendices</b></p>





	<p>Additional resources and tools are available in the appendices of this component. References to the appendices have been inserted in both the facilitator and participant manuals and are shaded in gray. Throughout the presentation, refer participants to this supplemental information in the appendices.</p>
<p><b>Slide 1</b></p>	<p><b>Common Elements</b></p>
<p><b>Slide 2</b></p>	<p><b>Learning Objectives</b></p> <ul style="list-style-type: none"> <li>• Define the medical home concept.</li> <li>• Define “<i>children and youth with special health care needs</i>” (CYSHCN).</li> <li>• Understand the reality of providing care for CYSHCN from all provider perspectives: physicians, allied health care professionals, and family members.</li> <li>• Define the common elements of medical home, and assess whether they have been incorporated into personal practices.</li> <li>• Understand the personal importance of providing a medical home.</li> </ul>

	<p><b>Section One: Defining <i>Children and Youth with Special Health Care Needs and Medical Home</i></b></p>
	<p>This section is designed to take <b>15 minutes</b>.</p>
	<p>To help identify the current level of knowledge, current thoughts, and goals of the participants, begin this component by asking, “What is the reason you came to this medical home training program?” or “What do you know about medical homes?”</p> <p>To help assess the “audience make-up,” ask participants to raise their hands to indicate the perspective they are bringing to the presentation. “How many physicians are with us today?” “How about nurses, social workers, or educators?” “How many families are in the room?”</p>
<p><b>Slide 3</b></p>	<p><b>CYSHCN: Definition</b></p> <p>Children and youth with special health care needs are those who have or are at <b>increased</b> risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.</p> <p>Maternal and Child Health Bureau, 1995</p>
<p><b>Slide 4</b></p>	<p><b>CYSHCN: Reality</b></p> <ul style="list-style-type: none"> <li>• Approximately 40,000 CYSHCN in the United States, or 13% of children, have a special health care need</li> <li>• Approximately 1 out of 5 homes in the United States has a child or youth with special health care needs</li> </ul> <p>Note: This does not include children and youth at risk for a chronic condition.</p> <p>MCHB/NCHS. National Survey of Children with Special Health Care Needs. 2002</p>


<p><b>Slide 5</b></p>	<p><b>CYSHCN: Financial Reality</b></p> <ul style="list-style-type: none"> <li>• CYSHCN account for 80% of pediatric health care expenditures</li> <li>• Annual cost of providing medical care to CYSHCN <ul style="list-style-type: none"> <li>- Hospitalization: 61%</li> <li>- Specialists: 14%</li> <li>- Durable medical equipment: 5%</li> <li>- Primary care: 5%</li> <li>- Other: 15%</li> </ul> </li> </ul> <p>Health Partners/Institute for Health and Disability, 1997</p>
<p><b>Slide 6</b></p>	<p><b>CYSHCN: Reality for Families</b></p> <ul style="list-style-type: none"> <li>• 39.5% indicate their child’s or youth’s condition impacts family’s financial situation</li> <li>• 13.5% say they spend 11+ hours/wk coordinating care for their child or youth</li> <li>• 24.9% indicate families cut back on work due to child’s or youth’s condition</li> <li>• 28.5% indicate families stop working due to child’s or youth’s condition</li> </ul> <p>MCHB/NCHS. National Survey of Children with Special Health Care Needs. 2002</p>
	<p>The commentary “A New Definition of Children With Special Health Care Needs” can be found in <b>Appendix A</b>.</p> <p>For an operationalized definition of medical home, reference the AAP Policy Statement on medical home in <b>Appendix B</b>.</p> <p>For recommendations on a pediatrician’s role in community pediatrics, reference the AAP Policy Statement in <b>Appendix C</b>.</p>
<p><b>Slide 7</b></p>	<p><b>What Is NOT a Medical Home?</b></p> <ul style="list-style-type: none"> <li>• Building</li> <li>• House</li> <li>• Hospital</li> </ul>

<p><b>Slide 8</b></p>	<p><b>What Is a Medical Home?</b></p> <ul style="list-style-type: none"> <li>• An approach to providing health care services in a high-quality, comprehensive, and cost-effective manner</li> <li>• Provision of care through a primary care physician through partnership with other allied health care professionals and the family</li> <li>• Acts in child's/youth's best interest to achieve maximum family potential</li> </ul>
<p><b>Teaching Point</b></p> 	<p>Making sure that all participants grasp the concept of medical home is an expectation of this component. When introducing the concept, make sure you are using language that is conducive to the education of all audience members, and framing it as a concept that has positive implications for all.</p>
	<p>Consider using <b>Appendix D</b>, There's No Place Like a Medical Home, when establishing what a medical home means to families.</p> <p>The National Center for Medical Home Initiatives fact sheet titled "What's a Medical Home?" is in <b>Appendix E</b> and can be used as a tool for educating others on what a medical home is following the presentation.</p>
<p><b>Slide 9</b></p>	<p><b>Who Is Part of a Medical Home?</b></p> <ul style="list-style-type: none"> <li>• Primary care physician</li> <li>• Family</li> <li>• Child/youth</li> <li>• Allied health care professionals</li> <li>• Family's community</li> <li>• Pediatric office staff</li> <li>• If necessary, pediatric subspecialists</li> </ul>


<p><b>Slide 10</b></p>	<p><b>Benefits of a Medical Home</b></p> <ul style="list-style-type: none"> <li>• Increased patient and family satisfaction</li> <li>• Establishment of a forum for problem solving</li> <li>• Improved coordination of care</li> <li>• Enhanced efficiency for children, youth, and families</li> <li>• Efficient use of limited resources</li> <li>• Increased professional satisfaction</li> <li>• Increased wellness resulting from comprehensive care</li> </ul>
<p><b>Teaching Point</b></p> 	<p>To illustrate how the medical home concept has benefits for the family, encourage a parent or family member of a child or youth with special needs to share a personal medical home success story.</p> <p>The family story should</p> <ul style="list-style-type: none"> <li>• Reflect or incorporate most of the common elements.</li> <li>• Mention excellent treatment from pediatricians, subspecialists, or other health care professionals.</li> <li>• State what the family and the child needed.</li> <li>• Describe the care the family and the child received.</li> <li>• Describe how the presence of an effective medical home increased the care received by their child.</li> </ul> <p>The use of a family story can be effective and powerful. Beginning the training program with such a story allows for all participants to see how the medical home concept impacts all of those providing care, especially the family. Contact your local Family Voices, Parent-to-Parent, or other parent support organization if you need assistance identifying a parent or family facilitator.</p>
<p><b>Slide 11</b></p>	<p><b>Barriers to Providing Medical Homes</b></p> <p>Pediatric primary care system is designed</p> <ul style="list-style-type: none"> <li>• For the 80% of children who DO NOT have special health care needs</li> <li>• To provide preventive care services and acute illness management</li> <li>• To support single service encounter</li> </ul> <p>Cooley WC. Developing primary care medical homes for CSHCN. Presented at: Institute for Leaders in State Title V CSCHN Programs; May 19, 2003; Baltimore, MD</p>

<p><b>Slide 12</b></p>	<p><b>Medical Home Initiative: Why Now?</b></p> <ul style="list-style-type: none"> <li>• Healthy People 2010 objective</li> <li>• Fragmented care (Institute of Medicine 2002)</li> <li>• More children with chronic conditions</li> <li>• Home- and community-based services preferred</li> </ul> <p>Cooley WC. Developing primary care medical homes for CSHCN. Presented at: Institute for Leaders in State Title V CSCHN Programs; May 19, 2003; Baltimore, MD</p>
	<p><b>Section Two: Common Elements of the Medical Home</b></p>
	<p>This section is designed to take <b>30 minutes</b>.</p>
<p><b>Slide 13</b></p>	<p><b>Medical Home Common Elements</b></p> <ul style="list-style-type: none"> <li>• Accessible</li> <li>• Family-centered</li> <li>• Continuous</li> <li>• Comprehensive</li> <li>• Coordinated</li> <li>• Compassionate</li> <li>• Culturally effective</li> </ul>
<p><b>Slide 14</b></p>	<p><b>Accessible</b></p> <ul style="list-style-type: none"> <li>• Personally <ul style="list-style-type: none"> <li>– Families or youth are able to speak directly to the physician when needed.</li> <li>– The practice is physically accessible and meets Americans with Disabilities Act requirements.</li> </ul> </li> <li>• Geographically <ul style="list-style-type: none"> <li>– Care is provided in the child’s or youth’s community.</li> <li>– Practice is accessible by public transportation, where available.</li> </ul> </li> <li>• Financially</li> </ul>

	<ul style="list-style-type: none"> <li>- All insurance, including Medicaid, is accepted.</li> <li>- Changes in insurance are accommodated.</li> </ul>
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	<p>New England SERVE is a health policy, research, and planning organization working to promote quality systems of care for CYSHCN and their families. They developed a Health Plan Checklist that features specific policies and procedures that can support quality care for CYSHCN. To view, visit</p> <p><a href="http://www.neserve.org/neserve/pdf/NES%20Publications/Shared%20Responsibilities%20Toolkit/Health_Plan_Checklist.PDF">http://www.neserve.org/neserve/pdf/NES%20Publications/Shared%20Responsibilities%20Toolkit/Health_Plan_Checklist.PDF</a></p>
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<p><b>Slide 15</b></p>	<p><b>Family-Centered</b></p> <ul style="list-style-type: none"> <li>• The medical home physician is knowledgeable about the child/youth and family and their needs.</li> <li>• Mutual responsibility and trust exists between the patient, family, and the medical home physician.</li> <li>• The family is recognized as the principal caregiver and center of strength and support for the child, as well as the expert.</li> <li>• Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.</li> <li>• Families and youth are supported to play a central role in care coordination and share responsibility in decision making.</li> </ul>
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<p><b>Teaching Point</b></p> 	<p>Fostering family-centered care is an important part in sustaining a medical home. To do this, health care providers and family members need to be aware of each other's intent and perspective. Stress to your audience the importance of direct and honest communication. Good communication is an efficient strategy for creating a partnership among providers and the family.</p>
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Reference “Where Are the Parents?” in **Appendix F** to educate audience members on what it might be like to be a parent of a child or youth with special health care needs.

**Slide 16**

**Continuous**

- The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.
- Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.
- The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

**Slide 17**

**Be Aware of the Impact of Transitional Change**

**Developmentally**

Birth → infant → toddler → preschool → school-aged → adolescent → young adult

**In Critical Life Events**

- Anniversaries
- Family changes (eg, birth of a new child without special needs, step-parents or siblings, moves, finances)
- Serious diagnoses or changes in the health status of the child
- Deaths

<p><b>Slide 18</b></p>	<p><b>Be Aware of the Impact of Transitional Change (cont'd)</b></p> <p><b>Across Levels of Care</b></p> <ul style="list-style-type: none"> <li>• Primary care physician → primary/frequent subspecialist → secondary subspecialist</li> <li>• Intensive care → inpatient unit hospital → extended care facility</li> <li>• Hospital → home and community → hospital</li> </ul>
<p><b>Slide 19</b></p>	<p><b>Be Aware of the Impact of Transitional Change (cont'd)</b></p> <p><b>Among Supports and Services</b></p> <ul style="list-style-type: none"> <li>• Early intervention → preschool</li> <li>• Grade school → high school</li> <li>• Vocational school or college → work</li> </ul>
<p><b>Slide 20</b></p>	<p><b>Comprehensive</b></p> <ul style="list-style-type: none"> <li>• Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.</li> <li>• Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.</li> <li>• Extra time for an office visit is scheduled for CYSHCN, when indicated.</li> </ul>
<p><b>Slide 21</b></p>	<p><b>Comprehensive (cont'd)</b></p> <ul style="list-style-type: none"> <li>• Preventive, primary, and tertiary care needs are addressed.</li> <li>• The child's or youth's and family's medical, educational, developmental, psychosocial, and other service needs are identified and addressed.</li> <li>• The physician advocates for the child or youth and family in obtaining comprehensive care.</li> <li>• Information is made available about private insurance and</li> </ul>





Richard C. Antonelli, MD, FAAP, and his staff at Nashaway Pediatrics in Massachusetts developed the Medical Home Family-Centered Health Care Plan that is in **Appendix G**.

Massachusetts Family Voices developed a family-centered brochure that discusses the importance of developing an individualized health plan and some suggestions for doing so. The Individualized Health Care Plan brochure is in **Appendix H**.

### Slide 24

### Compassionate

- Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions.
- Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.

### Teaching Point






### Suggest the following strategies to engage in compassionate care:


- Ask families and CYSHCN what they want and need.
- Identify family priorities and concerns.
- Be linguistically and culturally sensitive.
- Ensure privacy for discussions with families; create an unhurried atmosphere for families.
- Be prepared to repeat information to families, respond to questions, and follow up. When possible, give families written information.
- Respect choices the family makes and offer appropriate support and resources.

	<ul style="list-style-type: none"><li>• Consider all people significant to the patient’s care (ie, father and mother, siblings, friends, and grandparents).</li><li>• Respect the role and competence of other care providers involved with the child or youth and family.</li><li>• Be willing to be supportive with families. You do not always have to “fix” a problem.</li><li>• Be aware of the adjustment or sense of loss that some families of CYSHCN may experience multiple times.</li></ul>
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**Slide 25**

<p><b>Culturally Effective</b></p> <ul style="list-style-type: none"><li>• The child’s or youth’s and family’s cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan.</li><li>• All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of professional translators or interpreters, as needed.</li><li>• Written materials are provided in the family’s primary language.</li></ul>
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<p><b>Teaching Point</b></p> 	<p><b>Strategies to Consider for Culturally Effective Care</b></p> <ul style="list-style-type: none"> <li>• Awareness of one’s own cultural heritage, values, and workplace cultural variables</li> <li>• Openly address cultural barriers with respect</li> <li>• Knowledge of, respect for, and interest in the background of the family (eg, race, education, parent/child’s sexual orientation, socioeconomic status, religion)</li> <li>• Awareness of and willingness to adapt care strategies to family and cultural orientation</li> <li>• Provision of community-based cultural support</li> <li>• Availability of multi-language materials and interpreter and translation services</li> <li>• Volunteers of similar cultural background and familiarity of family’s language in office</li> </ul>
	<p>The AAP policy statement “Culturally Effective Pediatric Care: Education and Training Issues” is in <b>Appendix I</b>.</p> <p>A self-assessment checklist for professionals providing services to CYSHCN and their families, “Promoting Cultural Diversity and Cultural Competency,” is in <b>Appendix J</b>.</p>
<p><b>Section Three: Wrap-up</b></p>	
	<p>This section is designed to take <b>5 minutes</b>.</p>

<p><b>Teaching Point</b></p> 	<p>Reinforce to participants that it takes time, energy, determination, training, and resources to establish a medical home. Participating in this presentation and becoming more aware of the medical home concept is just the first step. Encourage them to review the resources in the appendices for further general information on medical home before reviewing the learning objectives.</p>
<p><b>Slide 26</b></p>	<p><b>Learning Objectives</b></p> <ul style="list-style-type: none"><li>• Define the medical home concept.</li><li>• Define <i>children and youth with special health care needs (CYSHCN)</i>.</li><li>• Understand the reality of providing care for CYSHCN from all provider perspectives: physicians, allied health care professionals, and family members.</li><li>• Define the common elements of medical home, and assess whether they have been incorporated into their personal practices.</li><li>• Understand the personal importance of providing a medical home.</li></ul>

## Appendices

A New Definition of Children With Special Health Care Needs	A
The Medical Home	B
The Pediatrician's Role in Community Pediatrics	C
There's No Place Like a [Medical] Home	D
What's a Medical Home?	E
Where Are the parents?	F
Medical Home Family-Centered Health Care Plan	G
The Individualized Health Care Plan	H
Culturally Effective Pediatric Care: Education and Training Issues	I
Promoting Cultural Diversity and Cultural Competency: Self-Assessment Checklist	J
Additional Resources	K

## Additional Resources

### Book

American Academy of Pediatrics. *A Pediatrician's Guide to Managed Care*. Elk Grove Village, IL: American Academy of Pediatrics; 2001.

### AAP Policy Statements

Search for any AAP Policy Statement at: <http://aappolicy.aappublications.org/>

### General Medical Home Web Sites

- **All Disability Links:** [www.eskimo.com/~jlubin/disabled/all.htm](http://www.eskimo.com/~jlubin/disabled/all.htm)
- **American Academy of Pediatrics:** [www.aap.org](http://www.aap.org)
- **American Academy of Pediatrics Committees:** [www.aap.org/visit/aapcomm.htm](http://www.aap.org/visit/aapcomm.htm)
- **American Academy of Pediatrics Sections:** [www.aap.org/sections/shome.htm](http://www.aap.org/sections/shome.htm)
- **AAP Department of Community Pediatrics:** [www.aap.org/commpeds/](http://www.aap.org/commpeds/)
- **Center for Medical Home Improvement:** [www.medicalhomeimprovement.org/](http://www.medicalhomeimprovement.org/)
- **Mi Peditra (Children's health information in Spanish):** [www.mipeditra.com.mx](http://www.mipeditra.com.mx)
- **National Center of Medical Home Initiatives:** [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)
- **Family Voices:** [www.familyvoices.org](http://www.familyvoices.org)
- **Hardin Meta Dictionary of Internet Health Sources:**  
[www.lib.uiowa.edu/hardin/md/index.html](http://www.lib.uiowa.edu/hardin/md/index.html)
- **Institute for Child Health Policy:** [www.ichp.edu](http://www.ichp.edu)
- **Institute for Family-Centered Care:** [www.familycenteredcare.org](http://www.familycenteredcare.org)
- **Maternal and Child Health Bureau:** [www.mchb.hrsa.gov](http://www.mchb.hrsa.gov)
- **National Association for Hospitals and Related Institutions:** [www.nachri.org](http://www.nachri.org)
- **National Information Center for Children and Youth with Disabilities:** [www.nichcy.org](http://www.nichcy.org)
- **The National Respite Locator Service:** [www.respitelocator.org/index.htm](http://www.respitelocator.org/index.htm)
- **Shriners Hospitals for Children:** [www.shrinershq.org](http://www.shrinershq.org)

## Accessibility Web Sites

- **Accessibility guidelines for buildings and facilities:** [www.access-board.gov/adaag/checklist/a16.html](http://www.access-board.gov/adaag/checklist/a16.html)
- **Americans with Disabilities Act:** [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)
- **Americans with Disabilities Act Accessibility Guidelines:** [www.jan.wvu.edu/links/adalinks.htm](http://www.jan.wvu.edu/links/adalinks.htm)

## Compassionate and Culturally Effective Web Sites

- **American Academy of Pediatrics Department of Community Pediatrics Web site on culturally effective pediatric care:** [www.aap.org/commpeds/cepc](http://www.aap.org/commpeds/cepc)
- **Assuring Cultural Competence in Health Care:** [www.omhrc.gov/templates/browse.aspx?lvl=1&lvlID=3](http://www.omhrc.gov/templates/browse.aspx?lvl=1&lvlID=3)
- **Cross Cultural Health Care Program:** [www.xculture.org/](http://www.xculture.org/)
- **Designs for Change:** [www.designsforchange.org/](http://www.designsforchange.org/)
- **Diversity Rx:** [www.diversityrx.org/](http://www.diversityrx.org/)
- **The Family Village:** [www.familyvillage.wisc.edu/](http://www.familyvillage.wisc.edu/)
- **Federation for Children with Special Needs:** [www.fcsn.org](http://www.fcsn.org)
- **The Kids Domain:** [www.kidsdomain.com/](http://www.kidsdomain.com/)
- **National Center for Cultural Competence:** [www11.georgetown.edu/research/gucchd/nccc/](http://www11.georgetown.edu/research/gucchd/nccc/)
- **Office of Minority Health Resource Center (OMHRC):** [www.omhrc.gov/](http://www.omhrc.gov/)
- **Our-Kids:** [www.our-kids.org/](http://www.our-kids.org/)
- **Special Needs Families Resource Center:** [www.specialfamilies.com/](http://www.specialfamilies.com/)

## Continuous, Coordinated, Comprehensive Care Web Sites

- **Ability Online Support Network:** [www.ablelink.org/public/default.htm](http://www.ablelink.org/public/default.htm)
- **American Council of the Blind:** [www.acb.org](http://www.acb.org)
- **American Foundation for the Blind:** [www.afb.org](http://www.afb.org)
- **American Society for Deaf Children:** [www.deafchildren.org](http://www.deafchildren.org)
- **Birth Defect Research for Children, Inc:** [www.birthdefects.org](http://www.birthdefects.org)
- **Center for Health and Health Care in Schools:** [www.healthinschools.org/about.asp](http://www.healthinschools.org/about.asp)
- **Center for Healthier Children, Families & Communities:** [www.healthychild.ucla.edu/](http://www.healthychild.ucla.edu/)
- **Children's Health Insurance Information (eg, SCHIP, Medicaid):** [www.aap.org/advocacy/schip.htm](http://www.aap.org/advocacy/schip.htm)

- **Commonwealth Fund Survey of Parents With Young Children:** [www.cmwf.org/surveys/surveys\\_show.htm?doc\\_id=240205](http://www.cmwf.org/surveys/surveys_show.htm?doc_id=240205)
- **CysticFibrosis.com:** [www.cysticfibrosis.com](http://www.cysticfibrosis.com)
- **Department of Health and Human Services:** [www.hhs.gov/](http://www.hhs.gov/)
- **Epilepsy Foundation:** [www.efa.org](http://www.efa.org)
- **Family Village School—Early Intervention Resources:** [www.familyvillage.wisc.edu/education/ei.html](http://www.familyvillage.wisc.edu/education/ei.html)
- **Muscular Dystrophy Association:** [www.mdaua.org](http://www.mdaua.org)
- **National Association for the Education of Young Children:** [www.naeyc.org](http://www.naeyc.org)
- **National Center for Education in Maternal and Child Health:** [www.ncemch.org](http://www.ncemch.org)
- **National Down Syndrome Society:** [www.ndss.org](http://www.ndss.org)
- **National Institute of Diabetes & Digestive & Kidney Diseases:** [www.niddk.nih.gov](http://www.niddk.nih.gov)
- **National Institute of Neurological Disorders and Stroke:** [www.ninds.nih.gov](http://www.ninds.nih.gov)
- **National Multiple Sclerosis Society:** [www.nmss.org](http://www.nmss.org)
- **National Organization for Rare Diseases:** [www.rarediseases.org](http://www.rarediseases.org)
- **National Spinal Cord Injury Association:** [www.spinalcord.org](http://www.spinalcord.org)
- **Office of Special Education & Rehabilitative Services (OSERS):** [www.ed.gov/about/offices/list/osers/index.html](http://www.ed.gov/about/offices/list/osers/index.html)
- **OMIM (Online Mendelian Inheritance in Man):** [www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM)
- **PACER Center:** [www.pacer.org](http://www.pacer.org)
- **Parents Helping Parents:** [www.php.com](http://www.php.com)
- **Pediatric Orthopaedic Surgery:** [www.peds-ortho.com](http://www.peds-ortho.com)
- **Rural Institute:** [www.ruralinstitute.umn.edu](http://www.ruralinstitute.umn.edu)
- **Special Needs Assistance Program for Children:** [www.snap4kids.org](http://www.snap4kids.org)
- **Spina Bifida Association of America:** [www.sbaa.org](http://www.sbaa.org)
- **Starbright Foundation:** [www.starbright.org](http://www.starbright.org)
- **United Cerebral Palsy Association:** [www.ucpa.org/](http://www.ucpa.org/)
- **Zero to Three:** [www.zerotothree.org](http://www.zerotothree.org)

## Family-Centered Care Web Sites

- **Beach Center on Disability:** [www.beachcenter.org/](http://www.beachcenter.org/)

- **Child Development Institute:** [www.childdevelopmentinfo.com](http://www.childdevelopmentinfo.com)
- **Designs for Change:** [www.designsforchange.org](http://www.designsforchange.org)
- **Family Support America:** [www.familysupportamerica.org](http://www.familysupportamerica.org)
- **Families USA:** [www.familiesusa.org](http://www.familiesusa.org)
- **Family Support Network:** [www.familysupportnetwork.org/](http://www.familysupportnetwork.org/)
- **Mayo Clinic:** [www.mayoclinic.com](http://www.mayoclinic.com)
- **National Resource Center for Family Centered Practice:**
- **ParentPals:** [www.parentpals.com](http://www.parentpals.com)
- **Parents as Teachers:** [www.patnc.org](http://www.patnc.org)
- **Parents for Inclusion:** [www.parentsforinclusion.org](http://www.parentsforinclusion.org)
- **Parents Helping Parents:** [www.php.com](http://www.php.com)
- **Parents Place:** [www.parentsplace.com](http://www.parentsplace.com)
- **Research & Training Center on Family Support and Children's Mental Health:**  
[www.rtc.pdx.edu](http://www.rtc.pdx.edu)

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