

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

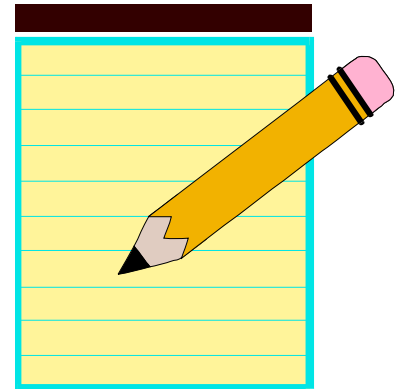
# **Component One: Common Elements**

***Participant 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**

## Authors and Contributors



Medical Home Children With Special Health Care Needs – Project Advisory authors:

Carl Cooley, MD, FAAP  
Antoinette Eaton, MD, FAAP

Family Voices authors: Polly Arango  
Martha Jean Madison

Shriners authors: Newton McCollough III, MD  
Betty Presler, RN  
David Wood, MD, MPH

NACHRI authors: Sue Dull, RN, MSN, MBA

Additional contributors: Nila Benito  
Amy Brin, MA  
Gilbert Buchanan, MD  
Frances J. Dunston, MD  
John Holtz  
Lauri Levin, MSW  
Bob Moore, MA  
Liz Osterhus, MA  
Thomas F. Tonniges, MD

For more information on the *Every Child Deserves a Medical Home* Training Program, please contact

Manager, Training Programs  
American Academy of Pediatrics  
Division of Children with Special Needs  
141 Northwest Point Blvd  
Elk Grove Village, IL 60007  
800/433-9016, ext 4924  
fax: 847/228-7035  
mhtraining@aap.org

## Component One: Common Elements

<b>Slide 1</b>	<b>Common Elements</b>
<b>Slide 2</b>	<b>Learning Objectives</b> <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><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>

- 39.5% indicate their child’s or youth’s condition impacts family’s financial situation
- 13.5% say they spend 11+ hours/wk coordinating care for their child or youth
- 24.9% indicate families cut back on work due to child’s or youth’s condition
- 28.5% indicate families stop working due to child’s or youth’s condition

MCHB/NCHS. National Survey of Children with Special Health Care Needs. 2002



The commentary “A New Definition of Children With Special Health Care Needs” can be found in **Appendix A.**

For an operationalized definition of medical home, reference the AAP Policy Statement on medical home in **Appendix B.**

For recommendations on a pediatrician’s role in community pediatrics, reference the AAP Policy Statement in **Appendix C.**

**Slide 7**

**What Is NOT a Medical Home?**

- Building
- House
- Hospital

**Slide 8**

**What Is a Medical Home?**

- An approach to providing health care services in a high-quality, comprehensive, and cost-effective manner
- Provision of care through a primary care physician through partnership with other allied health care professionals and the family
- Acts in child’s/youth’s best interest to achieve maximum family potential



Consider using **Appendix D**, There's No Place Like a Medical Home, when establishing what a medical home means to families.

The National Center for Medical Home Initiatives fact sheet titled "What's a Medical Home?" is in **Appendix E** and can be used as a tool for educating others on what a medical home is following the presentation.

**Slide 9**

**Who Is Part of a Medical Home?**

- Primary care physician
- Family
- Child/youth
- Allied health care professionals
- Family's community
- Pediatric office staff
- If necessary, pediatric subspecialists


**Slide 10**


**Benefits of a Medical Home**

- Increased patient and family satisfaction
- Establishment of a forum for problem solving
- Improved coordination of care
- Enhanced efficiency for children, youth, and families
- Efficient use of limited resources
- Increased professional satisfaction
- Increased wellness resulting from comprehensive care

<p><b>Notes:</b></p>	
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<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><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 <ul style="list-style-type: none"> <li>– All insurance, including Medicaid, is accepted.</li> <li>– Changes in insurance are accommodated.</li> </ul> </li> </ul>
	<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>

<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>
	<p>Reference “Where Are the Parents?” in <b>Appendix F</b> to educate audience members on what it might be like to be a parent of a child or youth with special health care needs.</p>
<p><b>Slide 16</b></p>	<p><b>Continuous</b></p> <ul style="list-style-type: none"> <li>• The same primary pediatric health care professionals are available from infancy through adolescence and young adulthood.</li> <li>• Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.</li> <li>• 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.</li> </ul>
<p><b>Slide 17</b></p>	<p><b>Be Aware of the Impact of Transitional Change</b></p>

	<p><b>Developmentally</b>  Birth → infant → toddler → preschool → school-aged → adolescent → young adult</p> <p><b>In Critical Life Events</b></p> <ul style="list-style-type: none"> <li>• Anniversaries</li> <li>• Family changes (eg, birth of a new child without special needs, step-parents or siblings, moves, finances)</li> <li>• Serious diagnoses or changes in the health status of the child</li> <li>• Deaths</li> </ul>
<b>Slide 18</b>	<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>
<b>Slide 19</b>	<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>
<b>Slide 20</b>	<p><b>Comprehensive</b></p> <ul style="list-style-type: none"> <li>• Care is delivered or directed by a well-trained physician</li> </ul>

	<p>who is able to manage and facilitate essentially all aspects of care.</p> <ul style="list-style-type: none"> <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>
<b>Slide 21</b>	<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 public resources.</li> </ul>
<b>Slide 22</b>	<p><b>Coordinated</b></p> <ul style="list-style-type: none"> <li>• A plan of care is developed by the physician, child or youth, and family and is shared with other providers involved with the care of the patient.</li> <li>• Care among multiple providers is coordinated through the medical home.</li> <li>• A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.</li> </ul>
<b>Slide 23</b>	<p><b>Coordinated (cont'd)</b></p> <ul style="list-style-type: none"> <li>• The medical home physician shares information among the</li> </ul>

	<p>child or youth, family, and consultant; provides specific reason for referral; and assists the family and child or youth in communicating clinical issues.</p> <ul style="list-style-type: none"> <li>• Families are linked to support and advocacy groups, parent-to-parent groups, and other family resources.</li> <li>• The medical home physician evaluates and interprets the consultant’s recommendations for the child or youth and family and, in consultation with them and subspecialists, implements recommendations that are indicated and appropriate.</li> </ul>
	<p>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 <b>Appendix G</b>.</p> <p>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 <b>Appendix H</b>.</p>
<p><b>Slide 24</b></p>	<p><b>Compassionate</b></p> <ul style="list-style-type: none"> <li>• Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions.</li> <li>• Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.</li> </ul>

<p><b>Slide 25</b></p>	<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>
<p><b>Notes:</b></p>	
	<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>

	<b>Section Three: Wrap-up</b>
<b>Slide 26</b>	<b>Learning Objectives</b> <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
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Promoting Cultural Diversity and Cultural Competency: Self-Assessment Checklist	J
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## 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.mipediatra.com.mx](http://www.mipediatra.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)
- **Internet Resources for Special Children:**
- **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)
- **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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