Care Planning and Coordination: The Importance of Family-Centered Care

Dennis Z. Kuo, MD, MHS
Associate Professor of Pediatrics
December 6, 2015
Disclaimer

• I have no financial conflicts of interest to disclose
Care coordination

- Patient and family-centered
- Proactive, planned, and comprehensive
- Promotes self-care skills and independence
- Emphasizes cross-organizational relationships

AAP COCWD (2014)
Care coordination

- Patient and family-centered
- Proactive, planned, and comprehensive
- Promotes self-care skills and independence
- Emphasizes cross-organizational relationships

AAP COCWD (2014)
Care coordination

• Successful care coordination addresses continuum of health
• Care coordinator work is driven by the needs of patients and families across the community
• Family-centered approach is critical for effective care coordination and planning
Care planning

• Care planning
  – “actionable” care plan with assigned tasks/roles
  – care plan document
• Developed and implemented with input from family and patient
• How to make most effective given all of the different parts?
A Parable

- Several blind men are led to an elephant
- Each one feels different parts of the elephant
- When asked to describe the elephant:
  - A pot (the head)
  - A winnowing basket (ear)
  - Plowshare (tusk)
  - Pillar (foot)
  - Etc.
The health care system elephant

• It’s hard to see the entire health care system
  – We all see individual components
  – Families see all the components but are the least empowered

• Health care outcomes may best be affected if we work with our families
  – Our families face more challenges than we are aware of
What is a system of care?

• A range of services and supports
• Guided by a philosophy
  – Family-centered and community-based
• Supported by an infrastructure

Stroul (2010)
Requirements

• Defined population
• Defined components
  – Community-based services, Medical Home, others
• Define roles of components
  – Relationships and ability to adapt
• Values and principles
Principles of the care system for CSHCN

• Responsive to family challenges, priorities, and strengths
• Developed in partnership with constituents
• Reflective and respectful of cultural norms and practices of families
• Accessible to everyone
• Affordable to those who need assistance
• Organized and coordinated through collaboration

Roberts (2004); Perrin (2007)
What is family-centered care?

• FCC is an approach to health care that places the family at the center of all health care decision making

• Considerations include
  – Interpersonal communication
  – Facilities and policies
  – Leadership

• Many misconceptions about FCC
  – Not simply asking what families what to do
  – Misunderstanding can cause more harm than good

Principles of FCC

- Information Sharing
- Respect and Honoring Differences
- Partnership and Collaboration
- Negotiation
- Care in Context of Family and Community

Kuo (2011)
How family-centered are we?

- Multiple unmet needs
- Physicians routinely underestimate the family needs for community referrals, access to care, and interpersonal communication
What families are saying

- “I feel like you guys have given me this devastating news that my child has a lifelong disability, and sent me afloat in an ocean and said, okay here it is, now go and do something about it....”
- "...No one has ever told me about what is available really. Other parents telling parents is where I get 99.9% of information.”
- “...We need stronger, more involved case management. We have a hotline for gambling and substance abuse, but nothing for those of us who deal with day to day (and sometimes minute to minute) airway problems.”

MacKean (2005); Wells/Family Voices (2000)
Family report of care burden

<table>
<thead>
<tr>
<th>Condition</th>
<th>Complex/chronic %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spend &gt;7 hrs/wk coordinating care</td>
<td>24</td>
</tr>
<tr>
<td>Provide home care around the clock</td>
<td>18</td>
</tr>
<tr>
<td>Financial problems</td>
<td>57</td>
</tr>
</tbody>
</table>

All percentages weighted. 2005-06 NS-CSHCN
Kuo (2011) Archives Pedia Adol Med
Table IV. Reported care coordination and management from PCP in the prior 12 mo

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥1 Regular well child checkup</td>
<td>95.4%</td>
</tr>
<tr>
<td>Sick visits for any reason</td>
<td>88.5%</td>
</tr>
<tr>
<td>Serve as primary point of contact</td>
<td>55.8%</td>
</tr>
<tr>
<td>Help referring to specialists</td>
<td>55.2%</td>
</tr>
<tr>
<td>Care coordination with therapies and specialists</td>
<td>49.5%</td>
</tr>
<tr>
<td>Make a care and emergency plan</td>
<td>42.7%</td>
</tr>
<tr>
<td>Chronic illness management</td>
<td>38.9%</td>
</tr>
<tr>
<td>Help referring to community services</td>
<td>32.8%</td>
</tr>
<tr>
<td>In-hospital care for child</td>
<td>27.7%</td>
</tr>
<tr>
<td>Help referring to family support services/networks</td>
<td>24.0%</td>
</tr>
</tbody>
</table>

Real-world care planning and coordination challenges

- No gas money
- No transportation
- No permanent address
- Cell phone paid for monthly
- Limited health literacy
- Solo parent
- Multiple children with special needs

- Resources, therapies not available locally
- Primary care providers who may not be comfortable with management issues

Wikimedia commons: Felix Andrews
# Health Services Need Before/After Enrollment

Three tertiary care clinics (ACH, Boston, Wisconsin)

<table>
<thead>
<tr>
<th>Health Service Need</th>
<th>Met Before</th>
<th>Met After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preventive care</td>
<td>82%</td>
<td>96%</td>
</tr>
<tr>
<td>Prescriptions</td>
<td>85%</td>
<td>96%</td>
</tr>
<tr>
<td>Eyeglasses/Vision Care</td>
<td>70%</td>
<td>85%</td>
</tr>
<tr>
<td>Hearing Care/Aid</td>
<td>67%</td>
<td>84%</td>
</tr>
<tr>
<td>Preventive Dental Care</td>
<td>63%</td>
<td>84%</td>
</tr>
<tr>
<td>Other Dental Care</td>
<td>51%</td>
<td>66%</td>
</tr>
<tr>
<td>Therapies (OT, PT, Speech)</td>
<td>78%</td>
<td>91%</td>
</tr>
<tr>
<td>Mental Health Care</td>
<td>34%</td>
<td>58%</td>
</tr>
<tr>
<td>Family Mental Health Counseling</td>
<td>22%</td>
<td>45%</td>
</tr>
<tr>
<td>Durable Medical Equipment</td>
<td>70%</td>
<td>91%</td>
</tr>
<tr>
<td>Genetic Counseling</td>
<td>56%</td>
<td>79%</td>
</tr>
<tr>
<td>Home Health</td>
<td>56%</td>
<td>75%</td>
</tr>
<tr>
<td>Respite Care</td>
<td>33%</td>
<td>53%</td>
</tr>
<tr>
<td>Referrals</td>
<td>51%</td>
<td>83%</td>
</tr>
</tbody>
</table>

Overall unmet needs decreased from 2.8 to 2.2. All p<.001

What can you do to improve the family-centeredness of care?

- Know the principles
- Respect families
  - Refrain from judging
  - Don’t use labels
  - Use person-first language, e.g. “child with autism”
- Model behavior for staff and associates
Additional steps

- Implement tools and templates that increase family participation
- Develop families as advisors
- Assess family needs, routinely
Teach parents to be effective advocates

• Ideal health care system
• Expectations for care coordination and planning
• Tools
  – Care plans
  – Medical summaries
• Family networking and support
Family-centered care

- Defines the system for coordination and planning
- Informs the structures and processes necessary to develop the system
- Improves and streamlines care delivery
- Creates the culture that is necessary to effectively coordinate and plan care
Effective care coordination and planning with families

• How’s your culture of family-centered care?
• How well do you incorporate family advisors and partners?
• How well do your tools, alerts and reminders incorporate family-centered care principles?