Family-Centered Care Coordination for Children and Youth with Autism Spectrum Disorder

AMCHP
Teleconference

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Division of General Pediatrics
Objectives for Today

- Understand the challenges and opportunities for improving quality of care for children, youth, and families/caregivers dealing with autism spectrum disorder

- Learn recent developments in the evolution of multidisciplinary care coordination that support training and quality improvement
Identical Twins with Autism
“We are tired of paying for garbage!”

• **Paul Grundy**, MD, Vice President, Global Well-being Services and Health Benefits, IBM Corporation, 2007 NCQA Annual Conference, describing the perceived value of the quality of healthcare purchased for their US-based employees.
“Anything that I can do to improve the quality of care in OUR practice will help me to help my children. All the other families in our community will also benefit.”

- **Parent Advisory Group member**, Nashaway Pediatrics, when asked why she works so hard as a practice improvement advisor.
“Care coordination is the answer! What is the question?”

- Carolyn Clancy, AHRQ
National Survey CSHCN data

- Difficulty with any bodily function: 43.8%
- Difficulty with participation in any activity: 58.1%
- Emotional or behavioral difficulty: 96.3%
- Among CSHCN WITH condition (%)
- Among CSHCN WITHOUT condition (%)
NSCSHCN: Impact on Family

% CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child
- ASD: 31.0
- non-ASD: 19.5

% CSHCN whose conditions cause financial problems for the family
- ASD: 38.6
- non-ASD: 16.7

% CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care
- ASD: 25.6
- non-ASD: 8.7

% CSHCN whose conditions cause family members to cut back or stop working
- ASD: 57.2
- non-ASD: 21.7

What Are Some of the Problems?

- Multifactorial condition
  - Family Support
  - Primary Care
  - Neurology
  - Developmental
  - Behavioral
  - Psychosocial
  - Educational
  - Respite
  - Financial
  - Vocational
  - Avocational
What is a Potential Strategy?

- Linking access to family-centered, community-based Medical Home system of primary care, integrated with necessary service delivery components
- Develop and sustain collaborative care models aligning families, Medical Homes, and mental/behavioral health providers
Central Mass Medical Home Network Initiative
Stringing the Pearls:
Families and Providers as Partners in expanding Medical Home capacity in Central Mass

Funded by US MCHB

Parent/ Professional Advocacy League
The Massachusetts Family Voice For Children’s Mental Health

Massachusetts's State Organization of Federation of Families for Children’s Mental Health, PAL promotes the development of strong partnerships between parents and professionals
Central Mass Medical Home Network Initiative
Stringing the Pearls:
Families and Providers as Partners in expanding Medical Home capacity in Central Mass

• Practice-based needs assessments indicated strong need for access to mental health services
• Input by families and office staff
Purpose: To find out what parents of children & youth with serious mental health and behavioral issues are:

- currently offered for services
- in need of beyond those services to give their children an integrated mental and behavioral health care plan facilitated by their community-based medical home
- feeling about the communication between their child’s medical & mental health providers.
Focus Groups

5 Focus Groups
21 participants from CMMHNI medical homes and PAL parents/caregivers (ages from 5-23)

Preliminary Findings
1. Families play a crucial role in the communication of the care plan
2. The system needs to move beyond “blaming” the parent
3. All families benefited from/ or wish they had parent-to-parent support-- Parents who had “walked the path with their own child”
4. Information is extremely difficult for families to find, locate and use
What Are Elements of an Integrated Health System?

- Family-Centered
- Shared Quality Goals
  - Clinical outcomes
  - Reduced variation in service delivery
- Shared Fiscal Accountability Across all Stakeholders
- Patient Receives the Right Care at the Right Time in the Right Place
- Value = quality / cost per unit time
- IOM Quality: STEEEP
- Health Information Technology
What Constitutes CC in a Pediatric Medical Home?
### Focus of Encounter – Aggregate Data –

<table>
<thead>
<tr>
<th>Primary Focus</th>
<th>% Encounters</th>
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<tbody>
<tr>
<td>Clinical / Medical Management</td>
<td>67%</td>
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<tr>
<td>Referral Management</td>
<td>13%</td>
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<tr>
<td>Social Services (ie. Housing, food, clothing…)</td>
<td>7%</td>
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<tr>
<td>Educational / School</td>
<td>4%</td>
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<tr>
<td>Developmental / Behavioral</td>
<td>3%</td>
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<tr>
<td>Mental Health</td>
<td>3%</td>
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<tr>
<td>Growth / Nutrition</td>
<td>2%</td>
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<tr>
<td>Legal / Judicial</td>
<td>1%</td>
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</table>
How Do We Develop Integrated Care Systems?

How Do We Develop, Support, and Measure Care Coordination?
Care Model for Child Health

Informed, Activated Child/Family

Prepared, Proactive Practice Team

Functional and Clinical Outcomes

Community Resources and Policies

Health System

Health Care Organization (Medical Home)

Care Partnership Support

Delivery System Design

Decision Support

Clinical Information Systems

Functional and Clinical Outcomes

Informed, Activated Child/Family

Family-centered

Coordinated

Timely & efficient

Evidence-based & safe

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Prepared, Proactive Practice Team
Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes.

Source:
MAKING CARE COORDINATION A CRITICAL COMPONENT OF THE PEDIATRIC HEALTH SYSTEM: A MULTIDISCIPLINARY FRAMEWORK
Richard C. Antonelli, Jeanne W. McAllister, and Jill Popp
The Commonwealth Fund, May 2009
Components of Care Coordination

Family-centered and Community-based

Proactive, Providing Planned, Comprehensive Care

Promotes the Development of Self Management Skills (Care Partnership Support) with Children, Youth and Families

Facilitates cross-organizational linkages and relationships

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MAKING CARE COORDINATION A CRITICAL COMPONENT OF THE PEDIATRIC HEALTH SYSTEM: A MULTIDISCIPLINARY FRAMEWORK
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Care Coordination Functions

- Provides separate visits and care coordination interactions
- Manages continuous communications
- Completes/analyzes assessments
- Develops care plans with families
- Manages/tracks tests, referrals, and outcomes
- Coaches patients/families
- Integrates critical care information
- Supports/facilitates care transitions
- Facilitates team meetings
- Uses health information technology
What Can We Do Now to Transform the System?
# 1 Care Plan Utilization

- Integrated Care plan can document “transactions” in the health care system!
- can be the template for any encounter
- family retains a practical plan designed to address most pressing current concerns
- should include emergency care plan elements
- THIS IS HOW WE WILL SUPPORT TEAM-BASED CARE!
Needs Assessment

• Develop a Standard Tool for Assessment  
  (HINT: create in conjunction with practice family advisory partners)
• Prioritize concerns of child/family.
• Clarify goals and values.
• Assist in linkages for the child/family.
• Categories should include health, mental health, financial, education, support groups, developmental needs, and social services.
# Medical Home-Based Care Plan

<table>
<thead>
<tr>
<th>Problem</th>
<th>Activity</th>
<th>Who will do</th>
<th>By When</th>
<th>Expected Outcome</th>
<th>Follow-Up</th>
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**Prepared for:**

**Primary Care Provider (PCP):**

**Prepared by:** Care Coordinator

Date Plan Prepared:
# 2 Access to What?

- Team-based Care in Family-Centered Medical Home
  - Families/ youth, MD, NP/ PA, RN, MA
  - Care Coordinators
    - Family-to-Family
    - Social Work
    - Nursing
    - Education
- Co-Management and Collaborative Care Models
<table>
<thead>
<tr>
<th>Model</th>
<th>Access to Primary Care</th>
<th>Access to Subspecialty Care</th>
<th>Complexity of Condition</th>
<th>Access to Specialized Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCP as Primary Manager</td>
<td>adequate</td>
<td>adequate or limited</td>
<td>low-moderate</td>
<td>limited or adequate</td>
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<tr>
<td>PCP/SP Co-Management</td>
<td>adequate</td>
<td>adequate</td>
<td>moderate-high</td>
<td>adequate</td>
</tr>
<tr>
<td>SP as Primary Manager</td>
<td>adequate or limited</td>
<td>adequate</td>
<td>high</td>
<td>adequate</td>
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PCP = primary care provider; SP = subspecialist

from Antonelli, Stille, and Freeman, 2005
Useful Websites

- [http://www.medicalhomeinfo.org](http://www.medicalhomeinfo.org): American Academy of Pediatrics hosted site that provides many useful tools and resources for families and providers
- [http://www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org): tools for assessing and improving quality of care delivery, including the Medical Home Index, and Medical Home Family Index
- [http://www.hrtw.org](http://www.hrtw.org): tools and resources to support youth transition to adult systems
References


• Antonelli, R., Stille, C. and Freeman, L., Enhancing Collaboration Between Primary and Subspecialty Care Providers for CYSHCN, Georgetown Univ. Center for Child and Human Development, 2005


