

SPECIAL ISSUE

Access barriers to genetic services for Spanish-speaking families in states with rapidly growing migrant populations

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Abstract

Hispanics are among the fastest growing U.S. population segments, accounting for the majority of growth since 2000. Hispanics are heterogeneous and include foreign-born and U.S. citizens, monolingual fluent English speakers, monolingual Spanish-speakers, multilingual speakers, and socioeconomically and educationally diverse subgroups. States within the central United States (U.S.), referred to as the Heartland, have numerically small Hispanic populations, but rapidly growing Hispanic populations that are expanding faster than the overall U.S. Hispanic population. The Hispanic populations across the U.S. are widely known to be medically underserved. This qualitative study identifies barriers native Spanish-speakers experience when locating and accessing genetic services for their children. After providing informed consent, 29 parents in three Heartland states were interviewed and asked about their awareness of available genetic services, utilization of available services and difficulties they encountered when using them. Interviewees reported delayed genetic service referrals, limited availability and inadequate interpretation services, verbal and written communication problems during clinic visits, culturally incongruent healthcare expectations and limited appreciation for how genetic services benefit them. Necessary efforts to understand and improve genetic service access and usefulness for Hispanic populations are underway in the Heartland and elsewhere and should continue to be expanded.

KEYWORDS

access, access to care, communication, community based care, disparities, genetic counseling, genetic services, health communication, health disparities, Hispanic, rural, Spanish-speaking, underrepresented populations, underserved populations

1 | INTRODUCTION

Health disparities research covers a broad range of issues, including health-related behaviors, the ability to access and participate in healthcare programs, and the impact of these issues on individuals and populations (Butler et al., 2016, p. 10). A robust body of research supports the claim that immigrant populations are more likely than

non-immigrants to be socioeconomically challenged, undereducated, not fluent in English and to experience significant challenges when attempting to locate, access and use available healthcare resources (Gulley, Rasch, & Chan, 2014; Pew Hispanic Center, 2012; Sohn, 2017).

A strong example of these posed challenges can be found in the rapidly growing and geographically expanding Hispanic population.

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Recent U.S. Census data show Hispanics are among the fastest growing ethnic population groups, increasing by more than 24 million (69.6%) between 2000 and 2018 (U.S. Census Bureau, 2019). To put this in perspective, growth in this community accounts for more than half of the total U.S. population growth. The largest Hispanic populations are located in the western states of California (15,540,142), Texas (11,368,849) and Arizona (2,266,343); in the northeastern states of New York (3,754,130) and New Jersey (1,839,359); and, in Florida (5,562,417) and Illinois (2,214,142; U.S. Census Bureau, 2019). See Table 1 for regional and demographic details. Many of the states with the largest Hispanic population increases are sparsely populated (rural).

1.1 | Diversity among Hispanic populations

Though Hispanics are thought by many to comprise a single cultural group, this population consists of recent immigrants from many Spanish-speaking countries, each with unique cultural, political, religious, and linguistic characteristics. This group also includes both long-term U.S. residents and naturalized citizens originally from countries throughout the Americas, and native U.S. citizens born to immigrant parents (Blendon et al., 2015; Garza, Glenn, Mistry, Ponce, & Zimmerman, 2017; Orom, 2016). Also, it includes persons ranging from fully fluent English- to exclusively Spanish speakers, with diverse religious and cultural beliefs, within families in higher

TABLE 1 Increase in Hispanic population in the United States

	2000 Census ^b	2010 Census ^b	2016 Estimate ^b	2018 Estimate ^b	Increase (#, %)
US population					
Total	281,421,906	308,745,538	318,558,162	327,167,434	45,745,528 (16.26%)
Hispanic	35,305,818	50,477,594	55,199,107	59,871,746	24,565,928 (69.58%)
Percent	12.55%	16.35%	17.33%	18.30%	53.70%
California					
Total	33,871,648	37,253,956	39,209,127	39,557,045	5,685,397 (16.79%)
Hispanic	10,966,556	14,013,719	15,214,117	15,540,142	4,573,586 (41.70%)
Percent	32.38%	37.62%	38.80%	39.29%	80.44%
Texas					
Total	20,851,820	25,145,561	27,937,492	28,701,845	7,850,025 (37.65%)
Hispanic	6,669,666	9,460,921	10,939,338	11,368,849	4,699,183 (70.46%)
Percent		37.63%	39.16%	39.61%	59.86%
Arizona					
Total	5,130,632	6,392,017	6,945,452	7,171,646	2,041,014 (39.78%)
Hispanic	1,295,617	1,895,149	2,162,819	2,266,343	970,726 (74.92%)
Percent		29.65%	31.14%	31.61%	47.56%
New York					
Total	18,976,457	19,378,102	19,641,589	19,542,209	565,752 (2.98%)
Hispanic	2,867,583	3,416,922	3,713,815	3,754,130	2,867,583 (30.92%)
Percent		17.63%	18.91%	19.21%	^a
New Jersey					
Total	8,414,350	8,791,894	8,874,516	8,908,520	494,170 (5.87%)
Hispanic	1,117,191	1,555,144	1,764,567	1,839,359	722,168 (64.64%)
Percent		17.69%	19.88%	20.65%	^a
Florida					
Total	15,982,378	18,801,310	20,629,982	21,299,325	5,316,947 (33.27%)
Hispanic	2,682,715	4,223,806	5,187,276	5,562,417	2,879,702 (107.34%)
Percent		22.47%	25.14%	26.12%	
Illinois					
Total	12,419,293	12,830,632	12,826,895	12,741,080	321,787 (2.59%)
Hispanic	1,530,262	2,027,578	2,175,890	2,214,142	683,880 (44.69%)
Percent		15.80%	16.96%	17.38%	^a

^aHigher rate of Hispanic immigrants than overall population increase indicates incoming Hispanics replaced those moving out of the state.

^bU.S. Census (2019).

and lower socioeconomic categories and with widely different levels of healthcare access (Andreeva & Unger, 2015; Kim, 2009; Nielsen, Wall, & Tucker, 2016).

Another important factor in characterizing the Hispanic population is its unequal geographic distribution. Some states, such as California and New York, serve as points of entry for many immigrant populations (Andreeva & Unger, 2015). In these states, immigrant populations are likely to be concentrated in socially distinct communities, surrounded by other distinct cultural groups with very different languages and cultures. This arrangement limits acculturation and promotes the maintenance of native customs and languages. Other states, such as Florida and Texas, due to their proximity to Latin America, are entry points primarily for immigrants from one specific country. Unsurprisingly, Florida has the highest percentage of immigrants from Cuba, while Texas has one of the largest populations of Mexican immigrants (Zong, Batalova, & Hallock, 2018). Those states closest to Hispanic's country of origin tend to have larger, more cohesive, and less acculturated immigrant populations than do other, similar states. Most research is done to identify the demographic and health-related characteristics of Hispanics; this research is typically done in regions with large Hispanic communities. These studies often lack generalizability.

1.2 | Research on diverse Hispanic populations

A large body of research was done at the University of Texas Health Science Center at San Antonio (Urdaneta, Livingston, Aguilar, Enciso, & Kaye, 2002; Urdaneta, Livingston, Aguilar, Suther, Enciso, & Kaye, 2002). Primarily interested in the large Hispanic cultural communities along the Mexican–American border, this group conducted interviews of itinerant Hispanic–American laborers, traditional healers and genetic service providers in Arizona, California, New Mexico, and Texas, between 1999 and 2001.

One key finding of the University of Texas (UT) study is the need for linguistic competence (p73), stressing not only the importance of healthcare providers' ability to communicate with Hispanic clients in Spanish, either directly or through interpretation services, but also the need for more culturally appropriate Spanish language written materials and a better appreciation of non-verbal communication styles. Also stressed is interpreters' need to be accurate in appropriately interpreting both medical and genetic terminology for Spanish-speaking populations and accommodating the specific educational and cultural needs of subgroups within this population. A second important point is that this population, due to its immediate proximity to Mexico, maintains strong ties with Mexico and, when needing healthcare services, often crosses the border in order to receive them. Moreover, these border communities tend to retain traditional culture-specific beliefs about health and illness, which are often inconsistent with those promoted by the U.S. Healthcare system. Though the research done by the Texas Health Science center is focused on genetics, its findings are specifically targeted to those

populations living in immediate proximity to the Mexican–American border. Additional research is needed to extend these findings beyond this rather limited population, research that takes into account the differences in country of origin, acculturation status, English proficiency, community size, and cultural beliefs and health-related behaviors.

1.3 | Regional genetic networks extend care into rural and underserved communities

In 2004, the Health Resources and Services Administration (HRSA) established seven Regional Genetic Service and Newborn Screening Collaboratives. Since their creation, these Collaboratives (now called Networks) have begun the task of identifying and overcoming the maldistribution of genetic services in their coverage areas. To accomplish this, they first identified specific geographic locations and populations that have been designated as medically underserved. Once identified, these populations were contacted and surveyed in order to identify barriers experienced by them, when attempting to access genetic services. In the most recent round of HRSA funding, the Regional Genetics Networks were asked to develop new practice models to overcome these barriers.

The Heartland Regional Genetic Services Network (Heartland), one of the seven HRSA regions, serves Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma and South Dakota. In overall numbers, Heartland states have lower percentage of Hispanics (7.7%), than the overall U.S. population has (18.3%); however, relative population sizes do not account for the rapidly growing Hispanic population within Heartland states (U.S. Census, 2019). For example, between 2000 and 2018, the Heartland's Hispanic population states increased by 128.1% compared to the national average at 69.6%. In that same time period, the fastest regional growth was in North Dakota (279.3%), South Dakota (233.9%), and Arkansas (168.4%). The overall Hispanic population increase in the Heartland between 2000 and 2018 was 984,344 resulting in a total population of 1,752,945 (Table 2).

Of the 2,132 outpatient visits for genetic services and 1,572 for genetic counseling visits reported at the University of Oklahoma Health Sciences Center's Children's Hospital, approximately 15% were Hispanic ($n = 320$ and 236 , respectively). Initially, this percentage appears to exceed the 10.88% of Hispanics in the general population. Christianson and colleagues, however, estimate that approximately 47.8 out of every 1,000 births are likely to have genetic conditions (Christianson, Howson, & Modell, 2006). Moreover, Hispanic children have a higher risk profile than do non-Hispanic whites (Wang et al., 2015). When these estimates are taken into consideration, the average number of Hispanic children seen by genetic professionals seen at this facility is low. U.S. Census data indicate that Oklahoma is home to 144,886 Hispanic children (U.S. Census, 2019). Applying Christiansen and colleagues' risk estimate suggests almost 7,000 Hispanic children in the state of Oklahoma are at risk for having a significant genetic condition requiring genetic specialty care.

TABLE 2 Rise in Hispanic Population of Heartland Collaborative States

	2000 Census ^a	2010 Census ^a	2016 Estimate ^a	2018 Estimate ^a	Increase (#, %)
Heartland					
Total	20,442,314	21,868,781	22,355,636	22,722,586	2,280,272 (11.15%)
Hispanic	768,601	1,364,062	1,561,292	1,752,945	984,344 (128.07%)
Percent	3.76%	6.24%	6.98%	7.71%	43.17%
Arkansas					
Total	2,673,400	2,915,918	2,947,036	3,013,825	340,425 (12.73%)
Hispanic	86,866	186,050	198,109	233,187	146,321 (168.44%)
Percent	3.25%	6.40%	6.70%	7.74%	42.89%
Iowa					
Total	2,926,324	3,046,355	3,106,589	3,156,145	229,821 (7.85%)
Hispanic	82,473	151,544	172,707	194,432	111,959 (135.75%)
Percent	2.82%	4.97%	5.56%	6.16%	48.72%
Kansas					
Total	2,688,418	2,853,118	2,898,292	2,911,505	223,087 (8.30%)
Hispanic	188,252	300,042	327,739	351,180	162,928 (86.56%)
Percent	7.00%	10.52%	11.31%	12.06%	73.3%
Missouri					
Total	5,595,211	5,988,927	6,059,651	6,126,452	531,241 (9.49%)
Hispanic	118,592	212,470	237,284	263,265	144,673 (121.99%)
Percent	2.12%	3.55%	3.92%	4.30%	27.23%
Nebraska					
Total	1,711,263	1,826,341	1,881,259	1,929,268	218,005 (12.74%)
Hispanic	94,425	167,405	191,802	215,872	121,447 (128.62%)
Percent	5.52%	9.17%	10.20%	11.19%	55.71%
North Dakota					
Total	642,200	814,180	736,162	760,077	117,877 (18.36%)
Hispanic	7,786	22,119	22,997	29,529	21,743 (279.26%)
Percent	1.21%	2.72%	3.12%	3.89%	18.45%
Oklahoma					
Total	3,450,654	3,751,351	3,875,589	3,943,079	492,425 (14.27%)
Hispanic	179,304	332,007	381,467	429,078	249,774 (139.30%)
Percent	5.20%	8.85%	9.84%	10.88%	50.72%
South Dakota					
Total	754,844	814,180	851,058	882,235	127,391 (16.88%)
Hispanic	10,903	22,119	29,187	36,402	25,499 (233.87%)
Percent	1.44%	2.72%	3.43%	4.13%	20.02%

^aU.S. Census (2019).

Moreover, this population is expected to grow, though the rate of growth has slowed (Flores, Lopez, & Krogstad, 2019; Krogstad, 2017). The Pew Center's population estimates suggest that by 2055, no single ethnic or racial community will exceed 50% of the U.S. population (Pew Hispanic Center, 2012). U.S. Census projections see this rapid growth continuing across the Heartland in the coming years (U.S. Census Bureau, 2019).

1.4 | Purpose of the study

Given the combination of a rapidly growing and medically underserved Hispanic community in the Heartland states, the nationally recognized trend for Hispanics to be medically underserved and a survey done by medical geneticists within Heartland regarding challenges of serving this population, the Heartland Hispanic Access (HA) Project was

initiated (Pew Hispanic Center, 2012; Sohn, 2017; U S Census, 2019). The current Heartland-sponsored study was done to identify barriers experienced by Spanish-speaking families when attempting to locate and access genetic services for children with genetic conditions. Specifically, the project attempted to identify: (a) Spanish-speaking community members' knowledge about genetics and the genetic services available to them; (b) how community members were informed about these services and whether they utilized them; and, (c) the specific issues they encountered when using these services.

2 | METHODS

2.1 | Overview

After receiving Internal Review Board approval from the University of Arkansas for Medical Sciences (IRB #202965), this descriptive/interpretative study employed a semi-structured, in-depth interview methodology (following , 1994; Broom, 2005; Charmaz, 2006) to identify the knowledge, attitudes, beliefs, experiences, and feelings of Spanish-speaking parents of children with a genetic condition, who access and use medical genetic services. Interviews were conducted in Spanish, in three states with Hispanic population growth exceeding the national average, between May and November of 2014.

2.2 | Participants

Interviewees were native Spanish-speaking caregivers of children with heritable conditions requiring genetic services. Participant interviews were conducted in three Heartland states, Kansas, Nebraska, and Oklahoma. Potential interviewees were contacted using outreach programs serving the Hispanic communities within these states. These outreach programs included the Oklahoma Family Network, PTI (Parent Training and Information) in Nebraska and a genetic counselor at the University of Kansas Medical Center. The consent process was conducted in Spanish and audio recorded. All participants provided verbal consent prior to the interview. Interview participation was strictly voluntary.

2.3 | Interview procedure

Interviews were carried out in Spanish. The interviewers included a genetic counselor and a public health specialist, both of whom are native Spanish speakers. The question set used in this interview (Appendix 1) was derived from preliminary work done by author Mary Ann Coffman, who has previously interviewed Hispanic outreach coordinators and other specialists as part of her role in the Heartland's Hispanic Access program. This work was done as part of the Heartland's needs assessment and the results were presented to the Heartland's Advisory Board, but were not published.

Following standard qualitative interview strategies, all questions were open-ended and designed to obtain a robust narrative

response from interviewees on the type, status and severity of their child's genetic condition and related healthcare needs, and on participants' knowledge, attitudes, beliefs, experiences and feelings regarding accessing and using medical genetic services. Participants were encouraged to provide as much information and detail as possible in response to these questions and were given verbal prompts follow-up questions to facilitate this. Interviews continued as long as respondents were willing to continue. Participants were interviewed either individually or, when both parents were available, as a pair. Interviews lasted between 2 and 3 hr. Audio recorded interviews were transcribed either by the interviewers or by Dr. Obregon-Tito, who is also a native Spanish speaker. These Spanish language transcripts were then reviewed by the study team and corrected for transcription errors. Following Morse (1994) and Tuckett (2004) the study initially planned to conduct between 10 and 45 interviews and determined, based on careful analysis of the transcripts that no new information was being obtained, that saturation had been reached after 26 interviews.

2.4 | Qualitative data analysis

De-identified interview transcripts were analyzed following standard qualitative procedures (Beck, 1994; Birks & Mills, 2011; Charmaz, 2006; Patton, 1990; Smith, 1998). Each transcript was independently reviewed by all three native Spanish-speaking analysts. Two of these analysts were born in Peru and one in Mexico and all immigrated to the U.S. All are women, and have maintained close ties to the Hispanic community.

After multiple readings, analysts identified and coded individual statements within each transcript expressing thoughts or feelings relevant to the study aims. Recurrent themes (i.e. those occurring either many times within one interview or across multiple interviews) were identified and direct quotes expressing these themes were extracted and translated into English. Themes and corresponding quotations, identified independently by each analyst, were then discussed by the research team and then re-conceptualized, based on group consensus. Each analyst then took these re-conceptualized themes and determined whether or not they accurately reflected statements made within the interviews. This iterative-interpretative process continued until a consistent set of themes emerged. Once the analysis of individual interviews was complete, the process was then broadened to identify a set of consistent themes representative of the overall set of interviews, across all three states.

No theme was considered valid unless all three Spanish-speaking analysts agreed that it was directly supported by the original Spanish-language data.

2.5 | Further conceptual analysis in collaboration with the Hispanic access advisory committee

A primary objective of this study was to assist the Heartland in complying with HRSA's goal of identifying barriers preventing underserved

populations from accessing and using genetic services and then developing new practice models to overcome these barriers. Pursuant to this, the results of this study were presented to the Heartland's Hispanic Access Advisory Committee (HAAC) at the yearly regional meeting in April of 2016. During the initial 2-hr meeting, HAAC members were invited to ask questions about the study design, data collection, analysis and findings and to assist researchers in developing implementation plans based on its findings. Monthly teleconferences between research team leaders and HAAC members began in May of that year and are ongoing at the time of writing this manuscript. Engaging community leaders when developing programs for that community are critical, both to ensure the programs meet their unique cultural needs and to gain their trust and cooperation. Without the direct involvement of the community leadership, members are likely to be mistrustful of any new programs offered them and reluctant to participate. The specific work products and practice models developed in these meetings will be outlined in future publications.

3 | RESULTS

3.1 | Interviews

In all, 26 interviews were conducted between May and November of 2014. Eight interviews were in Kansas, ten in Nebraska, and eight in Oklahoma. Three interviews were held with both parents present, resulting in 29 total interviewees.

3.2 | Interviewees

All single-parent interviewees were women and were the affected child's primary caregiver. Twenty-four were originally from Mexico (83%), two from Guatemala and one from Colombia. Seventeen were undocumented (66%), three were resident aliens, one was a naturalized U.S. citizen and eight did not provide immigration status.

All were parents of children with defined genetic conditions, except one. A total of 18 genetic conditions were reported: Sanfilippo syndrome, Kabuki syndrome, Down syndrome ($n = 8$), Bardet-Biedl syndrome, congenital myasthenia gravis, Cohen syndrome, DiGeorge syndrome ($n = 2$), Waardenburg syndrome, CASK-related intellectual disability, spina bifida, Menkes syndrome, Apert syndrome, achondroplasia, tetrasomy 18p, Rett syndrome, Goldenhar syndrome, Duchenne Muscular Dystrophy ($n = 2$), and one unknown syndrome with autism, congenital heart disease, and microcephaly.

Five primary themes relating to access and use genetic services were identified. These themes were: 1) delayed access to referral and diagnosis; 2) limited availability and quality of interpreting services; 3) inadequate or inappropriate written and non-verbal communication; 4) culturally incongruent expectations about healthcare; and 5) lack of understanding or appreciation of the potential benefits of genetic services.

3.3 | Theme 1: Delayed access to referral and diagnosis

Families reported receiving a delayed referral, particularly in Oklahoma. Some indicated primary healthcare providers either delayed or never referred them to a genetic service provider. Some were referred by a medical specialist, rather than a primary care provider and some self-referred after learning about genetic services from a Hispanic Family-to-Family community coordinator. Family-to-Family coordinators work within communities and serve as the key point of contact for families of special-needs children, assisting them in finding the resources to meet their child's medical, social, educational and financial needs. Typically, these individuals are members of the community they serve.

Families in two of the three states were told about the long waiting lists, often delaying their initial genetics appointment for six months or longer. One Kansas mother asked: 'How can [the appointment] be many months [away]? I was told because there are very few genetic doctors in the United States and that I am fortunate there is a genetic doctor in Missouri, but it is very full.' [Kansas interview, #07] An Oklahoma mother reported her child's physician never acknowledged the need for genetics referral. 'The doctor was never concerned about her, and used to say, [her features are] normal ... However, no one would give us an answer. No one would tell us to go to genetics. No one told us absolutely anything!' [Oklahoma interview, #01].

A Nebraska mother, whose child was eventually referred for genetic services, stated:

Yes, his little head is a bit flat, and I used to say to the doctor 'why does he have his little head like that?' And she used to tell me 'well, some kids are born like that.' After that, I started to notice he had the hiccups, but it wasn't like hiccups. It was something strange, and I asked the doctor and nothing [was done]. ... Later he started trembling a lot, so [the doctor] referred him to a neurologist who diagnosed convulsions.

[Nebraska interview, #06]

Some families reported receiving information from sources other than healthcare providers. For example, one Oklahoma family was informed by the Family-to-Family Hispanic outreach coordinator in their community: 'If I hadn't met the family outreach coordinator, I would still be in limbo... not knowing anything' [Oklahoma interview, #01].

3.4 | Theme 2: Limited availability and quality of interpreting services

The majority of participants had limited English proficiency (LEP) and many reported difficulties with available interpreting

services. In all, only one interviewee indicated English competence while all others relied either on family members or interpreting services at clinic visits. Difficulties with interpretation services, however, were more frequently cited in one state than the others. The most commonly reported problem, across all states, was the perception that Spanish-speaking families waited much longer to receive care compared with English-speaking patients. For example, one Kansas mother stated: 'When you do not speak English, you wait a long time for the doctor to arrive and then wait for the interpreter to arrive...and when we talk on the phone...if I ask for an interpreter ... sometimes I say I want to speak Spanish right now, and it takes too long.' [Kansas interview, #05] An Oklahoma mother, commenting on the lack of interpreters available at clinics, said:

I arrive and someone who is not Hispanic comes at the same time as me and they let them go through ... and that person can also ask, 'Why haven't you helped me?' I can't ask, and then [the person who speaks English] is helped and I remain seated because I can't say 'Why can't you help me?'

[Oklahoma interview, #06]

Families in all states also questioned the quality and accuracy of the interpretation services provided to them. One English-speaking Kansas mother said: 'I have had a lot of interpreters that do interpret everything well, and also I have had interpreters that do not interpret everything. I mean, they don't say the words that [the doctor] says.' [Kansas interview, #06] In some cases, where a bilingual family member was present, the perception of misinterpretation is even more acute. An Oklahoma father said:

I understand English, and I know what they are interpreting and then I have to tell my wife '[that] was not exactly what the doctor said, the doctor said this, this and this'...Sometimes I avoid talking in front of the interpreter. But the times I have... the interpreter stops interpreting and I have to interpret for my wife...The doctors tell them [the interpreters] an opinion, but they don't give us the same opinion, but give their personal opinion as a Latino.

[Oklahoma interview, #05]

A Nebraska mother, when referring to the verbal interpreting services, said: 'Sometimes—but I am not going to generalize this to all the interpreters but some—if they are thinking what the doctor is saying, sometimes they can't even define the words that are being told to them, nor the words the doctor is saying.' [Nebraska interview, #03].

Finally, in some instances, interpreters provided inaccurate or misleading information. In one case, the interpreter apparently told an Oklahoma mother that if her daughter's condition did not improve, then she would die:

The interpreter told me the doctor was saying that [the doctor] was going to take this [fluid from her brain] and that if [she] had no fluid in her brain, she would die when she was six months old. So, I told my aunt... [My Aunt] spoke English and she told [the geneticist], and [the geneticist] said, 'Sorry... I said that when children do not have fluid in the brain it is very difficult for them to survive.'

[Oklahoma interview, #06]

3.5 | Theme 3: Inadequate or inappropriate written and non-verbal communication

Informants frequently complained that written materials were often presented at inconvenient times or provided in a way that was not helpful. Statements given by two women clearly make this case. One Nebraska mother said: 'They gave me papers [with information about my child's condition] when [he] was born. Gosh, they filled a diaper bag with a lot of [it!] ... but my son was sick every day. Do you think I am going to be looking at the papers?' [Nebraska interview, #01] Another Nebraska mother, this time commenting on the quality of the Spanish language materials provided to her, said: 'Most of the people who come [to the U.S. from other countries], are [not as educated as] doctors nor lawyers ... for example the father [of my children] finished primary school [only], if [he] asks for information in Spanish they're going to give it to [him], [and he] will read it, and [he] will not understand anything even if it is in Spanish.' [Nebraska interview, #08] Later, she added: 'Well, they can give [papers] to you in Spanish...and...it is so difficult to understand. I sometimes understand more in English than in Spanish. If they give to me in Spanish and I say 'What is this word?'' [Nebraska interview, #08].

Later, when addressing the issue of interpretation quality, the same interviewee stressed the importance of having interpreters who are able not only to speak with them in correct and educationally appropriate Spanish, but who are able to help them understand what is being said when they come from different countries, or different regions of the same country and have very different dialects of conversational Spanish.

Sometimes [the interpreters] use words that are not common ... because it is difficult to [find the right words for] things. Maybe they hired a Puerto Rican to interpret. I am Mexican and I do not understand half of what the Puerto Rican [interpreter] says, even if it's in Spanish. If a Mexican interprets, it may be that someone from another country does not understand [them]. They have to look for [words] that are very common [in all countries] that speak Spanish.

[Nebraska interview, #08]

Also consistent with this point is the observation that some of the interviewees in this study were not able to read proficiently in either

Spanish or English. This study was approved for verbal consent, but interviewees were given supplementary written materials about the study. In some cases, these materials had to be read to study participants, even when they were verbally proficient in Spanish. Many informants stated that even if someone is fluent in either Spanish or English, even when they could understand what was spoken, this did not mean that they could read printed materials given to them in that language.

In addition to the difficulties encountered when presented with medical information and instructions written in Spanish, interviewees also reported non-verbal communication difficulties. When attempting to understand and interact with U.S. healthcare providers, predominantly Spanish-speakers were often confronted with what they perceived as either a lack of personal interest in them or with outright disrespect to them. For example, one Oklahoma mother said:

In our culture we are very physical, we like to be greeted... [We need to] trust them and to tell them about what is happening with [our] child. They should not be putting their hand on the doorknob ready to leave, or talking to the family while writing... Look them in the eye, right? And show interest, and ask what the child is doing. Oh yes, greet the child too, do not ignore [him] even if [he] is special, looks different. Greet the child many times, and when they greet our children, we feel 100% better than we came in...Because we are seeing that the provider has an interest in curing him... but also has a personal interest. The good doctors... tell you good morning, how have you been, how beautiful the weather is, right? Tell me a little about your child. What does your child do from 8 in the morning until 10 at night? Tell me again...does he exercise...Is he eating his vegetables? Review how [he] is doing and in 10 minutes the physician gets a lot of information... They are interested not only in the symptom, but they are also interested in the person...Give the mother an opportunity to speak too...without telling her that he [the physician] is hurried.

[Oklahoma interview, #09]

Another Oklahoma mother was upset when a provider motioned for them to come into the examining room, using a common hand gesture: 'They only call us with their hand "come here" ... they don't understand us...we don't understand them...so we stay quiet...I don't know. I don't know if they understand us...how we feel.' [Oklahoma interview, #02] Another interviewer, commenting on the same gesture said that was the way someone calls a dog, not a person.

3.6 | Theme 4: Culturally incongruent expectations about healthcare

Spanish-speaking families reported experiencing a perceived mismatch between their expectations about how medical services

should be delivered and their actual experiences when visiting American medical clinics. Respondents indicated that, when visiting a healthcare provider in their home country, they would always receive some kind of treatment or medication at the time of their visit: 'In my country,' said an Oklahoma father, 'I would go to the pediatrician for any small thing. They would give [my child] something quickly. My [child does] not have the same attention here.' [Oklahoma interview, #05] When referring to the U.S. healthcare system, he said: 'I took [my child] to the clinic [here] and they told me it was a virus, but [when I asked] 'Can't something be given so she can dry up?' [the doctor said] 'No, I can't give you anything, it's a virus.' So, I called my cousin in Guatemala who is a doctor and [he said], 'Why don't you take [your child] to the hospital, because some of that [virus] will go down inside and it will get worse.'" [Oklahoma interview, #05] In addition to expecting to always receive a 'treatment' when visiting a medical provider, Spanish-speaking, Hispanic families also expect that the care provided to them will be more personalized than what they frequently experience when visiting clinics within the U.S. healthcare system. 'It is more personalized [in Mexico]. They do not see [a patient] as the number seven, but they see [them] by name. They know what [their patients] like, what is bothering them and, their needs. Not here...it's number seven and then one says, 'What's going on?' We are losing too many things that we should not be losing as people.' [Oklahoma interview, #05].

A second area of concern for Spanish-speaking families was the professional status of those providing clinical services. Many with experience in the Mexican healthcare system expected that all clinical staff would either be doctors or nurses, as other provider classifications are rare or nonexistent outside the U.S. healthcare system. This resulted in anxiety and uncertainty among interviewees. An Oklahoma mother said:

[The person we saw] was not a doctor or a female doctor...not a midwife either, but she was a nurse like, not a practitioner, but they call her, ah ... nurse. Like she has a little more study but isn't a 'doctor' yet. But, yes, she was a nurse. Obviously, she did things...without much preparation. She measured the tummy. [she would ask] how far along was my pregnancy? Very basic, very limited.

[Oklahoma interview, #04]

Another Oklahoma mother, when receiving care at a teaching hospital, explained:

Now I know they are students, at that moment I did not know, at that moment I believed that they were all doctors, or they were all nurses, but now I know they are students. Why? Because [of] their name tag. It says there. I did not know how to read it or even why they wore one.

[Oklahoma interview, #06]

3.7 | Theme 5: Lack of understanding and appreciation of the benefits of genetic services

Another common misunderstanding among interviewees was the lack of appreciation for the value of genetic services and overall failure to recognize the importance of following the advice given to them by medical geneticists and genetic counselors. Some respondents felt that, because genetic conditions are incurable, there is little to be gained by taking the time—and incurring the expense—of seeing a genetics service provider. One Oklahoma mother said:

2007 was the last time that we went [to see a geneticist] ...because my husband said, Are they going to cure [our daughter]? Why are you [taking her to the doctor] so much? Oh, no, you just like to waste gas going to all the doctors, and they are not going to do anything for [her]. They are going to prick her, draw a lot of blood, [she] will cry, and will be in a bad mood all day.

[Oklahoma interview, #09]

Also, many who had received genetic services seemed to have little understanding of their child's condition and the risk of having another child with the same condition. When a child has Von Hippel-Lindau Syndrome, for example, the risk for a sibling to be born with the same disorder is greater than 50%. Many participants reported little or no concern about the risk of having another child with the same condition, even though, they remembered being told about the recurrence risk. On the other hand, a few mothers who reported becoming pregnant after the delivery of their affected child also reported being anxious that their next child would also have the same disease, even though the likelihood of having another child like the first was small.

One Oklahoma mother said that she never really appreciated the value of seeing a geneticist until one doctor took the time to explain that the reason for her daughter's condition was a faulty gene that she inherited. 'Until [then] I did not know why [my] girl was born like this...to be honest with you...I didn't even know the reason she was born like this or what I did, or was it something I took, or something that happened? I never knew why! The doctors only asked me if it was hereditary, but I said no, because no one in my family is like that.' [Oklahoma interview, #09].

And some, particularly those with exposure to traditional healing practices either in their home countries or in the United States, expressed health-related beliefs inconsistent with allopathic medicine. For example, one Nebraska mother, when asked what had caused her child's condition (achondroplasia), said: '[It is] something about the sun, I don't know, like the sun and the moon they told me, but I do not remember...later it was a friend that told me an eclipse took hold of my baby.' [Nebraska interview, #01].

Also, inadequate insight into the medical implications of genetic conditions sometimes led some parents to delay or ignore physician-recommended treatment in favor of a different, more culturally

aligned intervention, which was usually provided by a family member or traditional healer. One Kansas mother said:

The doctor told me we [should] wait six months to see if [my child] can eat, but my mom said, how will he learn to eat if he is not eating? ... I left the nutrition [program] because I definitely did not see that [my son] was improving. I told [the doctors] I cannot come here every week, so at home we started giving him eggs, broth, soups, everything...so then by the time they did the swallow study, they said 'Oh, he can eat! But make sure he does not eat too much.' I already knew he could eat because I was feeding him all the time, only I did not give him liquids.

[Kansas interview, #04]

4 | DISCUSSION

The findings of this study both validate and extend findings from previously completed related studies. Specifically, two emerging themes from the current study's findings, *limited available and quality of interpretation services* (Theme 2) and *inadequate or inappropriate written and non-verbal communication* (Theme 3), echo previous work by Urdaneta and colleagues describing health care disparities among Hispanic patients in Texas (2002). The current study differs; however, in three significant ways. First, its interviews were completed at least 13 years later than those included in the University of Texas (UT) study. Second, the current study was conducted in Hispanic communities that are not adjacent to the Mexican border and, therefore, with less access to healthcare services and family support networks in Mexico, due to the increased travel time and costs. And third, as indicated previously, the Hispanic communities in the UT study were both large in population and situated in states with a high percentage of Hispanics. It is reasonable to assume, therefore, that more native Spanish-speakers would reside in those communities, and the increased population concentrations in the UT study would have necessitated the mobilization of greater resources to meet their needs. The current study; however, is focused on the needs of areas where Spanish-speakers are far fewer and the resources needed to meet their needs are not available. For these reasons the current findings both validate and extend the earlier study's findings.

4.1 | Issues and strategies identified by the Heartland's Hispanic Access Advisory Committee

In addition to the previously mentioned themes, *delayed access to referral and diagnosis* (Theme 1), *culturally incongruent expectations about healthcare* (Theme 4) and *lack of understanding and appreciation of the benefits of genetic services* (Theme 5) are topics currently being discussed and addressed by various organizations, including the Heartland's Hispanic Access Advisory Committee. These themes

provide key insight into how genetic services can be expanded in underserved communities.

This study included an intermediary step of presenting its findings to the Heartland's Hispanic Access Advisory Committee and, with their input, developing new practice models for delivering improved genetic services to Hispanic communities in the region. In the process of making formal presentations and holding community conversations, several important issues were identified that, while present in many of the interviews had not been identified as key study findings. First among these is the importance of including bilingual, community-based health workers in the care-access model. In the Heartland, these individuals serve as family support network coordinators, hired through federally funded family support organizations, such as Parent to Parent USA, Family Voices and Family to Family Health Information Centers. They work specifically with families who have children with special health care needs and can serve as an initial point of contact for families needing specialty genetic services. Unfortunately, there are not enough of these specialists and those currently available are not known by many families who could benefit from these services. Meeting the medical needs of children with genetic conditions, especially in underserved communities, require both finding innovative business models to cover the cost of these services and training new professionals capable of performing them. Together, these will help to alleviate the first theme identified in the current study, *delayed access to referral and diagnosis*. All too often, families are not referred for genetic services either because they are not aware of these services or because their primary care providers are insufficiently equipped to recognize the need for a referral or unsure how to access available genetic services for their patients. Better care coordination and collaboration between community health care providers will help to overcome this issue.

A second important issue identified is the difficulty Hispanics with Limited English Proficiency experience when attempting to navigate the complex U.S. healthcare system. Limited English Proficiency patients' preference for Spanish-speaking providers and misunderstandings arising from differences in verbal and non-verbal communication styles have been widely reported as factors contributing to healthcare deficits among Hispanics (Blendon et al., 2015; Kim, 2009; Nielsen et al., 2016). Not only does this result in limited access to and inadequate healthcare (Andreeva & Unger, 2015; Blendon et al., 2015), it also creates fear, stress, and mistrust of providers and the healthcare system, preventing patients from utilizing the services already available to them (Bekteshi & van Hook, 2015; Dahal, Qayyum, Ferreyra, Kassim, & Pottie, 2014). The current study supports this already-robust finding, extending it into the area of genetic services. Specifically, this study found that in addition to the need for better interpretation services, interpreters need improved abilities to communicate genetic terms and concepts to patients and patient families. Trainings to educate interpreters on genetic terms and genetic counseling techniques, such as non-directive care, may be helpful.

While the obvious remediation to these issues would appear to be English proficiency training, combined with paralinguistic

communication skills training (Nielsen et al., 2016), this approach is insufficient. First, it places the burden of change on the patient, rather than the provider. Programs in states with larger Hispanic populations, such as California, Florida and Texas have focused on Spanish language care and linguistic education programs for healthcare providers. Unfortunately, the Heartland has fewer Spanish-speaking healthcare professionals and limited economic resources for filling this service gap. Changes need to be made at both secondary and higher education and in healthcare institutions to increase the number of qualified, well-trained, Spanish-fluent service providers.

Research has shown that 71% of Spanish-speaking Americans access the internet through smart-phones rather than personal computers (Brown, López & López, 2019). Given, the limited reading abilities, differences in regional dialects spoken and the need for better written materials reported by interviewees in the current study, efforts directed at providing better physical documents may be misguided. Perhaps a better approach to addressing Theme 3, *inadequate or inappropriate written and non-verbal communication*, would be to overcome the culturally based misunderstandings through the development and implementation of linguistically and population-appropriate resources, accessible through mobile applications (apps). Specifically, these online smartphone apps would be heavily visually oriented, text-limited, interactive, and include culturally appropriate audio.

Genetic and condition-specific videos and web resources should also be developed. This would help to overcome many of the issues raised by participants in both the current study and the previous UT study, where families reported misunderstanding basic medical and genetic concepts and sometimes attributed genetic conditions to supernatural causes Themes 4, culturally incongruent expectations about healthcare, and 5, lack of understanding and appreciation of the benefits of genetic services. Smart applications could provide contextual information to assist families in better understanding the nature of genetic conditions and the importance of seeking and following medical advice, and do so in a way that is both entertaining and culturally meaningful. These resources could then be integrated into all aspects of health care, helping patients to improve their understanding of the U.S. healthcare system, to make and keep scheduled appointments and to better understand what their health care providers ask and expect of them.

The final point to be made is that even if Spanish-speaking families were to gain access to available genetic services, long delays would still be common due to workforce shortages among medical geneticists (Kirch & Petelle, 2017) and genetic counselors (Hoskovek et al., 2018). Therefore, new and innovative healthcare delivery models are needed to meet the growing demand for genetic service, including the formation of collaborative partnerships between primary care providers, physician extenders, parent support organizations and genetics specialists. These delivery models may also use telemedicine and/or combine service with new mobile apps for education and support.

Meeting the unique challenges faced by Spanish-speaking families attempting to access genetic services is a complex task. This task involves making changes at the practice level by providing services that meet the social, cultural and linguistic needs of

patients. It also requires changes at the community and state level to identify and integrate community-based and state level workers who can more effectively direct and manage access to care. It requires changes at the cultural level, to develop culturally and linguistically appropriate patient materials. And, finally, it requires changes at the professional level to develop and implement new service delivery models with the capacity and flexibility to meet the needs of this diverse population.

4.2 | Practice implications

For medical geneticists and genetic counselors serving Hispanic communities, the Heartland is currently implementing strategies to improve access to genetic services and the ability of those services to meet the needs of medically underserved people, including Hispanics.

First, work was begun by attempting to cultivate relationships with medical interpreters within Heartland institutions and developing work flow systems to improve the overall experience for patients and providers alike. For example, the use of a certified medical interpreter to collect family histories and medical histories prior to appointments was recommended in order to reduce family wait time.

Second, the newly developed practice models partner with Parent-to-Parent USA, Family Voices, and Family-to-Family Health Information Centers throughout the Heartland. These programs have bilingual staff and can assist with available state and local services.

While it is unrealistic for providers to be culturally competent in every culture they will encounter in their practice, it is reasonable for them to be aware of and respectful toward patients' cultural beliefs, behaviors and treatment expectations. In medical genetics, physical examinations may seem unusual to patients (i.e., measuring inner canthal distance, checking nails, feet, genitalia, etc.). It is important for providers to be aware of how these physical examinations are understood by their patients, particularly when interacting with immigrant and ethnic minority populations. The Heartland has developed resources, including a series of training modules, for genetic counselors, family support organizations and families to introduce these concepts. Also, in 2017, the American College of Medical Genetics began a program for improving the ability of interpreters to assist medical geneticists and genetic counselors during patient care and treatment visits. Specifically, this group has developed a series of interpreter training modules focused on various care typologies, including prenatal counseling, cancer genetics and pediatric genetics. These training models are being incorporated into the Heartland's service provider training program. Links to all of these resources as well as other useful links are provided in Appendix 2.

4.3 | Study limitations

This study was conducted using standard qualitative measures and, as such, presents methodological challenges commensurate

with this methodology. Qualitative research is inherently descriptive and does not allow for generalization beyond the population from which the data were collected and other, similar populations. Methodologically, there are several issues which contribute to this limitation. First, is the issue of ascertainment bias. Study participants were recruited through accessing health service providers who work with Hispanic populations in the states from which data were collected.

A second, more significant, limitation concerns the nature of the questions asked and the respondents who answered them. Given that the empirical questions asked addressed barriers to genetic healthcare services, asking questions from those who were successful in obtaining these services is necessarily biased. It is hoped that by questioning those who were successful, some insight into what would prevent others from finding and using these services might be gained.

Another potential limitation is that the sample was overwhelmingly female. Given that, women in all cultures are more likely to be directly involved in overseeing their child's medical needs this sample bias seems to be both expected and justified.

One of the anticipated barriers that was not identified was families' inability to obtain insurance or Medicaid for their children. As it happened, the choice to use community support services to identify potential interviewees resulted in all respondents having received coverage for their children. At best, this serves as an indicator for those who have not yet accessed these services that financial help is available, at least for many. At worst case, it is a significant design flaw that prevented the identification of a major barrier to accessing genetic health care services.

Together, these study characteristics significantly limit the generalization of its findings to other, dissimilar Hispanic populations, even within the same or similar geographical regions. Analysis of these states individually indicates that some between-state differences exist, presenting challenges to the representativeness of these data to other Heartland states, and beyond. Finally, the literature is clear that the overall Hispanic population across the United States is highly variable, coming from many different countries and cultures, with different levels of acculturation and English language proficiency. This obviates the generalizability of these data to 'the overall Hispanic American' population. This, however, was not a goal of the current study. What is important here is to describe an important regional population, to advance the work of others in the past, and to provide useful insights into how to address these issues currently facing the Heartland states and will certainly face similar states in the future.

4.4 | Future directions

The current study represents the first stage in a larger body of research. Based on the findings of this study the Heartland Genetics Network has implemented new practice models for extending genetic and genetic counseling services to the Hispanic community

and similar programs for other underserved communities in the region. The Heartland's ongoing research involves tracking and assessing the quality of these new programs. Future research in other geographic areas and with other, similar populations is needed to provide a broader generalizability of the findings of this study.

5 | CONCLUSION

Predominantly Spanish-speaking parents of children with genetic conditions, residing in states with relatively small, but rapidly growing Hispanic populations, report significant challenges to obtaining and utilizing available genetic services for their children. These challenges include: delayed access to referral and diagnosis, limited availability and quality of interpretation services, inadequate or inappropriate written and non-verbal communication, culturally incongruent expectations about healthcare, and a lack of understanding of the benefits of genetic services. Given the current demographic trends of increasing number of Hispanic individuals not only in the Heartland states, but also across the U.S., a better understanding of the barriers to accessing genetic services and improved practice models for overcoming these barriers is critical to reducing disparities in access to care. Recommendations include the optimization and coordination of existing resources, the creation of language- and culture-appropriate educational tools for providers, interpreters and families, and the recruitment of new and emerging technologies to extend current practice models into rural areas.

AUTHORS CONTRIBUTIONS

H. Gene Hallford made substantial contributions to the conception, design, data analysis and interpretation, and manuscript writing of this work. Mary Ann Coffman, made substantial contributions to the conception, design, data collection, analysis, and interpretation, and manuscript review, editing and approval of this work. Alexandra Juana Obregon-Tito, made substantial contributions to the data analysis, and interpretation, and manuscript review and approval of this work. Anayeli Herrera Morales made substantial contributions to the conception, design, data collection, analysis, and interpretation, and manuscript review and approval of this work. Lori Williamson Dean made substantial contributions to the conception, design, data analysis and interpretation, and manuscript review, editing and approval of this work.

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COMPLIANCE WITH ETHICAL STANDARDS

Conflict of interest

H. Gene Hallford, Mary Ann Coffman, Alexandra Juana Obregon-Tito, Anayeli Herrera Morales and Lori Williamson Dean declare that they have no conflict of interest.

Human studies and informed consent

Prior to project initiation, this study was reviewed and approved by the University of Arkansas for Medical Sciences' IRB (#202965), which determined that it was consistent with both FDA and local requirements for human subjects' research. All participants provided verbal consent prior to study participation. The consent process was conducted in Spanish and audio recorded.

Animal studies

This article does not contain any studies with animals performed by any of the authors.

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APPENDIX 1 INTERVIEW QUESTIONS (IN ENGLISH) Services

- Children with special health care needs often need more specialized medical services including therapy and treatments that are not available at family medicine or community clinics. Do you or a family member take your child to specialized medical services?

If yes, what types of medical services (tests, treatments, therapies etc.) does your child receive?
- Do you believe that all the medical services your child needs is available to him/her?

If not, why not?
- How can the health care providers change or make their services better for Hispanic/Latino families so you can be more comfortable to come to clinic?
- (You may have mentioned this already) Is it hard for you to make your child's appointments with your healthcare providers?

If yes, why?
How could it be made easier for you to make your appointments?
- (You may have mentioned this already) If Spanish is your primary language, is it difficult to talk with or understand your healthcare provider? Could you please give us an example?

How could it be made easier for you and your health care provider to be able to talk and understand each other during your appointment?

6. Other than language, are there other reasons including cultural differences (beliefs) which may make it hard for you to understand your child's medical condition and his/her health care needs? In other words what does the health care provider have to know about your culture in order to assist you in deciding what is best for the medical care of your child?

Medicaid

1. If your child is receiving Medicaid what are some of the difficulties in applying for government assistance?
2. (If you have not mentioned this) Are there issues with language and other cultural differences that make the application process difficult?

What would make it easier for you to apply for these services?

3. If your child is not receiving Medicaid or other services do you know if your child is eligible for these benefits? Explain why or why not.
4. (You may have mentioned this already) Do you know of any specific problems or concerns that undocumented families have in applying for Medicaid even if their child was born in this country? Please describe these concerns or experiences?

Genetic condition

1. Can you tell me about your child's genetic condition?
2. Have you been able to meet with a provider who was able to explain the genetic condition, medical service needs and treatments to you in a way that you can understand? Please describe this understanding to me.

Was this provider a specialist in genetics? Please describe.

3. Do you still have issues or questions about your child's condition, medical service needs or treatment that have not been answered? If so, what are these?
4. Do you understand the genetics of your child medical condition? Please describe this understanding to me.
5. Does your family have an understanding of your child's medical condition and why it is considered a genetic condition? Please describe their understanding.
6. What kind of questions do you or your family have about the genetics of your child condition?

Genetic services

1. Please describe to me when at where your child first was seen by a geneticist?

How old was your child?

2. When you were referred to a genetics clinic or doctor what were your concerns or what worried you about the clinic and/or the staff?
3. Please describe your experiences in making it to your appointments at the genetics clinic.
4. Please describe to me your experience in the genetic clinic. What was it that you liked and did not like about the genetics clinic and the staff?
5. If Spanish is your primary language what bilingual services or tools did the genetics clinic have to assist you in understanding your child's medical condition?
6. How can the genetics clinic improve their bilingual services to make it more comfortable for Hispanic families?
7. Other than bilingual services how can the genetics clinic improve their services to make it easier for you to make your appointment and make the clinic more comfortable for Hispanic families?
8. Do you think that the genetics clinic staff understands the Hispanic culture? In other words do they understand you're traditional and religious beliefs which may make it difficult for you to understand your child's genetic condition or follow his/her treatment plan? Can you give an example of this?

INTERVIEW QUESTIONS (IN SPANISH)

Servicios

1. ¿En sus propias palabras me podría decir sobre la condición genética que tiene su niño/a?
2. Describame la historia de su niño/a desde que nació.

¿A dónde lo llevan para servicios médicos de pediatra?

3. Los niños con cuidados de salud especiales a menudo necesitan más servicios médicos especializados, entre ellos terapia y tratamientos que muchas veces solo están disponibles en centros especializados. ¿Usted o algún familiar lleva a su niño/a recibir estos servicios?

Si es así, ¿qué tipos de servicios médicos (exámenes, tratamientos, terapias, etc.) recibe su niño/a?

4. ¿Cree usted que todos los servicios médicos que su niño/a necesita están disponibles para él o ella?

Si no es así, ¿por qué no?

¿A dónde lo llevan para servicios médicos especializados?

5. (Puede que ya haya mencionado esto) ¿Es difícil para usted asistir a las citas médicas de su niño/a con los proveedores de atención médica?

(¿Es difícil hacer su cita?)

(¿Es difícil ir o llegar a su cita?)

(¿Transportación?)

Si es así, ¿por qué?

¿Qué se podría hacer para facilitar que usted pueda asistir a las citas?

6. Si el español es su primer idioma, ¿es difícil hablar o entenderse con su proveedor de servicios médicos? ¿Podría usted dar un ejemplo?

Durante la cita de su niño/a, ¿qué se podría hacer para que usted y su proveedor de servicios médicos puedan hablar y entenderse más fácilmente.

7. (Puede que haya mencionado esto) ¿qué es lo que su proveedor de servicios médicos debe saber acerca de su cultura para poder ayudarlo/a decidir el mejor cuidado médico para su niño/a?

8. ¿Que es lo que usted debe saber sobre su proveedor de servicios médicos para poder trabajar juntos y mejorar el beneficio para sus niños y so familia?

9. (Puede que ya haya mencionado esto) ¿Qué otras cosas pueden hacer los proveedores de servicios de salud para cambiar o mejorar los servicios para familias hispanas para que usted se sienta más cómoda para venir a la clínica?

Servicios Genéticos

10. Por favor descríbame, ¿Cuándo y dónde fue la primera vez que su niño/a fue visto/a por un especialista en genética?
¿Cuántos años (meses) tenía su niño/a?

11. ¿Cuándo lo/la refirieron a la clínica de genética o al doctor cuáles eran sus inquietudes o qué es lo que le preocupaba sobre la clínica?

12. Por favor describa su experiencia para asistir a las citas médicas en la clínica de servicios genéticos.

13. Si el español es su primer idioma, ¿qué tipos de servicios bilingües le ofrecieron en la clínica para ayudarlo a entender la condición médica de su niño/a?

14. Por favor describa su experiencia en la clínica de servicios genéticos.

15. ¿Le explicaron sobre la condición genética, las necesidades de servicios médicos y tratamientos en una forma que usted pueda entender? Por favor describa este entendimiento/comprensión.

¿Era una explicación fácil de entender?

¿Qué recuerda de su explicación?

(¿Era este proveedor de servicios médicos un especialista en genética? Por favor describa/explique.)

16. ¿Entiende usted la causa genética de la condición médica de su niño/a? Por favor describa este entendimiento/comprensión

*(¿Sabe cómo originó la condición?)

17. ¿Entiende su familia la condición médica de su niño/a y el por qué es considerada una condición genética? ¿Podría decirme como lo entienden?

*(Familia: ¿familia inmediata? ¿Familiares cercanos?)

18. ¿Qué preguntas tiene usted o su familia sobre la herencia o la transmisión genética de la condición de su niño/a?

19. ¿Tiene usted alguna inquietud o pregunta sobre la condición genética de su niño/a?

20. ¿Tiene usted alguna inquietud o pregunta sobre las necesidades de servicios médicos relacionados a la condición de su niña/o?

21. ¿Tiene usted alguna inquietud o pregunta sobre los tratamientos que no hayan sido contestados todavía?

¿Si es así, Cuáles son?

*(¿En que la/lo podemos ayudar?)

22. ¿Cómo puede la clínica mejorar sus servicios bilingües para hacer sentir a las familias hispanas más cómodas?

23. Aparte de los servicios bilingües, ¿cómo puede la clínica mejorar sus servicios para facilitar que usted asista a las citas y hacer sentir a las familias hispanas más cómodas?

24. ¿Piensa usted que el personal de la clínica entiende la cultura hispana? En otras palabras, que es lo que tienen que entender que pueda ayudarla/lo en su propio entendimiento de la condición genética y el plan de tratamiento de su niña/o? ¿Me puede dar un ejemplo?

25. ¿Compare los servicios médicos que su niño/as recibiría en su país comparado con los estados unidos?

26. ¿Cómo tratan a niños/as con discapacidades en su país comparado a los estados unidos?

Medicaid/ Medicare: (Sooner Care, Sooner Start SSI)

27. Si su niño/a está recibiendo Medicaid, por favor descríbame su experiencia en solicitar esta asistencia del gobierno.

28. ¿Cuáles son algunas de las dificultades en solicitar esta asistencia del gobierno?

29. (Si usted no ha mencionado esto) ¿Hay obstáculos con el idioma y otras diferencias culturales que hacen el proceso de solicitud más difícil?

¿Qué se podría hacer para facilitar el proceso de solicitar estos servicios?

30. Si su niño no está recibiendo Medicaid u otros servicios, ¿sabe usted si su niño/a puede recibir estos beneficios? Explique por qué o por qué no

31. (Puede que ya haya mencionado esto) ¿Sabe usted de algún problema específico que familias indocumentadas tienen para solicitar Medicaid, aún si su niño/a haya nacido en este país? Por favor describa estas preocupaciones o experiencias.

¿Escuela?

APPENDIX 2

Useful Resources for Obtaining Access to or Information About Genetic Services

American College of Medical Genetics Interpreter Training Modules: <https://nccrcg.org/focus-areas/genetics-and-genomics-education/interpreting-for-genetics/>

Family-to-Family Health Information Centers: <https://www.familyvoicesunited.org>

Genetic Alliance: <http://www.geneticalliance.org>

Parent to Parent USA: <https://fndusa.org/contact-us/programs/parent-to-parent/>

Regional Genetic Services Networks

Heartland Genetics Network: <http://heartlandcollaborative.org>

Midwest Genetics Network: <https://midwestgenetics.org>

Mountain States Regional Genetics Network: <https://www.mountainstatesgenetics.org>

New England Regional Genetics Network: <https://www.negenetics.org>

New York Mid-Atlantic (NYMAC) Regional Genetics Network: <https://www.wadsworth.org/programs/newborn/nymac>

Southern Regional Genetics Network: <https://southeastgenetics.org>

Western States Regional Genetics Network: <https://nccrcg.org/rgns/wsrng/>

Spanish Language Genetic Support and Lay Advocacy Organizations: <http://www.kumc.edu/gec/support/spanish.html>