

***Health Reform and Immigrant Children,
Youth, and Families:
Opportunities and Challenges for
Advancing Behavioral Health***

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Kaela, the mother of a Somali family of five, was happy to come to the United States. Somalia had experienced civil war, famine, and drought, and Kaela worried about the future of her family. She had learned to “keep her head down” and not ask too many questions to survive. Most of her children were adjusting well to their new home, but Aliya, her 10-year-old daughter, was not. Though she was excited about her new school, Aliya had nightmares and was startled by loud noises and unfamiliar sounds. When Aliya went to get immunizations to attend school, the nurse told Kaela that her daughter’s difficulties were “only a phase.” Kaela politely accepted the nurse’s advice, but continued to worry that she should look for more care for her daughter.

Few situations pose a greater adjustment challenge than moving to a new country. Situations that motivate families to relocate to the United States, as well as circumstances surrounding their moves, sometimes can compound existing health conditions. Studies have shown that a child’s migration experience can have a significant impact on his or her mental health status,¹ as numerous immigrant children and youth reach the United States emotionally distraught, wounded and needing mental health services.² Unfortunately, many immigrant children and youth in the U.S. endure severe and pervasive disparities in health status and outcomes, facing barriers to quality health care, public health, and especially mental and behavioral health services.

In March 2010, President Barack Obama signed into law the landmark Patient Protection and Affordable Care Act (P.L. 111-148) and Health Care and Education Reconciliation Act of 2010 (P.L. 111-152). Together, those two pieces of legislation form the most significant reform of our health care system in more than 40 years. Generally referred to as the Affordable Care Act (ACA) or Obamacare, that historic reform recognizes the impact of disparities in health status, health insurance coverage, treatment, and health services on vulnerable populations in the United States. It prioritizes the reduction of such disparities, as well as advancement of health equity in state and community systems of care.

¹ Perreira, K. & Ornelas, J. (2011). The physical and psychological well-being of immigrant children. *The Future of Children*, 21(1), 195–218. Retrieved from <http://www.jstor.org/stable/41229017>.

² Potochnick, S. & Perreira, K. (2010). Depression and anxiety among first-generation immigrant Latino youth: Key correlates and implications for future research. *Journal of Nervous and Mental Disease*, 198 (7), 470–7.

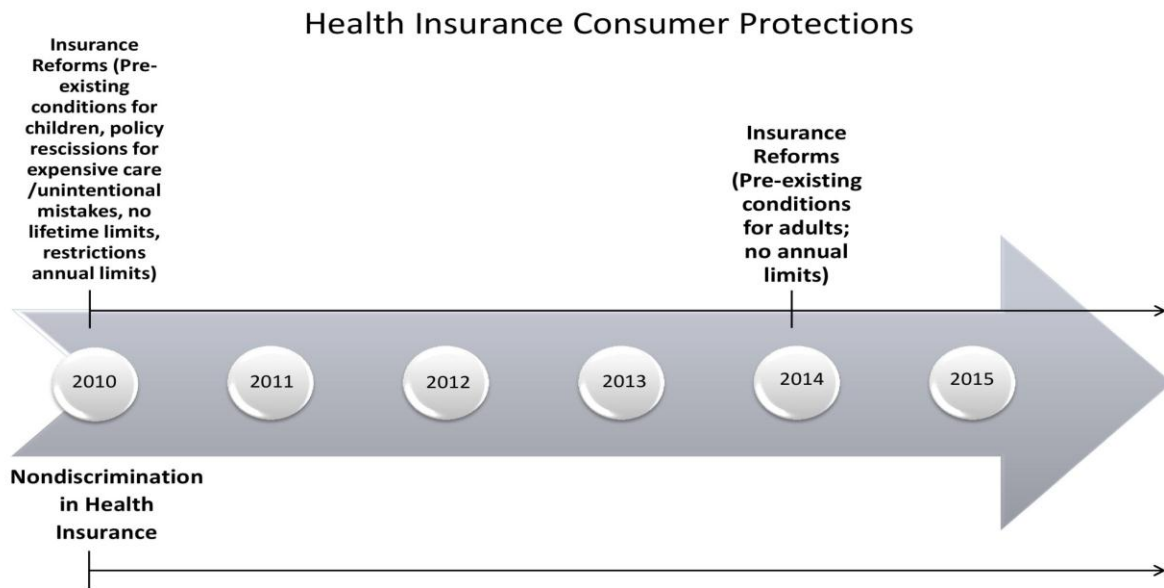
For children, youth, and families who have immigrated to the United States, however, the ACA presents certain challenges as well as benefits. It does not apply equally to all immigrants. Instead, the ACA's strict guidelines delineate which immigrant populations are eligible to gain access to the new health care benefits. This issue brief provides substantial insight into how the ACA addresses the unique health care challenges confronting children, youth, and families who have immigrated to the United States.

I. ACA Strengthening Protections for Children, Youth, and Families

Problems that have limited health care for many Americans:

- Individuals who are sick and have a pre-existing condition have a difficult time finding a health plan to cover them (Kaiser Family Foundation, 2008).
- Those who have managed to acquire health insurance coverage have found their policies rescinded or cancelled when they got too sick and the cost of treatment got too high (Robert Wood Johnson Foundation, 2009).
- Health insurance plans commonly have annual and lifetime limits, essentially leaving individuals facing a substantial health crisis financially unprotected (U.S. Department of Health and Human Services, 2010).

In September 2010, ACA provisions began to phase out those problems.



ACA prohibits health plans from imposing pre-existing condition exclusions³ for children, youth, and adults. Traditionally, health insurance plans frequently have charged patients more for, have limited, or even denied coverage to people who already had an illness or disability. Many people with coverage found that their insurance companies had used a technical provision to deny payment for services when a person got sick.⁴ In some cases, insurers rescinded or terminated an individual's coverage because of an inadvertent mistake. The ACA makes all such practices illegal, and ensures that being sick or having a disability no longer can prevent you from getting health insurance coverage, nor require you to pay more for coverage because of those conditions.

Since 2010, health plans also have been prohibited from denying coverage or charging a higher premium to children and youth under age 19 based on a pre-existing condition such as serious emotional disorders, substance use, diabetes, high blood pressure, cancer, or HIV/AIDS. Beginning in 2014, that same protection will extend to all adults age 19 and over. There is an exception for "grandfathered" individual health insurance plans (the kind you buy for yourself, not through an employer). But if you have a grandfathered plan, beginning in October 2013 you can apply to switch to a qualified health plan through your health insurance marketplace exchange to secure coverage for your pre-existing condition as of January 1, 2014. In addition, insurers no longer will be allowed to discriminate against women by charging more for their coverage on the basis of gender, nor will they be allowed to charge individuals higher rates because of their health status.

ACA prohibits health plans from rescinding or terminating insurance policies when an individual gets sick. Since 2010, ACA has prohibited health plans from canceling or rescinding an individual's coverage solely because his or her health needs become expensive to treat, or because he or she made an unintentional mistake on insurance forms. In cases of clear fraud, companies still may rescind coverage. This prohibition ensures that vulnerable persons who suffer from high rates of chronic conditions, such as serious mental illnesses, serious emotional disturbance, substance use, HIV/AIDS, cancer, and heart disease, are able to obtain coverage and remain insured.

ACA prohibits health plans from imposing lifetime and annual coverage limits. Traditionally, health insurance plans frequently have limited the dollar amount of care that people could receive, both within a single year and over the course of their lifetimes. Such limits caused great financial hardship to people fighting serious or chronic illnesses and conditions. Since 2010, the ACA has prohibited all health plans from imposing lifetime dollar

³ Final regulations define "pre-existing condition exclusion" as a denial of coverage, or limitation or exclusion of benefits, based on the fact that the individual denied coverage or benefits had a health condition that was present before the date of enrollment for the coverage (or a denial of enrollment), whether or not any medical advice, diagnosis, care, or treatment was recommended or received before that date. This would include exclusions stemming from a condition identified via a pre-enrollment questionnaire or physical examination, or the review of medical records during the pre-enrollment period.

⁴ <http://www.hhs.gov/healthcare/facts/timeline/timeline-text.html>

limits on essential health benefits; in addition, it has restricted all health plans from imposing unreasonable annual dollar limits on the amount of insurance coverage a patient may receive. In 2014 health plans will be banned from imposing any annual dollar limits. (The ACA does, however, allow the U.S. Department of Health and Human Services [HHS] to waive restrictions on annual limits in cases where a health plan or employer shows they would result in a significant increase in premiums or a significant decrease in access to benefits for covered members.)

ACA limits insurers' overhead costs. Since September 2010 health plans now are required to spend at least 80 percent of members' health insurance premiums on health services, as opposed to administrative costs. In any year that an insurance company fails to meet the 80-20 medical loss ratio, it must provide a commensurate rebate to its customers. The White House recently reported⁵ that 8.5 million Americans will receive rebates this year averaging \$100 each as a result of this provision.

ACA requires a fair and effective internal and external appeals process. Since 2010, health plans have been required to establish effective appeals processes with states for coverage determination and claim denial disagreements. That rule provides a way for consumers to appeal coverage determination or claim denials through a process outside of their insurance companies. The ACA also requires health plans available through health care marketplace exchanges in every state to present their members with a summary of benefits and coverage, notices about internal and external appeals processes, all in a culturally and linguistically appropriate manner. Any other information also must be presented in plain language.

Opportunities to Collaborate with Nonprofit, Tax-exempt Hospitals

- Hospitals that wish to qualify as nonprofit and tax-exempt now are required to conduct a community health-needs assessment once every three years to determine how well they are meeting the needs of their community. This expands opportunities for care systems to partner with local hospitals to ensure that the behavioral health needs of their children and youth are addressed in the course of those community health needs assessments.
- Nonprofit, tax-exempt hospitals now are prohibited from using extraordinary and aggressive collection practices to pursue bad debt, and must offer patients financial assistance as well as limit the charges to people who qualify for assistance. Their financial-assistance policies must be posted in easily accessible places for patients and community members. (Failure to meet those requirements incurs a \$50,000 tax penalty for the hospital.)

⁵ http://www.whitehouse.gov/share/health-care-rebate?utm_source=email&utm_medium=email&utm_content=email222-text1&utm_campaign=healthcare

II. Health Insurance Benefits

The ACA intends to provide individuals and families with more complete health care coverage than has been provided typically in the health insurance marketplace. It achieves this in two ways: by setting up minimum standards that all “qualified health plans” must meet, and by eliminating many limitations and restrictions that previously left people without coverage when they needed it the most.

A. Essential Health Benefits

The ACA sets up minimum standards of coverage that health plans must provide. In particular, all health plans sold in the new health insurance exchanges or marketplaces (including Qualified Health Plans [QHPs]: individual, small-group, and Medicaid benchmark plans) must provide a broad set of coverage known as “essential health benefits.” Each QHP must provide at least a defined minimum benefit in every one of the following 10 categories of services:

- ambulatory patient services
- emergency services
- hospitalization
- maternity and newborn care
- mental health benefits and substance use disorder services
- prescription drugs
- rehabilitative and habilitative services and devices
- laboratory services
- preventive and wellness services and chronic disease management
- pediatric services, including oral and vision care

To accomplish that, each state begins by selecting what is called a benchmark plan: an existing, popular health insurance plan that will serve as a starting point to define what services will be covered in the essential health benefits package. Those benchmark plans have now been selected by every state and approved by the federal government.⁶ The scope (that is, *what* is covered) and amount (that is, *how much* is covered) of benefits in each state’s benchmark plan largely will define the scope and amount of benefits covered in each of the 10 categories of essential services. For example, the maternity and newborn care services that a state’s benchmark plan covers basically will define the maternity and newborn care services that that state’s essential health benefits must cover.

On the other hand, in most cases, a state’s essential health benefits package also will incorporate the limits on services included in its benchmark plan (i.e., limits on the amount of services, and

⁶ Center for Consumer Information & Insurance Oversight, Center for Medicaid Services. Retrieved September 9, 2013, from <http://www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html>

prior authorization requirements). The ACA prescribes some restrictions on such limits through, for example, “nondiscrimination requirements” that all QHPs must meet. Benchmark plan requirements that violate nondiscrimination requirements for essential health benefits cannot be incorporated into that state’s essential health benefits package. State-defined essential health benefits certainly may opt to provide more benefits than those minimums required by the ACA. States that exercise that option are financially responsible for the additional costs of additional benefits.

B. Preventive Services at No Cost to Patients

One of the most important expansions in the scope of health care coverage under the ACA is the requirement of free coverage⁷ of preventive services. The ACA requires most health plans to offer a nationally consistent set of services that can prevent avoidable pain and suffering, as well as the need for more expensive health care treatment for problems that might otherwise go undetected until they worsen. Covered preventive health care services include well-child visits, childhood immunizations, and indicated iron and fluoride supplements; flu shots; Pap smears and mammograms for women; and evidence-based screenings and counseling, including colonoscopy screening for colon cancer in adults; behavioral and developmental assessments; and screening for autism, vision impairment, lipid disorders, tuberculosis, and certain genetic diseases for children.⁸

Before ACA provisions took effect, some health plans already covered preventive services, but millions of Americans were enrolled in health plans that did not. According to the Kaiser Family Foundation’s Employer Health Benefits Survey in 2012, more than two workers of every five with employer-sponsored group health plans have gained access to expanded preventive services at no cost to themselves.⁹ Recent Census Bureau data show that 173 million Americans ages 0–64 are enrolled in private health coverage,¹⁰ suggesting that in 2011 and 2012, more than 70 million Americans already had received expanded coverage for preventive services with no out-of-pocket cost.

C. Mental Health Parity and Addiction Equity

Historically, health insurance plans (especially employer-sponsored and other private insurance policies) tended to provide a far lower level of coverage for mental health treatment than for

⁷ That is, health plans may not charge any copayments, deductibles, or co-insurance to patients receiving these services.

⁸ US Preventive Services Task Force. *USPSTF A & B Recommendations*. Retrieved July 11, 2013, from <http://www.uspreventiveservicestaskforce.org/uspstf/uspstabrecs.htm>

⁹ Kaiser Family Foundation, and Health Research & Education Trust (2013), *Employer Health Benefits: 2012 Annual Survey*. Retrieved July 11, 2013, from <http://kff.org/private-insurance/report/employer-health-benefits-2012-annual-survey/>

¹⁰ Benjamin D. Sommers and Lee Wilson (2012), *Fifty-four million additional Americans are receiving preventive services coverage without cost-sharing under the Affordable Care Act*. Washington DC: U.S. Department of Health and Human Services, ASPE Office of Health Policy. Retrieved September 9, 2013, from <http://aspe.hhs.gov/health/reports/2012/PreventiveServices/ib.pdf>

other (“physical” or “primary”) health care needs. Significant restrictions on behavioral health clinical services, including therapy sessions and prescriptions, were commonplace.

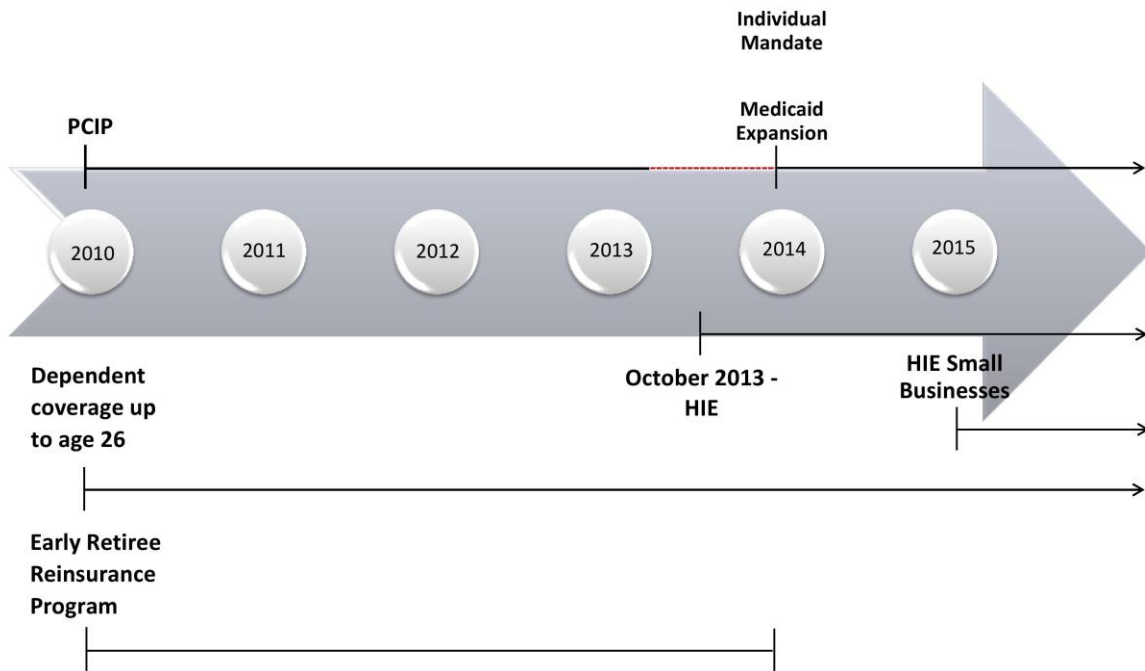
During the 1990s and since, a series of national laws and regulatory changes have prodded coverage for mental health and substance use problems to resemble more closely coverage for other health concerns—an equivalency referred to as “parity.” The 2008 Mental Health Parity and Addiction Equity Act (MHPAEA) ensures that children, youth and adults with mental health disorders, such as anxiety, depression, and substance use disorders, have better access to the treatment they need. The law requires private health insurance plans to provide equal coverage for mental health care as for physical health care. Adding one more missing piece to the “parity puzzle,” the ACA extends application of MHPAEA to qualified health plans that will be sold beginning January 2014 within the health insurance marketplace exchanges.

III. Coverage Expansion

An important aim of the ACA is to expand health care coverage for people who either have lacked health care coverage or whose coverage has been so limited or expensive that it has created great hardship for them, often to the point of having to delay or forego necessary health care. Not surprisingly, lack of health insurance coverage equates to less access to appropriate health services for many children, youth, and families, which contributes to the continuation of disparities in health status and health care. A key component of the ACA, therefore, is eliminating not only the disparities in health insurance coverage that many vulnerable populations experience, but also advancing equity in health status, services, and treatment. The law fulfills this goal by implementing a series of temporary (Pre-Existing Conditions Insurance Plan [PCIP] and Early Retiree Reinsurance Program [ERRP]) and permanent programs and initiatives (Health Insurance Exchanges and Medicaid Expansion). The Center for Consumer Information and Insurance Oversight¹¹ is charged with helping to implement many of these provisions.

¹¹ <http://cciio.cms.gov/>

Health Insurance Coverage Expansion



Temporary Health Insurance Programs

Both temporary health insurance programs that were established in 2010 (the PCIP and ERRP) no longer accept new enrollees. Those individuals who currently are enrolled in these programs will continue to receive benefits until the health insurance exchanges or marketplaces are established and fully operational, or until Medicaid is expanded at the individual states' option.

Permanent Health Insurance Programs

A. Dependent Coverage

Since 2010, the ACA has required insurance plans that cover dependent children to offer that coverage to adult children up to age 26. Health plans must provide that coverage to all eligible dependents, including those who are (1) not enrolled in school, (2) not dependents on their parents' tax returns, (3) married, or even (4) eligible for other insurance coverage. Those decisions now are up to each family. (There have been some exceptions to this requirement for some "grandfathered" plans, but those exceptions will cease by the first plan renewal date after January 1, 2014.)

Mei and David Tian came to the United States with their son, Bao, from China five years ago. They each work in different high-tech start-up companies, where their skills are in demand. They have good health insurance through David's employer, and were delighted when the new health care law allowed them to keep Bao on their insurance after he turned 18. He went to a private college in a neighboring state, and had a successful freshman year. The following year, though, Bao found it increasingly difficult to get out of bed, concentrate on his school work, or even make it to his classes. Bao returned home after the first semester. His parents sought an outpatient therapist, who recommended medications and a day program for Bao. Although his parents were uncomfortable with both recommendations, they did not want to challenge the "doctor." They began treatment for their son and later found other options through their health insurance.

For young people who were in foster care and enrolled in Medicaid at age 18 (or older, in states that extend foster care beyond age 18), the ACA now allows them to retain Medicaid coverage until they turn 26. This extension of coverage is important, as children and youth in foster care—often as a consequence of maltreatment—have high rates of acute and chronic medical and developmental problems. (Children in foster care use mental health services, both inpatient and outpatient, at a rate 15–20 times higher than the general pediatric population. Approximately 80 percent of children in foster care have a chronic medical condition, and 25 percent have three or more chronic health problems.¹²)

B. Medicaid Expansion

The ACA also intends to expand health care coverage by increasing the amount of income that people can have to qualify for Medicaid coverage. The ACA provided that, beginning in January 2014, individuals under 65 years of age with incomes below 133 percent of the federal poverty level would be eligible for Medicaid. For the first time, low-income adults without children would be guaranteed coverage through Medicaid, and parents of children would be eligible at a single, uniform income level across all states.¹³

In June 2012 the U.S. Supreme Court's landmark ruling on the ACA had the practical effect of allowing each state the option of choosing whether to participate in Medicaid Expansion. As of this writing, 29 states and the District of Columbia have decided to do so, 15 have decided not to, and six more states are still weighing their options. Some states sought and received permission to begin their Medicaid eligibility expansion without waiting until January 2014. There is no actual deadline by which states have to make their decisions, and it is even possible for states to

¹² <http://ccf.georgetown.edu/all/implementing-the-acas-extension-of-medicaid-to-former-foster-youth/>

¹³ <http://www.medicaid.gov/AffordableCareAct/Provisions/Eligibility.html>

change their decisions over time. Because this situation has been changing rapidly, you can check a special Kaiser Family Foundation website¹⁴ for updated news about your state.

C. Health Insurance Exchanges/Marketplaces

The law requires the creation of new state-based health insurance exchanges beginning October 1, 2013, to provide individuals and small businesses with a competitive “marketplace” to compare prices and benefits of qualified health plans and purchase health insurance. Some states will operate their own marketplace exchanges. Other states will operate an exchange in partnership with the federal government, and the remaining states will have a federally facilitated marketplace. As with any marketplace, consumers will be invited to “shop” at their exchanges—for affordable health care coverage.

The new marketplaces will operate much like online travel portals such as Travelocity and Expedia, and will guarantee that individuals with incomes above the federal poverty level can get insurance, regardless of pre-existing conditions, with subsidies available to offset much or most of the cost. In other words, this will help individuals who have been unable to obtain coverage through their employers, and who do not qualify for Medicare or Medicaid, to obtain affordable coverage of essential health benefits. Subsidies in the form of tax credits will be available to more than 3.5 million individuals and their families to purchase insurance through the exchanges if they have incomes between 100 percent and 400 percent of the federal poverty level. Using 2013 figures, individuals with incomes between \$11,490 and \$45,960—and families of four with incomes between \$23,550 and \$94,200—are eligible for subsidies to help them afford health insurance coverage in the marketplace exchanges.

2013 Federal Poverty Guidelines						
Family Size	100 percent	133 percent	150 percent	200 percent	300 percent	400 percent
1	\$11,490	\$15,282	\$17,235	\$22,980	\$34,470	\$45,960
2	\$15,510	\$20,628	\$23,265	\$31,020	\$46,530	\$62,040
3	\$19,530	\$25,975	\$29,295	\$39,060	\$58,590	\$78,120
4	\$23,550	\$31,322	\$35,325	\$47,100	\$70,650	\$94,200

¹⁴ <http://kff.org/medicaid/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>

Open enrollment in the marketplace starts October 1, 2013, and insurance coverage will be effective on January 1, 2014. Individuals and small business may visit www.healthcare.gov to find the information they need to prepare for open enrollment.

IV. Who Is Covered by the ACA?

Health insurance coverage mandate. The health reform law requires virtually every citizen, legal permanent resident, refugee, and other documented immigrant in the United States to obtain minimal essential health insurance coverage by January 1, 2014, or else pay a tax penalty of \$95 per year or 1 percent of income—whichever is greater. That penalty will increase to \$325 per year, or 2 percent of income, by 2015; and to \$695 per year, or 2.5 percent of income, by 2016. After 2016, the penalty will increase annually as indicated by cost-of-living adjustments.

Exceptions to Health Insurance Coverage Mandate

The ACA provides pathways to affordable health care coverage for individuals and families with limited incomes who cannot obtain coverage through their employer, and who do not qualify for Medicare or Medicaid. There are, however, some exceptions (see list in box). Of critical interest, *the ACA prohibits undocumented immigrants from obtaining public health care benefits, and from purchasing health insurance coverage through the health insurance exchanges.*

- undocumented immigrants
- financial hardship
- religious objections
- incarceration
- incomes below tax filing threshold
- membership in an American Indian tribe
- those who have been without coverage for less than three months
- those for whom the lowest cost plan option exceeds 8 percent of their household income

V. Documented Immigrants under the ACA

Legal Permanent Resident and Refugee Children and Youth with Behavioral/Mental Health Needs

With the ACA, legal permanent residents and refugees are eligible for the same benefits and protections as U.S. citizens, since they are considered lawfully present immigrants. For legal permanent resident and refugee children, adolescents, and families with mental and behavioral health conditions, this law will be extremely important in guaranteeing their access to mental and behavioral health services, including via the Children's Health Insurance Plan (CHIP). CHIP was

created in 1997 to assist states in providing health insurance for low-income children who lack the financial ability to pay for private insurance, and who are not eligible for Medicaid. Under the ACA, federal funding for CHIP was extended from 2015 to 2019 and, starting in 2014, states must extend Medicaid coverage up to age 26 for young adults who have aged out of the foster care system, including those aging out of the Unaccompanied Refugee Minors program.

Prior to the enactment of the ACA, in 2009, Obama signed into law the Children's Health Insurance Program Reauthorization Act of 2009, which eliminated a five-year waiting period required of children and youth before they were allowed to enroll in CHIP. As a result, legal permanent resident children and youth now may begin receiving mental health services much sooner. However, for adults seeking Medicaid eligibility, a five-year waiting period still is required.

Mariana was married in Columbia when she was just 16. Shortly after her twin daughters were born, her husband began beating her. Her third daughter, Daniela, was born two years later. Mariana tried to protect her daughters, but as they got older, her husband began hitting them, too. Mariana was dependent on her husband and felt unable to change things. One day, as Daniela was walking home, she was sexually assaulted. Mariana loved her daughters dearly and applied for refugee status, hoping life would improve. They were resettled in the United States. Shortly after the move, Daniela's behavior began to frighten her mother. She would cry for long periods and sometimes try to harm herself. Mariana was working at a low-paying job with no health insurance, and she began taking Daniela to the emergency room for care during the worst episodes, at least twice a month. A local health center received a grant to provide health care to immigrants from South America, so Daniela was able to receive limited care there. A case manager at the center was able to help Mariana enroll Daniela in her state's CHIP program; now Daniela's mental health needs are monitored on a consistent basis, and care can be arranged to address her needs as they arise.

VI. Deferred Action for Childhood Arrivals and Other Registered Provisional Immigrants

Deferred Action for Childhood Arrivals (DACA) began on June 25, 2012, and allows undocumented children and youth who meet specific requirements to delay their removal from the country. The removal is delayed for two years, and may be extended if the individual applies for renewal. As long as the individual can show proof of an economic need for employment, he or she is eligible to obtain employment authorization for the period of deferred action.¹⁵

¹⁵ Department of Homeland Security. (2013). *Deferred Action*. Retrieved June 14, 2013, from <http://www.dhs.gov/deferred-action-childhood-arrivals>

Undocumented children and youth who meet all the following requirements can apply for deferred action:

1. They were under age 31 as of June 15, 2012.
2. They came to the United States before age 16.
3. They have resided continuously in the United States since June 15, 2007, up to now.
4. They were physically present in the United States on June 15, 2012, and at the time of making their request for consideration of deferred action with the U.S. Citizen and Immigration Services.
5. They entered without inspection before June 15, 2012, or their lawful immigration status expired as of that date.
6. They are currently in school, have graduated or obtained a certificate of completion from high school, have obtained a general education development (GED) certificate, or are an honorably discharged veteran of the Armed Forces.
7. They have not been convicted of a felony, significant misdemeanor, three or more other misdemeanors, and do not otherwise pose a threat to national security or public safety.¹⁶

Impact of the DACA Policy

The DACA policy could allow as many as 1.7 million undocumented immigrants to receive deferred action.¹⁷ Undocumented children who have a mental illness may apply for deferred action provided they meet the requirements above. Approximately 520,157 requests for deferred action had been accepted in May 2013. Less than 1 percent, or 3,816, of those applicants have been denied deferred action, while 365,237, or more than 70 percent, have been approved.¹⁸ The remaining applications still are being processed.¹⁹

VII. DACA and Undocumented Immigrant Children with Mental Health Issues

All undocumented children, including those who have a mental illness or other behavioral health condition, may apply for deferred action, as long as they have a GED or high school diploma or are currently in school, and had come to the United States before they turned 16 years old, are currently 15 to 31 years old or have lived in the United States continuously since at least June 15,

¹⁶ Department of Homeland Security. (2013). *Deferred Action*. Retrieved June 14, 2013, from <http://www.dhs.gov/deferred-action-childhood-arrivals>

¹⁷ Brannon, J. (2013). "Deferred-Action Counter: Number of Accepted Applications Exceeds 450,000." *National Journal*. Retrieved June 14, 2013, from <http://www.nationaljournal.com/thenextamerica/immigration/deferred-action-counter-number-of-accepted-applications-exceeds-450-000-20121023>

¹⁸ U.S. Citizen and Immigration Services. (2013). *Deferred Action for Childhood Arrivals Process (June 2013)*. Retrieved June 24, 2013, from <http://www.uscis.gov/portal/site/uscis/>

¹⁹ U.S. Citizen and Immigration Services. (2013). *Deferred Action for Childhood Arrivals Process (June 2013)*. Retrieved June 24, 2013, from <http://www.uscis.gov/portal/site/uscis/>

2007. But a successful application under DACA does not mean the young person's mental health needs will be treated.

Indeed, both undocumented immigrants and DACA beneficiaries are not entitled to benefits under the ACA, CHIP or Medicaid, even if they meet all other eligibility criteria. Furthermore, undocumented children and adults, including DACA beneficiaries, are prohibited from obtaining subsidies to purchase coverage in the health insurance exchanges.

Some DACA beneficiaries and undocumented child immigrants might indirectly benefit from the ACA. Any legal permanent residents in their families may be eligible for subsidies to purchase coverage via the health insurance exchanges, or to enroll in Medicaid, thus decreasing the monetary strain on the whole family.

Sofia moved to the United States from the Dominican Republic four years ago to work in her family's bakery. She worried about leaving behind her son, Adrian, and wanted him to have a better life. She planned to send for him right away, but years went by. Adrian, now 13, began having difficulties at school and at home with his grandmother. Sofia decided the right time had come, and Adrian arrived. Once in the United States, she looked for health care for him, but did not have the required paperwork. Adrian's problems began to worsen. Sofia even went to the child welfare office, which can provide Medicaid to children in their custody, and asked for help, though she had heard they might take her son away. Adrian ended up at the emergency room in crisis; he was released a day later. Sofia believes the emergency room failed them. Sofia learned from a family-run organization about a health center that offered help for Spanish-speaking families. They were able to find a local program and get help for her son, even though he was undocumented. As a result, he received services through a private venue that did not use federal funds. In some states, state general funds are used to assist undocumented children and youth, as well as individuals who are ineligible for Medicaid, CHIP, and the health insurance exchanges and marketplaces.

HEALTHCARE.GOV AND CALL CENTER

The federal government has set up a website to help you start to find health coverage that fits your budget and meets your needs at **www.healthcare.gov**. The call center provides assistance in English, Spanish, and more than 150 other languages through an interpretation service as well as linguistically appropriate materials. Customer service representatives are available for assistance via a toll-free number: 800-318-2596. Hearing-impaired callers using TTY/TDD technology can dial 855-889-4325 for assistance. Find out how to contact your state's marketplace exchange at **www.healthcare.gov**; you also can learn more about your marketplace exchange by clicking on your state on the map at <http://kff.org/state-health-exchange-profiles/>.

Consumers in every marketplace exchange will be able to get help with applying for and choosing new insurance options. This assistance will be provided in a number of different ways: through “navigators,” in-person assistance personnel, and certified application counselors. In addition, insurance agents and brokers also will help consumers enroll in new insurance options.

ACA regulations²⁰ require multiple types of navigators to be available to serve you in your marketplace, including a community and consumer-focused nonprofit organization. The navigators are required to be trained to ensure they have expertise in the needs of underserved and vulnerable populations (e.g., rural populations, immigrants). Federal rules mandate that each marketplace exchange must provide consumer assistance, outreach, and education activities to educate consumers about insurance affordability programs and to encourage participation. Federal rules require navigators and other consumer assistance personnel to provide information in a manner that is culturally and linguistically appropriate.²¹

IX. Overview of Key Health Equity Provisions

➤ **Did you know?**

- Most legal immigrants do not qualify for public health benefits until they have been in the country for five years.
- Many immigrants come from cultures where it is considered rude to question a doctor.
- Many newcomers are uncomfortable advocating for their own or their children’s health care and only may do so when there is a crisis.
- Health literacy is a challenge for immigrants in this country. They may not understand what care they can access or how to navigate the health care system.
- Some cultures have great difficulty describing behavioral health problems because their language doesn’t include mental health concepts and terminology.
- Many immigrants can feel alone and scared when seeking health care. Patient navigators can play a crucial role.
- Even immigrants who seem to understand English well may need an interpreter since they will feel stressed during health care appointments.
- In some cultures, it may be difficult to ask for help. The person doesn’t want to ask too many questions or seem too demanding.
- Sometimes people come to the U.S. after traumatic life experiences that can lead to mental health conditions. They may not admit to their challenges until their symptoms become acute.

²⁰ 45 CFR § 155.205(d) and (e)

²¹ Affordable Care Act § 1311(i)(3) and 45 CFR § 155.210(e)

A. Health Equity in the Federal Agencies

Eliminating disparities in behavioral health status and health care, and increasing the cultural competence of service providers, are essential to improving health services for underserved children, youth, and adults. This is especially true for immigrant children and youth among racial and ethnic groups, because evidence shows that behavioral health services currently meet only 13 percent of those needs for children and youth in ethnic and racial groups.²² On the other hand, when services are delivered in a culturally and linguistically responsive manner, service utilization increases, and the rate of early terminations of treatment declines. The lack of attention to the behavioral health needs of children, youth and families who are immigrants; in racial and ethnic minority populations; lesbian, gay, bisexual, and transgender (LGBT); and in other vulnerable populations—as well as the inadequate provision of appropriate behavioral health care in these communities—demonstrates a clear need for encouraging collaboration and finding ways to close the gap in care.

The ACA addresses the unique behavioral health challenges confronting immigrant populations, and carves out critical roles for the government in addressing the issue of disparities in behavioral health. Indeed, the law establishes a priority for health equity among numerous executive agencies within the federal government. Federal agencies empowered to promote health care equity now include the Office of Minority Health (OMH). The ACA transferred that office to the office of the secretary of Health and Human Services, to be headed by the deputy assistant secretary for minority health. The law retains and strengthens the prior authorities that the OMH had to improve health and the quality of health care that people of color and other vulnerable populations receive, as well as eliminate racial and ethnic disparities. The OMH now has the authority to engage in quality measure development and determine where there are gaps in health care services for immigrant populations. For more information, visit www.minorityhealth.hhs.gov.

Additional Offices of Minority Health. The OMH actually will coordinate efforts with an extensive network of agency-specific offices of minority health. Agencies establishing internal offices of minority health include the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMSHA), the Agency for Healthcare Research and Quality (AHRQ), the Food and Drug Administration (FDA), and the Centers for Medicare & Medicaid Services (CMS). For more information on this network, visit <https://minorityhealth.hhs.gov/npa/> and click on the link for offices of minority health.

Office of Women’s Health. The ACA established an Office of Women’s Health (OWH) in the office of the secretary of Health and Human Services. OWH is charged with:

²² Stagman, S. & Cooper, J. (2010). Children’s Mental Health: What every policymaker should know. National Center for Children in Poverty, Mailman School of Public Health, Columbia University.

- Developing short- and long-range goals and objectives that relate to disease prevention, health promotion, service delivery, research, and public and health care professional education
- Providing expert advice and consultation regarding scientific, legal, ethical, and policy issues relating to women's health
- Monitoring activities concerning women's health
- Establishing a HHS Coordinating Committee on Women's Health
- Establishing a National Women's Health Information Center

The ACA also strengthened existing authority for offices of women's health at the CDC, FDA, and the HRSA, as well as an Office of Women's Health and Gender-Based Research at the AHRQ. For more information on the Office of Women's Health, visit <http://www.womenshealth.gov/>.

National Institute of Minority Health and Health Disparities. The National Center on Minority Health and Health Disparities at the National Institutes for Health (NIH) has been elevated to institute status. The resultant National Institute of Minority Health and Health Disparities will manage expanded research endowments; and will lead, coordinate, review, and evaluate NIH's research and activities on minority health and health disparities. For more information on the new institute, visit <http://www.nimhd.nih.gov/>.

B. Improving Data Collection and Reporting

The Institute of Medicine recognized in 2009 the absence of a comprehensive national system to accurately track disparities in health status and health care and gauge the level of health care and preventive services that vulnerable populations, including immigrants, are receiving (Institute of Medicine, 2009). Without accurate, detailed demographic data it is difficult to know how best to focus efforts to develop culturally and linguistically effective strategies to counter existing disparities.

Acknowledging an expanding body of evidence demonstrating the pervasiveness of health disparities in the United States, the ACA intends to reduce and eliminate health disparities, in part, by improving standards for the collection of data and improving and expanding data collection and reporting efforts. In particular, it required the secretary of Health and Human Services to ensure that by 2012, any federally conducted or supported public health or health care program (including Medicaid and CHIP), activity, or survey collects data on five self-reported variables:

- ✓ race
- ✓ ethnicity
- ✓ gender
- ✓ primary language
- ✓ disability status

The ACA authorizes the collection of data on subgroups, if practicable, and any other demographic data deemed appropriate by the Secretary, including immigrant, underserved rural

and frontier populations. HHS has chosen to approach this work in phases, and started with federal public health and health care surveys in 2012. Standards related to gender identity and sexual orientation will be developed and field tested for inclusion in later surveys. Many immigrant populations and other vulnerable populations experience inequitable care, but inadequate and inaccurate data collection and reporting has hidden the facts. The ACA's data-collection provisions will help to reduce these disparities because health providers no longer will be allowed to make judgments about an individual's race or ethnicity, primary language, and disability status based on their perceptions, or take the collection of data for granted. Instead, health providers will have to take steps to ensure that demographic data is self-reported and documented accurately.

For more information on the data collection and analysis requirements to address health disparities, visit <https://minorityhealth.hhs.gov/section4302/>.

Enhancing Nondiscrimination Protections

Several existing laws address a variety of discriminatory practices in the health care system, but the ACA obligates health care providers to take more active roles in eliminating health disparities among vulnerable groups in the United States. Coupled with the new data collection actions, the ACA's nondiscrimination provisions now provide consumers and providers with legal enforcement mechanisms to ensure that their rights under the law, including their protection from certain discriminatory practices, are upheld. Key nondiscrimination provisions include:

Prohibiting discrimination in health care generally. The health reform law strengthens and expands protections for population groups that have long endured discrimination in access to health care by prohibiting their exclusion from participating in, being denied the benefits of, or being subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance. This prohibition extends to any program or activity administered by any executive agency, or by any entity established under the ACA. The ACA also allows states to choose to provide additional protections.

Prohibiting discrimination in health insurance coverage eligibility. While the ACA recognizes and strengthens existing protections based on race, ethnicity, age, gender, color, religion, and disability, as provided in the Civil Rights Act of 1964, the Americans with Disabilities Act, and the Genetic Information Nondiscrimination Act, it goes further, prohibiting insurers and employers from using any of the following health status-related factors to determine eligibility for coverage:

- Medical condition (including both physical and mental illnesses)
- Claims experience
- Receipt of health care
- Medical history
- Genetic information
- Evidence of insurability (including conditions arising out of acts of domestic violence)

- Disability
- Any other health status-related factor determined appropriate by the secretary

This prohibition is particularly important to women, preventing insurers from denying them coverage or charging them more for coverage than they charge men. Before health reform insurers often based such actions on the premise that their very ability to become pregnant and bear children was, per se, a pre-existing condition. The ACA also prohibits higher costs or denial of coverage to rape victims.

Prohibiting discrimination against health care providers. The ACA also prohibits insurers from discriminating against health professionals with respect to participation under a plan or coverage, so long as they are acting within the scope of their license or certification under applicable state law.

Enhancing Behavioral Health Disparities Research

Significant gaps and gray areas in data that have limited our understanding of the nature and extent of health care disparities provided an important impetus to new research opportunities within the ACA that can underpin improvements in the health care and health status of cultural groups, including immigrant populations. HHS reported in 2001 that rates of mental disorders are not studied adequately in many racial and ethnic groups, both indigenous (American Indians, Alaska Natives) and immigrants (Asian-Americans and some Pacific Islanders), yielding a scarcity of quality research.²³ Studies have recognized that epidemiological studies often fail to include data on vulnerable, high-risk subgroups such as persons who are exposed to violence, homeless, incarcerated, institutionalized, or in foster care.²⁴ The Institute of Medicine noted in 2011 that studies examining issues affecting LGBT individuals have failed to adequately include adolescents.²⁵ Research gaps like those can have significant implications for health care. Low & Hardy (2007), for example, noted that diagnostic criteria developed with one racial group, may not be directly and simply applicable to other racial groups, such that instruments of assessment and diagnosis may be less appropriately applied in different groups.²⁶

The ACA provides unique opportunities to expand the scope of research related to behavioral health disparities, and to identify, develop, and disseminate appropriate pathways to reduce those disparities. President Obama and Congress recognized that a “one-size-fits-all” approach is

²³ U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General. (2001). *Mental health: Culture, race and ethnicity; A supplement to mental health: A report of the Surgeon General*. Rockville, MD: Substance Abuse and Mental Health Services Administration.

²⁴ American Psychological Association. (2009). *Psychological and behavioral perspectives on health disparities*. Washington DC: author.

²⁵ Institute of Medicine. (2011). *The health of lesbian, gay, bisexual and transgender people: Building a foundation to better health*. Washington DC: The National Academies Press.

²⁶ Low, N. & Hardy, J. (2007). *Psychiatric disorder criteria and their application to research in different racial groups*. BMC Psychiatry, 7(1), doi: 10.1186/1471-244X-7-1.

ineffective in both understanding the impact of certain chronic diseases on vulnerable populations including immigrants, and in developing proper treatments for diverse individuals.

The ACA established the Patient-Centered Outcomes Research Institute (PCORI), a private, nonprofit institute that is now responsible for identifying and carrying out national research priorities in comparative effectiveness research (CER),²⁷ in which two or more health care treatments, services, or items are compared for their effectiveness, risks, and benefits. Research might be generated, for example, to test the effectiveness of two drugs created to treat schizophrenia, and their impact on various populations.

PCORI research findings will be used to inform patients, clinicians, purchasers, and policymakers of the best health care practices available to treat health problems across the full spectrum of America's diversity. The systematic reviews of existing research, randomized clinical trials, observational studies, and other research will, as appropriate, take into account differences in the effectiveness of treatment, services, and items across populations, including racial and ethnic groups, women, people of varying ages, and groups with different medical conditions, genetic or molecular subtypes, or quality-of-life preferences.

PCORI has adopted a rigorous stakeholder-driven process that emphasizes patient engagement and uses forums and formal public comment opportunities to increase awareness of its work, and obtain public input and feedback prior to adoption of priorities, agendas, methodological standards, peer review processes or dissemination strategies. For more information on comparative effectiveness research, grant opportunities, or to learn more about PCORI's CER initiatives and provide input and feedback, visit <http://www.pcori.org>

X. ACA Promotes Person-Centered Models Advantageous to Some Immigrants

Evidence shows that good access to primary care can help us live longer and stay healthier. Easier access to primary care is key to improving the quality of health care overall and reducing high medical costs. A "medical home" describes a close partnership between the primary care provider (i.e., family doctor, internist, pediatrician, nurse practitioner) and the patient. The goal is to make sure the patient:

- Gets assistance in navigating the health care system

²⁷ According to the Agency for Healthcare Research and Quality, comparative effectiveness research "is designed to inform health-care decisions by providing evidence on the effectiveness, benefits, and harms of different treatment options. The evidence is generated from research studies that compare drugs, medical devices, tests, surgeries, or ways to deliver health care." For more information about comparative effectiveness research, visit <http://www.effectivehealthcare.ahrq.gov/index.cfm/what-is-comparative-effectiveness-research1/>

- Is included in decisions about treatment
- Receives care that is appropriate and well-coordinated

A person-centered medical home (PCMH) is a team-based approach to health care that includes the person, his or her health care providers, and family members when appropriate. The PCMH aims to organize care management, to treat each person in a holistic way, and to support individuals and families as they work toward self-management goals. Organized care management is especially important for some particular groups of people, including those living with chronic health conditions.

Person-centered medical homes can improve health outcomes and reduce expenses associated with a lack of care coordination, frequent visits to the emergency room, and unnecessary hospitalizations. The PCMH is one of the fastest-growing innovations in health care, and the ACA includes strong incentives for its wider adoption (Section 2703).

Individuals and families from diverse cultures have had less access to high quality primary care in the United States, resulting in worse health outcomes. Disparities in patient/provider communication have affected cultural groups in their receipt of poorer patient-centered care. Populations with limited literacy or English proficiency often encounter challenges to getting critical health information. On the other hand, efforts to improve communication and shared decision making contribute to better outcomes. Simple approaches like inviting family members to medical visits (or acknowledging the presence and roles of family members who accompany the patient) can strengthen the paths of communication. Family companions may be an important bridge to communication barriers in care alongside appropriately qualified and credentialed interpreters.

Nonadherence to medication is associated with worse clinical outcomes, and is disproportionately prevalent among many ethnic groups and cultures due to cost, health literacy or trust barriers. Interventions that enhance shared decision making can improve health outcomes, confidence in treatment and adherence to medication and other medical treatment. The Veterans Administration and Indian Health Service have long used combined Western and traditional medicine approaches with favorable results to treat ailing American Indian patients; and HRSA and SAMHSA promote adaptations of *promotores de salud* (promoters of health similar to community health workers) within culture-spanning community health care teams.

Much of chronic disease self-care involves lifestyle health behaviors such as physical activity or changes in diet. Many immigrants face structural barriers (i.e., lack of access to large supermarkets, neighborhood crime and violence that limit outdoor activity) that can interfere with health-promoting self-care practices. One academic/community partnership in Chicago links health centers, patients, and community resources by using local farmers markets and food

pantries to increase the capacity for self-care and problem solving of patients with diabetes.²⁸ Such models show early promise for reducing disparities.

Medical homes can improve connections to nonmedical resources, and can bolster preventive care by forming linkages with community resources, especially those that provide cultural and linguistic support.

The ACA encourages the use of care management models like the PCMH, and specifically provides a very high portion of the cost of “health homes” to promote a better patient experience, better health care results and a more cost-efficient approach than more traditional care has accomplished.²⁹ While it has many characteristics of the patient-centered medical home, the health home can be customized to meet the specific needs of low-income patients with chronic medical conditions, and is therefore viewed as the next step in improving the patient-centered medical home.

As the ACA helps as many as 35 million more people gain health care coverage, it raises concern that there may not be enough doctors and nurses to meet the increased demand. The ACA includes many mechanisms to recruit and develop a new generation of the health care workforce that can reflect the diversity of the population while growing to meet the new demand and the cultural and linguistic needs of individuals in the United States. In addition, comparative effectiveness research can validate changes in how health care is delivered, relying more on nonphysicians to provide care, and connecting people with supports in their communities that can create opportunities to promote wellness, prevent illness, and enable early detection and intervention. The law invests new funding to bolster not only the primary care workforce, but the mental and behavioral health, community health, allied health, nursing, and other critical health professions and ensure that a new generation of health professionals is trained to provide culturally appropriate health services to all individuals.

XI. Summary

While the ACA offers expanded benefits and coverage, it also presents challenges for children, youth and families who have immigrated to the United States. Legal permanent residents and refugees are eligible for the same benefits as U.S. citizens and will be offered increased options for insurance coverage. Their insurance benefits will include access to no-cost preventative care and coverage for dependents under age 26, which is especially important to families. Undocumented immigrants and beneficiaries of DACA, however, are prohibited from obtaining public health care benefits or from purchasing coverage through the health insurance exchanges and won't receive the full benefit of health care reform.

²⁸ Diabetes Project in Chicago's South Side. *HealthAffairs* (January 2012), 31:1187. Retrieved from <http://content.healthaffairs.org/content/31/1/1187.full>

²⁹ <http://www.integration.samhsa.gov/>

Many immigrants arrive having lived through experiences that affect their mental health and increase their need for behavioral health care. Those who can access insurance coverage through expanded Medicaid access and health plans through marketplaces/exchanges will be able to get their mental and behavioral health needs addressed. While the ACA provides approaches (improved data collection and opportunities for research) that may lead to innovations that reduce disparities in health care, these improvements only will be available to those who have access to care.

APPENDIX

ACA Terminology

The ACA represents a significant change in our national health care policy. Like many such changes, this new law is contributing new terms and phrases into our language that should be understood by those who are working hard to improve systems of care for children, youth and families. Many of those key terms are defined here. A more extensive list of ACA-related terms can be found at <https://www.healthcare.gov/glossary/>.

Deferred Action for Childhood Arrivals: A federal policy implemented on June 25, 2012, that allows undocumented children and youth who meet specific requirements to have their removal from the country delayed for two years.

Dual eligible: An individual who is eligible for Medicare and some Medicaid benefits.

Electronic health records: Digitized files of health information that can include contact information, patient and family history, immunizations, allergies, medications, medical and hospital visits, and insurance information.

Health information exchange: The transmission of health records across organizations such as clinics, hospitals, and health information organizations in a region or system. Such exchanges must ensure reliable and secure transfer of data. Their goal is to access information to provide safer, timely and more effective care.

Health insurance exchange: Beginning in 2014, new health insurance exchanges will be created by states to provide individuals and small businesses with a marketplace of qualified health plans in order to purchase health insurance. Individuals with incomes greater than 133 percent of poverty level can access insurance regardless of pre-existing conditions. Exchanges will assist individuals and small businesses in comparing and purchasing qualified health plans. If a state decides not to establish an exchange, the federal government will establish an exchange in that state.

Health literacy: A person's ability to read, understand and use health care information to make decisions about care and follow instructions for treatment. Studies show that up to half of people receiving care cannot understand basic information. This also contributes to health disparities.

Individual mandate: The ACA requires that most individuals obtain minimum essential coverage or pay a penalty beginning in 2014. Exemptions to this requirement include, but are not limited to, religious objections, individuals with incomes less than 100 percent of federal poverty level, American Indian tribe members, and hardship waivers.

Medicaid (Title XIX of the Social Security Act): A federally and state-funded program that provides medical assistance for certain individuals and families with low income and resources. The ACA expands Medicaid eligibility to non-Medicare eligible individuals with incomes up to 133 percent of the federal poverty level, establishing uniform eligibility for adults and children across all states by 2014.

Medicaid expansion: The ACA expands Medicaid to people under age 65 with incomes up to 133 percent of the federal poverty level. Individuals without dependent children or who are not pregnant will now be eligible for Medicaid in 2014.

Medical neighborhoods: Primary care practices, operating as medical homes, that are aligned with specialists and health systems to provide care that is coordinated and managed. Accountable Care Organizations can be high functioning medical neighborhoods.

Modified adjusted gross income: An individual's adjusted gross income plus any tax-exempt Social Security, interest, or foreign income you have.

Person-centered medical home: A team-based approach to health care that includes the person, his or her health care providers, and family members when appropriate. It aims to organize care management, treat each person in a holistic way, and support individuals and families as they work toward self-management goals.

Shared decision-making: An approach in which the providers of health care and those receiving it collaborate to make health care decisions together.