

PART 1: NO PAPERS, NO HEALTH CARE







There are an estimated one million undocumented Californians who remain uninsured since the Affordable Care Act (ACA) went into effect on January 1, 2014.¹ Without insurance, health care services are unattainable due to cost and inability to qualify for care.

Immigrant youth and their families have a pressing need for health services, yet opportunities for this population to access care are increasingly being restricted. In the interest of supporting the prosperity of California, it is important to remember that all health is communal and public, as illness is not confined by borders or neighborhood boundaries. Excluding undocumented Californians from access to care damages the wellness of the state as a whole.²



People are not aware of the hardships and trauma [being undocumented] causes, and don't really know how to help even if they want to.

—Female, 30, Los Angeles



Immigrants' health and well-being cannot be disconnected from the conditions of their political and social environment. Being undocumented in the United States results in a high potential for systematic and personal trauma; many face incarceration, deportation, loss of wages and personal relationships, career and life barriers, discrimination, and criminalization.

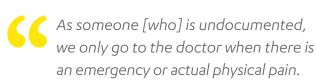
President Obama's administration has deported nearly two million people within the past five years; creating a climate of constant hypervigilance and fear of authorities that compromises immigrants' level of comfort and trust with the US health care system. This kind of social and systemic trauma takes a toll on the minds and bodies of the undocumented and their loved ones, increasing their risk for poor health. The health of immigrant communities cannot be separated from the need for immigration reform and an end to deportations.³



THE MAJORITY OF IMMIGRANT YOUTH HAVE A PRESSING NEED TO SEE A DOCTOR

Undocumented Californians often fear becoming sick because of the negative experiences and limited opportunities that come with that reality. A 29-year-old female survey participant from Central San Diego shared, "[I want] the opportunity to legalize so that I [am not] afraid to ask for health care." Without health insurance, undocumented Californians potentially face denial of care or being reported to authorities. Survey findings showed that 71 percent of uninsured immigrant youth have an existing need to access a doctor or specialist about their own health; however, 53 percent stated that they have not seen a doctor for more than a year.

Sixty-nine percent of immigrant youth report that they did not have health insurance in the past twelve months. By necessity or from inability to qualify or pay for services, immigrants commonly push through pain or illness until their health problems become quite severe. With medical care out of reach, immigrant youth often use Google as a stand-in doctor for medical diagnoses. Survey findings reveal that 58 percent of participants used Internet research as a substitute for medical attention.



—Female, 24, Orange County



TABLE 1: Immigrant Youth and Health Care Access

	Access to Health Care			
69%	do not have health insurance			
71%	currently need access to a doctor			
53%	have not seen a doctor in over a year			
58%	use the Internet as a source of care			
Mixed-Status Households				
53%	have family members with insurance			
75%	of family members with insurance are siblings			
Mixed-Status Family Members without Insurance				
56%	did not get the care they needed			
71%	minimized their own health problems			

*Source: Healthy California Survey 2014





HEALTH AND INCLUSION STARTS IN THE HOME FOR IMMIGRANT FAMILIES

One in seventeen children in the United States lives in mixed-status homes where household members have different immigration or citizenship statuses.⁴ Mixedstatus families are a growing demographic in the United States; the health outcomes of this population provide insight into the health of the future US population.

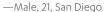
Within the survey, 53 percent of immigrant youth grew up with other family members who had health insurance; 75 percent of those with insurance are siblings who were raised in the same household. For undocumented children, being deprived of health care while growing up may result in feeling unworthy to seek or practice wellness.

Parents with mixed-status children struggle to negotiate the privileges and disadvantages within their families. Fifty-six percent of immigrant youth reported that family members without insurance did not receive the care they needed from formal health care systems. Seventy-one percent of survey respondents shared that household members without insurance often minimized their health problems. Downplaying symptoms is common for parents, who ignore their needs in order to prioritize the health of their children.

Immigrant youth are responding to the strength of their parents and caretakers by expressing their frustration with the health system's denial of care for their families. A 27-year-old male participant from Long Beach shared, "Dad [was] diagnosed with cancer and is afraid to go to the doctor because of the financial issues. [We] got him to go but because of money, he does not attend regular check-ups." With an increasing need to care for elders in the household, there is a growing demand to recognize health as a human right for all Californians.



I never really went to the doctor because we couldn't afford it. I couldn't get hurt or sick. It was always this constant pressure that we had to stay healthy.





My mom is getting older, she is the head of the family. She cares for us but she does not have care for herself.



-Female, 20, Watsonville

CONCLUSION

Anti-immigrant sentiment in the United States has resulted in the development of exclusionary and discriminatory policies, impacting the undocumented immigrant community across the nation. Immigrant families continue to suffer a lack of services and protections under the Affordable Care Act, which explicitly targets undocumented immigrant communities for exclusion.

The failure to fully support families does not fit the goals and objectives of the Affordable Care Act, and denying care to undocumented Californians has profound repercussions. Immigrant communities absorb and internalize their experiences of exclusion, leaving them ill, frightened, and without access to care.

Across immigrant communities, many are now calling for systemic policy reform that truly prioritizes health for all. Recognizing that health care is a human right, rather than a privilege, allows for a broader conversation that considers the well-being of all Californians.

RECOMMENDATIONS

We recommend the following in an effort to foster the health of future populations and the growing immigrant demographic in California:

- ✦ Health for immigrant families in California is connected to the need for immigration reform. Halting deportations and reforming the immigration system for the 11 million undocumented immigrants in the United States would have profound positive health outcomes nationwide. We recommend a clear pathway to residency and citizenship with access to health and social programs. Moving forward with immigration reform is essential to the well-being and prosperity of the country as a whole.
- ◆ The health of undocumented Californians is crucial to the well-being of the state. There is no such thing as individual health; all health is public and communal. We recommend expanding the Affordable Care Act to insure all Californians regardless of immigration status or income level. California can continue to lead and set an example by championing health as a human right; a public good for all.⁵



METHODOLOGY

This report presents the results of the first statewide survey about immigrant youth, led by immigrant youth. We asked participants a series of standardized questions about their experience accessing health care in California. We surveyed 550 undocumented and "DACAmented" (recipients of Deferred Action for Childhood Arrivals) Californians between the ages of 18 and 32, using a participatory methodology that allowed those directly excluded from health care access to lead the research process. A team comprised of 37 immigrant youth conducted face-to-face surveys with their peers during summer 2013. The data and analysis in the report reflects the experiences and real-life barriers to health care faced by undocumented people.

STUDY DEMOGRAPHICS

REGION	Los N	24% Iorthern alifornia	10% Orange County	10% San Diego	8% Inland Empire	7% Central Valley
IMMIGRATION STATUS	Deferred Childhoo	Action for od Arrival pient		2% umented	4% Othe	
AGE	47% 22–26 yrs		36 9 18-21 y		17% 27–32 yrs	
	55% emale	44% Male	0.7% Genderque	0.4 eer Transge		.2% ther
Lati	3% 3% na/o Asia panic	an M	ixed	0.7% Pacific Islander	White	0.2% Native merican
AGE UPON ARRIVAL	53% Months –6 yrs		5% 2 yrs	10% 13–16 yrs		% yrs
	6.3% 50.2% >12 yrs High School Diplom /GED	Associ- ol ates na Degree	16.8% Bach- elors Degree	1.1% 2° Some Gr Grad Sch School	ad Other	0.2% No response
SEXUAL 78% ORIEN- TATION	o- Gay			2% 2% Sbian Othe		0.7% Questioning
YEARS IN U.S.	65 9 11–20		23 21+		12% 1–10 y	

This research was made possible by The California Endowment. Thank you for your continued support to advance the health of immigrant communities.



- 1 Health Access Foundation, "California's Uneven Safety Net: A Survey of County Health Care," November 2013, http://www.health-access.org/files/expanding/California's%20Uneven%20Safety%20Net%20-%20 A%20Survey%20of%20County%20Health%20Care.pdf.
- 2 Human Impact Partners, "Family Unity, Family Health: How Family-Focused Immigration Reform Will Mean Better Health for Children and Families," June 2013, http://www.familyunityfamilyhealth.org/uploads/imaqes/FamilyUnityFamilyHealth.pdf.
- 3 Aviva Shen, "How Deportations May Be Hurting Obamacare Enrollment," December 29, 2013, Think Progress, http://thinkprogress.org/immigration/2013/12/29/3106511/latino-obamacare-deportation/.
- 4 Jeffrey S. Passel and D'Vera Cohn, "Unauthorized Immigrant Population: National and State Trends, 2010," February 1, 2011, Pew Research Center, http://www.pewhispanic.org/2011/02/01/unauthorized-immigrant-population-brnational-and-state-trends-2010/.
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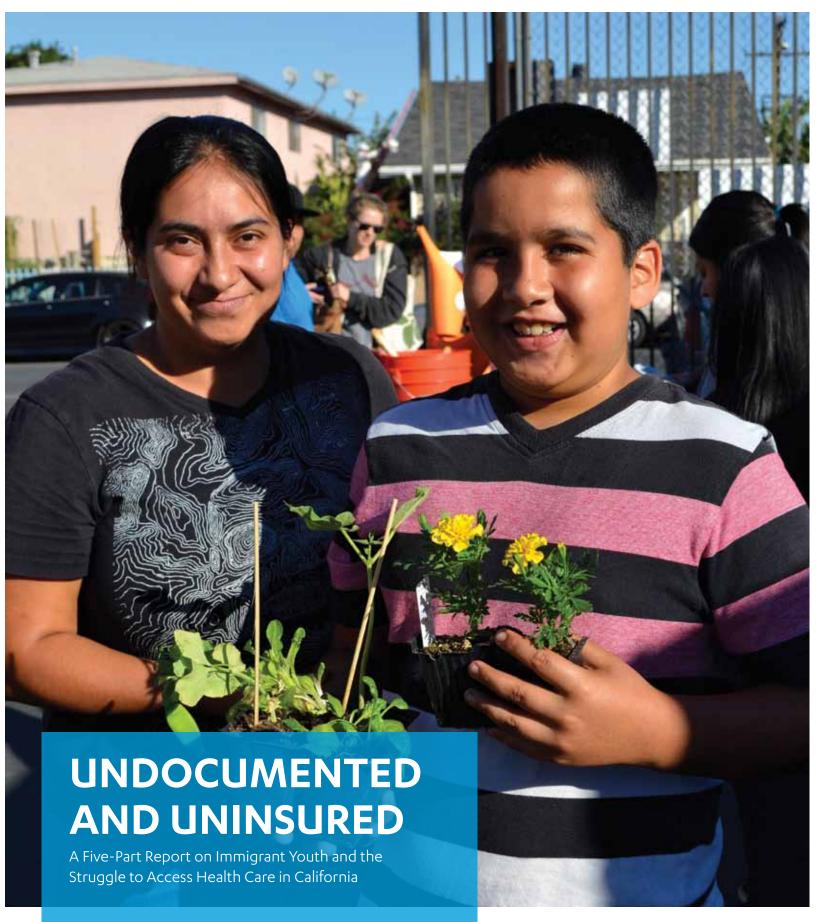
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PART 2: BAND-AID CARE





BAND-AID CARE FOR THE POOR AND UNINSURED

For immigrant families, access to medical care is both limited and a financial hardship. Immigrants tend to work in industries that do not offer employer-based insurance. In addition, undocumented immigrants do not qualify for most public health benefits, and more than half live below the federal poverty line, making it unlikely they can afford health insurance.²

When undocumented Californians do seek medical attention, the types of care available are Band-Aid options—basic services that provide a quick-fix or temporary remedy but do not address preventative, long-term, or sustainable health needs. These limited public programs are often the only option for uninsured Californians.

These barriers are essential to consider as California prioritizes health care for all and addresses wellness in the lives of vulnerable and unprotected populations.

Within our family, when we have health care issues, we think about money as opposed to thinking about our health. We tend to let it continue until it is really a pressing issue.

—Male, 22, Berkeley



IMMIGRANT YOUTH DELAY CARE, ENDURE PAIN, AND COVER THE COST

Survey findings show that in the past year, 50 percent of uninsured immigrant youth delayed getting the medical care they felt they needed. Of those, 96 percent reported that the main reason was cost or lack of insurance.

Many low-income, undocumented youth are forced to choose between paying for a medical visit or other basic needs that are essential to their survival and sustainability. A twenty-two-year-old male respondent from El Monte shared, "It's a struggle because we either pay our rent or go to the clinic, and the rent is our first priority."

The financial obstacles of being undocumented and uninsured are echoed by other immigrant youth across California. A nineteen-year-old male participant from South Los Angeles revealed: "I have a blood disease, and I have to constantly look for ways to stay healthy. My family stopped taking me to the hospital because it was getting expensive, and we couldn't pay." A twenty-six-year-old female respondent from Arvin shared the pressures of staying healthy for her family: "Getting sick is not an option. There [are] six children [in the family]. It would be painful for my parents. It's not an option."

Immigrant youth initially endure the pain when they are sick or injured, with the hope that they will recover without medical intervention. A twenty-one-year-old male participant from Huntington Park illustrated what a nightmare this experience can be: "I broke my arm and had to tolerate the pain for three days until I had to go to the emergency room to help with the pain." It is too common that the constraints of income and immigration status take priority over the need for medical attention.

When undocumented individuals are able to pursue care, survey findings show that immigrants in California pay out-of-pocket for the expense.

Thirty-nine percent of immigrant youth paid for treatment themselves, and 32 percent received support for medical expenses from friends or family.

Despite the common perception that immigrants drain social service programs, studies have shown that the use of the emergency room by undocumented communities is relatively low.³ Only 34 percent of immigrant youth in the survey had ever visited an emergency room. Because emergency care is generally a last resort, it is also the most costly. The price of one visit can become a paralyzing obstacle for the undocumented and uninsured. A twenty-two-year-old male participant from Rialto shared a familiar story: "On one occasion I [was] very sick and hospitalized for [several] hours, and the only thing that I [was prescribed]

was] Tylenol. I was charged about \$18,000 and was not able to pay for the bill." Minimal care and high costs contribute to immigrant families' mistrust of the health care system.

The incorrect assumption that low-income communities already have adequate access to services leads to the belief that poor health is a personal choice. Health care is a collective concern—not a personal issue. California has the opportunity to protect vulnerable populations by providing adequate services and access for all.

It is very frustrating and overwhelming because I have to go to the community clinics, which are slow and don't have a lot of resources. It takes months [to make] an appointment, [and] you'll be there all day.

—Female, 21, Los Angeles

BAND-AID SERVICES ARE INCOMPLETE AND THE DOMINANT SOURCE OF CARE FOR THE UNINSURED

Seventy-four percent of immigrant youth report they have received services from public safety-net programs, such as emergency Medi-Cal, public hospitals, and community or county health clinics. Undocumented Californians are able to access these forms of care due to their low cost, payment plans, sliding-scale fees, and no-cost services. While these programs may appear accessible, they are commonly understaffed, underfunded, overcrowded, and unable to meet the needs of many of those seeking care.

Stories of disappointment, pain, and distress in relation to the health care system were common among the immigrant youth surveyed. For one participant, a twenty-two-year-old female from Claremont, the lack of health care cost her family the life of her father. "After my father's passing, the health care system, I see it as a failure. It did not detect his cancer, passed over his ailments, and dismissed them." Tragedies like this that could have been avoided are common for low-income, undocumented Californians and will continue if high costs and ineligibility for care are not addressed. The State of California can demonstrate that it values the lives and contributions of immigrants through policies and legislation that provide access to health care resources.



TABLE 1: Health Facilities, Delayed Treatment, and Method of Payment for Immigrant Youth

Health Facilities Used				
Community or county clinics and public hospitals	74%			
Emergency room				
Delays in Seeking Treatment within the Last Year				
Delayed medical care	50%			
Of those, delayed due to cost or lack of insurance				
Method of Payment for Medical Care				
Out-of-pocket	39%			
Financial support from family and friends	32%			

TABLE 2: Additional Barriers to Accessing Health Services for Immigrant Youth

Barriers	
Not knowing where to go for care	17%
Feeling overwhelmed by the health care system	15%
Not knowing if they qualify for services	14%
Inability to take time off work	11%

UNDOCUMENTED CALIFORNIAN IN PURSUIT OF HEALTH CARE

MALE, 25, RIVERSIDE

Thad been coughing for two weeks and couldn't walk a block without gasping for air. My cough kept getting heavier, and it was becoming a lot more painful to breathe. I knew it was bad. I remember feeling something pressing heavily on my chest in the late night, as if something was about to crack wide open. I found myself lying on the couch, aching and taking small breaths to ease the pain. It was bad; I had to see a doctor.

I called mamá; she was half-asleep: 'Ama, no me siento bien, I don't feel well.' I didn't want to share with her that I was feeling ill for some time. I felt guilty for dragging her out to Riverside from Orange County at 2:00 in the morning. She had work in a couple of hours and didn't feel safe driving late at night because she feared the police.

Arriving at the emergency room, the receptionist asked me for information that I felt hesitant to answer. I was unable to complete the paperwork because I had no medical insurance. Being undocumented, I grew up without medical insurance, let alone frequent visits to the doctor. We only went when things were urgent or there was blood involved.

Sitting in the empty room, the doctor comes back in with results. He seems puzzled: 'You had an upper respiratory viral infection. Did you take any medication to treat it?' I look at him, 'No, just a home remedy I know.' We had grown up with homemade treatments: a tea full of honey and a drop of cinnamon for flavor. For mamá, there was no medical prescription; it was the only remedy she could give.

He stops signing papers and looks up: 'I don't know how you did it, but you're lucky your lungs didn't burst.'

CONCLUSION

The hardship of high health care costs and health care ineligibility leaves immigrant families with limited options, forces them to delay care and make tough choices between paying for medical expenses or other basic needs.

Health care neglect and exclusion comes at a high cost for immigrant communities. Public health systems are the most accessible to immigrant youth and are most commonly used by undocumented Californians. However, the Band-Aid services provided by public safety-net programs fail to provide long-term, preventative, or sustainable health support, resulting in untreated illnesses and injuries that can become matters of life and death for undocumented Californians.

RECOMMENDATIONS

Access to health care should be a collective, rather than a personal, challenge and should be prioritized as such. We recommend the following in an effort to provide all Californians with quality care that addresses the needs of the growing immigrant demographic:

- As undocumented Californians are excluded from insurance programs provided through the Affordable Care Act, protecting and strengthening the state's safety-net programs and services is essential to providing care for the uninsured. Prioritizing increased funding for these programs can lower the cost of services and increase access.
- Programs and clinics that work with low-income, undocumented Californians can make significant improvements to better serve vulnerable and unprotected populations in need of care. Survey recommendations include developments in quality care, such as language accessible materials; personnel who can provide translation services; culturally sensitive models of care; adequate staffing of nurses and doctors; and trainings for service providers on language, cultural literacy, and employee attitudes.
- Intentional outreach and education in low-income and undocumented communities is essential to shifting the perception of the health care system for immigrant families. Immigrant communities are overwhelmed by the health system and unaware if they qualify for care or where to seek it. Survey participants suggested an aggressive communications strategy directed toward fostering trust and changing the perception that health care is a luxury rather than a human right.
- Developing new medical centers in underserved low-income communities would address the needs of undocumented Californians who are currently unable to access services because medical facilities are too far away.



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YEARS IN U.S.		5% 0 yrs	23 ° 21+ y		12% 1–10 y	

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UNDOCUMENTED AND UNINSURED

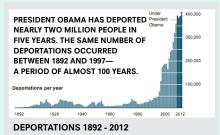






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I'VE HEARD SO MANY I DON'T WANT TO DRAW STORIES OF ATTENTION TO MYSELF DEPORTATION



2 WEEKS LATER...





surveyed had delayed their care, and 96% of them did so because of cost or lack of insurance.



OK, I CAN'T WAIT ANYMORE!

BAND-AID CARE

Seventy-four percent of immigrant youth report they have received services from public safety-net programs, such as emergency Medi-Cal, public hospitals and community or county health clinics.

While these services provide some relief, they are also understaffed, underfunded, overcrowded, and unable to meet the needs of many of those seeking care.

In the absence of care, community members are pooling resources and finding ways to care for each other. However, formal health care services are vital to address their needs.

AT THE FREE CLINIC...













