Family-Professional Partnership

American Academy of Pediatrics
Family Voices
Maternal and Child Health Bureau
National Association of Children’s Hospitals and Related Institutions
and
Shriners Hospitals for Children
Learning Objectives

- 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.
Family Centered Care is Best Practice
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.

Polly Arango, Family Voices, Algodones, NM
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; Sept. 5, 2003; Boston, MA
With a Medical Home

- Religious/Spiritual Support
- Medical Specialists
- Educational Services (including Early Intervention)
- Child/Youth and Family
- Parent Support Services
- Financial Assistance
- Mental Health Services
Without a Medical Home

- Religious/Spiritual Support
- Medical Specialists
- Educational Services (including Early Intervention)
- Child/Youth and Family
- Parent Support Services
- Financial Assistance
- Mental Health Services

Diagram showing the interconnectedness of various support systems.
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.
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
## Physicians’ and Parents’ Ranking of Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Physicians</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>-Respite care</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>-Day care</td>
<td>2</td>
<td>21</td>
</tr>
<tr>
<td>-Parent support groups</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>-Help with behavior problems</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>-Financial information or help</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>-After-school child care</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>-Assistance with physical household changes</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>-Vocational counseling</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>-Psychological services</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>-Homemaker services</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>-Recreational opportunities</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>-Information about community resources</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>-Dental treatment</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>-Summer camp</td>
<td>19</td>
<td>7</td>
</tr>
</tbody>
</table>
What families want depends on the difference between the support they already have and what they will need given their situation.
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.
How do we establish a collaborative partnership with families and CYSHCN?
Family-Professional Collaboration

- Promotes relationship in which family & professionals work together to ensure the best services for the child & family
- Recognizes & 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
Family-Professional Collaboration (cont’d)

- Facilitates open communication so families & 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
- Includes acknowledgment of mutual respect for each others’ culture, values, and traditions

How to Create Family-Professional Collaboration

- Have families fill out intake forms while in the waiting room to assess concerns and needs
- 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 honor
How to Create Family-Professional Collaboration (cont’d)

• Speak to the family directly, using his or her name, and ask if they have questions at the beginning & end of visit
• Make sure adequate time is given when scheduling CYSHCN, so there is time for communication with family
• Written information from the office to families, should be written in family-friendly language
• If possible, construct a family advisory group to the practice
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
- Identify family routines
- Recognize the expertise of families; listen to their ideas and opinions
Element 1: Recognize the family is the constant in the child’s life. Health care providers may change over time. (cont’d)

- 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
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
Element 2: Facilitate family and professional collaboration at all levels in health care. (cont’d)

- 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
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
Element 3: Honor the diversity of families.
(cont’d)

- 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
Recognize family strengths

- Identify strengths: communication, knowledge, parenting style, support systems, culture
- 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? Now?
  - What are your needs in the current situation?

- Develop the plan of care to build on family strengths
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.
Element 5: Share complete and unbiased information. (cont’d)

- 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
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)
Element 7: Incorporate developmental needs.

- Ask questions about developmental issues
- Listen for family concerns
- Conduct developmental surveillance and appropriate screenings
- 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
Element 7: Incorporate developmental needs. (cont’d)

- 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
Element 8: Implement comprehensive policies and programs.

- 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
Element 9: Design accessible health care systems that are flexible, culturally competent, and responsive to family needs.

- Be available (flexible hours, evening hours, and weekend hours)
- Consider transportation needs and options for families seeking care
- 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
Learning Objectives

• Promote family-professional partnerships within a medical home.
• Understand family-centered care.
• Define 9 elements of family-centered care.
• Identify applications for family-centered elements in daily practice.