

# *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

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# Overview for CYSHCN

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

♥ Why?

**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

# 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

# ♥ 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



# ♥ Emerging Technology

## 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](http://www.cahmi.org)
- NSCSHCN & NSCH – Data Resource Center:  
[www.childhealthdata.org](http://www.childhealthdata.org)
- Initial Core Set of Children’s Healthcare Quality Measures – [www.ahrq.gov/chip](http://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 + YAHCS – 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 Info Centers

## 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](http://www.childhealthdata.org))
- Family Voices works on BF standards, PHDS





# We Can Make a Difference

Where does the  
power come from,  
to see the race to the  
end?

It comes from within

*Chariots of Fire*

