Innovative Approaches to Family-Centered Care

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Session Objectives

- Identify core components of successful and innovative family-centered approaches within a pediatric setting
- Provide an overview of three family-centered interventions employed in a pediatric safety-net setting
- Develop guidelines to implement family-centered approaches in a health care practice
Presenter Disclosures

Yaminette Diaz-Linhart and Ivys Fernández-Pastrana presenters have nothing to disclose.

Agenda

- Overview
- Core Components
- Innovative Family-Centered Interventions
  - Family Navigation
  - Problem Solving Education
  - Navigation with depressed mothers
- Guidelines
- Lessons Learned
Overview

- Family Advocates of children with special health care needs advocating for improved care in hospital settings
- 1989: MCHB’s mission: “Provide and promote family-centered, community-based, coordinated care…and to facilitate the development of community-based systems of service for [children with special healthcare needs] and their families.”
- 1990’s: MCHB supported medical home learning collaboratives

Overview

- Family-Centered Care (AAP and IFCC, 2003)
  - Information Sharing
  - Respect and Honoring Differences
  - Negotiation
  - Care in Context of Family and Community
- Gaps in Medical Home in Pediatrics
  - Time with patients and families
  - Listening carefully
  - Sensitivity to family values
  - Parents as partners in care
  - Language and Cultural competencies
Core Components

- Built on family-centered care core principles
  - Why is this important to families?
- Expands on family systems theory
  - Child health is not separate from health of family system
- Utilized community health workers
  - Collaboration with families and providers
- Family-led
  - Shared agenda and action plans
- Partnerships with community-based agencies
  - Think outside of health care: child-care settings, Early Intervention agencies, schools, public programs

Innovation within a Safety-Net Setting

- Necessity to address gaps in care
  - Engagement with care
  - Lack of coordination and continuity of care
  - Child health is contingent on family health
- Target specific populations that would benefit most
- Since 2010, awarded 8 total grants on three different interventions delivered by Community Health Workers (CHWs)
Innovative Family-Centered Interventions

- **Family Navigation 1.0**
  - Gap: Families of children diagnosed with Autism do not engage with services
  - Goal: Deploy a “Family Navigator” (CHW) to increase service use and engagement

- **Family Navigation 2.0**
  - Gap: Families of children under 3 do not complete Autism assessments and once diagnosed, do not engage with services
  - Goal: Deploy a Family Navigator to follow up after failed screening, completed assessments and engagement with services (irrespective of Autism diagnosis)

Case Example: FN 1.0

- 3yo boy with severe cognitive delays, autism, hyperactivity, aggressive behaviors and severe behavioral dysregulation.
- Very limited or non-existent progress in all developmental spheres (language, social, adaptive, behavioral self-regulation skills)
- Navigation Tasks: Care Coordination, Transportation, Housing advocacy, School Advocacy
- Outcomes: Out of district placement, increased developmental skills, increased support for mother and siblings
- Challenges: Parent understanding of ASD and systemic barriers to care across school and health systems
Case Example: FN 2.0

- Twin boys with failed MCHAT. Non-English speaking parents.
- Navigation Tasks: Care Coordination, Transportation, Parent Education
- Outcomes: Completed ASD assessments and diagnoses, increased ASD Specialty Services
- Challenges: Parent understanding of ASD and systemic barriers to care across school and health systems

Innovative Family-Centered Interventions

- Problem-Solving Education (PSE)
  - Families of children recently diagnosed with Autism
  - Families of children in Head Start
  - Families with pre-term infants in NICU
    - Gap: Stressors of having special health care needs child, living in poverty and having a pre-term infant predispose to increased burden depressive symptoms; depression can have detrimental effects on the health of children
    - Goal: Test a problem-solving intervention delivered by CHWs to prevent depression, increase social support, decrease parenting stress, impact child health outcomes
Case Example: PSE

- **Family**
  - Homeless undocumented non-English speaking mother with two children ages 6 and 4, connected through Head Start
  - Disempowered

- **Challenges**
  - Housing Authority - Systemic barriers, eviction
  - PSE Intervention timeframe – 6 sessions

- **Outcomes**
  - Reconnection with housing and shelter
  - Empowered mother able, with minimal assistance, to advocate for herself and navigate complex systems

Innovative Family-Centered Interventions

- **Depression Navigation**
  - Gap: Helping families connect to formal mental health care for parental depression in community-based child care setting
  - Goal: Deploy an intervention by CHW to encourage formal mental health support for parent struggling with depression

- **Depression strategies for pregnant and postpartum women within a patient-centered medical home (OB/GYN and Pediatrics)**
  - Gap: Strategies for depressed women after screening for depression in primary-care settings
  - Goal: Deploy two different brief interventions by CHWs to encourage formal mental health treatment and care coordination
Case Example: Depression Navigation

- Single mother struggling with the suicide of her partner
- CHW conducted home visit to talk about “depression” in participants own words
- Recognition that mother wants things to be different
- Facilitating options to increasing mother’s ability to cope
- Mother chose to start with spiritual healer and by scheduling appointment with primary care provider
- CHW helped empower and navigate mother to contacting spiritual healer and primary care provider

Guidelines

1. Identify gaps by using the core-principles of family-centered care directly with families
   - Information Sharing: Are families receiving useful and affirming information?
   - Respect and Honoring Differences: Are these gaps a result of not honoring family values and beliefs? Are these gaps perpetuated by a deficit-based approach (versus strengths-based approach)?
   - Negotiation: Are these gaps due to a lack of collaboration with families and/or other members of the care team?
   - Care in Context of Family and Community: Are these gaps a result of not incorporating families at all levels of care?
Guidelines

2. Identify feasible family-centered goal to help target specific gaps
   - Think: What motivates a family to _____ (i.e. engage in services)?
   - Think: What makes this strategy helpful for a family?

3. Brainstorm solutions that align within the core principles of family-centered care
   - Partner with families and think outside the health care box

4. Ensure your team buys into family-centered care
   - What demonstrates buy-in during practice and within research?

Guidelines

5. Make time to reflect as a team build accountability
   - How do our actions demonstrate family centered-care?

6. Build accountability
   - Can we help each other promote family centered-care?

7. Operationalize & measure the goal
   - How will you know that you are meeting your goal?
   - Is this gap really being addressed in a family-centered way?

8. Continuously improve together with families
   - How can the experience and perspectives of families help meet our goal and improve our gaps?
Lessons Learned

- Families want to be part of the defining, creating, partnering in health
  - New perspectives
  - Be prepared to create new family-centered mechanisms within health care systems
- Research facilitates the process of innovating family-centered care
  - Dedicated time, salary support, committed team
- Clinical care has increased flexibility and opportunities to innovate
  - Draw on research and evidence-based strategies
  - Think Quality Improvement
  - Try fast, fail fast

Research Support

- MCHB Augustyn, R40MC19928
- MCHB Feinberg, R01MH10435
- NIMH Silverstein, Head Start, R01MH091871-01
- NIMH Silverstein, Depression Navigation, R21MH097925-01
- NICHD, Silverstein, NICU, R01HD072069-05
- NIMH Feinberg, Project Early, R01MH10435
- HRSA Silverstein, Transforming Primary Care, T0BHP29986
- PCORI, Silverstein, Improving Outcomes for Low-Income Mothers
References


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