NEW ENGLAND CHILDREN WITH GENETIC DISORDERS & HEALTH CARE REFORM

Information and Recommendations for State Policymakers

negc THE NEW ENGLAND GENETICS COLLABORATIVE

This document is available in alternative formats upon request.

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Acknowledgments

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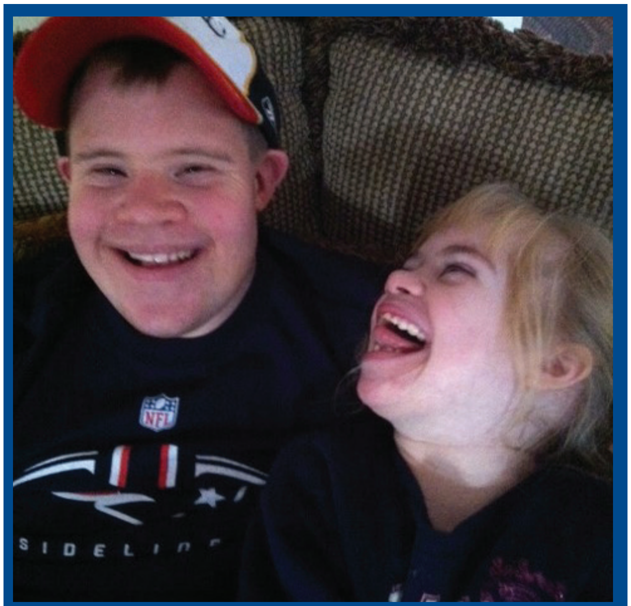
Executive Summary

Children with genetic disorders experience gaps in insurance coverage and benefits that put their health and well-being in jeopardy and their families at risk for overwhelming medical debt. Readers are encouraged to learn about some of the strengths and limitations of current health insurance policy as it relates to children with genetic disorders, as well as the multiple opportunities available to improve coverage and care for children with genetic disorders while reducing long term physical, social, and financial costs.

The majority of children with genetic disorders require an array of medical, behavioral and/or developmental health services. Insurance coverage is the primary gateway to health care; while it doesn't guarantee access, few families can afford the health care their children need without it. ***Being uninsured or underinsured can prevent children with genetic disorders from accessing the specialized and often expensive health care services they require, posing a serious threat to the child's health and well-being and their family's financial stability.*** Even children who do have health insurance may not have all their needs covered because of limitations in the duration and scope of benefits, high cost sharing, and other factors. ***The National Survey of Children with Special Health Care Needs (2009/10) tells us that while the majority of children with special health care needs (CSHCN) in the New England states have insurance (98.9% at the time of the survey), approximately a third (33.3%) have insurance that is inadequate, and 18.7% report that the child's health condition(s) cause financial problems for the family. In addition, 23.6% of New England families of children with special health care needs report spending $1,000 or more per year out-of-pocket on medical expenses for their child.***



Brendan & Courtney

Down Syndrome

The Patient Protection and Affordable Care Act of 2010 (Pub. L. 111-148) or ACA, which was signed into law on March 23, 2010, holds significant promise in expanding access to health care coverage. However, its primary focus is on reducing uninsurance, not on addressing the many gaps in care experienced by children with genetic disorders prior to the ACA. Most children with special health care needs, including those with genetic disorders, currently have insurance. A more prevalent problem is underinsurance, or having insurance coverage that does not meet the needs of the child. Typical examples of underinsurance include lack of coverage for medically prescribed, modified foods and formulas for children with metabolic disorders and applied behavioral analysis (ABA) treatment for children with autism spectrum disorders.

The health care reform law's consumer protection provisions should provide relief from many of the barriers to coverage and benefits gaps which impact children with genetic disorders. ***However, not every provision, including the essential health benefits, applies to every kind of policy or plan*** – large group, grandfathered and/or self-funded plans are sometimes exempt from a particular provision, so gaps will still exist. Additionally, since current insurance plans are largely based on previously implemented plans, major gaps in benefits are expected to continue. These include potential limits on the number of services an individual can receive as well as the type of medication that may be covered by insurance providers.

The urgent need to expand current strategies and promote new ones that both increase coverage and enhance benefits is more relevant than ever, especially in these times of economic vulnerability for families, providers and states and health care systems transition and transformation. The following is a list of policy recommendations, many of which have a proven track record of success in improving health insurance coverage and financing of care for children with special health care needs, including those with genetic disorders.

Under the ACA[i]

- Ensure monitoring, compliance and enforcement of consumer protection provisions;
- Promote ways for Medicaid, Children's Health Insurance Program (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;
- Collaborate with families, advocates and pediatric providers in evaluating the Essential Health Benefits;
- Adopt the Section 2703 Health Home State Plan Amendment for Medicaid enrollees and ensure pediatric providers and populations are included.

Other Policy Options

- 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;
- Adopt the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) Medicaid state plan option;
- Create catastrophic relief and trust funds;
- Implement premium assistance programs.

For far too long, many children with genetic disorders have experienced gaps in health insurance coverage and benefits, keeping them from the care they need to learn, grow and thrive. Their families have been at risk for overwhelming medical debt and financial hardship, adding to the stress of raising a child with a serious medical condition. The federal health care reform law offers hope in addressing some of the problems they have faced. State policymakers must be ready to take advantage of the opportunities created by the ACA for reducing barriers to universal and continuous, affordable coverage and adequate benefits. They must also be aware of, and prepared to act on, other policy strategies that can fill in the gaps that are predicted to continue under the ACA, most notably in the area of underinsurance. The following material offers a brief overview of what genetic disorders are and how children are impacted by insurance gaps and barriers. It describes the opportunities for improving coverage and benefits for children with genetic disorders under the ACA, as well as potential challenges that may remain. An array of recommendations for how gaps and barriers can be addressed using other policy strategies is included. It offers data from a survey of New England families of children with genetic disorders and closes with a list of resources for both policymakers and consumers.

NEW ENGLAND CHILDREN WITH GENETIC DISORDERS

What is a genetic disorder?

Our bodies are made up of a variety of different kinds of cells. Each of these kinds of cells has a specific task to carry out in order for the whole body to function properly. Each cell has 23 pairs of chromosomes in it. Each chromosome is made up of many genes. How do the cells know what to do to function properly? They get their instructions from the proteins made by genes. There are tens of thousands of genes in each individual cell.

A genetic condition or disorder occurs when there is a change, called a mutation, in the chemicals or DNA that make up genes. The impact of genetic changes on a person's health depends in part on the type of change and in what kind of gene it occurs. There are single-gene disorders, like cystic fibrosis. Another category is chromosomal abnormalities, like Down syndrome. Finally, multifactoral genetic disorders, like some instances of breast cancer, occur when there are changes in more than one gene. These can interact with or be influenced by environmental factors.

Who are children with genetic disorders?

It is challenging to talk about children with genetic disorders in broad terms, in part because genetic disorders are scattered across such a wide array of specific diagnoses. Some, like cystic fibrosis (1 in 3,700 live births[ii]) and Down syndrome (1 in 691 live births[iii]), are more common than others, but many are rare. To date, more than 15,000 genetic conditions have been identified and catalogued[iv]. It is certain that you, or someone close to you, know and care about a child with a genetic disorder.

What do we know currently about children with genetic disorders and gaps in their health insurance coverage and benefits?

The majority of children with genetic disorders require an array of medical, behavioral and/or developmental health services. Insurance coverage is the primary gateway to health care; while it doesn't guarantee access, few families raising children with genetic disorders can afford health care without it. Being uninsured or underinsured can prevent children with genetic disorders from accessing the specialized and often expensive health care services they require, posing a serious threat to the child's health and well-being and their family's financial stability. Even children who do have health insurance may not have all their needs covered because of limitations in the duration and scope of benefits, high cost sharing, and other factors. Uninsurance and underinsurance leave children at risk for poor health outcomes, preventable disability and developmental delay, and their families with significant financial burdens.

For example, if not maintained on a strict low protein diet, children with the genetic disorder Phenylketonuria or PKU (1 in 10,000 – 15,000 live births[v]) incur brain damage resulting in severe intellectual and behavioral disability. Foods modified to be low in protein, and special medical formulas are essential treatments, but often are uncovered by health insurance. The benefit of the treatment to individuals, families and society far outweighs its financial cost. Treatment with

> *"It takes more than 6 months to get denied for these services. Watching your child try to walk without braces and not be able to afford to get her the equipment immediately is a nightmare. The same holds true for the wheelchair. We purchased our own carriage (way too small for our child over age 12) just to get by."*
>
> - Quote from a parent respondent

medical foods and formulas allows children with PKU to develop, and become contributing members of the community as adults, while lack of treatment results in unavoidable intellectual and behavioral disability and creates a life-long financial responsibility for society.

As noted previously, it is difficult to generalize when discussing the health care coverage needs of children and youth with genetic disorders. There is no single source that collects data on all individuals affected by the thousands of different genetic diseases and disorders in a systematic way. However, the National Survey of Children with Special Health Care Needs (2009/10) does offer relevant data with regard to children with special health care needs (CSHCN)[vi] in general, and we can make some assumptions from this data with regard to children with genetic conditions, since they are represented among the CSHCN population.

HEALTH CARE REFORM – OPPORTUNITIES AND CHALLENGES

The Patient Protection and Affordable Care Act of 2010 (Pub. L. 111-148) or ACA, which was signed into law on March 23, 2010, holds significant promise in expanding access to health care coverage and in turn, access to health care itself. However, its primary focus from a consumer perspective is on reducing uninsurance. As shown in Table 1, most children with special health care needs currently have insurance (96.4%). A more prevalent problem faced by children with special health care needs, including those with genetic disorders, is underinsurance, as shown in Table 2 (34.3%). Examples of underinsurance include lack of coverage for medically prescribed foods and formulas for children with metabolic disorders (see above) and applied behavioral analysis (ABA) treatment for children with autism spectrum disorders.

Table 1. Insurance Coverage Type

Insurance Coverage Type for CSHCN	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 & 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 (2009/10). Retrieved 6/18/13 from http://www.childhealthdata.org

BREAKING DOWN BARRIERS TO COVERAGE AND BENEFITS

Consumer Protections in the ACA or the "Patient's Bill of Rights"

There are two primary ways the ACA is designed to reduce uninsurance: 1) reducing barriers to existing coverage options, and 2) opening new pathways to coverage, or expanding existing ones. The signature provisions in the ACA aimed at reducing barriers are known as the consumer protections or "Patient's Bill of Rights". However, not every provision applies to every kind of policy or plan – large group, grandfathered and/or self-funded plans are sometimes exempt from a particular provision, so gaps may still exist.

The following are examples from the Patient's Bill of Rights with direct relevance to children with genetic disorders:

- Prohibition against denying coverage to anyone based on a **pre-existing condition**. (Applies to all plans except individual grandfathered plans.)
- **Dependent coverage** for youth up to age 26 on their parent's plan, effective 2010. (Applies to all plans)
- No **rescission** of coverage regardless of the

cost or amount of services used, effective 2010. Private insurance companies are no longer permitted to look for excuses to cancel an enrollee's coverage when he or she gets sick or hurt. (Self-funded plans are exempt.)

- **Guaranteed issue** and **guaranteed renewal**, effective 2014. Private insurance companies must enroll anyone who is eligible and must renew coverage for those who remain eligible. (Individual and group grandfathered plans, as well as self-funded plans are exempt.)
- **Prohibition against discrimination** based on health status: explicitly lists "genetic information" among the health status factors that cannot be used in considering eligibility or coverage, effective 2014. (Applies to all plans.)
- **Annual and Lifetime Benefit Limits** (only individual grandfathered plans are exempt.)
    - No annual benefit cap in dollar amounts permitted

Table 2. Factors Influencing Insurance Coverage, Access to Care and Impact on Families

Prevalence	CT	MA	ME	NH	RI	VT	US
Total # of children	806,847	1,430,569	273,494	287,072	226,543	127,219	74,338,575
Estimated # of CSHCN	139,453	261,475	53,122	54,569	39,170	21,790	11,203,616
% of children who have special health care needs	17.3	18.3	19.4	19.0	17.3	17.1	15.1
Health Insurance Coverage	**CT**	**MA**	**ME**	**NH**	**RI**	**VT**	**US**
% of currently insured CSHCN whose insurance is inadequate	38.5	33.7	26.3	28.9	31.3	27.6	34.3
Access to Care	**CT**	**MA**	**ME**	**NH**	**RI**	**VT**	**US**
% of CSHCN with any unmet need for specific health care services	18.0	20.0	24.3	18.3	19.1	20.9	23.6
Impact on Family	**CT**	**MA**	**ME**	**NH**	**RI**	**VT**	**US**
% of 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
% of CSHCN whose conditions cause financial problems for the family	18.8	19.1	18.6	19.6	14.7	17.3	21.6
% of 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 (2009/10). Retrieved 6/18/13 from http://www.childhealthdata.org

- No lifetime benefit caps in dollar amounts permitted

While dollar amounts are no longer allowed to be capped, it is important to note that benefits or services can still be, thereby potentially limiting access to critically needed care (e.g. 15 physical therapy visits per episode of care, 15 mental health sessions per year). These benefit caps, while typically meeting the acute care needs of the general population, were not designed to meet the needs of individuals living with genetic conditions needing more intensive, long-term care.

EXPANDING COVERAGE OPTIONS

State Medicaid Expansion

The Medicaid expansion provision, as passed under the ACA in 2010, would have required all states to allow non-disabled, non-pregnant adults ages 19-64, with income under 138% of the federal poverty level (FPL),[vii] to enroll beginning in 2014. This provision included an expansion of both income and population eligibility (adults). Prior to the passage of the law, non-disabled, non-pregnant adults were generally ineligible for Medicaid, regardless of income. In the summer of 2012, the Supreme Court, in its ruling on the constitutionality of the ACA, said that the penalty to states for not complying with the Medicaid expansion provision was coercive and therefore unconstitutional. Under the Supreme Court ruling, the expansion for adults is still allowed, but as a state option, not a requirement (Table 3).

Expanding children's Medicaid income eligibility under the expansion to at least 138% of the FPL is NOT an option. The

Table 3. Status of State Action on the Medicaid Expansion Decision, as of January 28, 2014

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: Status of State Action on the Medicaid Expansion Decision, 2014. Retrieved 4/8/14 from http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/

Table 4. State Medicaid and CHIP Income Eligibility Standards Effective January 2014 as a Percentage of the Federal Poverty Level (FPL)

State	Medicaid ages 0-1 (% FPL)	Medicaid ages 1-5 (% FPL)	Medicaid ages 6-18 (% FPL)	Separate CHIP – all ages (% FPL)
Connecticut	196	196	196	318
Maine	191	157	157	208
Massachusetts	200	150	150	300
New Hampshire	318	318	318	n/a
Rhode Island	261	261	261	n/a
Vermont	313	313	313	312

Source: Centers for Medicare and Medicaid Services (CMS), State Medicaid and CHIP Income Eligibility Standards Effective January 1, 2014, for MAGI groups, based on state decisions as of October 24, 2013. Accessed January 29, 2014.

> *"Our insurance does not cover all the DME (durable medical equipment) we require. The premiums are expensive and the deductible is very high. Thank goodness for Medicaid as his secondary (source of supplemental coverage). Doctor visits and specialty care is covered. (A special state program) sometimes covers things that the insurance did not, such as a manual (or back-up) wheelchair. That program will go away next year."*
>
> - Quote from a parent respondent

Supreme Court's ruling applies only to the new population of non-disabled, non-pregnant adults. Low income children were an existing Medicaid-eligible population, so in 2014, maximum family income for kids, including those with genetic disorders, increased in every state to 138% of the FPL[viii] (Table 4). In addition, children in separate Children's Health Insurance Programs (CHIP) with family income of less than 138% of the FPL will move to Medicaid, which offers more comprehensive benefits and lower cost-sharing.

THE STATE HEALTH INSURANCE MARKETPLACES (THE "EXCHANGES") – AN OVERVIEW

As called for under Sections 1302 and 1311 of the ACA, each state now offers access to a Health Insurance Marketplace or Exchange, with coverage beginning January 1, 2014 for those enrolled. The goal of the Marketplaces is to provide a centralized location where consumers can easily compare and apply for affordable health coverage – making buying health coverage in the individual and small group markets easier and more affordable. Through the Marketplace, individuals and small businesses shopping for insurance coverage will be able to compare the benefits and cost-sharing requirements in the qualified health plans, get help with their questions, find out if they are eligible for tax credits and/or premium assistance or other coverage like the CHIP, and enroll in a health plan of their choice. The ACA requires everyone who can afford it to have health insurance starting in 2014, and the Marketplaces are one mechanism designed to help ensure both the accessibility and affordability necessary to meet the requirement.

THE ESSENTIAL HEALTH BENEFITS – POTENTIAL AND CONCERNS

For the first time under the ACA, federal law requires that individual and small group plans (whether offered through the Marketplaces or not) include "essential health benefits" (EHBs). *It is important for policymakers, consumers and others to note that plans covering large groups and grandfathered plans are exempt from the EHBs, as are self-funded (ERISA) plans.*

The following are the benefit design requirements under the ACA for the EHBs:

- The scope of benefits must reflect those covered by a "typical" employer plan. This raises a concern, since we know from the National Survey of Children with Special Health Care Needs data cited at the beginning of this paper that in 2009/10, 34.3% of families reported their child's coverage was inadequate in meeting their health care needs. Adhering to this requirement, which builds the EHBs on what is already available, runs the risk of replicating existing gaps in the new plans and policies. Work commissioned by the American Academy of Pediatrics further illuminates this concern[ix]. It looked at a representative sample of current plans that met the benchmark criteria and found the following:

  - The federal employee health benefits plans offers the most comprehensive benefits for children,
  - With some limited exceptions, small group plans offer the least comprehensive, with the highest cost-sharing,
  - Small group plans are likely to include state mandated benefits – many of which are important to specific sub-populations of CSHCN, like children with genetic disorders, and
  - NONE of the benchmark plans approach the Medicaid child benefit package (also known as Early, Periodic Screening, Diagnosis and Treatment or EPSDT) or those offered in separate CHIP programs in terms of benefits or cost-sharing.
- In determining the scope, duration and definition of the EHBs, policymakers cannot "make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life".
- The EHBs must take into account the health needs of diverse population groups, including children.
- The benefits must be balanced among the 10 required service categories described in the ACA, which include:
  - 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, and
  - Mental health and substance abuse services, including behavioral health.

Sophia

Tuberous Sclerosis

The Benchmark Plan Approach

Not every health service under the ten broad benefit categories is essential for everyone. For children with genetic disorders, however, access to unusual and/or expensive health services may make the difference between life and death. One of the biggest challenges in determining the EHBs was balancing robust, comprehensive coverage that pays for what people need, including those with special health care needs, chronic conditions and disabilities, all while remaining affordable for the population in general. Striking that balance between comprehensiveness and affordability is a significant challenge that states, advocates and insurers have all been wrestling with.

After careful consideration, in December of 2011 it was decided that instead of one standard EHB package for all state Marketplace and individual policies/small group market plans, the US Department of Health and Human Services (HHS) authorized states to choose one of the following four kinds of plans to use as a model or benchmark, to build their state-specific EHBs on:

Table 5. New England State Benchmark Plan Overview[x]

State	CT	MA	ME	NH	RI	VT
Plan Type	Largest HMO	Largest Small Group (HMO)	Largest Small Group (PPO)	Second Largest Small Group (HMO)	Largest Small Group (PPO)	Largest Small Group (HMO)
Plan Name	Connecticare HMO	Blue Cross/ Blue Shield of MA HMO Blue 2000 Deductible	Anthem Blue Cross/ Blue Shield Blue Choice 20 with Rx 10 30 50 50	Anthem Blue Cross/ Blue Shield Matthew Thornton Blue Health Plan	Blue Cross/ Blue Shield of RI Vantage Blue	BlueCare, The Vermont Health Plan, LLC, CDHP
Supplemented Categories – Pediatric Oral Health	State CHIP	State CHIP	FEDVIP	FEDVIP	FEDVIP	State CHIP
Supplemented Categories – Pediatric Vision	FEDVIP	n/a	n/a	FEDVIP	FEDVIP	FEDVIP
Habilitative Services Included in Benchmark?	No	Yes	Yes	Yes	No	No
Habilitative Services Defined by State?	No	n/a	n/a	n/a	Yes	No

Chart Key:

- State CHIP = the state's Children's Health Insurance Program
- FEDVIP = Federal Employees Dental and Vision Insurance Plan
- Source: State Summaries, Additional Information on Proposed State Essential Health Benefit Benchmark Plans, The Center for Consumer Information & Insurance Oversight, Centers for Medicare and Medicaid Services, US Department of Health and Human Services (2013). Retrieved 7/30/2013 from http://www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html

- Any of the three largest small-group plans in the state by enrollment;
- Any of the three largest state employee health plans by enrollment;
- Any of the three largest federal employee health benefits program plan options by enrollment; OR
- The largest insured commercial non-Medicaid HMO plan operating in the state.

Of these benchmark plans, 20 states chose a small group plan, 5 chose the largest non-Medicaid HMO and 3 chose a state employees health plan (see Table 5 for the New England states' choices). No state chose the federal employee health plan option as its benchmark plan. The list of ten service categories includes pediatric vision and pediatric oral health services, which are typically not included in traditional private insurance plans. States were required to supplement their benchmark coverage in order to meet this requirement. Seven states had pediatric vision services included in their benchmark plan but the other forty-two chose to supplement this service using the federal employee health plan, and two chose to use their state's CHIP program. For pediatric oral health services, 31 chose the federal employees health plan and 19 used CHIP. Only one found oral health services for children already included in the benchmark plan selected.

State Mandated Benefits and the EHBs

Mandated benefits are laws requiring some private insurers to cover specific health care benefits or services. Self-funded plans, sometimes known as ERISA plans, are exempt from state mandated benefit laws. They are also exempt from the EHBs. State governments generally issue mandated benefit regulations, although there is a handful of mandated benefits required by the federal government. Every state mandates at least some specific health services, or in some cases the availability of certain kinds of providers, or the extent of available coverage. There is great variability in the number, and also variety in the kinds of state mandated benefit laws currently on the books in the individual states.

Under the ACA, states must cover the cost of their mandated benefits that go beyond the EHBs. Rules issued after the ACA was passed confirm that mandated benefit laws that were in place before 12/31/11 are considered part of the EHBs, so there will be no additional cost to states for them. This is good news for legislative champions, families and advocates who worked hard to get mandated benefit laws in place for specific, often rare and/or expensive services. (Note that only mandated benefits that directly impact care, treatment or services apply to the EHB inclusion rule – not other kinds, like service provider or dependent type, for example.)

Preventive Services

All new plans effective after September 23, 2010 must cover the preventive services listed below without cost-sharing. Under Section 2713, the following recommendations and guidelines must be covered without co-pays, co-insurance or deductibles being charged or collected:

Dani

22q Deletion Velocardiofacial

- **Recommendations of the United States Preventive Services Task Force (USPSTF)** http://www.uspreventiveservicestaskforce.org/recommendations.htm (including BRCA screening and counseling for women at high risk of breast cancer; Congenital hypothyroidism screening for newborns; Hemoglobinopathies or sickle cell screening for newborns; PKU newborn screening)
- **Recommendations of the Advisory Committee on Immunization Practices (ACIP) adopted by CDC** http://www.cdc.gov/vaccines/hcp/acip-recs/index.html
- **Bright Futures: Comprehensive Guidelines Supported by the Health Resources and Services Administration (HRSA)** http://www.aap.org/en-us/professional-resources/practice-support/periodicity/periodicity%20schedule_FINAL.pdf (including Autism and developmental screening; Newborn metabolic/hemoglobin screening)
- **HRSA's Women's Preventive Services: Required Health Plan Coverage Guidelines** http://www.hrsa.gov/womensguidelines/
- **Recommendations of the Secretary's Advisory Committee on Heritable**

Disorders in Newborns and Children
http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendedpanel/uniformscreeningpanel.pdf

WHAT DO NEW ENGLAND FAMILIES OF CHILDREN WITH GENETIC DISORDERS SAY ABOUT HEALTH INSURANCE COVERAGE AND BENEFIT GAPS? FINDINGS FROM AN ONLINE SURVEY

As discussed previously, it is difficult to know exactly what and how gaps in health insurance coverage and benefits impact children with genetic disorders, because they are scattered across such a wide array of specific diagnoses and no single source collects data on the full population. In order to get a better understanding of the impact of the ACA on children with genetic disorders and how reform efforts might be improved upon, information on where the population stood prior to full implementation is needed. In 2012, the Health Care Access and Financing Work group (HCAF) of the New England Genetics Collaborative designed and implemented an online survey of families of children with genetic disorders living in the six New England states. The questions in the survey were based on the essential health benefit categories in the ACA (with the addition of medically prescribed foods and formulas) and were intended to identify specific benefits gaps for children with genetic disorders. The survey asked what kind of health insurance coverage a child had and if specific services, when needed, were covered in full, in part, or not at all.

Information about the survey was distributed to families in December 2012, through a network of state family advocacy organizations, including Family Voices, the Family-to-Family Health Information Centers and select condition-specific organizations in each New England state. Although parents from all six New England states participated, a significant limitation on the findings was the use of non-random sampling with 43 of the 95 respondents representing family perspectives from New Hampshire. As a result, we cannot write definitively about all the gaps experienced by families in the region. We can, however, shed some light on the kinds of gaps that exist and the impact that this can have at the family level. (See Appendix 5 for a statistical chart of the survey results.)

Key findings from the online survey

Outpatient services, care for emotional, behavioral or substance abuse issues, prescription drug coverage, rehabilitative and habilitative therapies, medical devices, pediatric services like developmental screenings, and prescribed medical foods were identified as particularly challenging areas of underinsurance. Even when a particular service appears to be covered, limitations on services or the type of medical support that is provided can have far reaching negative impacts. For example, many children with genetic disorders metabolize medications in unique ways; the difference between being able to access a brand name drug versus a generic at a reasonable cost may have direct clinical implications for its efficacy and safety.

Families reported cost as a major problem. High deductibles, co-pays and co-insurance were noted in almost every category. This data is consistent with findings previously

> *"Our insurance company will not pay for occupational therapy that is necessary and very expensive. The insurance company claims it is covered but will not share the "diagnostic codes" needed for approval. After many rejections we gave up."*
>
> - Quote from a parent respondent

Amarey

Sickle Cell Disease

published in the academic literature.[xi xii xiii] Gaps in benefits and high cost-sharing have serious consequences for the health and well-being of children and their families' financial stability. A study published in the journal Pediatrics in 2005 showed a strong association between adequate insurance coverage and access to care.[xiv] Children with special health care needs who were underinsured (had gaps in their benefits) were significantly more likely than fully insured children to have unmet health needs, and their families were more likely to report difficulty in obtaining specialty referrals and to experience financial problems.

Examples of other uncovered supports and services that parents reported were essential to their child's care, but which weren't asked about specifically in the survey because they are not strictly medical benefits, included:

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

Policy Implications

The ACA offers historic opportunities for expanding access to universal, continuous, affordable coverage through the state Health Insurance Marketplaces. It contains significant and meaningful consumer protections in the private insurance market, under the Patient's Bill of Rights provisions.

It does not do everything for everyone, for example:

- The Essential Health Benefits are built on existing coverage, potentially replicating gaps in benefits
- It creates economic pressure to standardize care at minimum cost for the general population, putting limits on the types and number of medical supports that can be offered - even when these restrictions are not in the best interests of the long term health outcomes for individual children with genetic conditions

The need for policymakers to take action to improve underinsurance for children with genetic disorders is critical. The following section provides a list of policy recommendations that have a proven track record of success in improving health insurance coverage and financing of care for children with special health care needs, including those with genetic disorders:

Policy Recommendations

Under the ACA[xv]

- **Ensure monitoring, compliance and enforcement of consumer protection provisions**

Many of the new consumer protections against discrimination in the ACA will have a direct, positive impact on children with genetic disorders, but only if insurance companies comply with them. States must ensure that there is meaningful monitoring to pick up on instances of non-compliance with the law and be prepared to follow up with strict enforcement if it does occur. Well-publicized and accessible lines of communication for families to report non-compliance must be available, as well as "plain language" education of consumers on their new rights and responsibilities under the ACA.

- **Promote ways for Medicaid, CHIP and the State Health Insurance Marketplace to target CSHCN in their outreach, enrollment and retention efforts**

State Medicaid programs are required under the ACA to make sure that vulnerable populations like CSHCN are included in outreach, enrollment and retention efforts. Partnering with state Title V CSHCN programs, the New England Genetics Collaborative, genetics clinics, state chapters of the American Academy of Pediatrics and the American Academy of Family Physicians, family leadership organizations like Family Voices and the state Family-to-Family Health Information Centers and diagnosis-specific advocacy and education groups can provide effective and efficient pathways to reaching families. Soliciting the input of these knowledgeable stakeholders in creating and formatting applications, notices, family education materials and other communication tools can help ensure they are culturally and linguistically accessible and meet the needs of the target population.

- **Ensure that CSHCN are identified and considered for needs-specific coverage at the time of application**

The ACA contains some promising new coverage options, including plans to be offered through the state Health Insurance Marketplaces that will include the Essential Health Benefits (EHBs) and the option for expansion of Medicaid income eligibility. Existing pathways to Medicaid coverage for children with genetic disorders and other special health care needs through diagnosis or functional limitations will continue to play an important role in getting and keeping them covered. Because of its robust set of childhood benefits[xvi] and limited cost-sharing, Medicaid is an especially important coverage option for children with genetic disorders. Incorporating methods of identifying CSHCN at the time of application, like using screener tools[xvii], can help ensure they are not only brought into coverage, but they are brought into and retain under the right coverage for their needs.

- **Collaborate with families, advocates and pediatric providers in evaluating the EHBs**

While the benchmark plans that the EHBs will be modeled on have already been chosen, the US Department of Health and Human Services (HHS) plans to evaluate this approach in 2016, once the plans modeled on the benchmark have been in effect for two years. Collecting qualitative and quantitative data on how they are working for children with genetic disorders and their families starting in 2014 will help ensure that future efforts to improve the EHBs are based on evidence.

Resource: Your Questions on the Essential Health Benefits Bulletin Answered (June, 2012) http://hdwg.org/catalyst/ehb

- **Adopt the Section 2703 Health Home State Plan Amendment for Medicaid enrollees and ensure pediatric providers and populations are included**

Section 2703 of the ACA is a way for states to promote and advance implementation of the medical home model - the evidence-based best practice for delivering primary care – for Medicaid enrollees with chronic illnesses. It is also a way for states to receive enhanced

> *"Our insurance finally covers this - but it was a two year fight to get her medical formula covered. Every so often, they deny something they have covered for years and we have to jump through some hoops to regain coverage."*
>
> - Quote from a parent respondent

federal matching funds to provide payment for core services that benefit individuals with chronic conditions. These services include: care management; care coordination; health promotion; transitional care from inpatient to other settings; individual and family support; and referral to community and support services. States that implement this optional Medicaid state plan amendment will receive a 90% federal match for the first two years the program is in operation.

Resource: Webinar: Children and the Medicaid Health Home State Plan Option http://hdwg.org/catalyst/news/2011-12-03/1 (Co-hosted by the Association of Maternal and Child Health Programs (AMCHP) and the Catalyst Center, December, 2011)

Resource: Section 9: What's New Under the Affordable Care Act [PDF], http://hdwg.org/sites/default/files/section9.pdf (A publication by the National Academy for State Health Policy (NASHP) for the Catalyst Center, February, 2012)

Resource: Your Questions About the Medicaid Expansion Provision of the Affordable Care Act Answered http://hdwg.org/catalyst/medicaid-expansion (October, 2012)

Resource: The Affordable Care Act: a side-by-side comparison of major provisions and the implications for children and youth with special health care needs [PDF] http://hdwg.org/sites/default/files/ACAsidebyside-catalystctr.pdf (February, 2011)

Additional Policy Options

- **Ensure pediatric-specific, robust risk adjustment is included in new and existing plans**

Risk adjustment is important for CSHCN and their families when the purchasers of health insurance – employers, government agencies, or health exchanges – pay a set amount to health plans for each person enrolled in the plan. Why? Because CSHCN by definition use more health care services than other children and inevitably incur higher costs. If payments to health plans are the same for all children, then families have little protection against health plan policies that might discriminate against CSHCN and their families, such as strict medical necessity definitions or limited access to specialty care. Risk adjustment is an important tool for correcting health plan payments when a plan's medical expenses are higher or lower than average, as a result of serving individuals whose costs are substantially higher or lower than average.

Ben

Cornelia de Lange

Resource: Risk Adjustment and Other Financial Protections for Children and Youth with Special Health Care Needs in Our Evolving Health Care System http://hdwg.org/catalyst/risk (May, 2012)

- **Monitor and expand state mandated benefits**

Mandated benefits address underinsurance by requiring private health insurance carriers to offer specific benefits. State legislatures across the country have passed mandated benefit laws, ensuring that people who are covered by private insurance have access to certain benefits such as early intervention, nutritional supplements, or services for autism. Sometimes mandated benefits are preventive services such as screenings, with the potential to save costs for the system as a whole by catching conditions before they become severe and costly to treat.

Resource: Mandated Benefits: Essential to Children and Youth with Special Health Care Needs http://hdwg.org/catalyst/essential-mandated-benefits (June, 2008)

- **Implement a Medicaid Buy-in program for children with disabilities whose families are over-income for Medicaid**

Medicaid buy-in programs are particularly important for underinsured children with disabilities, because they allow families to purchase Medicaid benefits that pay for specific services that are not covered or are covered inadequately by employer-sponsored insurance plans. Massachusetts and Vermont already offer this option.

Resource: Frequently Asked Questions about the Family Opportunity Act's Medicaid Buy-In Option http://hdwg.org/catalyst/faq-medicaid-buy-in-option (February, 2007)

Resource: Reducing Under-Insurance for Children and Youth with Special Health Care Needs through Medicaid Buy-In Programs http://hdwg.org/catalyst/reducing-under-insurance (November, 2006)

- **Adopt the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) Medicaid state plan option**

Under the TEFRA, states may provide Medicaid coverage to children with severe disabilities. When a child receives extended care in an institutional setting, like a pediatric nursing home, hospital or intermediate care facility, family income is disregarded as a qualification for Medicaid. The TEFRA State Plan Option makes it possible to do the same for a family whose child requires care at the level provided in an institution, but who choose to care for their child at home.

Resource: The TEFRA Medicaid State Plan Option and Katie Beckett Waiver for Children – Making It Possible to Care for Children with Significant Disabilities at Home http://hdwg.org/catalyst/tefraindicator (March, 2012)

- **Create catastrophic relief and trust funds**

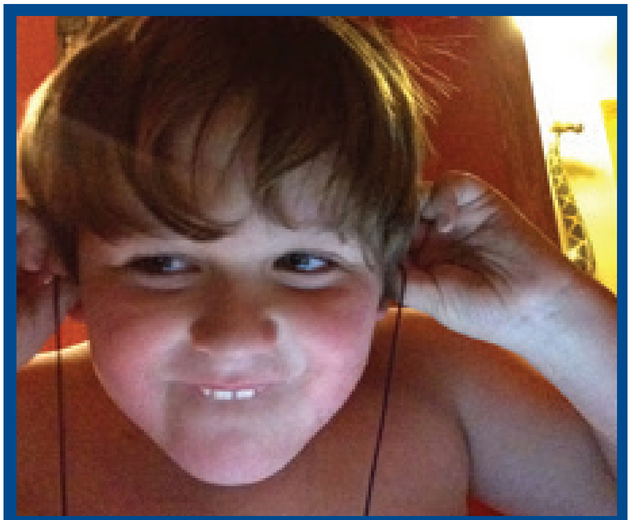
Several states operate relief or trust funds, which expand the availability of "last resort" funding for services or supports that CSHCN and their families may need but which aren't covered by any other source, including health insurance. The term "catastrophic" refers to the impact on a family's finances, not the illness, disease or disability itself.

Resource: Relief Funds: A Safety Net for Children and Youth with Special Health Care Needs http://hdwg.org/catalyst/relief-funds-safety-net (August, 2007)

- **Implement premium assistance programs**

Premium assistance programs offer another means by which states can increase the number of CSHCN with insurance coverage. In premium assistance programs, a state agency pays all or part of a family's private health insurance premiums. These programs are often implemented for low-income working families who cannot afford the expense of family coverage under an employer-sponsored plan. Premium assistance programs have grown in popularity with the advent of CHIP, in part as a strategy to ensure that low-income families do not drop their employer-sponsored coverage in order to obtain less costly CHIP coverage for their children.

Resource: Catalyst Center State Financing Strategies: Premium Assistance http://hdwg.org/catalyst/cover-more-kids/premium-assistance (2014)



Jack

Fragile X Syndrome

APPENDIX 1: CONSUMER RESOURCES

Family Leadership Organizations

Family Voices: Family Voices is a national nonprofit family-led organization promoting quality health care for all children and youth, particularly those with special health care needs.

- National Organization: http://www.familyvoices.org/
- State Affiliate Organizations in New England:
  - PATH Parent to Parent (Connecticut): http://www.pathct.org/
  - Maine Parent Federation: http://www.startingpointsforme.org/
  - Massachusetts Family Voices: http://fcsn.org/mfv/
  - New Hampshire Family Voices: http://nhfv.org/
  - Rhode Island Parent Information Network (RIPIN): http://www.ripin.org/
  - Vermont Family Network: http://www.vermontfamilynetwork.org/

Family-to-Family Health Information Centers (F2F HICs): The Family-to-Family Health Information Centers (F2F HICs) are family-staffed organizations that assist families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. F2F HICs provide support, information, resources, and training around health issues.

- National Organization: http://www.fv-ncfpp.org/
- In the New England states, the F2F HICs are all located in the same organizational home as the Family Voices State Affiliate. See the paragraph above for links to their websites.

New England State Insurance Regulators

- Connecticut Insurance Department: http://www.ct.gov/cid
- Maine Bureau of Insurance: http://www.maine.gov/pfr/insurance/
- Massachusetts Division of Insurance: http://www.mass.gov/ocabr/government/oca-agencies/doi-lp/
- New Hampshire Insurance Department: http://www.nh.gov/insurance/
- Rhode Island Division of Insurance Regulation: http://www.dbr.state.ri.us/divisions/insurance/
- Vermont Department of Financial Regulation: http://www.dfr.vermont.gov/

APPENDIX 2: HEALTH CARE REFORM RESOURCES

- **Association of Maternal and Child Health Programs' National Center for Health Reform Implementation:** The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs. http://www.amchp.org/Policy-Advocacy/health-reform/Pages/default.aspx
- **Centers for Medicare and Medicaid Services (CMS):** CMS is the federal agency that administers Medicare and oversees the states' administration of Medicaid and the Children's Health Insurance Program. http://www.cms.gov/
- **CMS Center for Consumer Information and Insurance Oversight:** The Center for Consumer Information and Insurance Oversight (CCIIO) is charged with helping implement many reforms of the Affordable Care Act, the historic health reform bill that was signed into law March 23, 2010. CCIIO oversees the implementation of the provisions related to private health insurance. In particular, CCIIO is working with states to establish new Health Insurance Marketplaces. http://www.cms.gov/cciio

> *"The variations between generic medications made by different companies is enough for my child to experience an increase in side effects, or a breakthrough seizure. We need to have access to brand name medications until generic medications are the same, regardless of manufacturer."*
>
> - Quote from a parent respondent

- **Commonwealth Fund Health Care Reform Resource Center:** The mission of The Commonwealth Fund is to promote a high-performing health care system that achieves better access, improved quality, and greater efficiency, particularly for society's most vulnerable, including low-income people, the uninsured, minority Americans, young children, and elderly adults. The Fund carries out this mandate by supporting independent, non-partisan research on health care issues and making grants to improve health care practice and policy. http://www.commonwealthfund.org/interactives-and-data/health-reform-resource-center
- **Kaiser Family Foundation's Health Reform Center:** The Kaiser Family Foundation is a non-profit, non-partisan foundation focusing on the major health care issues facing the U.S., as well as the U.S. role in global health policy. (The Kaiser Family Foundation is not associated with Kaiser Permanente or Kaiser Industries.) http://kff.org/health-reform/
- **State Refor(u)m:** State Refor(u)m is an online network for health reform implementation. It is an initiative of the National Academy for State Health Policy (http://www.nashp.org/), funded by the Robert Wood Johnson Foundation. The site connects state health officials looking for information and assistance with their peers and other experts who have relevant resources and experiences to share. https://www.statereforum.org/
- **US Department of Health and Human Services:** Healthcare.gov is the online portal to both the state and federally-run health insurance marketplaces. https://www.healthcare.gov/

APPENDIX 3: DATA RESOURCES

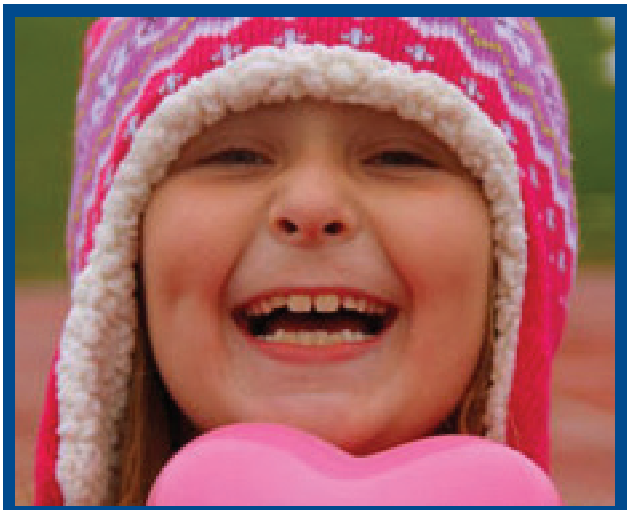
Catalyst Center State-at-a-glance Chartbook on Coverage and Financing of Care for Children and Youth with Special Health Care Needs, Boston University School of Public Health

The Catalyst Center's Online Chartbook provides data on carefully selected indicators of health coverage and health care financing for CYSHCN in every state plus DC and Puerto Rico. Using the online Chartbook, you can access data for your state and easily compare it with both national averages and other states' data. http://hdwg.org/catalyst/state-data-chartbook

Data Resource Center (DRC) for Child and Adolescent Health, Child and Adolescent Health Measurement Initiative, Oregon Health and Science University

The DRC website includes national and state-level data on hundreds of child health indicators from the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN). You can browse or search by keywords and topics to retrieve interactive data tables and graphs which allow users to select, view, compare, and download survey data results for the nation, all 50 states plus the District of Columbia and the 10 HRSA regions.

- The National Survey of Children with Special Health Care Needs: http://childhealthdata.org/learn/NS-CSHCN
- The National Survey of Children's Health: http://childhealthdata.org/learn/NSCH



Shawna

MCAD

Kaiser Statehealthfacts.org

State Health Facts is a project of the Kaiser Family Foundation and provides free, up-to-date, and easy-to-use health data for all 50 states, the District of Columbia, the United States, counties, territories, and other geographies. State Health Facts is comprised of more than 800 health indicators and provides users with the ability to map, rank, trend, and download data. Data come from a variety of public and private sources, including Kaiser Family Foundation reports, public websites, government surveys and reports, and private organizations. http://kff.org/statedata/

APPENDIX 4: GLOSSARY

Affordable Care Act (ACA)

The comprehensive health care reform law enacted in March 2010. The law was enacted in two parts: The Patient Protection and Affordable Care Act was signed into law on March 23, 2010 and was amended by the Health Care and Education Reconciliation Act on March 30, 2010. The name "Affordable Care Act" is used to refer to the final, amended version of the law.

Children's Health Insurance Program (CHIP)

Insurance program jointly funded by the states and the federal government that provides health coverage to low-income children and, in some states, pregnant women in families who earn too much income to qualify for Medicaid but can't afford to purchase private health insurance coverage.

Children with Special Health Care Needs (CSHCN)

As defined by the federal Maternal and Child Health Bureau (MCHB), children with special health care needs (CSHCN) are those from birth to age 21 who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and need health and related services of a type or amount beyond that required by children generally. Also referred to as Children and Youth with Special Health Care Needs (CYSHCN).

Cost-sharing

Cost sharing is the portion of health care costs that are not covered by health insurance and are instead paid by patients/families. Examples include copays, deductibles, and coinsurance.

Coverage

Health benefits that are included in an insurance policy and are therefore available for a policy holder to access.

Essential Health Benefits (EHBs)

A set of health care service categories that must be covered by certain plans, starting in 2014.

The ACA ensures health plans offered in the individual and small group markets, both inside and outside of the Health Insurance Marketplace, offer a comprehensive package of items and services, known as essential health benefits. EHBs must include items and services within at least the following 10 categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

Insurance plans and policies must cover these benefits in order to be certified and offered in the Health Insurance Marketplace. States expanding their Medicaid programs must provide these benefits to people newly eligible for Medicaid.

Home and Community-Based Services (HCBS) Waiver

A Medicaid waiver that permits a state to offer a wide array of home and community-based services that a disabled individual may need to avoid more costly institutionalization.

Habilitative Services

Health care services that help you keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn't walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings.

Federal Poverty Level (FPL)

A measure of income level issued annually by the Department of Health and Human Services. Federal poverty levels are used to determine your eligibility for certain programs and benefits. The FPL guidelines for 2014 are found at https://www.federalregister.gov/articles/2014/01/22/2014-01303/annual-update-of-the-hhs-poverty-guidelines

Grandfathered Health Plan

As used in connection with the ACA: A group health plan that was created—or an individual health insurance policy that was purchased—on or before March 23, 2010. Grandfathered plans are exempted from many changes required under the ACA. Plans or policies may lose their "grandfathered" status if they make certain significant changes that reduce benefits or increase costs to consumers. A health plan must disclose in its plan materials whether it considers itself to be a grandfathered plan and must also advise consumers how to contact the U.S. Department of Labor or the U.S. Department of Health and Human Services with questions. (Note: If you are in a group health plan, the date you joined may not reflect the date the plan was created. New employees and new family members may be added to grandfathered group plans after March 23, 2010).

Individual Policy

Private insurance policies for people that aren't connected to job-based coverage. Individual health insurance policies are regulated under state law.

Large-group Health Plan

In general, a group health plan that covers employees of an employer that has 101 or more employees. Until 2016, in some states large groups are defined as 51 or more.

Mandated Benefits

A benefit that must be covered by private insurers as a matter of state law. Companies that "self-insure" are exempt from such mandates.

Medicaid

A state-administered health insurance program for low-income families and children, pregnant women, the elderly, people with disabilities, and in some states, other adults. The Federal government provides a portion of the funding for Medicaid and sets guidelines for the program. States also have choices in how they design their program, so Medicaid varies state by state and may have a different name in your state.

Medicaid Buy-in Programs

Medicaid buy-in programs allow families who meet certain eligibility criteria (often disability-related) but who are over-income to purchase Medicaid benefits.

Medicaid Coverage

Medicaid provides coverage for health care and health-related services to low-income families and children, pregnant women, seniors, people with disabilities and others. It is funded by both state and federal dollars. The states administer their individual Medicaid programs, with some flexibility in how they design them. Eligibility and benefits vary from state-to-state under basic guidelines that are set by the Federal government.

Mental Health Parity

Equal health insurance coverage for mental and physical conditions; required of health insurers by law in some states. While parity is a strategy to improve mental health benefits, it does not assure comprehensive care.

Premium

The amount of money paid to a health plan to provide coverage for an individual or family over a specified time period.

Premium Assistance

The payment of all or part of an individual's or family's monthly private health insurance premium, usually by a public program such as Title V or Medicaid.

Self-insured

Coverage offered by a company, typically a large employer, that chooses to pay employees' health care costs directly, instead of purchasing health insurance coverage. Sometimes known as "ERISA" plans.

Small-group Health Plan

In general, a group health plan that covers employees of an employer that has 100 or fewer employees.

State Mandated Benefits

A benefit that must be covered by private insurers as a matter of state law. Companies that "self-insure" are exempt from such mandates.

Underinsurance

Underinsurance is when all the medically necessary services required by an insured individual aren't covered by his or her health insurance.

Adapted from glossaries found at Healthcare.gov (http://kff.org/statedata/) and the Catalyst Center (http://hdwg.org/catalyst/glossary)

APPENDIX 5. RESPONSES TO THE ONLINE SURVEY OF NEW ENGLAND FAMILIES OF CHILDREN WITH GENETIC DISORDERS ON ESSENTIAL HEALTH BENEFITS COVERAGE AND GAPS

Benefit Description	**Response:** *Insurance covers everything my child needs in this category*	**Response**: *Insurance DOES NOT cover everything my child needs in this category*	Specific examples of services that are NOT covered
Outpatient (ambulatory) services, such as visits to primary or specialty care doctors or clinics	**79.8%**	**20.2%**	• Alternative Medicaid/therapy (compound meds, swim or hippotherapy) • Out-of-network specialist • Coordination
Emergency services, such as visits to a hospital emergency room or urgent care center	**88.2%**	**11.8%**	n/a
Overnight stays in a hospital (admission)	**89.1%**	**10.9%**	n/a
Care related to pregnancy and birth; care of a new mother and her baby	**90.4%**	**9.6%**	n/a
Care for emotional, behavioral or substance abuse issues; for example, visits with a psychiatrist, psychologist, behaviorist, other counselor, social worker or developmental specialist	**68.7%**	**31.3%**	• Uncovered services (Genetic testing/ genetic counseling) • Service limits
Medicine you need a prescription to get	**67.8%**	**32.2%**	• Name brand vs. generic medication • Orphan drugs
Rehabilitative services, such as PT, OT, speech therapy to regain function for an existing skill lost due to illness, injury, or accident	**68.8%**	**31.2%**	• Service limits
Habilitative services, such as applied behavioral analysis (ABA), PT, OT, speech therapy, respiratory therapy, to gain a new skill or prevent worsening of function	**59.7%**	**40.3%**	• Service limits

Benefit Description	**Response:** *Insurance covers everything my child needs in this category*	**Response:** *Insurance DOES NOT cover everything my child needs in this category*	**Specific examples of services that are NOT covered**
Medical devices, such as wheelchairs, braces, hearing aids	**64.5%**	**35.5%**	• Choice limits
Laboratory services, such as blood tests and X-rays	**87.2%**	**12.8%**	• Genetic testing • Complex blood work
Services to prevent illness or health problems (such as immunizations and well-child check-ups) and services to help your child stay well, like weight management and nutrition counseling	**89.9%**	**10.1%**	• Nutritional supplements and counseling • Alternative medicine
Pediatric services, such as developmental screenings, education and counseling on child safety topics for parents and avoiding health risks for adolescents (like advice against smoking, drug use, etc.), dental and vision care	**67.8%**	**32.2%**	• Limits or no coverage for dental and vision services
Prescribed medical foods, essential nutritional replacements, feeding devices and supplies	**67.6%**	**32.4%**	n/a

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ENDNOTES

[i] Adapted from Farrell, K., Hess, C., & Justice, D. (2011). The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for Policymakers. The National Academy for State Health Policy and the Catalyst Center at the Boston University School of Public Health. Found online at http://hdwg.org/sites/default/files/ACAandCSHCNpaper.pdf

[ii] Centers for Disease Control and Prevention. Newborn Screening for Cystic Fibrosis. Morbidity and Mortality Weekly Report. October 15, 2004; 53(RR13):1-36

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[iv] McKusick VA. 1994. Mendelian Inheritance in Man: A Catalog of Human Genetics and Genetic Disorders, 11th Edition. Baltimore: The Johns Hopkins University Press

[v] MedlinePlus [Internet]. Bethesda (MD): National Library of Medicine (US); Phenylketonuria. [updated 2013 June 9; cited 2014 January 5]; [about 2 p.]. Available from: http://www.nlm.nih.gov/medlineplus/ency/article/001166.htm

[vi] According to the federal Maternal and Child Health Bureau, children with special health care needs (CSHCN) 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 greater than that required by children generally. McPherson, M., Arango P., Fox H., Lauver C., McManus M., Newacheck PW., Perrin JM., Shonkoff JP., & Strickland B. (1998). A new definition of children with special health care needs. Pediatrics, 102, 137-140.

[vii] A chart with the 2014 Federal Poverty Guidelines can be found at https://www.federalregister.gov/articles/2014/01/22/2014-01303/annual-update-of-the-hhs-poverty-guidelines

[viii] The ACA creates a major simplification in income eligibility by replacing state-specific income disregards with a national 5% across-the-board standard known as modified adjusted gross income, or MAGI. The language in the ACA uses 133% of the FPL but we use 138%, accounting for the 5% MAGI disregard that for practical purposes will be the new standard.

[ix] MacManus, P. July 2012. A Comparative Review of Essential Health Benefits Pertinent to Children in Large Federal, State, and Small Group Health Insurance Plans: Implications for Selecting State Benchmark Plans. http://www.aap.org/en-us/advocacy-and-policy/federal-advocacy/Documents/EssentialHealthBenefitsReportOctober2012.pdf

[x] Additional Information on Proposed State Essential Health Benefits Benchmark Plans (2013). Centers for Medicare and Medicaid Services' Center for Consumer Information and Insurance Oversight. http://www.cms.gov/cciio/resources/data-resources/ehb.html

[xi] Davidoff, AJ. Insurance for children with special health care needs: patterns of coverage and burden on families to provide adequate insurance. Pediatrics, Vol. 114 No 2 August 2004 pp 394-403.

[xii] Honberg L, McPherson M, Strickland B, Gage JC, Newacheck PW. Assuring adequate health insurance: results of the National Survey of Children with Special Health Care Needs. Pediatrics Vol. 115 No 5 May 2005 pp 1233-9.

[xiii] McGrath R, Laflamme D, Schwartz A, Stransky M, Moeschler J. Access to Genetic Counseling for Children With Autism, Down Syndrome, and Intellectual Disabilities. Pediatrics Vol. 124 Supplement 4 December 2009 pp. S443 -S449

[xiv] Kogan, M., Newacheck, P., Honberg, L., & Strickland, B. Association Between Underinsurance and Access to Care Among Children With Special Health Care Needs in the United States. Pediatrics Vol. 116 No. 5 November 2005 pp. 1162 -1169.

[xv] Adapted from Farrell, K., Hess, C., & Justice, D. (2011). The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for Policymakers. The National Academy for State Health Policy and the Catalyst Center at the Boston University School of Public Health. Found online at http://hdwg.org/sites/default/files/ACAandCSHCNpaper.pdf

[xvi] Early, Periodic Screening, Diagnosis and Treatment (EPSDT) makes up the child health benefit available to all Medicaid enrollees under age 21. It requires states to cover all medically-necessary services for children, whether they are included in the State Medicaid plan or not.

[xvii] One example of a validated screener tool for CSHCN is the 5-question Child and Adolescent Health Measurement Initiative (CAHMI) screener. To learn more about administering the CAHMI screener and to access a resource manual for State Medicaid and Managed Care Organizations on identifying CSHCN, go to http://www.cahmi.org/pages/Topics.aspx?section=10&topic=66

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