New England Children with Genetic Disorders and Health Care Reform: Information and Recommendations for State Policymakers

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Welcome and introductions

New England Genetics Collaborative at the University of New Hampshire's Institute on Disability

http://negenetics.org/

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Catalyst Center at the Boston University School of Public Health's Health and Disability Working Group

– http://catalystctr.org

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

What are genetic disorders?

- The human body is made up of a variety of different kinds of cells
- The cells get their instructions on how to function properly from proteins made by genes
- When there is a change in the chemicals or DNA that make up the genes, a genetic condition or disorder results
- There are three kinds of genetic disorders:
  - single gene disorders (like cystic fibrosis)
  - chromosomal abnormalities (like Down syndrome)
  - multifactoral genetic disorders (like some instances of breast cancer)

Who are New England children with genetic disorders?

- Ages 0-17, living in one of the six New England states
- Scattered across a wide range of diagnoses
- Some dxs are more familiar (Down syndrome, cystic fibrosis, sickle cell); many are rare
- No single source of comparable data for ALL genetic disorders
- Data for children with special health care needs (which includes children with genetic disorders) can be useful when generalizing is appropriate

What does the data tell us about CSHCN (including children with genetic disorders) and insurance?

- What kind of insurance they have (private, public benefit program, both, uninsured)
- Is it adequate in meeting their health care needs?
- What is the impact of insurance inadequacy on their families?

Breakdown of insurance coverage type for New England CSHCN

Insurance Type	CT	MA	ME	NH	RI	VT	US
Private insurance only	64.5%	63.6%	38.7%	59.4%	51.3%	38.8%	52.4%
Public insurance only	27.7%	24.4%	49.6%	31.6%	34.6%	48.8%	35.9%
Both public and private insurance	6.9%	11.2%	10.0%	6.9%	12.3%	11.3%	8.2%
Uninsured	1.0%*	0.8%*	1.7%*	2.0%	1.7%*	1.1%*	3.6%

*Estimates based on sample sizes too small to meet standards for reliability or precision.

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 1/17/14 from www.childhealthdata.org

Percentage of currently insured NE CSHCN whose insurance is **inadequate** in meeting their health care needs

% CSHCN whose insurance is inadequate	CT	MA	ME	NH	RI	VT	US
	38.5%	33.7%	26.3%	28.9%	31.3%	27.6%	34.3%

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 1/17/14 from www.childhealthdata.org

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Impact of insurance inadequacy on NE families of CSHCN

Impact on Family	CT	MA	ME	NH	RI	VT	US
CSHCN whose families pay more than $1,000 out-of-pocket in medical expenses per year for the child	24.6%	25.7%	17.4%	23.6%	16.8%	20.1%	22.1%
CSHCN whose conditions cause financial problems for the family	18.8%	19.1%	18.6%	19.6%	14.7%	17.3%	21.6%
CSHCN whose conditions cause family members to cut back on or stop working	24.9%	27.5%	23.9%	23.0%	25.6%	27.0%	25.0%

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
www.childhealthdata.org

2012 NEGC Health Care Access and Financing Workgroup Family Survey

- December 2012 online survey of NE families of children with genetic disorders
- Parents self-identified as having a child with a genetic disorder – variety of dxs represented
- Survey based on the Essential Health Benefit service categories in the ACA
- Research question: what EHBs are being covered prior to implementation in 2014 and where are there gaps?
- Response rate from each state was not high enough to generalize across the region, but gave us useful targets for future research and important insights from the family perspective

The 10 EHB service categories under the ACA

- Ambulatory care
- Emergency services
- Hospitalization
- Laboratory services
- Maternity and newborn care
- Pediatric services, including oral and vision care
- Preventative and wellness services, and chronic disease management
- Rehabilitative and habilitative services and devices
- Prescription drugs
- Mental health and substance abuse services; including behavioral health

What we learned from NE families of children with genetic disorders

EHB categories with specific gaps:

- Ambulatory services
- Care for emotional, behavioral or substance abuse issues
- Prescription drug coverage
- Rehabilitative and habilitative therapies
- Medical devices
- Developmental screenings
- Prescribed medical foods

What we learned from NE families of children with genetic disorders

Need for other uncovered supports and services reported by families:

- Respite care
- Transportation
- Services for transition to adult health care
- Residential services
- Personal care services
- Home and vehicle adaptations

What we learned from NE families of children with genetic disorders

- Cost is a major problem: premiums, high deductibles, co-pays, co-insurance, uncovered services were noted in almost every category
- Administrative burden on families is high and a significant problem; many families struggle to get services paid for, even with insurance

Coverage that meets the needs of CSHCN, including those with genetic disorders, must be:

- Universal and continuous
  - Every child has coverage and can stay on it without interruption
- Adequate
  - Coverage pays for what children need
- Affordable
  - Their families can afford the coverage and care they need without risking financial hardship, medical debt or bankruptcy

A step in the right direction…

- The Patient Protection and Affordable Care Act of 2010 (Pub. L. 111-148)

  signed into law March 23, 2010

- The Health Care and Education Reconciliation Act (Pub. L.111-152)

  signed into

Together, they're known as the Affordable Care Act, or ACA

Major Areas of Focus in the ACA

- Insurance reforms ("Patient's Bill of Rights" - consumer protections)
- New or expanded pathways to coverage (Medicaid expansion, MOE, Marketplaces), paired with Individual Mandate (everyone has to have coverage)
- Cost and Quality Provisions

ACA Insurance Reform and Consumer Protection Provisions – Selected Examples

- Prohibition against denying coverage based on a **pre-existing condition**
- **Dependent coverage** for youth up to age 26 on their parent's plan, effective 2010
- No **rescission** of coverage regardless of the cost or amount of services used, effective 2010

ACA Insurance Reform and Consumer Protection Provisions – Selected Examples

No more Annual and Lifetime Benefit Limits

- Effective Now
  - No annual benefit cap allowed
  - No more lifetime benefit caps for existing or new plans

- NOTE: benefits themselves can still be capped, e.g. 15 physical therapy visits, 15 mental health sessions per year

ACA Insurance Reform and Consumer Protection Provisions – Selected Examples

- **Preventative Services** w/o cost-sharing (no co-pay, co-insurance or deductible charged – in network only)
  - Applies to all new (non-grandfathered) group health plans (fully insured and self-funded) and new individual policies issued or renewed on or after August 1, 2012

Recommendations of the United States Preventive Services Task Force (USPSTF)
http://www.healthcare.gov/center/regulations/prevention/taskforce.html

Recommendations of the Advisory Committee on Immunization Practices (ACIP) adopted by CDC
http://www.cdc.gov/vaccines/recs/acip/

Comprehensive Guidelines Supported by the Health Resources and Services Administration (HRSA)
Bright Futures Recommendations for Pediatric Preventive Health Care
http://brightfutures.aap.org/pdfs/AAP%20Bright%20Futures%20Periodicity%20Sched%20101107.pdf

HRSA's Women's Preventive Services: Required Health Plan Coverage Guidelines

http://www.healthcare.gov/center/regulations/womensprevention.html

Recommendations of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

http://www.hrsa.gov/heritabledisorderscommittee/SACHDNC.pdf

New pathway to coverage: State Health Insurance Marketplaces

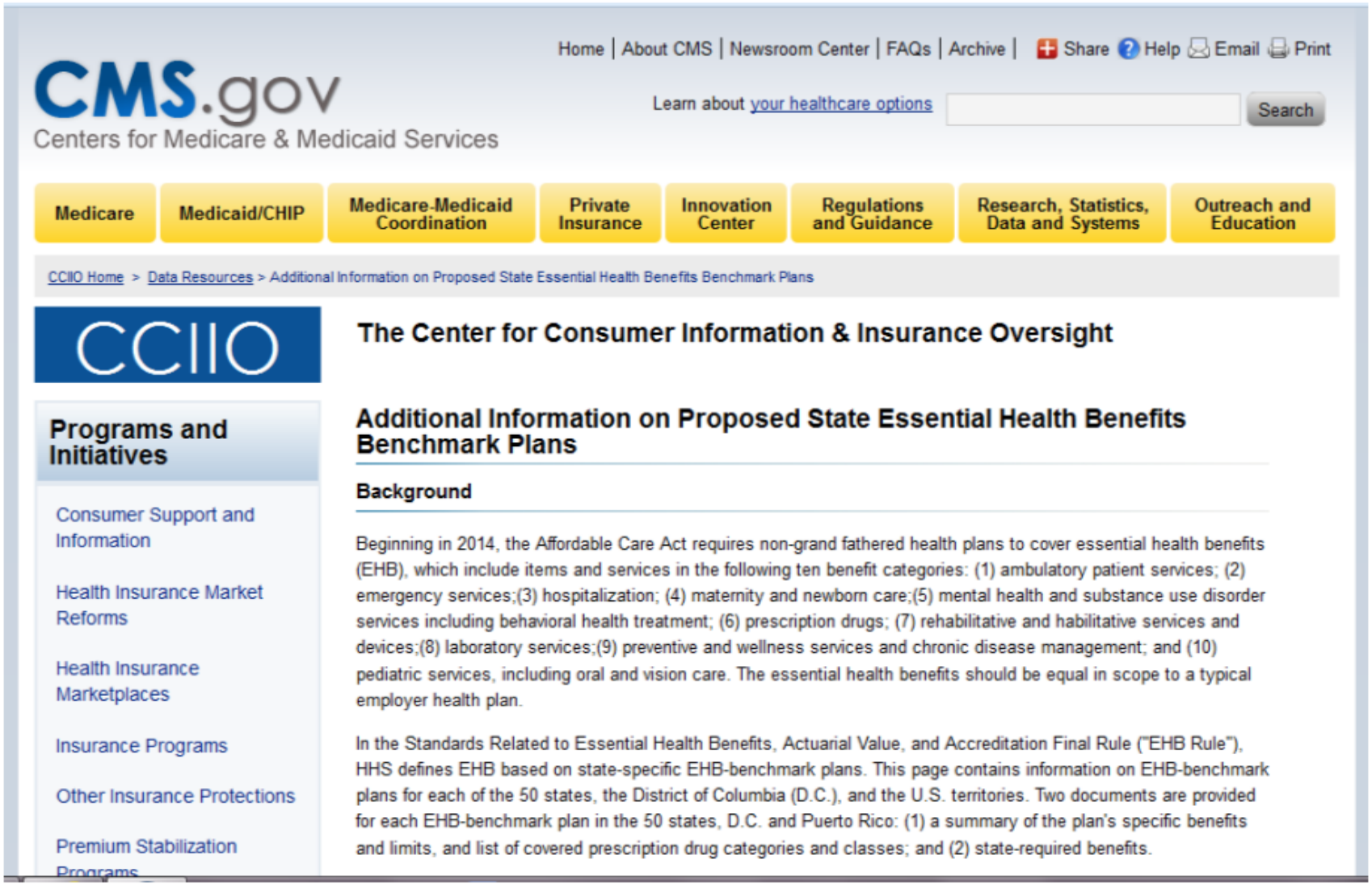
- Opened for enrollment Oct. 1, 2013
- Coverage began January 1, 2014
- Choice of different **individual** policies and **small group** plans (aka QHPs)
- Portal to **Medicaid/CHIP** eligibility determination (single application)
  - Open-ended enrollment for Medicaid and CHIP
- Help for consumers in choosing a plan – comparison website, call centers, navigators, assisters
- Tax credits and subsidies between 100%- 400% FPL

Essential Health Benefits (EHB)

- Went into effect January 1, 2014
- The ACA requires that individual and small group plans, including those offered through the Marketplace, include “essential health benefits”
- Also applies to Medicaid Alternative Benefit Plans (covering adult expansion population)
- 10 categories of health services were identified in the ACA (several specific to pediatrics)
- Private plans covering large groups and grandfathered plans are **exempt**, as are self-funded or ERISA plans.

Scope, duration and definition of the EHBs

- ACA as passed directed the Secretary of HHS to determine the **scope, duration** and **definition** of benefits under the broad EHB service categories
- 12/16/11 EHB Benchmark Bulletin
  - Instead of one standard benefit package for all state Marketplace and individual/small group plans, HHS authorized states to choose one of four kinds of current (2012) plans to use as a model or **benchmark....**



http://www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html

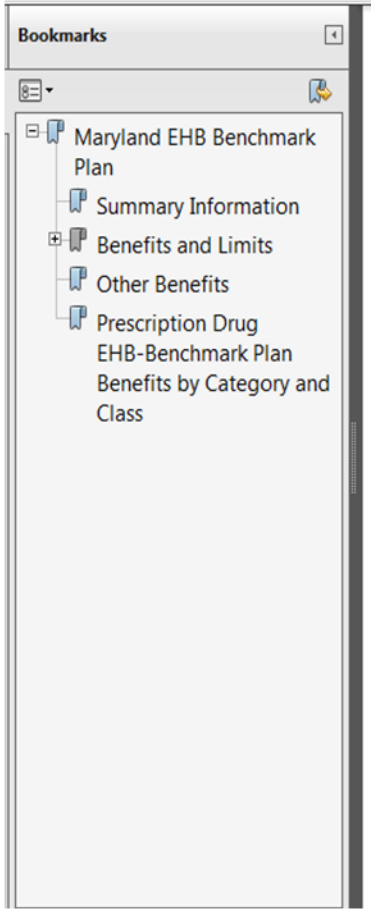
Summary of a benchmark plan

MARYLAND EHB BENCHMARK PLAN

SUMMARY INFORMATION

Plan Type	Plan from largest small group product, Health Maintenance Organization
Issuer Name	CareFirst BlueChoice, Inc.
Product Name	Blue Choice HMO HSA Open Access
Plan Name	Blue Choice HMO HSA Open Access
Supplemented Categories (Supplementary Plan Type)	• Pediatric Oral (State CHIP) • Pediatric Vision (FEDVIP)
Habilitative Services Included Benchmark (Yes/No)	Yes
Habilitative Services Defined by State (Yes/No)	Yes: Habilitative benefits in the State's EHB benchmark require plans to cover habilitative services benefits for members age 19 and above in parity with benefits covered for rehabilitative services.

Specific benchmark benefits and limits



Benefits and Limits

Row Number	A Benefit	B Covered (Required): Is benefit Covered or Not Covered	C Benefit Description (Required if benefit is Covered): Enter a Description, it may be the same as the Benefit name	D Quantitative Limit on Service? (Required if benefit is Covered): Select "Yes" if Quantitative Limit applies	E Limit Quantity (Required if Quantitative Limit is "Yes"): Enter Limit Quantity	F Limit Units (Required if Quantitative Limit is "Yes"): Select the correct limit units	G Other Limit Units Description (Required if "Other" Limit Unit): If a Limit Unit of "Other" was selected in Limit Units, enter a description	H Minimum Stay (Optional): Enter the Minimum Stay (in hours) as a whole number	I Exclusions (Optional): Enter any Exclusions for this benefit	J Explanation: (Optional) Enter an Explanation for anything not listed	K Does this benefit have additional limitations or restrictions? (Required if benefit is Covered): Select "Yes" if there are additional limitations or restrictions that need to be described
1	Primary Care Visit to Treat an Injury or Illness	Covered	PCP visit to treat an injury or illness	No							No
2	Specialist Visit	Covered	Specialist visit	No							No
3	Other Practitioner Office Visit (Nurse, Physician Assistant)	Covered	Other practitioner office visit	No							No
4	Outpatient Facility Fee (e.g., Ambulatory Surgery Center)	Covered	Outpatient Facility Services	No							No
5	Outpatient Surgery Physician/Surgical Services	Covered	Outpatient Surgery Physician/ Surgical Services	No							No
6	Hospice Services	Covered	Hospice Care	No							No
7	Non-Emergency Care When Traveling Outside the U.S.	Not Covered									
8	Routine Dental Services (Adult)	Not Covered									
9	Infertility Treatment	Covered	Infertility Services	No					In vitro fertilization, ovum transplants and gamete intra-fallopian tube transfer, zygote intra-fallopian transfer, or cryogenic or other preservation techniques used in these or similar procedures.		No

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Expanded pathway to coverage: Medicaid

- The ACA as passed required states to expand Medicaid income eligibility
- The required expansion and penalty for not complying was one of the questions the Supreme Court ruled on in 2012

What did the Supreme Court say?

- The individual mandate is a tax
- Congress has the power to levy taxes
- The law itself is constitutional. The provisions that had gone into effect remained in effect and those which were scheduled to roll out continued to do so
- There was one exception…..

Medicaid Expansion under the ACA

- Would have required all states to allow non-disabled, non-pregnant **adults** ages 19-64 to enroll – this is a **new population**
- It also raised the income level to 138% FPL for ALL populations (new & existing)
- The Supreme Court said the penalty to states for not complying was coercive
- The expansion is still allowed, but as a state option, not a requirement

NE state decisions on expanding Medicaid

State	Current Status of Medicaid Expansion Decision
Connecticut	Implementing Expansion in 2014
Maine	Not Moving Forward at this Time
Massachusetts	Implementing Expansion in 2014
New Hampshire	Implementing Expansion in 2014
Rhode Island	Implementing Expansion in 2014
Vermont	Implementing Expansion in 2014

Source: Kaiser Family Foundation, StateHealthFacts. Status of State Action on the Medicaid Expansion Decision, 2014. Retrieved 8/25/14 from

http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/

Expanding children's Medicaid income eligibility is NOT optional

- The Supreme Court's ruling applies only to the **new population** of adults
- Children are an existing Medicaid-eligible population; now, maximum family income has increased to 138% FPL in all states
- No change allowed in states with higher income eligibility levels till 2019 (MOE)
- Children in separate CHIP programs with family income <138% move to Medicaid

Policy implications re: ACA for CSHCN

- ACA offers historic reform opportunities, for example:
  - Improved access to **universal, continuous, affordable coverage** through the consumer protections and new and expanded pathways to coverage
- Simple coverage isn't enough – underinsurance has been and is predicted to remain a problem for CSHCN, including children with genetic disorders
- **Because the ACA doesn't do everything for everyone, work must continue on improving health care coverage and benefits for CSHCN**

State policy options for improving health care coverage and benefits for CSHCN

- Regarding the ACA:
  - Ensure monitoring, compliance and enforcement of consumer protection provisions
  - Promote ways for Medicaid, CHIP and the State Health Insurance Marketplace to target CSHCN in their outreach, enrollment and retention efforts
  - Ensure that CSHCN are identified and considered for needs-specific coverage at the time of application

Policy options re: the ACA continued

- Collaborate with families, advocates and pediatric providers in evaluating the Essential Health Benefits – HHS review planned for 2016
- Adopt the Section 2703 Health Home State Plan Amendment for Medicaid enrollees and ensure pediatric providers and populations are included

State policy options outside the ACA

- Ensure pediatric-specific, robust risk adjustment is included in new and existing plans
- Monitor and expand state mandated benefits
- Implement a Medicaid Buy-in program for children with disabilities whose families are over-income for Medicaid

State policy options outside the ACA continued

- Adopt the TEFRA Medicaid state plan option
- Create catastrophic relief and trust funds
- Implement premium assistance programs

Additional health care reform resources

- NEGC HCAF Workgroup policy brief
  - http://nhfv.org/wp-content/uploads/2013/09/NEGC-Policy-Report-final.pdf
- Catalyst Center at Boston University
  - hdwg.org/catalyst/resources
  - hdwg.org/catalyst/publications/aca
- State Family-to-Family Health Information Centers
  - fv-ncfpp.org/

Discussion and Questions

For more information, contact

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Thank you for attending!

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