

**TAKING CARE OF UNDOCUMENTED CHILDREN:
HOW PARENTS AND PROVIDERS SECURE HEALTH CARE
FOR UNINSURED LATINO CHILDREN IN A NEW GROWTH COMMUNITY**

by

Maria Amalia Pesantes Villa

B.A. in Social Sciences, Pontificia Universidad Católica del Perú, Peru, 2000

Licentiate in Anthropology, Pontificia Universidad Católica del Perú, Peru, 2002

M.A. in International Development & Social Change, Clark University, 2005

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This thesis was presented

by

Maria Amalia Pesantes Villa

It was defended on

June, 20th 2012

and approved by

Thesis Advisor

Patricia I. Documet, MD, DrPH
Assistant Professor
Behavioral and Community Health Sciences
Graduate School of Public Health
University of Pittsburgh

Committee Member

Martha Ann Terry, PhD
Assistant Professor
Behavioral and Community Health Sciences
Graduate School of Public Health
University of Pittsburgh

Committee Member

Andrea Fox, MD, MPH
Associate Professor
School of Medicine
University of Pittsburgh

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ABSTRACT

This research explores the decision-making process of Latino parents when confronted with the health needs of their undocumented children in Allegheny and Washington Counties of the Commonwealth of Pennsylvania, a New Growth Community where Latinos represent fewer than 5% of the population. The research objectives were to: (1) describe the strategies deployed by parents, social workers and healthcare providers to secure health care for uninsured Latino children in a New Growth Community, (2) illustrate the complexity of addressing the health needs of Latino children whose legal status in the USA prevents them from accessing health care, (3) identify the most effective strategies to provide health care for uninsured Latino children from the variety of approaches currently used by parents, social workers and healthcare providers, and (4) propose possible measures to ensure the long-term sustainability of these strategies.

During the summer of 2010, I conducted in-depth interviews with parents of undocumented children, social workers and healthcare providers serving Latinos. Testimonies indicated that health needs of undocumented Latino children in the study area are not addressed in a timely manner. This affected children's health status and their participation in school and afterschool physical activities.

Undocumented children in these counties do not have access to preventive health care and mostly rely on free or low-cost clinics, emergency room visits or the generosity of local doctors and providers. Lack of information about available services, fear of questions on

immigration status, and concerns about medical expenses make healthcare decisions harder for parents.

Parents and providers often depend on personal, professional and community networks to deal with urgent medical conditions and/or specialized care. Such strategies, by their very nature, are impermanent and unsustainable. Institutional healthcare options for undocumented uninsured children in this New Growth Community are few and not optimal.

This research is of public health importance because it suggests that Latinos and organizations that work with Latinos need to develop advocacy strategies that will guarantee access to low-cost health insurance for all children regardless of their immigration status. Arguments should center in both financial and public health implications of having uninsured children in the county.

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ACRONYMS

CHC:	Consumer Health Coalition
DPW:	Department of Welfare
CAO:	County Assistance Office
CBPR:	Community Based Participatory Research
EMA:	Emergency Medical Assistance
FQHC:	Federally Qualified Health Center
INS:	Immigration and Naturalization Services
ITIN:	Individual Taxpayer Identification Number
IRS:	Internal Revenue Service
LFC:	Latino Family Center
MA:	Medical Assistance
MFPC:	Monthly Free Pediatric Clinic
NGC:	New Growth Community
OTC:	Over the Counter
PCP:	Primary Care Physician
PRWORA:	Personal Responsibility and Work Opportunity and Reconciliation Act
SCHIP:	State Children's Health Insurance Program (also known as CHIP)
SHHC:	Squirrel Hill Health Center

SSA: Social Security Administration

SSN: Social Security Number

SSC: Social Security Card

UPMC: University of Pittsburgh Medical Center

WIC: Women, Infant and Children (federally-funded health and nutrition program for *women, infants, and children*)

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1.0 INTRODUCTION

Of the over eight million uninsured children in the United States of America (USA), around three million are estimated to be Latinos (Fry-Johnson, Daniels et al. 2005; Aizenmen 2007; KF 2009; NCLR 2009). The country is also host to 1.5 million undocumented Latino children, and a majority of them are not only uninsured but also “uninsurable” due to their immigration status¹ (Monheit and Cunningham 1992). The consequences of lacking health insurance are several:

- uninsured undocumented children do not have a regular source of healthcare,
- delivery of healthcare, when available, is delayed, and
- uninsured undocumented children have a higher chance of emergency room visitations.

The lack of health insurance has far-reaching effects on these children, from their social life to their academic development (Crosnoe 2006).

Latino children represent the biggest group of ethnic minority children in the USA, comprising approximately one out of every six children in the country (Flores, Fuentes-Afflick et al. 2002). Between 1997 and 2007, the number of children in the age-group of 0-17 years in the USA increased by 2.9 million, and second generation children of Mexico-born parents accounted

¹ Undocumented children are children who were born outside of the USA and were brought by their parents into the country without a visa or legal paperwork

for 70 percent (approximately two million individuals) of this growth (Gaspar, Acevedo et al. 2008). Due to this growth, these children experience health disparities that are not fully understood.

Health disparities, according to Whitehead (1991), are ‘differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust’ (p.9). Undocumented Latino children experience significant health disparities due to their citizenship status in the USA. Their immigration status, or rather the lack thereof, makes them ineligible for any form of public assistance services, including free or affordable health insurance. Given the challenges of obtaining health care for undocumented Latino children, there is an urgent need to document the various strategies that have been developed to address this problem and examine the possibility of their long-term sustainability.

This research explores the decision-making process of parents of undocumented children residing in Allegheny and Washington counties in Pennsylvania when confronted with the health needs of their children. Both counties are examples of what is known as New Growth Communities (NGC), an area with low (less than 5% of the population) but increasing concentrations of Latinos (Cunningham, Banker et al. 2006).

The study was partly inspired by a brief personal experience of working for three years (2008-2010) as a volunteer with various organizations that serve the Latino community in Pittsburgh. During these years, I witnessed the often desperate efforts by parents and providers to address the health needs of uninsured Latino children.

My research aimed to address two broad questions: (1) How do parents and providers address the health needs of undocumented uninsured Latino children in the NGC of the Allegheny and Washington Counties, Commonwealth of Pennsylvania, USA? and (2) Are the present-day strategies to meet health needs of undocumented uninsured Latino children sustainable in the long term?

2.0 BACKGROUND

2.1 LATINOS IN THE UNITED STATES

Latinos are the fastest growing population in the USA. Latinos represented 4.5 percent of the total population in 1990, 12.5 percent in 2000 and 16 percent in 2010; projections suggest that they will comprise 25 percent of the country's population by the year 2050 (Guzman 2001; USCB 2004). The dramatic growth of the Latino population can be explained by various factors including high birth rates, low death rates, and increased immigration, particularly for those who are undocumented (Delgado, Jones et al. 2005). Among Latinos living in the USA, those of Mexican origin comprise the largest group based on nationality, and this pattern holds true for Southwestern Pennsylvania (Documét 2001; Gaspar, Acevedo et al. 2008).

Not all Latinos have the same immigration status. While many are citizens of the USA, others fall into the categories of legal residents or undocumented immigrants. Being undocumented represents one of the biggest problems for Latinos living and working in the USA (Smith 2008). In 2002, around 9.3 million undocumented immigrants were estimated to live in the USA (Passel, Capps et al. 2004). Those arriving without a passport, visa², or work permit fall under the classification of undocumented (or "illegal" according to popular terminology) immigrants (De Genova 2002). The USA legal authorities have adopted a classification system

² Some arrive with a visa but remain in the USA for longer than allowed.

that differentiates between “illegal” and “legal” immigrants, and justifies differential access to services, rights and entitlements based on a person’s immigration status (De Genova 1998).

The use of the term “illegal,” though widespread, remains highly problematic due to its negative connotation. The term blames these immigrants for being in the country unlawfully, without mentioning the impossibility to obtain such legal permission or specifying that being “illegal” represents a status that can be changed. Using the term “illegal” to designate a group of people also obscures the broad sociopolitical conditions, frequently a result of USA foreign policies, which force many Latinos to leave their home countries and immigrate to the USA. However, with time, the term “illegal alien” has become for many, a broadly accepted category (De Genova 2002).

Several other negative stereotypes fuel discrimination and prejudice towards Latinos, in addition to the suspicion of being an illegal resident. The Latino’s “resistance to assimilate” to the rest of society in the USA is a common potent stereotype that conveniently ignores the generations of Cuban, Dominican, Central and South Americans who have successfully adapted to life in this country over the past century (Gonzalez 2000; Portes 2007). Further evidence refuting the anti-assimilation rhetoric can be found in indicators such as English Language acquisition within Latino communities. Portes (2007) found that while 98 percent of second generation Mexican-Americans are fluent in English, only about 35 percent are fluent in Spanish. In fact, Portes found that the pressure of assimilating into a monolingual culture was the primary reason behind Mexican-American children losing their ability to speak Spanish. Portes’ study successfully challenges the argument of “resistance” to Anglo culture championed by authors such as Huntington (2004).

In reality, low socioeconomic status, lack of legal documents, and relatively low rate of citizenship adoption pose major challenges for undocumented immigrants in their attempts to integrate with the rest of society in the USA (Gaspar, Acevedo et al. 2008). Furthermore, constant fear of deportation affects their everyday lives in ways that are hard to imagine for most legal residents. Undocumented immigrants have to be constantly on their guard, and be more cautious when they drive, sign contracts, apply for social services or seek health care (LaVeist 2005).

2.2 WORKING CONDITIONS OF LATINOS IN THE USA

Among Latinos, the undocumented are some of the most helpless and exploited workers in the USA, but their vulnerability is frequently overlooked (Portes 2006). They are often victims of low or unpaid wages, dangerous work conditions, uncompensated workplace injuries, discrimination, and other labor law violations (Peak, Gast et al. 2008; WF 2009). De Genova (1998), who studied Mexican immigrants living in the USA, argues that they are more desirable as undocumented workers than as legal citizens. Their “illegal” status makes it advantageous for the employers to deny basic civil rights to these immigrants and their children, while benefiting from their cheap labor.

There is general consensus that the primary reason behind the migration of Latinos to the USA is the search for gainful employment (Berk, Schur et al. 2000; Delgado 2007). Their lack of legal immigration status enables many employers to take advantage of the economic needs of this population as noted in this newspaper article:

There are businesses all over the country paying far lower wages to illegal immigrants that they would have to pay native-born employees. They know exactly what they are doing, and they are profiting from it handsomely (Times Free Press 2005).

As “illegal” immigrants without effective command of the English language and lacking a work permit, undocumented Latinos in the USA are limited to occupying the lower levels of the working class. As a result, they earn below-average wages and lack job security (Bean, Browning et al. 1984; Davila, Mora et al. 2008). Economic need and undocumented status force many Latinos to accept jobs that might not be unionized or where exploitation is blatant (Mendoza 1994). Having to work and live “in the shadows” results in fewer economic and social rights and fewer benefits for the workers and their families (Gaspar, Acevedo et al. 2008). The lack of fringe benefits, such as health and life insurance plans, even when working in hazardous jobs, affects the health of undocumented workers and that of their children (Berk, Schur et al. 2000; Lillie-Blanton and Hoffman 2005).

2.3 IMMIGRATION AND HEALTH

Immigration and health are closely linked. Studies have shown that immigration has a negative effect on health (Bean, Browning et al. 1984). For instance, the immigration process itself can be quite stressful, especially if immigrants do not speak the language of the destination country and come from a different cultural background (Kasl and Berkman 1983; Gaspar, Acevedo et al. 2008).

Health is a crucial asset for immigrants, their families, and the communities where they reside (Gaspar, Acevedo et al. 2008). The ability to work and provide financially for their families is very important for Latino workers (Walter, Bourgois et al. 2004). They need to stay

healthy to remain gainfully employed, but buying health insurance for themselves or their children is often an expense they cannot afford (Carrillo, Treviño et al. 2001; Documét 2001).

Latino immigrants in the USA are mostly employed in temporary and low-paid jobs, which are also less likely to offer any kind of health coverage (Del Pinal and Singer 1997; Carrillo, Treviño et al. 2001). Furthermore, as the USA healthcare system assumes that most working-age people and their dependents receive employment-based health insurance, those who hold temporary positions, work in small businesses or get paid in cash have no access to health benefits or a health insurance plan (Collins, Hall et al. 1999). The lack of legal status combined with low-paying jobs are important reasons why Latinos are the ethnic group with the highest proportion of uninsured people (32.1 percent) as compared with all other ethnicities (Acuña 2003; Lillie-Blanton and Hoffman 2005; James 2007; DeNavas-Walt, Proctor et al. 2009).

The limited access to healthcare for Latino workers and their children in the USA corresponds to broader ideological, economic, social and historical factors that have played and continue to play critical roles in perpetuating this situation (Aguirre-Molina, Molina et al. 2001). Restricting access to social and health services can be seen as a way of “punishing” undocumented Latino immigrants. One direct consequence of this punishment is the denial of affordable or free health insurance for the children of undocumented immigrants (Brach, Lewit et al. 2003).

2.4 MEDICAID AND SCHIP

Historically, protecting the health of children has been a major concern for several USA administrations. In 1965, the federal government passed the Social Security Act Amendments,

also known as the Medicare and Medicaid Acts. These acts were intended to protect the health of children, the elderly and other vulnerable populations, such as pregnant women and people with special needs, by providing them with government-subsidized health insurance (Fox 1996). Eligibility for Medicaid is determined by various factors, the most important ones being income, household composition, citizenship status and possessing a social security number (SSN) (USDHHS 2010). Legal permanent residents are ineligible for Medicaid for the first five years after they are granted legal status (Passel, Capps et al. 2004).

Despite these measures, Medicaid failed in its mission to provide health coverage for all low-income children under the age of nineteen. To remedy this situation, the State Children's Health Insurance Program (SCHIP) was created in 1997 by the USA Congress (Brach, Lewit et al. 2003). The SCHIP is a federal and state partnership that aims to offer health insurance to children from families whose earnings exceed the eligibility limit for Medicaid yet remain unable to afford private health insurance (Ario 2009). As part of the SCHIP partnership, the federal government made available USD 40 billion as matching funds to the states over a ten-year period. Though SCHIP is a small program compared to Medicaid that serves ten times as many children, it generated significant enthusiasm amongst those concerned about the need for providing health insurance for all children (Brach, Lewit et al. 2003). Since its inception, the SCHIP program has helped states offer healthcare coverage to over five million uninsured children in the USA (USDHS 2010). The 2000 economic crisis, however, induced changes in income eligibility limits of recipients, and eight states³ froze enrollment to their SCHIP in 2004 (Fry-Johnson, Daniels et al. 2005; FamiliesUSA 2008). Despite the setback, a 2009 report issued by the USA Census Bureau noted that the total uninsured proportion and the number of

³ Arizona, California, Florida, Georgia, Nevada, Rhode Island, South Carolina, and Tennessee

uninsured children are at their lowest since 1987, the first year for which comparable health insurance data were collected (DeNavas-Walt, Proctor et al. 2009). Low insurance enrollment among immigrant children, however, remains a matter of concern. In 2003, of the eight million uninsured children in the USA, almost three million belonged to Hispanic families (Fry-Johnson, Daniels et al. 2005). In 2005, forty-five percent of low-income immigrant children (Hispanic and non-Hispanic) were still uninsured, compared to seventeen percent of low-income non-immigrant (i.e. citizen) children (Wilkiscki and Spencer 2008). Multiple studies have shown that undocumented children constitute the biggest proportion of uninsured children in the USA, outnumbering all other minorities and whites (Capps 2001; Flores, Fuentes-Afflick et al. 2002; NCLR 2007; NCLR 2009).

The limited access to insurance for undocumented children makes sense if we take into consideration the active efforts to restrict access of public services to the immigrant population in the USA. Political arguments for denying public services to undocumented immigrants are twofold. First, fewer public services available for undocumented immigrants will discourage immigrants from coming to the USA illegally and reduce the number of immigrants in general (Fox 1996). Second, the State could divert the money saved by withdrawing services from immigrants for uses that benefit the legal residents of the USA⁴ (Fox 1996).

The most blatant example of such efforts is the federal Personal Responsibility and Work Opportunity and Reconciliation Act (PRWORA) of 1996. PRWORA made more stringent the eligibility requirements for various health and social services, essentially allowing the states to deny non-USA citizens access to these public programs (Capps February 2001). The PRWORA

⁴ Legal permanent residents (immigrants with green cards) are ineligible for Medicaid or SCHIP during their first five years in the USA. After five years, they become eligible for Medicaid and SCHIP. Undocumented immigrants however, are not eligible for neither of those two programs. Kaiser Commission (2006)

also prohibits states from using federal funds to provide SCHIP coverage to those who are in the USA without appropriate immigration documentation (Alegría, Cao et al. 2007). Several interpretations of the PRWORA have been contested in the courts, forcing the federal government to partially restore non-citizen eligibility for benefits and provide some basic welfare protections for the applicants' undocumented family members. The restrictive provisions of PRWORA, however, have led many immigrant families to voluntarily withdraw from these programs (Hagan and Rodriguez 1998).

In addition to the federal government, some states have also resorted to actions directed against undocumented immigrants. For example, in 1994, the state of California passed Proposition 187, which excluded undocumented immigrants from accessing several forms of public assistance, including publicly-funded health care. Proponents of the measure argued that providing health care to undocumented immigrants was draining state resources, thereby making it harder to serve the “legal” population (Berk, Schur et al. 2000). In addition to regular health care, Proposition 187 also barred undocumented immigrants from non-emergency medical and prenatal care, and access to public education (Fox 1996).

Limiting access to public services for undocumented Latinos has had a serious impact on their children. Although Latino families' income levels make their children eligible for SCHIP, lack of immigration status disqualifies almost 1.5 million Latino children in the USA from access to low-cost or free health insurance (Aizenmen 2007). This has affected the welfare of both citizen and non-citizen children, and produced negative health implications for families and the communities in which these children reside (Hagan, Rodriguez et al. 2003; Ross and Hill 2003).

Lack of citizenship and proof of legal residence are not the only barriers for Latino children wanting to enroll for Medicaid or SCHIP. Cultural issues, lack of language skills, and parents' working conditions are also important impediments (Ross and Hill 2003). Many immigrants lack the social skills to negotiate and understand the welfare system bureaucracy, and are deterred from applying to obtain benefits for their children (Carrillo, Treviño et al. 2001). The eligibility rules are often too complex or arcane for people with limited English-language proficiency (Documét 2001). In the case of farm-workers, their high inter-state and intra-state movement affects their capacity to apply for benefits for their children (Flores, Fuentes-Afflick et al. 2002).

If one compares access to children's healthcare to access to education, the differences become even starker. For instance, in Pennsylvania, while public health care is restricted to only residents with legal immigration status, access to public education is independent of such requirements. According to the Pennsylvania Department of Education

... a school district or charter school *may not request or require any of the following*: a social security number; the reason for a child's placement if not living with natural parents; a child's or parent's visa; agency records; or, except in the limited circumstances described in the next section, a court order or records relating to a dependency proceeding (CoF 2010, emphasis added).

In fact, the Pennsylvania Department of Education makes it a point to emphasize the unconstitutionality of any attempt to discriminate on the basis of citizenship:

A child's right to be admitted to school may not be conditioned on the child's immigration status. A school may not inquire regarding the immigration status of a student as part of the admissions process. Plyler v. DOE, a U.S. Supreme Court decision, held that it is unconstitutional to deny free public education to children who are not legally admitted into the United States (CoF 2010, emphasis added).

One can argue that access to affordable health care is equally as important as access to education for children. The current political discourse in the USA, however, seems to disagree.

2.5 LATINOS, TAXES AND USE OF PUBLIC SERVICES

One of the arguments often used against Latino immigrants in the USA is the increasing utilization of public services by undocumented households paid for by “legal” tax-paying citizens. This results in, it is argued, an unfair and unequal burden on those who pay taxes (Aizenmen 2007). This argument, which implies that immigrants drain taxpayers’ money, has been used time and again to encourage anti-immigrant sentiments (Berk, Schur et al. 2000). Some retain the belief that undocumented immigrants are drawn to the USA to take advantage of the available public assistance; this has been repeatedly proven to be inaccurate (Fox 1996; Berk, Schur et al. 2000; UNC 2006). Evidence shows that, on the contrary, many immigrants (both documented and undocumented) create more wealth than they consume; they also contribute far more in taxes than what they cost (Fox 1996).

2.5.1 Latinos’ tax contribution

In 2004, undocumented immigrants used Individual Taxpayer Identification Numbers (ITINs)⁵ to deposit USD 2.5 million in federal income tax with the USA Internal Revenue Service (IRS) (Loller 2008). The same year, payroll tax deductions, sales taxes and real estate/property taxes from undocumented immigrants contributed USD seven billion and USD 1.5 billion to the Social Security and Medicare funds respectively, even though undocumented immigrants are not eligible for either under the current legal statutes. According to the IRS, USD

⁵ The ITIN is a specially awarded identification number that allows those without a SSN to pay required federal income tax under the Internal Revenue Code IRS. (2010). "Individual Taxpayer Identification Number (ITIN)." Retrieved October 15, 2011, from <http://www.irs.gov/individuals/article/0,,id=222209,00.html>. The Internal Revenue Service (IRS) can issue an ITIN to any person living and working the USA. who reports or files a federal tax return. This system has been used for several years by foreigners without SSNs Gonzales, J (2000)

1.4 billion was deposited as federal income tax using ITINs in 2006, with 50 percent contributed by those living in the USA illegally (Loller 2008). In 2009, undocumented workers paid more than USD seven billion in federal income tax through the use of their ITIN. As an article in the San Diego Tribune (2005) explained:

If you live in the United States, the government will find a way to tax you. Illegal immigrants pay sales taxes every time they buy a shirt at a store or a gallon of gas for the car. They pay property taxes when they rent an apartment or buy a house... Illegal immigrants also fork a fortune in payroll taxes every year.

In the last decade, money contributed by undocumented immigrants to the Social Security Administration has amounted to over USD 50 billion a year (Delgado 2007). According to Acuña (2003), activists have estimated that the average immigrant pays USD 1300 or more a year in taxes. Thus, the argument that immigrants do not pay taxes yet profit from them is highly inaccurate.

Many citizens of the USA are unaware that undocumented immigrants contribute to public funds. This has led states to take legal actions against the federal government: “California, Florida, Arizona, and Texas... have sued the federal government to recover the costs of educating, housing, hospitalizing, and jailing undocumented immigrants” (Fox 1996:20). Many are motivated to support anti-immigrant reforms based on the erroneous assumption that undocumented immigrants benefit unfairly from public assistance programs without contributing to their funding in any manner (Dizikes 2010).

2.5.2 Latinos' Use of Public Services

Although some studies have argued that undocumented immigrant families are more likely than native-born families to utilize social services for which they are eligible (e.g. Women, Infants and Children's Nutrition [WIC], food stamps and free school lunch) this view is not uncontested (Aizenmen 2007). Fomby and Cherlin (2004) found that undocumented immigrant parents are less likely to apply for social services for their children born in the USA. Thus, these legally eligible children are less likely to receive social services compared to children of native-born parents. Though welfare programs targeted toward children are found to have higher rates of use than those targeted at adults, many undocumented Latino parents are often not fully aware that their USA-born children qualify for these programs (Berk, Schur et al. 2000; Fomby and Cherlin 2004). Other undocumented parents fear that participation in these programs might put them at risk of deportation or create problems during the process of becoming legal residents or citizens (Hagan, Rodriguez et al. 2003). Undocumented parents, skeptical about providing documents that might identify them as "illegal", often avoid applying for Medicaid or SCHIP for their children (Aizenmen 2007).

A growing body of evidence suggests that immigrants are avoiding public assistance to a greater extent than citizens, even when certain family members are eligible for such aid (Hagan, Rodriguez et al. 1999). Thus, rather than over-utilization, there is often under-utilization of public assistance by immigrant families. The quality of information available to immigrants regarding eligibility for public assistance of both their undocumented and legal children explains the large number of uninsured Latino children who are also USA citizens. For example, in 2007,

19 percent of eligible Latino children lacked health insurance, compared to 9 percent of African-American and 6 percent of non-Hispanic white children (NCLR 2009).

Latino immigrants have lower rates of utilization of ambulatory health care compared to non-immigrant Latinos and other ethnicities (Berk, Schur et al. 2000). Their rate of hospitalization is also comparable to that of other ethnicities except for hospitalizations for childbirth, which is higher among Latinas. A study conducted by the University of North Carolina (UNC 2006) found that despite the frequent rhetoric advocating limited access to public benefits for undocumented residents, there is no evidence “to support the supposition that access to public benefits attracts Latinos to a state or locale” (p.2). For example, though North Carolina operates one of the weakest public benefit programs for immigrants, it has ranked second in the nation as having the fastest growing Hispanic population over the last fifteen years (UNC 2006). Similarly, Allegheny County in Pennsylvania has experienced a significant increase of Latinos (68 percent increase between 2000 and 2008 based on USA Census Bureau Data) (Documét, Bachurski et al. 2010). In an earlier study, Documet and Sharma (2004) found that the increase in the Latino population in Allegheny County could not be linked to easy access to health services or other public benefits.

2.6 UNINSURED LATINO CHILDREN

Latino children under 19 years of age, the upper age limit for Medicaid and SCHIP, make up 29 percent of all uninsured children (Carrillo, Treviño et al. 2001). Currently three million Latino children are without medical insurance (CDF 2009).

Multiple studies have demonstrated that the health of children without insurance is poorer than that of children with insurance (Monheit and Cunningham 1992; Patrick, Madden et al. 1992; Spillman 1992; Cunningham and Hahn 1994; Stoddard, St. Peter et al. 1994; Himmelstein and S 1995; Kogan, Alexander et al. 1995; Ross and Hill 2003). Poor health was shown to be a result of various factors. Uninsured children are less likely than insured children to have a regular physician (Flores 2010), receive adequate preventive care (Gorman, Landale et al. 2001) or have made any medical visit in the past year (Rosenbach 1989). Uninsured children also utilize emergency or critical care more frequently than other health services (Zimmerman and Fix 1998). Lack of health insurance is correlated to the reduced use of health services, which in turn decreases the likelihood of referral for and use of other necessary services such as specialized care (Rudolph and Porter 1986).

Latino children are not the only ones who have reduced access to quality healthcare in the USA. Minority children, in general, are in a similar situation regardless of their socioeconomic status (Newacheck, Hughes et al. 1996). Latino children, however, are more likely to be uninsured than White or African-American children irrespective of family income (USDHHS 1998). The reason why Latino children are the most uninsured of all racial/ethnic minorities in the USA is unclear (Flores, Abreu et al. 2006). Some of the reasons put forward include: being an immigrant or having an immigrant parent (Lessard and Ku 2003), living in poverty (Holahan and Ghosh 2004), and having parents with limited English proficiency (Flores, Abreu et al. 2005); Latino children usually face all three (Flores, Abreu et al. 2006).

A comparative study conducted in eight USA states showed that health insurance coverage of immigrant children is directly related to liberal eligibility requirements for Medicaid, SCHIP and other public healthcare coverage (Capps 2001). Efforts to increase enrollment of

Latino Children in Medicaid by providing applications and information in Spanish or developing outreach strategies among Latino families, on the other hand, were not that successful (Perry, Kannel et al. 2000).

Peak et al. (2008) found that the use of healthcare services and the extent of usage were both affected by the lack of health insurance. Like adults, children lacking health insurance are less likely to have a regular source of care and instead depend on emergency facilities, free clinics, or clinics with sliding scale fees more often than children with health insurance (Becker 2001). Insurance status also influences the quality, quantity, and outcomes of care for children (Fry-Johnson, Daniels et al. 2005); thus, according to Peak et al. (2008), uninsured children are more vulnerable even if they manage to access some type of care. Other researchers, however, found that lack of insurance does not completely equate with inadequate emergency or in-patient care (Szilagyi, Shenkman et al. 2003; Mistry, Hoffmann et al. 2005), and that having insurance does not guarantee access, understood as the use of the healthcare system (Perchasky 1981; Olson, Tang et al. 2005). Lack of insurance is therefore only one of the explanations for poor health and access to healthcare among children.

The consequences of being uninsured are not limited to health outcomes. For children, the lack of access to health insurance can also affect academic attendance and ability to fully participate in various extra-curricular activities (Ross and Hill 2003). Such side effects of not having health insurance are usually overlooked while the debate remains focused on the entitlement of undocumented immigrants to social services (Fassin 2009).

Around 29 percent of immigrant children live in overcrowded housing, primarily to reduce the living expenses by sharing their lodging with other families (Capps 2001). Overcrowded housing has long been associated with increased risk of transmission of

communicable diseases, and such living conditions are likely to affect health outcomes for immigrant children (Hernandez and Charney 1998).

Poor health in children also impacts their educational progress. Poor health, both physical and mental, during childhood is likely to become a risk factor for early cognitive deficiencies or impairment (Crosnoe 2006). In the USA, non-white children usually begin elementary school with poorer physical health than their White peers. In a country where education is considered a key mechanism for social and economic ascendancy, poor health as a child hinders the possibility for Latinos and other minorities to succeed in their academic lives and escape poverty.

Since undocumented children will most probably reside in the USA well into their adulthood, access to health insurance could give them the opportunity to participate in activities that create responsible and productive members of the society.

2.7 MIXED-STATUS FAMILIES

The families of almost 30 percent of Latino children in the USA have annual incomes below the federal poverty level (USCB 2008). These families are also what the social science literature has defined as “mixed status families” in which “one or both parents is a noncitizen and one or more children is a citizen” (Fix and Zimmerman 2001:397). Though it is estimated that one out of every 10 families in the USA is a mixed-status family, the complexity of such families is poorly understood by policy makers (Fix and Zimmerman 2001). Amongst Mexican immigrant households in the USA, 58 percent are mixed status families (Gaspar, Acevedo et al. 2008). As a result:

[s]ome household members have different rights and privileges (meaning they are exposed to different risks and forms of vulnerability). In most of the cases the “mix” is due to the fact that the householder is not a U.S. citizen while some of the offspring are, having been born in U.S. territory (Gaspar, Acevedo et al. 2008:12).

Immigrant parents who have some undocumented children (and thus, ineligible for SCHIP or Medicaid) face difficult decisions when it comes to their children’s health. Within the Latino community, a large proportion of Mexican-American children belong to high-risk families characterized by poverty, low education, large family size, and barriers to health care access (Guendelman, English et al. 1995). It is, thus, not surprising that the health status of these children is poor in comparison to other ethnicities, especially if they lack health insurance (Flores, Fuentes-Afflick et al. 2002). Poverty, however, is a stronger predictor of poor health status than access to insurance (DeNavas-Walt, Proctor et al. 2009). Poor undocumented children have restrictions to benefit from public programs, such as Food Stamps and WIC. Both programs facilitate a better nutrition and could serve as protective factors from ill health. They are targeted at poor children but unavailable to undocumented ones.

There is a serious need to understand the variety of impacts experienced by uninsured Latino children due to limited access to health insurance. Lack of regular preventive dental, vision and mental care, and timely medical care are common among uninsured children and all of these unmet needs affects children’s lives and those of their families. These necessities could be addressed by guaranteeing continuous and adequate insurance coverage (Olson, Tang et al. 2005).

2.8 HEALTH STATUS OF LATINO CHILDREN

Children in the USA experience worse health outcomes than children in other industrialized countries (Berdahl, Owens et al. 2010). Furthermore, the USA is the industrialized country with the highest proportion of children living in poverty. Poverty, however, does not affect all children equally; poor children in the USA disproportionately belong to minority communities (Newacheck, Hughes et al. 1996; Flores, Abreu et al. 2006; CDF 2008). The high prevalence of poverty among Latino families ought to be taken into account when studying the health status of Latino children (Mendoza 1994).

Most studies on the health status of Latinos do not differentiate between children, adolescents or adults based on their legal status, i.e. whether they are citizens of the USA, legal immigrants, or undocumented immigrants (Mendoza 1994:46). This is a critical omission, especially in the case of Latino children, since many of them are undocumented and uninsured, and experience significantly more challenges to access healthcare. Overall, Latino children experience a far bigger burden of health risk factors, illness, low health status, underuse of health services, limited access to care, and health disparities (Flores, Fuentes-Afflick et al. 2002). This leads to a suboptimal health status, which means they spend more days in bed with various illnesses and make fewer physician visits than children of other ethnicities (Flores, Bauchner et al. 1999).

From a public health perspective, it is necessary to acknowledge that health problems that occur during childhood can have significant negative outcomes such as premature death, lifelong disabilities, chronic diseases, and preventable pain and suffering (Flores and Zambrana 2001). From an economic perspective, unresolved health problems from childhood can result in increased societal costs and use of resources, and affect the health of other children in their

cohort. Poor health can also keep children away from school throughout their lives, decreasing their earning capacity. Both public health and economic arguments could be used to support the expansion of SCHIP to cover undocumented children, or for the implementation of a primary care and preventive services insurance such as the Children's Medical Security Plan in Massachusetts. The Massachusetts plan insures children who are not eligible for Medicaid, including immigrant children without documentation of citizenship (Flores, Abreu et al. 2006).

2.8.1 Dental Care

Oral health is a crucial component of children's overall health, functional capacity, and social welfare (NIH 2000). During early childhood, the face, mouth and dentition undergo significant growth that requires the attention of a dental professional (Edelstein 2002). Children from certain groups, such as uninsured Latino children, are at a higher risk of lacking regular dental care making them more vulnerable to common diseases (Edelstein 2002). Furthermore, several studies have shown that Latino children experience substantial barriers to dental care (Berdahl, Owens et al. 2010). Among these barriers, the most common are lack of health insurance, lack of transportation, and limited English language proficiency (Ramos-Gomez, Tomar et al. 1999).

Caries is the most prevalent type of dental disease and is most common among disadvantaged children (Mofidi, Rozier et al. 2002). Some authors state that Latino children are the group with one of the highest prevalence of caries (Barker and Horton 2008). Other authors specify that Mexican American and non-Hispanic Black children are the two ethnic groups with high prevalence of caries (24 percent in 2006 in the two to four age group and 72.2 percent in the six to eight age group for that same year) (Tomar and Reeves 2009). Barriers to health care

also prevent early dental treatment among Latino children. For example, only 60 percent of Mexican-American children of 12 to 17 years of age have had cavities treated or filled, compared with 87 percent of White children (USDHS 1996). Such disparities cannot always be explained simply by the lack of insurance among Latino children. For example, many children in the state of California continue to suffer from caries even though most do have some kind of public insurance (Mofidi, Rozier et al. 2002). Other possible explanations include poor dental hygiene habits among Latinos, the low acceptance of Medicaid amongst dentists, and the lack of preventive dental care as part of the health insurance package. Shortages of Latino dentists, and other cultural and linguistic obstacles contribute to the high prevalence of dental diseases amongst Latino children (Flores, Fuentes-Afflick et al. 2002). For children insured by Medicaid, there is no provision for comprehensive dental care after the initial preventive visit (NIH 2000).

On average, Latino children are more likely than White children to have an unmet dental need, and to have gone more than two years without seeing a dentist (CPAC 2004; CDF 2009). While free or low-cost preventive dental care can be part of the solution, other factors are at play (Flores, Fuentes-Afflick et al. 2002). An ethnographic study conducted in California showed that often parents did not promote or supervise oral hygiene practices, and did not recognize visible dental caries as a disease but thought of them as harmless stains (“*manchas*”) (Barker and Horton 2008). Thus, caregivers’ lack of knowledge of Latino attitudes towards oral hygiene and dental diseases also explains the high prevalence of caries among Latino children. It also suggests the need of educating Latino parents about dental care for their children.

2.8.2 Asthma

Asthma is another health problem that appears to affect Latino children more than other ethnic groups (Berg, Wahlgren et al. 2004). The prevalence of asthma has increased over time among Latino children and this, in turn, results in more emergency room visits, hospitalizations, limits on physical activity, and the need for frequent urgent care (Flores 2010). Although the prevalence of asthma among Latino children is not higher than among children of other ethnic groups, the morbidity rate of asthma is higher in Latino children (Wood, Hidalgo et al. 1993). The proportion of Latino children with asthma in the USA is 8 percent (EPA 2005). As with other health issues, explanations include poverty, lack of health insurance, cultural and language barriers, and culture-specific health beliefs (Wood, Hidalgo et al. 1993).

There are differences between those Latino children with asthma who have some form of public insurance (e.g. Medicaid) and those who have private insurance (Merrick, Houchens et al. 2001). In California, Latino children covered by Medicaid are hospitalized about twice as frequently for an asthma episode as children with private health insurance (Merrick, Houchens et al. 2001). Besides hospitalizations, Latino children with asthma also experience different responses with preventive care and follow-up care following discharge from hospital (Berg, Wahlgren et al. 2004). It has been noted that uninsured children are less likely to receive free or affordable follow-up care.

2.8.3 Obesity

Being overweight and/or obese are common health problems affecting Latino children (NCLR 2006). Poverty and food insecurity are strongly associated with obesity among Latino

children, and 21.7 percent of Latino households experience these conditions (NCLR 2006; Buscemi, Beech et al. 2009). Food insecurity results in parents substituting nutritious food of better quality and reducing the variety of food with cheap food that has high-calorie and high-fat content (Sarlio-Lahteenkorva and Lahelma 2001; NCLR 2006).

Overweight and obesity cause several negative health conditions such as asthma, type 2 diabetes, high blood pressure, poor bone and cartilage development and sleep apnea, and lead to low self-esteem in children (Davis, Ventura et al. 2005). Interventions to prevent obesity and reduce its prevalence among Latino families are becoming increasingly necessary (del Rio-Navarro, Velázquez-Monroy et al. 2004).

2.8.4 The Hispanic Paradox & Adolescent Pregnancy

Among studies that look at the health status of Latinos, some revolve around what has become known as the “Hispanic paradox”. It refers to the fact that, despite sharing similar socioeconomic conditions with other ethnic groups, Latinos in the USA have far better health status (Jasso, Massey et al. 2004). Latino’s health is far better than that of African-Americans’ and often even better than the health of non-Hispanic whites whose economic resources are far superior. It has been argued that the protective effects of culture and norms within Latino families and communities can partially explain this paradox. The health of Latino communities is not only buffered by cultural norms that proscribe risky behaviors and promote healthy activities⁶; strong family support networks also provide important social and emotional support (Vega and Amaro, 1994). These arguments, however, do not explain the current health crisis, as

⁶ Although there are cultural norms that proscribe healthy behaviors - such as the use of condoms- and that promote unhealthy activities – such as regular drinking-.

described in earlier sections, amongst Latino children and adolescents, and others that affect Latino adolescents such as teenage pregnancy.

Pregnancy rates for Latina adolescents (between 11 and 19 years of age) are nearly 75 percent higher than the national average (Sterling and Sadler 2009). Despite the overall decline in adolescent pregnancies in the USA in the last decade, Latina adolescents still have disproportionately high pregnancy rates (Sterling and Sadler 2009:19). Though cultural values such as virginity and machismo, as well as acculturation have been used to explain this phenomenon, (Deardorff, Tschann et al. 2010) it should be noted that the Latinos are a diverse group with significant dissimilarities in language, values, cultural norms, ethnic backgrounds, and attitudes (Sterling and Sadler 2009:20). Therefore, explanations that rely on such simplistic analysis are most likely to be insufficient for designing interventions to address this and any public health concern.

The impact of adolescent pregnancy goes beyond the health of the young mothers. Adolescent pregnancy decreases the likelihood of completing high school or earning a college degree for Latina teenagers (Davis, 1989; George & Lee, 1997; Wolfe & Perozek, 1997). It also increases the risk for ectopic pregnancies, miscarriages and anemia for the adolescent mothers, and low-birth weight babies are a common product of adolescent pregnancies. In addition, children born to adolescents are at greater risk of parental abuse and neglect, and perform poorly at school (Sterling and Sadler 2009). Teenage pregnancy is, thus, another public health concern for those working with the Latino community.

2.9 SUMMARY

Latinos represent a significant portion of the population in the USA. They are not a homogenous group; not all Latinos, for example, have the same immigration status. Some are citizens, others are legal residents and many are undocumented immigrants. Those who are undocumented, face several challenges when looking for a job, a house or a doctor. Despite the different positions within the USA public opinion regarding “illegal” immigration, one issue that is often overlooked is their children’s situation.

Having undocumented children represents one of the biggest challenges for Latino parents in the USA. Lack of legal immigration status restricts the access of undocumented children to several public programs, health insurance being one of them. This results in limited access to a regular, timely and/or appropriate source of care when needed, which in turn is a root causes of the health disparities experienced by undocumented Latino children.

3.0 RESEARCH QUESTIONS

The existing literature on Latino children provides comprehensive information about numbers of uninsured children, the consequences of lacking health insurance, and the potential threats to public health. Most of the available information provides an overview of the situation of undocumented Latino children in the USA. There is, however, limited research on the decision-making process by Latino immigrant parents to secure healthcare for their uninsured children and the role healthcare providers' play to help parents address the health needs of their uninsured children.

My research focuses on these two important groups of decision-makers: parents and providers. It aims to understand their decision-making process, and enable the development of a more responsive and fair health care strategy. My research asks the following questions:

1. How do parents and providers address the health needs of undocumented uninsured Latino children in the NGC of the Allegheny and Washington Counties, Commonwealth of Pennsylvania, USA?
2. Are the present-day strategies to meet health needs of undocumented uninsured Latino children in a NGC sustainable in the long-term?

Research Objectives

1. Describe the strategies deployed by parents, social workers and healthcare providers to secure healthcare for uninsured Latino children in a NGC
2. Illustrate the complexity of addressing the health needs of Latino children whose legal status in the USA prevent them from accessing health care,
3. Identify the most effective strategies to provide health care for uninsured Latino children from the variety of approaches currently used by parents, social workers and healthcare providers, and
4. Propose possible measures to ensure long-term sustainability of the strategies to provide health care for uninsured Latino children in a NGC.

4.0 METHODOLOGY

In order to answer my research questions, I conducted in-depth interviews with a sample of parents of undocumented children residing in Allegheny and Washington counties, and with a sample of social and health service providers serving this population. Interviews focused on the strategies employed by both parents and providers to address the health needs of undocumented and uninsured Latino children. In addition, I made detailed notes of conversations held with parents before and after the interviews and obtained descriptions of health centers mentioned by parents through official websites.

The provision of health care for children is an emotional topic for both parents and providers. Given the circumstances, semi-structured interviews was considered to be the more appropriate method to thoroughly understand the challenges parents and providers face when an uninsured and undocumented child has a health need.

The in-depth interviews with the parents provided a nuanced understanding of the various factors they have to take into consideration before making a decision regarding where to take a sick uninsured child, and the various steps followed by parents to ensure child receives the required treatment either from a doctor or at a hospital emergency room. Asking questions in the interview format and my familiarity with the local Latino community developed during the three years I worked as a volunteer facilitated the development of a close rapport with the interviewees. As a result, I was able to solicit detailed information about the challenges they

faced, the support network and solutions they developed, and their unmet health needs. The semi-structured interview format enabled me to ask detailed questions about occasions when their uninsured child had a serious health problem and how they obtained medical treatment. I also digressed, if necessary, from the interview questionnaire to obtain a comprehensive understanding of parents' decision-making process.

Interviews with healthcare providers enabled me to comprehend the complexity of providing support to the families with uninsured and undocumented children. I learned about the frustrations, achievements and expectations providers experience while serving the local Latino population. Some shared specific episodes of helping a family find treatment options for their uninsured child's life-threatening illnesses. Providers also presented constructive ideas and arguments that could be used to advocate for insurance coverage and healthcare access for undocumented children.

4.1 INTERVIEW INSTRUMENTS

I prepared two interview questionnaires: one for providers (Appendix A) and one for parents (Appendix B). I conducted the interviews in person. The interview questionnaire for social and health service providers focused on their views on the major challenges facing the parents of uninsured children, the strategies providers have available to address these challenges, the impact of lack of insurance on the children's overall health, and ideas for advocacy efforts. The interview questionnaire for parents addressed the following topics: The decision-making process when their uninsured children need to access health care (e.g. periodic check-up, emergency treatments, specialized care); strategies used to access health services in a timely

manner; experiences at various health centers (e.g. hospitals, emergency rooms, pediatrician's chamber, dentist); main sources of information and support; and the impact of lack of insurance on the children's overall health.

4.2 MY POSITION IN THE LATINO COMMUNITY

Finding parents and providers willing to be interviewed for this research was facilitated by three years of prior involvement with the Latino Community in Pittsburgh. I started volunteering at the Latino Social Services Office, St. Regis Parish (South Oakland) in January 2008, where I met many Latino families and healthcare providers and first became familiar with the public health challenges facing Latino immigrants in Pittsburgh.

In August 2008, following a request to the Latino Social Services Office, I started to volunteer at the Consumer Health Coalition (CHC). My responsibilities at CHC consisted of managing the organization's Spanish-language telephone helpline, and providing advice and guidance regarding health services and health insurance to the local Latino population. The telephone helpline service disseminated information about the organization's activities, assisted in scheduling medical appointments and arranging interpreters to assist during the visit to the doctor. I helped Latino families with eligible children complete, submit and follow-up their children's MA and SCHIP applications with the local County Assistance Office (CAO). The two years at the CHC allowed me to get acquainted with many Latino families in the region. As part of my responsibilities at the CHC, I provided language assistance at the monthly free pediatric clinic in the Birmingham Clinic located in the Southside of the City of Pittsburgh where I got to

know many volunteer medical students and doctors from the School of Medicine, University of Pittsburgh.

Besides my involvement as a volunteer, in 2009 and 2010 I was a member of the organizing committee of the Fair “*Al Servicio de la Comunidad*”, an event sponsored by the Latino Catholic Community of Pittsburgh that provides information about various social services to the region’s Latino community. I contributed to a partnership between the School of Public Health, University of Pittsburgh, various social and health organizations, and community members to design and launch a Community Based Participatory Research of a lay health advisors network in Allegheny County. I also attended community meetings on immigrant’s rights.

My involvement in these various activities made me known and trusted among the local Latinos and their healthcare providers. This facilitated the process of finding willing interviewees for the study. Concurrently, I witnessed, first-hand, the challenging situations many Latino parents confront when their uninsured child could not access timely medical care. It should also be noted that this experience has influenced my opinions, as a researcher, regarding the lack of access to health insurance for undocumented children.

4.3 SELECTION OF INTERVIEWEES

The following sections explain the process of selecting and enlisting parents and healthcare providers as interviewees.

4.3.1 Providers

I prepared a list of potential provider interviewees from the professional network I developed while working with Latinos in Pittsburgh. These providers have been working with the Latino community for several years and have experience with providing medical aid to undocumented Latino children. I short-listed six providers, one from each of the six organizations that worked with Latino families with uninsured children in Pittsburgh: University of Pittsburgh Medical Center (UPMC), Salud para Niños, Nueve Lunas, CHC, Latino Family Center, and Catholic Charities.

I contacted the providers by e-mail, explaining the nature of the research, the characteristics of the interview (open-ended questions and confidentiality), the approximate duration of the interview (one hour), and the expected outcomes. As stated in the IRB form, I informed them their names or any information that could identify them would not be disclosed to protect their anonymity. Some said they did not mind having their names written in the final report, but I decided to keep all providers anonymous.

4.3.2 Parents

The list of potential parents to interview was developed using the client database of CHC, and through referrals provided by initial interviewees (snowball sampling) and colleagues working with the Latino community.

In order to access the CHC database, I first obtained authorization from the organization's Executive Director. As CHC helps families access public assistance, their database contains information about only children who are legal USA citizens. During the period

I spent in CHC, I remember meeting some families who had at least one undocumented child in addition to having a child who was a USA citizen (i.e. mixed-status families). To maintain the confidentiality of the clients' personal information and to avoid any form of coercion, I requested CHC's Spanish-language intern to contact those families on my behalf.

The CHC intern obtained the family's phone numbers and addresses from the organization's database and contacted them by phone. The intern used sections of the introductory script (Appendix A.1) to explain the proposed research to the parents, and asked if they would be willing to authorize CHC to provide their names and phone number to me. I obtained written permission from six families using the CHC database (see Appendix C) and succeeded in interviewing two families. The remaining four families could not be interviewed because:

- they lived too far away (one family),
- they did not fit the criteria (i.e. they did not have an uninsured child – one family),
- their phone had been disconnected (one family), and
- they were travelling at the time of contact (one family).

I requested the two parents I interviewed first to suggest other families who had an uninsured and undocumented child. I was able to contact and interview three more families through this method. I also requested a Latino mother, whom I have known through my work with Catholic Charities, for an interview and she accepted. I obtained permission from the final four families through colleagues who also worked with the Latino community and knew about my ongoing research. Of the ten families I interviewed, there was only one family whom I had not known previously from my work as a volunteer/intern at Catholic Charities, St. Regis Parish Social Services Office or CHC.

4.4 THE CHILDREN

At the end of the recruitment process, I interviewed 10 parents and six providers. Among the 10 families that were interviewed for this study, 16 undocumented children were uninsured at the time of the interview. Two other children were USA citizens but lacked health insurance⁷.

On average, each family had two uninsured children living with them at the time of the interview (see Table 1). The ages of the uninsured children ranged from four to 19 years of age (see Table 2). I include the nineteen year old because if that child had been a citizen of the USA he/she would have been still covered by MA or SCHIP. Most of the children were between eight and 11 years old.

Table 1. Number of Children per Participant’s Family by Insurance Status

Pseudonym of parents	# of children living at home	# of undocumented uninsured children	# of documented uninsured children
Francisca	2	1	0
Carola	2	2	0
Julieta	3	2	0
Elena	4	3	0
Graciela	3	2	0
Haydee	3	1	2
Delia	3	1	0
Irene	2	1	0
Andrea	3	1	0
Bertha	2	2	0
Total	27	16	2
Average	3	2	Non applicable

⁷ Their mother explained that the children were uninsured because the Social Security Card (SSC) of one of these children was lost and both parents lacked any form of government-issued photo identification that would enable them to request the lost SSC

Table 2. Age distribution of uninsured children in the sample

Age range	Number of children
0 to 3 years old	0
4 to 7 years old	5
8 to 11 years old	8
12 to 15 years old	3
16 to 19 years old	2
Total Number of Uninsured Children	18
Mode	8 to 11 years old

4.5 INTERVIEW PROCESS

The study received the necessary Institutional Review Board (IRB) approval (see Appendix D) in April 2010 following the submission of a letter of support from the CHC (see Appendix E). The interviews were conducted during June-July 2010. I recorded all the interviews using a digital recorder after obtaining permission from the interviewees. I took detailed notes during interviews with the parents.

4.5.1 Interviews with providers

I interviewed four social and two health service providers about their experiences serving the Latino population and helping children without health insurance access regular health care. I conducted five of those interviews at the providers' office and one in my university office, where we had the necessary privacy.

The interviews took between 25 and 45 minutes each, and were conducted in Spanish (2) or English (4) depending on the interviewee's native language. Providers did not receive any financial incentive for participating in this research.

4.5.2 Interviews with parents

I conducted interviews with 10 Latino parents with at least one uninsured and undocumented child. All the interviewees were Mexican women who had spent an average of seven years in the Allegheny and Washington Counties of Pennsylvania. Nine of 10 interviewees had arrived and lived in the same county for the entire duration they have been in the USA. Interviewees had an average of three children living with them in the USA; their ages ranged from six months to 17 years. None of them had children living in Mexico at the time of the interview. There were an average of two uninsured children per family, and eight families were mixed-status families with at least one child with US citizenship (see Table 1).

I conducted eight interviews at the home of the interviewees, and two interviews in public spaces (such as a coffee shop and a shopping center) as it was difficult to access their place of residence using public transportation. The interviews lasted an average of 30 minutes, though the total time spent with the interviewee was between one to five hours. The duration of the meeting was influenced by the interviewee's need to take care of the children and doing everyday household chores while answering questions. The interviewees often asked me for help with translation at the CAO, scheduling medical appointments, providing insurance information to hospital billing offices, applying for food stamps, and providing information regarding Medicaid, SCHIP and Emergency Medicaid. These side conversations often provided important contexts for their answers to the formal interview questions.

Since I had assisted many of the interviewees with insurance applications, medical bills and other related issues while I worked at the CHC, I used that knowledge to tailor some of the interview questions to their particular experiences. I asked them questions like: "Do you

remember when you called me because your son/daughter had an accident? Do you remember what happened? What did you do?”

Interviews were conducted in a conversational manner (Fetterman 1989). Questions were not always asked in a fixed order, some questions were eliminated if they had become irrelevant as a result of a previous answer, and additional follow-up questions were often posed to clarify certain issues. My prior acquaintance with most of the interviewees enabled them to share with me their experiences, sometimes beyond the context of the formal interview. The parents received a \$20 gift card to compensate them for their time, and this payment was approved by the IRB (see Appendix F)⁸.

4.6 DATA ANALYSIS

The data analysis involved extensive use of Atlas-ti, a qualitative data management software. To prepare the data for use in Atlas-ti, all the interviews (both in Spanish and English) were transcribed. I personally transcribed four of the 10 interviews with parents, and another native Spanish-speaker transcribed the other six. I transcribed three of the six interviews with providers and a native English-speaker transcribed the other three. I did not translate any of the interviews from its original language for analysis. Rather, I conducted the analysis in the original language and later coded using English terms for analysis in Atlas-ti.

⁸ The University of Pittsburgh IRB prefers researchers to use WePay, an in-house web-based payment system, for any form of reimbursement to interviewees. The WePay system, however, required interviewees to provide their SSN to access the funds. Since none of my immigrant interviewees were US citizens and may not possess a SSN, I asked the IRB to allow payments using gift cards, which was approved.

Atlas-ti is software that enables the researcher to analyze different types of data such as: text, voice (mp3), drawings (.jpg). For this research, I only analyzed text documents. In order to understand the data, it is necessary to create codes that will facilitate the data analysis. The coding process consists in selecting specific sections of the data that are relevant to a particular code you have created beforehand; for example “Experiences at hospital X”. The codes can be further grouped together in a ‘Family code’ by the researcher, for example “Experiences at Hospitals”.

The first step of analysis involved a close reading of the transcribed interviews. I began by analyzing parents’ interviews as they provided a more comprehensive account of the experiences related to the lack of health insurance among undocumented children. I took notes to: (1) identify interesting quotes and major ideas, (2) the context in which ideas were mentioned, and (3) connections between the ideas and research objectives (see Appendix G).

The second step involved creating codes and grouping them under a topic (see Appendix H). I analyzed the interviews with parents and providers separately. I choose to analyze the parents’ interviews first given that their stories and perspectives are at the core of this research. All initial codes, referred to as First Generation Codes, were created based on parents interviews (see Appendix I).

I used the First Generation Codes to analyze providers’ interviews. This proved useful and relevant since the interviews for both groups of respondents covered the same topics but from different perspectives. As the coding proceeded in Atlas-ti, it became apparent that in order to analyze providers’ interviews I needed more nuanced codes so new codes (Second Generation Codes) and sub codes were defined (See Appendix J). After a closer examination of providers’

interviews, it was necessary to create new codes to account for topics present in provider interviews but not in parent interviews (see Appendix K).

4.6.1 Quality Control

Once I finished coding all the interviews, I proceeded to do quality control. This was also done using the Atlas-ti software. The software has a command named “Codes-Primary Documents table”. Through this command, one is able to visualize all the codes used in each interview (i.e. “primary document”). For instance, many times the code “motherhood” or “minor health problem” was used in each interview and which were not used at all (Appendix L).

This table allowed me to identify which codes were not used in a particular interview. For example, I noticed that interviews #1 and #4 did not have any “Emergency” coded. This did not seem accurate given that I remembered that most interviewees shared an emergency story with me. To double-check this hunch, I used the “Find” command to search for the word “*emergencia*” in both interviews. I realized that I have missed two examples of an emergency situation in interview #1, and confirmed that interviewee #4 did not mention any emergency situation.

I reviewed all the codes and did similar processes in those instances where my memory indicated me that the frequency of codes did not resonate with what I remembered interviewees have spoken about.

Another way of quality control was to make sure the codes I used captured the information said by interviewees. I used the “Codes-Primary document” command to visualize a list of all codes and the frequency in which these codes appeared in all interviews. I identified the codes that have been used only once or twice, went back to the interviews to read that section to

determine whether those codes could be merged with other codes or whether it was important to leave them as they were. In several cases, I merged a code with another.

Once all of the existing codes with unusual frequencies were reviewed, I started the process of “requesting” the software for the quotes per code. Using the “command” tool I asked the Atlas-ti software to create a document where all the quotes for each of the codes used appear together. These are called “output” files. Each set of outputs was stored in a separate document, read and analyzed.

4.6.2 Comparing and Triangulating Data

Of the two groups of respondents, providers presented a more comprehensive perspective with insights on both the needs of parents and the institutions that constrained the ability of parents to address those needs. The providers also had experiences with several cases involving the healthcare needs of uninsured undocumented children, while the parents could only narrate their individual experiences. As a result of these differences, new codes had to be created for topics common to both groups of interviewees, to make sure the code included all the nuances of the descriptions. There were also codes shared between both sets of interviews.

The diversity of codes reflected the heterogeneous background of the providers; each of them occupied different positions in their relation with the region’s Latino community, and they had different opinions about the past efforts and future initiatives to better address the health needs of uninsured and undocumented Latino children. For example, although four of the providers could be broadly classified as providers of “social services,” the support they offered to the community was very different. One provider worked for a social service agency (Catholic Charities) that served both children and adults; one was part of a volunteer-based organization

(Nueve Lunas) that focused on pregnant Latino women; one worked at a non-profit (Latino Family Center) that dealt exclusively with mothers and children; and the last provider worked at an organization (CHC) that assisted at-risk populations access social benefits. Analyzing the interview data required taking into consideration all these perspectives and triangulating the data, which included: consulting field notes, interviews, analytical memos and tabulated quantitative data. Field notes were included in the Atlas-ti as memos, not as primary documents.

4.7 SUMMARY

Data collection was done mainly through in-depth interviews with both parents and providers. I complemented the information with field notes made during the home visits and internet searches on the healthcare options in Allegheny and Washington Counties mentioned by participants. Interviews proved to be an appropriate methodology since interviewees were able to share stories in detail and did not censor themselves when discussing immigration status. The latter was only possible because they knew me from beforehand and trusted me as somebody that had been working for the Latino community for three years.

I went through various stages of data-revision in order to define codes that would allow me to have a nuanced understanding of parents and providers views and experiences. Given that the Latino community in Allegheny and Washington Counties is relatively small, I was able to validate the examples provided by mothers with those given by providers and triangulate both sources of data. Furthermore, providers' perspectives were diverse given that their professional experiences with the Latino community were different.

5.0 RESULTS

I originally planned on organizing the results along the stated research objectives: (1) the strategies deployed by parents, social workers and healthcare providers to secure healthcare for uninsured Latino children (2) the complexity of these strategies (pros and cons) (3) an analysis of the most effective strategies and (4) ideas to ensure the long-term sustainability of these strategies.

As I analyzed the data, it became apparent that in order to understand the strategies deployed by parents there were several factors narrated by participants that I needed to present first. Thus, I organized my results to show the complexity of the decisions parents make and the role of providers in those decisions. Decisions rely on the available services and children's health care needs. Parents' decisions are not always successful or straightforward.

Understanding the factors underlying their decisions is key to understand the outcomes of the strategies participants deployed. I begin this section with a description of the available services for undocumented uninsured children in Allegheny and Washington Counties (5.1.) followed by a description of the sources of health-related information and support mentioned by interviewed parents (5.2.). During the data analysis it became apparent that the parents I interviewed still have several information gaps. These gaps in the information framed the strategies used by parents and I realized it was relevant to describe them before presenting the research results (5.3.). The previous experiences with the health care system (5.4.) and the

decision-making process around a health need (5.5.) are at the core of the results section. Sub sections 5.3. and 5.4. describe the strategies deployed by parents and the considerations they take into account.

Finally, I present the perceived health implications that being uninsured has in the everyday lives and overall health of undocumented children (5.6) and the suggestions made by providers regarding advocacy efforts that ought to be done in order to improve access to health care for uninsured undocumented children (5.7).

5.1 AVAILABLE SERVICES

This subs section presents the existing healthcare options for uninsured children in Allegheny and Washington Counties. The options that both parents and providers mentioned the most during the interviews were: (1) the Monthly Free Pediatric Clinic (MFPC) and (2) one of the four low-cost health clinics located in the Allegheny and Washington Counties⁹. The MFPC, also known as *Salud para Niños*, is a once-a-month clinic hosted by the Birmingham Clinic. At present, the clinic depends completely on volunteer doctors from the University of Pittsburgh Medical School paired with bilingual interpreters who are also volunteers. The MFPC, in addition to the monthly free clinic, operates a mobile clinic called the Ronald McDonald Mobile Care, known colloquially within the Latino community as “*El camioncito*”¹⁰. The mobile clinic

⁹ Based on my ties as a volunteer with the Latino community I remember that one of the services mothers would look us for were (1) making appointments for them and (2) arranging for someone to go with them as an interpreter.

¹⁰ This is a mobile care service sponsored by the Ronald McDonald House Charities of Pittsburgh, According to its website (www.rmhcpgh.org/content/care-mobile), the Care Mobile is “a 40-foot vehicle designed and built specifically for the delivery of pediatric health care, is equipped with two modern exam rooms on each side of the vehicle. There “Pediatricians, nurses, nurse practitioners and respiratory therapists from Children’ Hospital of

visits different city locations on different days of the week and offers its services in Spanish on the day of the operation of the MFPC. The four Federally Qualified Health Centers (FQHC) that parents from Allegheny and Washington Counties mentioned as places they could take their uninsured children were as follows:

- Allegheny County - The Lincoln-Lemington Clinic, the East Liberty Healthcare Center, and the Squirrel Hill Health Center (SHHC).
- Washington County - Family Practice at the Washington Hospital.

The Lincoln-Lemington Clinic and the East Liberty Healthcare Center belonged to the same network of clinics, the East Liberty Family Healthcare Center. They were located in two low-income neighborhoods in Pittsburgh. Both were open Monday through Friday from 8:30 a.m. to 4:30 p.m. (twice a week until 8 p.m.) and offered a wide variety of medical services. The clinics, however, did not always have Spanish-speaking staff and – at the time of the research – did not offer pediatric services. The third low-cost option, the Squirrel Hill Health Center (SHHC), operated Monday through Thursday between 9:00 a.m. and 5:00 p.m.; Fridays from 8:00 a.m. till 4:00 p.m. and had some evening and Sunday appointments available. The SHHC had Spanish-speaking staff and offered pediatric services. The Family Practice at Washington Hospital offered services on Monday, Wednesdays and Friday, 8:00 a.m. - 5:00 p.m. and Tuesday and Friday, 8:00 a.m.- 7:00 p.m. No services in Spanish were available.

For regular care, such as immunizations and monthly check-ups, mothers in Allegheny County preferred the MFPC, and those in Washington County mentioned Family Practice at the Washington Hospital.

Pittsburgh of UPMC provide medical care to children and adolescents who are unable to visit a doctor regularly. They also offer health education to teach parents, guardians and children about healthy lifestyles and safety.”

The MFPC “*Salud para Niños*” was the most popular facility amongst the interviewees. One of the reasons behind its popularity is its use of Spanish as the preferred language of communication:

The biggest advantage is that the staff are bilingual and can speak Spanish to everyone, considering that a lot of the families don’t speak English well enough to be able to communicate effectively with the doctor. And that’s probably the biggest issue which a great part of going to the Birmingham Free Clinic. (Provider 3)

The popularity of *Salud para Niños* amongst the Latino parents I interviewed was evident by the various names they used to refer to the clinic: *La clínica de los sábados en el Southside*, *La clínica Birmingham para niños* or simply *Donde el Doctor Diego* (after the clinic’s pediatrician).

All providers interviewed were in agreement about the importance of *Salud para Niños* for uninsured Latino children. For instance, Provider 5 stated, “I don’t know where the community would be without *Salud Para Niños*, one Saturday a month, get them there, get them regular care to avoid major problems cropping up.” At the same time, both parents and providers said they hoped that the clinic would be able to offer services during the weekdays or, at least, more often than the present once-a-month schedule.

One of the biggest issues participants mentioned regarding the other available options was that they often asked for documents parents did not have: “[A]ny of the other places that are primary healthcare centers, [things] get very complicated when it comes to the billing and the lack of a social security card number” (Provider 5). For Provider 2, access to primary care centers was not enough to address the health needs of Latino children. This provider explained that they were not equipped for specialized care or serious ailments: “When you need a specialist, unless somebody advocates for you, and is lucky enough to find a specialist that’s willing to cooperate, children cannot have specialist”.

5.2 SOURCES OF INFORMATION AND SUPPORT

I questioned mothers about their information sources on existing social and/or health services and individuals whose advice regarding health care they followed. Analysis made apparent that obtaining healthcare for uninsured children was a two-step process: (1) obtain information about the available health services for undocumented children, and (2) when necessary, securing additional assistance to obtain the required health service for the children. It was evident that the mothers were receiving considerable assistance through the close relationships they were able to establish with local social and health providers.

5.2.1 Sources of Information

The Latino mothers who participated in my research obtained useful information about available social and health services for their uninsured children from various sources. The Catholic Church frequented by the Latino community was the primary source of information. The church dispensed information from its social service office and through church members involved with the Latino community and who often managed the social services office for the St. Regis Parish. The participants also relied on friends and family members for information, especially those with young children of their own and, thus, likely to be knowledgeable about available pediatricians. Carola learned about a Latino pediatrician through a friend:

“Y una vez en una platica con mi comadre, ellas estaban organizando una fiesta y era para un doctor (...) y me invitaron y yo fui, y mi comadre me comenzó a decir ‘Mira él es buen doctor, él ayuda, él es (...) Es latino, él ayuda mucho a los niños y da recetas gratis y todo’. Y ya yo le pedí su número del doctor y me empecé a contactar con él y de ahí fue cuando empecé a ir yendo.”

“And once when chatting with a friend, they were organizing a party and it was for a doctor (...) and they invited me and I went and my friend started telling me that he was a

good doctor, that he helps out (...) He is a Latino, he helps children a lot and he gives prescriptions for free and everything. And so I asked for the doctor's phone number and that is when I started going [to his clinic]."

Mothers also inquired and received information about other available health services from the health providers:

"Casi siempre cuando piden ayuda es para saber con quién atender a los niños. Es decir con quién me puedo atender. Algunas veces se quejan de que no les gusta un doctor que los atiende y entonces quieren cambiar porque hay algo que no les ha gustado, entonces vienen con nosotros." (Provider 1)

"It is almost always the case that when they ask for help it is about where can they take their children, that is, with whom can I take my children. Sometimes they complain that there is something about a doctor they don't like and they want to change their doctor and it is because there is something they have not liked and they come to us."

Provider 2 explained that parents with uninsured children usually came to know of his services "... [e]ither from the Parish, or the Latino Family Center for certain issues; and word of mouth too. Because people tell me that I helped their friend with something and then they call me for help. Word of mouth is probably more than any of the other ones." In addition to friends (30%), family members (20%) and health providers (20%), women's shelters and food banks (20%), and the internet (10%) were also found to be important sources of information about children's health services (see Table 3).

5.2.2 Sources and Kinds of Support

The strategies to secure healthcare benefits for the children varied depending on the kind of help the mothers needed. The following sections describe the efforts by interviewed mothers to obtain various kinds of medical care, find assistance to complete official paperwork, and receive moral support during stressful times.

5.2.2.1 Medical Treatment, Tests, and Interventions

Uninsured children with chronic illnesses with the need for long-term treatments were in an especially difficult situation. Some of the mothers I interviewed said they had been able to obtain regular consultation and secure a regular supply of medications for their uninsured child through informal relationships with local doctors. For example, Andrea, whose child had epilepsy, narrated that she received help from a local pediatrician who provided the child with the necessary medicines and regular examinations to prevent adverse side effects from the pills he had to take. This doctor, as the other providers interviewed, used personal contacts to obtain medications or free diagnostic tests for uninsured children. Graciela shared her case:

“...y lo hicimos [el examen médico] a través de una persona que se ofreció, que tiene una clínica privada y se ofreció a hacerle el estudio. (...) A través del Dr. [X], nos encontró una persona que estaba dispuesta a decir ‘tengo mi clínica, yo tengo los aparatos, yo se lo hago’.”

“... and we did it [medical examination] through a person who has a private clinic and offered to do the study. (...) Through Dr. X we were able to find a person who was willing to say ‘I have a clinic, I have the instruments, I will do it’.”

Informal support was available even when the medical need involved surgery. Participating mothers recounted the occasions when people from their support network steered them to sympathetic doctors who, in turn, helped them find the surgeon and complete the necessary paperwork. Francisca, whose daughter needed surgery, said she was helped by a doctor who organized the operation at Children’s Hospital for free.

Apart from the doctors, various non-medical providers also used their personal and professional networks to provide assistance:

... we actually had someone who had a kidney transplant, but getting her to see the specialist, we can’t get her to see the specialist. So, what has to happen is that they [doctors] have to agree to see her so there is a long and a lot of work on our part. Basically, they [uninsured children] have the doors closed and basically it makes it very difficult to take care of them. And not all kids are healthy, they all have problems. So

those situations are stressful for us 'cause we have to basically ask people to do us a favor (Provider 6).

Similarly, a social service provider recounted the time she was able to obtain low-cost dental care for an uninsured child who “desperately” needed it: “In this case, I went out and begged funds for this child. I wasn’t able to cover it all from my begging, but at least it helped mom some” (Provider 5).

Aside from the help provided by doctors and providers, many of the mothers I interviewed, like Francisca, Irene and Bertha talked about episodes when they were often quite proactive in visiting organizations and agencies that they thought could provide help. For example, Francisca told me how she was able to obtain financial support for dental care through the social services office of her children’s school; the office introduced her to the organization “Community Action” that paid for all the expenses.

5.2.2.2 Applications, Appointments, and Bill Payments

Health care is not limited to consultation with doctors, obtaining medications and undergoing surgery; mothers also had to negotiate and complete a series of bureaucratic and official procedures that are often as important as the actual treatment. Providers noted that Latino mothers were often terrified about the application processes even before they had started filling out the forms; the forms were complicated and lengthy, often available only in English, and asked for a lot of information. In fact, sometimes even experienced providers found the process challenging. Provider 4 recounted his experience of applying for health insurance for a child:

Es decir yo con un grado de médico, (...) hablando inglés, ya era difícil para mí, ¿Cómo podría ser de difícil para un persona que a duras penas podía hablar en español o leer en español! Porque tenemos varias personas que son analfabetas en español, un poco complicado, entonces la labor de alguien que ayuda, que asista, es muy importante.

I mean, me with a medical degree, (...) fluent in English, it was already difficult for me. How harder could it be for somebody who could hardly speak or read in Spanish!

Because we have several people [in the Latino community] who are illiterate in Spanish, it is somehow complicated. So having somebody that can help them is very important.

From the stories that parents shared throughout the interviews, I realized they obtained help from whoever would provide it. According to providers, Latino parents constantly asked them to help locate low-cost or free health providers, schedule medical appointments, and fill out the necessary applications. Some mothers used the Spanish-language telephone helpline operated by the CHC to obtain assistance with applications for financial aid for medical bills. The stories recounted by two mothers, Francisca and Bertha, showed they used similar networks to pay medical bills, negotiate bill reductions or find affordable healthcare.

While in general, providers were keen to offer help with such paperwork, some were concerned that such unconditional assistance might discourage the parents from becoming proficient with the process. For example, Provider 1 has changed her strategy:

“Yo siento y en verdad yo creo que nosotros como proveedores pecamos de hacerlo... y yo últimamente he tratado de evitar [llenarles las aplicaciones]. Yo he tratado de hacerlo menos: ‘No, llénalo tú. Cuando ya te trabes me avisas, y si quieres yo te lo reviso después, pero llénalo tú.’ (...) Como que se vuelve que el mecanismo de lograr la cosa es ‘voy a donde fulanito y fulanito me lo hace’.

I feel that honestly, I believe that us as providers are doing a disservice by doing it [filling applications for Latino families] and lately, I have been trying to avoid [doing it]. I have tried to do it less: ‘No, fill it out yourself and when you get stuck let me know and if you want I can take a look at it later, but fill it out by yourself.’ (...) Because otherwise it seems that the mechanism to achieve something becomes ‘I go to so and so and that person will do it’.

5.2.2.3 Moral Support

The various providers in Pittsburgh identified “moral support” as an important component of their outreach. Moral support refers to efforts by the providers that encourage the parents to take action. Encouragement to the parents took many different forms, including providing advice, engaging in conversation or making suggestions to do something constructive.

While moral support was not mentioned explicitly by the mothers, all the interviewed providers talked about its importance during the interviews.

For example, providers explained they often encouraged mothers to resubmit the insurance application for their child, after it had been denied despite being eligible. Based on their experience, providers said that Latino mothers often got frustrated with the process and did not reapply for insurance. Provider 4 talked about a case in which:

the only way that I could help that person was telling him ‘don’t give up, go again, tell them that the girls were born here, show them their birth certificates, insist, insist...’; and he did it. His case even made it to a report that was done later (...) and they showed the importance of having somebody empowering him, somebody supporting [the] dad’s efforts.

Another provider said that:

The thing that I have started telling people maybe... when I am doing applications like that and [they get rejected]. I try to remind them of the rights of their children, and the thing that I tell them is that “your child can grow up to be the president of the United States because they are citizens” so they get a kick out of that (laughs) (Provider 3).

5.3 INFORMATION NEEDS

Decision-making is based on information parents have at their disposal when confronted with a health problem. Providers interviewed for this study identified the information they considered relevant for the parents to make the right decision for their uninsured children. On the other hand, parents mentioned ways in which the lack of appropriate information affected them or someone they knew in negative ways. This section focuses on the information needs narrated by both sets of participants.

5.3.1 Use of the ER facility

One of the information gaps parents had involved strategies to avoid unnecessary and potentially expensive visits to the ER. Interviewees recognized the ER as an option for health care. However, according to the providers, many parents did not know of the high financial costs of taking their child to the ER or were unaware of alternative options:

...a lot of the times the family might not be aware of what other options are out there like financial assistance, or the just the fact that sometimes knowing what is an emergency and what is not an emergency and other things you could do to avoid even having those bills to begin with. But there's definitely confusion around how things would be paid for and the ramifications for not paying those bills in the future (Provider 3).

Provider 3 encouraged parents to consult the primary care physician regularly and avoid visiting the ER for minor ailments. Other providers said they educated the parents about the high cost of non-emergency ER visits and the difficulty of obtaining EMA coverage even in the case of an medical emergency: “there has to be someone that can help them with the [EMA] paperwork, which is immense and convoluted, and requires a lot of advocacy, a lot of fighting it out with case-workers” (Provider 5).

Providers explained that the application process for the EMA, after their child had been to an ER, was complicated, and that mothers often needed assistance to obtain all the required documentation, complete the application form and follow through on the paperwork. Frequently, parents explained, this help was provided by friends or church members involved with social services. As Bertha said: “*Está una señora de la tienda mexicana... ella es la que luego nos echa la mano en esas cosas que necesitamos, si.*” / “There is a lady in the Mexican store,... she is the one who helps us in those things we need, yes.”

Some providers mentioned they were concerned that parents of uninsured children are often misinformed by friends and family members about the appropriate use and possible

expenses of an ER visit. The interviews with parents showed that participants often failed to differentiate between medical conditions that justified a visit to the ER and those that did not. As Provider 3 explained, just because the neighbor's uninsured child received treatment at the ER and the expenses were paid through EMA does not necessarily mean that all medical conditions would receive the same benefits.

5.3.2 Language-related rights

Lack of English-language skills and lack of Spanish-speaking translators were significant barriers to obtaining effective health care not only for the uninsured children but sometimes delayed care even for the insured children. Carola said she always tried to find help with translation when she visited doctors: "*Siempre trato de buscar alguien que me pueda traducir porque yo no sé el inglés, pero sí es mucho batallar.*" "I always try to find someone that can translate for me because I don't speak English, it is a lot of hassle." Delia, another mother, said she could not schedule doctor appointments by herself and was dependant on her husband and his work schedule.

Mothers who did not speak English said they felt frustrated with their inability to communicate with the doctors. Elena told me that once her child was suffering from a swollen head after hurting himself in the bathtub. After waiting for two days, during which time the child had fever, she took him to the hospital. After a wait of several hours, Elena said she was confused when the doctor chose not to conduct any tests and only prescribed Tylenol. Despite Elena's elder son efforts to translate, he was unable to explain every detail to Elena given that he was a child himself.

Elena said she was unaware that she could have requested a translator at the hospital; however, some of the mothers interviewed for this research knew of this option. These mothers advise other Latino mothers: “[*Si vas a la emergencia*] pide un traductor. Te tienen que atender porque no pueden dejar morir al niño.” (Irene) / “If you go to the ER, request an interpreter. They have to see you because they cannot let your child die.” Providers agreed that Latinos need to be educated about their right to an interpreter if none of the employees at the health center speaks Spanish. Five of the interviewed mothers did not feel confident about requesting an interpreter, this illustrates that being able to demand certain services is not simply about information and access, it is also about parents feeling confident and comfortable asking for them.

Interviewed providers also stressed the importance of not focusing exclusively on the availability of bilingual physicians but rather the presence of bilingual employees in different segments of the healthcare system:

...there needs to be more bilingual [staff] ... you can't just have bilingual physicians, you need a bilingual receptionist, the person answering the phone needs to be bilingual, the nurse needs to be bilingual. So (...) you need people who are bilingual all along the line and not just the physician (Provider 6).

According to Provider 1, it is, in fact, more important to have bilingual administrative staff than bilingual physicians because:

muchas veces la gente tiene que hablar más rato con la gente administrativa que con el médico. Al médico lo ve quince minutos, diez minutos. Mientras que con el otro tienes que llamar, tienes que hablar, tienes que sacar la cita, tienes que (...) pagar el bill, tienes que no sé, hacer todas esas cosas (Provider 1).

often, people spend more time talking with the administrative staff than with the doctor. You see the doctor for fifteen minutes, maybe ten minutes. While you have to call, speak, make appointments, pay the bill and do several things with the administrative staff.

5.4 THE HEALTHCARE SYSTEM

According to the United States Department of Health and Human Services (USDHHS 2000), health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”. In order to understand the level of health literacy among the interviewed parents, I asked them to compare the parents’ experiences and perceptions of the USA healthcare system with those of their native country. The mothers’ experiences with the USA healthcare system were not homogenous. Some were appreciative of the available services and felt pleased with the interactions with the medical staff. Others, however, said they experienced rejections from certain services or had limited access because of their undocumented status.

For Andrea, the USA healthcare system is better compared to the Mexican system, because the former does not withhold treatment without upfront payment. According to Andrea, the providers in Mexico require parents to guarantee payments before delivering medical services to the children. Carola, another mother, found the attention of providers in the USA to be gratifying: “...*la atención médica de aquí se me hace muy buena, muy cordiales los doctores; ayudan mucho. Te atienden rápido a comparación de Méjico.*” “...health provision here is very good, doctors are very polite; they help you a lot. They will see your child promptly, unlike Mexico.” There were, however, disagreements amongst the mothers about wait times at the medical centers in the USA and Mexico.

Interviewed mothers spoke of the unpleasant aspects to the healthcare system in the USA too. The mothers found the frequent request for ‘papers’ (i.e. residency documentation) proving eligibility for medical attention a constant source of anxiety. According to Bertha: “[*En México*] *es más confiable, son menos preguntas, es menos complicación que cuando vas aquí creo que te*

preguntan hasta cuando nació la mamá...”/“In Mexico I feel I can trust things more, there are less questions, less complications. When you go to a health center here they even ask you when the mother was born.” The fear of being asked for information that most undocumented immigrants are hesitant to share came up frequently during the interviews with the mothers. Their precarious legal status made them easy believers of baseless rumors:

Yo he oído decir que una vez hubo un caso, no será cierto, que atendían a personas que ya directamente los echan con migración, yo no sé si eso es verdad. Me platicaron que eso fue así, del hospital lo echaron con migración, porque seguro era mucho y no iba a poder pagar. No sé si eso sea cierto (Haydée).

I have heard that there was once a case, don't know if it is true, but they said they will see people [at the hospital] and then take them straight to immigration. They told me that it was like that, that the hospital itself reported people to immigration because probably the treatment was very expensive and the person could not pay. I don't know if it is true.

While some mothers said they found it easier to receive financial support from providers and charitable organizations for medical bills and consultation with specialists in the USA, others stated they viewed the USA healthcare system as a rigid organization that does not make accommodations for uninsured individuals. Irene, one of the mothers I interviewed explained: “*Aquí como que son más duros de corazón: ‘No, no, si no tienes seguro médico no puede.’ Eso te baja mucho la moral.*”(Irene)/“Here it seems they are harder: ‘No, if you don't have health insurance it is not possible.’ That makes you feel really sad.”

Lastly, some interviewed mothers stated they were unsatisfied with the type of care they received from the doctors. According to the interviews, Latino parents expect to receive some kind of treatment when they take the child to the hospital, and when that does not happen, they get disappointed and upset. If the doctors prescribe over-the-counter (OTC) medications or they tell parents their child does not need any specialized test (as in the case narrated by Elena in page 55) parents expressed they get confused. In the episode narrated by Elena, she said she was exasperated after having spent a whole day in the hospital only to be told her child was fine.

When Elena protested, the hospital suggested that she take the child to a pediatrician: “...*yo digo para qué lo voy a llevar. Ya estuve acá perdiendo toda la noche no dormí, y otro día voy ir a perder el tiempo allá y no me le van a dar nada.*” (Elena)“...I say ‘what for?’ I had been here all night wasting my time without getting any sleep and I will have to waste another day there and they are not going to give him anything.”

5.5 DECISION-MAKING AROUND A HEALTH NEED

The decision-making process explained by Latino mothers varies depending on the intensity of the health problem their child faces. Throughout the interviews, participant mothers shared their pathways when their child had a minor health problem, needed a check-up or developed a serious ailment.

5.5.1 Minor Health Problems

Based on the interviewees’ accounts, the decisions parents partake about treatment options for their uninsured child, are based purely on their personal assessment regarding the type and severity of the ailment. Interviewed parents said that if they consider the ailment to be something minor such as a slight fever, a stomachache or the flu, they would avoid consulting a doctor and instead use home remedies or OTC medications.

Home remedies or *remedios caseros* usually refers to herbal teas or cultural practices used to treat minor ailments. One of the common cultural practices includes covering a pyretic child with a blanket to make them “sweat out” the fever. Tylenol, Motrin and Panadol are the

OTCs most commonly used by mothers of uninsured children. Tylenol was the most-preferred OTC medication and was often combined with the various home remedies, such as hot teas for a cold. Elena explained: “*Si no es grave... le doy Tylenol... que aguante... lo curo, lo arropo.*”/“If it is not serious... I give him Tylenol... let him cope... I heal him, I cover him.” Mothers also obtain non-OTC allopathic medications from their home countries in Latin America where they are sold without the need for a prescription. A relative or friend travelling to Pittsburgh from the home country is often asked to bring the medications. One mother, Bertha, has also received non-OTC medications by international mail.

The decision to use OTC medications is not an easy one, and a couple of mothers voiced their concern about not knowing the exact nature of the ailment. Carola told me that she would pray after giving OTC medication to her children, hoping she made the right decision and that the medication would work. If the OTC medications and home remedies do not work or the ailment aggravates, mothers do not hesitate to seek professional help.

Nine parents reported that the Monthly Free Pediatric Clinic (MFPC) facility is their first choice if home remedies and OTC medicines failed to alleviate their children’s ailments. The monthly schedule of the MFPC, as pointed out by Carola, Bertha and Irene, was a major drawback. The overreliance on MFPC often resulted in delay of professional consultation when the children needed medical attention in the middle of the clinic’s monthly cycle. Similar situations arise when children fall sick on weekends or clinic holidays. One of the interviewed moms from Washington County said she has access to a free clinic in her county, but the clinic is not open on weekends. Thus, if her children fall sick on a weekend she is forced to care for them at home:

Cuando es fin de semana [y se enferman, lo que hago es] tratarlos de controlar un poquito con el Tylenol, con medicamento o con tecitos, casi son más medicina natural,

casera, más que nada casera, porque si el fin de semana toca que se enferman, yo no los puedo llevar a ... algo de emergencia, si es algo pequeño.

When it is a weekend [and they fall sick, what I do is] try to control the ailment with Tylenol, with medications, with teas, they are almost always natural medicine, home made, mostly home made because if they fall sick on a weekend, I can not take them to... to the ER, if it is something small.

Faced with the need to consult a doctor when they do not have access to immediate health care, the stories narrated by the interviewed mothers show that they improvise. Carola, for example, told me she calls a Latino pediatrician who knows about her uninsured daughters, and the doctor provides advice over the phone. Graciela and Irene said they take their children to the other low-cost clinics or the Ronald McDonald mobile clinic. Graciela, who is fluent in English, explained that she takes advantage of her language skills to consult the doctors serving onboard the mobile clinic. She visits the mobile clinic website to find its current location and then takes her ailing children there.

Interviewed mothers, who had both insured and uninsured children within the same household, explained that they choose a different course of action for similar ailments depending on the insurance status of their children. The parents told me they often used the services available to their insured child to procure medical assistance for their uninsured child. Two mothers, Irene and Haydee, had occasionally used medical advice provided during the treatment of a particular illness afflicting their insured child to treat a similar illness affecting their uninsured child. The mothers said they also took advantage of medical consultations scheduled for their insured child to ask about the ailment of their uninsured child.

5.5.2 Major Health Problems: Emergencies

When interviewed mothers decide that their uninsured child's health problem is not minor and requires urgent care, the most common course of action they mentioned was to take him/her to a hospital's ER, particularly the Children's Hospital ER.

...si es una emergencia no nos queda de otra... correr a un hospital (Bertha).
...if it is an emergency, we do not have another way out but to run to the hospital.

All the mothers interviewed for this study noted that the ER personnel were polite and helpful although they did not speak English.

Parents explained that first they try to evaluate whether the health condition really requires immediate medical attention. In fact, mothers noted that they do not take their child to the ER as soon as they start complaining about a health problem. Rather, mothers wait until the last possible moment, usually when the child has a long-lasting high fever or intense pain.

Empezó con un dolor de estómago y se estriñó, se tapó, no pudo más. "Mami, no hago popó", y él siempre hace popó. Empezó con dolor y después ya no quería caminar, caminaba así agachadito, pero lloraba, mucha fiebre. Y fue cuando lo llevé a emergencia. Porque dije "¡esto ya no!" (Irene).

It all started with a stomachache and then he got constipated, he was blocked and he could not stand it anymore: 'Mommy, I am not pooping' and he always poops. He started with some pain and then he did not want to walk, he'd walk like this, bent over, he cried and had a high fever. And that is when I took him to the ER. Because I said 'This can't go on!'

There are, however, other situations when the parents take them straight to the ER; for example if the child had been involved in an accident and is badly injured. Based on the parents' accounts, 10 of sixteen uninsured children of the respondents have visited the ER at least once. All together, they were admitted to the ER 12 times even though not all these instances were recognized as emergencies by the doctors, thus leaving the parents with a large bill (See table 4).

Table 3. Reasons for visiting emergency room

Type of emergency	Number of visits
Broken bone	3
Fever	2
Head injury	2
Intense Pain (stomach, tooth)	3
Urgent surgery	1
Child fell and fainted	1
Total cases	12

Parents are very conscious of the financial implications of taking their child to the ER but choose to overlook the consequences when faced with the urgent need to provide medical care. As Andrea put it: *“Si es grave, ya pues, a urgencias, y a pagar ese bill.”* /“If it is serious, of course, we take them to the ER and then pay that bill.”

Francisca, one of the interviewed mothers, talked about being distraught at the thought of medical bills every time she had to make the decision of taking one of her children to the ER. Irene, another mother, had to take her son to the ER to treat his appendicitis and got a shock when a USD 25,000 bill arrived. Fortunately, in the case of Irene, providers at the hospital helped her apply for Emergency Medical Assistance (EMA) to pay the medical bill. Despite the dependence of uninsured children on the ER facilities, health providers noted that many Latino parents were unaware that their undocumented children are eligible for EMA if a doctor at the hospital certifies the visit as an emergency.

Most mothers said they learned about EMA when they began asking around for financial assistance to pay the medical bills. Elena learned that her child ER treatment was eligible for EMA on a visit to the Social Services office at her church.

... yo le dije pues a ella [persona en la oficina de servicios sociales] que me ayudara con el bill, para hacer planes porque me había llegado mil cuatrocientos dólares. Y yo le dije que me ayudara, que hablara para que hiciera un plan de pago porque yo quería que se recobre. (...)Y me dijo: ‘No, lo podemos mandar con esto’ dice.... Y sí me llegó la tarjeta,

una tarjeta Access Amarilla. Y me dijo 'Con esta no vas a pagar'.

...I told her [person at the social services office] to help me out with the bill, to make plans because it was for fourteen hundred dollars. And I told her to help me out, to call the hospital and arrange for a payment plan because I wanted to pay. (...) And she told me 'No, we can send the bill with this' and yes, I later got the card, a yellow Access card. And she told me 'You are going to pay with this'.

Graciela told me she was informed at the hospital that she could apply for EMA for her child's condition, while Carola said she was instructed by her child's pediatrician to contact the CHC for EMA guidance. Some of the mothers learned about the EMA through their social network.

It was obvious from the interviews that the information about the EMA program is not well-publicized within the immigrant community. Many of the interviewed parents did not learn about their child's ER visit qualifying for EMA until it was too late either because they had already started paying the bills or the deadline to apply for EMA has passed. Based on the participants' experiences, not knowing about EMA had resulted in some immigrant parents going into debt because of large medical bills. At the time of the interviews, four mothers had outstanding medical bills resulting from trips to the ER for their children.

There are even instances where some mothers were convinced that their children needed emergency care, but discovered that the EMA application was denied when their child's condition was classified as non-life-threatening. On some occasions, the mothers were instructed by the ER medical personnel to get some tests to determine the intensity of their child's health problem. The parents were left with the bills when the tests showed that the health problem was not an emergency. For example, Julieta's husband was asked to get X-rays done to verify if any bones in his child's hand had broken after an accident:

...una vez en la escuela se fracturó, bueno no se fracturó, se lastimó una mano y lo mandaron traer a mi esposo de la escuela, ahí estaba mi esposo ... y él se lo llevó a esa clínica nuevamente, que es económica. Lo volvió a llevar allí y le dijeron vaya usted y

sáquele una radiografía en el Children's, él se fue, saco la radiografía y la regresó y le dijeron 'no, no se preocupe, sólo fue una leve lesión', pero el bil llegó de mil dólares.

...once at school he fractured, well he didn't fracture he hurt his hand and they sent for my husband. My husband went there... and he took him to that clinic, the one that is cheap. He took him there again and was told to go and get the X-Rays at the Children's Hospital. He went, got the X-rays and brought them back and he was told 'no, don't worry, it was only a small problem' but the bill arrived for thousands of dollars.

Despite the high financial costs of taking a child to an ER, parents are often without other options during medical emergencies. As a coping strategy, some of the mothers said they advised their uninsured children to take additional precautions while playing to prevent accidents that may require a trip to the ER. Providers also said that Latino parents warned their uninsured children about having an accident while playing.

5.5.3 Financial Concerns and Delayed Care

The high costs associated with primary and emergency health care for uninsured children are a constant source of anxiety for the mothers. These financial concerns forced them to discourage their children from participating in activities that might increase the risk of getting hurt. According to Graciela, children who are uninsured:

“can't do the things that other kids do, such as my son who wants to play hockey and I have not allowed him to do so because if he gets hurt playing hockey, they are going to send him to the hospital and it will be very expensive...”

“Tampoco pueden hacer cosas que pueden hacer otros niños, como por ejemplo mi hijo quiere jugar hockey y no lo he permitido porque si se lastima algo en el hockey lo van a mandar al hospital y me va a salir carísimo...”

Other mothers confessed that they delayed getting professional help to minimize expenses associated with any visit to the doctor. One of the interviewees, Haydée, experienced a similar situation; her child was sick and hoped that she would not have to take him/her to the hospital:

En una ocasión que él tenía vómitos yo dije “¡Ay! ¿Cómo lo llevo? y este, todo luego sale bien caro” y luego que uno a veces no tiene los recursos, entonces ya compramos... fuimos a la farmacia y compramos una medicina que era buena para eso. Parece que era algo pasajero, suero y con eso se compuso. Menos mal que no era algo grave, yo estaba asustada.

“Once, he was throwing up and I said “Oh my God! Where do I take him? Because everything afterwards is very expensive” and sometimes one does not have the resources, so we bought... we went to the pharmacy and bought a medicine that was good for that. It appears it was something temporary, serum and with that, he got better. Luckily, it was not something serious, I was scared.

The providers explained they understood that parents resisted taking their children to the doctor until the last moment to avoid often unaffordable, expenses. Interviewed providers acknowledged that the parents medicate their children because of the high cost of a visit to the doctor appointment. Provider 2 explained that the lack of health insurance resulted in the children being assigned the highest possible rate for any visit to the doctor. So, while people who can afford health insurance receive some of the cheapest rates for medical services, low income families without health insurance are levied the most expensive healthcare fees.

Even resources like EMA do not have provisions for follow-up care, and can lead to extreme measures by the parents. Provider 5 recounted an incident of an uninsured child whose treatment expenses were covered, only in part, by EMA:

One of the prime examples I often go to is a little boy who fell and broke his arm, and he was able to get that arm set in the emergency room, and that was taken care of. But, to get the follow-up treatment, there was no way to get that follow-up treatment [covered]. I am not sure how they took the cast off or when they decided to take the cast off, mom and dad, I just don't know.

Overall, financial concerns were identified as the biggest factor influencing health-related decisions made by parents. There was, however, one mother who did not consider such expenses a decisive factor. For Bertha, making sure her children were healthy was more important:

O no, no, no me preocupaba por eso [costo de la consulta]... ¿estoy trabajando para

ellos, no? ¿qué va a hacer uno de madre no? Mejor es pagar que ver a tus hijos enfermos.

Oh no, I did not worry about that [the price of the medical appointment]... I am working for them, right? What is a mother going to do? It is better to pay than to see your children ill.

While Bertha was the only interviewee unconcerned about medical expenses, her children were also the oldest amongst all the mothers interviewed for this study and thus they did not need regular check-ups for vaccinations because they had completed all of them.

5.5.4 Motherhood

Irrespective of their financial concerns, their “role as mothers” appeared to be a central element in participants’ narratives. The phrase “mothers have to do what is best for their children” was most used by all the parents to describe their decision-making process; Francisca exemplifies this attitude:

...cuando fuimos a aplicar a esta clínica fue Karen conmigo. Fue a la primera a la que yo le saqué la cita. Me empezaron a preguntar muchas cosas y ella dice ‘mamá vámonos, están empezando a preguntar cosas y esas cosas no las puedes contestar, límitate.’ Y le dije ‘No, no me voy a limitar porque esto es importante para ti, va a ser un beneficio de ustedes, entonces lo tengo que hacer y si lo voy a lograr, lo voy a lograr, así tenga que dar aquí casi mis huellas digitales lo voy a hacer’.

...when we went to apply to that clinic, Karen came with me. It was the first time I had made an appointment there. They started asking many things and she said ‘mom, let’s go, they are beginning to ask things and those are things you cannot answer, limit yourself.’ And I told her ‘No, I am not going to limit myself because this is important for you, it is going to be a benefit for all of you, so I have to do it and yes, I am going to get it, I am going to get it even if I have to leave my fingerprints, I am going to do it’.

Participants used their responsibility as mothers to explain their demanding behaviors at health centers on behalf of their uninsured children:

Yo lo que siempre hago es decirles la verdad [al personal de salud], yo no tengo dinero, yo necesito la ayuda, no puedo dejar a mi hijo así. (Francisca)
What I always do is tell [health personnel] the truth, that I don't have money, that I need help, I can't leave my child like that.

Interviewed mothers' sense of responsibility was heightened by the fact that it was their decision to immigrate to the USA that complicated their children's access to health care. For example, Carola was concerned about bringing one of her daughters who suffered regularly from asthma in Mexico:

... la niña la mayorcita tiene asma y en Méjico se enfermaba mucho, no duraba un mes que no estuviera enferma, y era muchas medicinas muchos tratamientos, muchos doctores y estar yendo al hospital y al doctor. (...) y mi temor era de venir para acá y como me platicaban que acá nevaba mucho, hacía mucho frío, mi miedo era venir y que ella se me empeorara.

... my daughter, the eldest one has asthma and in Mexico she used to get sick often, every month she was sick and it required many medications, many treatments, many doctors, going back and forth to the hospital, to see the doctor. (...) and my concern when coming here was that I was told it snowed a lot here, that it got very cold and my concern was to come and have her get worse.

Bertha, whose son had epilepsy, wanted to ensure that she would be able to provide all the medications before bringing him to the USA. As result, the son lived in Mexico with his grandmother for six years before Bertha felt confident in relocating both of them to Pittsburgh.

As mentioned in an earlier chapter, most of the families interviewed for this research were mixed-status families; i.e. some of the members, including the children, were citizens/legal residents of the USA while others were undocumented. While mothers tried their best not to make a distinction between her children, such efforts were complicated by differential access to various social services based on USA citizenship, for example health insurance.

I observed the interviewed parents' frustration when acknowledging they sometimes have to discriminate between their children. These decisions appear to be stressful for the parents I interviewed who often became emotional during the interviews when discussing this topic.

Elena, for example, started crying as she explained: “*y a veces sí, uno tiene que escoger entre el que tiene seguro y el que no.*”/ “sometimes yes, you have to choose between the child who has insurance and the one who doesn’t.” Another of the interviewed mothers, Julieta, whose eldest child is undocumented and uninsured, explained:

...por ejemplo el niño grande me dice hay ocasiones en que me dice ‘me duele mucho el corazón’ o ‘me duele mucho el pecho’ o ‘me duelen mucho las manos y el corazón’, y nos preocupamos, pero ha ido a chequeos de rutina y le dicen ‘no, no, está bien’ y yo pienso que si él tuviera aseguranza en el momento en que le duele puede decir ‘yo voy a mi doctor’.

... for example, the older kid sometimes tells me ‘my heart aches really badly’ or ‘my chest is aching’ or ‘my hands are in a lot of pain, and so is my heart’, and we worry, but he had been to regular check-ups and they say ‘no, no, he is fine’ and I think that if he had health insurance I would be able to say ‘I’ll take him to the doctor’ the moment it starts to ache’.

While nine mothers confirmed that their preferred course of action would be different if their children were insured, one mother, Andrea, did not want to base her decision-making on her children’s insurance status. Andrea considers her children health to be too important and would take them to the hospital even if there is a possibility of receiving a large bill.

Haydée’s story provides further insight into the difficulty mothers face while distinguishing between their children. Besides an undocumented child, Haydée has two daughters who are US citizens but, due to a mistake, one of them did not have a social security card and, as a consequence, could not apply for MA or SCHIP. Haydée felt it was only fair that neither of them have health insurance when one of them could not, to avoid discriminating between her two American daughters.

aunque nunca he aplicado [para Anita] por que yo estaba mal, hubiera aplicado para Carmencita que ya tenía su seguro [social security card] y yo decía: “¿cómo voy a aplicar para una y la otra no?”, y estaba mal, siquiera hubiera aplicado para una...
although we never applied [for Anita, the daughter without social security] because I was wrong, I should have applied for Carmencita who had her Social Security Card and I said: ‘How am I going to apply for one of them and not for the other?’ and it was wrong, I should have applied at least for one of them...

This impasse continued for four years until the CHC was able to obtain a letter from the Social Security Administration (SSA) that helped convince the Pittsburgh DPW of Anita's citizenship. Following this, Haydée applied for health insurance for both children.

5.6 HEALTH IMPLICATIONS OF BEING UNINSURED

In the previous sections, I have shown that mothers state that undocumented children do not have access to preventive healthcare and mostly rely on free or FQHC, emergency room visits or the generosity of local doctors and providers. The following sections detail the impacts of the lack of insurance on the children's lives.

5.6.1 The consequences of delayed care

While the interviewed mothers were hesitant to elaborate on the consequences of home remedies and self-medication, providers, on the other hand, were more forthcoming in explaining the negative outcomes of delayed care. They shared stories that illustrate how the parental decision to defer consultation with doctors about minor ailments could potentially lead to a more complicated and expensive medical situation later on:

[T]uvimos el caso de un muchacho, un niño que no tenía seguro, dos casos (...) donde comenzaron a presentar síntomas de apendicitis con dolor abdominal con fiebre, que demoraron ir al médico, demoraron ir al médico, demoraron ir al médico, y en uno de ellos la condición que desarrolló fue peritonitis. Y eso significó una hospitalización de siete días con operación abierta, con una cantidad de antibióticos, y los costos elevadísimos. (Provider 4)

We had a case in which a kid did not have insurance... two cases actually where they started showing appendicitis symptoms, with abdominal pain, fever and they delayed going to the doctor, they delayed and delayed and in one of the cases the kid developed peritonitis. That meant a seven day hospital stay, with an open surgery, with a lot of antibiotics and very expensive costs.

All providers interviewed for this study agreed that the deterioration of a health problem and expensive treatment are the two major implications of delayed care. As Graciela, Irene and Carola said during the interviews, large medical bills are a huge financial burden for immigrant Latino families. Even if the cost for a child's treatment is eventually compensated by EMA, it represents a drain on public funds, one that could have been avoided with timely primary care.

Provider 6 gave a couple of examples of the practical benefits of preventive medicine:

So, if you leave a child who has an ear infection that goes untreated and let's say it ruptures and then the infection spreads to the brain. Now you are looking at someone hospitalized with very expensive costs that could have been prevented. So, very simple treatments upfront can prevent a lot of problems down the road. And the same things goes with immunizations so as long as these children are getting immunizations along the way, you are preventing a big problem down the road. You give them a flu shot now, it will prevent all the problems they would have gotten later.

According to providers, the exclusion of preventive care for uninsured children under the current MA and SCHIP eligibility criteria has created a public health conundrum.

5.6.2 Persistent Chronic Conditions

Children with chronic conditions were especially at risk in the absence of health insurance, as they were unable to receive regular medical attention and medication to keep their symptoms under control. Provider 5 described two instances: one child who suffered from repeated and severe tonsil infections and needed a tonsillectomy, and the other involved a girl who had a significant growth of calcium in a bone that continued to grow in size.

Irene, one of the mothers, shared that she had an uninsured son who diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). The monthly therapy sessions and daily medications needed to treat this condition were expensive, but the lack of insurance meant that Irene had to bear the expenses. Given the financial insecurity of most undocumented immigrant families, Irene said she dreaded the moment she might not have enough money for the therapy sessions or medications.

5.6.3 Early detection of health problems

Irene's child could be considered fortunate as he was at least diagnosed with ADHD. According to the health providers, uninsured children with access only to free or low-cost PHC centers do not get to consult specialists or receive certain kind of tests. This often results in the delay in detecting some types of developmental or speech deficiencies and, later, to receive therapies to address those issues. Conditions such as autism are also difficult to diagnose if the child is uninsured. According to the providers, these developmental conditions are likely to become worse or harder to treat if left untreated for a long time.

5.6.4 Restrictions on school activities

The interviews with the providers and mothers revealed that uninsured children are restricted from certain activities and denied some benefits at their schools. Graciela, one of the mothers, was informed by her son's school that it requires the students to have health insurance before they are allowed to participate in any kinds of sports. Provider 5 recounted hearing a similar story from one of the mothers with an uninsured child: "They have actually said to [the]

mom “No, we cannot have your child play sports because she does not have health insurance.” Graciela said she was once made to buy short-term insurance by the school so that her son could participate in a school camping trip.

Besides the social isolation and reduced physical activity resulting from restricted participation in sports and camping trips, limited access to dental and eye care also affects the academic progress of uninsured children. Having toothaches can limit a child’s ability to concentrate and eye problems can also affect them:

[Imagine not] being able to see the chalkboard (...) If you can’t afford to get glasses then you can’t see the board and that’s affecting your learning. And I think that, not being able to see a doctor that can help you may be with your diet or informing you about the benefits of exercise, and the importance of that might affect the eating habits of the family which in turn will come back to their health (Provider 3).

5.7 ADVOCACY

Advocacy, despite its challenges, is an important component of ensuring affordable healthcare for undocumented children. I asked parents and providers for opinions on advocacy for changes in the current health services.

5.7.1 Providers’ Perspective

The challenges of improving the current healthcare system to accommodate the specific needs of Latinos are substantial, and begged the question: Who should advocate for these changes? Providers interviewed for this study argued that advocacy has to come from various actors within the Latino community: leaders, organizations, and the healthcare consumers.

Interviewed providers also stated that community members have to think beyond their individual and immediate needs and take responsibility for their health and the community's health.

Obtaining appropriate language assistance was identified as an important issue for advocacy. As discussed earlier (see section 5.3.2), providers suggested that the availability of bilingual personnel at every level and in every department within the healthcare system –not just physicians, but nurses and administrative staff– would lead to significant improvement in the quality of service. Providers agreed that, in theory, this would be easy to implement in an institution like the UPMC, beginning with bilingual assistance for scheduling appointments, but advocacy needs to be done.

Some providers opined that the lack of progress in the language issue could, perhaps, be explained by the misplaced emphasis of the Latino community and its supporters. It seemed that the people being targeted, for example to advocate for the need for bilingual staff, were not the people who had the authority to make such decisions. Some providers suggested alternate strategies for advocacy, for example letter campaigns, and using data from academic research on Latino residents in the region to promote awareness on the negative impact on healthcare due to the lack of bilingual staff.

Providers who were more conversant about the functioning of the Department of Public Welfare (DPW) underscored the lack of knowledgeable personnel, especially regarding the complexities of mixed-status families and health insurance of children from such families:

Well, I think that the people in the higher levels of the DPW understand the child's rights and the complexity of mixed-status families. But not everybody at the DPW understands that. So, if you have a family out there whose English is proficient enough to do the application then, they can be rejected by a caseworker for some illegal reason... For a reason that doesn't reflect the actual regulations.(...) So, I think there is a need for education down to every level of the DPW (Provider 2).

Providers with more experience in social work stated that the lack of trained personnel within various government departments often leads to ill-informed and incorrect decisions regarding eligibility for public benefits, for example a child's access to public health insurance.

Some providers suggested the importance of including arguments based on public health approaches to support efforts that provide insurance to all children irrespective of their legal status:

These are public health issues so that if a child has a cough that is contagious, most coughs are virus, you don't have to treat them with antibiotics but eventually they can get worse; then it becomes a public health issue because now you have the spread of an infectious disease. So, documented or not documented (...), from my perspective, people need basic health care regardless of documentation status. And then from a moral and ethical side, of course I think they do, but if you want to look at the public health issue that is an important argument (Provider 6).

Similarly, some providers mentioned that the dependence of uninsured children on the local ERs can be seen as a burden on the public health system due to the exorbitant financial expenses associated with the EMA.

A provider mentioned that one of the biggest challenges in advocating for undocumented children is the greater ongoing national debate on immigration and the rights of immigrants. Provider 6 argued that the undocumented status of the children often causes some organizations to retreat from their healthcare advocacy efforts.

Due to the disproportionate impact of the larger immigration debate on undocumented children's healthcare, some providers believed that federal immigration reform was a necessary first step:

In our country, we should not be letting children suffer, absolutely not, no matter whether they are undocumented. And the healthcare reform needs to be pushed that one step further. But, before we will even get that, we have to have comprehensive immigration reform, which will give these children some status, and then they can get their health insurance. We desperately need comprehensive immigration reform (Provider 5).

Providers are hopeful of finding allies in organizations that work with children:

I think anybody that deals with children and having healthy kids in general, whether it be people that work for schools, and for any kind of children's issue should be involved in it because it affects children all through their lives and going into adulthood, making them into healthy adults (Provider 3).

There was general agreement among the providers I interviewed that change is needed on multiple fronts. There is also a need for an organized advocacy effort, which has been missing so far and has resulted in random successes.

5.7.2 Parents' Suggestions

When asked about the improvements or changes they would like to see implemented, some mothers hoped that the healthcare system would give their undocumented children the same rights as documented children:

[Les diría] Que puedan pues, ayudarlos. Que darles las oportunidades que los niños también tienen que tener aquí, porque no son nacidos de aquí. Tienen derecho pienso yo, como los demás niños que son de aquí, de padres americanos (Bertha).

[I would tell them] to help them, to give the children as well, the opportunities they can have here because they have not been born here. They have rights I think, just like other children who were born here, with American parents.

Entonces yo pienso que pos eso (...) el gobierno de no verlo mal, ver que uno también aunque no seamos, no tengamos papeles, no seamos de este país, también tenemos derecho a... porque somos humanos, tenemos derecho a un doctor (Haydée).

So I think that (...) that the government shouldn't see it in a bad way, that we also, even if we don't have papers, or that we are not from this country, we still have rights because we are humans and we have the right to see a doctor.

Other mothers, such as Elena and Julieta, wanted the healthcare authorities to understand that children get sick and need health care, regardless of their citizenship status. The mothers also wished that the decision-makers were more sympathetic towards the mothers' requests to provide insurance for their undocumented children. According to Irene: "*Necesitan estar en nuestra*

situación para que ellos logren entender la necesidad que tenemos de que nuestros niños que no son nacidos acá tengan un seguro, una cobertura médica...”/“They need to be in our situation so as to understand the need we have to provide our foreign children with health insurance.”

5.7.3 Cultural challenges

Providers emphasized the need for developing a better cultural understanding of the Latino community to encourage more active participation by the parents in advocacy efforts to secure healthcare for their undocumented children. The lack of proficiency in English is, of course, another important reason complaints and protests are directed at the Spanish-speaking providers, instead of the responsible person or organization.

5.8 SUMMARY

This section has presented the challenges and solutions developed by parents, social workers and healthcare providers to address the health needs of uninsured Latino children. The process of securing health care for these children is not easy, especially given the limited understanding of the system that parents have and the lack of services tailored to the Latino community. Undocumented children are able to get the health care they need through a series of favors and goodwill of social workers and health providers.

6.0 DISCUSSION

This research provides a closer look at the decision-making process by immigrant parents regarding their uninsured children's health problems in a NGC. The public health literature on uninsured Latino children rarely focuses on the strategies of parents, social workers and health care providers, choosing instead to concentrate on the health outcomes. Due to such oversight, I considered it necessary to document and offer a critical analysis of these strategies, as well as the challenges parents face when they opt for institutionalized care. This study presents the information using the voices and experiences of the immigrant families, and provides insights on their attempts at securing health care for their uninsured children in a NGC where Latinos are often invisible from public services and policies. The study also complements other studies on healthcare access for uninsured Latino children that have investigated the problem from a more quantitative perspective (Stoddard, St. Peter et al. 1994; Holl, Szilagyi et al. 1995; Szilagyi, Zwanziger et al. 2000; Flores, Fuentes-Afflick et al. 2002; Brach, Lewit et al. 2003).

The results of this study show that the parents had no straightforward strategies but rather depended on a network of relatives and friends, and required connections and persistence to find a solution. The research highlights the relative efficacies of the various strategies, and the negative health implications of failed efforts to obtain healthcare for uninsured immigrant children. The results also demonstrate the wider societal impact of poor health resulting from

absent healthcare and the need for organized responses to address the lack of health insurance among undocumented children.

6.1 THE STRUGGLE FOR HEALTH CARE

As documented in the previous chapter, the immigrant Latino parents who participated in this study face constant and unique challenges in their efforts to find accessible and affordable healthcare for their uninsured children. These challenges result not only from the tenuous legal circumstances of the children, but are also the consequences of belonging to a population that suffers from social, economic and racial vulnerability. The following sections contextualize the challenges, achievements, and gaps of the parents' efforts, and discusses possible strategies to create a more responsible and equitable way forward.

6.1.1 Challenges faced by parents

Participants with uninsured children encounter many challenges, including language barriers, expensive medical costs, and lack of information about available treatment options, to name a few. These challenges limit access to care for uninsured children. These results confirm findings from the literature which state that children without health insurance end up missing regular preventive care (Gorman and Braverman 2008) or lacking a PCP who knows their medical history (Flores 2010).

In addition to stable social ties, access to information has been identified as an important factor that influence mental and physical health status (Berkman and Syme 1979; Vega, Kolody

et al. 1991). Macia (2011) found that Latino residents in Pittsburgh feel the critical need for informational support (as opposed to material support): “Although material support is needed, and does happen through donations, gifts, or lending of money, the most important form of support that is offered (and sought) in the Latino community is one of information and navigation of the system” (Macia 2011:248). Latino parents in my study are often unaware of various resources that are available to them (e.g. a translator) on request in clinics and hospitals, and end up in desperate need for information and help from others. During the interviews with parents, it became clear another way in which lack of information impacted their children’s use of health services was the poor understanding of the medical coverage provided by EMA. Misinformation about EMA coverage would leave them saddled with expensive medical bills.

My interviews revealed a parental preference for health and social services providers who speak Spanish and/or are Latinos. When asked to explain this preference, the parents recounted experiences where they felt misunderstood by DPW workers who are mostly non-Latinos and do not speak Spanish.¹¹ Documet (2001) found a similar situation when she interviewed Latinos in Southwestern Pennsylvania. Her participants stated that they appreciated personal and warm relationships with their providers and they often complained that health care providers in the U.S. were “cold, distant, impersonal or business-like” (Documét 2001:225). Furthermore, a study conducted by Ayon (2010) in California found that Latino clients often have difficulty in developing good relations with case workers in the state’s welfare system “because their parenting values may be questioned or misunderstood, they may have undocumented status, and their community may lack resources such as advocacy and financial support” (p.267).

¹¹ During the three years I worked with the Latino community in Pittsburgh, I interacted with only one DPW case worker who spoke some Spanish.

Language has been identified as a crucial barrier to health care for Latinos in the U.S.A. (Caraway and Timmins 2002; Ross and Hill 2003). In Southwestern Pennsylvania Documet (2001) found that language, cultural incompatibilities and confusion about health insurance represented barriers to healthcare for Latinos. It is, thus, not surprising that the interviewees in this study demonstrated incomplete knowledge about the functioning of the health and public assistance systems, and this affected their strategies to secure health care. This has been observed by other researchers as well (Ayón, Aisenberg et al. 2010; Ayón 2011).

The parents in this study were unaware of the eligibility of their children for different kinds of assistance, and were unfamiliar with the document requirements and multi-step procedures necessary to process the assistance applications. Hagan et al. (2003) found that the complicated nature of the eligibility and procedures often led to eligible children from mixed-status families losing access to public health insurance.

Latino immigrants in my research were frequently not aware of their rights as a patient in places like public hospitals, and the absence of interpreters made any visit a very challenging experience. Flores and Abreu (1998) found in a study conducted with 207 Latino children, that lack of interpreters was an important barrier to care identified by parents in their sample. Lessard and Ku (2003) found in their study of insurance gaps among immigrant children, that lack of information about the processes of renewing insurance plans resulted in uninsured children. Documet (2001) found that misinformation about eligibility criteria for health insurance and available health facilities was widespread among Latinos in Southwestern Pennsylvania. Their lack of information was explained in some cases by lack of English proficiency and/or absence of culturally appropriate materials (Documét 2001).

In my study, the lack of awareness about the functioning of the health and public assistance systems, absence of service providers who are conversant in Spanish and the anxiety about healthcare costs also led to other undesirable situations. Interviews revealed that untreated or mistreated ailments led to instances where parents were compelled to seek treatment for their children at the emergency rooms of local hospitals. Being able to identify an emergency and act accordingly is a good predictor for positive health outcomes, and undocumented immigrants often see it as the only available source of care (Chan, Krishel et al. 1996). In a study conducted by Mistry and Hoffman (2005) around the relationship between the use of emergency departments between two generations of family members (parents and children) identified the importance of explaining to people what constitutes an emergency in order to reduce unnecessary ER visits.

One of the most important reasons parents in this study said they delayed taking their children to the doctor was financial. This could have resulted in the worsening of a medical condition. Delaying care has been identified by other researchers as a common consequence of not having access to healthcare (Monheit and Cunningham 1992; Carrillo, Treviño et al. 2001). This study shows that limited availability of affordable healthcare services for uninsured children and their lack of knowledge of the available options led parents to make uninformed decisions regarding their children's health needs. Such actions can have repercussions for the local public health system and life-long health consequences for the child.

The use of folk medicine and OTC for minor ailments by Latinos, as documented in my study, is another money-saving strategy in the absence of accessible and affordable healthcare and has been noted by other researchers (Risser and Mazur 1995; Dole, Rhyne et al. 2000; Documét 2001; Zenk, Shaver et al. 2001). My interviewees, however, were aware that using

home remedies and OTC medications could turn out to be a risky gamble. Studies on the use of home remedies have also found that Latino parents often fail to inform their healthcare provider about the medicinal herbs used as home remedies (Howell, Kocchar et al. 2006). Such omissions raise possibilities for negative interactions with medications prescribed by the doctors. Parents interviewed in my study, however, did not discuss whether or not they told doctors about their use of home remedies.

The high cost of medical services has been shown to increase reliance on free and low-cost healthcare options (Skinner and Mayer 2007). Uninsured children have been found to depend on emergency facilities, free clinics, or clinics with sliding-scale fees more often than children with health insurance (Becker 2001). The lack of health insurance in Latino children is also correlated with a reduced use of available services, and the decreased likelihood of referral for and use of other needed services (Rudolph and Porter 1986); the children in my study were no exception. The free healthcare services available to parents of uninsured children in Pittsburgh were not free of inconveniences. The wait-time at the clinics was unpredictable and, due to the high demand of such services, those arriving late on the day of the clinic often did not receive an appointment and had to wait a whole month for another chance to consult the doctors. This increased the chances of a child with a minor condition returning with an aggravated health problem a month later.

The health needs of many immigrant children also go unattended as parents fear being questioned about their immigration status (Aizenmen 2007). Rodriguez et al. (2003) found that concern about immigration questions is a common reason for delayed healthcare among Latinos. Fear of deportation due to their immigration status also results in parents not renewing, opting for inadequate health insurance for their documented children or not applying at all (LaVeist

2005; Wilkiski and Spencer 2008). In my study, parents mentioned their concern about being asked to present paperwork about their immigration status in order to use a healthcare facility. Situations where documented children are uninsured shows the fragility of the insurance status of U.S.-born Latino children (Cunningham and Hahn 1994).

6.1.2 Parents' strategies

Participants residing in Allegheny and Washington counties were fully aware that their undocumented children were not eligible for the existing state and federal health insurances, as in most other states. Securing preventive and curative care for the children was a formidable challenge for the parents, and not being able to provide them was a source of frustration. Parents in my study would eventually find resourceful ways of getting information and support for the well-being of their child. Other times, they got into debt, to address the health need of their children.

Documet's study (2001) found that Latinos in Southwestern Pennsylvania

“are more responsive to the health needs of their children than to their own. Most people took getting preventive care seriously when the person in need of such care was a child. They said they keep all their children's appointments; in fact, most of the children in the survey had a medical visit in the past year” (pg231).

This would explain the concerns Latino parents in my study expressed about having to delay care for their child due to lack of health insurance.

The sacrifices that Latino mothers narrated in this study were, nevertheless, not a source of complaint. Rather, sacrifices were something mothers felt good about because they are considered to be part of being a mother. The mothers I interviews took pride in their ability to endure hardships for their children. This has been described as *Marianismo*: “Marianismo is a

gender-specific value that applies to Latinas. Marianismo encourages Latinas to use the Virgin Mary as a role model of the ideal woman. Thus, Latinas are encouraged to be spiritually strong, morally superior, nurturing, and self-sacrificing” (Baez 1999:183).

As part of a NGC, Allegheny and Washington counties are characterized by a relatively small Latino population and a limited availability of appropriate social services (Macia 2011). Furthermore, the dispersed nature of the population in the Pittsburgh NGC limits the effectiveness of distributing information about available resources (Documét and Sharma 2004). Nevertheless, my research found that parents have managed to create a network of friends, family and providers to obtain information, support and advice necessary to make health-related decisions. Macia’s (2011) dissertation in the Pittsburgh area about Latinos mechanisms to deal with grievances and Documet’s (2001) on healthcare access for Latinos reached similar conclusions.

Documet’s (2001) study found that her participants were often part of a close network and operated as an extended family. Her study showed that this informal network takes part in healthcare decision-making and supports the sick person in multiple ways. These arrangements, she explained, “rely on the concepts of familism, personalismo and communalism, found in Latino groups throughout the U.S.” (p.265). The social network built by Latino parents in my sample helped them identify providers and health centers where their undocumented children could be treated for any health problem that cannot be solved at home using home remedies or OTC medications. Latino parents within this network frequently helped other parents find healthcare for their children. Formation of such networks of people who belong to a family or circle of friends has been referred in the literature as a cultural trait amongst Latinos (Marín and Marín 1991). Some authors refer to this cultural characteristic as *familismo*: “Familismo stems

from a collective worldview; it involves the strong identification and attachment to nuclear and extended family. Loyalty, reciprocity and solidarity among members of the family is a key characteristic of this cultural value” (Santiago-Rivera 2003:2). It appears that in a NGC where family ties are small, other Latino friends are perceived as family members and treated as such.

My research also revealed that in addition to family and friends the support network also included social service and healthcare providers who are aware of the children’s uninsured status and understand their challenges of obtaining healthcare. These providers helped parents find free specialized care and financing for their medical expenses. The weakness of such support networks is their overt dependence on good Samaritans instead of a formal and institutionalized solution that addresses the healthcare needs of uninsured children.

6.1.3 Providers’ efforts

The results show that social and health service providers in Allegheny and Washington counties have tried to address the needs of uninsured Latino children in various ways. Besides their services, the providers have played a key role in providing information and supporting the community network for parents in need of free or low-cost health care for their children.

Data showed that while the parents have managed to take advantage of the limited pediatric primary care resources available in the region for uninsured children, there were invariably situations when these services proved inadequate. When an uninsured child needs specialized tests, specialized care, expensive treatments or surgery, the local social service and health providers step in to ensure that the patient receives the necessary care. A study conducted in five counties found that parents in Everett County, MA considered physicians as key assets for their children’s health, even when there was a gap in their insurance (Hill, Stockdale et al. 2006).

Providers interviewed for this research said they had to go to great lengths, often pleading with other doctors or asking for personal favors, to procure pediatric services for the children.

Providers provided informal arrangements, understood as:

...ways of getting health care by circumventing the established health system. These arrangements include using of traditional western medicine and other kinds of cures. They are frequently free; they are commonly obtained through acquaintances or people who belong to a network. From one contact, another contact was called, then another one. These were the “links” of a “chain” that ended in the provider. The use of the network and the formation of the chain tended to involve personal relationships (Documét 2001:246).

As noted earlier, such informal arrangements are not sustainable in the long-term. In addition, children whose parents lack personal ties with providers could potentially find themselves at the margins and unable to access medical care.

It was clear from interviews that the service providers offer important support to Latino parents in their efforts to address the health needs of their uninsured children. As Cohen (2004) notes, assistance by the healthcare and social services personnel often extends to providing emotional support that “involves the expression of empathy, caring, reassurance, and trust and provides opportunities for emotional expression and venting” (pg. 677). At the same time, the providers interviewed for my study are painfully aware that their current strategies to help the Latino community – the use of personal connections and private efforts – are mostly temporary in nature. Participants would prefer fundamental institutional reforms that change the way the system accommodates undocumented immigrants, and results in bigger, long-lasting impact.

In Allegheny and Washington counties, parents interviewed in the study mobilized their network of social service providers, doctors, church members, and friends to use their personal connections and knowledge to help their undocumented and uninsured Latino children.

Advocacy efforts appeared to be few and far between. For example, CHC has contacted the

DPW to complain that application forms arrive in English to families that have noted that they prefer all paperwork to be sent in Spanish. While there is an acknowledgement that organized advocacy efforts by both the providers and community members are necessary to address the health needs of undocumented children, the tenuous legal status of the Latino families and the current anti-immigrant fervor in the Commonwealth of Pennsylvania have proven to be significant hurdles. Furthermore, the Latino community in Pittsburgh is not yet a strong one; this can be seen in the few existing community initiatives which –in turn- can be explained by the fact that Allegheny and Washington Counties are New Growth Communities (Documét 2001). This leaves the providers alone in their efforts in advocating for change.

6.1.4 Impact on children's lives

According to Crosnoe (2006), undocumented children experience several restrictions in their everyday routines as a consequence of being uninsured or uninsurable. Playing sports or educational trips are not only considered core components of a child's social life in school but such physical activities also contribute to good health. Despite such obvious benefits, parents interviewed for this research said they dissuaded their uninsured children from such activities. In some cases, school administrations were found to have restricted children from participating in sports or outdoor activities unless they had health insurance. Kogan et al. (1995) found that uninsured children often missed school days as a result of limited access to health care. A social provider interviewed in my study highlighted the impact on a child's education due to the lack of access to free or affordable eyeglasses.

Based on my research, the limiting factor for social integration among school-going uninsured Latino children seems to have one of the most important collateral consequences of

the lack of health insurance. Social integration, as defined by Brisette et al. (2000) is the participation in a broad range of social relationships; it implies active engagement in a wide range of social activities or relationships that provides a sense of communality and identification with one's social roles. Social integration has been identified as an element that can, in turn, affect people's health (Mulvaney-Day, Alegría et al. 2007); for instance it has been found that strong family support (a component of social integration) has an impact on Latino mental and physical health (Bird, Canino et al. 2001).

Despite their best efforts, the parents of undocumented children and health and social service providers have been unsuccessful in shielding the children from certain consequences of being uninsured. From these data, it appears that the lack of health insurance begins to impact undocumented children's life in more ways than one from an early age. Providers interviewed for this study, for example, mentioned that often, uninsured children are ineligible to receive a free car-seat or basic psychological testing to detect conditions like autism. Uninsured children are also less likely to receive preventive care (Rosenbach 1989; Peak, Julie et al. 2008). As a result, as providers in my research explained, not only did some illnesses go undetected in such children, there was a lower probability that their parents would be exposed to information about common childhood disease prevention usually provided by pediatricians during routine preventive care visits. Unfortunately, as my research shows, it was common for many parents to delay care hoping against hope that their child's health problem was not a serious one.

Delayed care or lack of information about preventive measures can have terrible consequences for the health and life of an uninsured child (Ross and Hill 2003) far beyond the economic costs that it will represent for the family or for the public welfare system. These children are less likely than insured ones to have a regular physician (Flores 2010) or receive

adequate preventive care (Gorman, Landale et al. 2001). While my research was not designed to be comparative, mothers with both citizen and non-citizen children (i.e. insured and uninsured children, respectively) did indicate that their health-seeking behaviors differed based on the children's insurance status. As a result, mothers in my study would not hesitate to take their insured child to the doctor at the first sign of illness, while they delayed care for their uninsured child. Zimmerman and Fix (1998) found similar information, and their article stresses that uninsured children utilize emergency or critical care facilities more frequently than preventive health services.

6.1.5 Final thoughts on advocacy

In this study, the importance of advocacy was highlighted by providers as a mechanism to address the challenges associated with providing healthcare for undocumented children. Advocacy however, should not only rely on providers but also in the Latino community itself. Providers in the study whose vantage position is that of someone working within the public bureaucracy and medical establishments, have a better sense of the big picture and the broader debates surrounding health care for undocumented individuals. According to the providers, advocacy efforts would have a higher chance of success if they can be presented as a case of civil rights for immigrants requiring a comprehensive reform of federal immigration policies. Immigrant parents, concerned about lack of access to basic health care and long-term health insurance for their children, can be counted on as natural allies for any such advocacy efforts. The Latino community of Allegheny and Washington counties needs more organized and sustainable response to the needs of undocumented Latino children. One first step would be the design of coordinated advocacy efforts.

Providers in the study, however, cautioned against expecting vocal public support given the tenuous legal status of most Latino immigrants. Latino parents were often hesitant to voice their concerns outside of the network of family, friends and volunteer providers, unless pushed into a corner. For example, Latino parents would not register their complaint at the DPW when they received application materials in English after having requested them in Spanish. Instead, they would ask assistance from a provider for help with translating the questions.

Learning from similar efforts from other parts of the country is important. The Children's Health Initiatives (CHI) in Santa Clara and San Mateo counties in California attempted to offer a new insurance program to those not eligible for other insurance and help to all uninsured children. Needless to say, they faced several obstacles: "First they must establish a governance structure, either inside or outside the local government, to oversee the CHI's development and operation. But their greatest challenge is raising funds locally for the new insurance program and the outreach/enrollment activities" (Howell and Hughes 2006:525). This experience points to the importance of a well-thought-out advocacy strategy, especially in a state increasingly known for anti-immigration policies. Advocates would have to be ready to defend the Latino children from political and legal attacks based on their immigration status.

In addition to highlighting the appropriateness of the civil rights discourse, financial arguments could be used to support the case of providing children with free access to preventive care. For example, the Children's Defense Fund found that one out of every five Latino two-year olds is not fully immunized, "yet every dollar spent vaccinating children against measles, mumps, and rubella, saves \$16 in future costs" (CDF 2009). Further cost savings can also be achieved by eliminating the need for undocumented children to be treated at the emergency and critical care facilities at great expense to the taxpayer. Providing preventive, affordable and

accessible healthcare to the children would take away the need for desperate parents to rush them to these already-overwhelmed facilities as a measure of last resort.

6.2 RECOMMENDATIONS FOR ADVOCACY AND FUTURE RESEARCH

There is an urgent need for the Latino community and its benefactors (providers) to find strategic allies who understand the importance and public health benefits of providing insurance for all children. While the current healthcare facilities for uninsured children in Allegheny and Washington counties (i.e. Monthly Free Pediatric Clinic, Lincoln-Lemington, Washington's Hospital Family Practice, Squirrel Hill Health Center and East Liberty Healthcare Center) have done a commendable job, there is a need for more sustainable options. The population of Latinos in Allegheny and Washington counties is growing and a strategic plan needs to be prepared to address the health needs of the undocumented children from these families. Rather than focus on expansion of existing services, efforts should be concentrated on making undocumented children eligible for health insurance.

A comparative study done by Newacheck (1998) found that

“health insurance is a powerful predictor of children’s degree of access to and use of primary care, including such aspects as entry into the health care system, identification of a regular clinician, level of satisfaction with care, whether care is delayed or missed, and the amount of physicians’ services received” (p.517).

Another study that analyzes the impact of the California insurance program for children “Healthy Kids” shows that in addition to cutting uncompensated ambulatory care costs, Healthy Kids could also reduce uncompensated care for hospitalization and emergency department use (Cousineau and Farias 2009:4). Such evidence could prove essential to advocate for the creation

of a health insurance plan for children who live in Pennsylvania, and one that does not have citizenship as a requirement.

Another relevant topic in which providers in Allegheny and Washington counties could focus advocacy efforts, is the need for professional interpreters at various healthcare sites. Different studies identify language as a barrier to provide effective service and care to immigrant Latino children (Caraway and Timmins 2002; Flores, Abreu et al. 2005); in the area covered in this research, it became apparent that interpreters ought to be available at low-cost health centers and FQHC where Latinos go. Advocacy efforts to have professional interpreters ought to be done at least in the following levels: (1) at the doctor's office during the medical appointment and (2) with administrative staff in charge of making appointments and explaining financial matters. Funding could come from grants focused on improving healthcare access for minorities.

Future research on uninsured Latino children should compare healthcare access of uninsured and insured Latino children. Some of the indicators that it should focus on are: last time they went to see a doctor in the last month and year, visits to the ER, missed school days, delayed care, and other related topics.

From another perspective, several studies have looked at the relationship between social integration and mental and physical health status in adults. It would be relevant to study if lack of health insurance in children has a relationship to their social integration (among their peers) or if parent's social support network has an impact on children's well-being. In order to assess this, the first step would be to measure the social support of parents of Latino children and divide them into two or three groups according to their level of social support. Afterwards, their children's health status would be measured and compared among the different groups of parents' social support.

Another topic in need of further study is how the current –fragile– network is preserved and enlarged even in the face of frequent changes. Provider might change jobs and positions, others might leave and information about how to help uninsured children needs to be constantly updated and shared to serve newcomers.

The parents I interviewed were the ones that are somehow connected to and informed about the existing pediatric options for their uninsured children; yet, many of these children had not always received timely care, and had not see a doctor as regularly as the parents would like to. Thus, a weakness of this study is that it focused on those parents that were “connected” to the existing support network formed by social and health services providers. A future study should try to look for those families that are not –yet– tapped into the existing network of services, and focus on the health implications of not knowing about the available health care options. The perspectives of “unconnected” Latino families were not part of this research and we do not know about the health status of undocumented children at the margins of health care. One challenge would be to find these families.

Another limitation is the small size of the sample. This research however, provides a first glimpse into an important area of research: decision-making health care decisions for immigrants and their children. Another study should focus on Federally Qualified Health Centers in order to understand the way in which they are tailoring their services to Latino children.

To have a better understanding of the actual health impacts of not being insured due to immigration status, a study could be done comparing insured and uninsured Latino children in the counties of Allegheny and Washington. It could follow two groups of children for a year, controlling for things such as children ages, parents’ English proficiency, time in the USA, access to public and/or private transportation and networks.

7.0 CONCLUSIONS

This research has identified supporting arguments around the need to increase healthcare access to undocumented children. The testimonies of both parents and providers show that uninsured Latino children's health needs in the New Growth Community of Allegheny and Washington counties were not timely addressed. They also showed the complexity of securing specialized care when a child's condition calls for it. Furthermore, this study shows that beyond healthcare access, uninsured Latino children's lives are affected: schools often prevent them from participating in physical activities and parents are usually advising them not to get involved in activities that may put them at risk of an accident. Both situations affect their children's social lives.

Institutional strategies to provide health care for undocumented uninsured children in a NGC were few and not necessarily optimal. They did not happen with the frequency parents needed and many of the existing institutional strategies did not offer a cultural competent environment. There was a need not only for interpreters and bilingual staff, but also for a more comprehensive view of Latinos and their immigration status and that of their children.

Parents in the study openly said that their health decisions regarding their uninsured children would be different if they had insurance. Financial concerns would be put aside and care will not be delayed unnecessarily if children were insured. Providers on the other hand, were aware that lack of insurance is not the only problem or the key one. Information about the

importance of preventive care and what constitutes an emergency, as well as changes in both the DPW and the health system will be necessary if we want to increase the access to care for Latino children.

Both parents and providers have been able to work together to provide the necessary care for children, however the efforts are isolated and not possible to be generalized since they are based on individuals doing favors and exceptions. There is a need to have organized community efforts to find the best ways of advocating for providing health insurance and thus, healthcare access, to children in Allegheny and Washington counties regardless of their immigration status

APPENDIX A: INTERVIEW GUIDE WITH PROVIDERS

A.1 INTRODUCTORY SCRIPT IN SPANISH

Muchas gracias por mostrar interés ser entrevistado para mi investigación. Como le dije en el e-mail, el objetivo de este proyecto de investigación es conocer y comprender cómo los padres de familia latinos que viven en Allegheny County toman decisiones sobre la salud de sus niños. En el marco de este estudio voy a entrevistar a 10 padres de familia y a 5 personas que dan servicios sociales o de salud a familias latinas con niños.

Calculo que la entrevista tomará aproximadamente una hora. El riesgo en participar es que usted puede sentirse incómodo con las preguntas. No sienta que tiene que contestar esas preguntas. No hay beneficios directos para usted por participar.

La entrevista es completamente confidencial, lo que significa que solamente yo voy a saber que usted fue entrevistada. La información es confidencial, ni su nombre ni nada que la pueda identificar aparecerá en el reporte final, a menos que usted lo desee. La participación en esta entrevista es voluntaria.

Esta investigación es la base para mi trabajo final en la maestría de salud pública. Quisiera grabar la entrevista porque esto va a facilitar el análisis de los datos después, pero si usted desea que no lo haga, apagaré la grabadora. Si me permite, tomaré notas durante la entrevista.

Si en algún momento usted desea detener la entrevista porque ya no quiere continuar o para posponerla para otro momento, más conveniente para usted, no dude en decírmelo.

Acá está la tarjeta de mi asesora: la dra. Patricia Documet y mi tarjeta con mi teléfono por si tiene preguntas en el futuro.

A.2 INTRODUCTORY SCRIPT IN ENGLISH

Thanks for accepting being interviewed for my research. As I informed you in the e-mail, the purpose of this research study is to describe and understand the decision-making process of Latino immigrant parents in Allegheny County regarding their children's health. I am conducting

10 interviews with Latino parents and 5 among social and health service providers that serve the Latino community in Allegheny County.

I estimate that the interview will last approximately hour. The risk of participating is that you may feel uncomfortable with some of the questions. You can choose not to answer those questions. There is no benefit to you in participating.

The interview is completely confidential which means that only I will know that you were interviewed. The information you will provide me will be confidential, your name or anything that could identify you will not appear in the final report, unless you don't mind appearing there. Your participation in this research study is voluntary.

This study is a key component of my final project at the School of Public Health in the University of Pittsburgh. I am planning to audio-tape the interview so that it becomes easier afterwards to analyze the data. However, if you do not want me to record the interview let me know and I will take notes.

If you want to stop or pause the interview at any given moment, please let me know and we can stop the interview and/or continue it later at a time that is more convenient for you.

Here is my advisor's card: Dr. Patricia Document and my card with my name and phone number for any further questions you might have.

A.3 INTERVIEW GUIDE IN ENGLISH

1. How long have you been working with the Latino community of Pittsburgh?
2. How did you first become involved with them?
3. What are the main challenges that Latino families have to face when they have to deal with the healthcare system in Pittsburgh?
4. As a person who regularly interacts with Latino families that have both insured and uninsured children, what is your main concern regarding the access to health insurance among Latino children?
5. Can you share with me a story you remember about a family whose uninsured child had a health problem and the challenges this represented for the family?
6. What are the available options in Allegheny County for uninsured children ineligible for Medicaid or CHIP?
7. What are the main advantages and disadvantages of these options?
8. What else could be done to improve the healthcare access of uninsured children?
9. From your experience, what are the main problems that children without health insurance face when they need medical care?

10. Would you say that lack of health insurance is the main problem for some Latino children or what other factors impact their health status?
11. Do you think that parents whose children are not insured have to make difficult choices when it comes to looking for health care? Can you give me some examples?
12. If children who have not been born in the U.S. could also get free or low-cost health insurance, how do you think this would impact their health or their lives in general? (school, afterschool activities, etc.)
13. As you know, even children who are eligible to have insurance sometimes do not have it... what are the main barriers for this eligible children getting health insurance?
14. Is there anything regarding health insurance and children that we have not talked about and you would like to comment on?

A.4 INTERVIEW GUIDE WITH PROVIDERS IN SPANISH

1. ¿Hace cuánto tiempo trabajas con la comunidad Latina de Pittsburgh?
2. ¿Cómo así te empezaste a trabajar con la comunidad Latina?
3. ¿Cuáles dirías tú que son los principales retos que las familias latinas que viven en Pittsburgh tienen cuando necesitan acceder a servicios de salud?
4. ¿Como alguien que se relaciona frecuentemente con familias latinas que tienen hijos con seguro médico y sin seguro médico... cuál es tu principal preocupación en relación a los niños latinos y su acceso a la salud?
5. ¿Tienes alguna historia de algunas de las familias que tienen un niño sin seguro con un problema de salud y los problemas y retos que esta situación significó para la familia?
6. ¿Cuáles son las opciones para obtener cuidado médico para los niños que no son elegibles ni para MA ni para CHIP?
7. ¿Cuáles son las ventajas y desventajas de estas opciones?
8. ¿Qué más crees que se pueda hacer para mejorar el acceso a servicios de salud de niños sin seguro médico?
9. En base a tu experiencia, ¿cuáles son los principales problemas que los niños sin seguro médico enfrentan cuando necesitan cuidado médico?

10. Dirías que la falta de seguro médico es uno de los principales problemas de los niños latinos o qué otros factores están afectando su salud?
11. Piensas que los padres de familia con niños sin seguro médico tienen que tomar decisiones difíciles cuando el niño/niña necesita ir al doctor? ¿me puedes dar un ejemplo?
12. Si los niños que no han nacido en Estados Unidos pudieran obtener seguro médico gratuito o de bajo costo... qué impacto crees que esto tendría en su estado de salud o en sus vidas en general?
13. Como sabemos, a veces aún los niños que son elegibles para MA o CHIP a veces no tienen seguro médico... ¿cuáles son las principales barreras que estos niños tienen para obtener seguro médico?
14. Is there anything regarding health insurance and children that we have not talked about and you would like to comment on?

APPENDIX B: INTERVIEW GUIDE FOR PARENTS

B.1 INTRODUCTORY SCRIPT IN ENGLISH

Thanks for accepting being interviewed for my research. As I told you when we spoke over the phone, the purpose of this research study is to describe and understand the decision-making process of Latino immigrant parents in Allegheny County regarding their children's health. I am conducting 10 interviews with Latino parents and 5 among social and health service providers that serve the Latino community in Allegheny County.

You are being invited to take part in this anonymous interview for this research study because you are Latino parent, at least 18 years old, and live in Allegheny County. I estimate that the interview will last approximately hour. The risk of participating is that you may feel uncomfortable with some of the questions. You can choose not to answer those questions. There is no benefit to you in participating; the report that comes out of this study will be shared with agencies that currently provide services to the Latino community.

You will receive a \$20 compensation for your time once the interview is finished.

The interview is completely confidential which means that only I will know that you were interviewed. The information you will provide me will be confidential, I will not register your name or anything that could identify you at any point of this research. No identifiers will appear in the final report, in the tape or interview data. In order to guarantee this I will ask you to give me an "alias" that is a fake name that I will use throughout the interview to avoid using your name. Your participation in this research study is voluntary.

This study is a key component of my final project at the School of Public Health in the University of Pittsburgh. I am planning to audio-tape the interview so that it becomes easier afterwards to analyze the data. However, if you do not want me to record the interview let me know and I will take notes.

Here is my advisor's card: Dr. Patricia Documet, and my card with my name and phone number for any further questions you might have.

B.2 INTERVIEW GUIDE IN ENGLISH

1. How long have you lived in Pittsburgh?
2. Where did you live before coming to Pittsburgh?

3. What was the more challenging aspect of the process of adapting to life in Pittsburgh?
4. How many children do you have?
5. Are all of them here with you in Pittsburgh?
6. Do all the children that live with you have health insurance? Why?
7. Do you think the fact that not having a health insurance has a negative impact on their health? How?
8. What happens when one of your uninsured children falls sick... where do you take them? What do you do?
9. And... when one of your insured children falls sick? Is the process different? How?
10. For those children who do not have health insurance... when was the last time you took them to a doctor? How did you learn about this doctor?
11. Were you asked to schedule a follow-up visit? Did you? (if answer is no; ask why)
12. Did you have problems paying for the medical bills of that visit?
13. Do you think that the cost of medical care is going to make you think twice the next time you have to bring your child to the doctor?
14. Has there been a time where you wanted to take any of your children to the doctor and you could not... can you tell me what happened?
15. Have you ever taken any of your children to the E.R? Why? What happened? How was your experience there?
16. If you were in (home country) and one of your children got sick... what will you do? What are the options you have over there? (social network, relatives, health center, etc.)
17. What are the differences between health care back home and health care here?
18. Given the fact that some of your children are insured and others are not... what do you think is the main impact on your children's everyday activities?
19. If your children who were not born in the U.S. were offered the opportunity of having health insurance... how will that change their health or the way you make decisions about their health needs?
20. If a friend from your hometown that has recently moved to Pittsburgh calls you because one of her children who is uninsured has a fever, and asks you for advice... what will you suggest her to do? Where would you suggest them to take the child?
21. Is there anything regarding health insurance and children that we have not talked about and you would like to comment on?

B.3 INTRODUCTORY SCRIPT IN SPANISH

Muchas gracias por mostrar interés ser entrevistado para mi investigación. Como le dije cuando hablamos por teléfono el objetivo de este proyecto de investigación es conocer y comprender cómo los padres de familia latinos que viven en Allegheny County toman decisiones sobre la salud de sus niños. En el marco de este estudio voy a entrevistar a 10 padres de familia y a 5 personas que dan servicios sociales o de salud a familias latinas con niños.

Le estoy pidiendo que participe en este proyecto de investigación porque Ud. es un padre de familia Latino, mayor de 18 años de edad, y vive en el condado de Allegheny. Calculo que la entrevista tomará aproximadamente una hora. El riesgo en participar es que usted puede sentirse incómodo con las preguntas. No sienta que tiene que contestar esas preguntas. No hay beneficios directos para usted por participar; el reporte final de esta investigación será dado a las instituciones que dan servicios a familias Latinas.

Recibirá una compensación de \$20 en agradecimiento por su tiempo una vez que la entrevista concluya.

La entrevista es completamente confidencial, lo que significa que solamente yo voy a saber que usted fue entrevistada. La información es confidencial. No voy a registrar su nombre o algún dato que la pueda identificar en ningún momento de esta investigación. Tampoco habrá nada que la pueda identificar en el reporte final, en el audio o en el reporte de esta entrevista. Para garantizar la confidencialidad, le voy a pedir que me de un "alias" es decir un nombre falso que yo usaré a lo largo de la entrevista para no usar su verdadero nombre. La participación en esta entrevista es voluntaria.

Esta investigación es la base para mi trabajo final en la maestría de salud pública. Quisiera grabar la entrevista porque esto va a facilitar el análisis de los datos después, pero si usted desea que no lo haga, apagaré la grabadora. Si me permite, tomaré notas durante la entrevista.

Acá está la tarjeta de mi asesora, la Dra. Patricia Documet y mi tarjeta con mi teléfono por si tiene preguntas en el futuro.

B.4 INTERVIEW GUIDE IN SPANISH

1. ¿Hace cuánto tiempo vive en Pittsburgh?
2. ¿Dónde vivías antes de venir a Pittsburgh?
3. ¿Cuál ha sido el mayor reto de adaptarse a vivir en Pittsburgh?
4. ¿Cuántos hijos tienes?
5. ¿Todos están acá contigo en Pittsburgh?
6. ¿Todos tus hijos tienen seguro médico? ¿Por qué?

7. Piensas que el hecho que algunos de tus niños no tengan seguro médico afecta su salud de una manera negativa? ¿Cómo?
8. ¿Qué pasa cuando uno de tus niños que no tienen *aseguranza* se enferman? ¿Qué haces? ¿A dónde lo llevas?
9. ¿Y si uno de tus niños con seguro médico se enferma? ¿Haces algo diferente? ¿Qué?
10. En relación a tus niños sin *aseguranza*... cuándo fue la última vez que los llevaste al doctor? ¿cómo te enteraste de este doctor?
11. ¿Te dijeron que hagas una cita para hacerle seguimiento a tu niño? ¿Sacaste la cita? (si la respuesta es no, preguntar ¿por qué?)
12. ¿Has tenido problemas par apagar los *biles* de esta cita médica?
13. ¿Piensas que el costo de llevar a tu niño al doctor va a influir la próxima vez que lo quieras llevar al doctor?
14. ¿Alguna vez has querido llevar a tus niños al doctor y no has podido hacerlo? ¿me puedes contar qué pasó, cómo fue?
15. ¿Alguna vez has tenido que llevar a alguno de tus hijos a la emergencia? ¿por qué? ¿cómo fue tu experiencia allí?
16. ¿Si estuvieras en tu país y uno de tus niños se enfermara, qué harías? ¿Qué opciones tendrías allá? (ayuda de familia, doctores, etc.)
17. ¿Cuáles son las diferencias entre los servicios de salud allá y acá?
18. Como alguno de tus niños tienen *aseguranza* y otros no... ¿cual piensas que es el principal impacto de tener seguro médico o no, en las actividades diarias de los niños?
19. Si tus hijos que no han nacido en Estados Unidos se les ofreciera la posibilidad de también tener seguro médico, cómo crees que esto cambiaría la salud de tu niño o las decisiones que harías en relación a su salud?
20. Si una amiga que viene del mismo lugar que tú y que acaba de mudarse a Pittsburgh te llama porque uno de sus niños tiene fiebre, y te pide consejo sobre qué hacer... ¿qué le sugerirías que haga? ¿a dónde le dirías que lleve a su niño?
21. ¿Hay algo sobre el seguro médico y los niños latinos de lo que no hayamos hablado y sobre lo que te gustaría comentar?

APPENDIX C: PERMISSION LETTER SENT TO PARENTS BY CONSUMER

HEALTH COALITION (IN SPANISH ONLY)

PERMISO PARA COMPARTIR INFORMACION

Estimada amiga de Consumer Health Coalition,

El motivo de esta carta es solicitar su autorización para que le demos su número telefónico y nombre a Amalia Pesantes, quien trabajó con nosotros durante dos años apoyando a las familias latinas.

Ella es estudiante de la universidad de Pittsburgh y como parte del proyecto final de la universidad, está interesada en hacer una investigación sobre el acceso a la salud de los niños latinos.

Por favor firme la parte inferior de esta carta y envíela en el sobre que le estamos mandando, si es que nos autoriza a que le demos su nombre y número telefónico a Amalia para que ella las contacte y las invite a participar en su investigación.

¡Muchas Gracias!

Consumer Health Coalition

Autorizo que le den mi nombre y número telefónico a Amalia Pesantes para que ella me contacte para su investigación

Firma: _____

Fecha: _____

APPENDIX D: IRB APPROVAL LETTER

<https://www.osiris.pitt.edu/osiris/Doc/0/3372170MRS54H8H6072K9E...>



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.irb.pitt.edu>

Memorandum

To: Maria Pesantes Villa
From: Sue Beers, PhD, Vice Chair
Date: 4/30/2010
IRB#: [PRO10030282](#)
Subject: Latino Immigrant Children Access to Health Care

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2).

Please note the following information:

- If any modifications are made to this project, use the "Send Comments to IRB Staff" process from the project workspace to request a review to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a "Study Completed" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX E: SUPPORT LETTER FROM CONSUMER HEALTH COALITION



Pittsburgh, April 2010

Dear Ms. Maria Amalia Pesantes,

We have read your research proposal "**Latino Immigrant Children's Access to Healthcare**", and considered your request for support from Consumer Health Coalition.

As an organization dedicated to the eradication of disparities in health access and outcomes, we believe your research will contribute to the work we, and other organizations that provide services to the Latino community of Pittsburgh provide.

It is CHC's policy not to give out client information without a signed release form. To assist you in finding families willing to participate in your study we will ask our clients if they are interested in participating, and mail release forms to those that are. Once we receive the signed authorization form back from the Latino family, we will provide you their name and phone number only. At that point you will be able to contact the individual directly, and select those families that most closely meet your criteria.

We wish you the best of luck in your research and studies.

Regards,

A handwritten signature in black ink, appearing to read "Beth Heeb", is written over a faint, larger version of the signature.

Beth Heeb
Executive Director

Centre City Tower • 650 Smithfield Street, Suite 2130 • Pittsburgh, PA 15222
Phone 412-456-1877 • Fax 412-456-1096 • www.consumerhealthcoalition.org

APPENDIX F: WE PAY APPROVAL LETTER



University of Pittsburgh
Institutional Review Board
Christopher M. Ryan, Ph.D., CIP
Director, Institutional Review Board
Professor of Psychiatry, Psychology, and
Health & Community Systems

Office: 3501 Forbes Avenue, Suite 718
Mail: 3811 O'Hara Street
Pittsburgh, PA 15213
Phone: 412.246.5392
Fax: 412.246.5425
e-mail: ryanem@upmc.edu

Approval of SSN Exception Request

Date: 7 June 2010

IRB Protocol Title: Latino Immigrant Children's access to Healthcare
IRB Number: PRO10030282
Investigator: Maria Amalia Pesantes

Thank you for submitting a request for an exception to the requirement to collect social security numbers for subjects receiving payments from WePay for participating in the above referenced research study. I have carefully reviewed all of the materials provided to me about this project and on that basis, approve your request for an exception to obtaining SSNs when using the WePay system.

Please note that we are granting exceptions as part of a feasibility study that examines the extent to which subjects participate in multiple research studies over the course of a calendar year and obtain \$600 or more in incentive payments. Should we subsequently discover that subjects in this 'exception' program have reached that IRS reporting threshold, we may modify or disband this program. If that happens, you will be notified in a timely manner.

If you have any questions, please don't hesitate to contact me directly.

Best wishes,

A handwritten signature in cursive script, appearing to read 'Chris'.

Christopher M. Ryan, Ph.D.
Director, University of Pittsburgh Institutional Review Board
Professor of Psychiatry, Psychology, and Health & Community Systems

**APPENDIX G: ANALYTICAL CONNECTION BETWEEN RESEARCH OBJECTIVES
AND INTERVIEW QUESTIONS**

Research Objective	Providers Questionnaire	Parents Questionnaire
<p>Document the challenges Latino immigrant parents in a NGC face to address the health needs of their uninsured children.</p>	<p>What are the main challenges that Latino families have to face when they have to deal with the healthcare system in Pittsburgh?</p> <p>From your experience, what are the main problems that children without health insurance face when they need medical care?</p>	<ul style="list-style-type: none"> - Do you think that the cost of medical care is going to make you think twice the next time you have to bring your child to the doctor? - Has there been a time where you wanted to take any of your children to the doctor and you could not... can you tell me what happened? - Have you ever taken any of your children to the E.R? Why? What happened? How was your experience there? - If you were in (home country) and one of your children got sick... what will you do? What are the options you have over there? - If your children who were not born in the U.S. were offered the opportunity of having health insurance... how will that change their health or the way you make decisions about their health needs?
	<p>Can you share with me a story you remember about a family whose uninsured child had a health problem and the challenges this represented for the family?</p>	<ul style="list-style-type: none"> - What happens when one of your uninsured children falls sick... where do you take them? What do you do? - What do you do when one of your insured children falls sick? Is the process different? How?
<p>Describe the strategies deployed by parents of uninsured Latino children to secure healthcare for their children.</p>	<ul style="list-style-type: none"> - What are the main advantages and disadvantages of these options? - Do you think that parents whose children are not insured have to make difficult choices when it comes to looking for health care? Can you give me some examples? - Do you think that if undocumented children were able to be insured there would be an impact in their overall health? 	<ul style="list-style-type: none"> - If a friend from your hometown that has recently moved to Pittsburgh calls you because one of her children who is uninsured has a fever, and asks you for advice... what will you suggest her to do? Where would you suggest them to take the child? - Have you ever taken any of your children to the E.R? Why? What happened? How was your experience there? - What are the differences between health care back home and health care here? - When was the last time you took them to a doctor? - Do you think you act differently when your uninsured child falls sick than when your insured child falls sick?

<p>Describe the way social service and health service providers address the needs of uninsured Latino children.</p>	<p>What are the available options in Allegheny County for uninsured children ineligible for Medicaid or CHIP?</p> <p>Can you share with me a story you remember about a family whose uninsured child had a health problem and the challenges this represented for the family?</p>	<ul style="list-style-type: none"> - When was the last time you took them to a doctor? How did you learn about this doctor? - Did you have problems paying for the medical bills of that visit? Did you receive help to pay the bills? - (After they have shared a story of a health problem, I asked) Who helped you? How did you learn about this person/place
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**APPENDIX H: TOPICS IDENTIFIED IN INTERVIEW AFTER FIRST ROUND OF
ANALYSIS**

Topic	Explanation
Motherhood	Interviewee talks about her role as a mother to explain her concerns about a health-related decision.
Health implications of being an uninsured child	Interviewees' perception of the way not being insured affects the health status of her child.
Other implications of being an uninsured child	Interviewees' perception of the way not being insured affects the everyday activities of her child.
Actions taken/ suggested by parents for a minor health problem of an uninsured child	Description of what parents do, or suggest other parents to do, when their uninsured children needs to go for check-ups, stomach ache, fever, or any other minor health problem.
Actions taken/ suggested by parents for a major health problem of an uninsured child	Description of what parents do, or suggest other parents to do, when their uninsured children experienced intense pain, long lasting fever, broken bone, or anything they deemed as an emergency.
Information sources on health services	Interviewees explain where or from whom did they get information regarding a doctor, health center, or how to apply for financial aid
Support from others	Interviewees describe the ways someone helped her in addressing the health need of her child.
Visits to health centers	Interviewees share their experiences when taking their uninsured child to hospitals, dentists, pediatricians, or the emergency room.
Experience as an immigrant	Interviewees talk about their experience as immigrant. Often this story is related to limitations to access information or services for their children.
Opinions of U.S. Health system	Interviewees talk about the positive or negative characteristics of the US health system in comparison with the Mexican health system
Medications	Interviewees talk about how or from where they get medications for their children.
Illness	Interviewees talk about a specific health problem of their child, usually it was a chronic condition.

**APPENDIX I: CODES DEVELOPED WHILE CODING PARENTS' INTERVIEW IN
ATLAS-TI**

Family Codes	Code (some overlap)	Definition
EXPERIENCES AT HEALTH SYSTEM (9 codes)	Condition as Immigrant	Any mention about the challenges or experiences they or their children encounter because they are immigrants
	Health System US	Any description of the US health system, either positive or negative.
	Health System: Mexico	Any description of the Mexican health system
	Language	Any mention to the way language was or not a barrier to something related with the health system or adapting to living in Pittsburgh.
	Suggestions: Southside	Suggestions made by mothers regarding the service provided at the Southside on Saturdays.
	Visit: Dentist	Description or mention of a visit to a dentist or where they obtain dental care.
	Visit: ER	Description or mention of a visit to the Emergency Room.
	Visit: Hospital	Description or mention of a visit to a hospital or health provider for other reason than an emergency.
DECISION-MAKING PROCESS (9 codes)	Decision: Minor Health Problem	Decision-making around a minor health need of an uninsured children.
	Decisions: Delay Care	Description the process by which mother decided to not take her child to the doctor and wait for an improvement.
	Decisions: Financial Concerns	Mention of role that the potential cost of the doctor visit in the decision mother took.

(continued)

DECISION-MAKING PROCESS (9 codes)	Decisions: Major Health Problem	Decision-making around a major health need of an uninsured children.
	Emergency	Description of an emergency situation
	Lack of Care	Mothers explain that they decided to not take their child to a doctor and hope the child to get better.
	Strategy: To Address Health Need	Description of a strategy used by mothers to address the health need of their children.
	Strategy: To avoid being asked about insurance	Description of a strategy used by mothers to avoid being asked about the health insurance of their undocumented children
	Homecare: Automedicamos	Interviewees describe that they take care of their children at home either with " <i>remedios caseros</i> ", over the counter medications or prescription medications they had with them (usually brought from Mexico). The term used by mothers is " <i>automedicarse</i> ".
SOURCES OF SUPPORT (6 codes)	Bill Payment	Description of how mother went about paying a medical bill.
	Emergency MA	Mention to the process or anything related to obtaining Emergency MA
	Medications: Obtain	Any mention of how they do to secure the necessary medications for their uninsured children.
	Support from Church	Interviewee explains they got support (besides information) from the church or a church member.
	Support from Health Provider	Interviewee explains they got support (besides information) from a health provider or health center
	Support from/to Other	Interviewee explains they got or gave support (besides information) from others than the church or health provider
IMPLICATIONS UNINSURED CHILD (4 codes)	Chronic Illness	Interviewees talk about the chronic condition of their children and how they go about it given that the child is not insured.
	Everyday Restrictions	Description of the way being an uninsured or undocumented child affects the everyday activities of children.
	Insured Vs. Uninsured	When parents present the fact the way they will act differently if their uninsured child had insurance. Sometimes they also explain the way they usually act with their insured child and how this is different with what they do regarding their uninsured child.
	Emergency	Description of an emergency situation
MOTHERHOOD (3 codes)	Motherhood: Challenges	Interviewees share the challenges and concern they have as mothers of an uninsured child
	Motherhood: Decisions	Interviewees discuss the role being a mother plays in making a decision regarding their sick child.
	Motherhood: Role	Interviewees discuss their role as mothers and how this was a factor in making a decision
SOURCES OF INFORMATION (3 codes)	Information from Place	The interviewee explains that the information about a health service, etc was given by an institution (and mentions the place)
	Information from Person	Interviewees explains that the information about a health service, etc was given by someone (and mentions the person)
	Information from other source	Interviewees explain that they got information about a service, etc through a way that is not a person or an institution.
OTHER ISSUES (not a family)	Barriers Insurance	Interviewees talk about the difficulties they have had to apply or get insurance for their children who have been born in the U.S.
	Pregnancy	Any mention to pregnancy
	Suggestions Welfare	Interviewees suggest changes in the way the welfare system makes decisions about undocumented children
	Lack of Information	Interviewees explain how they lacked information about something to do with addressing health needs
	Suggestions Welfare	Suggestions mothers voice that they will give decision-makers at the Welfare office regarding the non-eligibility of their children to health insurance

**APPENDIX J: DEFINITION OF CODES USED TO ANALYZE PROVIDERS’
INTERVIEWS**

Codes	Definition
Advocacy	Providers suggest or explain advocacy efforts that has been done or that could be done to address the health needs of Latino children.
Advocacy with Latino parents	Providers explain the kind of information they give Latino parents to make them aware of their rights and promote an active advocate to make sure those rights are respected.
Appointments	Providers talk about instances where they helped their clients/patients to make appointments
Available Options Uninsured children	Providers explain what are the options uninsured undocumented children have to address their health needs
Benefits of Insurance	Providers explain what are the benefits children get when they are eligible for MA or SCHIP
Consequences of being uninsured	Providers explain what are the various negative impacts on a children’s life as a consequence of not being insured
Cultural Competence	Examples given by providers about how their knowledge of Latino culture and immigrant’s lives is used in the way they treat their patients or clients
Filling Applications	Providers explain the process and challenges of filling an MA, EMA or CHIP application for their clients.
Health Needs Latino	Providers talk about the general health needs of the Latino community in Allegheny county
Request for help	Providers share a story when a Latino family requested them for help and explain what they did to offer that help.
Latino Culture	Providers argue that some aspect of Latino culture is a factor to take into account in order to understand a particular situation.
Preventive Care	Providers talk about preventive care (either as an example of what they do or a topic they discuss with their clients)
Suggested Changes by Provider	Providers talk about changes that can be done both from the institutions that work with the Latino community and from the Latino community itself to improve the current health services they have access to.

APPENDIX K: CODES USED IN THE ANALYSIS OF PROVIDERS' INTERVIEWS

Codes used only for providers' interviews	Shared Codes	Codes used only for parents' interviews	
Advocacy	Bill Payment	Condition as Immigrant	Lack of Information
Advocacy with Latino parents	Emergency	Barriers Insurance	Motherhood: Challenges
Appointments	Emergency MA	Chronic Illness	Motherhood: Decisions
Available Options Uninsured children	Everyday Restriction	Decision: Minor Health Problem	Motherhood: Role
Benefits of Insurance	Health System US	Decision: Delay Care	Pregnancy
Consequences of being uninsured	Lack of Care	Decision: Financial Concerns	Strategy: To Address Health Need
Cultural Competence	Language	Decision: Major Health Problem	Strategy: To avoid being asked about insurance
Filling Applications	Medications: Obtain	Health System: Mexico	Suggestions: Southside
Health Needs Latino	Suggestions Welfare	Homecare: Automedicamos	Support from Church
Request for help	Support from Health Provider	Information from other source	Support from/to Other
Latino Culture		Information from Person	Visit: Dentist
Preventive Care		Information from Place	Visit: ER
Suggested Changes by Provider		Insured Vs. Uninsured	Visit: Hospital

APPENDIX L: OUTPUT OF THE CODES PRIMARY DOCUMENT COMMAND

CODES	PRIMARY DOCS										Totals
	1	2	3	4	5	6	7	8	9	10	
Barriers Insurance	1	0	0	0	0	1	0	1	1	0	4
Bill Payment	0	2	0	0	0	0	2	1	1	1	7
Chronic Illness	1	0	1	0	0	0	0	0	1	1	4
Condition as Immigra	1	3	1	0	1	3	1	4	2	2	18
Decision: Minor Heal	1	0	0	3	4	1	2	2	1	1	15
Decisions: Delay Car	0	0	0	0	0	1	3	2	2	1	9
Decisions: Financial	0	2	1	0	0	4	1	1	1	1	11
Decisions: Major Hea	1	2	2	2	2	0	1	1	3	1	15
Emergency	0	1	3	0	1	1	1	1	2	1	11
Emergency MA	0	0	0	0	0	1	1	0	2	1	5
Everyday Restriction	1	2	0	2	0	1	2	0	0	0	8
Health System US	1	0	1	0	3	0	1	0	1	0	7
Health System: Mexic	4	1	1	1	1	0	4	1	2	2	17
Homecare: Automedica	1	1	1	2	1	0	1	1	0	1	9
Information from oth	0	0	0	0	0	0	2	0	0	0	2
Information from Per	0	1	1	2	1	1	0	0	1	1	8
Information from Pla	1	1	1	0	0	0	1	0	0	1	5
Insured Vs. Uninsure	3	1	1	1	0	0	2	2	1	1	12
Lack of Care	0	0	0	0	0	1	0	0	0	1	2
Lack of Information	0	0	1	0	0	1	0	0	1	0	3
Language	1	2	1	1	2	1	2	2	2	0	14
Medications: Obtain	3	1	2	1	1	0	1	1	0	1	11
Motherhood: Challeng	0	2	1	1	0	1	0	1	0	0	6
Motherhood: Decision	2	2	1	0	1	0	1	1	1	0	9
Motherhood: Role	0	1	0	0	0	3	0	0	0	0	4
Pregnancy	0	1	0	0	0	1	0	0	0	0	2
Strategy: To Address	2	3	2	1	0	4	0	0	4	0	16
Strategy: To avoid b	0	0	1	0	1	1	0	0	0	0	3
Suggestions Welfare	1	1	0	1	1	1	1	1	1	1	9
Suggestions: Southsi	0	1	0	0	0	0	1	0	0	0	2
Support from Church	0	1	0	0	2	0	0	0	2	1	6
Support from Health	2	2	0	0	0	1	1	0	0	1	7
Support from/to Othe	0	3	0	0	0	4	0	1	2	0	10
TimePitt	1	1	1	1	1	1	1	1	1	1	10
Visit: Dentist	0	0	0	0	1	1	0	1	1	1	5
Visit: ER	1	1	0	0	1	0	0	0	0	1	4
Visit: Hospital	3	0	0	0	0	0	0	1	1	1	6
Totals	32	39	24	19	25	35	33	27	37	25	296

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