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Children with Genetic Disorders: What Is the Impact of the Affordable Care Act (ACA) on Access to Coordinated Care in the Mountain States?

The Patient Protection and Affordable Care Act (ACA), enacted by the US Congress and effective March 23, 2010, promotes structures and incentives for states to expand health care coverage. On February 20, 2015 the Centers for Medicare and Medicaid Services of the Department of Health and Human (HHS) released its Notice of Benefit and Payment Parameters for the 2016 final rule (2016 Rule). This rule addresses the continuing implementation of the ACA for 2016 (Jost, 2015).

State legislatures and administrative agencies are reviewing and revising marketplace exchange insurance policies and essential health benefit coverage in light of the 2016 Rule. We discuss the specific implications of the ACA and the 2016 Rule for meeting the healthcare needs of children and youth with genetic disorders.

Purpose of Brief

The purpose of this brief is to inform policymakers and administrators in the Mountain States Region (AZ, CO, MT, NV, NM, TX, UT and WY) about the impact of ACA in relation to children with genetic disorders (Patient Protection and Affordable Care Act, 2010). We analyze how current ACA policies impact families and can be improved to close benefit gaps, cover more children, and improve access and integration of services for children with genetic disorders living in the Mountain States Region.

Background

Insuring Children and Youth with Genetic Disorders and Special Health Needs

Families of children with genetic disorders face considerable challenges even with the best medical care. Individuals with genetic disorders usually have chronic conditions that impact their health and function over the lifespan. In addition, many genetic disorders affect more than one body system, making care complex. Further, families of children with genetic disorders almost always have greater health care expenditures than families with only basic health care needs. These financial challenges put children's health and well-being at risk. It is common for underinsurance, high medical costs and high cost sharing to result in serious financial burdens, and a cycle of debts that families cannot financially manage.

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Barriers to comprehensive insurance coverage and policy limitations can be detrimental to children with genetic disorders (Grosse et al., 2009). Prior to President Obama signing the ACA into law (March 23, 2010), approximately one in five children in the Mountain States with special health care needs had one or more periods during a year with no health insurance if the family income was below 200% of the poverty level (Table 1). As a result of the recent recession (2007-2009), private health insurance companies cut costs by increasing premiums (U.S. Department of the Treasury, 2013), adding additional barriers to comprehensive coverage. On October 1, 2014, the US Health Insurance Marketplace opened for enrollment. By 2014, many Americans gained access to additional health insurance options as a result of the ACA.

Table 1. Mountain States Children with Special Health Care Needs: Gaps in Health Insurance Coverage and Program Participation Prior to ACA

State	Percent with One or More Periods without Health Insurance During Past Year (2009/10) Reported by Federal Poverty Level (FPL):			
	0-199% FPL	200-299% FPL	300-399% FPL	400% FPL or more
Arizona	20.2	16.5	11.9	2.5
Colorado	20.9	12.0	5.2	2.4
Montana	18.0	23.9	13.2	1.4
Nevada	21.0	27.7	5.4	3.9
New	12.5	12.7	3.3	3.5
Texas	25.6	13.6	8.7	3.1
Utah	21.9	13.5	4.0	3.8
Wyoming	19.0	14.0	6.2	1.2

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 [07/21/2015] www.childhealthdata.org.

The consumer protections provided by ACA include coverage for those with preexisting conditions, no lifetime limits, coverage for children up to age twenty six on their parents' policies, and Medicaid coverage to young adults aging out of foster care. These protections greatly reduce financial barriers to families of children with genetic disorders. However, with the high cost of treatments necessary for children with genetic disorders, caps and limits (e.g., behavioral health care coverage) continue to present significant barriers to comprehensive health care coverage. This brief explores the unique needs and challenges that families with children with genetic disorders face under the new law.

What Are the Health Needs of Children with Genetic Disorders?

Diagnosing and identifying the health needs of children with genetic disorders is complicated and changing over the life span. The impact of genetic changes on a person's health depends in part on the type of change and in which gene or genes it occurs. A genetic condition or disorder occurs when there is a change or mutation in the genetic material within cells. Chromosomes are the large structures inside cells that carry the genes. Some genetic disorders are caused by having an extra or a missing chromosome, which would involve many extra or missing genes. Other genetic disorders are caused by a change or mutation in a single gene. Among the thousands of genetic disorders that are known, cystic fibrosis is a condition caused by mutation in a single gene, while Down syndrome is a condition caused by an extra chromosome. More common birth defects, such as heart defects and cleft palate, have genetic causes as well as environmental triggers. Many genetic disorders, including breast cancer and high cholesterol, manifest later in life. Other conditions such as phenylketonuria (PKU) can be detected through routine newborn screening; when treatment is initiated in the first weeks of life, outcomes are excellent.

Comprehensive treatment of many genetic disorders requires extensive and costly health services including medical, behavioral and developmental services. This high cost of health care becomes more personal when you consider that with thousands of genetic conditions affecting Americans, it is likely that you or someone close to you knows and cares for a child with a genetic disorder (WHO, 2015).

How Does the ACA Reduce Health Insurance Barriers?

The ACA is designed to combat uninsurance and underinsurance in two ways.

- It aims to reduce barriers to existing coverage options.
- It opens new pathways to coverage or expands existing means of obtaining coverage.

The signature provisions in the ACA aimed at reducing barriers are known as the consumer protections or the Patient's Bill of Rights. Particularly relevant protections to children with genetic disorders include (New England Genetics Collaborative, 2014):

- 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 cancel an enrollee's coverage when he or she gets sick or hurt. *Self-funded plans are exempt.*

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- 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, self-funded, and group grandfathered plans are exempt.*
- Increased protection against health status discrimination.
- Annual and lifetime benefit limits are limited to individual grandfathered plans, and no annual benefit caps in dollar amounts are permitted.
- No lifetime benefit caps in dollar amounts permitted.

While dollar amounts can no longer be capped, it is important to note that benefits or services differ widely across states by type and amount. Sections 1302 and 1311 of the ACA provide that each state offer access to a Health Insurance Marketplace. States have the option of setting up their own Marketplace or of allowing the federal government to operate the Marketplace. The Marketplace contains information on plans available in the state in the individual and small group market. Each state could identify a base benchmark plan from a menu of employer-offered options, and this benchmark plan then defined the Essential Health Benefits (EHBs) that all non-grandfathered plans in the individual and small group market in the state had to cover (Jost, 2015). The Marketplace, or 'Exchange,' provides transparent information regarding insurance policy terms, limits, and coverage options, and enables consumers to easily navigate and apply for affordable health insurance. However, benchmark plans are based on small group plans in the state. The American Academy of Pediatrics estimated that 34.3% of families of children with special health care needs, enrolled in small group plans (MacManus, 2012), do not have coverage for needed services. These small group plans offered the least comprehensive list of services with the highest cost-sharing. Although benchmark plans were modified to include all of the required EHBs, none of the new plans came close to offering the comprehensiveness and affordability of Medicaid and CHIP policies.

States differ by type of Health Care Marketplace administration (Table 2) and their definitions. Further, **limits in types and amounts of covered health care services differ by state.** For example, the Arizona Marketplace limits their benefit for Home Health Care Services to 42 visits per year. In Nevada, the individual plan restricts the Mental and Behavioral Health Outpatient benefit to include only mental health outpatient services, which means that behavioral health services are not included. Other limits also vary greatly from state to state, sometimes limiting access to some of the necessary health services needed by children with genetic disorders. While the limitations may be reasonable based on the general population's health care needs, the ACA requires states to balance the needs of the many with the needs of the few and develop comprehensive, affordable coverage options. Consumers can interact with the U.S. Department of Health and Human Services website ([HHS.gov](http://www.hhs.gov)) to learn how the ACA is working to make health care more affordable, accessible and of a higher quality in their state <http://www.hhs.gov/healthcare/facts/bystate/nm.html>.

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Table 2. Types of ACA Health Care Administration in the Mountain States

State	Health Care Marketplace
Arizona	Federally-facilitated Marketplace
Colorado	State-based Marketplace
Montana	Federally-facilitated Marketplace ¹
Nevada	Federally-supported, State-based Marketplace
New Mexico	Federally-supported, State-based Marketplace ²
Texas	Federally-facilitated Marketplace
Wyoming	Federally-facilitated Marketplace
Utah	Federally-facilitated Marketplace ³
¹ Montana received HHS approval to conduct plan management activities to support certification of qualified health plans in the Federally-facilitated Marketplace. ² New Mexico operates the Small Business Health Options Program (SHOP) marketplace ³ Utah operates the SHOP marketplace; the federal government operates the Individual marketplace. Source: Status of State Action on the Medicaid Expansion Decision; Retrieved [1/9/15] http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/#note-8 .	

The ACA has the potential to be the beginning of a movement toward better patient centered health care, where both financial and mental stressors are reduced.

- The ACA Marketplace reduces the pressure on families to find affordable health care.
- ACA requires transparency and clear provisions from insurance companies in describing available insurance plans.
- The ACA-established state-based insurance exchanges (2014) enable individuals and small businesses to easily price shop several insurance policies and purchase the health insurance coverage that meets their personal or business needs.

State policymakers have passed legislation, and continue to evaluate state policy options, to make children's health care more affordable and accessible through the Health Insurance Marketplace. Underinsurance results in elevated cost-sharing burdens, delayed services and poorly coordinated care of children with genetic disorders and special health care needs. State policies that eliminate or reduce underinsurance can enable families of children with genetic disorders to access needed services and coordinate their children's care with their primary care provider. New Mexico and Colorado are among the states that expanded Medicaid under the ACA to individuals with family incomes at or below 133% FPL (generally \$32,253 for a family of four in 2015). As of January 2015, HHS.gov reports that 230,151 New Mexicans and 411,622 Coloradans gained Medicaid or CHIP coverage since the beginning of the Health Insurance Marketplace first open enrollment period.

As the Health Insurance Marketplace expands and ACA is implemented more broadly, the rates of underinsured and uninsured children in the Mountain States Region will

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decrease, accompanied by greater access to expanded benefits (e.g., preventive services, mental health care), removal of lifetime dollar limits on health benefits, and elimination of discrimination for pre-existing conditions.

The ACA expands health care options for Native American citizens who qualify for health care via the Indian Health Services (IHS). Native Americans can apply for an IHS exemption or a tribal membership exemption available to members of federally-recognized tribes. The exemptions eliminate the ACA shared responsibility payment for not maintaining the minimum essential insurance coverage requirement. The ACA also benefits IHS facilities, such as hospitals and clinics, through the ACA provisions for ensuring health care quality and reducing health care disparities for underrepresented minorities.

State-Level ACA Policymaking and Medicaid Expansion

National policymakers originally crafted ACA to mandate Medicaid expansion in every state, requiring all states to extend eligibility, by 2014, to non-disabled, non-pregnant adults (19-64 years), with income under 138% FPL. This provision included an expansion of both the means (income) test and the categorical limitations (gender/parentage) test for Medicaid qualification. Currently in non-Medicaid expansion states, men and women without children that are not disabled *are not eligible* for Medicaid coverage regardless of their income. While the Supreme Court upheld the individual mandate requiring every American to provide proof of insurance coverage, eligibility for an exemption, or to pay a fine, the Medicaid expansion provision of the ACA was deemed unconstitutional. The ruling was based on what the Supreme Court termed an “overextension of the commerce clause” because the penalty to states for not complying with the Medicaid expansion provision was overly coercive and therefore unconstitutional. While states may choose to comply with the Medicaid expansion requirement, they are not penalized for not expanding their state’s Medicaid eligibility for adults.

Despite the expanded benefits included in the ACA, barriers to enrollment exist which may limit the number of individuals who receive these benefits. These barriers include enrollment documentation requirements, enrollment challenges related to health literacy and navigation of the Marketplace, and difficult prerequisites to CHIP enrollment such as the requirement for in-person interviews.

Now, we change our focus to the health insurance gaps families of children with genetic disorders and special health care needs face. The gaps include eligibility, coverage for needed behavioral, habilitation and rehabilitative services, nutritional counseling and durable equipment.

Children with Genetic Disorders: Current Gaps & Barriers

Underinsurance for needed health care services (e.g. habilitation services) increases risk of preventable disability among children with genetic disorders. Underinsurance results when a health insurance policy requires high cost-sharing on the part of the consumer, and policy holders cannot cover out-of-pocket health care costs. Underinsurance and high cost sharing for essential health benefits often lead to poor health care outcomes (Schoen, Collins, Kriss and Doty, 2008; Fischer and Rogowski, 2014).

Underinsurance is often evidenced by data on medical bankruptcy and uncompensated care. Families with children are at a disproportionate risk for medical bankruptcy as compared to childless adults (Warren, 2002). Warren explains that bankruptcy is not simply a tool to benefit those that make bad credit decisions, but ultimately it can be a tool of last resort to protect the economic survival of an entire family and their household (2002). However, since ACA implementation, fewer families have utilized this tool; and medical bankruptcy, as well as uncompensated care rates, have gone down (US Department of Health and Human Services Economic Impact of the Medicaid Expansion Report, 2015). Gross and Notowidigdo noted that pre-ACA Medicaid expansions were clearly linked to a reduction in health care bankruptcy (2011). During the year following ACA implementation, researchers conducting the Oregon Medicaid experiment noted a 25% decline in the probability of having an unpaid medical bill sent to a collection agency (Finkelstein, 2012).

Table 3. The Ten Essential Health Benefits (EHBs)

1. Ambulatory patient services (outpatient care you get without being admitted to a hospital)
2. Emergency services
3. Hospitalization (such as surgery)
4. Pregnancy, maternity, and newborn care (care before and after your baby is born)
5. Mental health and substance use disorder services, including behavioral health treatment (this includes counseling and psychotherapy)
6. Prescription drugs
7. Rehabilitative and habilitative services and devices (services and devices to help people with injuries, disabilities, or chronic conditions gain or recover mental and physical skills)
8. Laboratory services
9. Preventive and wellness services and chronic disease management
10. Pediatric services, including oral and vision care for children 18 and under

Source: HealthCare.Gov. Retrieved [07/21/2015] <https://www.healthcare.gov/coverage/what-marketplace-plans-cover/>.

Note: Consumers may find that large group health insurance plans, self-funded ERISA plans, and grandfathered plans that are exempt from the EHBs have fewer benefits compared to those available through the Marketplace or the small group plans incorporating the EHBs.

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Private health insurance plans offered in the Marketplace all offer the same set of essential health benefits (EHB); however, coverage of specific health care services related to the EHBs differs across states. The ten EHBs (Table 3) are arguably the most important provision for children with genetic disorders. However, children with genetic disorders in different states experience insurance gaps in coverage for specific types of needed health services, prescription drugs and devices.

State policymakers determine the depth and breadth of the EHBs by defining the scope and duration of benefits, and by narrowing or expanding definitions of key words in the policy. Age, disability, and lifespan discrimination through the prescribed design of reimbursement rates, incentive programs, or benefits crafted in a discriminatory manner is prohibited. However, other limitations of benefits are permitted. Policy makers and legislators are therefore faced with crafting legislation that reflects the needs of their citizens.

Likewise, state legislatures also affect policy limits through the creation of state mandated essential health benefits. Nonetheless, enacting this type of legislation can be a lengthy process as exemplified in Wyoming's efforts to pass an act to guarantee insurance coverage for inherited enzymatic disorders. The bill was first proposed in 2010, but because Wyoming has a truncated legislative session in even number years and in odd number years the session is still just forty days long, it took a sustained effort until February 25, 2013 for the bill to pass both Chambers in Wyoming's state legislature. On March 1, 2013 Governor Mead signed the act into a law, and coverage for inherited enzymatic disorders including PKU became a state mandated health benefit in Wyoming (WY Stat § 26-20-401, 2014).

State mandated health benefits may provide additional benefits to those mandated by the Patient Protection and Affordable Care Act, and both are guaranteed in their state's ACA insurance plan. However, it may be challenging for consumers to find a consolidated list of the state and federal essential health benefits applicable in their state as seen in Wyoming's benchmark plan which does not mention inherited enzymatic disorders or PKU despite the state's statutory mandate to provide such coverage. Consumers should be aware that they may need to consult not only the ACA benchmark plan but also their state's Department of Insurance to review all available essential health benefits to which they may be entitled. Table 4 describes the limits in the Essential Health Benefits (EHB) Benchmark Plans for PKU and other disorders in each of the eight Mountain States."

The seven Mountain States provide some coverage for PKU or nutritional counseling. As states review EHBs in consideration of the 2016 Rule, they may take this opportunity to fill the gaps in nutritional counseling and PKU coverage. Nutritional counseling is highly important for children with PKU and certain other hereditary metabolic disorders. To prevent severe brain damage, individuals with PKU must maintain a diet restricting protein and phenylalanine, an

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essential amino acid. Individuals with other metabolic disorders require other dietary restrictions to prevent brain damage and even death.

Table 4. Scope of Supportive Health Services Covered by the Ten Essential Health Benefits (EHB) Benchmark Plans of the Mountain States

Health Service	AZ	CO	MT	NV	NM	TX	UT	WY
PKU Services	X	X	X	X	X	X	X	X (State EHB)
Nutritional Counseling	X	X	Not Covered	Not Covered	Not Covered	X	X	Not Covered
Habilitation Services	Not Covered	X	\$50,000 ABA* (0-8 years); \$20,000 ABA (9-18 years)	\$36,000/Year for Autism Spectrum Disorder	X	35 Visits/Year Combined Total	20 Visits/Year Combined Total	Not Covered
Outpatient Rehabilitative Services	60 Visits /Year	X	X	60 Visits /Year	X			20 Visits /Year
Rehabilitative Physical Therapy	X	20 Visits /Year	X	X	Not Covered	X	X	60 Visits /Year
Rehabilitative Speech Therapy	X	20 Visits /Year	X	X	Not Covered	X	X	20 Visits /Year

X = Covered Without Specified Limitations

*Applied Behavior Analysis

Source: Centers for Medicare and Medicaid Services (CMS), State Essential Health Benefits; Retrieved [1/9/15] from <https://www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html>.

Coverage of habilitative services, outpatient rehabilitative services, rehabilitative physical therapy, and rehabilitative speech therapy is uneven across states, and in some states, there is no coverage. Depending on the individual state definition, habilitative services may include services that help children and adults improve skills and functioning for daily living. Habilitative services and devices aim to help a patient attain, maintain, or prevent deterioration of a skill or function never learned or acquired due to a disabling condition. Rehabilitative services and devices focus on helping a patient regain, maintain, or prevent deterioration of a skill or function that has been acquired but was subsequently lost or impaired due to illness, injury, or a disability.

New Mexico and Colorado have no coverage limitations for habilitative services, while Arizona and Wyoming provide no coverage. Nevada limits habilitative coverage to \$36,000 per year for

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Autism Spectrum Disorder. Montana provides \$50,000 of coverage for applied behavior analysis (ABA) services for members 0-8 years and \$20,000 for ABA services for members 9-18 years. Utah and Texas group rehabilitative and habilitative services together, capping the allowable number of visits. These limitations have a significant impact on children with some genetic disorders. State Medicaid coverage of habilitative services also varies across states; however, in general Medicaid benefits are more comprehensive and affordable (New England Genetics Collaborative, 2014).

Limitations on durable medical equipment coverage are significant gaps in health care coverage for children with genetic disorders. Coverage for durable medical equipment varies across the mountain states. Capping payment and/or limiting renewal of devices or equipment creates a heavy financial burden on families. For example, a number of children with genetic disorders benefit from braces and specially designed orthopedic shoes that may be quickly outgrown, but Utah's plan does not cover foot orthotics at all. Similarly, Nevada places a \$4,000 cap on durable medical equipment that may quickly be met when children outgrow expensive but necessary medical devices that help them to maintain their physical well-being. High cost sharing fees for durable medical equipment and devices can limit children's access to needed equipment.

With the full spectrum of challenges facing children with genetic disorders, mental health services are critical to maintaining their wellbeing. The ACA specifically seeks to improve insurance coverage for mental health care in America. The Mental Health Parity Act was signed into law by President Clinton in 1996 (P.L. 104-204), and its supplement, the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act (MHPAEA), was signed into law in 2008 by President Obama. These laws aim to prevent group health plans from imposing greater limitations on those benefits than on medical or surgical benefits. The legislation did not achieve the intended widespread impact; the act was amended by ACA to further apply to individual health insurance coverage. Each of the Mountain States provides mental health or substance use disorder benefits. Arizona, Colorado, Montana, and New Mexico set limitations on these services. Nevada, Texas, Utah, and Wyoming limit coverage of Mental and Behavioral, Inpatient and Outpatient Services to a specific number of days or visits per year. Nevada does not cover outpatient behavioral services. Inpatient and outpatient behavioral and mental health services are particularly important to children with genetic disorders. As the importance of mental health gains political momentum, removing limitations to these services is an important objective for policymakers seeking to aid children with genetic disorders.

The Future of EHBs & 2016 Benefit & Payment Parameters Rule

The 2016 Benefit and Payment Parameters rule finalizes many standards relating to the EHBs. The majority of the rule became effective April 28, 2015, with the exception of a few selected provisions (Sec. 156.235, 156.285(d) (1) (ii), and 158.162) which will go into full effect on

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January 1, 2016. Several clarifications are set forth including a definition of habilitative services, age limits for pediatric services and coverage of prescription drugs. The rule also describes inadvisable discriminatory plan designs.

The Department of Health and Human Services recognized that grouping habilitative and rehabilitative services together did not result in the comprehensive coverage needed by many Americans with disabilities. Section 156.115(a)(5) of the ACA originally allowed for habilitative services to be grouped with rehabilitative services if they were similar in scope, amount and duration. In the new rule, the Department of Health and Human Services put forth a more specific definition of habilitative services. The new rule seeks to close those unintended gaps resulting from the less restrictive wording in the original Section 156.115(a)(5). There is now a uniform definition of habilitative services that may be used by States and issuers, and the rule removes Section 156.110(c) (6), which is the provision that gave issuers the option to determine the scope of habilitative services (80 FR 10749 at 10811).

By defining habilitative services, the rule clarifies the difference between habilitative and rehabilitative services. As described previously, habilitative services and devices aim to help a patient attain, maintain, or prevent deterioration of a skill or function never learned or acquired due to a disabling condition, while rehabilitative services and devices focus on helping a patient regain, maintain, or prevent deterioration of a skill or function that has been acquired but was subsequently lost or impaired due to illness, injury, or a disability. Furthermore, the rule adopts the Universal Glossary definition of habilitative services which is included in Appendix Four (80 FR 10749 at 10811).

Additionally, the definition of pediatric services has been further clarified by Section 156.115(a) (6), explaining that pediatric services should continue at least until the end of the month in which the enrollee turns 19. Furthermore, state policymakers are strongly encouraged to continue to cover services listed under the pediatric service EHB category beyond an enrollee's 19th birthday month if non-coverage of those services would negatively affect care (80 FR 10749 at 10812).

The rule's clarification regarding prescription drug coverage is in progress. While the rule clarifies minimal provisions of prescription drug lists, it also sets forth new parameters to create a pharmacy and therapeutics committee in each state to meet quarterly and review drug lists to make sure that prescriptions remain part of best practices for a condition or disease (80 FR 10749 at 10813). Because the states will be in charge of enforcing the attendance requirements of their pharmacy and therapeutics committees, the rule waits until 2017 to finalize these new provisions. With state policymakers meeting quarterly to discuss prescription drug coverage in plans, this offers an opportunity for advocates for children with genetic disorders to educate the committee members in their states on the needs of the states' children (80 FR 10749 at 10813).

The rule also provides examples of potentially discriminatory practices that are relevant for children with genetic disorders: (1) refusal to cover a single-tablet drug regimen or extended-release product that is customarily prescribed and is just as effective as a multi-tablet regimen, absent an appropriate reason for such refusal; and (2) placing most or all drugs that treat a specific condition on the highest cost tiers (80 FR 10749 at 10822).

However, beyond requesting an issuer to submit justification with supporting documentation to the federal department of HHS or their State to explain how the plan design is not discriminatory, it is the responsibility of enrollees to seek alternative means of enforcement through the judiciary. The rule directs consumers to the protections of the Americans with Disabilities Act, section 1557 of the Affordable Care Act, Title VI of the Civil Rights Act of 1964, the Age Discrimination Act of 1975, section 504 of the Rehabilitative Act of 1973 and state specific laws (80 FR 10749 at 10822).

King v. Burwell: Future of Subsidies

Tax subsidies provided by the ACA increase the affordability of health insurance and help citizens to avoid violating the ACA's health insurance mandate. The Supreme Court heard the case *King v. Burwell* in order to determine the legality of health insurance subsidies provided to low- and middle-income people in the 34 states where the federal government (not the state government) is operating the insurance Marketplace under the [Affordable Care Act \(King v. Burwell, 2015\)](#). On June 25, 2015, the Supreme Court upheld the Patient Protection and Affordable Care Act Section 36B, allowing tax credits to individuals who purchase health insurance on an exchange created by the federal government. The IRS is justified in issuing tax credits or subsidies to residents of states that did not set up their own Exchanges or Marketplaces.

Recommendations: Informing and Protecting Families of Children with Genetics Disorders

The Mountain States Genetics Regional Collaborative (MSGRC) has adopted the recommendations of New England Genetics Collaborative for informing and protecting families of children with genetic disorders (New England Genetics Collaborative, 2014):

Monitoring, compliance and enforcement of consumer protection provisions should be ensured. 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**

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for families to report non-compliance must be available, as well as "plain language" education of consumers on their rights and responsibilities under the ACA.

Under the advisement of the Department of Health and Human Services 2016 Benefit & Payment Parameters Rule, consumers should be proactive in protecting themselves against health policy discrimination. For families with children with genetic disorders, several laws offer protection at the federal and state levels. The Genetic Information Nondiscrimination Act (GINA) of 2008 sets the federal standard of the minimum protection that must be met by all states. However, many states have more stringent discrimination protections for citizens with genetic disorders, and GINA does not weaken the protections provided by state laws. Legal counsel can help to determine what nondiscrimination and civil rights laws may apply including but not limited to the aforementioned GINA, the Americans with Disabilities Act, section 1557 of the Affordable Care Act, Title VI of the Civil Rights Act of 1964, the Age Discrimination Act of 1975, section 504 of the Rehabilitative Act of 1973 and State specific laws (80 FR 10749 at 10822).

CSHCN should be targeted by Medicaid, CHIP and the State Health Insurance Marketplace 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 Mountain States Genetics Collaborative, genetics clinics, state chapters of the American Academy of Pediatrics, 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.

CSHCN should be 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 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, can help ensure they are not only brought into coverage, but they are brought into and retained under the right coverage for their needs.

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APPENDIX I: 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/>
- Family Voices State Affiliate: Arizona: <http://www.raisingsspecialkids.org/>
- Family Voices State Affiliate: Colorado: <http://familyvoicesco.org/>
- Family Voices State Affiliate: Montana: <http://www.pluk.org/>
- Family Voices State Affiliate: Nevada: <http://www.familytiesnv.org/>
- Family Voices State Affiliate: New Mexico: <http://www.parentsreachingout.org/>
- Family Voices State Affiliate: Texas: <http://www.txp2p.org/about/partnerships.html>
- Family Voices State Affiliate: Utah: <http://www.utahfamilyvoices.org/>
- Family Voices State Affiliate: Wyoming: <http://www.upliftwy.org/>

National Center for Family Professional Partnerships: 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/>

State Departments of Insurance

- Arizona: <https://insurance.az.gov/>
- Colorado: <http://cdn.colorado.gov/cs/Satellite?c=Page&childpagename=DORA-HealthIns%2FDORALayout&cid=1251615908885&pagename=CBONWrapper>
- Montana: <http://www.csi.mt.gov/>
- Nevada: <http://doi.nv.gov/>
- New Mexico: <http://www.osi.state.nm.us/>
- Texas: <http://www.tdi.texas.gov/>
- Utah: <https://insurance.utah.gov/>
- Wyoming: <http://doi.wyo.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/>.

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/>.

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: <http://kff.org/health-reform/>. (The Kaiser Family Foundation is not associated with Kaiser Permanente or Kaiser Industries.)

State Re-forum: State Reform is an online network for health reform implementation. It is an initiative of the National Academy for State Health Policy: <http://www.nashp.org>, and 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: <https://www.healthcare.gov> is the online portal to both the state and federally-run health insurance marketplaces.

Health and Human Services Notice of Benefit and Payment Parameters for 2016 is an online pdf relating a number of changes for 2016 to current qualified health plan (QHP) benefits rules and a number of clarifications and deletions (many relating to EHBs) most of which go into effect on April 28, 2015 and all go into effect on January 1, 2016: <https://www.federalregister.gov/articles/2015/02/27/2015-03751/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2016#h-105>.

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 (CSHCN), 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 data for other states: <http://www.hdwg.org/>.

Data Resource Center (DRC) for Child and Adolescent Health: 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://www.childhealthdata.org/learn/NS-CSHCN>.
- The **National Survey of Children's Health:**
<http://www.childhealthdata.org/learn/NSCH>.

Kaiser 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 TERMS

Note: Glossary was adapted from terms defined at HealthCare.Gov, the Catalyst Center, and the Uniform Glossaries:

- <https://www.healthcare.gov/glossary>
- <http://www.hdwg.org/catalyst/glossary>

Affordable Care Act (ACA)

The comprehensive health care reform law enacted in March 20 10. 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, 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

Sharing trusted information on access to quality genetics services under the ACA

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 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.

Federal Poverty Level (FPL)

A measure of income level issued annually by the Department of Health and Human Services. 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).

Habilitative Services: Uniform Glossary Definition

Health care services that help a person keep, learn or improve skills and function 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.

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.

Individual Policy

Private insurance policies for people that aren't connected to job-based coverage.

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 federally and state funded 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 assurance.

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Authors

Christine Cardinal JD, MPH (University of North Texas Health Science Center)

Celia Kaye, MD, PhD (Project Director, MSGRC, and the University of Colorado Denver)

Sharon M. Homan, PhD (Evaluator, MSGRC, and the University of North Texas Health Science Center)

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