

Stories of the Newly Enrolled

How new ACA coverage options are impacting women and families raising children with special health care needs



Introduction

The Impact of Health Coverage Expansions

The 2010 *Patient Protection and Affordable Care Act* (ACA) offers an important opportunity to improve access to affordable, quality health care to populations served by Title V programs. In states that expanded Medicaid, many women, children and families became eligible for the program, some for the first time.¹ For those who are uninsured and not eligible for Medicaid, or for those who cannot access employer-sponsored insurance, the Health Insurance Marketplace (Marketplace) has provided an important pathway to coverage.

The Marketplace is an online portal where families and individuals can learn about their health insurance options and enroll in coverage. Qualified health plans (QHPs) are the insurance plans sold in the Marketplace. These plans provide essential health benefits (EHBs), follow established limits on cost-sharing and meet other legal requirements. QHPs are the only source of coverage that provides consumers with income-based federal subsidies, to make insurance more affordable. In the most recent open enrollment period, which ended January 31, 2016, 12.7 million consumers had enrolled in Marketplace coverage, including four million first-time enrollees.²

Behind these national statistics are women, young adults and families, including those raising children with special health care needs, who have unique stories to tell about enrolling in and receiving care through ACA health insurance coverage. The stories featured here have been collected by Family Voices through interviews with a diverse group of family leaders, ACA navigators and assisters, and individuals from across the U.S., residing in both Medicaid expansion and non-expansion states. Five stories were chosen that highlight the opportunities as well as the challenges of receiving ACA coverage.

To protect the privacy of the individuals and families, their names and states of residence have been changed or omitted.

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The Challenge of Narrow Provider Networks

Families with children diagnosed with rare disorders often face distinct challenges when their children require specialized pediatric care. Some states may have no specialists with expertise in a particular disorder, forcing parents to seek care for their children in neighboring states. Many QHPs limit the number of pediatric specialists in their provider networks. Often plans will not pay for out-of-state providers, placing a significant burden on families needing specialized care for their children. For families enrolled in QHPs, the issue of “network adequacy”—the ability of a health plan to provide enrollees with timely access to a sufficient number of in-network providers—has become a major concern for parents of children with rare disorders.

Florence is a recently divorced woman who lost the employer-based coverage that she had through her former spouse. She and her five-year-old daughter, Sasha, were able to obtain new coverage through the Marketplace. The family’s enrollment process went smoothly, due to the ACA’s “no wrong door” policy, in which consumers are simultaneously assessed for their eligibility for Marketplace plans, Medicaid, and the Children’s Health Insurance Program (CHIP), and enrolled in the right coverage immediately. Florence and Sasha enrolled in a QHP and qualified for a federal subsidy, based on Florence’s income.

Florence and Sasha live in a rural area of their state. A visit to their primary care physician entails a 70 mile trip to and from their home. Within a year after securing new coverage, Sasha’s pediatrician noticed symptoms of a rare immune system disorder, PANDAS (pediatric autoimmune neuropsychiatric disorder), which is a known complication of strep infections. Evaluation and care of her disorder required that Sasha see a pediatric neuropsychologist, in addition to several behavioral specialists, on a regular basis.

The state in which Florence lives has one pediatric neuropsychologist who is located in an urban area, over 300 miles from Florence’s rural town. The waiting list to see this specialist is typically months long. Given the urgency of Sasha’s situation and her deteriorating health, Florence chose to see a specialist in a neighboring state who had immediate availability. Unfortunately, Florence’s QHP did not cover out-of-state specialists. This meant that the family was required to pay out-of-pocket for all visits to the neuropsychologist until the in-state provider became available.

Under ACA regulations, QHPs must maintain a network that is sufficient in number and types of providers, including providers that specialize in mental health and substance use disorder services, to ensure that all services will be accessible without unreasonable delay.³ In addition, the network must include some but not all “essential community providers,” who serve predominantly low-income or medically underserved patient populations. Federal ACA regulations do not establish requirements for coverage of out-of-network or out-of-state health care services.

Depending on the state, either state or federal officials assess network adequacy to determine whether a plan can qualify as a QHP. In the final [Benefit and Payment Parameters for 2016](#), the Centers for Medicare & Medicaid Services (CMS) made certain amendments to network adequacy standards, but did not address coverage or cost-sharing for out-of-network providers. In responding to comments on the proposed rule, CMS declined to follow recommendations that would require QHP issuers to have an internal exceptions or appeals process to obtain out-of-network services at in-network cost, when adequate access is not available. CMS also declined to follow up on recommendations that would require QHP issuers to count cost-sharing for out-of-network services toward the insured’s annual cost-sharing limit. In Florence and Sasha’s situation, this limitation not only has implications for the family’s financial stability, but also undermines continuity of Sasha’s

care by necessitating a change in qualified provider simply to obtain coverage.

PANDAS:

Pediatric autoimmune neuropsychiatric disorder occurs when strep infection triggers a misdirected immune response, resulting in inflammation of a child's brain. This rare disorder causes life-changing symptoms, including obsessive compulsive disorder, anxiety, tics, personality changes, and a decline in math and handwriting abilities, sensory integration issues, and restrictive eating. PANDAS Network estimates that PANDAS affects as many as 1 in 200 children.

ACA and Autism Treatment Coverage

Treatment for children with autism spectrum disorder (ASD) can be costly, and insurance coverage for this population varies widely. Treatment of ASD falls within the “rehabilitation and habilitation” category of the essential health benefits, a common set of health care service categories required in all individual and small group health plans, as per the ACA. States have wide latitude in defining the specific services that are included within their EHB packages. Twenty nine states specifically require all QHPs sold in the Marketplace to include Applied Behavior Analysis (ABA), an evidence-based treatment modality for children with ASD.^{4,5}

Nathan is a four-year-old boy who lives with his parents and two older siblings in a Medicaid expansion state. Nathan was diagnosed with autism at age two and is non-verbal. In the absence of ABA coverage through the family's employer-sponsored insurance, Nathan's parents have paid out-of-pocket for their son's ABA treatment, which created a significant financial burden for the family.

Seeking more comprehensive and affordable coverage for their son, Nathan's parents dropped their employer-sponsored plan and enrolled in a QHP. Fortunately for Nathan, his family lives in one of the 29 states where autism services are included as a covered benefit in

the state's EHB package. Insurance coverage for ABA has saved Nathan's family thousands of dollars per year.

Coverage of costly but important treatment modalities such as ABA can improve a child's functioning and provide financial relief to families. Furthermore, the complexity of coverage decisions for families with children on the autism spectrum makes ACA navigators—particularly those trained to work with families who have children with complex health conditions—an invaluable resource during the health insurance enrollment process.

Alternative Pathways to Obtaining Coverage of ABA:

Medicaid supplemental coverage: Some children who have private insurance coverage, through a QHP or an employer-sponsored plan obtained outside the Marketplace, may also be eligible for secondary coverage under Medicaid. In such cases, Medicaid can serve as a payer for uncovered services such as ABA. As a secondary payer, Medicaid can also cover co-payments and deductibles.

Child-only plans: The ACA requires health insurers who offer coverage through the Marketplace to also offer “child-only plans.” In a state with an autism insurance mandate, a child receiving coverage through a child-only plan could receive ABA services.

ACA Coverage for Native Americans

Access to affordable and appropriate health care on Native American reservations has been historically challenging. The federal Indian Health Service (IHS) is the primary source of health care for more than two million Native Americans who are members of federally recognized tribes. The ACA has provided thousands of Native Americans with additional choices for affordable health care. Tribes have boosted coverage rates through the use of indigenous outreach and enrollment navigators (also known as “*cultural brokers*”) who possess knowledge of specific tribal communities and their cultural practices.

The Sun Dance is one of the most important ceremonies practiced by Native Americans. For the Plains Indians, it is a challenging and enduring spiritual ceremony, which symbolizes rebirth, renewal and healing. For Mina, a mother and grandmother, it was a 40-year tradition until rheumatoid arthritis made her unable to dance. In addition to arthritis, Mina also suffered from diabetes.

Employer-based insurance was unaffordable for Mina. Like many Native Americans, she sought health care through the IHS. But many tribes consider the IHS network of hospitals, clinics and health stations to be unequally distributed and underfunded, making it difficult to meet the health care needs of all Native Americans. At IHS, Mina's doctors had recommended double knee surgery. The waiting time to have the surgery at an IHS facility was inordinately long, and Mina could not afford to have the procedure done at a local hospital. Instead, she took medication, sought spiritual healing and used herbal remedies, which did little to alleviate the pain.

Mina lives in a state with a large Native American population that did not expand its Medicaid program. Nevertheless, the state has an effective ACA outreach and enrollment effort focused on the Native American population, using culturally appropriate messaging. Mina was able to purchase QHP coverage for herself with reasonable deductibles and co-pays. Recently, Mina was able to have a double knee replacement at a private hospital. Mina's experience influenced her decision to become an ACA navigator, whereby she is able to help other Native Americans get the information they need to obtain coverage.

Across the country, tribes, health care advocates, cultural brokers and navigators are promoting the ACA as an option for Native Americans to receive treatment from private doctors and hospitals. In addition, as growing numbers of Native Americans gain coverage through QHPs, IHS health centers will become less overburdened and more able to

offer timely care, which will broadly benefit the Native American population.

ACA Coverage for Immigrant and Refugee Women

Under the ACA, [legal immigrants](#) are eligible to purchase QHP coverage in the Marketplace. However, insufficient access to interpreters, lack of knowledge about the specifics of ACA coverage, fear of deportation and other barriers can impede enrollment.

Zeb was a pregnant Laotian refugee who had been living and working in the U.S. legally for four years, but was uninsured. Pregnancy complications related to her diabetes led to job loss and financial hardship due to mounting medical bills. Zeb had a weak command of English. With no access to professional interpretation, Zeb and her health and social service providers were unable to communicate with each other effectively. Without this resource, she was unable to obtain important information regarding her insurance coverage options. Finally, the public health department in her state referred Zeb to a Family Voices health insurance navigator.

Zeb and the Family Voices navigator engaged Zeb's partner as an informal interpreter. His English was limited, and he had no knowledge of medical or insurance terminology. Through limited three-way communication, the navigator was able to ascertain important information that would determine Zeb's coverage options. Although Zeb was reluctant to share details of her decision to migrate to the U.S., the navigator determined that Zeb had formal refugee status. Refugees, as lawfully present immigrants, are eligible for the same protections and benefits under the ACA as U.S. citizens, and are exempt from the five-year waiting period to receive Medicaid. Despite the involvement of a navigator, the path for Zeb to enroll in coverage was complicated due to misunderstandings of the ACA as it applies to immigrants and refugees.

Marketplace representatives in her state were not aware that refugees were eligible to purchase QHP coverage. Similarly, when Zeb applied for Medicaid, she was incorrectly informed that she needed to complete the five-year residency requirement prior to enrollment. When the misinformation was finally corrected, Zeb was enrolled in emergency Medicaid.

Three days before she gave birth, Zeb was notified that she would receive QHP coverage for herself and her baby. Zeb's state also agreed to back-date her emergency Medicaid coverage for 90 days, to pay for her third-trimester expenses.

Refugee status is a form of protection that may be granted to people who meet the definition of refugee, are of special humanitarian concern to the U.S., and are unable or unwilling to return to their home country because of the potential for serious harm. The benefits and protections in the ACA are particularly important for refugees, who often arrive in the U.S. after years without access to proper medical care, and in many cases work for employers who do not provide health insurance.⁶

Immigration and Citizenship Verification:

To ensure access to Marketplace coverage, the ACA mandates that only the person applying for coverage be required to present proof of legal residency status. Furthermore, no information about immigration status collected in the Marketplace enrollment process can be used for immigration enforcement. In addition, several states have provisions in their Medicaid laws to provide prenatal care to pregnant women regardless of immigration status.⁷

ACA Coverage for Young Adult Women

College is a time of intense transition and for many students, health care coverage is not a priority. Decisions about health insurance coverage are often delayed until an emergency occurs, at which time many young adults are faced with paying for health care services out of pocket.

Maddie was a 20-year-old college student living in a non-Medicaid expansion state. Initially covered as a dependent on her family's health insurance policy, Maddie lost her coverage when her parents divorced. Once divorced, neither parent could afford dependent coverage, thus leaving Maddie uninsured.

An active young woman, Maddie took a hard fall and broke her arm during a soccer game. Being uninsured, Maddie was financially responsible for the treatment of her broken arm, which included the emergency room visit, casting, and subsequent physical therapy. Her wages from her job at a local restaurant were insufficient to pay her medical bills.

The financial burden of her injury prompted Maddie to realize the importance of health insurance coverage. The ACA navigator at Maddie's college explained her coverage options, including federal subsidies for which she might qualify, and helped her enroll in an affordable QHP. With her QHP coverage, Maddie will be covered for accidental injuries, as well as regular preventive care.

Under the ACA, private health plans must provide coverage for a range of preventive services, including well-woman visits, contraception, HIV and sexually transmitted infections counseling, domestic violence screening and other services, all without cost-sharing. These requirements apply to all private plans—including individual, small group, large group, and self-insured plans, except those plans that maintain grandfathered status.

Catastrophic Health Plans:

In addition to standard QHPs, people under 30 can enroll in catastrophic health insurance plans, also sold through the Marketplace, which have low monthly premiums and high deductibles. In addition, the ACA allows young adults to remain as dependents on their parent's insurance plans until the age of 26.

Conclusion

These five case studies illustrate some of the benefits of the ACA's new coverage options for women and families with children and youth with special health care needs (CYSHCN). These include savings on out-of-pocket expenses for preventive care and payment for services that were often denied prior to passage of the ACA, such as Applied Behavioral Analysis (ABA) for children on the autism spectrum.

These stories also illustrate the challenges that remain in closing gaps in care and ensuring appropriate coverage for vulnerable populations. Network adequacy and rules regarding use of out-of-network providers in QHPs warrant further examination. These issues are particularly important for families with CYSHCN.

Enrollment practices tailored to the needs of ethnically and linguistically diverse communities, such as Native American and immigrant populations, can increase coverage and access to care. To achieve this goal, navigators must be recruited from these communities and properly trained. Additionally, health care, public health and social service personnel must be trained in the basics of ACA coverage—and in the use of culturally appropriate communication—in order to potentially boost enrollment in QHPs. Strengthening interpretation services, which are mandated by the ACA, may also improve enrollment, particularly among immigrant populations.

Although challenges remain, QHPs offer the opportunity for improved coverage and access to care for vulnerable populations.

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AMCHP Contact Information

This issue brief is part of a series of AMCHP tools, documents and resources on implementation of the Affordable Care Act and its impact on maternal and child health populations. For more, please visit the [National Center for Health Reform Implementation](#). All AMCHP staff can be reached via phone at (202) 775-0436.

End Notes

¹ As a result of the ACA, in 20 states, children were moved from CHIP to Medicaid, when the Medicaid eligibility threshold for all children under the age of 19 was raised to 138 percent of the Federal Poverty line (FPL). Many parents also gained coverage in states that expanded their Medicaid programs to include all adults under 138 percent of the FPL.

² Center for Medicare & Medicaid Services. Health Insurance Marketplace Open Enrollment Snapshot: <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-02-04.html>

³ Centers for Medicare & Medicaid Services. *Key Priorities for Federally Facilitated Marketplaces (FFMs) Compliance Reviews for the 2014 Benefit Year*. Retrieved 3/4/16 from: https://www.cms.gov/CCIIO/Resources/Forms-Reports-and-Other-resources/Downloads/Compliance_Review_Table_032814_508.pdf

⁴ Autism Speaks. *Coverage for ABA through the Health Insurance Marketplace*. Retrieved 3/3/16 from: <https://www.autismspeaks.org/node/300226>

⁵ Additionally, there are 41 states that have autism insurance mandates, which require all fully-funded, state-regulated (non-QHP) insurance plans to provide ABA services to young children with autism. These state mandates generally do not apply to self-funded, or employer-sponsored plans,

which are covered under federal ERISA law (see: <http://www.autismhealthinsurance.org/resources/which-states-have-autism-mandates>).

⁶ The Refugee Health Technical Assistance Center (RHTAC). *Affordable Care Act*. Retrieved 3/4/16 from: <http://refugeehealthta.org/access-to-care/affordable-care-act/>

⁷ The Hastings Center, *Undocumented Immigrants and Access to Prenatal Care: Relevant State-Level Policy Provisions*. Retrieved 3/4/16 from: <http://www.undocumentedpatients.org/wp-content/uploads/2014/09/Access-to-Prenatal-Care-Chart.pdf>

The Association of Maternal & Child Health

Programs (AMCHP) supports state maternal and child health (MCH) programs and provides national leadership on issues affecting women and children. AMCHP works with partners at the national, state and local levels to promote women's health; provide and promote family-centered, community-based, coordinated care for women and children; and facilitate the development of community-based systems of services for women, children and their families.

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. Working with family leaders and professional partners at the local, state, regional and national levels since 1992, Family Voices brings a family perspective to improving health care programs and policies and ensuring that health care systems include, listen to, and honor the voices of families.