Children with special health care needs:
Who they are and how we know whether we are serving them well

Jenifer Cartland, PhD
Vice President, Data Analytics and Reporting
Many Hats of a Parent of a Child who is Medically-Fragile/Technology Dependent

Please Note:

This graph relates to the medical side. It is a summary rather than an exhaustive list.
It does not include managing the behavior side of this child who is also on the Autism Spectrum.
It does not include typical parenting subject matter.
It does not include caring for other sibling(s) or spouse.
It does not include the unimaginable grief and loss of purpose when this child loses her battle.

Health Care
- Medical Home within the Home (run by parent)
  - Class during hospital stays
- Special Education
  - IFSP & IEP
  - Therapist: Opt, PT, SPL, Vision, Hearing, Social Work
  - One-on-One Nurse
- Finance
  - Accommodation
  - With insurance, coordinate bills from different hospitals,
  - Critical care not covered by insurance: therapies, medication, medical bills
  - Joy of unexpected milestones: Smile, Sitting independently
  - Nursing Shortage: Inability to keep a job
  - Sleepless Nights
  - Always wondering how long your child will live
  - Unexpected ER visits or hospital stays
  - Finding answers to complex medical issues
  - Having a child without a diagnosis
  - Lack of team players

Child with DisAbilities & Family
- Follow up: Each segment could be broken down further

Parent or Guardian
- Parent or Guardian

Emotional Roller Coaster
- Watching your child suffer while trying to explain that this _____ is good for her.

Presented by: Mary Fitzsimmons Szelienbaum
Mauri’s Mother Forever

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Background

• The current healthcare system rarely addresses the medical needs of medically complex children and adolescents
• These children often do not get needed or timely outpatient services because of the disjointed nature of the healthcare system
• The lack of highly coordinated care puts the well-being of medically complex children at risk and uses very expensive disconnected services in a sub-optimal manner
• Costs associated with this population can be 7 times the average costs for the pediatric population
Who are children with special health care needs?
<table>
<thead>
<tr>
<th>Term:</th>
<th>Used to describe children who require:</th>
<th>Examples:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with special needs</td>
<td>Educational, health care or other supports that are not typical</td>
<td>Autism, dyslexia, all health care needs</td>
</tr>
<tr>
<td>Children with special health care needs</td>
<td>Health services that are not typical (often also need educational supports)</td>
<td>Cerebral palsy, sickle cell, mental health conditions, epilepsy</td>
</tr>
<tr>
<td>Children who are medically fragile</td>
<td>Supportive technology</td>
<td>Some cerebral palsy, some epilepsies</td>
</tr>
<tr>
<td>Children with chronic conditions</td>
<td>Ongoing care (of any level)</td>
<td>Asthma, diabetes, cerebral palsy</td>
</tr>
<tr>
<td>Children with medical complexity</td>
<td>Care across many systems and medical specialties</td>
<td>Cancer, cerebral palsy, muscular dystrophy, some epilepsies, severe mental/emotional problems</td>
</tr>
</tbody>
</table>
More precision (3M Clinical Risk Groupings):

<table>
<thead>
<tr>
<th>CRG Status</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Healthy (no recent procedures or significant acute conditions)</td>
<td>Well child</td>
</tr>
<tr>
<td>2</td>
<td>Recent history of a significant acute disease</td>
<td>Recent significant injury</td>
</tr>
<tr>
<td>3</td>
<td>Single minor chronic disease</td>
<td>One condition - ADHD, excema, allergic rhinitis</td>
</tr>
<tr>
<td>4</td>
<td>Minor chronic disease(s) affecting multiple organ systems</td>
<td>More than one condition - ADHD, excema, allergic rhinitis</td>
</tr>
<tr>
<td>5a</td>
<td>Single dominant chronic disease</td>
<td>Asthma, obesity</td>
</tr>
<tr>
<td>5b</td>
<td>Single dominant chronic disease</td>
<td>Diabetes Type I, sickle cell</td>
</tr>
<tr>
<td>6</td>
<td>Significant chronic disease affecting multiple organ systems</td>
<td>Diabetes Type I with mental health problem, sickle cell with respiratory problem</td>
</tr>
<tr>
<td>7</td>
<td>Dominant chronic disease affecting three or more organ systems</td>
<td>Endocrine conditions</td>
</tr>
<tr>
<td>8</td>
<td>Dominant, metastatic and complicated malignancies</td>
<td>Cancer</td>
</tr>
<tr>
<td>9</td>
<td>Catastrophic and progressive conditions</td>
<td>Muscular dystrophy; transplants</td>
</tr>
</tbody>
</table>

Lurie admissions: 67%
How do we know if we are serving them well?
Well-coordinated care saves costs and increases access to services

Service pattern to achieve savings is different than other populations.

<table>
<thead>
<tr>
<th>Service</th>
<th>Cost Savings</th>
</tr>
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<tbody>
<tr>
<td>Inpatient</td>
<td>-40%</td>
</tr>
<tr>
<td>Outpatient</td>
<td>+10%</td>
</tr>
<tr>
<td>Emergency Room</td>
<td>-20%</td>
</tr>
<tr>
<td>Primary Care Services</td>
<td>+30%</td>
</tr>
<tr>
<td>Prescription Drugs</td>
<td>+10%</td>
</tr>
<tr>
<td>Medical Cost Savings</td>
<td>-13% to -10%</td>
</tr>
</tbody>
</table>

Care coordination studies generally focus on the CRG 5b-9 group.

Studies of Lurie Children’s efforts generally replicate findings from other, published studies.

Summary of Available Evidence and Methodology for Determining Potential Medicaid Savings from Improving Care Coordination for Medically Complex Children; Dobson & DaVanzo, 2013
Well coordinated care assures access to needed services

<table>
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<tr>
<th>Medical/health home indicators:</th>
<th>Private insurance</th>
<th>Medicaid/public insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN has no usual source of sick and well care</td>
<td>7.6%</td>
<td>17.5%</td>
</tr>
<tr>
<td>CSHCN has no personal doctor or nurse</td>
<td>3.6%</td>
<td>10.1%</td>
</tr>
<tr>
<td>CSHCN receives family-driven care</td>
<td>74.8%</td>
<td>59.5%</td>
</tr>
<tr>
<td>CSHCN has problems getting a needed referral</td>
<td>18.4%</td>
<td>29.4%</td>
</tr>
<tr>
<td>CSHCN has care that meets all care coordination requirements</td>
<td>47.4%</td>
<td>41.0%</td>
</tr>
</tbody>
</table>

Source: 2009/10 National Survey of Children with Special Health Care Needs (Illinois)
Well coordinated care provides integration across sectors

<table>
<thead>
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<th>Indicators of cross-sector coordination</th>
<th>Private insurance</th>
<th>Medicaid/public insurance</th>
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<tr>
<td>Difficulty/delayed in getting community-based services in last year</td>
<td>27.0%</td>
<td>33.8%</td>
</tr>
<tr>
<td>Never frustrated getting services in last year</td>
<td>73.2%</td>
<td>55.5%</td>
</tr>
<tr>
<td>Communication was needed between the physician and the school in the last 12 months</td>
<td>26.8%</td>
<td>38.7%</td>
</tr>
<tr>
<td>Very satisfied with the physician-school communication in the last year</td>
<td>56.5%</td>
<td>55.8%</td>
</tr>
<tr>
<td>CSHCN has an IEP</td>
<td>27.1%</td>
<td>33.9%</td>
</tr>
</tbody>
</table>

Source: 2009/10 National Survey of Children with Special Health Care Needs (Illinois)
Metrics relevant to children with special health care needs
## Proposed metrics

<table>
<thead>
<tr>
<th>Patient satisfaction surveys (CAHPS survey for children with chronic conditions)</th>
<th>HEDIS (claims-based)</th>
<th>HFS (claims-based)</th>
</tr>
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<tr>
<td>Access to and use of specialized services</td>
<td>Influenza immunization rate</td>
<td>Vision screening</td>
</tr>
<tr>
<td>Access to and use of prescription medication</td>
<td>Developmental screening in the first three years of life</td>
<td>Ambulatory follow-up after IP visit and ED visits</td>
</tr>
<tr>
<td>Family-centered care</td>
<td>Preventive dental services</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Well child visits (through adolescence)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lead screening</td>
<td></td>
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</table>
Questions?
HFS Subcommittee on Quality

A Brief Overview on Illinois Oral Health Disease Burden & Utilization
6.9.2017

Mona Van Kanegan, DDS, MS, MPH
Division of Oral Health, Chief
Office of Health Promotion
Foundational Concepts for better oral health for all ages

• Disease causative organisms are spread through kissing, sharing contaminated utensils such as spoon or a glass.

• To decrease transmission causative organism needs to be controlled/eliminated through prevention and treatment modalities.

• Good habits and practices that limit causative bacterial load need to be sustained life-long.

• Limiting inflammation in oral tissues decreases potential systemic impact.
Disease Burden

Dental caries and periodontal disease are common oral infections yet, are almost completely preventable

• 2011-2012 National Health and Nutrition Examination Survey report that 27% of adults 20 to 64 have untreated dental caries.

• 2012 Centers for Disease Control and Prevention report that 47.2% of adults aged 30 and over have active periodontal disease and

• 70% of people 65 and older have untreated periodontal disease
Role of Inflammation and Systemic Disease

Inflammatory cascade and the potential systemic spread of pro-inflammatory mediators such as fatty acids, interleukin 1, and TNFα are being studied to explain the observed link between oral disease and a wide range of systemic diseases.

There is strong evidence for a causal link between periodontal disease and diabetes and emerging evidence for:

– Obesity
– Coronary artery disease
– Metabolic syndrome
– Oral health after menopause
– Helicobacter Pylori
– Adverse pregnancy outcomes

Oral Health Surveillance System

National Oral Health Surveillance System (NOHSS)
Joint effort between CDC, Association of State and Territorial Dental Directors (ASTDD) & Council of State and Territorial Epidemiologists (CSTE)

- monitor the burden of oral disease
- measure progress toward meeting HP 2010 objectives
- monitor status of community water fluoridation on both a state and national level.

Illinois Oral Health Surveillance System (IOHSS)

- Feed data into NOHSS
- Emergency Department Use, 2010-2015 - limited data presented here
- Oral Health Workforce
- Craniofacial Anomaly
- Safety Net Dental Clinics
- Other Secondary Data
The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services.

- **Early**: Assessing and identifying problems early
- **Periodic**: Checking children's health at periodic, age-appropriate intervals
- **Screening**: Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
- **Diagnostic**: Performing diagnostic tests to follow up when a risk is identified, and
- **Treatment**: Control, correct or reduce health problems found.
The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based program that gathers information on risk factors among Illinois adults 18 years of age and older through monthly telephone surveys. Established in 1984 as a collaboration between the U.S. Centers for Disease Control and Prevention (CDC) and state health departments, the BRFSS has grown to be the primary source of information on behaviors and conditions related to the leading causes of death for adults in the general population.
I know it was important to care for my teeth and gums during my pregnancy.

A dental or other health care worker talked to me about how to care for my teeth and gums.

I had my teeth cleaned by a dentist or dental hygienist.

I had insurance to cover dental care during my pregnancy.

I needed to see a dentist for a problem.

I went to a dentist or dental clinic about a problem.
Use of Emergency Departments Associated with Delayed/Untreated Disease

• Illinois Department of Public Health Division of Patient Safety and Quality provided Emergency Department (ED) discharge summary data for ICD9 and ICD10 for non-traumatic oral health concern

• Data analyses were conducted on visits where the dental issue was one or more of the first three diagnoses
Overall rates of ED visits for oral health reasons are increasing over the six year period. They have increased by 17% between 2010 and 2015.
1. Larger increases in ED rates for adults and older adults compared to youth (5% increase). Young adults (18-24) declined by 8.8%.
   a. 25-34 age group: 15.9%
   b. 35-49 age group: 21%
   c. 50-64 age group: 61%
   d. 65+ age group: 101.2%

2. Adult age groups: 25-34 and 35-49 have the highest rates of ED visits.

3. Rates doubled for adults over 65, even though they have lower rates overall.

Source: Illinois Department of Public Health, Hospital Discharge Dataset, 2010-2015; Analysis by IDPH Office of Health Promotion
2013 saw an increase in ED visits among Medicaid and decline among self-pay. Medicare visits also increased. Recall 7/2012-6/2014 SMART Act limitations for dental care were in effect; ACA expansion was initiated in January of 2014.

Source: Illinois Department of Public Health, Hospital Discharge Dataset, 2010-2015; Analysis by IDPH Office of Health Promotion
What data are missing?

To better inform oral health program goals: is health status improved, timely & quality care delivered in an appropriate setting that is cost effective? A better understanding of the below is needed:

Children
- Annual Dental Visit
- Children who received at least on fluoride treatment
- Children (6-9 and 10-14) who receive at least one dental sealant

Adults
- General adult access/utilization of any dental service in a dental setting (not EDs) including that of special populations such as diabetics
- Preventive and periodontal access/utilization during pregnancy
- Number of ED visits that had a follow up visit with a dentist within 30 days.

Satisfaction
If you or your child sought dental care, did you receive services when you needed them?