Family Perspectives: Child Health Care Quality and Quality Measurement

Workshop on Pediatric Health and Health Care Quality Measurement and Information
National Research Council and Institute of Medicine
Committee on Pediatric Health and Health Care Quality Measures
Board on Children, Youth and Families
Washington, DC

Nora Wells
nwells@familyvoices.org
March 23, 2010
Copyright © 2010. All Rights Reserved.
Overview for CYSHCN

- Why important to families?
- Some current gaps from family perspective
- Sources most commonly used by consumers
- Challenges and Opportunities
- Family Voices
How are the Children?

African tribal greeting
Why do Families Want Information?

- To be knowledgeable consumers – to have tools to make decisions about their individual child/youth: re health plans, providers, treatments

- To become more effective partners in improvement and advocacy – knowledge about disparities, areas of unmet need point to opportunities for improvement

- Quality an abstract concept competing with other demands on families and family organizations – families need to learn professional concepts and have access to the information
Family Perspective

What do families want to know?

• Child health status
• Influences on child health
• Access to care and services
• Pediatric quality
Gaps in Knowledge

- Wellness for CYSHCN
- Impact of family role in care giving
- Factors that reduce disparities
- Differences in outcomes by protocols and settings
Gaps in Knowledge

- Impact of elements of family-centered care
- Changes needed to achieve family-centered care
- Impact of community based services and support
Gaps - individual child level

- What should I expect?
- How do my providers compare?
- How do protocols compare?
- How do health plans compare?
Family Perspectives on Quality FCC

- Help families understand and explain diagnosis
- Help families access, understand, add to records
- Culturally sensitive help in defining parent role in decision making
- Including extended family in decision making
- Jointly deciding desired outcomes
- Consideration of impact of care/treatment on child and family

Taken from The Family-Centered Care Self-Assessment Family Tool, http://www.familyvoices.org/pub/projects/fcca_FamilyTool.pdf
Family Perspectives on Quality FCC

- Process to resolve/negotiate differences
- Provider knowledge of and referral to community service systems
- Support of and referrals to peer support
- Work with families and youth to prepare for and make transition to adult care
- Consideration of family values in transitions
- Opportunities for feedback

Taken from The Family-Centered Care Self-Assessment Family Tool, http://www.familyvoices.org/pub/projects/fcca_FamilyTool.pdf
Gaps - systems level

• Lack of transparency in interpretation and use of measurement data

• Inadequate opportunities for families to gain knowledge, training on quality measurement and improvement

• Inadequate partnership with families in program/policy level quality improvement efforts
Family concerns and hopes

• Privacy

• Access

• Use

• Design to meet needs

• Opportunities to influence
Data Sources for Consumers

• CAHPS – Reporting

• PHDS + Y AHCS – www.cahmi.org

• NSCSHCN & NSCH – Data Resource Center: www.childhealthdata.org

• Initial Core Set of Children’s Healthcare Quality Measures – www.ahrq.gov/chip
Data Sources for Consumers

- Foundation and Advocacy reports, ex. Kaiser Family Foundation, Kids Count, Commonwealth Fund
- State level sources, ex. Medicaid, MCHB
- Data collected within family organizations, ex. F2F HICs
- Less frequent– admin data sets, pop studies w/out public website, academic journals
Questions?

- Need for consumer input acknowledged in public process – how to make it a meaningful reality?
- CAHPS – What’s most useful, What level, how transparent, how used?
- NSCSHCN & NSCH – How to get resources to train families/advocates in use of the DRC?
- PHDS + Y AHCS – Funding to spread use through consumer groups?
- Initial Core Set of Children’s Healthcare Quality Measures – How to include family perspective?
Challenges

- Consensus on information needed
- Consensus on meaning of transparency
- Will and knowledge to capitalize on present opportunities!
Challenges

• Commitment to value of engaging all communities

• Investment of time and money needed to educate, engage, support family participation

• Selling why participation is important to both professional and family constituents
Challenges/Opportunities

• Share/integrate information from multiple sources

• Include family stakeholders in interpreting information/deciding what and how it is reported

• Provide support for substantive family/consumer role
Family Voices Mission

Achieve family-centered care for all CYSHCN

- A national network of family leadership
- Family tools/support to make informed decisions and to become partners
- Advocating for improved policies
- Building partnerships among professionals and families
- Serving as a trusted resource on health care
Family Voices

Links Family Leaders around the country:

• Technical Assistance to Family-to-Family Health Information Centers in every state; peer support and leadership development

Supports KASA Youth Leaders:

• Informing youth about their rights; providing peer support and training; changing systems to include youth

Partners with Professionals who serve CYSHCN:

• Improving services and systems
Family-to-Family Health Information Centers:

• 51 Family-run projects in every state and DC
• Funded by MCHB
• Linked through TA from FV
• Provide assistance to families
• Provide partnership with providers
• Funding continues through 2012 under Health Care Reform
Families Measure Systems of Care

• Family Voices and Brandeis University - 1998 conduct a national family survey “Your Voice Counts” to identify family experiences with health care

• Family Voices Interviews Managed Care Organizations around the country - 2001 to identify their experience with CYSHCN

• Families in Program and Policy: Interviews with Title V Programs 1992 & 2002 to identify roles for families in MCHB programs
Families Contribute to Standards

- Family Voices helps to develop the NS CSHCN “screener” to identify CSHCN

- Family Voices leaders help to develop questions for NS CSHCN 2001; help revise questions for NS CSHCN 2005 & 2009

- Family Voices partners with CAHMI to develop the Data Resource Center to ensure that data is transparent and available to the public (www.childhealthdata.org)

- Family Voices works on BF standards, PHDS
Where does the power come from, to see the race to the end?

It comes from within

*Chariots of Fire*