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The ACA and Insurance Implications for Children with Special Health Care Needs

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Introduction

Children with special health care needs (CSHCN) have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and require health and related services of a type or amount beyond that required by children generally (McPherson, Arango, & Fox, 1998). Approximately fifteen percent of U.S. children under the age of eighteen, or about 11.2 million children, have a special health care need and 23 percent of U.S. households with children have at least one child who meets this definition (Maternal and Child Health Bureau, 2013). Importantly, these children use the majority of pediatric health care services and are more vulnerable to poor outcomes when unable to access those services (Berry, Agrawal, Cohen, & Kuo, 2013). As a result, health insurance, public or private, that is universal, continuous, affordable and adequate for the level and scope of care needed is essential.

Significantly, although nearly 40 percent of CSHCN have public insurance coverage, which includes Medicaid, the Children's Health Insurance Program (CHIP) or military health care, the majority of CSHCN are covered by private insurance and 8.2 percent rely on both private and public insurance (Maternal and Child Health Bureau, 2013). Consequently, changes to the private insurance market under the Patient Protection and Affordable Care Act (ACA) are likely to impact large numbers of CSHCN. As high utilizers of health care services, how CSHCN fare under the law will serve as a test of its ability to meet the needs of all children.

State Health Insurance Marketplace and Market Reforms

The ACA increases health insurance coverage among both children and their parents through the creation of Health Insurance Marketplaces (HIM), theoretically improving their

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access to health care. Almost four million children may eventually receive coverage via these marketplaces (Kenney, Buettgens, Guyer, & Heberlein, 2011). The HIMs play a major role in the purchase and sale of health insurance by supervising marketing and competition in the small-group and non-group markets, overseeing standardization of plan benefits and cost-sharing, and administering the distribution of tax credits for lower- and middle-income individuals who lack access to employer sponsored insurance but earn too much to qualify for Medicaid. Under the ACA, states are allowed to establish one or more state or regional marketplaces, partner with the federal government to run the marketplace, or to merge with other state marketplaces. This flexibility however, and regulatory latitude for determining benefits in each state, creates substantial interstate variability in covered benefits and poses challenges for increasingly mobile families or those living in non-traditional households.

The ACA also contains provisions to reform access to the insurance market, many of which significantly impact CSHCN. For example, effective in 2010, children cannot be denied enrollment or coverage because of a pre-existing condition, health insurers cannot rescind coverage regardless of the cost or amount of services used by the child, and children up to age 26 who are not eligible for employment-based benefits can remain on their parent's policy (Farrell, Hess, & Justice, 2011). However, "grandfathered" plans (plans in effect when the ACA was enacted), which include individual plans and employer self-insured plans, are exempt from many provisions, including coverage of preventive care without cost-sharing and limits on out-of-pocket costs, and individual plans can still deny coverage to children under age 19 who have a pre-existing condition (Barr, 2013). Since as many as 80 percent of parents with employer-sponsored insurance may be covered by "grandfathered" plans, the impact on their children's access to coverage and care is significant (Farrell et al., 2011).

Finally, while new out-of-pocket spending limit protections exist, which include restrictions on expenditures for co-pays, coinsurance and deductibles, they are income based and do not include premiums and non-covered services, resulting in persistent financial burden for many families with CSHCN. Given the variability across states, some families are likely to spend substantially more to get the same care from a plan purchased on the HIM than they would have received from comparable CHIP coverage (Medicaid and CHIP Payment and Access Commission, 2014). Therefore, costs still have the potential to impede access to care for many CSHCN.

Essential Health Benefits and Qualified Health Plans

Insurance plans sold in the HIM, known as "qualified health plans," (QHPs) must cover particular services, termed "essential health benefits" (EHB) (Duderstadt, 2014). Although children stand to gain important benefits under the EHB standard, notable limitations exist. The EHB requirement does not apply to the above noted "grandfathered," self-insured or large group plans resulting in substantial gaps in coverage for many children (Touschner, 2012). Secondly, states can define their marketplace's EHB by modeling coverage from among one of the following ten plans operating in the state: the three largest small group plans, the three largest state employee health plans, the three largest federal employee health plan options, or the largest HMO offered in the state's commercial market (Kaiser Family

Foundation, 2013). The selected plan then serves as the benchmark for determining EHB coverage.

These insurance plans however, frequently fall short in pediatric rehabilitative and habilitative services, including oral, vision and hearing services (McManus, 2012). Rehabilitative services are traditionally defined as those that support *regaining* functional capacity and generally do not target the needs of the developing child. Alternatively, habilitative services, defined as health care services and devices that help a child *attaining and maintaining* skills and functioning for daily living, focus on helping a child to meet his or her full potential. These services can mean the difference between talking and not talking, or walking and not walking, or between needing special education and joining the regular classroom. The frequency and intensity of habilitative services received during the critical developmental periods of infancy and childhood can significantly reduce the need for later care. Current guidelines do not explicitly define habilitative benefits. Instead, the final regulations implementing EHB allows states and plans extraordinarily broad discretion to determine which services are included in that category (45 CFR 156.110) and do not define medical necessity as applied these services (Department of Health and Human Services, 2013). Moreover, states may authorize insurers to substitute one set of covered items and treatments for another, as long as the package containing the substituted benefits is the actuarial equivalent of the EHB benchmark. In other words, insurers may offer a lesser degree of habilitative coverage in favor of a richer rehabilitative benefit package in hopes of attracting new adult customers (Rosenbaum, 2013). States are still ultimately required to supplement the benchmark plan to meet federal requirements, but more explicit and comprehensive definitions of pediatric services, especially habilitative services, are needed to ensure that children gain access to all appropriate medically necessary services.

States also have significant flexibility in determining QHP provider network requirements. While a QHP's provider network must include a sufficient number of essential community providers (ECPs) to ensure reasonable and timely access to a broad range of providers for low-income, medically underserved populations, implementation rules do not require QHPs to contract with any willing ECP. This gives states substantial leeway in determining the number and type of providers that must be included in a network in order to be considered adequate and qualify for sale in the marketplace. Moreover, coverage of specific pediatric providers is not mandated, which significantly impacts CSHCN who generally require care from pediatric subspecialists and who benefit from having care coordinated among a variety of medical and non-medical pediatric providers. In response, in October 2013, Seattle Children's Hospital (SCH) filed suit against the Washington Office of the Insurance Coordinator (OIC) based on its approval of plans to be sold on the state HBE that did not include SCH in their network (Carlson, 2013). Although the lawsuit was dismissed in April 2014, SCH proceeded with an administrative appeal seeking reversal of the OIC decision to approve plans that do not include SCH in their networks (Ostrom, 2014). Clearly, narrow networks have the potential to delay, fragment and threaten the quality of care and increase the cost of care for this vulnerable population (Touschner, 2012).

Conclusion

The ACA has the potential to ensure universal, continuous, adequate and affordable coverage for all, including CSHCN. How state policy makers interpret, implement and manage its provisions, and address the gaps in or unintended consequences of this legislation will determine how well the ACA fulfills its promise (Farrell et al., 2011). Given the role of states in defining EHB and guaranteeing QHP network adequacy, state health policy becomes an increasingly important vehicle for strengthening coverage and ensuring access to care for CSHCN. Pediatric providers must educate state policy makers regarding the practical impact of their decisions regarding coverage standards and provider networks. In addition, they can work with families to identify “gaps” in the system and share their stories. The ACA holds promise but it also has the potential to create unanticipated challenges for unique populations. Pediatric nurse practitioners must offer and support thoughtful solutions.

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