

What Do Children and Youth With Special Health Care Needs Require From Health Care Reform?



HRSA/MCHB D-70 Grantees
Conference Call
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The Catalyst Center – Who Are We?

- **Funded by** the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services
- **A project of** the Health and Disability Working Group at the Boston University School of Public Health
- **The National Center dedicated to the Healthy People 2010 outcome measure:** "...all children and youth with special health care needs have access to adequate health insurance coverage and financing".

Our goals: to work with states and stakeholder groups on:

1. Covering more kids
2. Closing benefit gaps
3. Paying for additional services
4. Building capacity

What do we do?

The Catalyst Center:

- Creates resources (publications, topical conference calls, annual meetings)
- Answers TA questions about health care financing policy for CYSHCN
- Guides stakeholders to data sources outside our own work
- Connects those interested in working together to address complex financing issues

What can't we do?

- No direct advocacy for individuals or groups
- No lobbying

Who are children with special health care needs (CSHCN)?

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

How many children have special health care needs (CSHCN)?

- Over 10 million children and youth
OR
- Nearly 14% of the US child population under age 18

Unless otherwise noted, statistics in this presentation from the Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved 09/25/09 from www.cshcndata.org

Why is health care reform important to children with special health care needs?

There are major gaps in the current system that cause significant financial hardship for families and problems for children in accessing care....

Coverage statistics

- Private coverage alone = 60.3%
- Public coverage (Medicaid, SCHIP, etc.) = 28.6%
- Combination of private/public coverage = 7.5%
- Uninsured = 3.6%

TOTAL # of CSHCN with COVERAGE:
96.4%

But simple coverage
isn't the whole story....

Pathways to hardship

- **Uncovered medical expenses -**
 - 20% of US families report they spend more than \$1,000 per year on their child's medical expenses
- **Higher expenses for 'routine' things every family spends money on -**
 - 18.1% report their child's SHCN have caused financial problems for the family
- **Loss of employment income -**
 - Almost 23.8% report at least one adult having to stop working or cut back on work hours

When families are the payer of last resort....

- Medical debt is responsible for 62% of all bankruptcies (2007)

Medical Bankruptcy in the US: Results of a National Study, Himmelstein, D. , et al. American Journal of Medicine. Volume 122, Issue 8, Pages 741-746 (August 2009) Retrieved 09/28/09 [www.amjmed.com/article/S0002-9343\(09\)00404-5/abstract](http://www.amjmed.com/article/S0002-9343(09)00404-5/abstract)

When families are the payer of last resort, continued....

- Child does not receive needed services
- Family as a whole is affected – fewer funds for food, clothing, housing, etc.

Material Hardship in US Families Raising Children with Disabilities, Parish, S., et al. Exceptional Children, Vol. 75, No. 1, pages 71-92. Retrieved 9/27/09 from <http://bhrp.sowo.unc.edu/susanparish/files/2008%20Except%20Children%20material%20hardship.pdf>

So what is the solution?

Starting point is coverage that is:

- Universal and continuous
- Adequate
- Affordable

Universal, continuous coverage

- No coverage exemptions based on health status, age, national origin, or immigration status
- Safety net coverage for CSHCN whose parents experience a gap in coverage
- No waiting period for SCHIP or other public coverage for CSHCN

Universal, continuous coverage, continued

- Premium assistance based on family income for low income families
- Guaranteed issue and guaranteed renewability
- Transition coverage to allow CSHCN entering adulthood to remain on their family coverage

Adequate coverage

- Keep what is working intact – specifically, the Medicaid program; its provisions for Early Periodic Screening Diagnosis and Treatment (EPSDT) provides the breadth of coverage needed by CSHCN
- Extend EPSDT provisions to any expansion of coverage for CSHCN
- Ensure that a safety net option such as a Medicaid buy-in program is available **nationally** to CSHCN based on a sliding fee scale

Adequate coverage, continued

- Eliminate pre-existing conditions provisions
- Provide minimum creditable coverage
- Promote medical home

Affordable coverage

- Eliminate life-time benefit caps and implement reforms that include stop-loss coverage for catastrophic illness
- Cap annual deductibles **and** copayments at a reasonable level, based on family size and income
- Cap the difference in premium price among health insurance plans

Where can I learn about the components of the individual health care reform bills?

Two examples:

- Kaiser Family Foundation – publications and side-by-side bill comparisons

- <http://healthreform.kff.org/>

- Georgetown Center for Children and Families – publications and blog

- <http://ccf.georgetown.edu/index/publications-health-care-reform>

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THE HENRY J. KAISER FAMILY FOUNDATION

HEALTH CARE REFORM PROPOSALS

Achieving comprehensive health reform has emerged as a leading priority of the President and Congress. This summary of the Senate Finance Committee America's Healthy Future Act of 2009, the Senate HELP Committee Affordable Health Choices Act (S. 1679) and the House Tri-Committee America's Affordable Health Choices Act of 2009 (H.R. 3200) describes the key components of these leading health reform proposals. The House Tri-Committee summary incorporates the major amendments to the legislation adopted by the three committees of jurisdiction during their mark-ups of the bill. These amendments are identified using an abbreviation for the House panel that approved it – "E&C" for the Committee on Energy and Commerce, "E&L" for the Committee on Education and Labor, and "W&M" for the Committee on Ways and Means.

	Senate Finance Committee America's Healthy Future Act of 2009	Senate HELP Committee Affordable Health Choices Act (S. 1679)	House Tri-Committee America's Affordable Health Choices Act of 2009 (H.R. 3200)
Date plan announced	September 16, 2009 (passed by Committee October 13, 2009)	June 9, 2009 (passed by Committee July 15, 2009)	June 19, 2009
Overall approach to expanding access to coverage	Require most U.S. citizens and legal residents to have health insurance. Create state-based health insurance exchanges through which individuals can purchase coverage, with premium and cost-sharing credits available to individuals/families with income between 100-400% of the federal poverty level (the poverty level is \$18,310 for a family of three in 2009) and create separate exchanges through which small businesses can purchase coverage. Assess a fee on certain employers that do not offer coverage for each employee who receives a tax credit for health insurance through an exchange, with exceptions for small employers. Impose new regulations on health plans in the exchange and in the individual and small group markets. Expand Medicaid to all individuals with incomes up to 133% of the federal poverty level.	Require individuals to have health insurance. Create state-based American Health Benefit Gateways through which individuals and small businesses can purchase health coverage, with subsidies available to individuals/families with incomes up to 400% of the federal poverty level (or \$73,240 for a family of three in 2009). Require employers to provide coverage to their employees or pay an annual fee, with exceptions for small employers, and provide certain small employers a credit to offset the costs of providing coverage. Impose new regulations on the individual and small group insurance markets. Expand Medicaid to all individuals with incomes up to 150% of the federal poverty level.	Require all individuals to have health insurance. Create a Health Insurance Exchange through which individuals and smaller employers can purchase health coverage, with premium and cost-sharing credits available to individuals/families with incomes up to 400% of the federal poverty level (or \$73,240 for a family of three in 2009). Require employers to provide coverage to employees or pay into a Health Insurance Exchange Trust Fund, with exceptions for certain small employers, and provide certain small employers a credit to offset the costs of providing coverage. Impose new regulations on plans participating in the Exchange and in the small group insurance market. Expand Medicaid to 133% of the poverty level.

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SIDE-BY-SIDE OF MEDICAID, CHIP AND LOW-INCOME PROVISIONS TO HEALTH CARE REFORM PROPOSALS TO CURRENT LAW: HR 3200 America's Affordable Health Choices Act and America's Healthy Future Act

This side-by-side compares the Medicaid provisions in the House Tri-Committee, America's Affordable Health Choices Act (with key Committee amendments) and the Senate Finance America's Healthy Future Act (as modified on September 22, 2009) to current law. This analysis focuses on Medicaid coverage and financing changes; how Medicaid and CHIP interface with a new health insurance exchange; how subsidies for low-income individuals work and other Medicaid benefits and access changes. A more comprehensive side-by-side of health reform proposals can be found at: www.kff.org/healthreform/sidebyside.cfm

	Current Law	House Tri-Committee America's Affordable Health Choices Act	Senate Finance Committee America's Healthy Future Act
Date plan announced		July 14, 2009	Introduced September 14, 2009 (modified on September 22, 2009)
Status		Bill passed out of Ways and Means, Education and Labor, and Energy and Commerce Committees.	Mark-up of the Chairman's Mark is scheduled to begin September 22, 2009.
Overall approach to expanding access to coverage		Requires most individuals to have health insurance through a combination of public and private coverage expansions. Expands Medicaid to 12% of the poverty level and provides premium and cost-sharing credits to individuals/families with incomes up to 400% of poverty and not eligible for coverage through Medicaid or employers to purchase health coverage in a new Health Insurance Exchange in 2014.	Requires most individuals to have health insurance through a combination of public and private coverage expansions. Provides premium credits to individuals and families with incomes between 120-400% FPL in 2010, and including individuals and families with incomes between 100-120% FPL in 2014, to purchase insurance through the Health Insurance Exchanges. Expands Medicaid to 13% of the poverty level in 2014 and CHIP eligibility to all children up to 205% of poverty.
Medicaid and CHIP Coverage Changes			
Medicaid eligibility for children, pregnant women, parents and individuals with disabilities (traditional Medicaid eligibles)	Individuals must meet categorical and income standards to be eligible for Medicaid. The federal government sets minimum eligibility standards and states have flexibility to expand coverage beyond these minimum levels for most groups. In general, states also have flexibility to determine income and resource methodologies for purposes of determining Medicaid eligibility.	<ul style="list-style-type: none"> Establishes a minimum Medicaid coverage threshold for all children, parents and individuals with disabilities under age 65 (Traditional Medicaid Eligible Individuals) up to 120% FPL (with no resource test) in 2010. States that currently cover children between 100% and 120% FPL under a separate CHIP program would be required to shift that coverage to Medicaid. 	<ul style="list-style-type: none"> Establishes a minimum Medicaid coverage threshold for all children and parents with incomes up to 120% FPL. Starting January 1, 2014. Existing law does not change for pregnant women. Effective January 1, 2014, eligibility would be based on modified adjusted gross income (MAGI) without income disregards except for groups eligible through another program like foster care, low-income Medicare beneficiaries and Supplemental Security Income (SSI).

MEDICAID AND CHILDREN'S HEALTH INSURANCE PROGRAM PROVISIONS: America's Affordable Health Choices Act & America's Healthy Future Act
Last Modified: September 24, 2009

Where can I learn more about health care reform advocacy?

Resources from external policy analysis/advocacy groups – three of the best!

- Community Catalyst http://www.communitycatalyst.org/projects/national_reform
- Families USA <http://www.familiesusa.org/>
- Family Voices <http://www.familyvoices.org/>

Catalyst Center Resources

- *Breaking the Link Between Special Health Care Needs and Financial Hardship*
- Health Care Reform Briefs:
 - *Essential Components of HCF for CSHCN*
 - *What Do CSHCN Require from HCF?*
 - *HCF and CSHCN: Coverage is Not Enough*

Other Catalyst Center resources

- *Medicaid as a Second Language*
- *Frequently Asked Questions about the Family Opportunity Act's Medicaid Buy-in Option*
- *Online State-at-a-glance Chartbook on Coverage and Financing of Care for Children and Youth with Special Health Care Needs (state pages)*

Summary:
For CSHCN, health care reform must.....

- Provide protections for families against financial hardship and medical debt
- Give CSHCN access to quality health care so that they can LEARN, PLAY and GROW to their fullest potential!

Questions?

For more information, contact:

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