

EVERY CHILD DESERVES A MEDICAL HOME

**Component Two:
Family-Professional
Partnerships**
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**

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Component Two: Family-Professional Partnerships

Slide 1	Family-Professional Partnerships
Slide 2	Learning Objectives <ul style="list-style-type: none">• Promote family-professional partnerships as a natural part of establishing a medical home.• Understand family-centered care.• Define 9 elements of family-centered care.• Identify applications for applying family-centered elements in daily practice.
	Section One: Family-Centered Care in the Medical Home
Slide 3	Family-Centered Care Is Best Practice
Slide 4	<p>Families are big, small, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support.... A family is culture unto itself, with different values and unique ways of realizing its dreams; together, our families become the source of our rich cultural heritage and spiritual diversity.... Our families create neighborhoods, communities, states, and nations.</p> <p>Polly Arango, Family Voices, Algodones, NM</p>

Slide 5

Why Is a Medical Home So Important to Families?

- 20% of all visits to the pediatrician's office are developmental or behavioral in nature.
- 70% of children diagnosed with mental retardation are diagnosed by providers other than their pediatrician.
- 80% of parental concerns are correct and accurate.

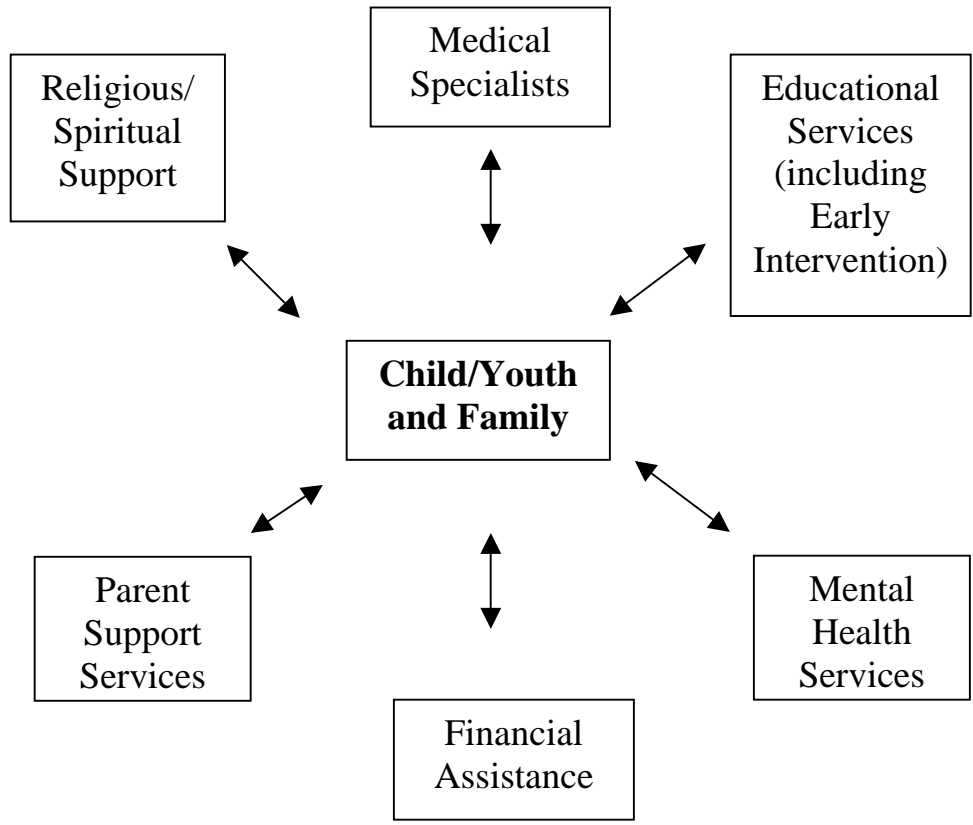
Olson AC. How to establish family professional partnerships. Presented at: International Family Centered Care Conference; September 5, 2003; Boston, MA

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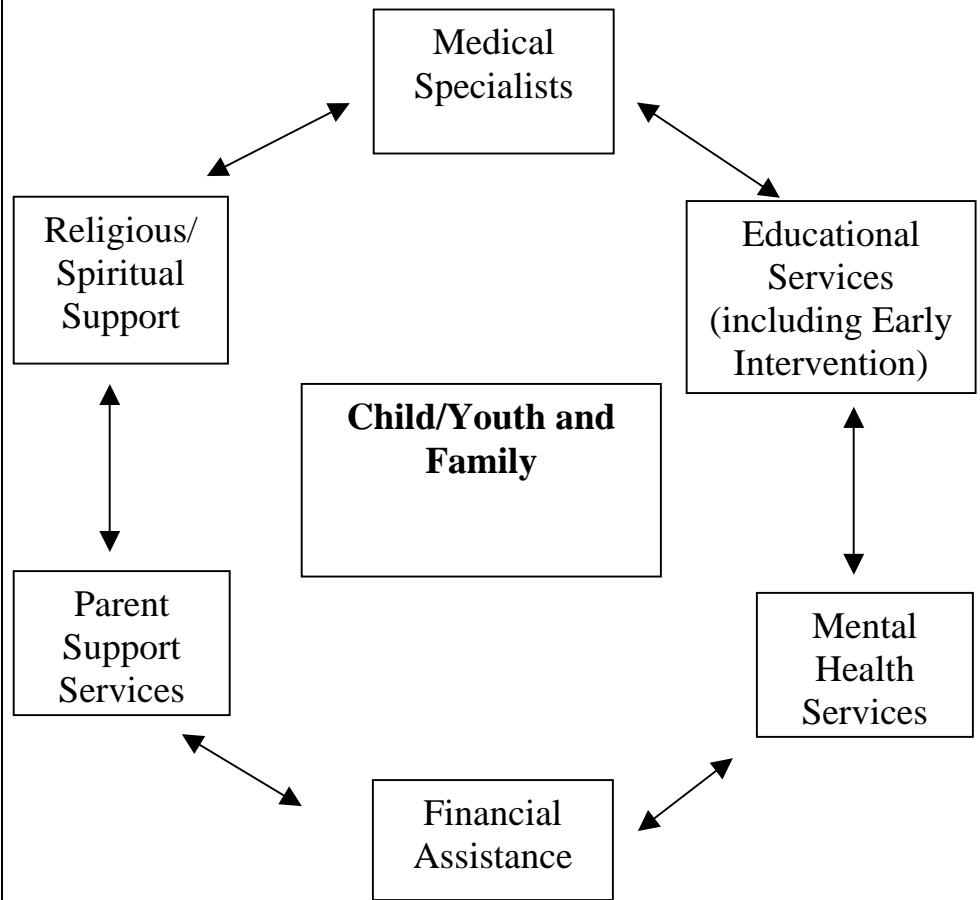
Slide 6

With a Medical Home



Slide 7

Without a Medical Home



Slide 8

What a Medical Home Means to Families

- I can get care for my child 24 hours a day, 7 days a week.
- I am a valued and respected member of my child's medical team.
- I get the same doctor or office staff with every visit.
- My child's doctor never gives up on meeting my child's needs.

Slide 9

What a Medical Home Means to Families (cont'd)

- I can easily receive referrals to specialists or specialty care when my child needs it.
- My child's providers are familiar with who my child is and his/her health condition(s).
- My child and I are treated with genuine concern and compassion.

McCauley T. How to establish family professional partnerships. Presented at: Institute of Family Centered Care; September 5, 2003; Boston, MA



The National Center for Medical Home Improvement developed a family/caregiver survey. This tool is for families/caregivers to complete about their child or youth with special health care needs. The family/caregiver survey is in **Appendix A**.

Slide 10

Physicians' and Parents' Ranking of Services

*In order of importance for CYSHCN, each service is ranked 1–22.

*Ranking

Service	Physicians	Parents
-Respite care	1	9
-Day care	2	21
-Parent support groups	3	3
-Help with behavior problems	4	10
-Financial information or help	5	2
-After-school child care	6	20
-Assistance with physical household changes	7	15
-Vocational counseling	8	6
-Psychological services	9	5
-Homemaker services	10	22
-Recreational opportunities	13	4
-Information about community resources	14	1
-Dental treatment	16	8
-Summer camp	19	7



Physicians' and Parents' Ranking of Services excerpted from Liptak GS, Revell GM. Community physician's role in case management of children with chronic illnesses. *Pediatrics*. 1989;84:465–471

A summary of results from Liptak and Revell's research is in **Appendix B**.

Slide 11

What families want depends on the difference between the support they already have and what they will need given their situation.

Notes:



The AAP Policy Statement titled “Family-Centered Care and the Physician’s Role” is in **Appendix C**.

Slide 12

Family-Centered Care = Best Practice

- Families involved in decision making are more satisfied with their primary care provider.
- Families active in developing a CYSHCN care plan are more likely to follow and maintain the care plan.



A fact sheet on defining family-centered care and application strategies is in **Appendix D**. Refer participants to use it when educating others on the concept.

Slide 13

How do we establish a collaborative partnership with families and CYSHCN?

Slide 14

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 a collaborative relationship

Slide 15

Family-Professional Collaboration (cont'd)

- Facilitates open communication so that families and professionals feel 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
- Includes some acknowledgment of mutual respect for each others' culture, values, and traditions

Bishop KK, Woll J, Arango P. *Family/Professional Collaboration for Children with Special Health Care Needs and Their Families*. Burlington, VT: Family/Professional Collaboration Project, Department of Social Work, University of Vermont; 1993:15

<p>Slide 16</p>	<p>How to Create Family-Professional Collaboration</p> <ul style="list-style-type: none"> • Have families fill out intake forms while in the waiting room to see what their concerns and needs are. • Put a suggestion box in the waiting room to help facilitate communication. • Make sure the office setting is reflective of various cultures and traditions that families would honor.
<p>Slide 17</p>	<p>How to Create Family-Professional Collaboration (cont'd)</p> <ul style="list-style-type: none"> • Speak to the family member/caregiver directly, using his or her name, and ask if they have questions at the beginning and end of visit. • Make sure adequate time is given when scheduling CYSHCN, so there is time for communication with family members/caregivers. • When families receive written information from the office, make sure that it is written in family-friendly language. • If possible, construct a family advisory group to the practice.
	<p>A national initiative focusing on quality improvement within a primary care office setting is underway. Spear-headed by the National Center for Medical Home Improvement, many states/practices are creating quality improvement teams to assess a practice's "medical homeness." Parents play a vital role on this team, as they lend feedback on current procedures, and are an active voice in establishing the needed changes within the practice. <i>A Guide for Parent and Practice "Partners" Working to Build Medical Homes for Children with Special Health Care Needs</i> discusses parents' roles on these teams, and is available at</p> <p>www.medicalhomeimprovement.org/assets/pdf/CMHI_PP_Guide.pdf</p>

Section Two: Elements of Family-Centered Care

Slide 18

Element 1: Recognize the family is the constant in the child's life. Health care providers may change over time.

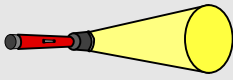
- Acknowledge who the key family members are.
- Ask families what they value. Goals?
- Identify family routines. What is a typical day like?
- Recognize the expertise of families; listen to their ideas and opinions.
- Invest in teaching the family what they need to know to care for their child.
- Mold the treatment plan to match family strengths, needs, concerns, and resources.
- Share decision-making.
- Support families as the number one caregiver of their child, including family coping strategies.



The child's or youth's condition influences the family dynamic. Physicians should be proactive in acknowledging such stressors, as well as making appropriate referrals and recommendations in the child's or youth's health plan. Two tools that can assist physicians in that process are available in the appendices

- “Situational Stressors and Family Risk Assessment” (**Appendix E**)
- “Effect of Child's Disability on Family Members Interview” (**Appendix F**)

Spotlight Example



Hearing a family's story greatly assists in understanding the importance of providing a medical home, but also in creating a greater awareness for the family's experience when their child becomes diagnosed with a special health care need. Below is one mother's story:

“ Our stories are all very different, and yet somehow they are all the same. That said, let me tell you a little of my story.

I will never forget the day that my son's reading teacher called me to tell me about yet another bad day in reading. She then went on to suggest that he be tested because he most certainly would be diagnosed with ad/hd and need medication. I sat on my bedroom floor, and cried. Those tears would be the first of a mighty river I would cry over the next few years.

Tears shed over a battle that will never be won. **The battle is between what is considered the norm and my son's inability to perform in it.** In the beginning, I hid the fact that my son had been diagnosed with ad/hd and was on medication. I even kept it from my family. But as you can see, somethings have changed; I now talk to anyone who will listen. I now fight every day to make sure my children are succesful in whatever they choose to do. That will never change.”

Christeen Mauerman. 2004. Mother of two children with special health care needs.

Slide 19

Element 2: Facilitate family and professional collaboration at all levels in health care.

- Listen to families and follow their lead.
- Be accessible to families.
- Build confidence in families, and tell them often what they do well.
- Support families in their role as an advocate for their child.
- Create win-win solutions.

- Create family options; be sensitive to energy and resources.
- Assist families to learn how to be good historians, keepers of information, and care coordinators.
- Provide families with information and resources.
- Involve families in designing, implementing, and evaluating a health care plan for their child.



Communication is a critical component to collaboration, especially for developing and sustaining a family-professional partnership. Effective communication can be difficult when many people, all with differing opinions and perspectives, are trying to make decisions. The guide “Communicating With Your Doctor” is in **Appendix G**. This guide outlines communication strategies to use and explores the provider and parent perspectives that may be present throughout an office visit.

Slide 20

Element 3: Honor the diversity of families.

- Learn about other cultures; ask questions.
- Be aware of your own values and beliefs and how they help shape your actions and decisions.
- Respect family values and beliefs, including interest in alternative remedies.
- Be nonjudgmental.
- Consider ways to sensitize the entire office staff about the diversity of families.
- Provide educational materials in multiple languages as needed, and offer translation and interpreter services.
- Decorate the office to reflect cultural diversity.
- Recognize what nonverbal behaviors are communicating to the family and vice versa.

Slide 21

Element 4: Recognize family strengths.

- Look for and identify strengths: communication, participation, interest, knowledge, parenting style, support systems, culture, and spiritual values.
- Ask families
 - What are your strengths? Concerns?
 - What are your child's likes? Dislikes?
 - What is the best way to approach your child?
 - What do you want? Need?
 - What has worked in the past? What might work now?
 - What are your opinions and needs in the current situation?
- Develop the plan of care to build on family strengths.



For resources and a complete listing of tools to help parents of CYSHCN cope with the diagnosis, management of the care plan, and role as an advocate for their children, please visit

www.coping.org

Slide 22

Element 5: Share complete and unbiased information.

- Encourage families to write down information, questions, and suggestions before an office visit.
- Avoid making assumptions or speaking in jargon.
- Offer opinions, but be sure the family understands all options.
- Repeat critical information, expectations, and next steps.
- Invite questions and expressions of concern.
- Provide written information, videotapes, audiotapes, or illustrations when possible as a backup
- Be available for follow-up discussions.
- Schedule adequate time to talk with the family. Provide privacy.
- Suggest families contact a family resource center in the community or a local hospital.



As time is essential for all involved in providing care to CYSHCN, preparation is a key ingredient to a successful office visit. Exeter Pediatrics in New Hampshire developed “Hot Tips for Busy Parents” (**Appendix H**) to assist parents in effectively preparing for an office visit. While these tips are specific to Exeter’s office procedures, they serve as helpful guidelines for all.

Slide 23

Element 6: Promote family-to-family support and networking.

- Be sensitive to family needs and the need for support.
- Validate the value of family-to-family support.
- Provide information about resources.
- Be informed about area support groups and/or encourage families to create support groups, if possible.
- Recognize the child’s need for support.
- Recognize the support needs of other family members (grandparents, siblings).




Family Voices is a national, grassroots organization of families and professionals speaking on behalf of CYSHCN. They promote family-professional partnerships and advocate for health care services that are family-centered, community-based, comprehensive, coordinated, and culturally competent. Every state has Family Voices network members that can help families and professionals locate training, advocacy, and support opportunities, as well as resources. Visit them at


www.familyvoices.org

Slide 24

Element 7: Incorporate developmental needs.

- Ask questions about developmental issues.
- Listen for family concerns.
- Conduct developmental surveillance and appropriate screenings.

	<ul style="list-style-type: none"> • Assist families to understand and support the developmental needs of their children. • Make referrals to developmental specialists and support services. • Become informed about special education programs and services. • Make certain that treatment is adapted and adjusted for the developmental stage of the child. • Encourage family advocacy. • Encourage families to model self-advocacy skills for their child. • Design office space to accommodate developmental needs of children. • Plan for and support developmental transitions.
<p>Slide 25</p>	<p>Element 8: Implement comprehensive policies and programs.</p> <ul style="list-style-type: none"> • Ask families what they need (a checklist can help). • Inform families of available programs and resources; keep brochures and applications on hand. • Develop a resource library for families and CYSHCN. • Develop a parent advisory group to assist in designing and implementing care, services, and programs.
	<p>Managing prescription medication is a common part of a parent's/caregiver's role in caring for CYSHCN. Massachusetts Family Voices has developed a brochure that guides parents/caregivers through this process. "Prescription for Success." is in Appendix I.</p>
<p>Slide 26</p>	<p>Element 9: Design accessible health care systems that are flexible, culturally competent, and responsive to family needs.</p> <ul style="list-style-type: none"> • Be available (flexible hours, evening hours, and weekend hours). • Consider transportation needs and options for families seeking care.

	<ul style="list-style-type: none"> • Eliminate financial barriers to the greatest extent possible (flexible payment options, assist families to apply for services such as Medicaid, SSI, Title V). • Use community-based care coordination services to help families gain access to needed community-based services.
	<p>Family Voices developed “Parents Partnering with Managed Care Plans” as a resource for parents to use in discussions with managed care plans. See Appendix J.</p>
	<p>Section Three: Wrap-up</p>
<p>Slide 27</p>	<p>Learning Objectives</p> <ul style="list-style-type: none"> • Promote family-professional partnerships as a natural part of establishing a medical home. • Understand family-centered care. • Define 9 elements of family-centered care. • Identify applications for applying family-centered elements in daily practice.

Appendices

Family/Caregiver Survey	A
Community-based Care	B
Family-Centered Care and the Physician's Role	C
All Care in a Medical Home Is Family-Centered	D
Situational Stressors and Family Risk Assessment: Anticipatory Guidance for Families of Children with Disabilities and Chronic Conditions	E
Effect of Child's Disability on Family Members Interview	F
Communicating With Your Doctor: Suggestions for Parents of Children With Disabilities	G
Hot Tips for Busy Parents	H
Prescription for Success: Managing Prescription Medications for Children & Youth with Special Health Care Needs	I
Parents Partnering with Managed Care Plans: A Discussion Guide on Services for Children with Special Health Care Needs	J
Additional Resources	K

Additional Resources

Books

Search the Medical Home Bibliography at: www.medicalhomeinfo.org/publications/bibliography.html

Family-Centered Care Web Sites

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

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