



Reducing Health Disparities for Hispanic Children with Special Health Care Needs



a report to the
US Maternal and
Child Health Bureau

from the
National Center for
Community-Based Services

authored by
Judith Palfrey
Myra Rosen-Reynoso
Nerlie Ogilus
Susan Foley

2013



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Acknowledgements

This Report was produced with support from Grant No. U42MC18283 from the Maternal and Child Health Bureau, Department of Health and Human Services, Division of Services for Children With Special Needs. The paper formed the focus of a Working Meeting held at and co-sponsored by the HSC Foundation on November 8, 2012. We gratefully acknowledge the support of our colleagues at the American Academy of Pediatrics (AAP), Association of Maternal and Child Health Programs (AMCHP) and PACER Center in numerous activities that made the completion of this report possible. The contents of the paper are solely the responsibility of the authors and do not necessarily represent the official views of the Maternal and Child Health Bureau, Health Resources and Services Administration, or HHS.

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The Report

The Problem

Children and youth with special health care needs benefit greatly from community-based services that support their health, development, education, vocation, therapies, recreation and transition to adulthood. Despite this, recent data from the Data Resource Center on CYSHCN document that fully 40 percent families from Hispanic* communities do not have an easy time using community-based services (as contrasted with 32 percent of non-Hispanic whites) (<http://childhealthdata.org/>).¹ Frequently this is because of lack of availability of services, long wait times and the absence of linguistic services.

This report has been prepared for the U.S. Maternal and Child Health Bureau by the National Center for Community-Based Services (<http://www.communitybasedservices.org/>) to document the problems that Hispanic families of CYSHCN and their providers confront, explore innovative solutions and suggest a number of areas that warrant further policy consideration.

Background Data

The Growing US Hispanic Population

The most recent census reports for 2011 show that of the 308.7 million people living in the US, 52 million (16 percent) are of Hispanic origin.^{2,3} This is an increase from 35.5 million (13 percent) in 2000. In other words, their 10-year increase was slightly greater than that of all other non-Hispanic combined.³ Not only do Hispanics represent the fastest-growing demographic group, the US Census estimates that this population will continue increasing substantially in the next several years from the current 16 percent of the total population.³

TABLE 1: **U.S. POPULATION, BY RACE AND ETHNICITY, 2010 AND 2000 (THOUSANDS)**

U.S. POPULATION	2010	2000
Hispanic	50,478	35,306
White	196,818	194,553
Black	37,686	33,948
Asian	14,465	10,123
American Indian and Alaska Native	2,247	2,069
Native Hawaiian and Pacific Islander	482	354
Some other race	604	468
Two or more races	5,966	4,602

Notes: Racial groups include only non-Hispanics. Hispanics are of any race.

Source: Pew Hispanic Center tabulations of U.S. Census Bureau Redistricting_Files-PL_94-171 for states—Pew Hispanic Center

* The 2010 Census provides the definition of “Hispanic or Latino origin as a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.” Although the authors of this report do not use the terms Hispanic and Latino interchangeably, it is necessary to be consistent with the several data sources referenced in this report. Therefore, the term Hispanic is used.

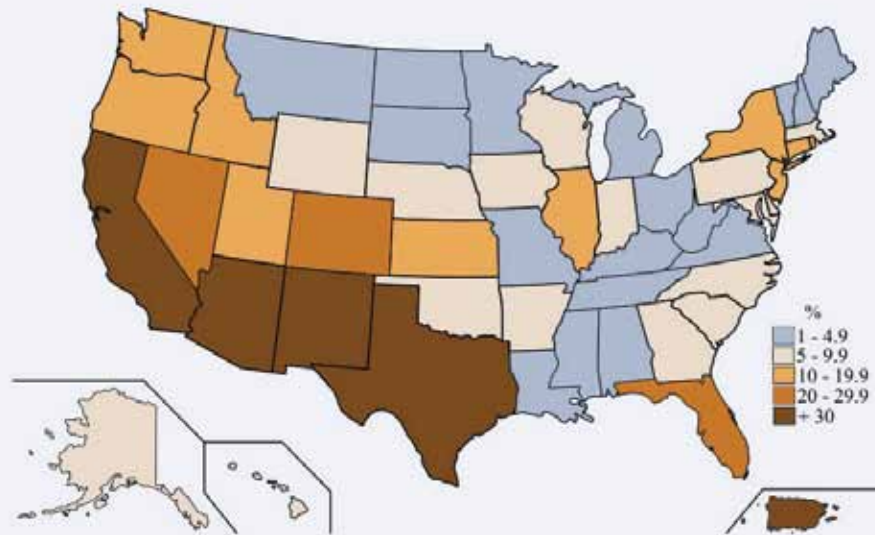


It is projected that the percentage of the US population that will be of Hispanic descent will be 132.8 million in 2050 (which will represent 30 percent of the US population).² Further, while the overall US population is getting older, the Hispanic population remains young. The median age of the Hispanic population is 27 years old, more than ten years younger than the non-Hispanic white median age of 38 years. The Hispanic under-18 group reached 23% of the US population in 2010.⁴

Hispanic families come from a wide variety of backgrounds. For instance, Hispanic families in California and parts of the Southwest were among the first European settlers in America, arriving in the 1500s. Other Hispanic families have come to the United States more recently from the Caribbean, Central and South America—to find work, education and opportunity. Still others have come seeking refuge and asylum. Each family brings a strong heritage, customs and community values.

Hispanic families live in every state. In New Mexico, Texas and California, over 30% of the population is Hispanic. In Arizona, Nevada, Florida and Colorado, over 20% of the population is Hispanic. While these states have traditionally been the home states for Hispanics, the past decade has seen significant population growth of Hispanic families throughout the United States.⁵ Below is a map depicting where Hispanics live in the United States based on the 2010 Census.

MAP 1: **WHERE HISPANICS LIVE IN THE UNITED STATES (BASED ON THE 2010 CENSUS)**



U.S. 2010 Census Hispanic Population map (from US Census) / http://commons.wikimedia.org/wiki/File:2010_US_Census_Hispanic_map.svg
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Among the 10.7 million American Hispanic families, 61 percent have children under 18. The majority of Hispanic children live in two-parent families (66.9 percent).² The median income for Hispanic families in 2010 was \$37,759 and the poverty rate was 26.6 percent, up from 25.3% in 2009.² The great recession of 2008 and had a particularly large impact on the working poor and

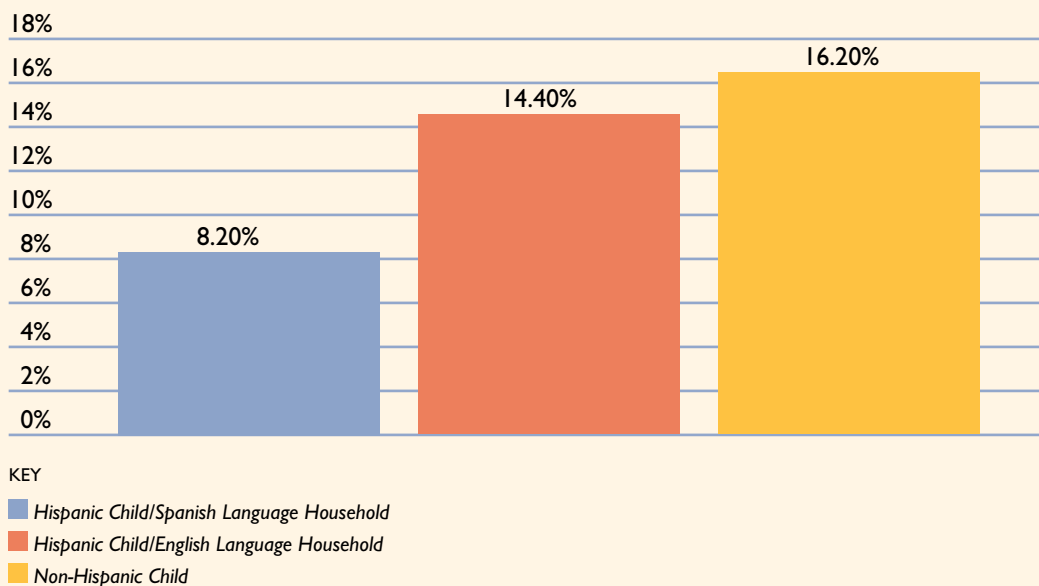
Hispanics, moving many children down into poverty. In 2010, nearly a third of Hispanic families lacked health insurance (30.7 percent).² This percentage might have been even higher had it not been for the Maintenance of Effort provisions under Medicaid and CHIP.

These statistics mean that many Hispanic families face the multiple social stresses of poverty and day-to-day hardship, such as housing inadequacy and food insecurity. The immigrant experience often brings with it dislocation and isolation. As families seek work, they can often find only low-wage, physically demanding jobs. Often, both parents in a family must work two jobs to make ends meet. These stresses and employment demands leave little flexibility in their highly constrained lives. When a Hispanic family also has a child with a special health care need, they frequently find many challenges in engaging the health care and related service sectors.

Hispanic Children and Youth with Special Health Care Needs

The Maternal and Child Health Bureau defines children and youth with special health care needs (CYSHCN) as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁶ Data from the Data Resource Center show that among non-Hispanic US families, parents report that 16.2% of children and youth have a special health care need. Among Hispanics who are English speaking, the percentage who report that their child has a special health care need is 14.4% and among Hispanics who speak predominantly Spanish, the percentage is 8.2 % (Figure 1).¹

FIGURE 1: **HOW MANY CHILDREN/YOUTH HAVE SPECIAL HEALTH CARE NEEDS**
CHILDREN AGES 0-17 YEARS • NATIONWIDE



Data from the National Study of Children with Special Health Care Needs, 2010 as found at www.childhealthdata.org

The parents of Hispanic CYSHCN report that their children have a higher proportion of severe conditions than do the parents of the general population of US children. For instance, 31.4% of parents of Hispanic CYSHCN report that daily activities are often affected a great deal as con-

trusted with 26% for Hispanic families who are predominantly English speaking and 35.5% for CSHCN from households where Spanish is the primary language.¹ Data from other national studies also indicate disparities in the health and health care for these children.^{7, 8}

MCHB has set six core goals for improving the national system of care for children with special health care needs. Each of these goals is accompanied by an outcome indicator as seen below in Table 2.⁹ National monitoring of these indicators shows that Hispanic CYSHCN are not receiving the same level of services as non-Hispanic children. The chart below shows that for each of the six MCHB core outcomes for CYSHCN, Hispanic Spanish speaking children receive fewer services than do non-Hispanic CYSHCN. English speaking Hispanic children are screened (indicator 4) as often as non-Hispanic children, but for each of the other core outcomes, they also lag behind in the receipt of the services MCHB deems important for their care and development.

TABLE 2:
PERCENTAGE OF FAMILIES MEETING THE 6 CORE MCHB OUTCOMES FOR CYSHCN¹

INDICATOR	NON-HISPANIC	HISPANIC/ ENGLISH SPEAKING	HISPANIC/ SPANISH SPEAKING
Families are partners in shared decision-making for optimal health	71.6%	65.6%	59.5%
Children receive of coordinated, ongoing comprehensive care in a medical home	44.9%	37.4%	24.9%
Children have consistent and adequate public or private insurance	61.9%	56.1%	48.8%
Children are screened early and continuously for special health care needs	79.3%	80.3%	64.3%
Children can access community-based services easily	66.3%	60.2%	57.3%
Youth receive services needed for transition to adulthood	42.4%	31.6%	12.4%

Data Generated for this Report

The National Center for Community-Based Services has been collecting information about the difficulties that surround the provision of community-based health and related services for CYSHCN from Hispanic families.

- In the winter of 2011-2012, the Center sponsored 2 family focus groups in association with the PACER Center in Minnesota and Hispanic families shared their major concerns about obtaining health and related services in the community.
- The Center has been conducting an Action Learning Collaborative (ALC) in partnership with the Association of Maternal and Child Health Programs (AMCHP). Six states were selected to focus

on addressing state policies and practices that enable ease of use of services for Hispanic families with CYSHCN. These states include: North Carolina, Oregon, Indiana, New Hampshire, New Mexico, and Rhode Island. The Title V program in each of these states has been working on a specific project with a variety of partners, such as Family-to Family Health Information Centers, the American Academy of Pediatrics, LEND programs, local school districts, Medicaid, Head Start, and Hispanic Community-based Organizations.

- The National Center worked with the newly formed American Academy of Pediatrics Special Interest Group on Immigrant Children's Health to identify 22 generalists and 2 specialists who have had extensive experience in serving the Hispanic population of children in general and those with special health care needs. A semi-structured interview protocol was used to explore: 1) barriers and challenges in providing care to Hispanic CYSHCN; 2) solutions they have found to make improve ease of use for these families; and finally, 3) an on-the-ground perspective of policy recommendations that would help to reduce health disparities for Hispanic CYSHCN.
- In addition, we have reviewed the literature and relevant publicly available data. The National Survey of Children with Special Health Care Needs (2009-10) from the DRC has been of particular value to this endeavor.

A number of repeated themes have emerged from this work.

¡Habras español?: Language, Translation, and Interpretation Issues

Fifty-two million people, 21%% of the U.S. population, speak a language other than English at home. Of these, 42% speak English "less than very well."¹⁰ Estimates of the number of people with Limited English Proficiency (LEP) range from 11 million to 21 million people.¹¹

The number of people that were 5 years and older who spoke a language other than English at home has more than doubled in the last three decades and at a pace four times greater than the nation's population growth, according to a new U.S. Census Bureau report analyzing data from the

2007 American Community Survey and over a time period from 1980 – 2007.¹² In that time frame, the percentage of speakers of non-English languages grew by 140 percent while the country's overall population grew by 34 percent. Spanish speakers accounted for the largest numeric increase — nationwide, there were 23.4 million more speakers in 2007 than in 1980 representing a 211 percent increase.¹² Unlike other population groups, for Spanish speakers, roughly an equal number were native-born as foreign-born (17 million vs. 17.5 million).¹²

Not surprisingly, language and availability of

language services arose as a significant issue in the experiences of providers and families that we contacted for this report. Universally, the parents and doctors we interviewed pointed to language as a central concern. Families spoke of their difficulties understanding medical information and resource suggestions. They found that many technical and unfamiliar terms are not adequately defined for them. They talked about how difficult it was to express their needs and mentioned that they often



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did not feel that they were being “listened to” or understood . Many family members indicated their own reluctance to ask questions or to make suggestions when they were in a health care setting. The parents in the focus groups and Action Learning Collaborative expressed how much better their experience with providers was when they could have a full conversation. They found they could do this either when the health care provider was bilingual/ bicultural or when there were well-trained personnel who provided faithful interpretation of the information.

Numerous parents with limited English proficiency recounted incidents in which they were certain that the interpretation of the doctor or nurse’s information provided by the assigned interpreter was inaccurate. Many written materials parents were given were not translated or inaccurately translated. In instances when a document was translated and a phone number for further assistance was provided, the organization often did not have staff that could answer the phone in any language other than English.

The doctors we interviewed mentioned that when there are not enough providers and office staff who speak Spanish, the care experience is severely compromised. They pointed to ways in which information about appointments (when, where, what type, how long an appointment) routinely are garbled to the disadvantage of all involved. Because of language difficulties, patients often did not fully understand the diagnostic and treatment information that health care providers were attempting to share with them. Several spoke of a “power dynamic” in which patients were uncomfortable telling the doctor that they did not understand the information.

The doctors we interviewed were all committed to serving Hispanic patients and so had made specific programmatic interventions in their own practices. Some of the most successful were:

- Hiring bilingual, bicultural administrative staff;
- Recruiting bilingual, bicultural clinical staff;
- Hiring at least one interpreter;
- Translating or developing materials in Spanish;
- Adding a notation to their prescription blank that the pharmacy should print the medicine label in Spanish.

Translation and interpretation services should be routinely provided in the health and developmental service sectors as a result of the Limited English Proficiency Mandate. The Civil Rights Act of 1964 Title VI assures that all citizens can receive health care by making it illegal to discriminate on the basis of race, color, ethnicity, and language. It states: “No person in the United States shall, on ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assis-



tance.”(42 U.S.C. § 2000d.)^{13,14} In 2000, President Clinton issued Executive Order 13166 to assure that people with Limited English Proficiency were not discriminated against because of language issues. This guidance was particularly directed to health care providers who receive federal funds.¹⁵

Medicaid reimbursement for translation and interpretation services is available to states through a 75% matching program. In 2009, The National Health Law Program did a study of to determine the number of states participating in this program and found an extremely low up-take of the program—only 13 states participating.¹⁶

To augment this information, we have reviewed the state websites offering information on Early Intervention and Special Education. We found that 28 of the 50 states and DC offer materials in another language. Of those 28, 13 offer the website/webpage to be translated in its entirety. Fifteen of the 28 states provide only certain materials in other languages. In order to navigate the links on the websites, often English is needed. For Special Education, the findings were similar. While 13 of the states and DC have information in Spanish, only 4 states offer website/webpage translations. The other sites’ navigation supposes some level of English proficiency. The table illustrates these findings by state.

TABLE 3: LIMITED ENGLISH PROFICIENCY SERVICES BY STATE

STATE	LEP MEDICAID	LEP EI	LEP SPEC ED
Alabama		■	
Alaska		■	
Arizona		■	
Arkansas			
California		■	
Colorado		■	
Connecticut		■	
Delaware		■	■
Florida		■	
Georgia			
Hawaii	■		■
Idaho	■	■	
Illinois			
Indiana			
Iowa			
Kansas	■	■	■
Kentucky		■	
Louisiana			
Maine	■	■	

KEY

- has taken advantage of Medicaid reimbursement for translation services.
- Website is fully translated into Spanish
- Website minimally or partially translated into Spanish

(TABLE CONTINUES ON NEXT PAGE)

TABLE 3: **LIMITED ENGLISH PROFICIENCY SERVICES BY STATE**

(TABLE CONTINUED FROM PRECEDING PAGE)

STATE	LEP MEDICAID	LEP EI	LEP SPEC ED
Maryland			
Massachusetts		■	
Michigan		■	
Minnesota	■		
Mississippi			
Missouri	■	■	
Montana			
Nebraska			■
Nevada		■	
New Hampshire	■	■	■
New Jersey			
New Mexico		■	■
New York		■	■
North Carolina		■	■
North Dakota			
Ohio		■	
Oklahoma			
Oregon		■	
Pennsylvania		■	
Rhode Island		■	
South Carolina		■	
South Dakota			
Tennessee			
Texas			■
Utah	■		
Vermont	■		■
Virginia	■	■	■
Washington	■	■	
West Virginia			
Wisconsin			■
Wyoming	■		■
Washington DC	■	■	■

KEY

- has taken advantage of Medicaid reimbursement for translation services.
- Website is fully translated into Spanish
- Website minimally or partially translated into Spanish

This review of the availability of Limited English Proficiency services and information reveals that the reality is very far from the mandate's intention.

Systems Issues

High on the list of problems that families and health care providers spoke to us about was the difficulty many Hispanic families of CYSHCN had with the health care system. Families told us it was hard to find appropriate services for their children. They discussed how much difficulty they had getting help when they were concerned that something was different or “not right” with their child. In some instances, parents explained missing out on certain services their children were eligible for because by the time they found out about them their child had aged-out. This was particularly the case for early intervention services that are only available until a child is 3 years of age. Families with limited English proficiency found the intricacies of networks, prior authorizations, generalist/specialist relationships and insurance requirements particularly puzzling.

The doctors spoke repeatedly about the difficulties families had in getting appointments and then in being able to attend the appointments. Often the problems related to health care clinic schedules that made it difficult for working parents to keep the appointments.

Parents described a significant lack of flexibility. They told how they had to accommodate to clinic hours that conflicted with their work schedules or children’s schooling. The parents described the stress of missing work and possibly losing their jobs due to frequent medical appointments. For several single mothers, the threat of losing their employment greatly impacted their own health as well as that of the child. They mentioned the limited options of location of services and the difficulties they encountered



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obtaining transportation since they often depended on a friend or relative for a ride and had to accommodate to that person’s tight employment schedule as well as their own.

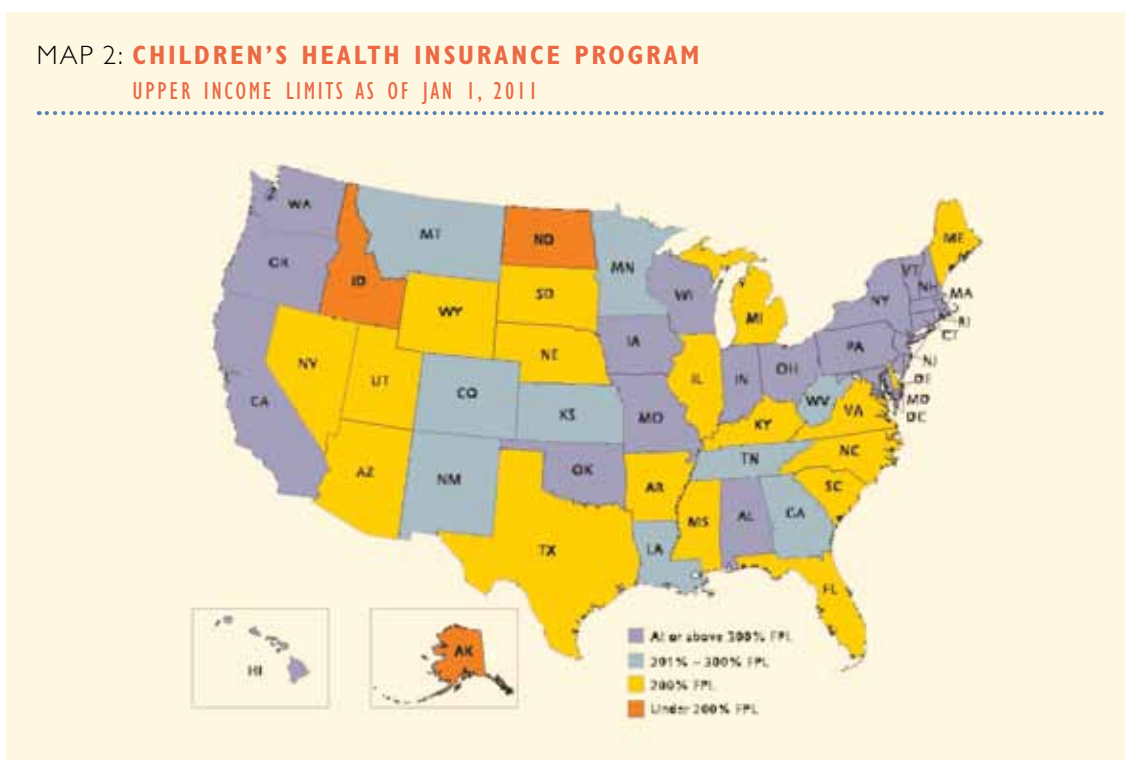
Rather than an organized “system” per se, they described one clinic or one doctor that either helped them or did not. For immigrant families, many described health care service in their native countries as being simple and consisting of the local doctor in their community. Most of their health care needs were resolved in the neighborhood clinic with large hospitals reserved for seriously ill. Parents said they were fearful of going outside of the group of providers that they knew and trusted. Many of the families interviewed were either US citizens or mixed-status families with the children being US born. Parents explained that many gatekeepers requested information about the parents’ documentation status as a way to deter them from requesting services for their CYSHCN.

INSURANCE

The doctors pointed to the critical importance of health insurance coverage for Hispanic CYSHCN. They had all encountered families struggling because of lack of health insurance and pointed to

the variety of reasons for the lack. Despite major gains in insurance coverage for children over the past few years, insurance coverage for Hispanic children and youth is still a significant problem. Because a large percentage of Hispanic families live at or just above the poverty level, many families depend for their health insurance coverage on Medicaid and CHIP. For instance, data from the NS-CSHCN (2009-10) indicates that 46% of Hispanic families are covered by public insurance versus 27% of non-Hispanic Whites. While 20 states do cover children up to 300% of poverty under CHIP, the majority of states do not, including states that have large populations- namely Texas, Florida and Arizona. (see Figure from Connecting Kids to Coverage ¹⁷ below.)

MAP 2: **CHILDREN'S HEALTH INSURANCE PROGRAM**
UPPER INCOME LIMITS AS OF JAN 1, 2011



While the problem of lack of insurance is most prominent and severe for children who are undocumented, the doctors pointed out that the system for obtaining (and maintaining) insurance coverage is so complex and convoluted in many states that fully documented families often have a hard time signing up for coverage in the first place. Those signed up may find themselves re-assigned to a different doctor at each re-enrollment period. In states with frequent re-enrollments, the children may fall off the rolls, a common occurrence referred to as “churning” because parents often do not receive the forms to fill out or do not understand what is being asked of them. While this is a problem for all poor children, it is compounded for families with limited English proficiency because the information is even more difficult to obtain. In 2006, 36.5 percent of uninsured children were Hispanic, yet 70 percent of Hispanic children were actually eligible but not signed up for Medicaid or CHIP.¹⁸ In 2009, three states (each with a large Hispanic population) accounted for 40 percent of the eligible but uninsured children.¹⁹ These states are Texas, California and Florida.

POOR ACCESS EVEN WITH INSURANCE OR COVERAGE DOES NOT MEAN ACCESS
Having an insurance card was not an access solution for many families. The doctors we spoke to from Texas, for instance, reported the large number of health care providers in that state refuse to

care for patients with Medicaid and CHIP. Providers refuse public insurance for a variety of reasons, but one of the most cited is that in many states the reimbursement rates are very low. With the new ACA regulations that take place in January of 2013, some of this problem may be alleviated as providers will now receive a substantial increase in payment for many primary care services.²⁰ Families also encounter access problems getting to clinics that do accept public insurance related to the location of services and the difficulty of obtaining transportation.

Interviewees pointed out the fragmentation and excessive bureaucracy of the health care system. They also pointed to the fact that poor families have many appointments to keep with their social service providers, WIC and other programs that they are continually on the go from one agency to the next. One provider said that for Hispanic families of CYSHCN “it’s very hard to keep track of what you need to do when. And the bureaucracy of the system is very hard.” She summed up her comments about how hard it is for her patients saying that for them there are “Language barriers for every single answer of every single question” as they try to access care and services.

EXEMPLARY SYSTEMS SOLUTIONS

When we probed for solutions to these problems, there were some stories of success. We asked about models that seem to be working well with regard to health insurance. Examples of successful programs included: state policies that were for “all” children regardless of documentation status and community benefits programs from health systems that included children who could not otherwise be insured (Kaiser Permanente Community Benefits Program). Medicaid buy in which exists in 5 states could be a solution for more states. Some programs are experimenting with single lane applications for school lunch, WIC and insurance to cut down on the problem of complex in-take procedures.

The safety net that most of the doctors referred to was the Federally Qualified Health Centers (FQHCs). With 1214 FQHCs and 159 migrant health centers,²¹ there is potential for a quite robust system. The interviewees indicated that FQHCs, however, are overwhelmed with the volume

of requests for service and do not always have the range of subspecialty services needed by CYSHCN. A promising program is developing between Dallas Children’s Hospital and their local FQHC.

Academic health centers also offer many services to CYSHCN, but the services may be ad hoc and fragmented. Among our interviewees, one doctor had worked for years developing a Spanish Program within a Children’s Hospital. He had developed a network of providers and services that were used to working with him and his patients and he found that this

defined system that was dedicated to Hispanic CYSHCN worked extremely well. Another doctor had recently co-located services with psychiatry and mental health services and was finding that the families were having a much smoother time accessing services within this system.



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Subspecialty Care

Difficulty in getting access to subspecialty care stands out as a very significant problem, endorsed over and over again by families and providers. Families report difficulty finding their way to subspecialists because the referral process is filled with barriers. Physicians find they must spend substantial amounts of time monitoring the referrals because there are so many ways in which a referral can get off track. For children and youth with special health care needs with multiple problems requiring visits to multiple specialists, the lack of coordination of care places huge burdens on the family in terms of missed work that they often cannot afford.

Beyond the hassles of getting referral appointments, both parents and providers report significant dissatisfaction with the consultation experience. While the problem with Limited English Proficiency Services is serious in primary care settings, it is greatly magnified in specialty clinics and in many diagnostic and hospital settings. Few subspecialty practices have translation capability and most of the clinical material is not offered in Spanish. Parents report difficulty understanding what has been found by the doctors and little ability to discuss options in treatment plans. Referring primary care physicians indicate frustration in obtaining follow up information and find they join the parent in being unsure of the specialist's recommendation. This, of course, is not always the case, but the preponderance of concern about sub-specialty access, experience and coordination was high enough to make us feel that this is an area that needs immediate attention. Children's Hospitals (including the Boston Children's Hospital, the National Children's Hospital, Henry Ford Hospital and the Packard Children's Hospital) are now employing patient navigators who attend appointments with Hispanic CYSHCNs and help them ask the questions that are on their minds. The patient navigators also have access to many community resources and are often themselves parents of CYSHCNs.

One of the big concerns with subspecialty care is that many of the medications and services that CYSHCN may be prescribed require prior authorization or are not covered by the insurance a family has. For uninsured children, obtaining medications and equipment can be a daunting experience. Since the children's conditions are chronic, these problems recur month-to-month and year-to-year.

Coordination of Care, Community Outreach and Medical Home Services

A theme that has run through all of the activities related to improving services for Hispanic CYSHCN has been the need for a true medical home that includes coordination of care and the promise of using community-based personnel resources to optimize health and developmental care for Hispanic children with special health care needs. Several of the doctors talked about experiences they had in partnership with community and family based groups that enhanced their ability to provide high quality care for families. One physician talked about his work with the Hispanic community as an honor and said he found programs in the community that work on safety, CPR training and financial issues. He has partnered with these groups and found them extremely helpful. Another doctor mentioned that he gets tremendous support from a local Hispanic family organization that has provided many services for children with special health care needs. Between the family group and the local public health services he finds he can address many of the serious issues facing the Hispanic families of CYSCHN.

During the Action Learning Collaborative, we heard about the successes in Oregon with a nurse home visiting model (CaCoon which has recently been strengthened by the addition of a pro-

motora program.)²² The families in the catchment area for these programs benefit greatly. These services are currently limited to the 4 counties with the highest number of Hispanic families with CYSCHN. Another service that has great impact on families is Enlace de los Asuntos Hispanos, the Hispanic family outreach program of the North Carolina Autism Society.²³ The outreach coordinator travels across the state creating natural community support groups for families of children with autism. Often these support groups help families address the isolation and barriers to community engagement they face because of language, cultural and immigration status.

Another model that helps break through many of the cultural barriers is having families train health care providers about caring for CYSHCN. In New Mexico, the Families as Faculty program²⁴ is designed to have medical trainees visit with families in their homes to learn about the community, the natural strengths and supports as well as the challenges and hurdles that families face. Project DOCC (Delivery of Chronic Care) is a multistate program with a similar mission and outcomes.²⁵

Transition Services

Increasingly, youth with special health care needs are living into adulthood.^{26,27} This increased life expectancy translates into an even greater need for well-coordinated services that address health, educational, vocational, and recreational needs for YSHCN. Transition services are defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems”.²⁸ Transition services are not well provided for youth in general,²⁹ and Hispanic youth with special health care needs face particularly large challenges as they grow up.³⁰

The Data Resource Center provides national data on whether YSHCN are receiving a system of care that supports the transition to adulthood (Indicator 6). In the NS-CSHCN (2009-10), the usual patterns of disparity were evident. For instance, approximately 75% of Hispanic youth did not meet Indicator 6 compared to only 54% of non-Hispanic youth. And, 74% of youth covered by public insurance and 80% of uninsured youth compared to 50% of those covered by private insurance did not meet Indicator 6. Seventy-one percent of youth without a medical home did not get adequate transition services. For those youth residing in homes where a language other than English was spoken, 83% did not get adequate transition services.¹

One of the biggest problems that young adults with special health care needs face is the loss of health insurance coverage. Hispanic youth and young adults have high rates of uninsurance. It remains to be seen whether Medicaid expansion and the other provisions of the ACA will improve the situation for Hispanic youth with special health care needs. For privately insured families, the new provisions under the Affordable Care Act that allow young adults up to the age of 26 to remain on their parents health care should help correct this problem. Unfortunately, since the provision depends on the parents having stable employment with health insurance coverage, the gap could potentially widen for Hispanic young people.



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We heard from Hispanic parents of adolescents and young adults about their experiences with the various systems that were involved in their youth's life. They spoke of sudden changes in their insurance coverage and/or abrupt termination of certain services their youth relied upon. These interruptions or termination of services (such as physical therapy), resulted in their youth losing certain skills that would help impact their health and facilitate their independence (i.e., tying their shoe laces, brushing their teeth).

Pediatricians and specialty providers often told us about continuing to provide care for their patients with special health care needs well into young adulthood because providers of adult care were either unable or unwilling to accept patients with special health care needs. This pattern did not happen with their patients that did not have special health care needs. When we asked Hispanic parents about their expectations for transition planning, some explained they had complete trust in their youth's pediatrician and were therefore hesitant and skeptical that they would be able to find an adult care provider that they felt the same about. Others, had experiences in their country of origin where a person, sometimes an entire family, received care from the same provider throughout the lifespan.

As youth with special health care needs enter adulthood, they need to find primary care internists, ob/gyn doctors and other sub-specialists to serve as their medical team. In the United States, transition services may be well coordinated by family practitioners, medicine-pediatric physicians as well as adolescent specialists. There may be a need for these groups to become more familiar with the particular concerns of Hispanic CYSCHN. A big challenge is to find specialists who have expertise in the dealing with the health, developmental and emotional issues that are particular to youth and young adults who also are knowledgeable about the cultural issues that the young adults are facing. If the youth are Spanish speaking, it can be a significant challenge to find an interpreter who can adequately facilitate the patient-doctor dialogue about transition.



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Special Issues OfThe Undocumented

DIFFICULTY ACCESSING SERVICES

Families whose members are undocumented (the entire family or some members of the family) face a set of circumstances that make obtaining health care and related services particularly difficult. We heard from families and providers how stressful the situation can be both for children who themselves are undocumented as well as for “mixed” families where the child who is a citizen (perhaps by being born in the US) but the parents, aunts, uncles or grandparents are not. In the focus groups and the Action Learning Collaborative, we learned of the extraordinary experiences that families have been through to get to and to stay in the United States, often motivated by the hope of obtaining health and related services for their child with a special health care need. Once in the United States, the families often rely on the informal community networks of other immigrant families.

Without papers it is very hard for the families to avail themselves of services such as child care and development subsidies, earned tax credits, food stamps and housing assistance. Undocumented families cannot get housing assistance and except in a few states are ineligible for Medicaid and CHIP. While they can get school lunch and emergency medical services, undocumented children cannot receive SSI or Temporary Assistance for Needy Families.²⁶

There are, however, some mechanisms for the families to obtain medical care.^{33, 34, 35} Sixteen states (Alaska, California, Delaware, Florida, Hawaii, Illinois, Massachusetts, Minnesota, New Jersey, New Mexico, New York, Ohio, Pennsylvania, Rhode Island, Virginia and Washington) and the District of Columbia use state-only funding to cover select groups of “non-qualified” immigrants, but this may be only immigrants of a certain age, living in a certain county with a particular condition.³³ A few states have more comprehensive coverage for undocumented children. California’s “FIRST 5” supports undocumented children up to age 5 through Prop 10 and a cigarette tax. In Illinois, the “All Kids” program provides health care regardless of immigrant status. In New York, the “Child Health Plus” program is similar in providing care without regard to immigrant status. Washington State, Washington DC, and Massachusetts also provide medical coverage for children no matter what their status.³⁶

Title V funds for CYSHCN can be used by states for services for undocumented children. For instance, in 2005, the state of Texas reported spending \$15,960,962 in Title V funds for “non-citizens” serving 1,452 clients.³⁷

THE “FEAR” FACTOR

Finally, one thing that was very striking in the interviews with the doctors was that almost all of them spontaneously mentioned the word “fear” in their remarks as they talked about the patients’ experiences in obtaining health care and other services for their children. As both the parents and the physicians spoke, they emphasized the critical importance of trusting relationships such as those developed in the medical home. A focus of any efforts in alleviating some of the hardship that the current immigration policies impose is the development of human connections, the medical home and community-based supports.

Recognizing the delicate situation that many families find themselves in if they are undocumented, Senator Al Franken (D-MN) and Representative Lynn Woolsey (D-CA) introduced the Humane Enforcement and Legal Protections for Separated Children (HELP) Act, which seeks to mandate standards for immigration enforcement when involving children.³⁸ The bill would ensure that undocumented parents who are undergoing legal procedures (including detention and/or deportation) are kept informed about and are able to continue to make decisions about the care of their children. The HELP Act would implement critically needed reforms to protect children, families and communities that are impacted by immigration enforcement. The Immigration and Customs Enforcement (ICE) and local law enforcement agencies often do not consider the collateral harm that their actions cause to children, families and communities. Detained parents are frequently separated from children, many times permanently. This separation can come at great costs to the child’s well-being and safety. The passage of this bill would help mitigate some of the effects children by involving community and other supports and seeking to avoid having the children end up in foster care while their family members are detained or deported.

The DREAM Act^{39, 40} addresses the dilemma of young undocumented immigrants who have grown up in the United States, often brought here undocumented by relatives. Many of these young

people have never known any other home than the United States. They naturally want to attend American colleges and find lawful employment in the United States. The DREAM Act would allow current, former, and future undocumented high-school graduates and GED recipients a pathway to U.S. citizenship by attending college or serving in the military. In June 2012, President Obama signed an executive order that gives an estimated 800,000 young people who are undocumented in the United States “deferred action” status and a work permit. This pilot activity may lead to a Congress making a serious review of the issues and moving toward passage of legislation when the DREAM Act comes up again for consideration in 2013.

Emerging Policy Ideas

1. **Limited English Proficiency** (Interpreter services, Translation of health and developmental information, Health literacy)
 - States should take advantage of the Medicaid and CHIP provisions for language service reimbursement to directly pay providers for the cost of language services. With the reauthorization of CHIP, there should be consideration of increasing the federal cost share for language services to above 75%
 - Parents, guardians, adolescents and young adults should be provided with a small card they can show at each appointment indicating that programs that receive federal funds are obligated to provide language services under Title VI of the Civil Rights Act, the Affordable Care Act as well as Executive Order 13166
 - Health Insurance programs should reimburse for the additional time in providing clinical care to patients with LEP (to reduce errors in treatment and promote prevention)
 - A national clearinghouse should be established to provide translated materials focused on CYSCHN
 - Regionalized sharing of tele-based interpreter services should be explored
 - All websites presenting information about health and related services for Latino CYSCHN should have a readily identifiable icon that allows families to get to the information in Spanish without having to use any English. This icon could be universal for translation of websites into all languages

The National Health Law Program makes the following strong recommendations for improving LEP services through Medicaid and the ACA:

 - The requirement to collect and report data about language
 - Taglines on websites
 - Thresholds for translating documents should be lowered. Done as a total number (500-1000) or a percentage 5% of the population served
 - There should be oral interpreting for every language for every service
2. **Systems Issues** (Insurance, Service availability and access, Workforce)
 - States should expand their insurance policies to include “All children” as Illinois (ALL KIDS) New York (CHILD HEALTH PLUS), Washington State, Washington DC and Massachusetts have done
 - Translation of all public and private health insurance enrollment materials into Spanish
 - Ensure adequate payment under Medicaid/CHIP for services provided

- Ensure that Qualified Health Plans select Essential Community Providers who have demonstrated strong outreach to Latino Community and are knowledgeable about special health care needs and the medical home
- Assure that exchanges develop detailed materials in Spanish that help families evaluate which health insurance program will best meet their children's needs
- Expansion of FQHCs to meet the needs of the communities where they are located
- Coordination of FQHCs with other parts of the health care system, with particular attention to the newly forming state health exchanges
- Information regarding state health exchanges including benefits offered should be readily available in Spanish
- Expand pipeline programs for Latino young adults interested in health careers
- Increase loan forgiveness for practice in Latino communities
- Explore tying state licensure to the requirement to accept Medicaid
- Ensure interoperative electronic health records... IHPs available to families in Spanish

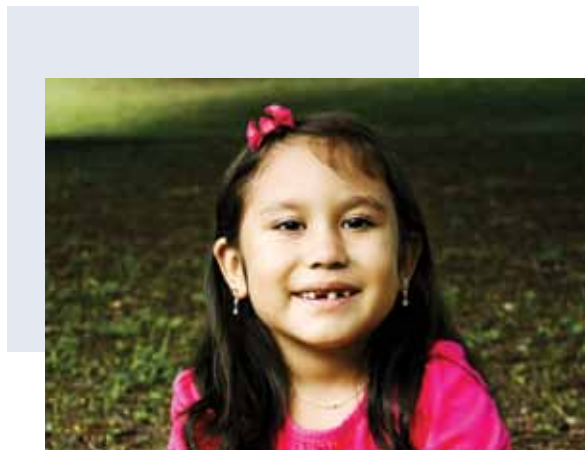
3. **Subspecialty Care** (Availability, Access and Coordination)

- Ensure adequate pediatric subspecialty workforce
- Support subspecialty careers for Latino providers
- Pipeline programs for Latino youth interested in health careers
- Establish stronger identification of networks of subspecialists with the staff resources and capability to provide health care and related services to CYSHCN in the Medical Home
- Assure access of all “safety-net” providers (such as FQHCs) to subspecialty providers
- Assure interpreter services and longer visit times for LEP families
- Telehealth solutions
- Coordination of academic health centers with FQHCs and Exchanges

4. **Coordination of Care in the Medical Home , Community**

Outreach and Services (Family faculty, Promotoras, Home visiting, School and community-based services)

- Practice based coordination of care through the Medical Home supported by health insurance
- Integrated models of care coordination. Co-location of public health and practice settings
- Co-location of health and mental health services
- Continuation of support for Family to Family programs
- Leadership development programs for families
- Interoperability of individualized health plans with individualized education plans (with family consent and ownership)
- Scaling up of successful community and family based outreach and coordination services



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5. **Transition Services** (Outreach to adult services providers)

- Assure the prompt initiation of transition planning with materials available in Spanish
- Legal documents regarding guardianship prepared according to LEP guidelines
- Careful attention to the potential change of health care insurance as the YSCHN turns 18
- Materials in Spanish explaining the new choices of health insurance and outlining what benefits are included in each health insurance package
- Identification of appropriate primary care provider
- Identification of network of sub-specialists

6. **Special Issues OfThe Undocumented**

- Rescind the prohibition on access to health care for applicants to the Deferred Action for Childhood Arrivals (DACA) program. This would assure that those individuals who are granted deferred action would have access to the full benefits of ACA
- Pass the Dream Act: Recipients should receive the benefits and protections of ACA
- Enact comprehensive immigration reform including assurance of health care access. Ensure that health and immigration policies are working in concert
- Avoid long waiting periods for enrollment on Medicaid and CHIP for new immigrant families
- Look for opportunities in Comprehensive Immigration Reform to assure medical homes for CYSHCN from Latino families
- Underscore the specific concerns for CSHCN in the HELP legislation

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Hispanic Children with Special Health Care Needs
Working Meeting on Ease of Use of Services

November 8, 2012

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References

1. Data Resource Center. <http://www.childhealthdata.org/learn/NS-CSHCN> as accessed on November 1, 2012
2. U.S. Census : Hispanic Americans: Census Facts — Infoplease.com <http://www.infoplease.com/spot/hhmcensus1.html#ixzz27VXXuMvB> as accessed on November 3,2012
3. Pew Hispanic Center (March 2011). Census 2010: 50 MillionLatinos. Hispanics Account for More Than Half of Nation's Growth in Past Decade. Washington DC. <http://www.pewhispanic.org/2011/03/24/hispanics-account-for-more-than-half-of-nations-growth-in-past-decade/>
4. US Census Bureau, 2012 (http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb12-ff19.html).
5. Ennis SR, Rios Vargas M and Albert NG. The Hispanic Population, 2010 Census Briefs. US Census as found at <http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf>. December 31, 2012
6. McPherson M, Arrango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin J, Shonkoff J, Strickland B. A New Definition of Children With Special Health Care Needs, *Pediatrics* 1998;102;137-139
7. Flores G; Committee On Pediatric Research. Technical report-racial and ethnic disparities in the health and health care of children. *Pediatrics*. 2010 Apr;125(4):e979-e1020.
8. Berry JG, Bloom S, Foley S, Palfrey JS. Health inequity in children and youthwith chronic health conditions. *Pediatrics* 2010; 126 Suppl 3: S111
9. Strickland BB, van Dyck PC, Kogan MD, Lauver C, Blumberg SJ, Bethell CD, Newacheck PW. Assessing and ensuring a comprehensive system of services for children with special health care needs: a public health approach. *Am J Public Health*. 2011 Feb;101(2):224-31.
10. US Census Bureau. Language Spoken at Home. http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_11_1YR_S1601&prodType=table as accessed January 24, 2013
11. US Census Bureau. Fact Finder http://factfinder.census.gov/servlet/QTTable?_bm=y&-geo_id=01000US&-qr_name=DEC_2000_SF3_U_QTP17&-ds_name=DEC_2000_SF3_U as accessed January 24, 2013.
12. Shin, Hyon B. and Robert A. Kominski. 2010. Language Use in the United States: 2007, American Community Survey Reports, ACS-12. U.S. Census Bureau, Washington, DC.
13. Youdelman MK. The Medical Tongue: U.S. Laws And Policies On Language Access Health Affairs, 27, no.2 (2008):424-433.
14. US. Code, sec. 2000d.
15. Executive Order 13166 as found at <http://www.lep.gov/13166/eo13166.html> and <http://www.gpo.gov/fdsys>
16. Youdelman M. Medicaid and SCHIP reimbursement models for language services (2009 Update). NHELP. <http://www.gchc.org/wp-content/uploads/2011/07/Medicaid-and-SCHIP-Reimbursement-Models-2010-update.pdf> as accessed on November 3, 2012.
17. CHIPRA 2010 Annual Report http://www.insurekidsnow.gov/professionals/reports/chipra/2010_annual.pdf/pkg/FR-2000-08-16/pdf/00-20938.pdf as accessed on November 3, 2012
18. Robert Wood Johnson. Covering Kids and Families. <http://www.coveringkidsandfamilies.org/press/factsheets/2006HispanicFactsheet.pdf>
19. Robert Wood Johnson Foundation. What are the most recent trends for children's participation in Medicaid and CHIP. http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2012/rwjf72063
20. Center for Health Care Strategies, Inc.http://www.chcs.org/usr_doc/PCP_Rate_Increase_Issue_Brief_FINAL.pdf

21. Guzmano MK. Undocumented immigrants and the United States. US health policy and access to care. <http://www.undocumentedpatients.org/issuebrief/health-policy-and-access-to-care>. As accessed on November 3, 2012.
22. CaCoon Program. <http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/ISDocs/Cacoon.pdf> as accessed on November 4, 2012.
23. Enlace de los Asuntos Hispanos http://www.autismsociety-nc.org/index.php?option=com_content&view=article&id=314&Itemid=714 as accessed on November 4, 2012
24. Families as Faculty. <http://www.parentsreachingout.org/programs/faf/>. As accessed on November 4, 2012.
25. Project DOCC. http://www.uhfnyc.org/initiatives/project_docc. As accessed November 4, 2012.
26. Reiss JG, Gibson RW. Health care transitions: destinations unknown. *Pediatrics*. 2002;110(6 pt 2):1307–1314
27. Palfrey JS, Foley SM, Sharma N. Developmental and behavioral disorders grown up. *J Dev Behav Pediatr*. 2008 Dec;29(6):524–33.
28. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the society for adolescent medicine. *J Adolesc Health*. 1993;14(7):570–576
29. McManus M, Fox H, O'Connor K, Chapman T and McKinnon J. Pediatric perspectives and practices on transitioning adolescents with special health care needs. http://hscfoundation.org/aboutus/publications/Fact%20Sheet_508.pdf
30. Lau ML, Lin H, Flore G. Racial/ethnic disparities in health and health care among US adolescents. *Health Services Research*. 2012; 47:2031–2057.
31. Callahan ST, Cooper WO. Gender and uninsurance among young adults in the United States. *Pediatrics* 2004;113:291–7.
32. Mendoza F. Health disparities and children in immigrant families: A research agenda. *Pediatrics* 2009;1224:S187–195.
33. Fortuny K and Chandry. A comprehensive review of immigrant access to health and human services. Report submitted to HHS. June 2011. As accessed at <http://www.urban.org/UploadedPDF/412425-Immigrant-Access-to-Health-and-Human-Services.pdf> on November 4, 2012
34. ASPE. Issue Brief . Overview of immigrant eligibility for SNAP, TANF, Medicaid and CHIP. March 12 http://aspe.hhs.gov/hsp/11/ImmigrantAccess/Eligibility/ib.shtml#_edn12. As accessed on November 4, 2012.
35. Seiber EE. Which states enroll their Medicaid-eligible, citizen children with immigrant parents? *Health Serv Res* 2012 Sep 25. doi: 10.1111/j.1475-6773.2012.01467.x. [Epub ahead of print]
36. National Immigration Law Center. Health care coverage for immigrant children. www.nilc.org/healthcoverage-maps.html as accessed January 24, 2013.
37. See (<http://www.window.state.tx.us/specialrpt/undocumented/4health.html>) as accessed on November 4, 2012
38. Joanna Derby, “How today’s Immigration Enforcement Policies Impact Children, Families, and Communities” Center for American Progress, August 2012 PDF- <http://www.americanprogress.org/wp-content/uploads/2012/08/DrebyImmigrationFamiliesFINAL.pdf> as accessed on December 10, 2012
39. Immigration Policy Center http://www.immigrationpolicy.org/sites/default/files/docs/DREAM_Act_Economic_Fact_Sheet_120810.pdf as accessed on December 10, 2012
40. Immigration Policy Center http://www.immigrationpolicy.org/sites/default/files/docs/Dream_Act_updated_051811.pdf Survey Reports, ACS-12. U.S. Census Bureau, Washington, DC.



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