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IMPROVING FINANCING OF CARE for Children & Youth WITH SPECIAL HEALTH CARE NEEDS

Care Integration for Children with Special Health Needs: Improving Outcomes and Managing Costs

National Governor's Association
Center for Best Practices

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The Catalyst Center: Who are we?

- **Funded by** the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau
- **A project of** the Health and Disability Working Group at the Boston University School of Public Health
- **The National Center dedicated to the MCHB outcome measure**: "…all children and youth with special health care needs have access to adequate health insurance coverage and financing".

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What do we do?

- Provide technical assistance on health care financing policy and practice to states and stakeholders
- Conduct policy research to identify and evaluate financing innovations
- Create educational resources (such as policy briefs and webinars)
- Connect those interested in working together to address complex financing issues

Who are children with special health care needs?

- The federal Maternal and Child Health Bureau defines children with special health care needs as "*...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*"

McPherson, M, et al. *A new definition of children with special health care needs* (Elk Grove Village, IL: Pediatrics, 1998),102: 137-140

CSHCN – Some numbers....

- How many children in the US have special health care needs?

Approximately 11 million or...
15% of all children

Source: National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/6/12 from www.childhealthdata.org

What percentage of CSHCN have health insurance and what kind?

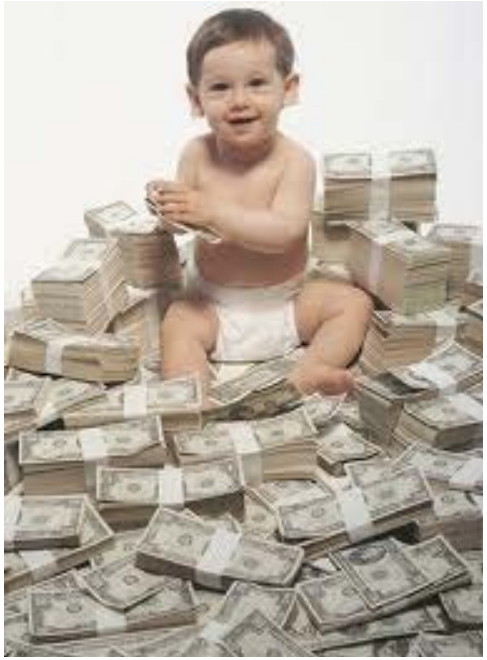
Private	52.4%
Public	35.9%
Private and Public	8.2%
Uninsured	3.6%
Total insured	**96.4%**

What financial impact does the presence of special health care needs in children have on their families?

Currently insured CSHCN whose insurance is inadequate to meet their needs	**34%**
CSHCN whose families paid $1,000 or more out-of-pocket in medical expenses in past 12 months	**22%**
CSHCN whose health conditions cause financial problems for the family	**22%**
CSHCN whose health conditions cause family members to cut back or stop working	**25%**

Source: National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/6/12 from www.childhealthdata.org

Costs: Comparing children in general, CSHCN and adults with health issues



- Most children are typically healthy and typically developing
- By definition, CSHCN use a disproportionate share of pediatric health care services
- Attention to reducing costs in health care has generally been focused on adults with disabilities and chronic illnesses, who are a much larger population than CSHCN and who consequently cost more overall

Differential Epidemiology: children compared with adults

- Children: small numbers scattered among many diagnoses, under broad categories. Examples:
  - Asthma and other respiratory problems
  - Genetic disorders and congenital anomalies
  - Mental/behavioral health issues
  - Developmental Disabilities, including Autism
- Adults: higher numbers tend to concentrate among a smaller number of specific diagnoses. Examples:
  - Heart disease/stroke
  - Cancer
  - Diabetes
  - Arthritis

So why should we be concerned about costs for CSHCN?

- Budget constraints
- Increasing numbers
- Increasing emphasis in health care on VALUE for all populations
- Life course context

Budget constraints

Every stakeholder group is experiencing economic pressure:

–Patients and families

–Providers

–Purchasers

–Payers

–States

No one has “money to burn”

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Increasing numbers of CSHCN with complex conditions are now living into adulthood

The average cost of care for a person with CF living in the United States in 2006 was just over $48,000 a year, more than 22 times higher than that of someone without CF

Source: Ouyang L, Grosse SD, Amendah DD, Schechter MS. *Healthcare expenditures for privately insured people with cystic fibrosis*. *Pediatric Pulmonology* 2009;44:989–996.

- Example - Cystic Fibrosis (CF):
  - In the 1950s, few people with CF lived long enough to begin elementary school
  - In 1986, the median survival age was approximately 27 years
  - In 2010, the predicted survival age was 38.3 years

Source: Cystic Fibrosis Foundation Patient Registry, 2010 Annual Data Report (2011)

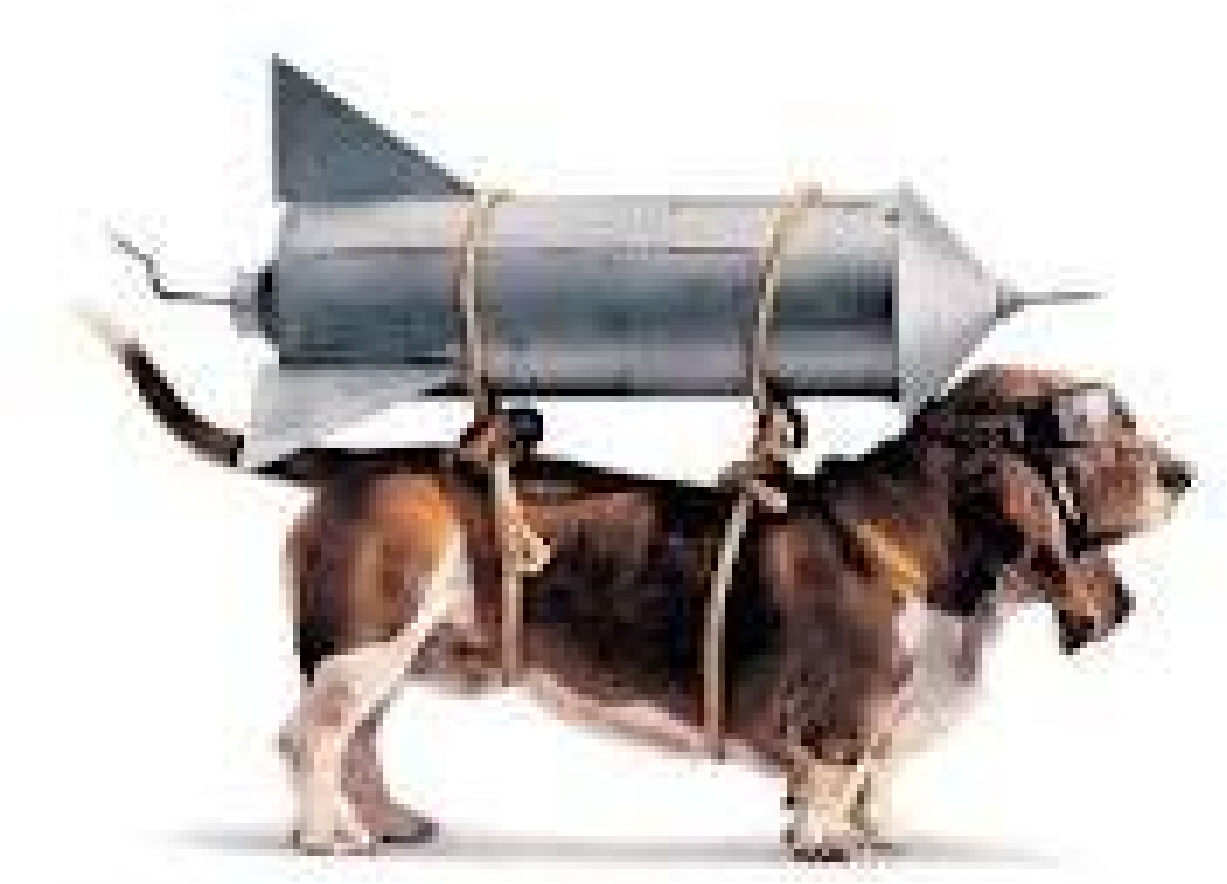
Increasing emphasis in health care on VALUE for all populations

- Value is increasingly defined not only as cost savings but also as cost *effectiveness* – are we getting as much "bang for our health care buck" as we can?
- Cost effectiveness efforts must include quality measurement and improvement
  - Outcomes can include early identification of SHCN, waste/fraud/harm reduction, increased efficiencies, greater stakeholder satisfaction (providers and patients/families especially)
  - Better health outcomes can = lower costs in the short and long term or at least stabilization/slowing of cost increases

Life course context

- Many CSHCN grow up to be adults with disabilities, chronic illnesses and special health care needs. As stated earlier, adults are the major cost drivers.
- If we can improve or eliminate health issues earlier in life, overall costs should be lower; not only health care costs for the care of individuals but also associated societal costs (lost wages, employment loss, family instability, bankruptcy and medical debt, just to name a few.)

Everyone has a dream.....



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Vision of an integrated system of services for children with special health care needs

- An integrated system of services is:
  - Patient- and family-centered
  - Comprehensive
  - Community-based
  - Culturally competent
  - Coordinated

Leadership in developing an integrated system of services for CSHCN by the federal Maternal and Child Health Bureau (MCHB)

– Legislative authority:

- Omnibus Budget Reconciliation Act of 1989 – established the Maternal and Child Health Bureau's authority to facilitate the development of systems of services for CSHCN and their families

- **Healthy People 2010 Objectives 16-23 (c. 2000)**
  - "Increase the proportion of "States and territories that have service systems for children with special health care needs"
  - Core outcome measures, which define the system of services:
    - Families of children with special health care needs (CSHCN) will participate in decision-making at all levels and will be satisfied with the services they receive
    - CSHCN will receive regular, ongoing comprehensive care within a medical home
    - Children will be screened early and continuously for special health care needs
    - Families of CSHCN will have access to adequate public and/or private insurance to pay for the services they need
    - Community-based service systems will be organized so families can use them easily
    - Youth with special health care needs (YSHCN) will receive the services necessary to make transitions to all aspects of adult life
  - **Healthy People 2020 Objective MICH-30**
    - "Increase the proportion of children, including those with special health care needs, who have access to a medical home"

To achieve this “dream” system, how care is delivered must change

Emphasis on delivering care that is:

- Patient- and family-centered
- Comprehensive
- Community-based
- Culturally competent
- Coordinated
- *Cost-effective*

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Example: “Health Home”, Medical Home, Care Coordination

- Section 2703 of the Affordable Care Act: Medicaid state plan option to establish primary care “health homes” for populations with chronic conditions
- 90% enhanced federal match for 8 quarters (two years)
- Rhode Island: two approved Section 2703 State Plan Amendments: one for CSHCN
- Built on existing infrastructure: *CEDARR* Family Centers for Children and Youth with Special Health Care Needs

- Services required by Section 2703 are integral to the CEDARR Centers:
  - Comprehensive Care Management
  - Care Coordination and Health Promotion
  - Transitional Services
  - Individual and Family support
  - Referral to Community and Social Support Services

To learn more, listen to a recording with slides of a recent webinar on Section 2703 sponsored by the Association of Maternal and Child Health Programs (AMCHP) and the Catalyst Center at http://hdwg.org/catalyst/news/2011-12-03/1)

The way care is paid for must change, also...

- Moving from fee for service standard payment model
  - Fee-for-service: incentives for how *much*, not how *well*….
- Innovation is urgently needed to align incentives in order to:
  - Reduce health care spending
  - Improve outcomes for individual and population health
  - Increase stakeholder satisfaction (providers, patients, families, payers, purchasers, etc.)

Payment reform – some examples

- Primary care case management
- Specialty managed care plans and contracting specifications specific to CSHNC in managed care
- Global/bundled payments
- Pediatric Accountable Care Organizations (ACOs), ACOs with pediatric components, Community Accountable Care Organizations
- Pay for Performance (P4P)

Financial protections

- Risk adjustment for CSHCN
  - What is risk adjustment?
    - Important to payers
    - Important to purchasers, providers, patients and families
- Other financial protections: carve-outs, risk sharing/stop-loss, benefit exception protocols, Medicaid buy-in programs

To learn more about risk adjustment and CSHCN, see the Catalyst Center issue brief ***Risk Adjustment and Other Financial Protections for Children and Youth with Special Health Care Needs in Our Evolving Health Care System*** *at http://hdwg.org/catalyst/risk)*

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The importance of quality measurement and improvement

- Helps identify opportunities to increase “value”
- Helps set efficiency and health outcomes benchmarks
- Patient safety initiatives to reduce waste and harm; increase effectiveness of care
- Patient/family satisfaction

For more information,
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