

BREAKING BARRIERS

Improving Health Insurance Enrollment and Access to Health Care

April 2015



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INTRODUCTION

SIGNED INTO LAW IN MARCH 2010, THE PATIENT PROTECTION AND AFFORDABLE CARE ACT (ACA) aimed to bring the uninsured more fully into the health care delivery system, improve access to health care providers, spur new approaches to patient well-being and disease prevention, attack racial disparities in health care and outcomes in communities of color, and hold providers accountable with respect to costs. To begin making progress on these lofty goals, the first step was getting health insurance coverage to the more than 30 million uninsured through both expanding Medicaid and subsidizing insurance premiums for low- and moderate-income people who would enroll through a “competitive insurance marketplace” or health care “exchange.” Some states developed their own exchanges but most relied on an exchange developed by the federal government.

By January 2015, 29 states, including the District of Columbia, had expanded Medicaid. By February 2015, the official end of the second yearly enrollment period, 11.4 million Americans had signed up for private health insurance coverage through marketplace exchanges.¹ An additional 8.7 million people gained coverage through Medicaid and the Children’s Health Insurance Program (CHIP).² The percentage of uninsured Americans dropped from 18 percent in 2013 to 12.9 percent at the end of 2014.³ By any standard these numbers are impressive. However, as usual, the devil is in the details. How is this newly emerging health care system working on the ground? A closer look by policy makers and advocates alike is in order, if we are to further refine enrollment processes and health care delivery and come closer to the ACA’s goals.

THIS REPORT

With support from the WK Kellogg Foundation, the Alliance for a Just Society conducted grounded research in 10 states (California, Florida, Idaho, Louisiana, Michigan, Mississippi, Montana, New Mexico, Oregon, and Texas) to explore how those who need health care the most—low-income people, immigrants, and people of color—are experiencing ACA implementation. The methodology includes an examination of public data, interviews with state-based navigators, policy and health care professionals, and advocates, and 1,200 surveys in Spanish, Cantonese, and English with low- to moderate-income health care consumers at food pantries, health clinics, and homeless service centers. This report examines the following questions: Who was able to sign up for health insurance? How effective was outreach to underserved communities? How accessible are health care services to newly enrolled patients? And finally, what changes might make the current health care delivery system more effective in serving low-income communities, immigrant communities, and communities of color?

OVERVIEW OF THE ACA ROLLOUT

Thousands of column-inches and web pages exposed the problems of both the federal and state-based marketplace websites in the initial months

By January 2015, 29 states, including the District of Columbia, had expanded Medicaid. By February 2015, the official end of the second yearly enrollment period, 11.4 million Americans had signed up for private health insurance coverage through marketplace exchanges. An additional 8.7 million people gained coverage through Medicaid and the Children’s Health Insurance Program.

of the first open enrollment period that began in October 2013. A Fall 2013 *Wall Street Journal* article pointed to “a design element that requires users of the federal site, which serves 36 states, to create accounts before shopping for insurance.”⁴ Subsequent reports noted that despite an \$840 million price tag the site began with “coding issues that may be complicating account creation,”⁵ and those seeking to enroll experienced numerous site slowdowns, inordinately long waits for online chats, and, even on the last day of enrollment, site crashes.

Despite these technological glitches during the first open enrollment period, close to 20 million people *have* gained health coverage through the marketplaces or expanded Medicaid coverage as of February 2015. But difficulties with enrollment have not been evenly distributed across racial groups or between urban and rural residents.

ENROLLMENT GOALS AND OUTCOMES

Of the 10 states we studied, all but one (Michigan) had higher percentages of uninsured residents than the national average of 17.3 percent in 2013. Several—Texas at 27 percent, Mississippi at 22.4 percent, Louisiana at 21.7 percent, and California at 21.6—were among those with the nation’s highest proportions of uninsured residents. Of the 17 million people expected to qualify for subsidies, the states in our study contained over 7 million; three (Texas, California and Florida) had more than 1 million each, while Mississippi, Michigan, and Louisiana each had between 200,000 and 400,000. The number of uninsured in the remaining four states, Montana, New Mexico, Idaho, and Oregon, ranged between 97,000 and 187,000. Three of the 10 states had opted for Medicaid expansion before October 2013, and one, Michigan, opted to expand Medicaid beginning in April 2014. Six, including Texas and Florida, which had the second and third largest number of tax-credit-eligible residents and the largest share of uninsured Latinos who were potentially eligible for coverage, refused Medicaid expansion (see table 1).

TABLE 1
Percentage of Uninsured Residents and Estimated Number of Tax-Credit-Eligible Individuals and Potential Market for Marketplace Coverage, by State, 2013

	Percentage of Uninsured Residents ⁶	Number of Tax Credit Eligible Residents ⁷	Potential Market Size ⁸	Medicaid Expansion as of October 2013?
National	17.3	17,187,000	28,605,000	
California	21.6	1,903,000	3,291,000	Yes
Florida	22.1	1,587,000	2,545,000	No
Idaho	19.9	130,000	202,000	No
Louisiana	21.7	344,000	489,000	No
Michigan	12.5	436,000	725,000	Yes
Mississippi	22.4	204,000	298,000	No
Montana	20.7	97,000	152,000	No
New Mexico	20.2	118,000	193,000	Yes
Oregon	19.4	187,000	337,000	Yes
Texas	27	2,049,000	3,143,000	No
Total in States studied: 7,055,000				

Despite these technological glitches during the first open enrollment period, close to 20 million people *have* gained health coverage through the marketplaces or expanded Medicaid coverage as of February 2015.

In sum, states' decisions to accept or reject Medicaid expansion was the single most important factor in whether residents in low-income communities and communities of color were able to obtain health insurance.

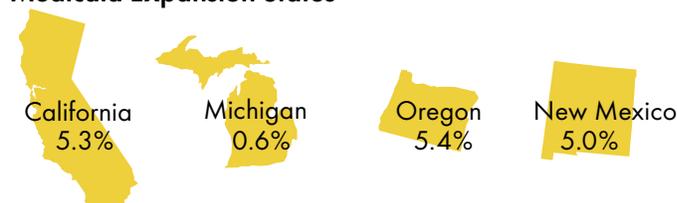
But who was able to sign up for health insurance and who was not? The variable that most accurately predicted the answer was whether the state expanded its Medicaid program.

In the states we studied, the contrasts in successful enrollment between Medicaid expansion and non-expansion states is clear. The percentage of uninsured went down across the board: by an average of 4.1 percentage points in expansion states and 2.9 percentage points in non-expansion states.⁹ And, the 30.8 percent increase in Medicaid and CHIP enrollment in Medicaid expansion states clearly exceeded the 6.8 percent increase in non-expansion states studied.¹⁰ Even more significant was the ongoing difference in the percentage of state residents who remained uninsured: 14.4 percent in expansion states but 19.4 percent in non-expansion states.¹¹

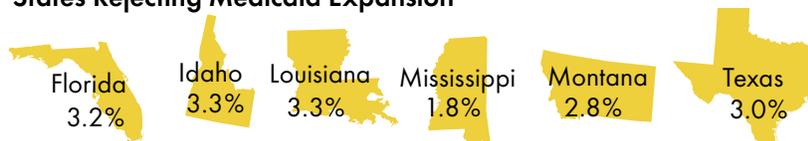
TABLE 2

Reduction in Uninsured (Percentage Points), November 2013-April 2014¹²

Medicaid Expansion States



States Rejecting Medicaid Expansion



In sum, states' decisions to accept or reject Medicaid expansion was the single most important factor in whether residents in low-income communities and communities of color were able to obtain health insurance. And the controversy over Medicaid expansion still rages in a number of states. As Linda Quick, President of the South Florida Hospital and Healthcare Association, points out, "Trying to convince legislators with economic arguments has NOT persuaded the supposedly 'business-oriented' chambers-of-commerce-backed legislators about Medicaid expansion. Their objection is clearly ideological, not practical. 'Florida is losing \$7 million a day' etc. did not move one legislator."¹³ In Idaho, Delmar Stone, Executive Director of the National Association of Social Workers (NASW) observes, "The legislature has taken an ideological stand against expanding Medicaid. No argument, even that it will save money, has moved them. No matter how well enrollment has gone, without Medicaid expansion, it is meaningless for thousands of Idahoans."¹⁴

While failure to expand Medicaid was the biggest barrier to enrollment, it was not the only barrier. In our 10-state survey we found that cost, technology, language access, and difficulty understanding the complexities of health insurance all made the enrollment process more difficult—particularly in communities of color.

TABLE 3

Percentage of U.S. Residents Uninsured in 2010, By Race^{15 16}

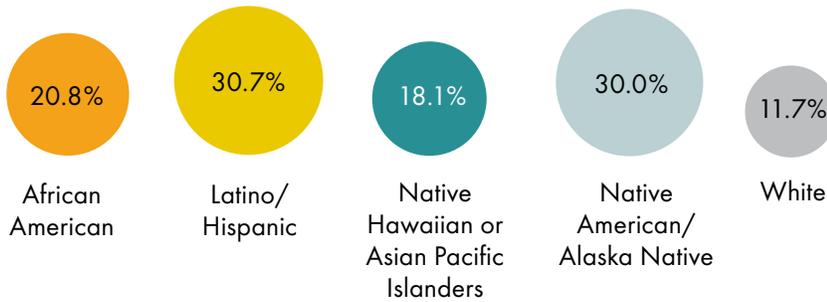
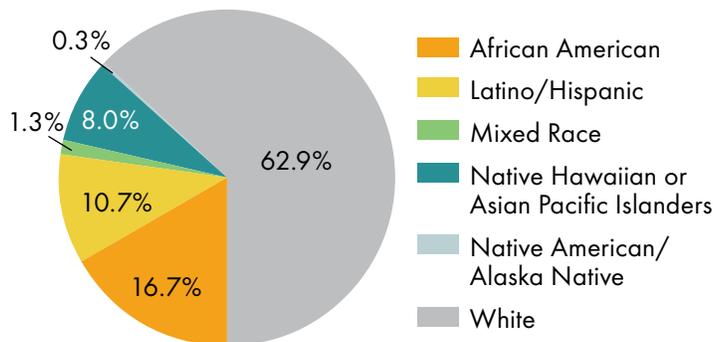


TABLE 4

Distribution of U.S. Marketplace Enrollees through April 2014, by Race (where race/ethnicity is reported)¹⁷



This study treats racial disparities in enrollment and whether coverage leads to care as the primary measure of the ACA's effectiveness for a number of reasons. First, as one of our interviewees, Marino Bruce, Professor of Criminal Justice and Sociology at Jackson State University in Mississippi observes, "the ACA has been framed in a way that has been racialized. For instance, when it comes to Medicaid expansion, the discourse in the media is 'we are against it, and we don't want handouts.' 'Handouts' is racialized language that goes back to the Reagan era. People equate Medicaid to welfare."¹⁸ Second, as table three illustrates, people of color are disproportionately uninsured and a stated purpose of the ACA is to improve the quality of health care for racial/ethnic minorities. Thus both the coded language of many ACA opponents and the reality of health care inequities suggest a very basic question: does the ACA rollout, as currently structured, lessen or exacerbate racial inequities in health care? While it is too early for a definitive answer, examining trends in both enrollment and access to care for whites and people of color can offer some preliminary conclusions.

BASELINE RATES OF INSURANCE

At approximately 30 percent for each group, Latinos and Native Americans were most likely to be uninsured prior to the ACA. African Americans were uninsured at a rate of 21 percent, Native Hawaiians/Asian-Pacific Islanders at 18.1 percent, and whites at 11.7 percent. Nonetheless, in the first enrollment period, whites were 62.9 percent of total enrollees, almost exactly their percentage of the U.S. population (62.6), while Latinos (17.1 percent of the

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population) were under-enrolled both as a percentage of the population and as the group most likely to be uninsured.

TABLE 5
AJS Survey Respondents with Medical Coverage, by Race

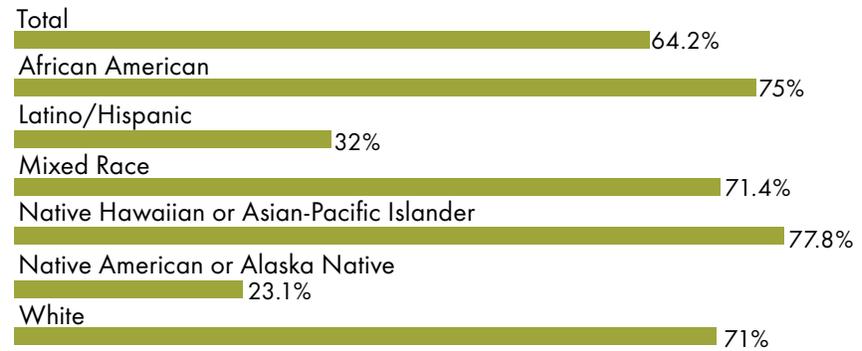
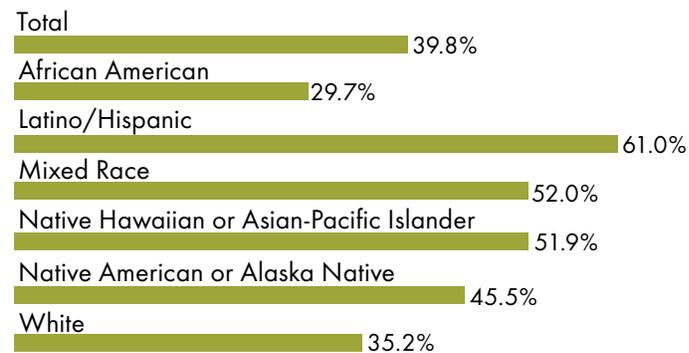


TABLE 6
AJS Survey Respondents with Insurance Coverage Who Obtained Their Coverage within the Previous 12 Months, by Race



As Table 5 indicates, 78 percent of Native Hawaiians/Asian-Pacific Islanders, 75 percent of African Americans, and 71 percent of both whites and people who identified as racially mixed among our survey respondents had medical insurance, compared to 32 percent of Latinos and 23 percent of Native Americans/Alaska Natives. In this sample, about 40 percent of those with medical coverage were new enrollees (Table 6). The highest percentages of those with coverage who were new enrollees were Latinos (61 percent), Native Hawaiians/Asian-Pacific Islanders (52 percent), people who identified as racially mixed (52 percent), and Native Americans/Alaska Natives (46 percent). Whites (35 percent) and African Americans (30 percent) had the lowest percentages of new enrollees. While national sources have found that African Americans and Latinos had substantially larger gains in enrollment than Asian-Pacific Islanders and whites,¹⁹ in our survey the coverage rates for Latinos and Native Americans were disturbingly low. One possible reason for the discrepancy could be our respondent sample, which included homeless and undocumented residents and a substantial number of Native Americans who were uninsured but received health care through the Indian Health Service (IHS). In addition, six of the ten states in our study have rejected Medicaid expansion, increasing the percentage of low-income people sampled who fell into the Medicaid coverage gap.

OBSTACLES TO ENROLLMENT

TABLE 7

Newly-Enrolled AJS Survey Respondents Who Found the Enrollment Process “Somewhat” or “Very” Difficult, by Race

Race/Ethnicity	Percentage who Reported Somewhat or Very Difficult
Total	28.5%
African American	28.8%
Latino/Hispanic	26.9%
Mixed Race	25.0%
Native American or Alaska Native	16.7%
Native Hawaiian or Asian-Pacific Islander	37.5%
White	30.5%

TABLE 8

Enrollment Problems Identified by AJS Survey Respondents Who Got Coverage

Problem Type	Percentage who identified problem
Cost of insurance options	13%
Language issues	12%
Total time required for application/enrollment	11%
Difficulties with the online program	10%

TABLE 9

AJS Survey Respondents Who Did Not Speak English at Home and Who Were Unable to Enroll in Their Own Language



With small variation by race, approximately 29 percent of respondents found the enrollment process either “somewhat” or “very” difficult. Over one-third of Asian-Pacific Islanders found the process difficult, as did 30 percent of whites and over one-fourth of African Americans, Latinos, and mixed race respondents. Specific barriers included costs—identified as the top barrier by both the currently insured (13 percent) and respondents who did not yet have insurance (32 percent)—and language issues (12 percent). Of respondents whose first language was not English, language difficulties were paramount: 13.3 percent of Latinos and 22.2 percent of Asian-Pacific Islanders were unable to enroll in their own language.

“[T]his was hard even in English; people who’d never had insurance, or who hadn’t in a really long time, didn’t understand health insurance lingo and had to be educated.”

Community advocates explained these obstacles further:

Francis Calpotura, Executive Director of the Oakland-based Transnational Institute for Grassroots Research and Action, noted that “the ID e-verify system is set up for middle-class people with a pretty standard credit profile. If you have to submit documents you can wait days for a reply. And if you don’t get verified, the process is even longer. Add translation and the enrollment can take weeks. This is not an immigrant-friendly process—even if you have papers.”²⁰

Charlotte Roybal, director of New Mexico’s Policy Connections, explained that “for enrollment they had an 800 number and things in Spanish, but most of the outreach was in English. The federal government did a lot of advertising on Telemundo, but it was national and not targeted. Because the Spanish language is spoken differently across the country, it wasn’t as effective. And there wasn’t a [local] phone number to call. A lot of people were confused about what the local and national news was saying about ACA and didn’t know what to believe.”²¹

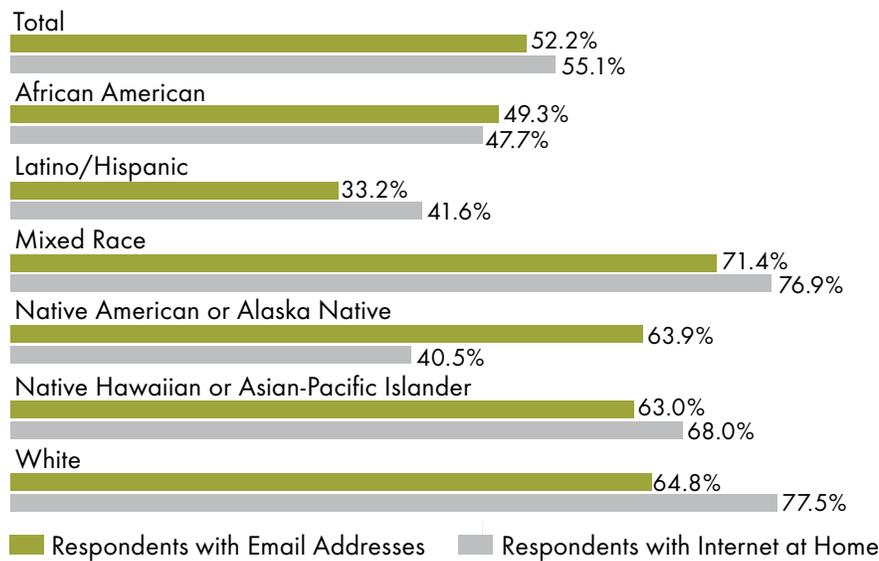
An experienced navigator from the Los Angeles office of the National Korean American Service & Education Consortium noted that “although the Covered California site claims materials in 17 languages, the material available in each language is not the same. Most languages have the application but not necessarily the supporting or explanatory documents. And, if we need help over the phone, sometimes we get someone who is knowledgeable, other times we don’t and have to start over with a new person. It is very time consuming.”²²

And David Chase of the Mountain States Group (Idaho) observed that “this was hard even in English; people who’d never had insurance, or who hadn’t in a really long time, didn’t understand health insurance lingo and had to be educated.”²³

TABLE 10
AJS Survey Respondents Who Had Help with Enrollment

Race/Ethnicity	Percentage Yes
Total	45.9%
African American	45.9%
Latino/Hispanic	54.8%
Mixed Race	42.9%
Native American or Alaska Native	50.0%
Native Hawaiian or Asian-Pacific Islander	75.0%
White	36.1%

TABLE 11
AJS Survey Respondents Who Had Access to Email and Internet



Forty-six percent of respondents had help in applying for insurance coverage; Native Hawaiians/Asian-Pacific Islanders had the highest percentage of assistance at 75 percent and whites the lowest at 36.1 percent. Email addresses are necessary to apply online. Latino respondents had the lowest percentage of email addresses at 33 percent, followed by African Americans with just under 50 percent. Similar proportions, averaging 64 percent, of whites, Asian-Pacific Islanders, and Native Americans had email. Although home Internet access is not a prerequisite to enrollment, it is the principal sign-up medium for the ACA and potentially a prime tool for communicating with both insurers and providers. The racial divide evident in reported email addresses is also evident with respect to home Internet access: 78 percent of whites, 77 percent of mixed-race people and 68 percent of Asian-Pacific Islanders have such access, compared with 42 percent of Latinos, 41 percent of Native Americans, and 48 percent of African Americans.

“We frequently found people who didn’t have access to an email address or Internet and actually spent time getting people an email address,”²⁴ recounts Tiffany Hogue, Health Care Program Director at the Texas Organizing Project. “Technology was a barrier but even people who were technically savvy wanted to talk through what they were seeing online with a real person to ensure that they understood their options correctly.” Joseph Martinez of Health Action New Mexico added that, “rural and low-income communities don’t have Internet access in the first place and the availability and functionality of the federal website was a problem. After a first (unsuccessful) attempt, a lot of people got frustrated and walked away. This problem was compounded for the immigrant population.”

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Sometimes it's deciding between medication and food. I can get food in other ways – like go to the food pantry. But if my care and medication is not covered in my plan I have to figure out how to pay the bill. My life insurance got cancelled. I have bad credit because of my medical bills. If Medicaid won't pay for it we can't access health care.

TABLE 12
AJS Survey Respondents Who were Informed about Possible Financial Support

When you enrolled were you informed that financial support was available for low-income people?

Race/Ethnicity	Percent Yes
Total	47.2%
African American	38.8%
Latino/Hispanic	62.4%
Mixed Race	47.8%
Native American or Alaska Native	20.0%
Native Hawaiian or Asian-Pacific Islander	44.0%
White	49.6%

TABLE 13
AJS Survey Respondents with Knowledge of Covered Services and Costs

Many of the new health plans are pretty complicated; do you know which services are included in your coverage and which you'll have to pay extra for?

Race/Ethnicity	Percent Yes
Total	46.8%
African American	42.1%
Latino/Hispanic	43.3%
Mixed Race	54.2%
Native American or Alaska Native	52.6%
Native Hawaiian or Asian-Pacific Islander	19.2%
White	54.8%

Only 20 percent of Native American and 39 percent of African American respondents knew about the availability of financial support. Less than 20 percent of Native Hawaiians/Asian-Pacific Islanders and less than half of African American and Latino respondents knew which services were included in their insurance. Lack of information about the availability of financial assistance combined with a lack of clarity about the intricacies of insurance coverage sets up a significant barrier to actually using the coverage. Marjorie Mitchell of the Michigan Universal Health Care Access Network observed that “affordability is a major issue. We still don’t have good products that are really affordable and we have a lot of advocacy work to do on that.” Illustrating Mitchell’s point, qualitative responses from New Mexico survey respondents pointed out:

Sometimes it's deciding between medication and food. I can get food in other ways – like go to the food pantry. But if my care and medication is not covered in my plan I have to figure out how to pay the bill. My life insurance got cancelled. I have bad credit because of my medical bills. If Medicaid won't pay for it we can't access health care.

We have insurance but it is still very expensive because of the administrative fees. Billing process for MRIs, blood tests and x-rays are contracted out and billing is processed separately. It is especially expensive to get an MRI or x-ray. Many of these tests are urgent and needed.

FROM COVERAGE TO CARE

The ACA's intent goes beyond expanding insurance coverage to, in addition, improving the delivery and quality of health care. To promote wellness the Act created paths to alternative medical modalities, funded coordination of primary care among an array of providers, expanded requirements for linguistically and culturally appropriate services, and required insurance companies to act to reduce racial disparities. Thus, it is important not only to examine barriers to enrollment but also to assess obstacles to access to health care, screening, and treatment. By 2019 an estimated 24 million people will obtain health insurance through marketplaces and one in four will speak a language other than English at home.²⁵ Future assessment of the ACA will doubtless use longitudinal data to evaluate how effectively it improved the quality of health care. While it is still too early to draw definitive conclusions, our survey does point to some trends that, if they continue, may actually exacerbate the health care gap between whites and people of color. In the first section of this report, focused on enrollment, we documented racial gaps in coverage, access to technology, Medicaid availability, and language access. In this section we explore how respondents are actually able to use the health care system.

TABLE 14
AJS Survey Respondents Who Reported Living with a Chronic Disease

To determine the relative health of different groups, our survey asked respondents to self-report their experience with hypertension, heart disease, diabetes, cancer, arthritis, asthma, excess weight, alcohol or drug problems or other chronic disorders. The results are as follows:

Race/Ethnicity	Percent with Chronic Health Conditions, by Race
Total	45.2%
African American	45.9%
Latino/Hispanic	48.6%
Mixed Race	55.6%
Native American or Alaska Native	28.6%
Native Hawaiian or Asian-Pacific Islander	33.3%
White	46.5%

Almost half of respondents reported living with a chronic condition, and 16.5 percent of Latinos, 18.7 percent of African Americans, 20.9 percent of whites, and 22.2 percent of people who identified as mixed race reported living with two or more chronic conditions.

While it is still too early to draw definitive conclusions, our survey does point to some trends that, if they continue, may actually exacerbate the health care gap between whites and people of color.

TABLE 15**AJS Survey Respondents Who Reported having a Personal Doctor, by Race**

Race/Ethnicity	Percent with a Personal Doctor
Total	73.1%
African American	69.0%
Latino/Hispanic	67.2%
Mixed Race	68.0%
Native American or Alaska Native	45.0%
Native Hawaiian or Asian-Pacific Islander	73.1%
White	82.8%

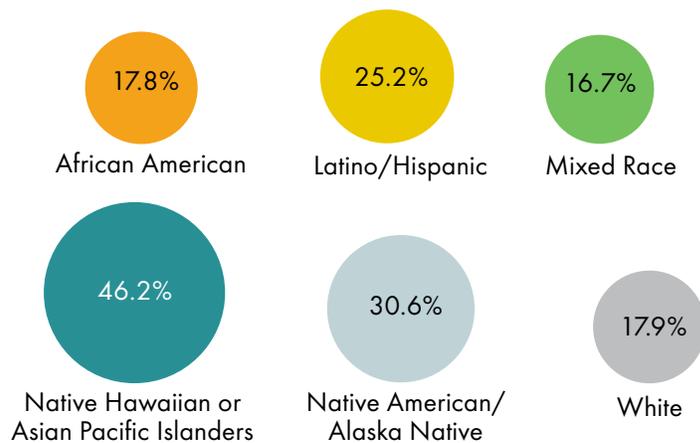
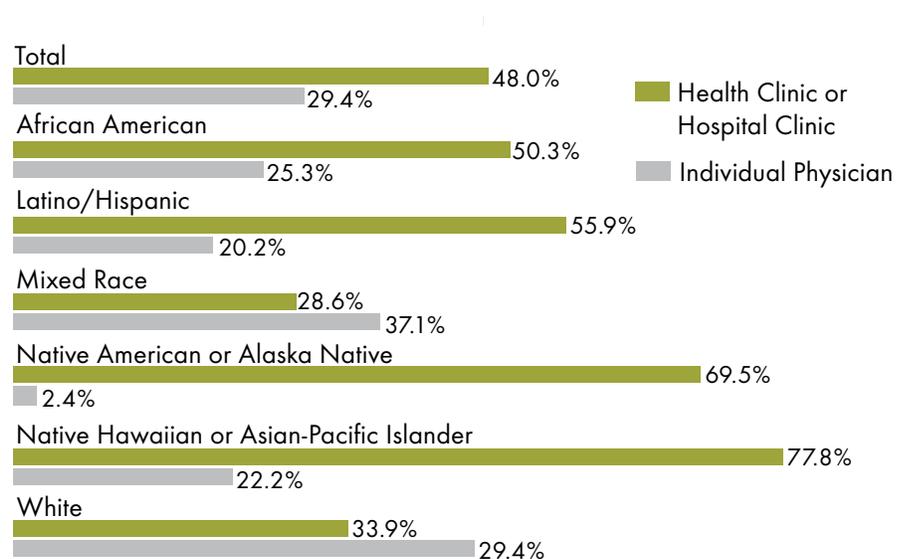
TABLE 16**AJS Survey Respondents who haven't seen a doctor in more than a year****Percentage Who Have Not Seen a Doctor in More Than a Year****TABLE 17****AJS Survey Respondents Who Use Health or Medical Clinics vs Individual Physicians for Primary Care, by Race**

TABLE 18
AJS Survey Respondents with no Medical Home, by Race

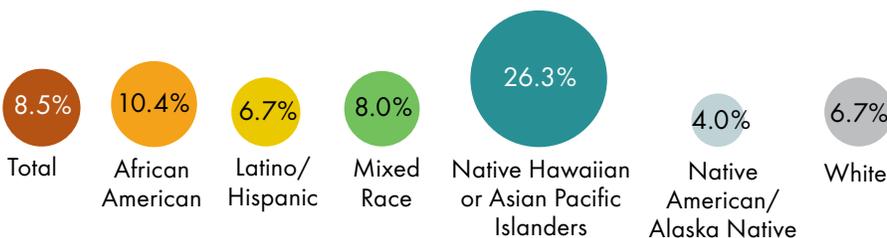
Race/Ethnicity	Hospital ER or “No Regular Place to Go”
Total	22.6%
African American	24.5%
Latino/Hispanic	23.9%
Mixed Race	34.3%
Native American or Alaska Native	28.0%
Native Hawaiian or Asian-Pacific Islander	N/A
White	19.5%

According to the Health Resources and Services Administration, nearly 20 percent of Americans live in areas with too few primary care doctors, 16 percent in areas with too few dentists, and 30 percent in areas with too few mental health providers.²⁶ An ACA goal is to link patients with personal doctors, and three of four survey respondents indicated that they did have a personal doctor. However, as Table 15 shows, racial disparities are still evident: all groups of survey respondents of color are significantly less likely than white survey respondents to have personal doctors. Relatively few African American, white, and mixed race respondents have not seen a doctor in more than a year but more than a quarter of Latinos, 31 percent of Native Hawaiians/Asian Pacific Islanders and almost half (46 percent) of Native Americans surveyed have not visited a doctor in more than a year.

Moreover, although nearly three quarters of respondents reported having a personal doctor, less than 30 percent see an individual doctor for their primary health needs – 47 percent of whites versus 22 percent of people of color overall and only 2.4 percent of Native Americans. Instead, 54 percent of people of color use hospital or health clinics for their primary health needs versus 34 percent of whites. Over 1 in 5 respondents (22.6 percent) either use a hospital emergency room or have no regular place to go for care, with white respondents reporting 19.5 percent, mixed race respondents at 34.3 percent, Native Americans at 28 percent, African Americans at 24.5 percent and Latinos at 23.9 percent.

ACCESS TO PROVIDERS

TABLE 19
AJS Survey Respondents Who Travel More Than 1 Hour to See Their Health Care Provider



According to the Health Resources and Services Administration, nearly 20 percent of Americans live in areas with too few primary care doctors, 16 percent in areas with too few dentists, and 30 percent in areas with too few mental health providers.

TABLE 20

AJS Survey Respondents Reporting Need for Urgent Care in the Last 6 Months

Race/Ethnicity	Percent Yes
Total	35.5%
African American	32.4%
Latino/Hispanic	33.1%
Mixed Race	52.2%
Native American or Alaska Native	36.8%
Native Hawaiian or Asian-Pacific Islander	17.9%
White	39.9%

TABLE 21

AJS Survey Respondents Reporting a Wait of More than 7 Days for Care Needed Right Away

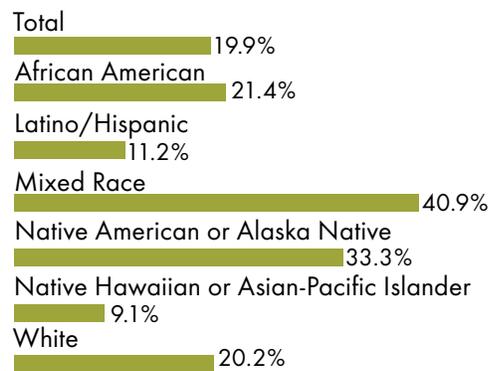


TABLE 22

AJS Survey Respondents Reporting Only Sometimes or Never Getting Care As Soon As They Needed



Although a relatively small percentage of respondents reported traveling more than an hour to see their provider (8.5 percent), the percentage of Native American respondents (26.3 percent) was almost three times that of any other group. Although Native Americans reported a need for urgent care in the last six months (37 percent) consistent with the average for other respondents, one-third reported waiting more than seven days to get care and almost half of Native American respondents (47.1 percent) reported that they “sometimes or never” received urgent care as soon as they thought they needed it. Almost a quarter of all respondents reported that they did not get urgent care as soon as they thought they need it: 19.4 percent of whites and 34.6 percent of people of color.

ACCESS TO ALTERNATIVE MEDICAL MODALITIES

TABLE 23

AJS Survey Respondents Reporting Their Provider Only Sometimes or Never Discussed Alternative Medical Modalities in Last 6 Months

Race/Ethnicity	Percent Sometimes or Never
Total	51.8%
African American	46.7%
Latino/Hispanic	50.4%
Mixed Race	60.9%
Native American or Alaska Native	63.2%
Native Hawaiian or Asian-Pacific Islander	61.1%
White	55.5%

Although the ACA makes provision for insurance networks to include alternative modalities like diet, exercise, meditation, or chiropractic care, over half of our survey respondents, including 47 percent of African Americans, 50 percent of Latinos, 56 percent of whites and over 60 percent of mixed race, Native American, and Native Hawaiian/Asian-Pacific Islander respondents, reported that their health provider never discussed non-medical modalities like acupuncture, chiropractic care, meditation, diet, or exercise.

INTERNET USE FOR HEALTH COMMUNICATIONS

TABLE 24

AJS Survey Respondents who use the internet for health-related communications.

Race/Ethnicity	Respondents with Health Coverage Who Use the Internet for Health Communication with Providers or Insurance Company
Total	36.8%
African American	33.6%
Latino/Hispanic	22.7%
Mixed Race	48.0%
Native American or Alaska Native	28.6%
Native Hawaiian or Asian-Pacific Islander	42.9%
White	46.1%

Overall, only 37 percent of survey respondents used the Internet to communicate with insurance companies or health providers. Whites and mixed race respondents (46.1 percent and 48 percent, respectively) reported the highest use, at a rate more than double that of Latinos (22.7 percent). Consistent with the access data on email and Internet at home, only slightly more than one-third of respondents overall utilized the Internet for health communications.

SUMMARY OF FINDINGS

The first two ACA enrollment periods reflect an important start in the long road to affordable health care for all U.S. residents. Many community organizations, service providers, key governmental organizations, and key advocacy groups pulled together to conduct massive outreach and enrollment efforts in both the ACA marketplaces and in Medicaid and CHIP enrollment. In focusing on the dynamics in low-income communities, particularly those of people of color, we have attempted to understand and lift up potential barriers to the ACA's future success and to construct recommendations to improve practices and outcomes, both in terms of enrollment and in translating expanded coverage into effective access to care, in the future.

I. OBSTACLES TO ENROLLMENT

A number of racial disparities appear in the initial ACA enrollment rollout. Sixty percent of uninsured African Americans and 40 percent of Latinos live in states that have rejected Medicaid expansion, and lack of access to Medicaid is the largest determinant of prolonged uninsured status. Our study, which includes both expansion and non-expansion states, identified the following barriers to enrollment for people of color:

Language: Many of the websites, both state and federal, had most documents translated into Spanish but not other languages. This was particularly problematic for the Asian-Pacific Islander population. Even when sites claimed to offer translation, timely access to competent and knowledgeable translators was a consistent problem in California, New Mexico, Idaho, and Texas.

Technology: African American, Native American, and Latino respondents had significantly lower access to Internet service at home than did whites, Asian-Pacific Islanders, or mixed race respondents. While the ACA enrollment process did not create this gap, neither did it do much to alleviate this barrier, which was (and is) a problem that community and advocacy groups had to address. As Erik Lujan, Assistant Director of Health Education and Outreach for Native American Professional Parent Resources in New Mexico, pointed out, “The Navajo Nation is about 800 square miles with mostly dirt roads. And because of the lack of technology, you have to go back to offices in these areas 4-5 times to get people to fill out and correct paper applications.”²⁷ The digital divide, evident in both enrollment and ongoing communications with providers and insurance companies, will continue to be an obstacle to efficient reenrollment and addressing tax issues for low-income people.

Literacy: Less than half of African American and Latino respondents knew which services were included in their insurance, as did less than 20 percent of Native Hawaiian/Asian-Pacific Islander respondents. Lelia Keys, Retired Director for Medical Social Services and Community Outreach and Health Care at the Northwest Mississippi Regional Medical Center, noted that “You have two levels of literacy. One is in the area of reading level. The second layer is professionalized language and health care jargon, which doesn’t help people reading on the 3rd, 4th or 5th grade level. Even if you have a college degree, understanding the complexity of insurance is difficult. We need plain language.”²⁸ “It’s even confusing to those of us who are informed,” says Chris Shea, Executive Director of Cherry St. Health Services in Grand Rapids, Michigan. “And,” he continued, “combined with the technology glitches on the exchange, many people tried to apply and then faded away.”²⁹ Literacy issues are not only prevalent in the enrollment process. In a conversation with one of our surveyors in Detroit, one respondent reported that he’s been “glad to get health insurance,” but hadn’t been to a doctor because, “I am really not sure how much it’s going to cost.”

Legal and Cultural Barriers: “Back home people just walk into doctor’s office. They don’t need to make an appointment. If the doctor says you need some procedure, it’s not your responsibility to find out if insurance covers it,” says Madiha Tariq, public health manager of ACCESS (formerly the Arab Community Center for Economic and Social Services) in Michigan.³⁰ “Cultural disparities definitely exist,” says Idaho’s Delmar Stone of the National Association of Social Workers. “Lack of education, poverty, access to computer, and mixed status families all come together to make it difficult for the large Latino population in Idaho to enroll. People were afraid because they might expose undocumented family members and many of these families just stayed away.” In addition, difficulties with the identity verification system (which initially was not multilingual), along with fear of legal reprisals for mixed status families and lack of familiarity with culturally-specific insurance and medical terms, combined to pose a formidable barrier.

Potential legal barriers to enrollment are reflected by the practices of insurance brokers, as New Mexico's Strong Families advocate Adriann Barboa points out: "There is an unlevelled playing field between the state brokers and the community groups. The brokers are getting more money for the people they enrolled. So at big enrollment events there ends up being a fight to get to people. You get more money when you enroll more people. If you have a mixed status family, you were put down lower on the list and the brokers moved on to signing up the easier clients. Local groups doing community enrollment had a harder job enrolling the more-difficult-to-serve populations. On top of it the brokers were given their grant money from the state upfront, while the community groups were given delayed payments *after* they did the work."³¹

II. OBSTACLES TO ACCESS TO CARE

While many of the enrollment obstacles are either short-term or correctable with redirection of resources, the obstacles to care access are more structural. These include:

Insurance Costs: A key barrier for both insured and uninsured people is premium costs and the subsequent costs of doctor visits and medication. Thirteen percent of insured respondents cited cost as their number one barrier to care, while almost a third of those who did not have coverage cited cost as the major barrier.

Supply of Health Care Providers, Particularly Doctors: Currently only 29 percent of low-income survey respondents see a doctor regularly; over 25 percent have not seen a doctor in the last year and 23 percent have no medical home. The increase in the population over age 65 in addition to the millions newly insured under the ACA suggests a demand that the current supply of doctors will soon be unable to meet. While some have argued for a broader range of health care providers that would include physician assistants, nurse practitioners, and others, long lines for care and a scarcity of providers, particularly for Medicaid patients, are already becoming apparent in states like California and Idaho. Even the best and most racially equitable enrollment system cannot address the potential unequal access to care at the other end of the pipeline. Indeed, success in enrollment may actually exacerbate racial inequities in care.

Failure to Incorporate Alternative Medical Modalities: Although this study only scratched the surface of discovering how primary care physicians relate to alternative modalities (acupuncture, chiropractic services, mental health counseling, etc.), it is clear that few insurance programs or primary care providers have integrated these into their caregiving repertoire. Failure to integrate the benefits of these modalities will only increase the long lines for care, particularly in low-income communities and communities of color.

Failure to Enforce the Directive to Reduce Racial Disparities: HHS has not actively enforced the ACA's statutory provisions that require insurers to act to reduce racial disparities or taken steps to monitor insurers' disparity-reduction plans and programs, especially outreach and outcomes. Racial disparities in health are well-documented, including by HHS' own research data, but without active monitoring the statutory provisions are meaningless.

RECOMMENDATIONS

In order to improve enrollment and care options, we recommend the following:

I. SAFEGUARDING ACCESS TO HEALTH INSURANCE

Expand Medicaid to meet the needs of low-income families across the country.

Strengthen and enforce language access: Establish a right to enroll in in the enrollee's primary language and require plans give enrollees notice of their right to language services.

Streamline enrollment: Require states to automatically enroll in Medicaid people who already receive need-based benefits like SNAP (food stamps), Supplemental Security Income (SSI), WIC, or free or reduced-price school meals, as well as people released from incarceration with no immediate source of income or assets.

Eliminate enrollment waiting lists and ensure that enrollment decisions are made within two weeks of filing.

Make shopping easier and more transparent: Simplify print and electronic descriptions of plans and benefits, make costs transparent, and ensure easy comparison of services available with no co-pay. Require that information about providers be up-to-date and include contact information, languages spoken, hospital affiliations, specialties, and whether new patients are being accepted.

II. MOVING CONSUMERS FROM COVERAGE TO CARE

Reduce racial disparities by enforcing and monitoring insurers' quality improvement plans and penalizing plans that underperform.

Increase Medicaid beneficiaries' access to doctors by setting Medicaid provider reimbursements at least at the Medicare level.

Strengthen community-based health care infrastructure (i.e. "essential community providers"), including community clinics, individual physicians, and small community practices that have historically served patients of color.

Make free translation and interpretation services available to all enrollees with limited English proficiency; publicize the availability of these services in all languages spoken by enrollees; ensure interpreter competence by using a reliable interpreter credentialing or licensing system.

Expand and extend the role of navigators to encompass teaching new enrollees how to use insurance coverage and recruiting enrollees to participate in marketplace-sponsored evening and weekend clinics focusing on health education, specific mobile services, and access to different medical modalities.

Measure results: Require plans to track health outcomes, disaggregated by race, ethnicity, primary language, gender, disability, and sexual orientation.

Require health plans to have adequate networks:

- Ensure that enrollees are able to make appointments with their primary care providers within 10 business days of seeking an appointment.
- Ensure that patients can see a doctor before or after work.
- Require plans to have at least one full-time primary care provider for every 2,000 patients.
- Give patients the opportunity to have a free physical exam and appropriate screening within 60 days of enrollment and establish annual check-ups, immunizations, counseling, and screenings at no out-of-pocket cost.
- Reinforce women’s right to no-cost “well-woman preventive” care by ensuring that all plans available through the marketplace include reproductive health care services.
- Adopt geographic access standards ensuring that, for at least 90 percent of enrollees, primary care providers are available within 10 miles or 30 minutes average driving or public transit time and specialists within 45 miles or one hour.

III. BUILDING AN INFRASTRUCTURE TO PROMOTE PREVENTIVE HEALTH CARE

Enforce requirements for Quality Improvement Plans: Offer incentives to plans that adopt a broad view of health benefits and tackle underlying social determinants of health.

Build a strong community-based health care system through a combination of innovative strategies, including:

- Reduce reliance on institutionalized care by adopting home- and community-based services in the state Medicaid plan.
- Direct Medicaid resources to care coordination and community support for high-risk individuals with chronic diseases.
- Use Medicaid waivers to leverage federal funds to facilitate population-based promotion of public health in addition to individual service health care.
- Expand medical-legal partnerships as an avenue toward the broad array of issues that lead to poor health in low-income communities (e.g., mold in housing, domestic violence).
- Expand school-based health clinics with attention to medically-underserved communities.
- Develop integrated care models for joint Medicare and Medicaid beneficiaries known as “dual eligibles.”
- Move to delivering health care through accountable care organizations, like those Minnesota has established, which deliver population-based health care that includes social services.

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