

Affordable Care Act Implementation in Illinois:

Overcoming Barriers to Immigrant
Health Care Access



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What Does the Affordable Care Act Mean for Illinois?

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The Patient Protection and Affordable Care Act (ACA), signed into law by President Obama in 2010, requires states to participate in or set up health care exchanges by October 1, 2013. These health care exchanges serve as a marketplace for individuals and small businesses to purchase health insurance, including many individuals who have never had insurance, such as immigrants. Illinois plans to establish a partnership exchange in which the State will divide the responsibilities with the U.S. Department of Health and Human Services (HHS). The federal government, in this type of partnership, “will operate everything from consumer eligibility and enrollment to financial management and risk corridors,” whereas the State will be responsible for plan management, basic supervision of the exchange, as well as matters such as in-person assistance.

This report addresses the challenges of Affordable Care Act implementation in Illinois. First, it provides demographic information regarding Illinois’ immigrant population and characteristics that have implications for implementation of the Affordable Care Act. Second, this report highlights the barriers that immigrants in Illinois face as they attempt to access health coverage—barriers that will become more salient as the Affordable Care Act is implemented this October. Finally, this report offers an existing model, the Immigrant Family Resource Program (IFRP), that was developed to address the barriers for immigrants that surfaced in the wake of the 1996 federal welfare law. The report will demonstrate that a similar programmatic model will be necessary to address the barriers that immigrants will face as they attempt to utilize the new marketplace in Illinois.¹

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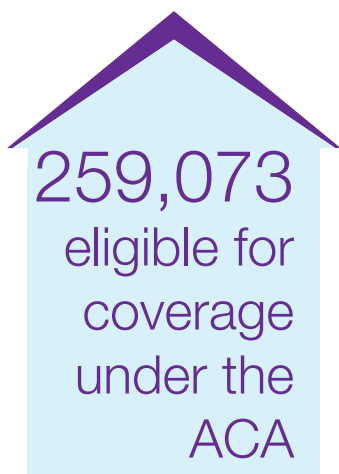
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With Support from:



Demographic Profile



259,073
eligible for
coverage
under the
ACA

Approximately 63% of native born children have visited the doctor, compared to 52% of children whose parent is a LPR and 47% of children whose parent is a non-permanent resident.

By 2014, 1,647,527 Illinoisans (13.1% of Illinois' population) will have affordable health insurance available to them as a result of the Affordable Care Act. These uninsured individuals will have different options of coverage based on their income and family size. Of the more than 1.6 million uninsured, it is estimated that 610,821 may qualify for the New Medicaid; 776,040 will be able to buy insurance through the exchange/marketplace and qualify for tax credits that allow consumers to purchase more affordable health insurance; and another 260,666 will be able to buy insurance through the marketplace but will not be eligible to receive tax credits.²

The complexity of these options increases for uninsured immigrants, whose options are based on both income level and immigration status. Illinois is home to 1,754,808 immigrants, 785,705 of whom are naturalized U.S. citizens (45%) and an additional 969,103 are either Legal Permanent Residents (LPRs) (55%) or undocumented.³ Non-citizens are three times as likely to be uninsured as U.S.-born residents.⁴ An estimated 539,931 immigrants (30% of total uninsured population in Illinois) are uninsured and about 259,073 (48 %) are eligible for coverage under the ACA.⁵

In Illinois, of the total uninsured immigrant population, 77% are Latino, 16% are White immigrants, and 11% are Asian. When examining each immigrant group by ethnicity, however, the uninsured rates are very similar among naturalized citizens and LPRs. Among the 109,790 uninsured naturalized immigrants, 22% are Asian, 32% are White immigrants and 40% are Latino. In its study, "Limited English Proficient Individuals in the United States: Number, Share, Growth, and Linguistic Diversity," the Migration Policy Institute found

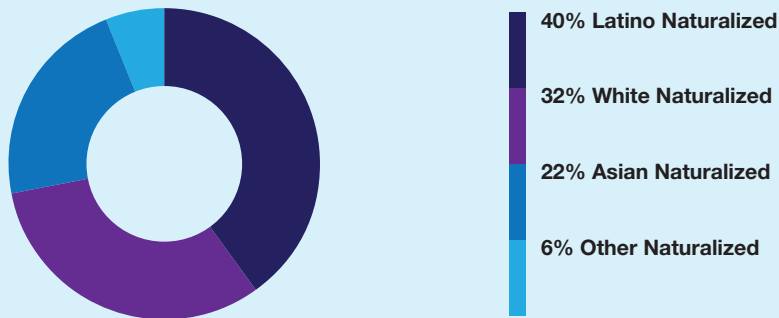
that Illinois has the fifth largest Limited English Proficient population in the country.⁶ According to the American Community Survey, 2,625,941 residents of Illinois speak a language other than English at home, and 1,146,812 are LEP.

Many immigrants live in families with mixed immigration statuses, such as U.S.-born citizen children residing with non-citizen parents. In 2009, 22% of all children in the United States were U.S. citizens living with at least one non-citizen parent.⁷ Research suggests that there is disparate access to resources and opportunities for mixed-status families; for example, children of immigrants are much less likely to have health insurance than native children.⁸ Additionally, children living with parents who are not naturalized "experience worse health and less access to care even when controlling for important demographic, socioeconomic, and health insurance variables."⁹ This is especially true of children living with a non-permanent resident parent, the study finds. On average, children whose parent--the head of household--is a legal permanent resident (LPR) or non-permanent resident are less likely to have visited a dentist or doctor. Approximately 63% of native born children have visited the doctor, compared to 52% of children whose parent is a LPR and 47% of children whose parent is a non-permanent resident.^{10 11} These findings highlight the importance of differentiating the immigration status of parents when considering their participation in health care programs. Additionally, this study illustrates the need for an immigrant-friendly and culturally-competent marketplace as well as a navigator program that will cater to the complex needs of Illinois' large uninsured immigrant population.

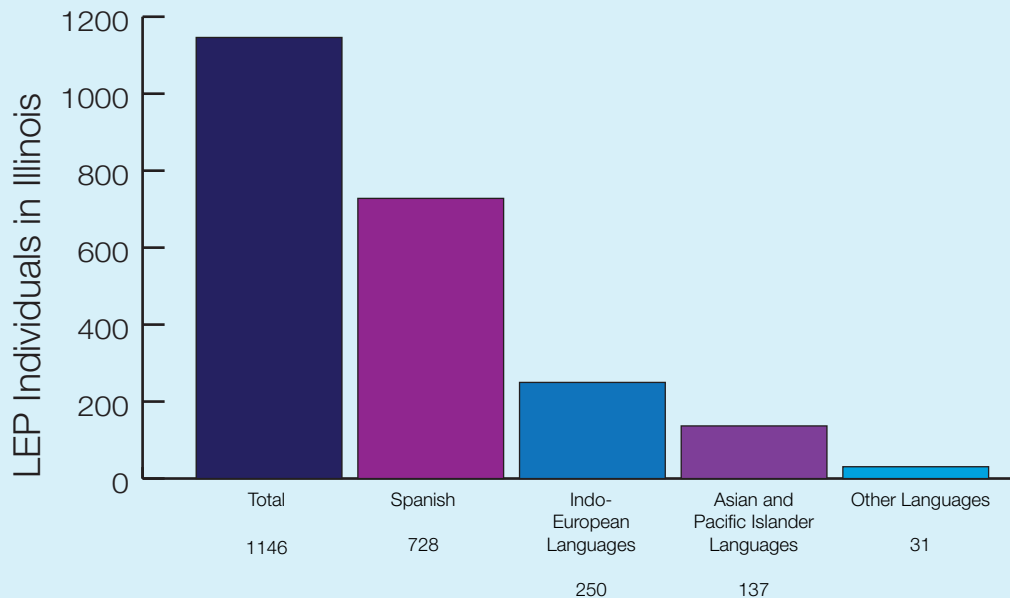
Naturalized No Health Insurance



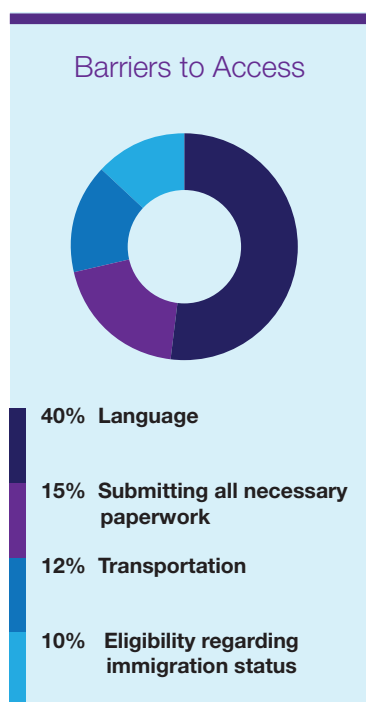
LPRs No Health Insurance



Languages Spoken by LEP Individuals in IL (in thousands)



Barriers to Access



This report is partially informed by studies commissioned by the U.S. Department of Health and Human Services (HHS) that assess and explain immigrant access to health services, including the barriers that confront immigrants. The Department's Immigrant Access to Health and Human Services project "aims to identify and describe federal, state, and local program eligibility provisions related to immigrants, major barriers (such as language and family structure) to immigrants' access to health and human services for which they are legally eligible, and innovative or promising practices that can help states manage their programs."¹² The project's issue brief "Barriers to Immigrants' Access to Health and Human Services Programs" observed that despite the fact that many immigrants and their children are eligible for health and human services, a significant number do not actually apply, or begin the application process but do not complete it.¹³

In addition, the Immigrant Family Resource Program (IFRP)¹⁴ conducted focus groups and consumer surveys to learn and understand how immigrants access health information and how they make health insurance decisions. The IFRP is a partnership between the State of Illinois, the Illinois Coalition for Immigrant and Refugee Rights (ICIRR), and 37 ethnic community based organizations (CBOs) that helps limited English proficient (LEP) individuals navigate health and human services. The surveys include a total of 241 Illinois immigrants who receive service through the IFRP. To supplement the data gathered directly from immigrant consumers, the IFRP conducted five focus groups with service providers who work daily with immigrant individuals and families. Focus group participants were asked about their perceptions of immigrant health issues and access. We

will summarize the findings of the HHS report as well as the IFRP focus groups and surveys, and introduce the reality of limited computer literacy—an additional barrier not studied in these reports that is likely to emerge through the marketplace.

The pie chart "Barriers to Access" identifies the top four obstacles that stand between immigrant and limited English proficient (LEP) families and prevent them from accessing needed services.¹⁵ Illinois must successfully address the barriers identified by the HHS and by IFRP partners as the State endeavors to implement the ACA and insure every eligible Illinoisan.

Language, Literacy and Cultural Barriers

Under the Affordable Care Act, more than 200,000 immigrants in Illinois will be eligible to buy health insurance starting October 2013, but many of them are LEP, making the enrollment process even more difficult. The "Barriers" issue brief highlights six ways in which language, literacy and cultural barriers prevent effective service delivery to immigrant families:

- Language posed barriers for many immigrant families interested in learning about or applying for programs.
- Across sites, administrators and CBOs expressed an urgent need for more bilingual and bicultural staff to better serve immigrants.
- The reliance of public agencies and service providers on untrained interpreters such as friends or applicants' own minor

children posed risks for clients.

- Public agency reliance on phone-based interpretation potentially reduced the quality of service received by immigrant clients.
- Aside from language barriers, immigrants from less developed countries tended to have minimal formal schooling and limited literacy.
- Some immigrants from less developed countries had cultural beliefs and practices that inhibited their interactions with public agency staff and/or caused them discomfort navigating Western medical systems and bureaucracies more generally.¹⁶

The Complexity of the Application Process and of Eligibility Rules

In its issue brief “Barriers to Immigrant Access to Health and Human Services Programs,” the HHS Immigrant Access project found that “the specific policies and requirements related to immigrant eligibility and verification changed rapidly” and were highly complex, making it difficult for immigrants to understand the process as well as whether or not they met eligibility requirements.¹⁷ In addition, “immigrant families had difficulties understanding the applications for benefit programs and rules requiring proof of citizenship and Social Security numbers.”¹⁸

A common barrier to access found by IFRP—submitting all necessary paperwork—may be more central under Affordable Care Act since most Americans are still not aware of how the ACA benefits them or when they are able to begin buying insurance.

On March 20, 2013, the Los Angeles Times reported on a study by the Kaiser Family Foundation that found that the Affordable Care Act “remains largely a mystery to most Americans, three years after the president signed it” and that “ignorance about the law is even higher among Americans who stand to benefit most, with more than two-thirds of people without health insurance reporting they don’t have enough information.”¹⁹

In addition, the eligibility requirements for tax credits, which will be crucial to access affordable health insurance, may be burdensome for immigrants. The tax credits will be generally available to individuals and families with incomes between 100% and 400% of the federal poverty level (\$23,550-\$94,200 for a family of four in 2013). In Illinois, about 90% of the total uninsured immigrants live under 400%

of the federal poverty level or lower. Of these, an estimated 150,000 will be eligible for tax credits.

Logistical and Public Education Challenges

The issue brief found three logistical barriers to access:

- Even when linguistic and cultural challenges could be overcome, getting to and from a public agency presented complications for immigrants with limited access to transportation.
- Work obligations also resulted in logistical barriers to applying for and receiving public assistance services
- The reliance on word of mouth to inform immigrants about public assistance benefits also potentially reduced enrollment and limited access to benefits.²⁰

The IFRP focus groups found that word of mouth and community networks are important sources of health-related information. The service providers mentioned that immigrants rely heavily on social service providers in their communities for information, and few immigrants get their information from the Internet.

The IFRP surveys found that 58% of immigrants trust their doctors when it comes to getting health-related information and 33% turn to family members and community based organizations. Similarly, they learn about health matters from their relationships with doctors, family members, and community based organizations.

Generally, immigrants make appropriate use of health services, with 74% going to doctors’ offices, clinics, or pharmacies when they are sick. Still, 34% use the emergency room as the health care avenue of their choice.

The high use of emergency rooms may be due to several factors, including the lack of health literacy or limited access to specialists. Additionally, 61% of immigrants surveyed select insurance plans based on the cost of insurance premiums and the services covered even though 50% of the respondents are not sure or do not understand how insurance works.

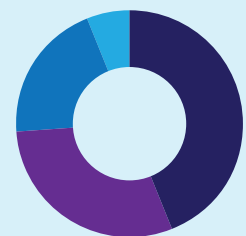
The focus groups found that many immigrants lack adequate understanding of how the American medical and health insurance system works.

As the chart to the right shows, only 44% understand how insurance works, 20% are not sure and 30% do not understand it. As a result,

Language posed barriers for many immigrant families interested in learning about or applying for programs.

Additionally, uninsured immigrant adults tend to go to the doctor only when they are sick.

Do you understand how health insurance works?



107, 44% Yes

73, 40% No

47, 20% Not sure

14, 6% No answer



they feel confused and timid, fear asking questions, and are disempowered.²¹

Climates of Fear and Mistrust, Particularly Among Mixed-Status Families

Some immigrants are deterred from applying for public services because of fears of mistreatment and deportation, especially immigrants in mixed-status families who may have U.S. citizen children that are eligible for benefits. Parents who may be undocumented are afraid to come in contact with a governmental agency out of fear that their information could be given to Immigration and Customs Enforcement, and therefore they refrain from applying for benefits for their children.²² The “Barriers” issue brief points out that “applications for benefits do not always clearly indicate that parents only need citizenship information and Social Security numbers for their children, not themselves, when applying for child-only benefits.”²³ Furthermore, the issue brief finds that though refugees are generally more likely to be eligible for benefits than other immigrant groups, the services may be “more difficult to access due to language, literacy, and cultural issues.”²⁴

Starting this October, each State’s marketplace will need to verify an individual’s immigration status and family income. Though the marketplace may only ask minimal immigration-related questions, IFRP has consistently witnessed how questions deter individuals in mixed-status family from applying for which they qualify—and

this deterrent effect will likely carry over to insurance and tax credits.

Administrative Burdens

The “Barriers” issue brief highlighted the complexity for caseworkers of analyzing many immigration documents to determine eligibility for benefits and for recertification. The issue brief notes that many cases are left open while the agencies waited for additional guidance to determine legal status.²⁵ In addition, budget cuts overburdened public agency staff, leading, in some states, to benefits being terminated “at the time of renewal simply because staff did not have time to review the required paperwork.”²⁶ The brief acknowledged the critical role of CBOs, noting that “CBO staff provided substantial support to public agencies that helped reduce these burdens.”²⁷

Limited Computer Proficiency

In the context of the Affordable Care Act and the marketplace, limited computer proficiency among the immigrant population must be taken into account. The marketplace will be accessed online, yet many immigrants may not have the computer skills necessary to reach and utilize it. A 2004 report by researchers at the University of California, Santa Barbara states that “substantial evidence exists at the national level that access to computers and the Internet is less common in low-income households, and in particular in the households of low-income, immigrant Latinos and other minority groups (National Telecommunications and

Information Administration, 2000).”²⁸

In 2011, there were 376,148 immigrants in Illinois who were 55 or older, or 24.6% of the total immigrant population in the state.²⁹ This is the age group that is most likely to have limited computer literacy, as well as other challenges like being limited English proficient.

Parents who may be undocumented are afraid to come in contact with a governmental agency out of fear that their information could be given to Immigration and Customs Enforcement, and therefore they refrain from applying for benefits for their children.

Overcoming barriers

IFRP's 37 partners have language capacity in 45 languages that work to ensure that immigrant families and other LEP persons are able to thrive and receive the services that they need for proper health, well-being and economic self-sufficiency.

The Immigrant Family Resource Program (IFRP) was designed to address many of these barriers. IFRP is a partnership between immigrant-serving agencies throughout Illinois, the Illinois Coalition for Immigrant and Refugee Rights (ICIRR) and the Illinois Department of Human Services (IDHS) to support immigrant access to health and human services. ICIRR subcontracts with 37 community organizations to conduct outreach, serve as navigators and case managers, provide professional interpretation and translation, and serve as cultural brokers. IFRP's 37 partner organizations provide information and screening to immigrant families to determine the eligibility criteria and immigration issues related to applying for and receiving public benefits and services. The partners also offer accurate interpretation and translation services for immigrants who have difficulty communicating with the Illinois Department of Human Services, as well as case management services to immigrant families who need long-term assistance accessing and maintaining benefits and services. Additional services include outreach activities that inform immigrants about the availability of public benefits and other services that support personal and family well-being and economic self-sufficiency, as well as information about the eligibility criteria and immigration issues related to applying for and receiving public benefits and services. IFRP partners conduct these outreach activities in locations immigrants frequent, including faith based institutions, local businesses, community health providers and clinics, and at mass events such as health fairs and neighborhood festivals.

ICIRR administers IFRP and adds centralized ethnic media, data tracking, and accountability to make the program effective and efficient.

ICIRR IFRP staff also provides quarterly trainings and technical assistance to all 37 CBOs. As new policies and laws are implemented in Illinois, these partners are updated with information and additional training that they may need to better serve the immigrant community. Additionally, ICIRR creates materials (fact sheets, brochures and other guides) in multiple languages, which we provide to IFRP partners, State offices and other locations that immigrants and refugees frequent.

IFRP has been instrumental in improving the lives of more than 425,000 immigrants and refugees in the past 13 years by connecting them to valuable services and navigating them through the challenging process of integration. Annually, with state, federal, & private investments, IFRP's estimated impact is:

- \$16 million in food assistance benefits;
- \$29 million pumped into local economies;
- Nearly 7 million meals to needy homes;
- 74,298 individuals assisted, including 19,447 with matching funds

Addressing Language, Linguistic and Cultural Barriers

IFRP's 37 partners have language capacity in 45 languages that work to ensure that immigrant families and other LEP persons are able to thrive and receive the services that they need for proper health, well-being and economic self-sufficiency. IFRP partners recruit and hire bilingual staff from their target communities, and ICIRR provides a 40 hour interpreter training for these staffers on a yearly basis. The top ten languages spoken by IFRP partners include Vietnamese, Hindi and Gujarati—languages

which, according to researcher Rob Paral, are used by recent immigrant groups who are more likely to have lower incomes and require assistance.³⁰ Paral further found that IFRP appears to be reaching underserved areas in Chicago with substantial numbers of low-income immigrants. In addition, IFRP has also made “inroads into suburban areas that are home to relatively newer communities of immigrants in need of assistance.”³¹

In addition to assistance with the application process, completion of applications and the provision of accurate information, IFRP partner staffers accompany immigrant and refugee families to the local IDHS offices to provide interpretation services. IFRP partner staff members work closely with the State local offices to ensure immigrant families receive culturally and linguistically competent services. State agencies frequently call upon IFRP partners for this service, on many occasions to provide interpretation as well as eligibility information. IFRP has become the hub for interpretation services for the majority of the local offices as well as immigrant and refugee families.

Addressing Complex Eligibility Rules

IFRP works with community members and State staff to clarify what documents are required, assist in collecting documents, explain why these documents are required, and educate mixed-status families regarding the information they need to ensure that these families are aware of their rights to access services. Additionally, IFRP provides comprehensive case management services to each family, including assistance with completion of applications, collecting documents, and accompanying families to the State offices, if needed. The IFRP staff at the program partners track the status of each application until the client is approved or denied the benefits. These services have decreased the burden on overworked State case workers while increasing access for the most vulnerable immigrant families.

IFRP has provided trainings to the Illinois Department of Human Services, Rehabilitation Services, Illinois Department of Employment Security, Illinois Department on Aging, Chicago Public Schools, Chicago Food Depository, and individual food pantries on how to work with immigrant and refugee families, immigrant eligibility for public benefits, how to utilize interpreters, domestic violence in immigrant communities, cultural awareness trainings,

how to work with mixed status families and where to refer immigrant and refugee families. Each site was given the Immigrant Family Resource Program Partner list which includes community/language served and contact information for each partner.

Addressing Logistical and Public Education Challenges

Engaging “hard to reach” populations is labor-intensive yet familiar to IFRP. Linguistic isolation, fear on behalf of undocumented family members, concerns of jeopardizing lawful immigration status, and fast spreading myths leave many immigrants out of programs and services for which they are eligible. IFRP’s work on human services outreach and enrollment has found successful ways to reach immigrants: trusted ethnic community organizations, religious institutions, and ethnic media.

The IFRP partner institutions are located within the communities they were built to serve. As a result, they are significantly more accessible for individuals and families than many governmental offices or agencies that are located farther away. With these institutions closer to home, it is both cheaper and faster for individuals to access them, and those seeking services are less likely to have to take a day from work to attend scheduled appointments. Some IFRP partners are also open after regular business hours (i.e. until 7pm) and on weekends, dramatically increasing their accessibility.

Addressing the Climate of Fear and Mistrust

Immigrants, particularly mixed-status families and those with low English proficiency, are less likely to seek out services from providers than the native-born. But culturally and ethnically appropriate community organizations form a bridge between immigrants and mainstream institutions. By engaging the institutions that immigrants trust and frequent, IFRP is able to effectively reach the significantly uninsured immigrant community. The trust that the institutions and CBOs have created is mainly due to their ability not only to serve immigrants and refugees in their own language but also in the manner they feel comfortable with. Many of the services IFRP partners help clients navigate are accessible via the Internet but due to limited English proficiency and limited computer literacy many of their clients do not know how to access and navigate the

applications for these services, making an in-person visit necessary for families to receive service IFRP partners, already trusted by the communities they are based in, are the obvious places for immigrants to go for help.

Addressing Administrative Burdens

The IFRP model—in which ICIRR re-grants to and trains 37 partner organizations—in addition to being a cost-effective way to reach a difficult-to-access population, lifts significant administrative burdens from State agencies. Highly qualified ICIRR IFRP staff provide the partner organizations with the training needed to provide health services and other human services, reducing the burden on the State and state staff to provide such trainings. Additionally, IFRP partners are often an important resource for State agencies. When State agencies are dealing with a difficult case or are unable to provide interpretation services, they sometimes turn to IFRP partners for assistance, allowing them to move forward with the case rather than delaying approval of benefits or having to use other State resources.

Addressing Limited Computer Literacy

All of our 37 partners have a computer and access to the internet, though many continue to use paper applications in order for their clients to feel more comfortable and so that direct communication is not lost by typing in front of them. With the online marketplace, partner organization staff will have the ability to fully assist clients with limited computer literacy in navigating the marketplace, while assisting them in their own language and being culturally sensitive.

Conclusion

The barriers to access for immigrant families leave a large number of immigrants uninsured, with negative effects—both in terms of health as well as medical costs—on individuals, families, schools, communities, and the State. Immigrant families face numerous barriers to accessing existing services, including confusion regarding their eligibility, fear of immigration enforcement, concerns about harming their status or the status of their family members, and language and literacy challenges. The Immigrant Family Resource Program, over its 13-year history, has developed and refined a highly effective model to address these barriers through its partnership with governmental agencies and community-based partner organizations. As the Affordable Care Act takes effect and the marketplace is set up, the IFRP model will be instrumental to reaching Illinois' large and growing immigrant population.



This report was made possible by:



Endnotes

As the Affordable Care Act takes effect and the marketplace is set up, the IFRP model will be instrumental to reaching Illinois' large and growing immigrant population.

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