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

AMCHP

Teleconference

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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**

A True Vignette

- **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.

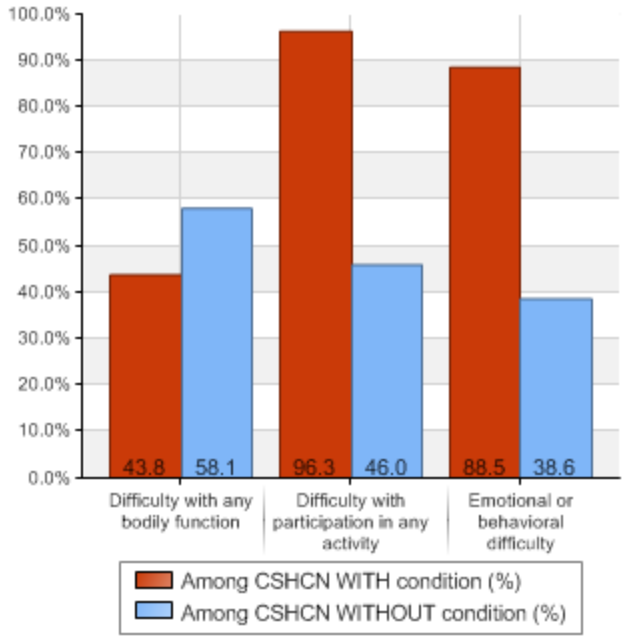
“Anything that I can do to improve the quality of care in OUR practice will help me to help my children. All the other families in our community will also benefit.”

- **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



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

http://www.cshcndata.org/Conditions/Cond_Report.aspx?gid=0&rt=2&pgid=103&ind=55#

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

- **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?

National Study of Care Coordination Measurement in Medical Homes

Antonelli, Stille, and Antonelli, 2008

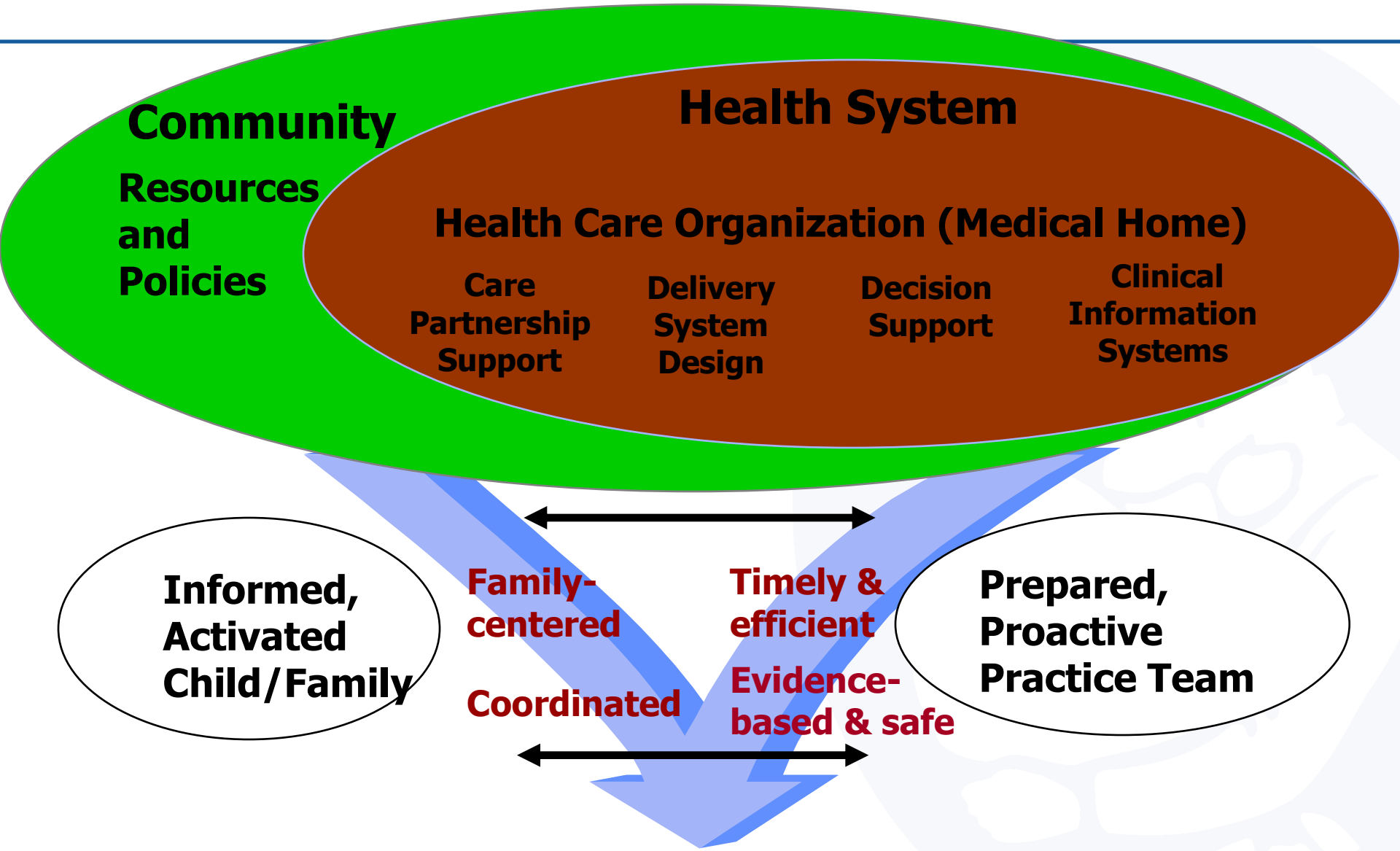
Focus of Encounter – Aggregate Data –

Primary Focus	% Encounters
Clinical / Medical Management	67%
Referral Management	13%
Social Services (ie. Housing, food, clothing…)	7%
Educational / School	4%
Developmental / Behavioral	3%
Mental Health	3%
Growth / Nutrition	2%
Legal / Judicial	1%

How Do We Develop Integrated Care Systems?

How Do We Develop, Support, and Measure Care Coordination?

Care Model for Child Health



Defining Care Coordination

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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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.**

Care Plan Elements

Medical Home-Based Care Plan

Prepared for: Primary Care Provider PCP: Prepared by: Care Coordinator
Date Plan Prepared:

Problem	Activity	Who will do	By When	Expected Outcome	Follow-Up
	.				

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 1: Patient, Provider, and Community Characteristics as Determinants of Models of Co-Management for CYSHCN				
Model	**Access to Primary Care**	**Access to Subspecialty Care**	**Complexity of Condition**	**Access to Specialized Services**
PCP as Primary Manager	adequate	adequate or limited	low-moderate	limited or adequate
PCP/SP Co-Management	adequate	adequate	moderate-high	adequate
SP as Primary Manager	adequate or limited	adequate	high	adequate
PCP = primary care provider; SP = subspecialist				

from Antonelli, Stille, and Freeman, 2005

Useful Websites

- **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: tools for assessing and improving quality of care delivery, including the Medical Home Index, and Medical Home Family Index**
- **http://www.hrtw.org: tools and resources to support youth transition to adult systems**

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