Children with Special Health Care Needs and those with Complex Chronic Conditions
Affordable Care Act
2016
I have no conflict of interests to disclose or any financial interests in any products in my presentation.

John M. Neff M.D.  May, 2016
Objectives

• Present Funding Patterns and Data on Prevalence and Costs Distribution of health conditions in children.

• Present an overview of the initiatives in the Affordable Care Act and their intent.

• Discuss how the affordable care act might impact children with special needs with a focus on those with complex chronic health conditions.
Government Funding for US Health Care increased in 1980-2011 from 31.1% to 42.3%.

Hospital, professional services, drugs and devices and administrative costs account for 91% of all increases.
• Government Funding for US Health Care increased in 1980-2011 from 31.1% to 42.3%.

• Hospital, professional services, drugs and devices and administrative costs account for 91% of all increases.

• Chronically ill account for 84% of all health care costs.

• Hospitals and other care facilities account for 42% of health care expenditures.
Population 0-18 years are about 27% of population and account for 13% of all health care expenditures.

Children with Complex Chronic Conditions represent about 2% of children and approximately 0.5% of the overall population.
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Children with Complex Chronic Conditions represent about 2% of children and approximately 0.5% of the overall population.

Children with Complex Conditions account for 15% of health care expenses for children and perhaps 2% of all health care expenses.
Cripple Children’s Funds was the first Federal Initiative to pay for the care of children with disabilities. Initiated in the 1930s.

Paid for direct care for certain designated, categorical, conditions including children with neuro-developmental conditions.
Funding of Children with Neuro-developmental Disorders

Medicaid was initiated in the 1960s and paid for medical care of children in poverty including many with neuro-developmental disorders.

In the 1980s the funds that has been designated for crippled children were folded into state block grants, designated Title V funds, giving state’s discretionary power on how to fund these programs.
In the 1980s the Maternal Health Bureau broadened the number of children who needed support to include almost any child who had a physical, developmental or mental health condition that lasted at least a year and required health care above the average patients.

These Children were called: “Children with Special Health Care Needs.” CSHCN
In the 1990s many states including Washington, redirected Title V funds away from direct patient care to overall public health oversight.

Children with neuro developmental disorders ceased to be a line item in health care budgets.

Now children with developmental disorders along with other children with chronic conditions are folded into Medicaid Programs.
Utilizers of Pediatric Health Care Resources:

Who are the Children?
What are their costs?
What are their Vulnerabilities?
Those who have or are at increased risk for a physical, developmental, behavioral, or emotional condition (lasts for at least 12 months-chronic) and who require health and related services of a type and an amount beyond that required by children generally
Children with Special Health Care Needs represented in 2000 approximately 20% of all children and consumed between 40%-60% of health care resources devoted to children.

The majority of children never get sick or have minor acute conditions and consume minimal health services.
Common Chronic Conditions in Childhood

- Mental Health Conditions: 11%-20%
- Obesity: 14%-18%
- Attention Deficit Disorders: 4%-6%
- Learning Disorders: 5%-10%
- Asthma: 4%-8%
- Neurodevelopmental Delays: 0.4%-3%

The costs of these conditions are often delayed until adult ages and difficult to risk adjust.
Definitions that Describe Different Patterns (trajectories) of Outcomes in Administrative Data

- **Non chronic** – Conditions that last less than 12 months.

- **Episodic chronic** – Conditions that are expected to last at least a year, are highly variable in manifestation and with treatment are not likely to last past childhood.

- **Life Long Chronic (single body system)** – Conditions that are likely to be life long and are generally static.

- **Complex Chronic**
  Significant chronic conditions in two or more body systems and/or conditions that have shortened life expectancies.

- **Malignancies**
Episodic Chronic Conditions that Can Improve

- Asthma
- Non morbid obesity
- Simple Seizures
- Skin conditions - Atopic Disease
- Attention Deficit and Hyperactive Disorders
- Depression
- Conduct and Behavioral Disorders
Chronic Conditions that may be Static and Controlled

- **Type One Diabetes**
- **Cerebral Palsy with Monoplegia or Diplegia**
- **Hydrocephalus with Shunt**
- **Congenital Hypothyroid**
Chronic Conditions that are Complex and/or may get Worse

- Acquired or Congenital Quadriplegia or Paraplegia
- Cerebral Palsy or Encephalopathy with Multi-System Involvement
- Cystic Fibrosis
- Muscular Dystrophy
- Certain Chromosomal Abnormalities
- Technology Dependent Children
- Life Long Chronic Conditions with Significant Comorbid Conditions such as Asthma, Obesity, Mental Health Conditions, or Seizures
## Summary Complex or Life Long Chronic Conditions
Prevalence and Cost 2007

### Children with Life Long and Complex Chronic Conditions

<table>
<thead>
<tr>
<th>Health Plan</th>
<th>%Children</th>
<th>%Charges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Plan Administrative Data</td>
<td>2.5%</td>
<td>15%</td>
</tr>
<tr>
<td>Children’s Hospital Discharge Data</td>
<td>40%</td>
<td>60%</td>
</tr>
</tbody>
</table>
Health Initiatives in the early 1990s

Washington State Health Plan
Clinton’s National Health Initiatives
Enroll all of Washington State population from fee for service into state approved managed care plans that would compete with each other to provided the best care at the lowest cost.

Clinton Health Plan based on the Washington State Health Plan.
• Washington State Health Plan repealed along with Clinton’s plan.

• Principals of Competitive Managed Care were continued for Medicaid Patients in Washington State.
Medicaid Capitated Care 1990 to 2010

• Unevenly Distributed Risk (patient complexity).

• Savings were not Returned to Providers.

• Generally Exempted Complex Patients from Mg Care.

2011 approx 70% of patients with complex conditions stayed in Fee for Service.
Unintended Consequences

• Many Plans and Physicians Opted out of Medicaid Contracts.

• Many Patients with Complex Chronic Conditions in Fee for Service were not well Managed.

• Increase use of Emergency and Hospital Services.

• Children with Complex Chronic Conditions Managed in Specialty Clinics.
Recession 2008
Initiation of Apple Health
Eligibility Medicaid to 300% LOP

Increase Enrollment in Medicaid
Especially those with chronic conditions
# State of Washington Medicaid Enrollment

<table>
<thead>
<tr>
<th>Enrollment Year</th>
<th>Medicaid Enrollment</th>
<th>Increase in Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Children Apple Health</td>
<td></td>
</tr>
<tr>
<td>January 2006</td>
<td>571,649</td>
<td></td>
</tr>
<tr>
<td>September 2015</td>
<td>830,643</td>
<td>258,994 45% Ten year increase</td>
</tr>
</tbody>
</table>
## Prevalence of Chronic Conditions in Medicaid 2004-2015

<table>
<thead>
<tr>
<th>Data Set Year</th>
<th>Percent with Chronic Condition</th>
<th>Percent of Costs of those with Chr. Cond.</th>
<th>Percent with Complex Chronic</th>
<th>Percent of Costs of those with Complex Chronic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2004 New York Medicaid</strong></td>
<td>15%</td>
<td>44%</td>
<td>3%</td>
<td>15%</td>
</tr>
<tr>
<td><strong>2013 Truven Seven State Medicaid</strong></td>
<td>40%</td>
<td>78%</td>
<td>11%</td>
<td>47%</td>
</tr>
</tbody>
</table>
Affordable Care Act

Impact on Children with Complex Chronic Conditions
Initiatives in the Affordable Care Act

• Provide health insurance and quality health care to all individuals.

• Create competitive insurance program to allow one to select the best plan at the lowest cost.

• Insurance plans can pool buying power through state monitored exchange programs.
Initiatives in the Affordable Care Act

- Expand Medicaid and preserve CHIP.

- All Medicaid patients will be in an insurance managed care program.
Goals for Controlling Health Care Costs

• Increase available resources in insurance pool by including those with lower health care costs.

• Control the costs of chronically ill by increasing case management and preventing adverse events.
Targets for Cost Control
Affordable Care Act

• Hospitals.
• Specialty Providers.
• Those with Chronic Conditions.
1) Initially the first enrollees in the exchange programs will be those with chronic conditions.

The financial success of the exchange programs depends on having a large pool of healthy patients to offset the cost of the chronically ill.
Vulnerability of Children with Chronic Health Conditions in the Exchange Programs

1) Initially the first enrollees in the exchange programs will be those with chronic conditions.

2) Children with Complex Chronic Conditions will all be enrolled in managed care.

In the past 70% of those with complex chronic conditions have been in fee for service.

Now about 70% are in managed care programs.
Vulnerability of Children with Chronic Health Conditions in the Exchange Programs

1) Initially the first enrollees in the exchange programs will be those with chronic conditions.

2) Children with Complex Chronic Conditions will all be enrolled in managed care.

3) Fear that competing qualified health plans will not contract with the children’s hospitals for all children but will direct only children with the most complex care to Children’s Hospitals.
Vulnerability of Children with Chronic Health Conditions in the Exchange Programs

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2) Children with Complex Chronic Conditions will all be enrolled in managed care.

3) Fear that competing qualified health plans will not contract with the children’s hospitals for all children, but will direct only children with the most complex care to Children’s Hospitals.

4) Adverse events are most prevalent in children with complex conditions.
<table>
<thead>
<tr>
<th>Age</th>
<th>Number in Qualified Health Plans</th>
<th>Children Enrolled in Medicaid</th>
<th>Number of Children &lt;19 Wash</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total under 19</td>
<td>7,665</td>
<td>842,943</td>
<td>1.8 Mil</td>
</tr>
</tbody>
</table>
Issues for Children under 19 years
Most will be in Medicaid

• **Benefit Package**-
  Medical Benefits are better in Medicaid than in Qualified Health Plans (QFP).

• **Access to providers and hospitals**-
  Should not be a problem. Medicaid Plans and all QFPs have included Children's Hospital as a provider.

• **Managed Care for patients**-
  Most will be in Managed Care for first time.
Issues about Care Management

• Managed Care is a payment system.

• Care Management is the way to provide efficient coordinated care at the lowest cost.

• There is no data that reflect the costs savings anticipated from care management.

• We have not demonstrated the optimal way to provide care management.
Issues for population over 19 years
Most will be in Qualified Health Plans

• **Benefit package.**
  Benefit package is less in QHPs than Medicaid.

• **Access to providers and hospitals.**
  Will depend on the scope of QHP.

• **How will managed care be instituted?**
  Will likely follow adult models.
• Transition to adult plans and providers.

• Plans in Exchanges will need to include specialty hospitals and specialty physicians.

• How do we provide managed care?

• Unresolved question of who is the optimal primary care provider for children with chronic conditions.
Long Term Issues

- Ability to reward long term costs savings and integrate child into an adult society.

- Sustained political will to improve health care systems for the disadvantaged.
Next Steps and Conclusions

• Open Discussion
Conditions in Children with Chronic Conditions
Conditions in Children with Complex Chronic Conditions Compared to Children with Single System Involvement

- Data Summarized from the Children’s Hospital Corporation of America Pediatric Health Information System (PHIS) Discharge Data from 28 US Freestanding Pediatric Hospitals 2004-2009 using CRGs adapted for Hospital use

Authors: Jay Berry et al.
Summary

- Children with Complex Chronic Conditions have Different Condition Patterns than Children with Chronic Conditions in Single Body Systems

Complex Chronic Conditions are Dominated by Cerebral Palsy, Chromosomal Abnormalities, Congenital Heart Disease and Bronchopulmonary Dysplasia

Co morbid Conditions that Dominate are Asthma, Cardiac Dysrhythmias, Obesity and Scoliosis
### Episodic Chronic Conditions in Single Body Systems

From CHCA Data Jay Berry et al

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>35.7%</td>
</tr>
<tr>
<td>Sleep Apnea and Related Conditions</td>
<td>4.3%</td>
</tr>
<tr>
<td>ADHD</td>
<td>3.8%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>3.2%</td>
</tr>
<tr>
<td>Ventricular or Atrial Septal Defects</td>
<td>3.1%</td>
</tr>
<tr>
<td>Cardiac Dysrhythmia or Conduction Disorders</td>
<td>2.9%</td>
</tr>
<tr>
<td>Conduct, Impulse Control/Other Disrup Behav</td>
<td>2.7%</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>2.3%</td>
</tr>
<tr>
<td>Vesicoureteral Reflux</td>
<td>1.9%</td>
</tr>
<tr>
<td>Urinary Tract Obstruction</td>
<td>1.9%</td>
</tr>
<tr>
<td>All Other Episodic</td>
<td>38.2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100.0%</strong></td>
</tr>
<tr>
<td>Condition</td>
<td>Percent</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Major Congenital Heart Disease</td>
<td>16.6%</td>
</tr>
<tr>
<td>Sickle Cell Disease</td>
<td>12.0%</td>
</tr>
<tr>
<td>Type I Diabetes</td>
<td>9.5%</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>6.6%</td>
</tr>
<tr>
<td>Down's Syndrome</td>
<td>5.6%</td>
</tr>
<tr>
<td>Anomal of Trach, Larynx and Bronch</td>
<td>5.1%</td>
</tr>
<tr>
<td>Chromosomal Anomalies</td>
<td>4.6%</td>
</tr>
<tr>
<td>Craniofacial Anomalies</td>
<td>4.6%</td>
</tr>
<tr>
<td>Bronchopulmonary Dysplasia</td>
<td>4.5%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>4.2%</td>
</tr>
<tr>
<td>All Others</td>
<td>31.3%</td>
</tr>
<tr>
<td>Total Percent of Patients</td>
<td>100.0%</td>
</tr>
<tr>
<td>Condition</td>
<td>%</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>-----</td>
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<tr>
<td>Asthma</td>
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<tr>
<td>Cardiac Dysrhythmia and Conduction Disorders</td>
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<tr>
<td>Conduct, Impulse Control/ Other Disrupt Behav Dis</td>
<td>3.4%</td>
</tr>
<tr>
<td>Disorders of Phosphorus, Calcium</td>
<td>3.2%</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>3.0%</td>
</tr>
<tr>
<td>Skin and Subcutaneous Tissue Conditions</td>
<td>2.7%</td>
</tr>
<tr>
<td>Spinal Cord Conditions</td>
<td>2.6%</td>
</tr>
<tr>
<td>All Other</td>
<td>41.3%</td>
</tr>
<tr>
<td>Total Percent of Diagnoses</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
## Life Long Chronic Conditions in Complex Chronic
From CHCA Data Jay Berry et al

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Cerebral Palsy</td>
<td>14.6%</td>
</tr>
<tr>
<td>Chromosomal Anomalies</td>
<td>6.5%</td>
</tr>
<tr>
<td>Congenital Heart Disease</td>
<td>6.2%</td>
</tr>
<tr>
<td>Bronchopulmonary Dysplasia</td>
<td>6.1%</td>
</tr>
<tr>
<td>Anomalies of Trachea, Larynx and Bronchus</td>
<td>5.2%</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>4.2%</td>
</tr>
<tr>
<td>Diabetes Type 1</td>
<td>3.8%</td>
</tr>
<tr>
<td>Coagulation Disorders</td>
<td>3.5%</td>
</tr>
<tr>
<td>Down's Syndrome</td>
<td>3.0%</td>
</tr>
<tr>
<td>Craniofacial Anomalies</td>
<td>2.9%</td>
</tr>
<tr>
<td>All Other Diagnoses</td>
<td>44.0%</td>
</tr>
<tr>
<td><strong>Total Percent of Diagnoses</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
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