“Well child” for children with medical complexity

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Overview

Goal: Understand the approach to the well child check for children with medical complexity (CMC)

Objectives

- Appreciate the definition and epidemiology of special needs and children with medical complexity
- Identify the components of goal setting and care planning
- Discuss health supervision issues for CMC
Special Needs vs CMC

- Children and youth with special healthcare needs (CYSHCN) = increased healthcare above general population

- Children with medical complexity

## Texas Children with Medical Complexity

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Percent</th>
<th>Number (millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN</td>
<td>18.2</td>
<td>1.31</td>
</tr>
<tr>
<td>1 health condition</td>
<td>16.3</td>
<td>1.17</td>
</tr>
<tr>
<td>2+ health conditions</td>
<td>16.7</td>
<td>1.20</td>
</tr>
<tr>
<td>Daily activities moderately affected some of the time</td>
<td>27.3</td>
<td>0.69</td>
</tr>
<tr>
<td>Daily activities significantly affected, often a great deal</td>
<td>8.6</td>
<td>0.22</td>
</tr>
</tbody>
</table>

[http://childhealthdata.org/browse/survey](http://childhealthdata.org/browse/survey) 2016 National Survey of Children’s Health (TX)
Texas Children with Medical Complexity

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<tr>
<th>Indicator</th>
<th>Percent</th>
<th>Number (millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usually/always feel aggravation with parenting (non-CSHCN)</td>
<td>1.7</td>
<td>0.09</td>
</tr>
<tr>
<td>Usually/always feel aggravation with parenting (CSHCN)</td>
<td>18.2</td>
<td>0.24</td>
</tr>
<tr>
<td>Stop or cut back on working due to child’s health condition (CSHCN)</td>
<td>14.6</td>
<td>0.19</td>
</tr>
<tr>
<td>Avoiding changing jobs to keep health insurance for child (CSHCN)</td>
<td>16.7</td>
<td>0.22</td>
</tr>
</tbody>
</table>

http://childhealthdata.org/browse/survey 2016 National Survey of Children’s Health (TX)
## Health Services for Children with Special Needs

<table>
<thead>
<tr>
<th>Question</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serve as the primary care coordinator</td>
<td>71.2</td>
</tr>
<tr>
<td>Integrate a child’s care plans with other providers</td>
<td>48.1</td>
</tr>
<tr>
<td>Discuss potential needs for nonmedical services</td>
<td>40.5</td>
</tr>
<tr>
<td>Involve families in decisions regarding their child’s health care</td>
<td>86.2</td>
</tr>
<tr>
<td>Attempt to incorporate a family’s believes and requests for alternative treatments</td>
<td>39.5</td>
</tr>
</tbody>
</table>

Components of Goal Setting and Care Planning
Goal setting

• Goals of care is the process of discussing the priorities of care plans
• Components
  • Short and long term goals
  • Prognosis
  • Advance care directives

• “Where they want to be and how they want to live their lives”
Setting goals

• Components
  • What is the goal?
  • Who is driving it?
  • When?
• REMAP
  • Reframe
  • Expect emotions
  • Map out the future
  • Align with values
  • Plan treatments that match values

**Example: Medical roadmap**

<table>
<thead>
<tr>
<th>Goal</th>
<th>Diagnosis</th>
<th>Action required</th>
<th>Person responsible</th>
<th>Time frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decrease severity of dystonic spasms and improve function.</td>
<td>Cerebral palsy</td>
<td>See PM&amp;R specialist annually</td>
<td>PM&amp;R</td>
<td>Annually</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increase baclofen when sick</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve classroom experience</td>
<td>Severe intellectual disability</td>
<td>Add modifications during ARD</td>
<td>PCP</td>
<td>By June 2018</td>
</tr>
</tbody>
</table>

Adapted from Routine preventive care for CMC. Dewan et al. Presented at AACPDM 9/27/2016
Prognosis and care directives

- Asking about prognosis
  - “What have they told you to expect for his seizure disorder”
  - “What is your understanding of how his health will be in 5 years”
- Family goal setting (PESST)
  - Physical
  - Emotion
  - Social
  - Spiritual
  - Trajectory

Care plans

• Summary of diagnoses and related care
  • EPIC problem list
  • Summary
• What to do when sick?
  • Sick plan / interventions
  • Action plans
Example: Care summary

• Primary diagnosis: presumed FIRES

• Respiratory: History of respiratory failure, s/p tracheostomy
  - Meds: Flovent twice daily
  - Baseline: HME / HTC
  - Airway clearance: VEST twice daily with albuterol
  - Sick plan: VEST four times daily
  - Pulmonologist: Dr Wheezy

• Neuro: Seizure disorder
  - Meds: Epidiolex, phenobarbital, zonisamide, levetiracetam
  - Baseline: 4-6 seizures per day
  - Rescue: VNS for seizure clusters, Diastat as needed
  - Neurologist: Dr Shakey
Health Supervision
Issues with CMC
Family experience

“I never had a well child check for my child (with extreme prematurity). We weren’t well, so I assumed it wasn’t for us.”

“We see the doctor almost every other week. What do you mean, we need another visit for a check-up?”
Preventive Care

• Definition: To protect, promote, and maintain health and well-being and prevent disease
• Promoting proactive care
• Categories
  • Development
  • Nutrition
  • Behavior / sleep
  • Injury prevention & safety
  • Immunizations

Talking about health supervision

- Resources
  - Family advocacy groups
  - AAP policy statements and clinical reports
  - Up to date

Thank you!

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