CARE COORDINATION FROM A FAMILY/PATIENT PERSPECTIVE

Massachusetts Child Health Quality Coalition Meeting
March 27, 2012
Cristin Lind
Project Associate/Family Leader
Mass Family Voices
clind@fcsn.org
(617) 236-7210 x 302
Objective

- Current role families play in care coordination
- Two family experiences
- For, to, and with: Collective Empowerment in care coordination
- Considerations and questions as we move forward
Are Parents Comfortable Playing Liaison Role?

More parents (83%) than PCPs (56%) or specialists (30%) felt it was very important that parents played an active role in communication between PCPs and specialists.

57% of parents were very or somewhat uncomfortable in the role of primary conduit.

No disease or demographic characteristics (income, parent age/education) were associated with parent comfort in the role of primary information conduit.

Indicator 14: CSHCN whose families spend 11 or more hours per week providing and/or coordinating child's health care

CSHCN age 0-17 years

Massachusetts vs. Nationwide

<table>
<thead>
<tr>
<th>Description</th>
<th>Massachusetts</th>
<th>Nationwide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 hour per week</td>
<td>45.1</td>
<td>39.2</td>
</tr>
<tr>
<td>1-4 hours per week</td>
<td>36.4</td>
<td>37.2</td>
</tr>
<tr>
<td>5-10 hours per week</td>
<td>7.0</td>
<td>10.5</td>
</tr>
<tr>
<td>11 or more hours per week</td>
<td>11.5</td>
<td>13.1</td>
</tr>
</tbody>
</table>
Indicator 14: CSHCN whose families spend 11 or more hours per week providing and/or coordinating child’s health care

CSHCN age 0-17 years

Massachusetts vs. Nationwide

11 or more hours per week x Emotional/behavioral/developmental issues

- One or more emotional, behavioral or developmental issues
- No qualifying emotional, behavioral or developmental issues

<table>
<thead>
<tr>
<th></th>
<th>Massachusetts (11 or more hours per week)</th>
<th>Nationwide (11 or more hours per week)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more emotional, behavioral or developmental issues</td>
<td>16.3%</td>
<td>19.8%</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issues</td>
<td>8.7%</td>
<td>10.0%</td>
</tr>
</tbody>
</table>

2009/10 National Survey of Children with Special Health Care Needs
MCHB Core Outcome #5: CSHCN who can easily access community based services

CSHCN age 0-17 years

Massachusetts vs. Nationwide

Outcome successfully achieved x Emotional/behavioral/developmental issues

- One or more emotional, behavioral or developmental issues:
  - Massachusetts: 54.6%
  - Nationwide: 49.7%

- No qualifying emotional, behavioral or developmental issues:
  - Massachusetts: 76.4%
  - Nationwide: 72.3%
Implications of Childhood Autism for Parental Employment and Earnings

Compared to mothers of children with no health limitation, mothers of children with ASD:
• earn 56% ($14,755) less
• are 6% less likely to be employed
• work 7 hours less per week

Family earnings of children with ASD are:
• 21% ($10,416) less than those of children with another health limitation and
• 28% ($17,763) less than those of children with no health limitations

“I think it's a case of the mother becoming the case manager and the advocate for the child. If these kids were appropriately cared for it wouldn't be such a burden for the family.”

-- David Mandell to Reuters

Implications of Childhood Autism for Parental Employment and Earnings
Cidav, Z., Marcus, S., Mandell, D. Pediatrics, March 19, 2012
Parent Panel

Susan Arndt
Family Leader, Framingham
508.558.7220
susanarndtinteriors@yahoo.com

Pat MacNeil
Family Leader, Stoughton
781.344.9126
pmacneil155@gmail.com
Zac
This chart does not represent internal coordination at school and hospitals.
MR. GREEN PREPARES FOR HIS CHILD'S IEP MEETING
SOME IDEAS FOR CARE COORDINATION

• Create one resource for parents on how to navigate the system (insurance, MassHealth, school/healthcare coordination, government and other organizations).

• Empower parents to learn negotiation and communication skills and how to advocate for their child.

• Create a general toolkit for families to help them navigate the system (school, government and healthcare) online so they can customize it to meet their child’s needs.

• Inform parents of what to look for with their child’s diagnosis to avoid additional medical problems that often occur with a certain diagnoses.

• Remember every family and child is different. One size does not fit all.
Fetal Alcohol Spectrum Disorder (FASD)

- Language Based Learning Disability
- PTSD
- Trauma
- Depression
- Neglect
- Anger
- Attention Deficit Disorder
- Anxiety
- Dyslexia
- Dyscalculia
- Traumatic Brain Injury
- Executive Function Disorder
- Emotional dysregulation
- "just stubborn"
- Sensory Integration Disorder

Left Hemispheric Dysfunction

Sasha

Help
# The Evolution of Family-Professional Partnership Models

## TABLE 27.1. Evolution of Relationships

<table>
<thead>
<tr>
<th>Type of power</th>
<th>Family-professional partnership model</th>
<th>Type of decision making</th>
<th>Participants</th>
<th>Communication</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power-over</td>
<td>Parent counseling/psychotherapy; parent training involvement</td>
<td>Exerting control</td>
<td>Professionals, with parents (usually mothers)</td>
<td>Full of clinical jargon, maintenance of professional distance, and directive</td>
<td>Often limited to existing service-system resources within professionals’ control</td>
</tr>
<tr>
<td>Power-with</td>
<td>Family-centered services</td>
<td>Collaborating</td>
<td>Parents (usually mothers) and professionals</td>
<td>Courteous and candid</td>
<td>Existing service-system resources, plus family resources</td>
</tr>
<tr>
<td>Power-through</td>
<td>Collective empowerment</td>
<td>Synergizing</td>
<td>Parents, family members, friends, community citizens and professionals</td>
<td>Insightful (“head”), caring (“heart”), and dynamic</td>
<td>Creation of new and preferred resources</td>
</tr>
</tbody>
</table>

A Framework for Highly Performing Pediatric Care Coordination

**PEDIATRIC CARE COORDINATION FRAMEWORK**

**Care Coordination Definition:**

*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.*

**Defining Characteristics of Care Coordination**

1. Patient and family-Centered (PFC)
2. Pro-active, planned, & comprehensive
3. Promotes self-care skills & independence
4. Emphasizes cross-organizational relationships

**Care Coordination Competencies:**

1. Develops partnerships
   - Proficient communicator
   - Uses assessments for intervention
   - Facile in care planning skills (PFC)
   - Integrates all resource knowledge
   - Possesses goal/outcome orientation
   - Approach is adaptable & flexible
   - Desires continuous learning
   - Applies solid team/building skills
   - Adept with information technology

**Care Coordination Functions:**

1. Provide separate visits & CC interactions
2. Manage continuous communications
3. Complete/analyze assessments
4. Develop care plans (with family)
5. Manage/track tests, referrals, & outcomes
6. Coach patient/family skills learning
7. Integrate critical care information
8. Support/facilitate all care transitions
9. Facilitate PFC team meetings
10. Use health information technology for CC

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## Care Coordination Measurement Approach

<table>
<thead>
<tr>
<th>Levels for Measurement</th>
<th>Structure</th>
<th>Process</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care practice</td>
<td>• Process for tracking referrals</td>
<td>• Reason for referral provided to family</td>
<td>• Clinical outcomes</td>
</tr>
<tr>
<td></td>
<td>• Designated staff to coordinate with other</td>
<td>• PCP discusses results with patients</td>
<td>• Functional status</td>
</tr>
<tr>
<td></td>
<td>services</td>
<td></td>
<td>• Patient/Family perceptions of care</td>
</tr>
<tr>
<td>Medical specialty</td>
<td>• Process for tracking consult request</td>
<td>• Results sent to PCP</td>
<td>• Value</td>
</tr>
<tr>
<td>practices</td>
<td></td>
<td>• Specialist discusses results with patients</td>
<td></td>
</tr>
<tr>
<td>Other service providers</td>
<td>• Designated staff to coordinate with other</td>
<td>• Results sent to PCP</td>
<td></td>
</tr>
<tr>
<td>(e.g. early Intervention, rehabilitation services)</td>
<td>services</td>
<td>• Treatment plan updated</td>
<td></td>
</tr>
<tr>
<td>Hospitals/Facilities</td>
<td>• Designated staff for post-admission f-up</td>
<td>• Admission info shared with PCP</td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>• Navigator to work with families</td>
<td>• Updated care plan</td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>• Service Capacity</td>
<td>• Updated care plan</td>
<td></td>
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Considerations and questions

• Is care coordination something that happens to a family, for a family, or with a family?

• As we support care coordination implementation by developing core processes, systems, outcomes, how will we know that what we are creating collectively empowers both families and professionals?

• How do we build a system that relieves families of their current burden of coordinating their child’s care while building their capacity and participation skills?
Thank you!

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