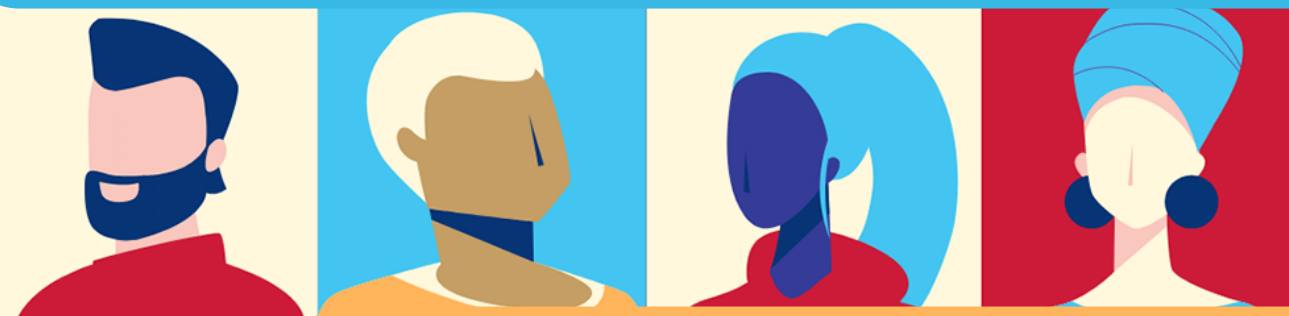




Promoting Equitable Access to Language Services for Families of Children and Youth with Special Health Care Needs



Environmental Scan Report
March 2024

Contents

03

Acknowledgements and
Introduction

05

Survey of Families

23

Family Focus Groups

34

Survey of Health Care
Providers

47

Key Informant Interviews
with Pediatric Providers

58

Medical Interpreter Focus
Group



Acknowledgements

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About FAMILY  VOICES®

Family Voices transforms systems of care to better work for all children and youth, especially those with special health care needs and disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes. For more information, visit www.familyvoices.org.

About Our Project

The surveys, interviews and focus groups included in this report were conducted as part of Promoting Equitable Access to Language Services (PEALS) for Families of Children and Youth with Special Health Care Needs (CYSHCN), funded by the Office of Minority Health in the United States Department of Health and Human Services, with the overarching goal to improve the quality and use of language access services in health care settings for families whose preferred language is not English.

About the Terminology in This Report

Throughout this report, the phrase “families whose preferred language is not English” is used to describe the population of families who do not or cannot speak, write or communicate primarily in English. While much of the field uses the term “Limited English Proficiency (LEP),” the communities we worked with shared that “LEP” describes their language use in terms of a deficiency, which is stigmatizing and problematic.

Furthermore, the phrase “families whose preferred language is not English” acknowledges that while people may communicate, and may even be fluent, in English, they might prefer to receive complex information, like health information, in their language of origin. Receiving information and services in the preferred language can reduce the cognitive load of interpretation, even for those who are proficient in English.

Survey Methods

The family and surveys were conducted in July and August 2023 by Family Voices and its partnering organization, the American Academy of Pediatrics (AAP). The provider surveys were shared with American Academy of Pediatrics, National Association of Community Health Workers (NACHW) and other professional organizations, academic medical centers, hospitals, clinics, health centers, hospital foundations, and learning communities. The family surveys were shared with individuals and families served by:

- Health care and disability-related advocacy and policy groups
- Community-based organizations
- CYSHCN/disability-specific organizations
- Education, early education, and preschool programs
- Facebook groups for families of CYSHCN
- Family-led organizations
- Family-to-family organizations
- Foundations
- Hospitals, clinics, health centers
- Latino/Latina-specific organizations
- Maternal child health programs
- State agencies
- State agency grantees
- State senatorial committees, subcommittees and task forces
- Translation service providers
- Vietnamese-specific organizations
- YMCA



Survey of Families

The purpose of the family survey is to identify the barriers or challenges experienced by families who do not speak, understand, read, or write English while trying to use health services for their children with disabilities or themselves.

Survey findings will be used to inform program activities, training content, guidance documents, and educational resources to increase awareness, understanding, and use of language access services in health care settings for families of CYSHCN whose preferred language is not English.

Family Survey Methods

The family survey was developed collaboratively by the Family Voices PEALS project team and the PEALS Project Advisory Committee (PAC). The 14-item survey was developed in English and translated into 7 languages, including Arabic, Farsi, Chinese, Russian, Spanish, Ukrainian, and Vietnamese. The survey was administered online (SurveyMonkey) from July to August 2023.

An invitation with an anonymous link to the survey was disseminated to families of children with special health care needs by:

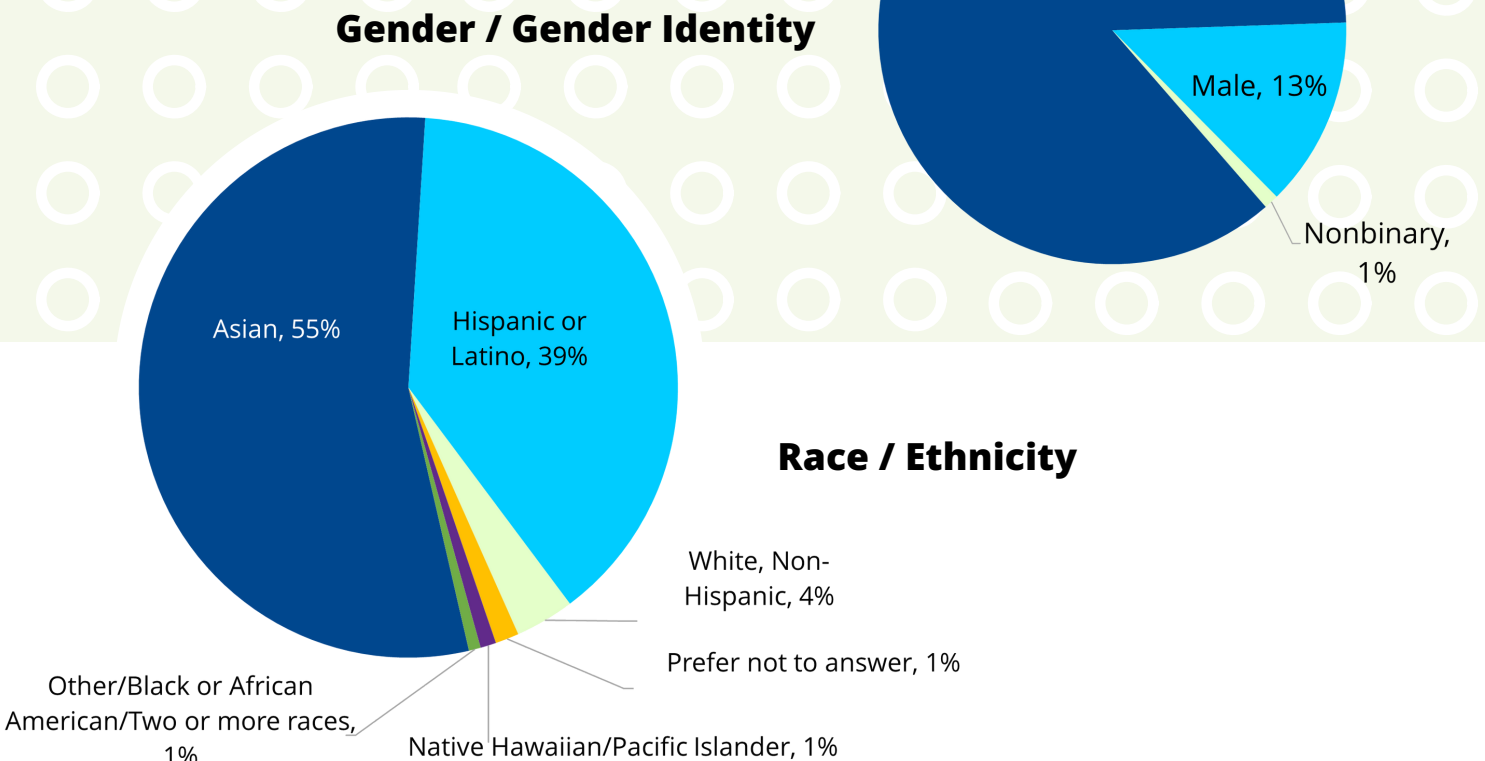
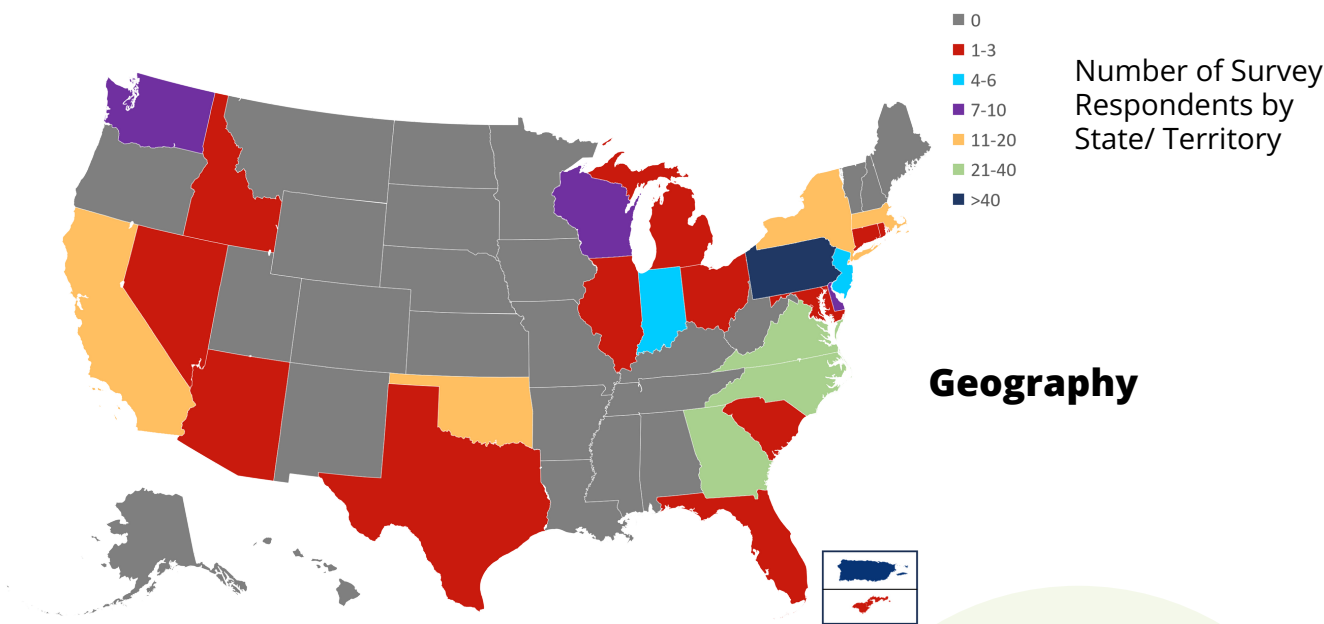
- The Family Voices network of Family-to-Family Affiliate Organizations and Family Voices Health Information Centers in each state, the District of Columbia, three tribal nations, and five territories, and;
- Project Advisory Committee members, who shared the survey link with the communities and families they serve.

A total of 449 completed surveys were received. Because the number of individuals who received the survey invitation is unknown, it is not possible to calculate a survey response rate.

Twenty-five (25) surveys were excluded from the analysis because they were completed by individuals who reported that they speak only English, leaving a total of 424 surveys. The 424 surveys included 272 non-English-speaking respondents and 152 bilingual respondents (who speak English and another language).

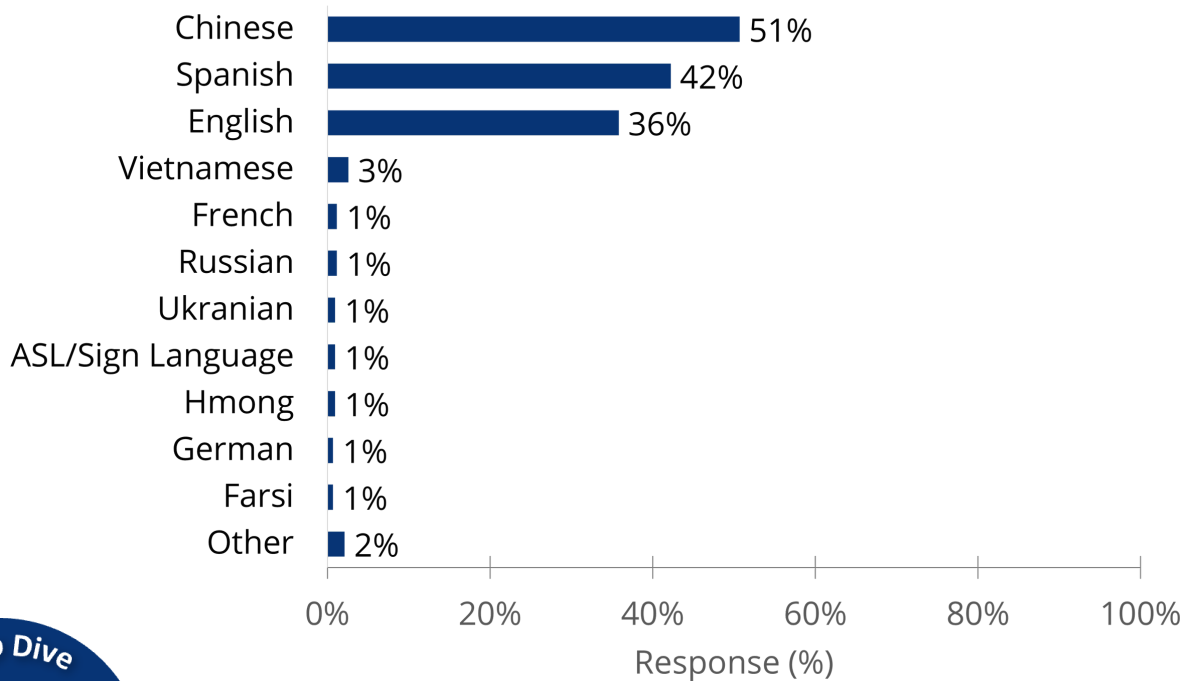
Survey of Families

Respondent Characteristics

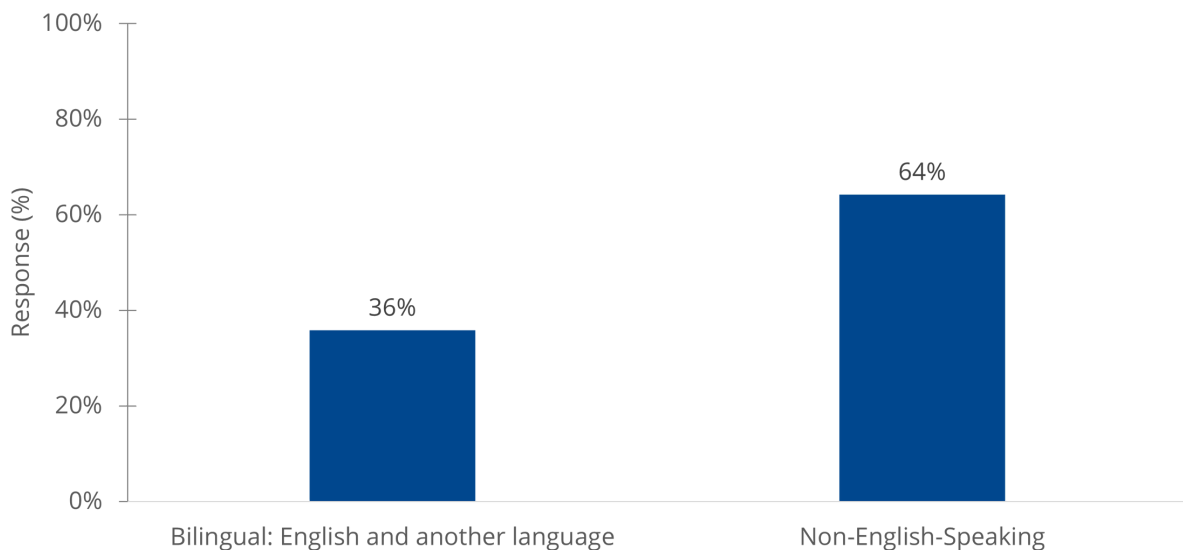


Survey of Families

Languages Spoken by Respondents



Percentage of Respondents Who are Bilingual (Speak English and Another Language) vs. Non-English-Speaking



Survey of Families

Understanding Patient Rights

Knowledge of Language Access Rights

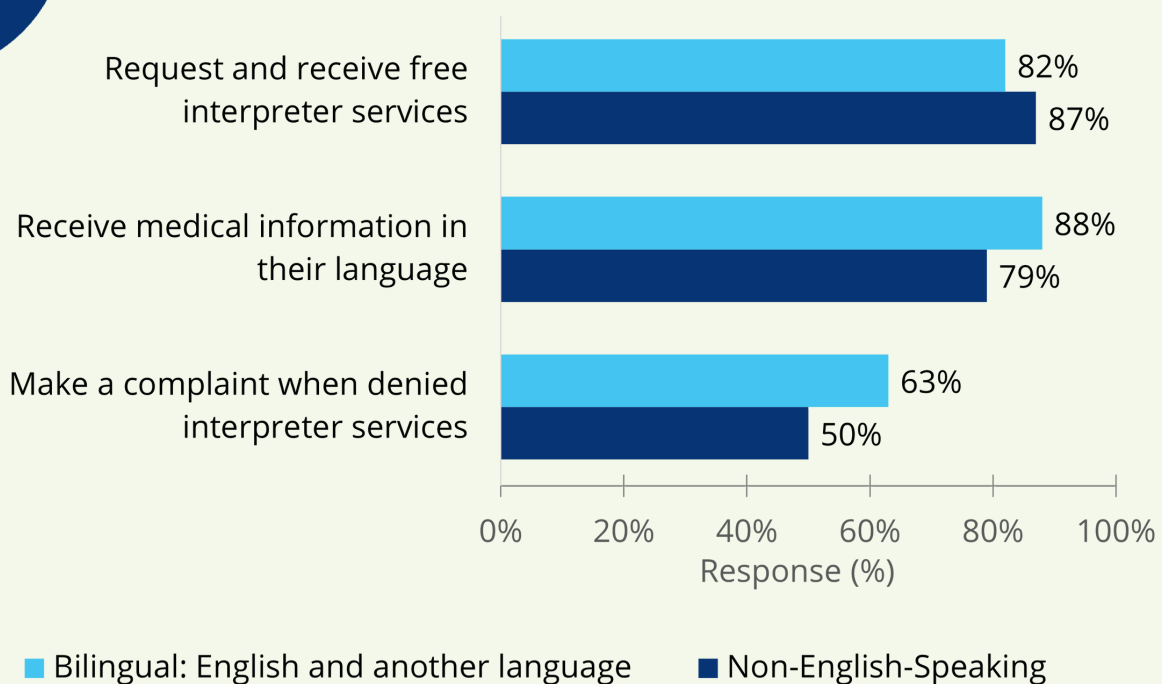
85% of respondents know about their rights to request and receive free interpreter services.

82% of respondents know about their rights to receive medical information in their language.

54% of respondents know about their rights to make a complaint when denied interpreter services.



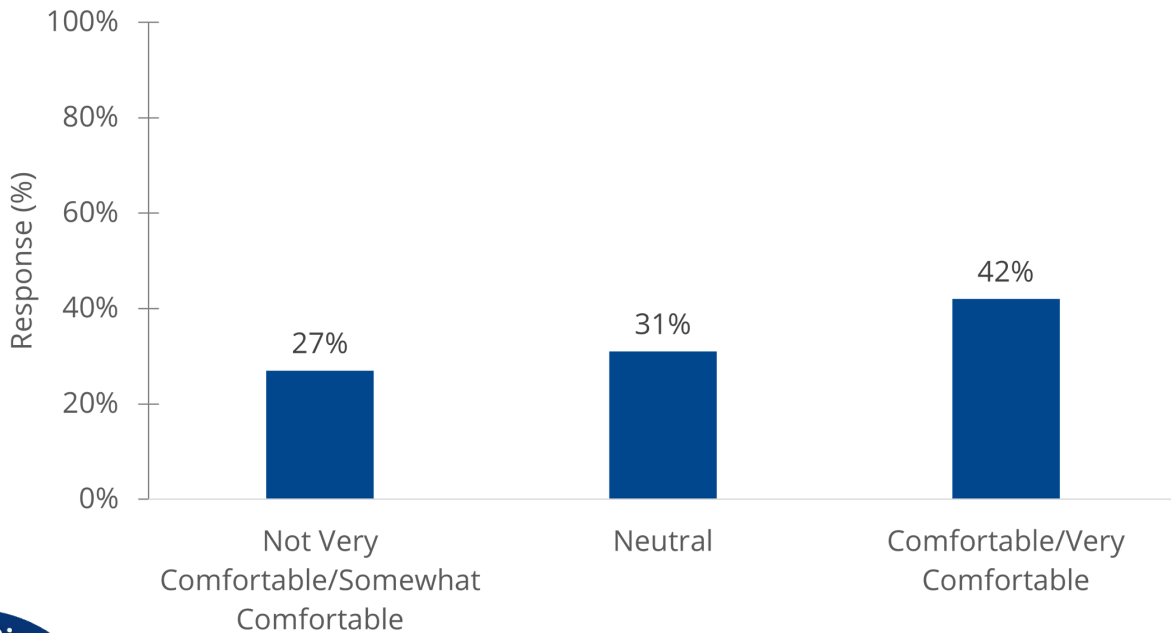
Percentage of Respondents Who Reported Knowing They Have the Right to...



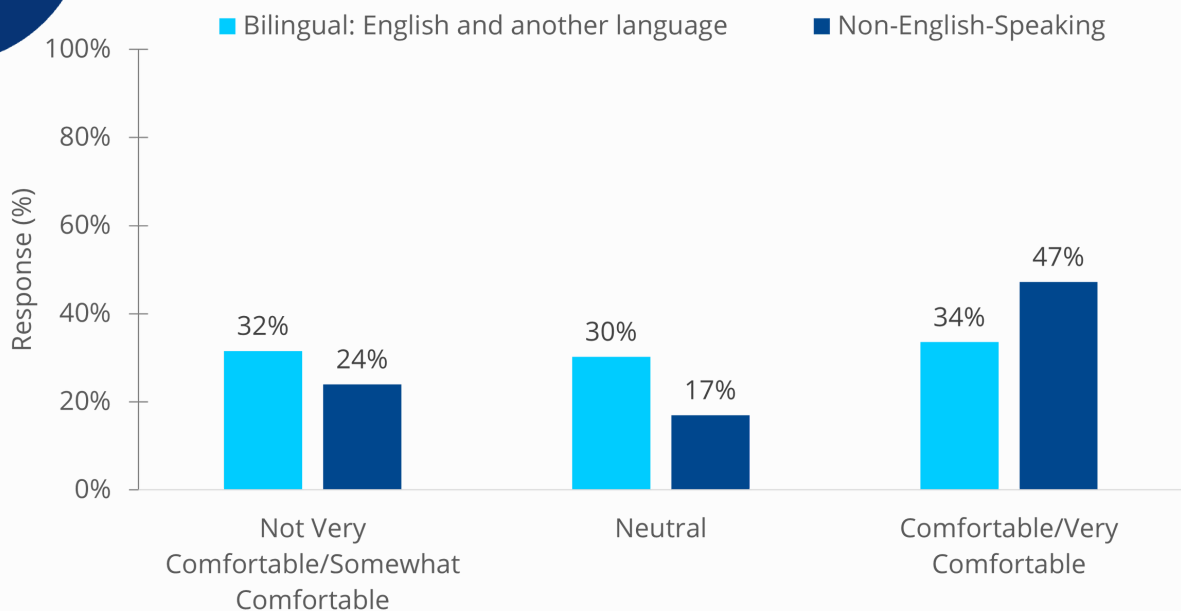
Survey of Families

Comfort with Interpreters

How comfortable are you with having an interpreter?



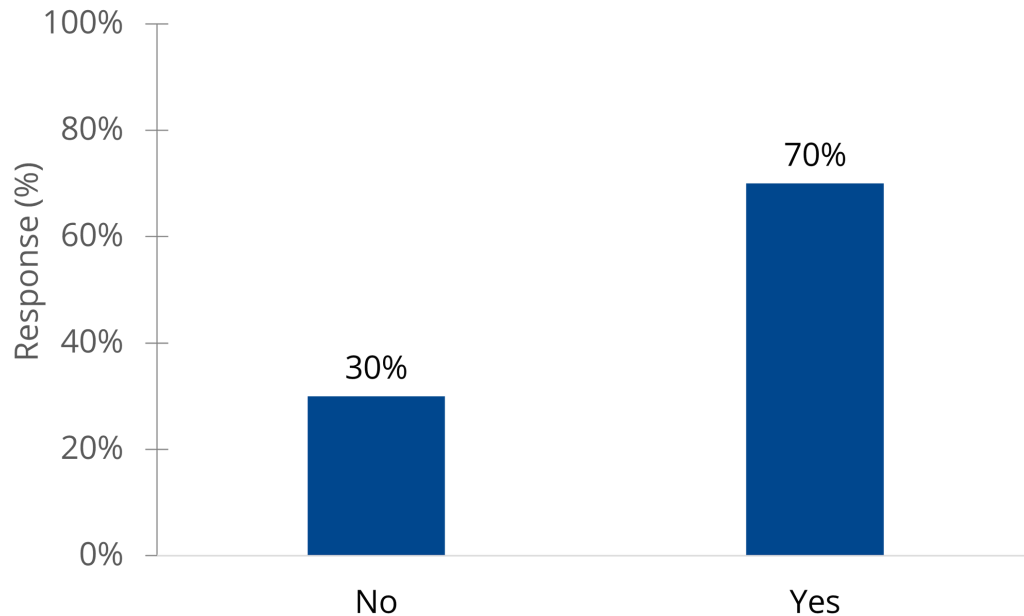
How comfortable are you with having an interpreter?



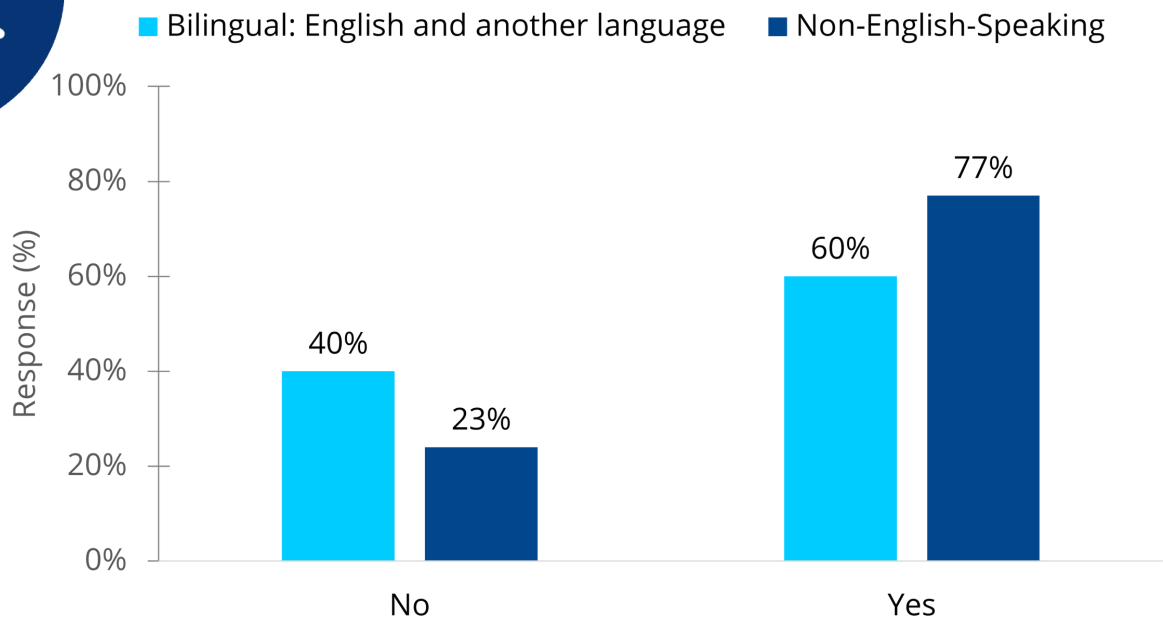
Survey of Families

Collection of Language Data

Has your provider asked you about the language you use?



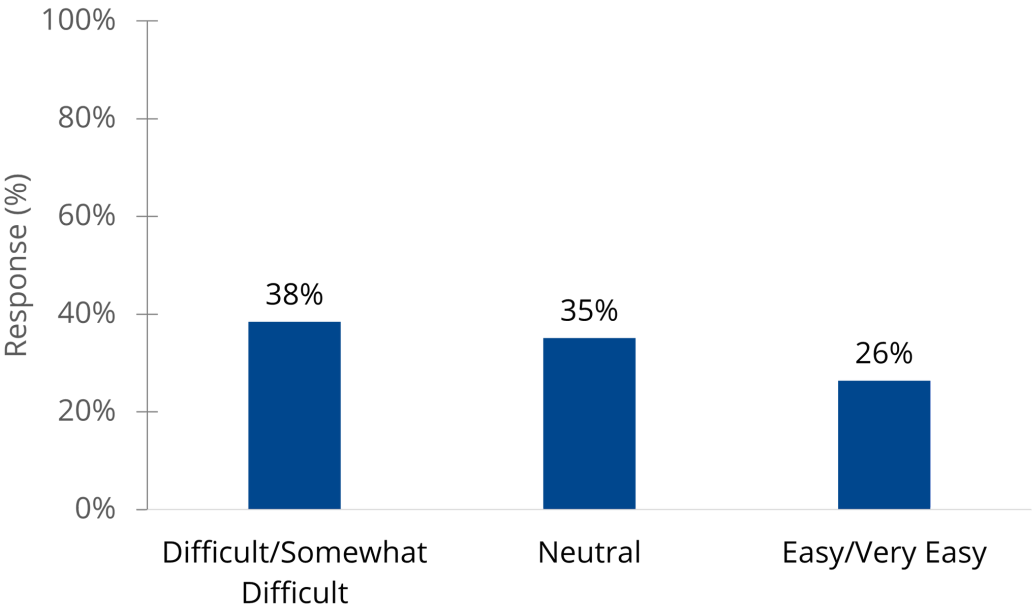
Has your provider asked you about the language you use?



Survey of Families

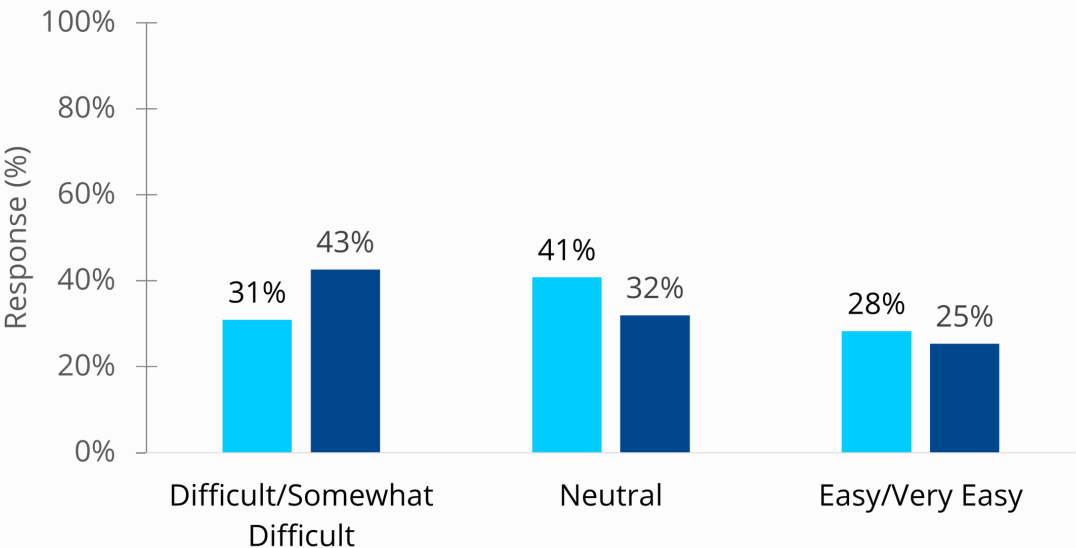
Ease of Accessing Language Supports

Has getting support in your language been easy?



Has getting support in your language been easy?

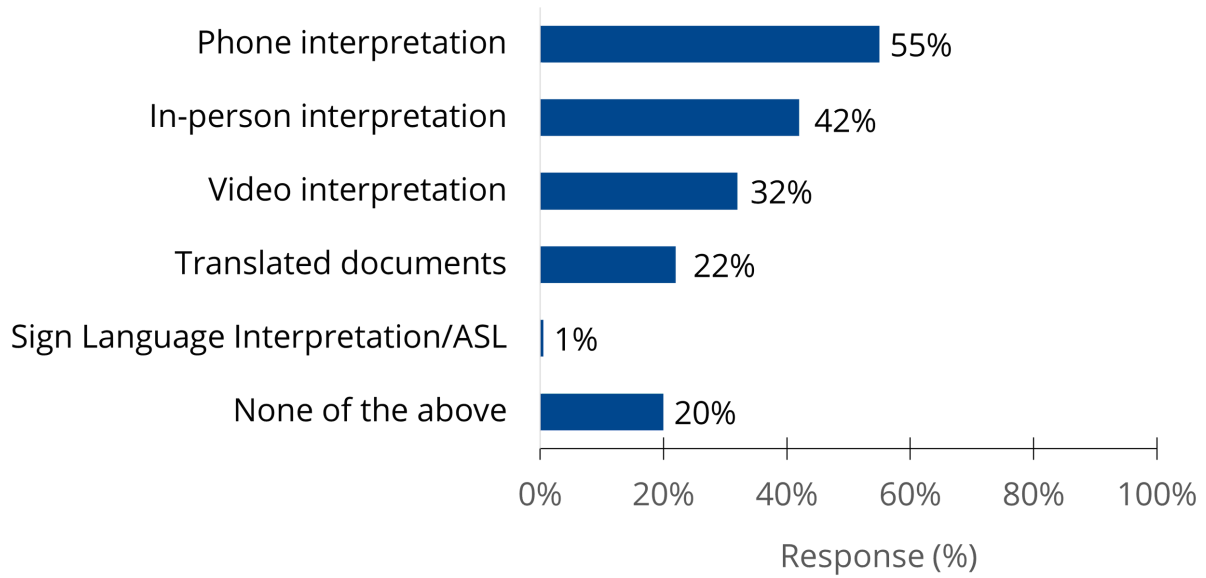
■ Bilingual: English and another language ■ Non-English-Speaking



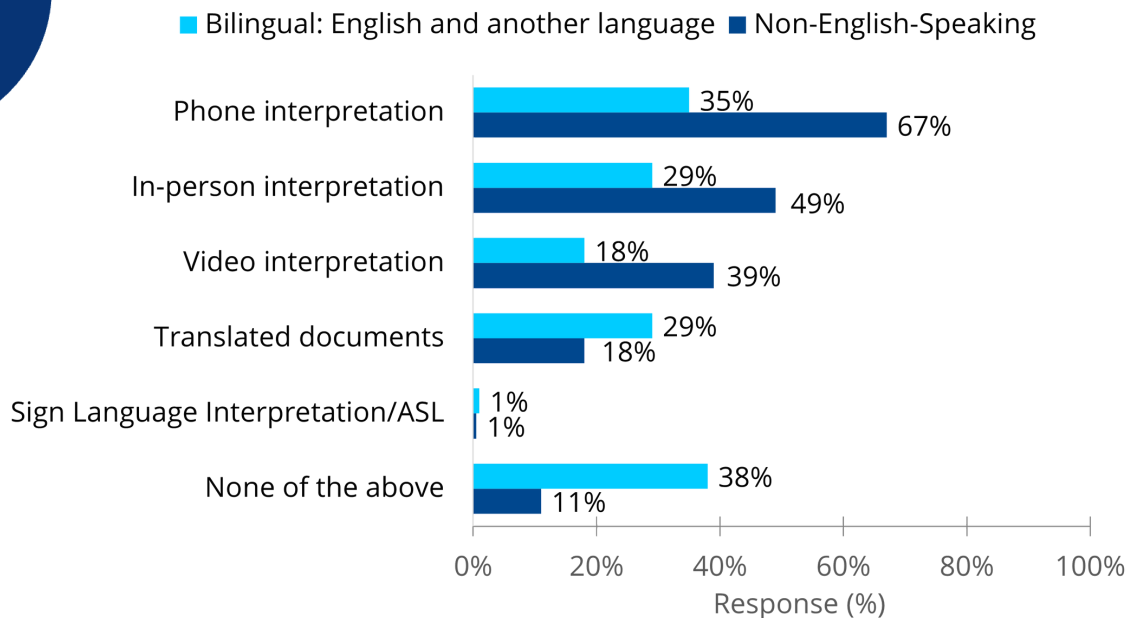
Survey of Families

Types of Language Supports Used

What kinds of support have you used in your language?



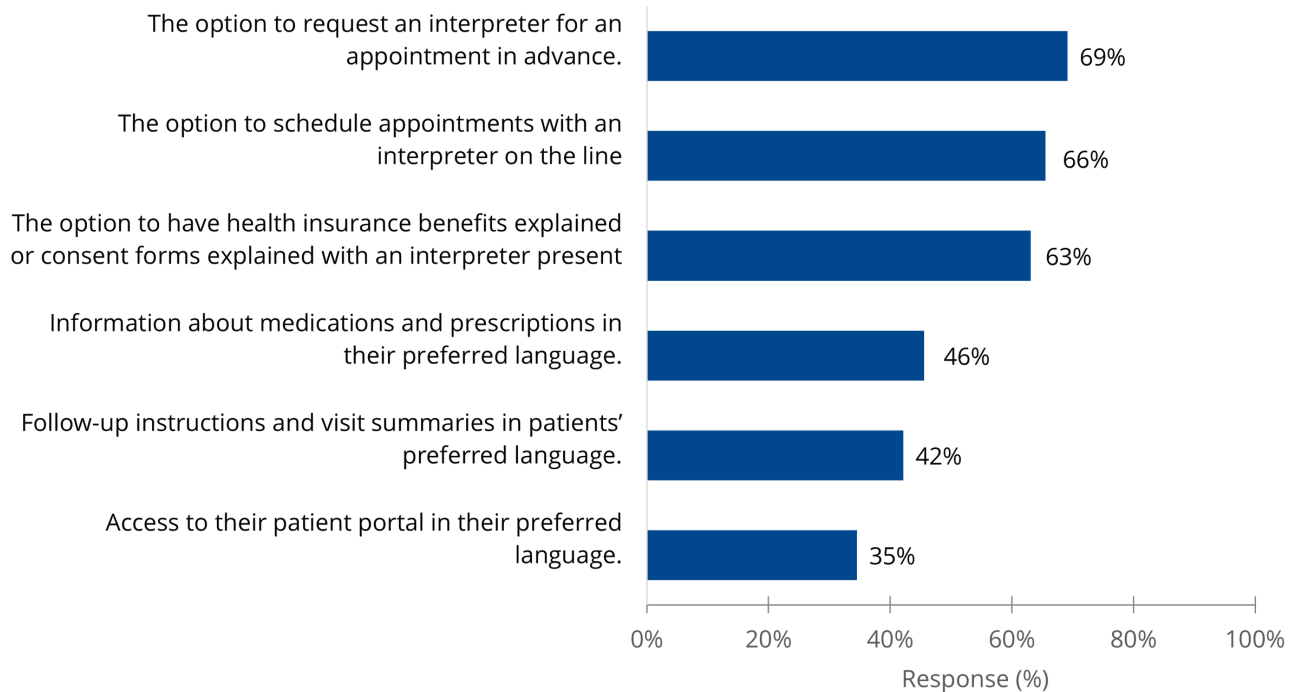
What kinds of support have you used in your language?



Survey of Families

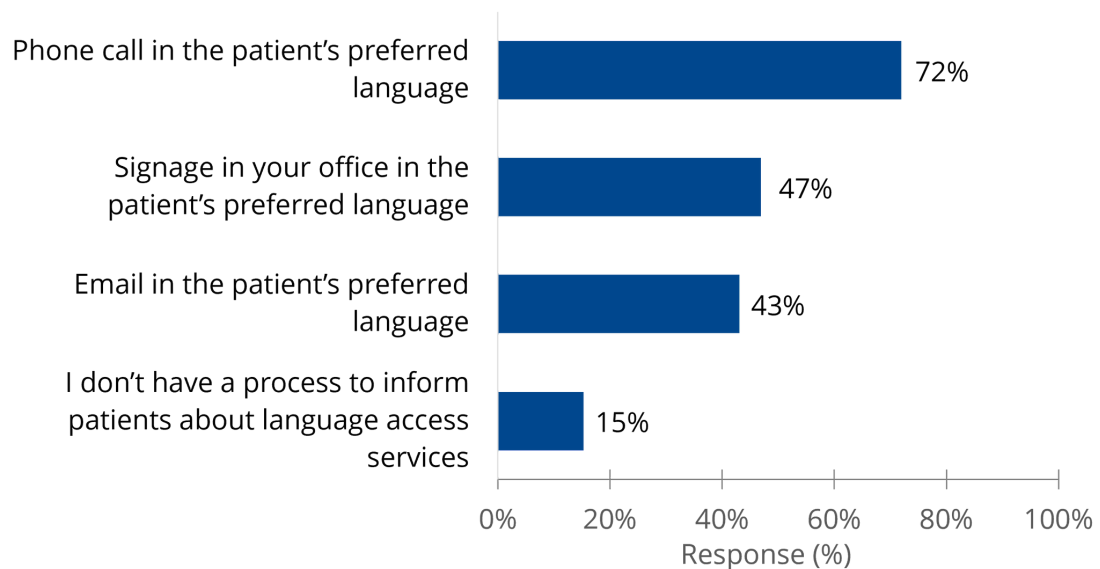
Language Access Services Available to Families

Services Families Have Used



How Frequently Information is Provided to Patients in Various Formats

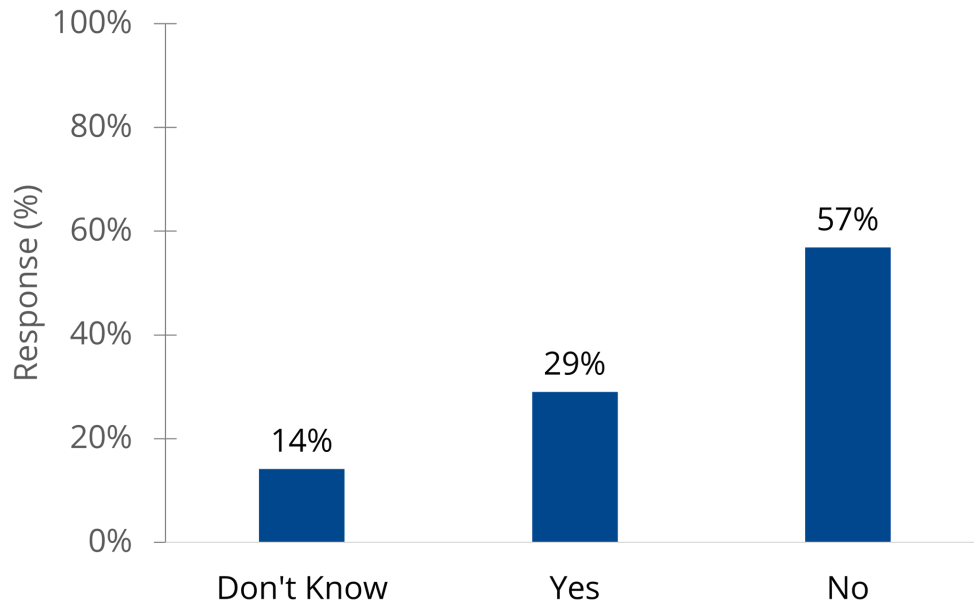
Percentage of "Always" or "Often" Responses



Survey of Families

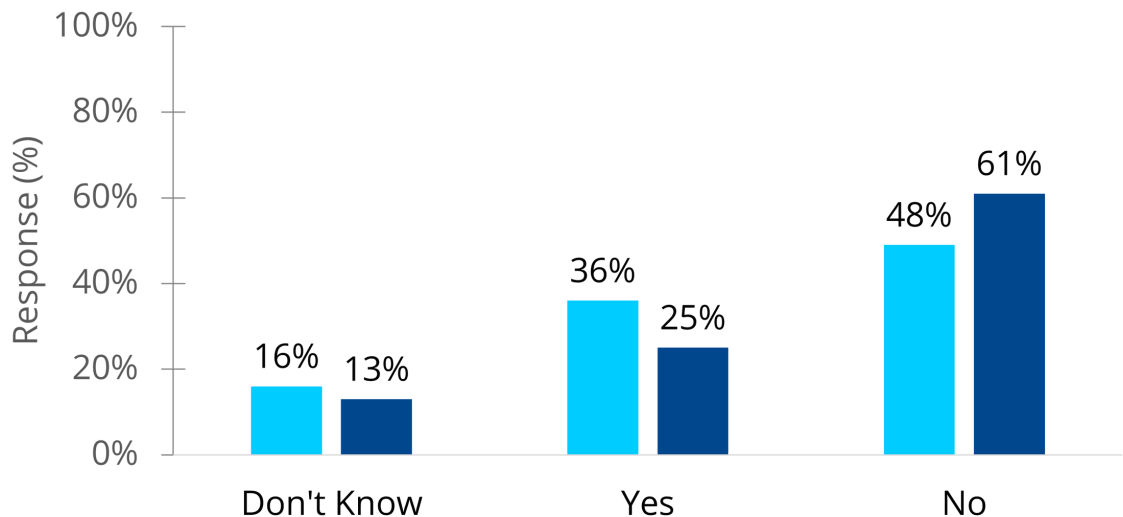
Language Access and Medical Records

Are your child's medical records in your language?



Are your child's medical records in your language?

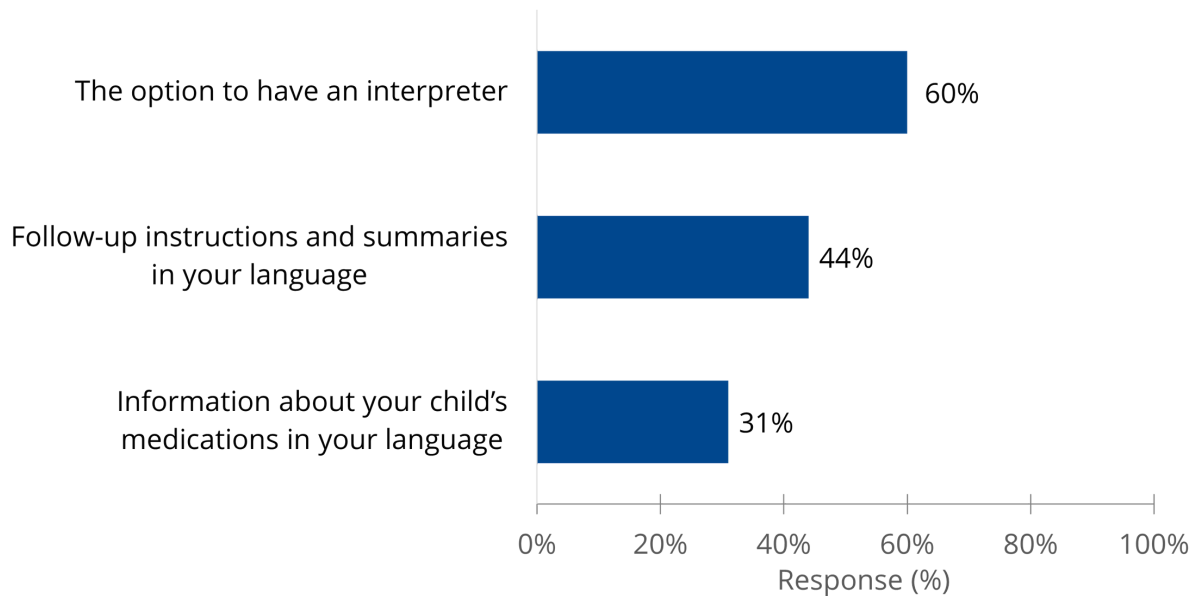
■ Bilingual: English and another language ■ Non-English-Speaking



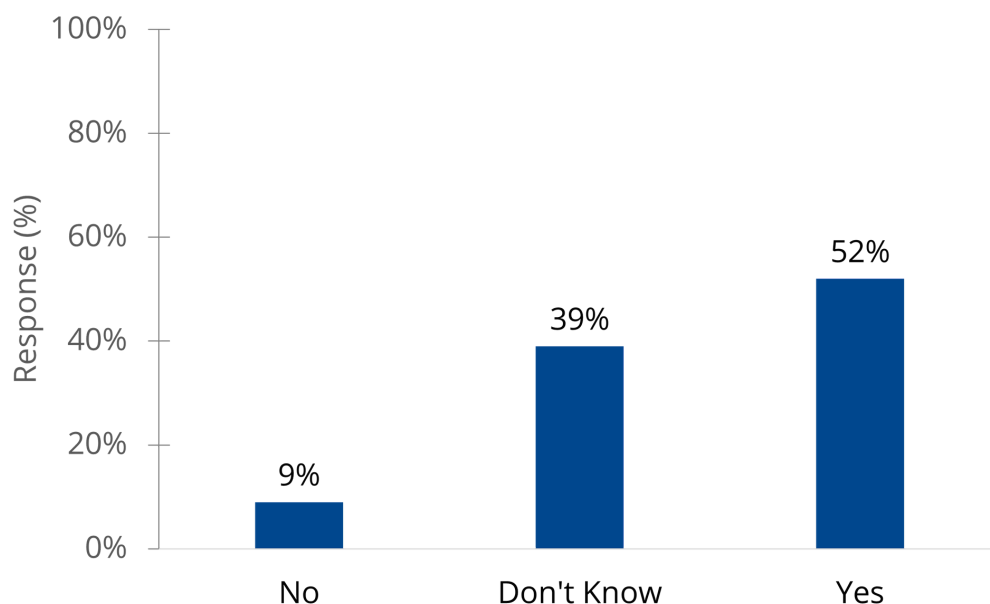
Survey of Families

Experiences with Providers

Does your provider give you:



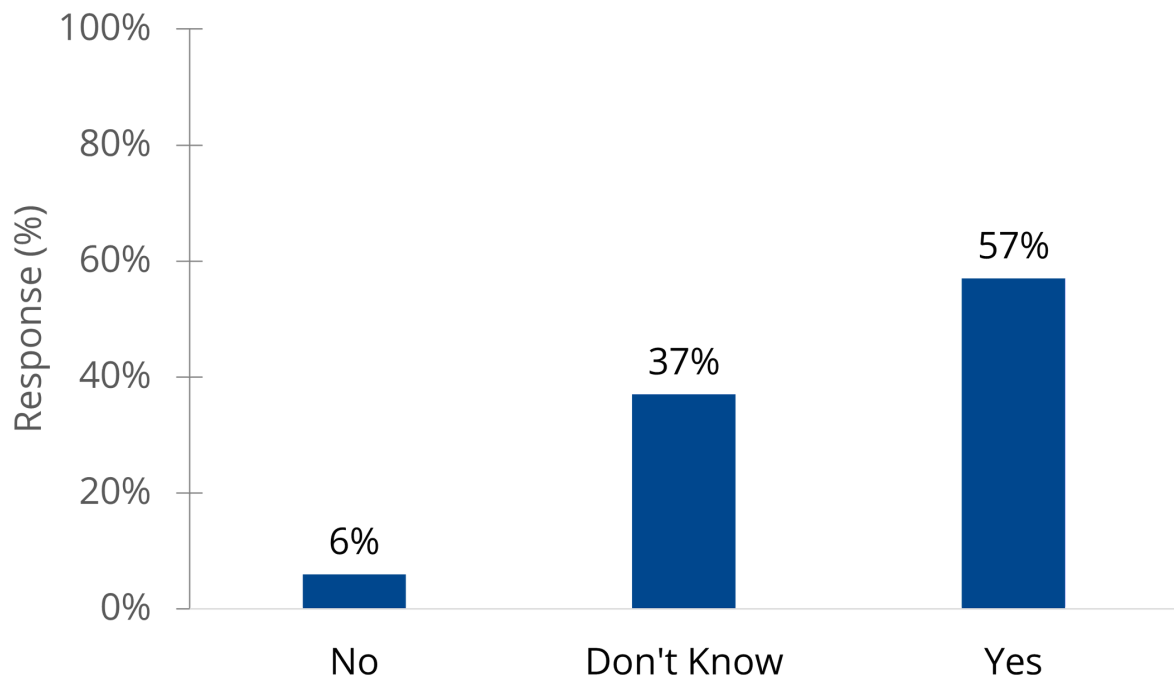
Do you think your provider knows your rights to communicate in your language?



Survey of Families

Providers' Respect for Language Access Rights

Do you think your provider respects your rights to communicate in the language you use?

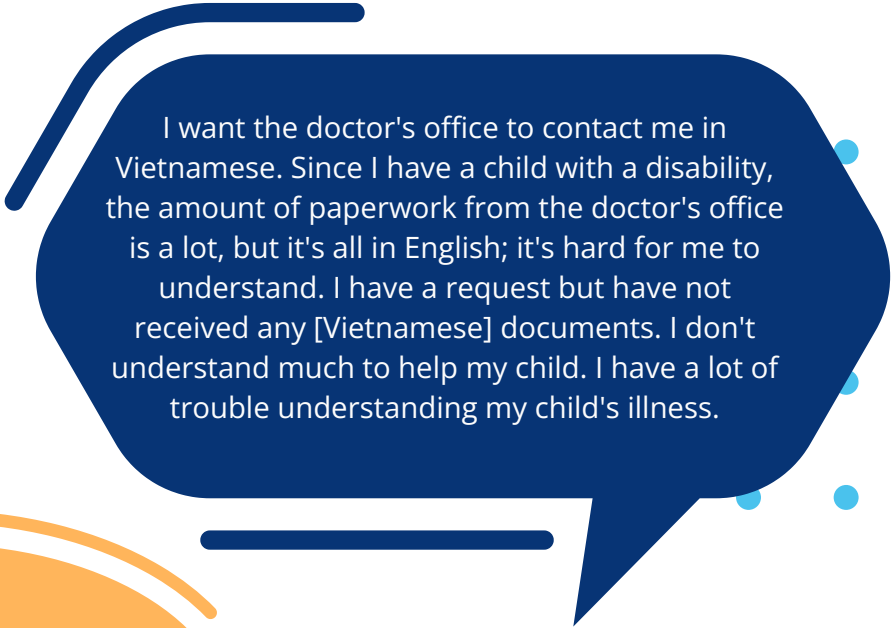


Survey of Families

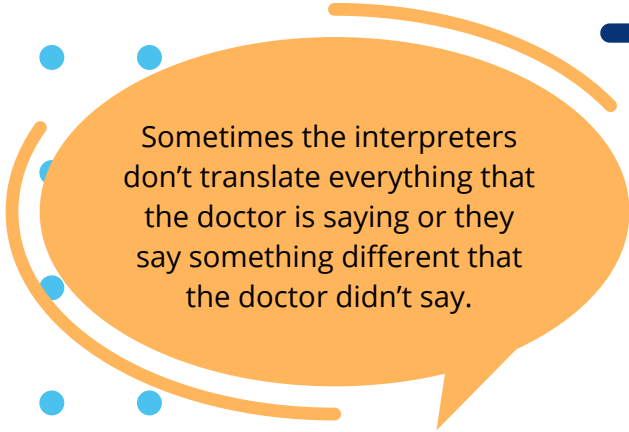
Key Themes for Non-English-Speaking Respondents

Respondents' Questions, Concerns, Experiences

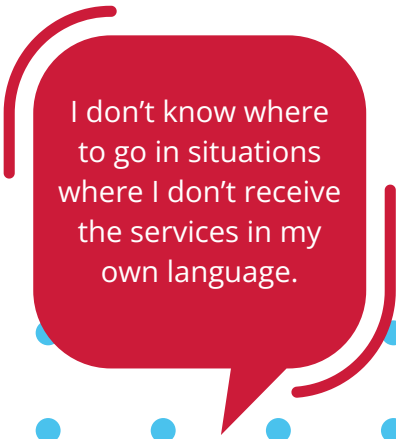
- Translation inaccuracy and other quality issues
- Lack of access to interpretation services
- Important documents, reports, and medication instructions are not translated.
- Many expressed frustration with not knowing how to get the language access services they need.



I want the doctor's office to contact me in Vietnamese. Since I have a child with a disability, the amount of paperwork from the doctor's office is a lot, but it's all in English; it's hard for me to understand. I have a request but have not received any [Vietnamese] documents. I don't understand much to help my child. I have a lot of trouble understanding my child's illness.



Sometimes the interpreters don't translate everything that the doctor is saying or they say something different that the doctor didn't say.



I don't know where to go in situations where I don't receive the services in my own language.

Survey of Families

Key Themes for Non-English-Speaking Respondents

It's harder to receive my child's reports in Spanish. I know I received the doctor's explanation in Spanish by the interpreter, but the report is written only in English. Sometimes the check-in is only available in English and the questions are hard to understand.

The Hispanic staff is not always qualified to provide information in Spanish but the providers always rely on them to provide a mediocre service. Many times these people don't know good Spanish and even get upset with you if you don't understand what they are talking about. Many times they talk in a mixture of English and Spanish or they are not fluent completely in Spanish. It's a shame.

In my county, it is very difficult to get access to an interpreter, especially in therapy clinics, and it's even harder to have one at my child's school. This is an obstacle even when I use tools like the Google translator app, because it's not the same idea of what I would like to express. Of course, in my case it is very important and necessary to have the help directly from an interpreter.

Survey of Families

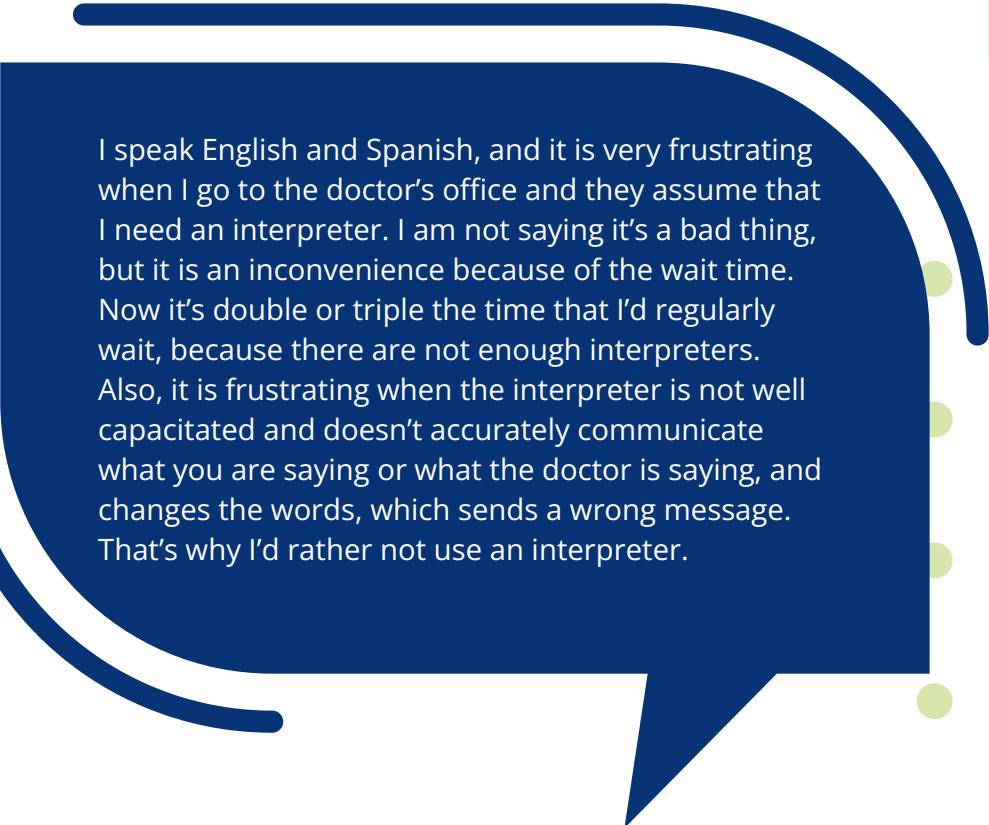
Key Themes for Bilingual Respondents

Respondents' Questions, Concerns, Experiences

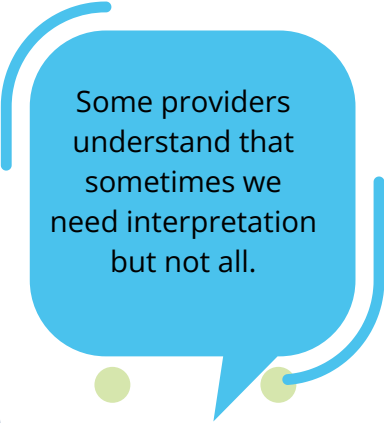
- Translation inaccuracy and other quality issues
- Some providers make assumptions about the need for an interpreter without asking
- Experiences vary by provider for respondents with multiple providers
- Some respondents expressed satisfaction and appreciation for their providers

Respondent questions included the following:

- What legal rights do undocumented families have to request or solicit information or medical interpretation if we are not protected citizens by the federal laws?
- Does this also refer to the interpretation and medical information that is discussed at the school meetings?



I speak English and Spanish, and it is very frustrating when I go to the doctor's office and they assume that I need an interpreter. I am not saying it's a bad thing, but it is an inconvenience because of the wait time. Now it's double or triple the time that I'd regularly wait, because there are not enough interpreters. Also, it is frustrating when the interpreter is not well capacitated and doesn't accurately communicate what you are saying or what the doctor is saying, and changes the words, which sends a wrong message. That's why I'd rather not use an interpreter.



Some providers understand that sometimes we need interpretation but not all.

Survey of Families

Key Themes for Bilingual Respondents

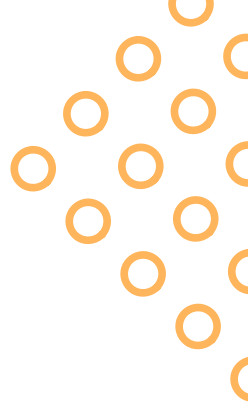
The interpretation or translation of any document continues to be a challenge, perhaps because the translation support they rely on to translate documents uses unconventional language. With interpreters born in the USA, some of them do not know the language or proper or correct synonyms for the interpretation, and at the same time when they use a tablet, the translation could be wrong.

I have many doctors for my children. Some of them do take into consideration, others assume and use interpreters and information in Spanish, but they do not ask me. Sometimes I don't understand the interpreters and understand the doctor better, and they get upset because I speak directly to the doctor, because I am afraid they won't understand me.

Just a compliment of how satisfied co-worker provider services and hospitality, very helpful and understandable in any way that they somehow help children with autistic needs.

Survey of Families

Conclusions

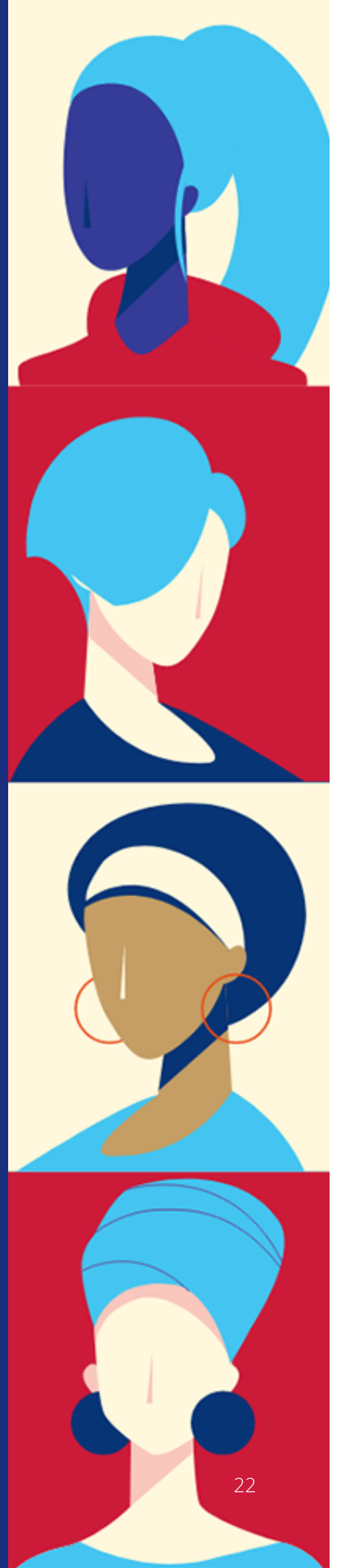


- While most family respondents reported knowing that they have the right to request free interpreter services (85%) and receive medical information in their language (82%), only about half (54%) reported knowing that they have the right to make a complaint when denied interpreter services.
- Less than half (42%) of family respondents reported that they are Comfortable or Very Comfortable with having an interpreter. More non-English-speaking respondents (47%) reported being Comfortable or Very Comfortable with having an interpreter compared to bilingual respondents (34%).
- The majority of respondents reported that their provider asked them about the language they use; however, the percentage was smaller among bilingual respondents (60%) compared to non-English-speaking respondents (77%).
- Only 29% of family respondents reported that their child's medical records are in their language.
- A small majority (60%) of respondents reported that their provider gives them the option to have an interpreter, while less than half reported that their provider gives them follow-up instructions and summaries in their language and/ or information about their child's medication in their language.
- Slightly over half of respondents think that their provider knows their rights to communicate in their language and respects their rights to communicate in their language.
- Non-English-speaking respondents shared feedback and concerns that focused on translation inaccuracy and other quality issues; lack of access to interpretation services; important documents, reports, and medication instructions not being translated; and frustration with not knowing how to get the language access services they need.
- Bilingual respondents shared similar concerns about translation inaccuracy; as well as variation in experiences for families with multiple providers; and issues with providers who make assumptions about their need for an interpreter without asking. Some respondents expressed satisfaction and appreciation for their providers.

Survey of Families

Recommendations

- Plan activities that include additional focus on families' right to make a complaint when denied interpreter services and guidance on the process for making a complaint.
- Identify and promote strategies to increase family satisfaction with the accuracy and reliability of interpreter and translation services.
- Promote opportunities for improving and enhancing language access services among providers, with focus on translation quality; translation of documents, reports, and medication instructions; and improving patient and family access.



Family Focus Groups

The family focus groups were conducted in December 2023 and January 2024 by Family Voices and its partners. The purpose of the family focus groups was to identify the barriers or challenges experienced by families who cannot speak, understand, read, or write English while trying to use health services for their children and youth with special health care needs (CYSHCN) or themselves.

Focus group findings will be used to inform program activities, training content, guidance documents, and educational resources to increase awareness, understanding, and use of language access services in the health care settings for families of CYSHCN.

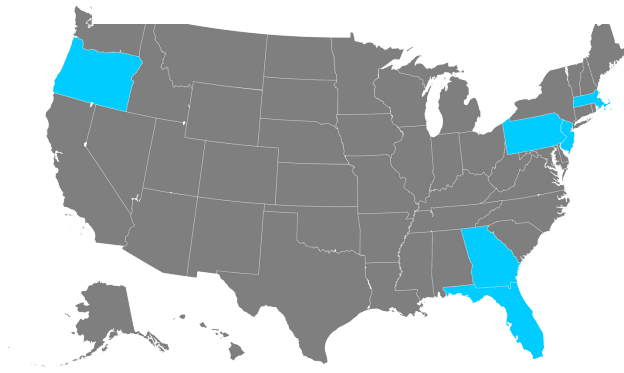
Methods

Four (4) one-hour, semi-structured focus groups were conducted virtually via Zoom in Spanish, Mandarin Chinese, Farsi, and Vietnamese with parents of CYSHCN. The Family Voices PEALS project team and the PEALS Project Advisory Committee (PAC) collaboratively developed a seven-question focus group discussion guide.

- Focus group participants were recruited using a purposive sampling approach. An interest form was disseminated online to families of CYSHCN through the Family Voices network of Family Voices Affiliate Organizations and Family-to-Family Health Information Centers in each state. The form was supplemented with targeted outreach to identify additional participants.
- Ten (10) individuals participated in the focus groups. The individuals spoke Spanish (4), Mandarin Chinese (2), Farsi (2), and Vietnamese (2). Participants received a stipend of \$250 for their participation.
- In addition to the facilitator, a medical interpreter and note taker were present during the focus groups.
- The note takers' notes from each group were combined and analyzed qualitatively using thematic and content analysis. Interest form data were analyzed quantitatively using descriptive statistics.

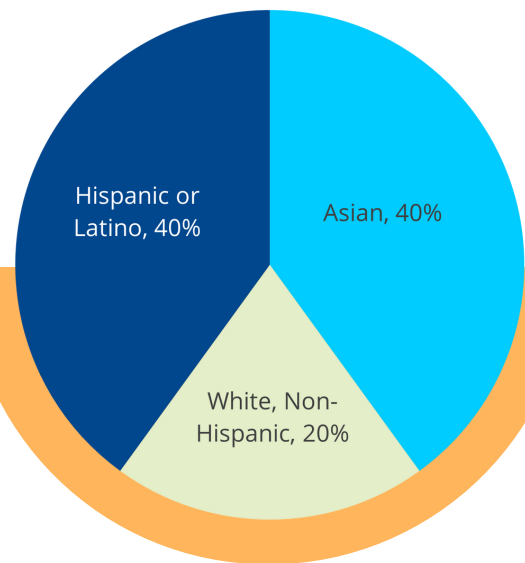
Family Focus Groups

Participant Characteristics



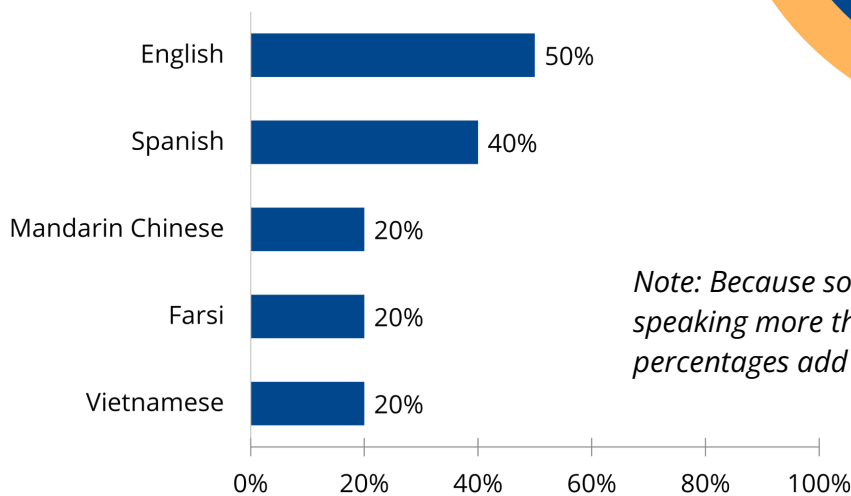
Geography

State of Residence for Family Focus Group Participants

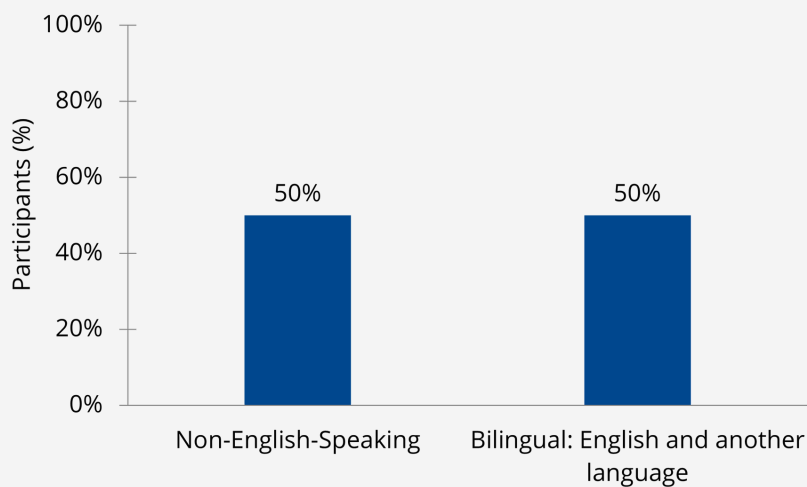


Race/ Ethnicity

Languages Spoken



Note: Because some participants reported speaking more than one language, the percentages add up to more than 100%.



Bilingual vs. Non-English-Speaking

Family Focus Groups

Family Experiences with Using Language Access Services

Participants' Knowledge about Language Access Law



Participants' knowledge about language access law was mixed:

- Some participants reported knowing that they have a right to an interpreter and translation services.
- Some participants reported that they do not know about the law or do not know a lot about the law.

When I had my child, I had a very rough time. My English was extremely limited and at times the interpreters and I couldn't understand each other. The stigma about speaking another language made me hesitant to receive interpreting services. Everything that I practiced and learned in English was because of the work that I had to do to try to understand and communicate with my medical providers.

I did not know of the law. For me, it was something very new and I began to look into it-- if it was shared on TV or newspapers. I didn't know this was a thing. I only thought that in the court system, having an interpreter was permissible. My child's healthcare provider barely speaks English and didn't speak Spanish either, so we had to basically sign or act out what we were trying to communicate.

I don't know a lot, but I know in a medical service you can request those services.

I have two children with disabilities. I usually go to the hospital and usually use the language access services. I know that if I don't speak English, the medical providers will provide interpretation via phone or in-person. That's all I know.

My experience is with the Department of Education. I know parents have the right to an interpreter and translation services so that they can have an active involvement in their child's care. But parents must ask, really beg, for this service.

Family Focus Groups

Family Experiences with Using Language Access Services

Participants Who Know About Language Access Law...



- Learned about language access law through their experiences as a parent trying to get medical care and/ or education supports for their child/ children with special health care needs and/ or disabilities.



- Know that it is a legal right to have an interpreter and if you need one, you can ask.



- Know people have a right to an interpreter, but they were never offered this service; they had to learn about it on their own and had to ask or “beg” for it with little or no provider support.



- Did not know about the law when they were new to the United States and experienced great difficulty, frustration, and delays in getting care for their child/children.

Participants' Use of Language Access Services



- Most participants have used language access services.
- Some participants reported they rely on bilingual family members and/ or Google Translate.



Yes. I've used [language access services] in the medical setting...because there is a lot of terminology that is very different. That's why I wanted to use a medical interpreter to be able to fully understand everything.

I have used in-person, virtual, and phone interpretation. I love having in-person interpreters. I feel like it is important to hire more first-language interpreters. I prefer in-person interpretation because there is a lot of body language that sometimes helps to facilitate communicating what we are trying to say.

Family Focus Groups

Family Experiences with Using Language Access Services



Participants who have used language access services reported dissatisfaction with interpreter quality and translation accuracy.

- **Interpreters lack training and understanding** of dialects and cultural differences that affect translation accuracy.
- Interpreters often simplify or **translate only part of what was said**, leaving out important information.
- Participants prefer **in-person translation** over phone translation because being able to see body language helps with communication.
- Medical, education, and legal **terminology makes understanding and translation difficult** for both the speaker and the interpreter.
- Seeing **office signage in other languages** can help people know they can ask for an interpreter.



I have used translation services for my children's speech therapy and occupational therapy but many times the translations were inaccurate. Of course, there are good interpreters, but because interpreters are often assigned randomly, most of the time the translation services are not very satisfactory.

The interpreters could not accurately express the opinions I needed to communicate with the therapists. For example, I spoke for a long paragraph and clearly explained the reasons for the matter and the expected results, but the interpreter often just used a very simple sentence instead. So many times, I had to give up using the language assistance services and use Google translator.

Family Focus Groups

Family Experiences with Using Language Access Services

Most participants feel uncomfortable having an interpreter.



Stigma is a major issue, being perceived as “other.”



Ask for interpreter services despite feeling uncomfortable because there is no other choice.



Privacy concerns; “it’s a small community.”



Takes away parent’s agency and empowerment.



Takes additional time.



The interpreter was from Central America, and my sister is from Puerto Rico, so the difference in culture and dialect influenced the interaction. But I also know that in some instances, it is a factor of an interpreter not having a sufficient understanding of the topic [for example, special education] and/or the interpreter is changing one’s words.



No, I have never used interpreter services. I tried my best to understand, but my husband and I would sit with our 6-year-old to try to translate everything with my child or with Google.

I had a concern that my other child was developmentally delayed. I ended up having to take a trip to Puerto Rico to seek services from a doctor who spoke Spanish. It was the first time that I had any relief in terms of my belief in the care of my child.

Family Focus Groups

Family Experiences with Using Language Access Services

Most participants feel a lack of understanding and respect from providers.

- Interpretation services and translation of materials are not provided or are difficult to access and inaccurate/ poor quality.
- Treated rudely by provider when requesting language access services.
- Told that there were no bilingual doctors in-network and/ or referred to doctors that are far away.
- Provider communication is directed more towards the husband who speaks English.



Sometimes I was given materials in Spanish but I often could not understand it. I think because of the cultural difference, or dialect, some things were not understandable in Spanish so I used to always ask for the English version as well. The Spanish that is used in those translations is not standard so not everyone can understand and read it.

I don't really feel that providers respect this, because whenever they find out that I cannot understand in English and request interpretation they can be rude. Most of the time they are not really putting the effort to take care of me because Farsi interpretation is hard to come by.



My sister drives two hours to see a pediatrician who speaks Spanish. When we asked for a bilingual doctor, they told us they didn't have any in-network.



I believe they do because they respect the law but the only problem is that the ease in which support can be provided is not there.



I think that while the providers don't understand the language, but I feel like they do respect my right.

My daughter's doctor has always preferred to communicate with my husband who speaks English.



Family Focus Groups

Key Barriers to Using Language Access Services



Most participants feel a lack of understanding and respect from providers.

- Stigma
- Inaccurate, poor quality interpretation services
- Confusing medical terminology and acronyms
- Lack of interpretation services, especially in some languages such as Farsi
- Interpreters are not available when needed; long wait times
- Providers assume incorrectly what you are saying
- Lack of awareness of language access law
- Privacy concerns make parents reluctant to have an interpreter or bilingual family member present during the appointment
- Frustration from not being able to communicate
- Fear or lack of confidence with speaking English

Family Focus Groups

Positive Experiences

I have had positive experiences with some interpreters before. Interpreters have heard my story and expressed empathy. They have also given me advice for the types of questions I should ask for my child. These successes are not very common and I wish the quality of interpreters was better so more families can get the support they need.

I was forced to learn and speak English. Because I have learned, I am more comfortable communicating when I need people to slow down. I also currently work with translations and because of my experiences and I try really hard to make sure that what I translate is done in an appropriate manner.

I have seen a difference in the accuracy of information translated in medical offices now compared to when I first moved to this country. I used to look around and laugh at all of the grammatical errors in signs but now I see that things are translated correctly or at least have fewer errors.

I really care to communicate the concerns I have for my son's care. Sometimes the interpreters really understand what I want to communicate, but I have also had experiences where I can't understand the interpreter.

Family Focus Groups

Conclusions

Participants' **knowledge about language access law was mixed.**

Some reported knowing that they have a right to an interpreter and translation services, while some reported that they do not know about the law or do not know a lot about the law.

Participants **learned about language access law through their experiences** as a parent trying to get medical care and/or education supports for their child/ children with special health care needs or disabilities.

Some participants know that people have a right to an interpreter but reported that they were **never offered this service**; they had to learn about it on their own and had to ask or "beg" for interpreter services with little or no provider support.

Participants **did not know about the law** when they were new to the United States and experienced great difficulty, frustration, and delays in getting care for their child/children.

Most participants have used language access services, while some reported they rely on family members and/or Google Translate.

Most participants are **dissatisfied with interpreter quality and accuracy**, including lack of understanding about dialects and cultural differences that affect translation accuracy; and interpreters who simplify or translate only part of what was said, leaving out important information.

Participants **prefer in-person interpretation** over phone interpretation because being able to see body language helps with communication.

Most participants are **uncomfortable having an interpreter** due to stigma, privacy concerns, the additional time it takes, and that they feel an interpreter takes away the parent's agency and empowerment.

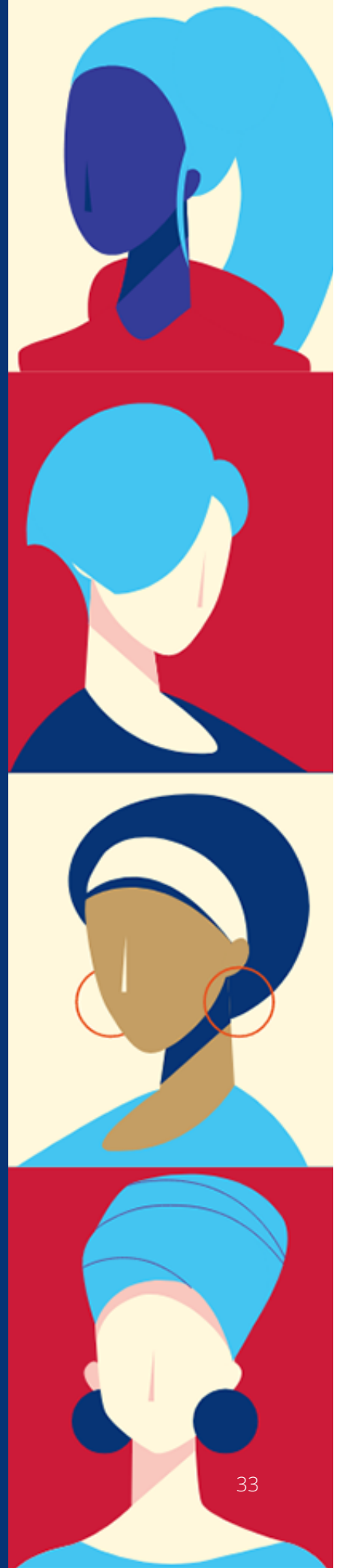
Most participants feel a **lack of understanding and respect** from providers, and report that interpretation services are not provided or are difficult to access, inaccurate, and/or poor quality. They also report rude treatment when requesting services; a lack of bilingual doctors in network; and referrals to doctors that are far away.

In addition to the challenges and barriers, some participants reported **positive experiences**, such as becoming inspired to work as a translator; appreciation for the uncommon interpreters who are empathetic and helpful; and noticing improvements in translation accuracy in medical offices.

Family Focus Groups

Recommendations

- Identify opportunities for **provider and staff training** focused on helping families whose preferred language is not English to feel more **welcome and respected** when requesting and using interpreter services.
- Promote strategies to **increase family satisfaction with the accuracy of interpreter and translation services**, including strategies to address interpreters' understanding of dialects and cultural differences that may affect translation accuracy.
- Continue to **raise awareness of language access law and families' right to interpretation/translation services**, especially for families who are new to the United States.



Survey of Health Care Providers

The purpose of the provider survey is to gain understanding of the challenges faced by health care providers related to using language access supports, gaps in resources that support equitable language access, and technical assistance and training needs to improve access to services and tools to communicate health information for individuals whose preferred language is not English.

Survey findings will be used to inform program activities, training content, guidance documents, and educational resources to increase awareness, understanding, and use of language access services in health care settings for families of CYSHCN whose preferred language is not English.

Provider Survey Methods

The provider survey was developed collaboratively by the Family Voices project team and the PEALS Project Advisory Committee (PAC). The 15-item survey was administered online (via SurveyMonkey) from July to August 2023.

AAP staff distributed an invitation with an anonymous survey link via AAP member listservs and e-newsletters, with an estimated reach of over 57,000 subscribers.

A total of 150 completed surveys were received. Because the number of individuals who actually received the survey invitation is unknown, it is not possible to calculate a survey response rate.

Respondent Characteristics

Profession

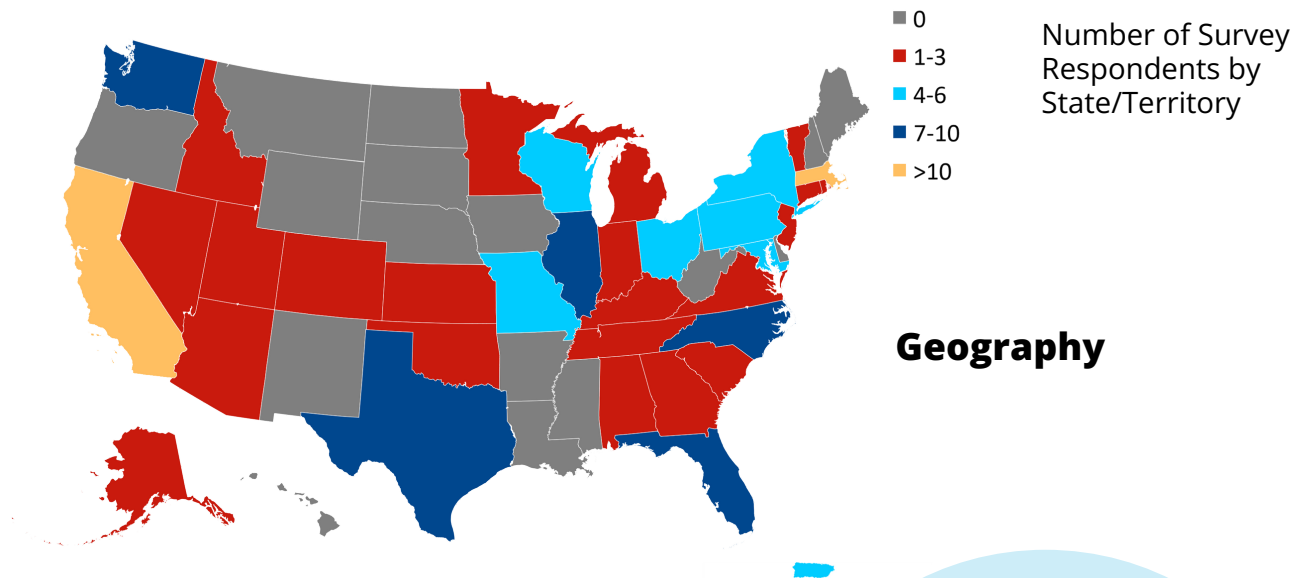
- Pediatrician/ Physician
- Nurse (APRN, RN)
- Social Worker
- Dietician
- Music Therapist
- Other

Specialty

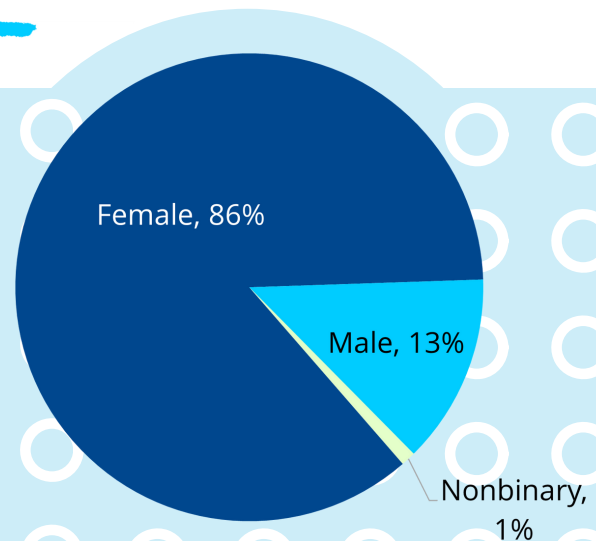
- General Pediatrics
- Developmental & Behavioral Pediatrics
- Palliative Care
- Neurology / Child Neurology
- Neuropsychology / Psychology
- Pediatric Emergency Medicine
- Physical Medicine & Rehabilitation
- Pediatric Critical Care
- Pediatric Complex Care
- Neonatology
- Other

Survey of Health Care Providers

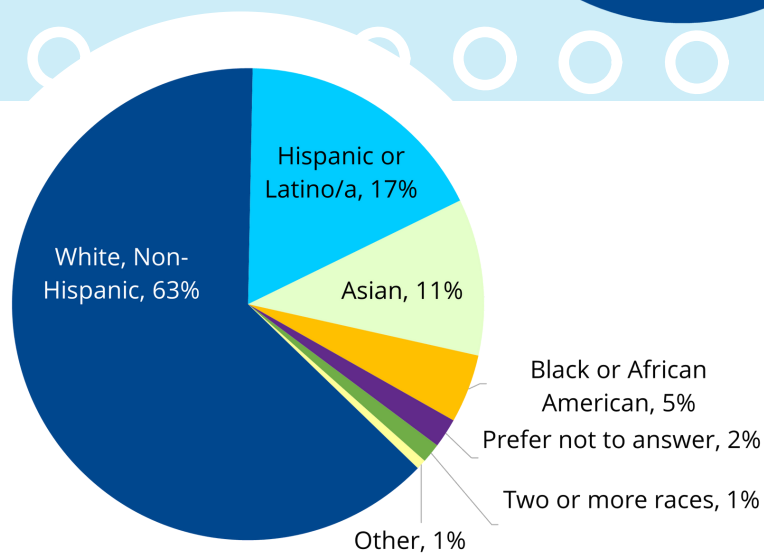
Respondent Characteristics



Gender / Gender Identity



Race / Ethnicity



Survey of Health Care Providers

Provider Knowledge and Training

Knowledge of Patients' Rights

97%

of respondents know about their patients' rights to communicate in their preferred language during a medical or virtual (telehealth) appointment.

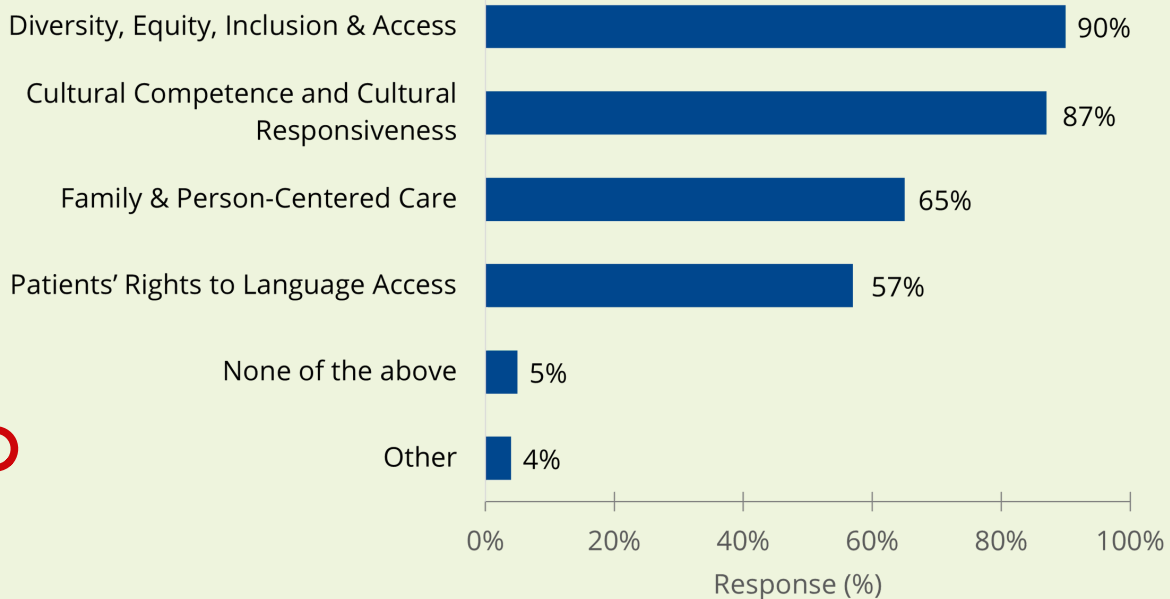
97%

of respondents know about their patients' rights to request an interpreter in the health care or virtual (telehealth) setting.

93%

of respondents know about their patients' rights to receive medical information in their preferred language in the health care or virtual (telehealth) setting.

Relevant Provider Training



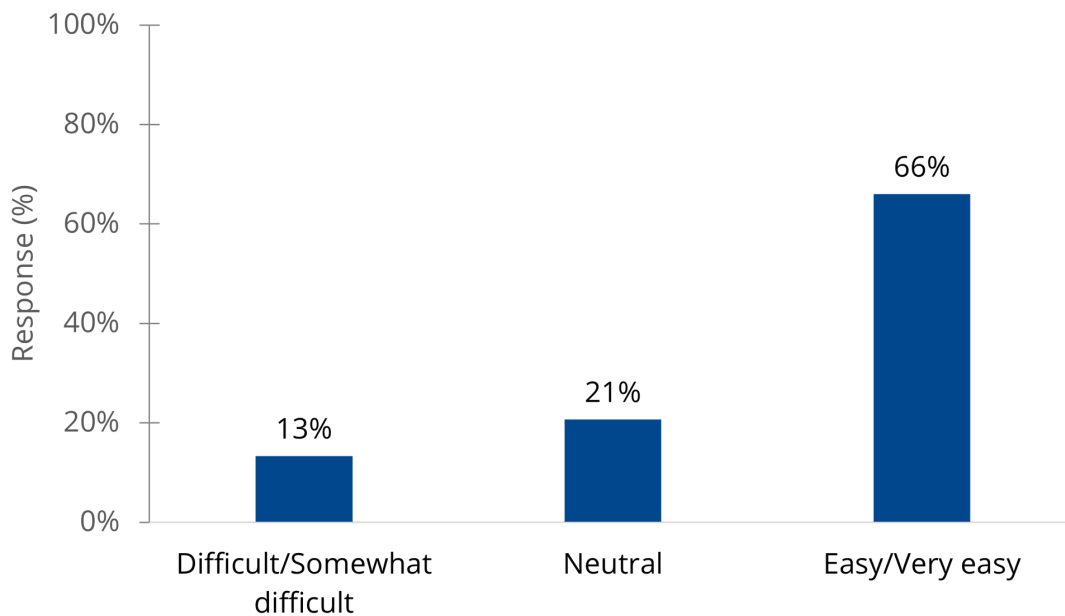
The training providers received came from:

- Department; Faculty
- Residency; Fellowship
- Online; Modules
- Self-Directed
- Colleagues; Conferences
- Workplace; Employer
- Hospital; Health System; Health Center
- University
- Institution
- Professional Organization

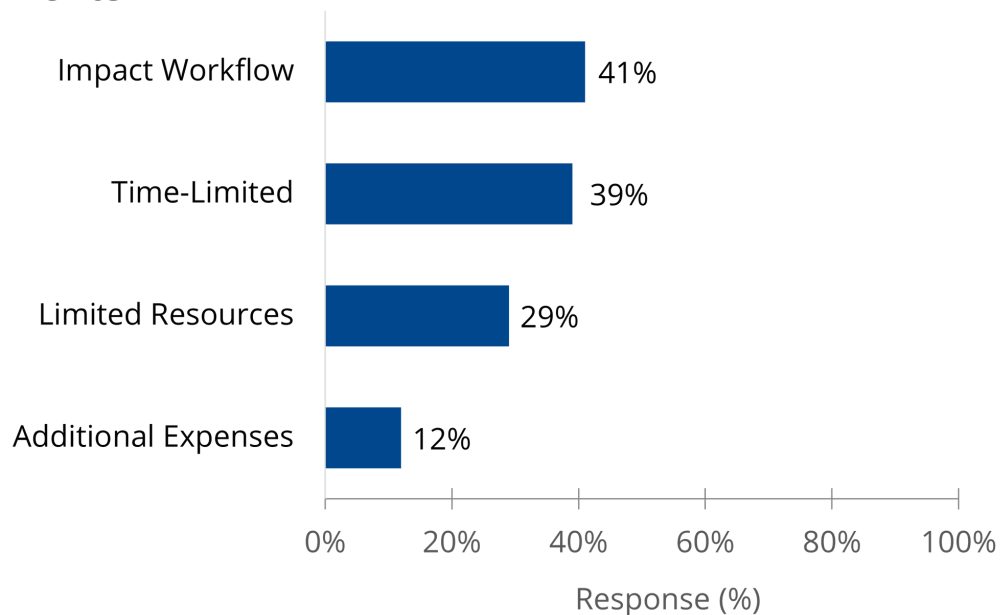
Survey of Health Care Providers

Ease and Concerns about Language Access

Ease in Accessing Language Access Services



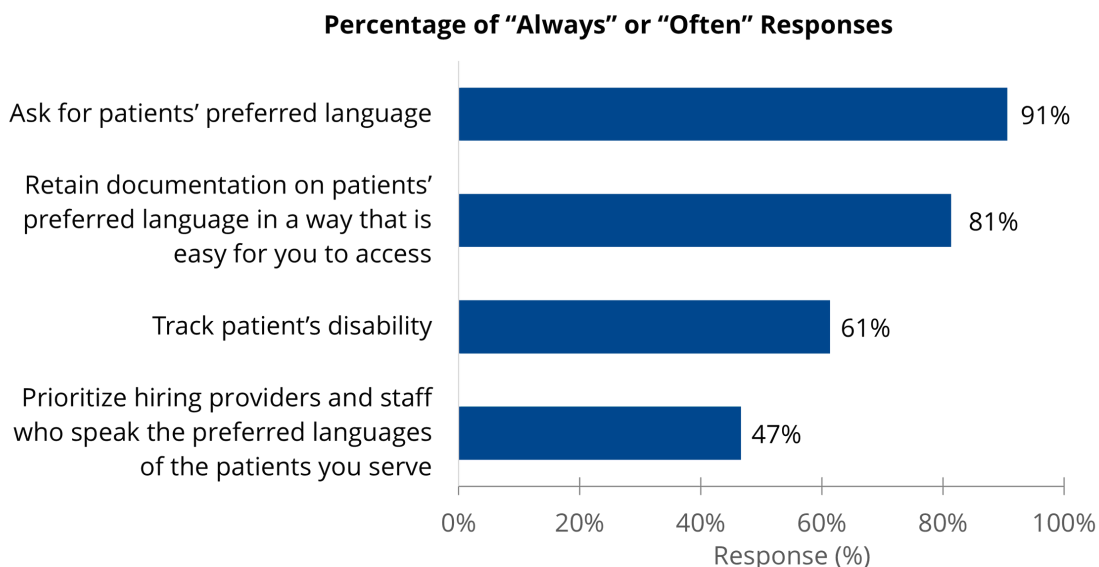
How Providers Felt about Having Interpreters in Medical Appointments



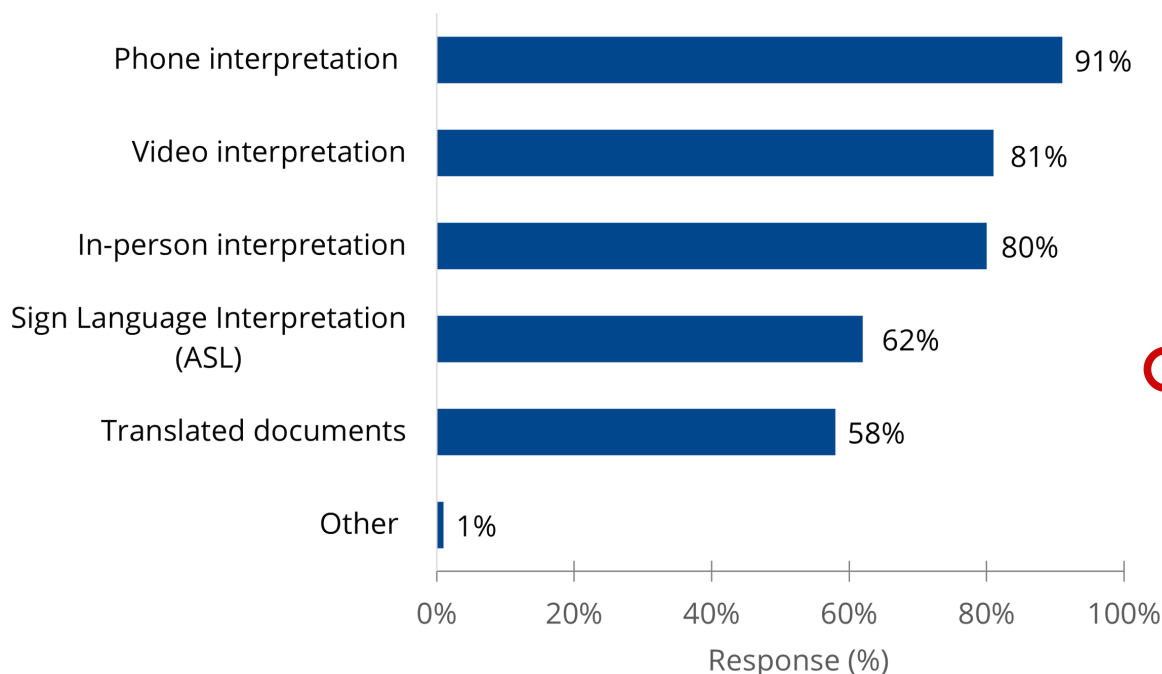
Survey of Health Care Providers

Facilitating Language Access Services

How Offices and Health Systems Facilitate Language Access



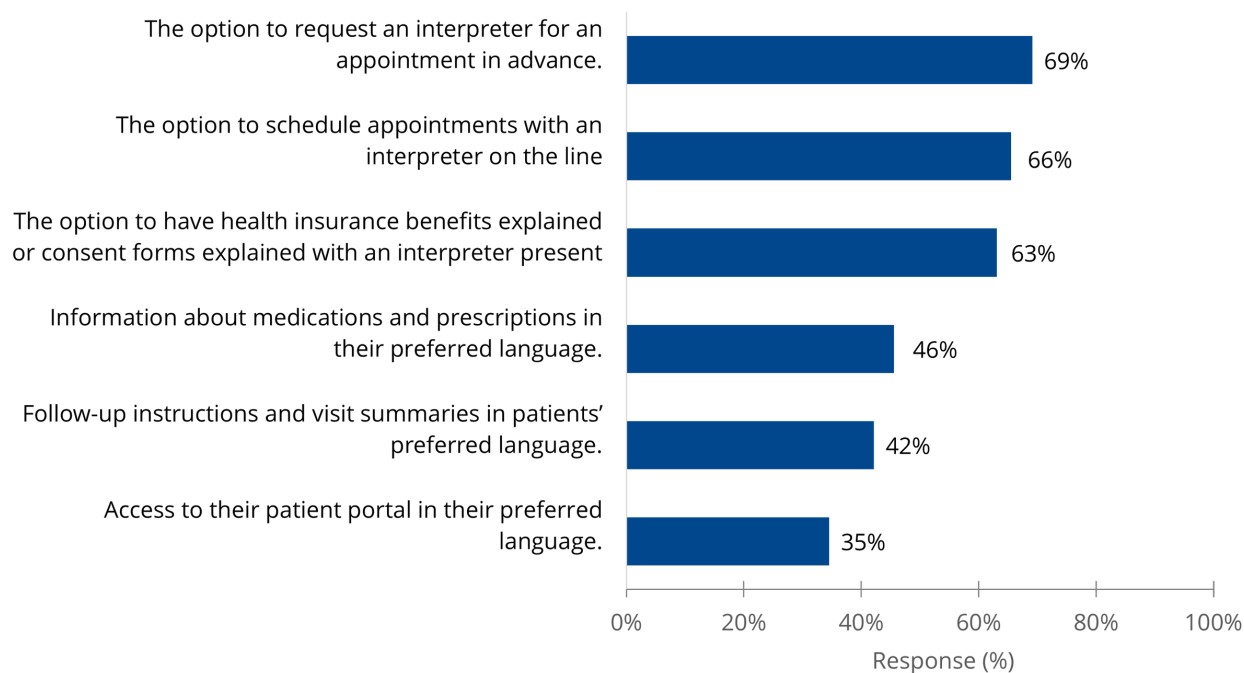
Types of Language Access Services Used



Survey of Health Care Providers

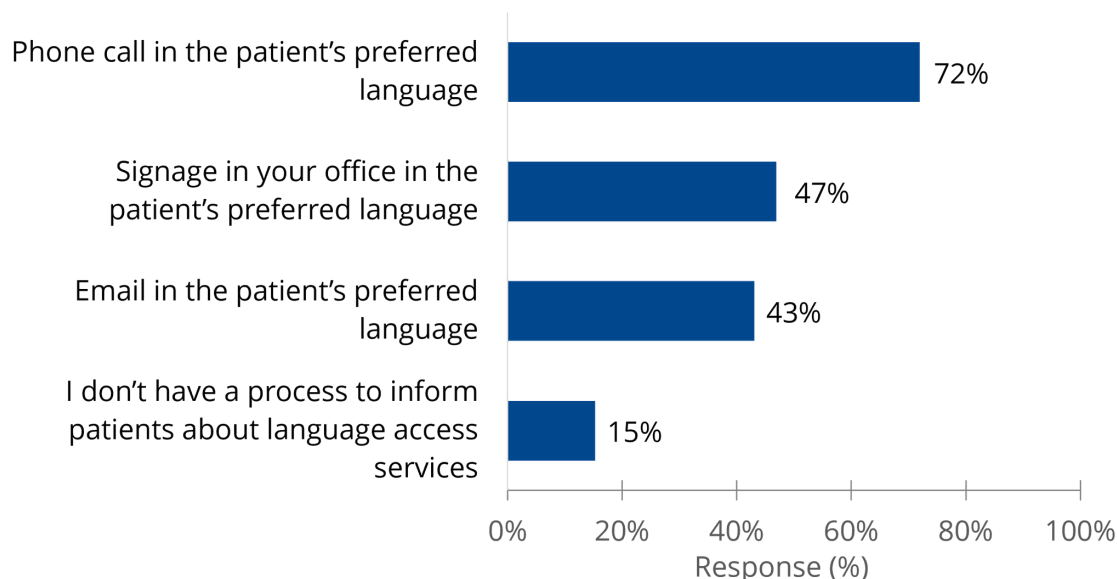
Providing Services and Information

Services Provided to Patients



How Frequently Information is Provided to Patients in the Various Formats

Percentage of "Always" or "Often" Responses

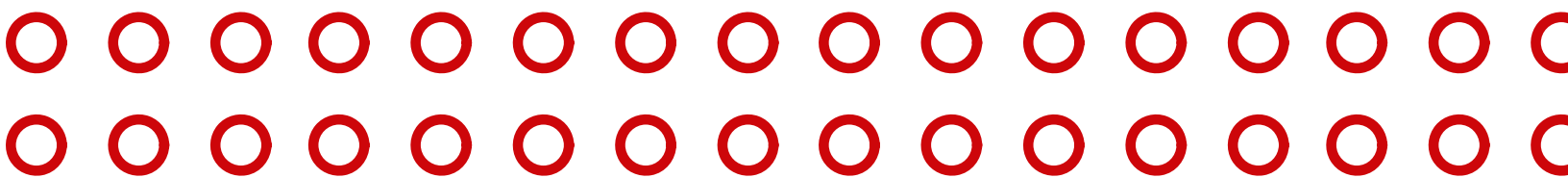
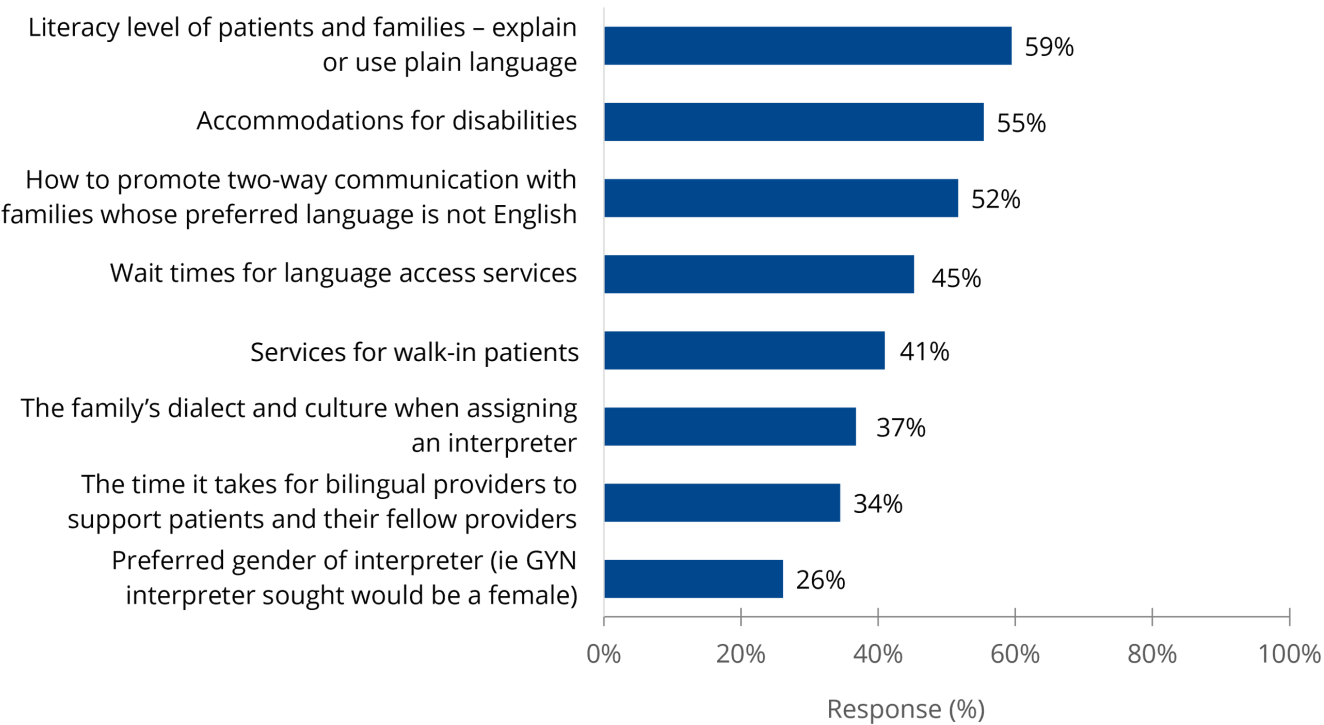


Survey of Health Care Providers

Barriers and Considerations

What considerations do providers make when engaging language access services?

Percentage of “Always” or “Often” Responses

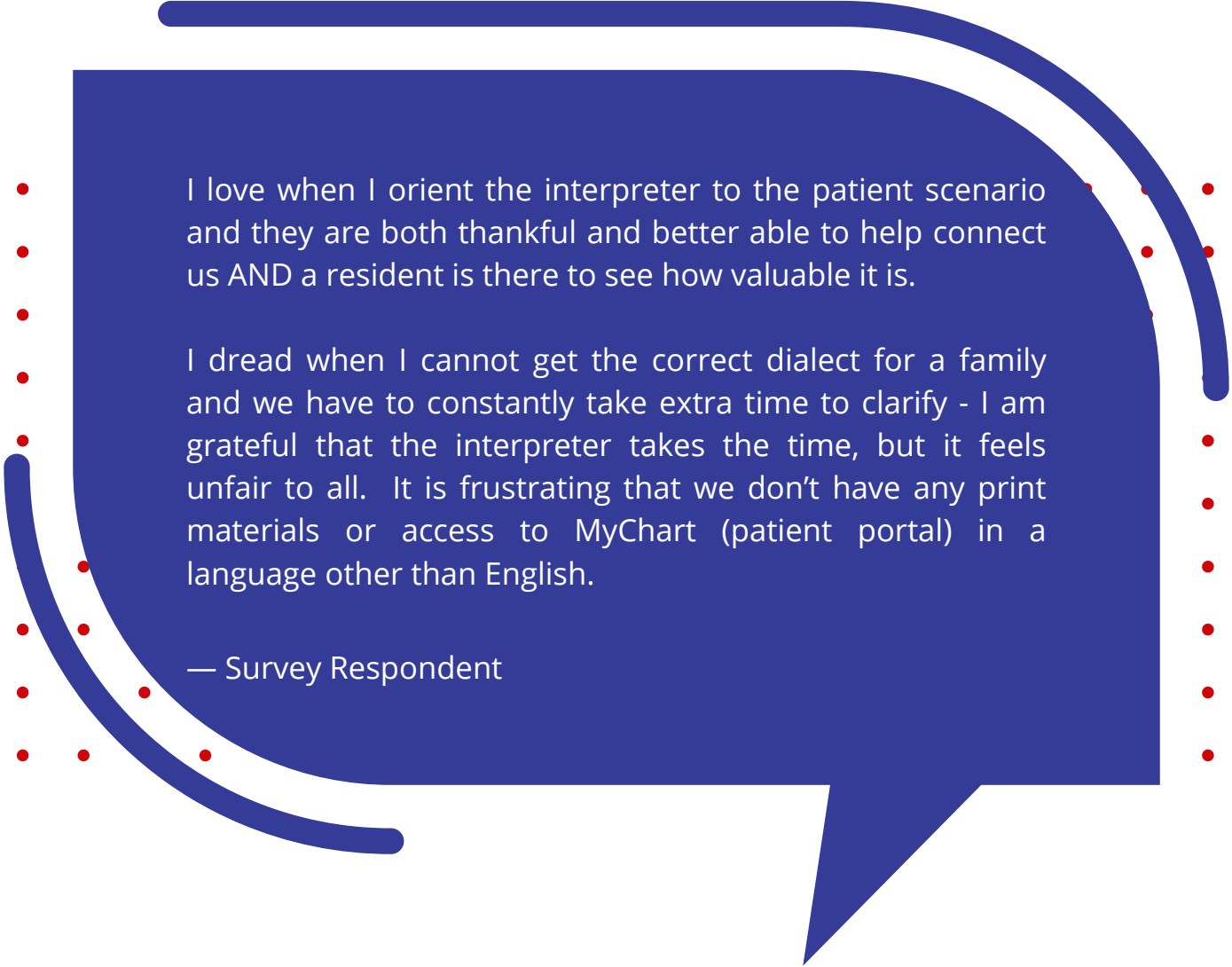


Survey of Health Care Providers

Key Themes

Positive Experiences

- Interpreters are “necessary,” “essential,” and “critical” to patient care.
- Working with a good interpreter helps to build rapport and trust with patients and families.
- Having an interpreter prolongs visit time, but the benefits are worth it.
- There is a preference for in-person interpreters.



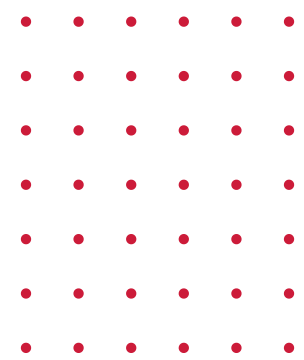
I love when I orient the interpreter to the patient scenario and they are both thankful and better able to help connect us AND a resident is there to see how valuable it is.

I dread when I cannot get the correct dialect for a family and we have to constantly take extra time to clarify - I am grateful that the interpreter takes the time, but it feels unfair to all. It is frustrating that we don't have any print materials or access to MyChart (patient portal) in a language other than English.

— Survey Respondent

Survey of Health Care Providers

Issues Providers Reported



1 Access to interpreters is limited.

- Certain languages and dialects are not available.
- Interpreters are not always available when needed.
- Long wait times (often hours or days).

2 Interpreter quality varies.

3 Accuracy Issues.

- Important details become lost in translation, often due to dialect and cultural differences.
- Interpreters lack sufficient medical knowledge to explain diagnoses, treatment considerations, patient education, medication instructions, etc.

4 Specific types of communications are particularly challenging, such as medical history, anticipatory guidance, care and end-of-life discussions or planning.

5 Prolongs patient visit time, sometimes by hours, which can be especially difficult for small children and children with special health care needs.

6 Frequent connectivity and technical problems.

7 Issues specific to phone interpreters.

- More difficult for phone interpreter to pick up on patient and family emotions or non-verbal cues.
- Audio interference is common.
- Speaking into speakerphone is often difficult and distracting for parents, especially if child is upset or crying.

8 Many respondents reported that despite the issues, they believe interpreter services are valuable and critically important to providing high quality, equitable patient care.





I have a practice with many children with special health care needs and in most cases, they are non-English-speaking. In the past five years, I have offered an autism diagnostic clinic. It is so common that parents have not gotten a true definition of autism in other settings, mostly because of language barriers.

I use an interpreter, but I often have to reiterate many times, because even certified interpreters often are not trained in developmental language. Additionally, I've often cared for families from cultures that didn't even have words to describe the developmental delays that we need to discuss.

Recently, a parent came back to me and specifically thanked me for being so persistent in educating her on the IEP (Individualized Educational Plan) process; her rights as a parent in both the health care and educational setting; and taking our time in ensuring full understanding of her child's diagnosis, treatment, options, and strengths. Often the families I meet have not been given adequate interpretation in the school setting, so I must advocate for both health care and educational setting interpretation and translation.

— Survey Respondent





Survey of Health Care Providers

10 Most Commonly Reported Barriers

1. Lack of access to interpreters, including certain languages and dialects
2. Time constraints
3. Cost or lack of sufficient resources, including video equipment
4. Technical and connectivity issues
5. Long wait times
6. Inconsistent quality and skills among interpreters
7. Written information (discharge instructions, reports, etc.) and print materials are not translated
8. Interpreters' lack of sufficient medical knowledge to accurately communicate diagnoses, treatment options, instructions, etc.
9. No process in place for providers to confirm translation accuracy
10. Patient portal or telemedicine platform is not translated

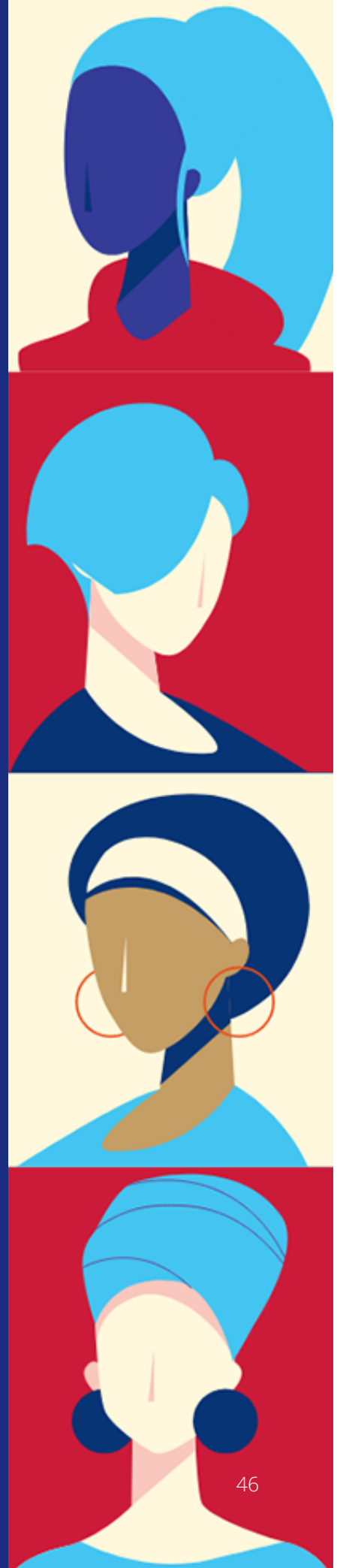
Survey of Health Care Providers

Conclusions

- The vast majority of survey respondents reported that they know about their patients' rights to language access, including the right to communicate in their preferred language during a medical or virtual (telehealth) appointment; request an interpreter in the health care or virtual (telehealth) setting; and receive medical information in their preferred language in the healthcare or virtual (telehealth) setting.
- A large majority of respondents have received training in Diversity, Equity, Inclusion, & Access and Cultural Competence and Cultural Responsiveness within the past 5 years, while a much smaller percentage received training in Family and Person-Centered Care and Patients' Rights to Language Access, suggesting a need for more training in these topic areas.
- Most respondents reported that their office or health system asks for, and documents patients' preferred language, but respondents were less likely to report that their office or health system tracks patients' disabilities and/or prioritizes hiring providers and staff who speak patients' preferred languages, suggesting possible opportunities for education and improvement efforts.
- The majority of respondents reported using a variety of language access support services, including phone interpretation, video interpretation, in-person interpretation, sign language interpretation (ASL), and translated documents.
- While most respondents reported that they Always/Often provide patients or caregivers with the option to request an interpreter in advance; schedule appointments with an interpreter on the line; and have health insurance benefits and consent forms explained with an interpreter present; less than half reported that they Always/Often provide patients or caregivers with information about medications and prescriptions; follow-up instructions and visit summaries; and access to the patient portal in the patients' preferred language, suggesting additional opportunities for education and improvement efforts.
- Reported barriers to accessing language access services included limited access to interpreters, especially for certain languages and dialects, time constraints, cost or lack of sufficient resources, technical and connectivity issues, and long wait times.
- Many respondents reported that despite the issues, they believe interpreter services are valuable and critically important to providing high quality, equitable patient care.

Survey of Health Care Providers Recommendations

- Offer additional provider training opportunities that focus on patients' rights to language access and family- and person-centered care.
- Continue to promote the importance of hiring providers who speak the preferred languages of patients served by the clinical site.
- Identify and disseminate relevant resources and tools to support clinical sites in developing a language access plan that addresses providing patients and caregivers with information about medications and prescriptions; follow-up instructions and visit summaries; and access to the patient portal in their preferred language.
- Continue to seek feedback from health care providers in planning activities to address identified barriers to using language access services.





Key Informant Interviews with Pediatric Providers

In November and December 2023, the American Academy of Pediatrics (AAP) collaborated with Family Voices to conduct key informant interviews with pediatric providers. The purpose of the pediatric provider interviews was to understand barriers, challenges, and successes in using language access services in the health care setting.

Provider interview findings will be used to inform program activities, training content, guidance documents, and educational resources to increase awareness, understanding, and use of language access services in health care settings for families of CYSHCN.

Family Survey Methods

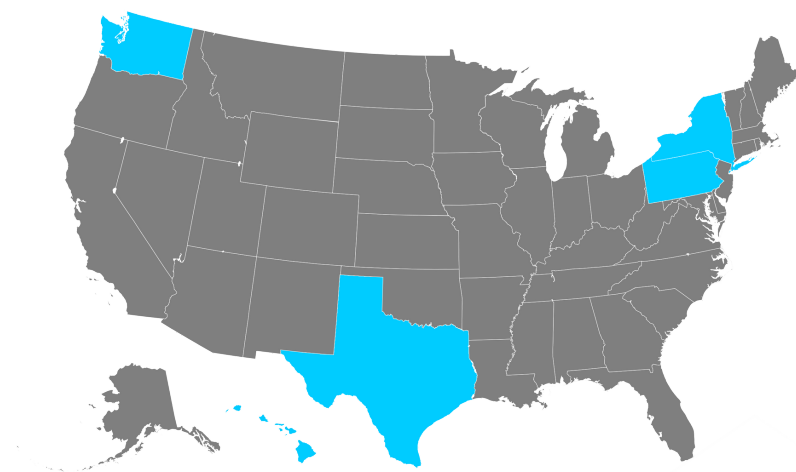
The AAP collaborated with Family Voices to develop interview protocols and recruitment materials. The project was approved by the AAP Institutional Review Board (IRB) in September 2023. Interview participants were recruited using a purposive sampling approach:

- A recruitment announcement with an online application form was disseminated to the AAP network of relevant Committees, Councils, and Sections (a total of 92 AAP membership entities).
- The recruitment announcement was promoted in the AAP weekly news magazine AAP News OnCall and to the 64 AAP chapters.
- Recruitment information was shared with other relevant organizations, including the National Association of Pediatric Nurse Practitioners, American Academy of Family Physicians, National Rural Health Organization, and the National Association of Community Health Workers.

Of 70 applicants, five pediatric providers were selected to participate based on diversity indicators including geographic location, specialty, experiences with language access, and race/ ethnicity. Individual 30- to 45-minute, semi-structured interviews were conducted virtually via Zoom with the 5 pediatric providers. Interviews were recorded with participants' consent. An AAP staff member facilitated the interviews with two Family Voices staff, who also took notes. Participating providers who completed the interview received a \$250 honorarium.

Key Informant Interviews with Pediatric Providers

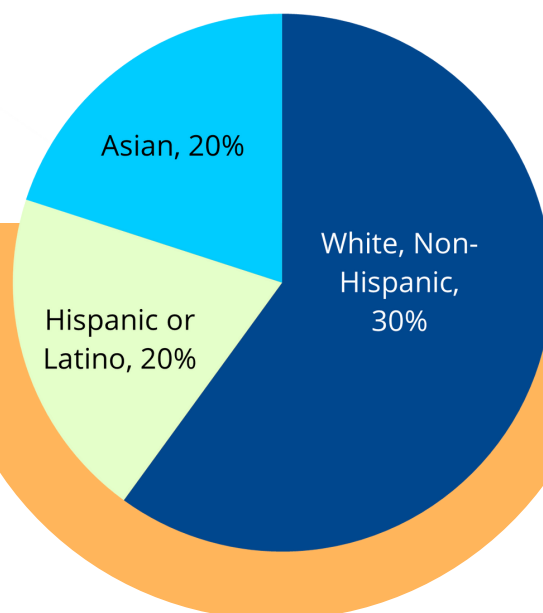
Participant Characteristics



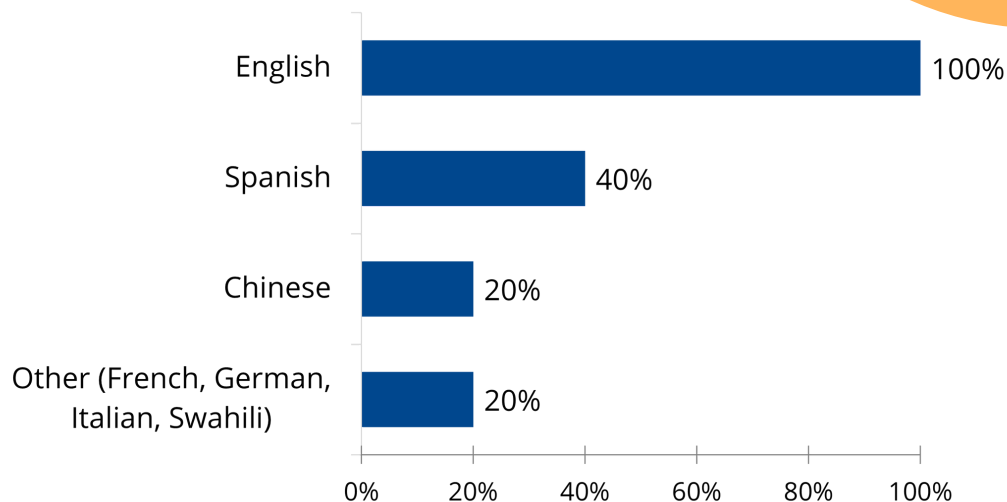
Geography

State of Residence for Interview Participants

Race/ Ethnicity



Languages Spoken



Note: Because some participants reported speaking more than one language, the percentages add up to more than 100%.

Key Informant Interviews with Pediatric Providers

Provider Experiences with Using Language Access Services

Participants' Knowledge about Language Access Law



- All participants had a basic understanding that families and patients should receive care in their preferred language and that this service is free to families and patients.
- Participants did not have a comprehensive understanding of the details around patient and family legal rights related to language access.

Participants' Use of Language Access Services



- All participants had experience using language access services with patients and families, including in-person and telehealth (audio only/ audio and video).
- Most participants reported that patients and families prefer in-person language interpretation services; however, these services are frequently more expensive (for the hospital or practice) and much less available when needed.

In-Person Interpreter Services: Provider Insights and Observations

In-person interpreter services often need to be reserved in advance, resulting in challenges when patients or families have unplanned visits.

In-person interpreter services are important for longer diagnostic evaluation appointments for developmental disabilities such as autism spectrum disorder.



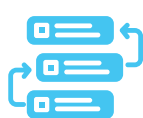
Some hospitals/ practices encourage use of telehealth interpretation services over in-person services because in-person services are more costly for the hospital or practice.

In fast paced settings such as an emergency room, in-person interpretation services are almost never available, and audio only interpretation services can be especially challenging if there is a lot of background noise.

Key Informant Interviews with Pediatric Providers

Provider Experiences with Using Language Access Services

Prioritizing Patient/Family Needs When Interpretation Services are Limited



Providers sometimes need to prioritize which patients and families will receive interpreter services when there is limited availability of these services.

Priority is given to patients and families with higher levels of medical and social complexity, including:

- New patients
- Newborns
- Patients and families with long hospital admissions (such as in a neonatal intensive care unit)

Access to Interpreter Services is More Difficult for Less Commonly Spoken Languages



- All participants reported challenges with accessing language interpretation services for less commonly spoken languages.
- Interpreter services for less commonly spoken languages are often only available through telehealth (audio only or video/audio) and require a longer wait time.
- Accessing these services is even more challenging during unplanned visits, such as those in the emergency room or inpatient hospital settings.

Key Informant Interviews with Pediatric Providers

Provider Experiences with Using Language Access Services

Some Families Decline Using Language Access Services.

Participants suggested the following possible reasons why some families whose preferred language is not English decline language access services:



- Privacy concerns, particularly for families that speak less common languages and the interpreter may be from their community.



- Bias and discrimination that families may experience due to their preferred language and/or country of origin.



- The way families are asked about their language preferences may influence how willing families are to disclose the need for interpretation services.



Language Access Services/ Supports May be Needed for Families Who Decline Interpretation Services

- Some families may decline interpretation services for a variety of reasons, providers should not always assume that patients and families understand what is being discussed.
- This is particularly important for patients and families with a low to medium level of English proficiency.
- Extended family members may also need language access services even if other families and caregivers do not (for example, grandparents).



Key Informant Interviews with Pediatric Providers

Challenges and Barriers

Challenges/ Barriers to Providing Language Access Services

Participants suggested the following possible reasons why some families whose preferred language is not English decline language access services:



Interpreter workforce shortages



Technology issues



Requires additional time



Difficulty connecting families to language access services for community referrals



Medical notes are usually only available in English.

Key Informant Interviews with Pediatric Providers

Challenges and Barriers

Interpreter Workforce Shortages



Interpreter workforce shortages are a barrier to securing language access services, especially for:

- Less commonly spoken languages.
- Situations when multiple patients/families need services in the same language at the same time but only one interpreter is available.

Technology Issues



Many participants reported technology issues when using telehealth interpretation services, including dropped calls and internet connectivity problems.

Technology issues disrupt the appointment by having to restart the appointment multiple times, often with a different interpreter each time.

This disruption can lead to distrust with the family and makes communication even more difficult, especially when discussing challenging and emotionally charged issues related to medical complexity, advance care planning, and/or end-of-life care.

Requires Additional Time



Most participants reported that the amount of time required to secure an interpreter and facilitate an appointment with an interpreter is a barrier to providing language access services.

It takes more time to care for a patient with language access needs than a patient whose primary language is English.

Participants acknowledged that while additional time is a barrier, it is also a necessary component of providing high quality care to patients and families.

Key Informant Interviews with Pediatric Providers

Challenges and Barriers

Difficulty Connecting Families to Language Access Services for Community Referrals



Many gaps in language access services exist outside the provider setting; it is difficult to find referrals for community supports and services that offer families needed language access.

Systems that serve CYSHCN are difficult to navigate and include many therapists, schools, and early childhood centers that often are only available in English.

Processes such as applying for Supplemental Security Income are especially difficult for families whose primary language is not English.

Medical Notes are Usually Only Available in English



Medical notes are usually only available in English, which creates further inequities for families whose preferred language is not English and who need access to their child's medical records.

Translated medical notes are especially important for families of children and youth with complex medical needs who need access to the detailed information included in medical notes, but whose preferred language is not English.

Informing Patients About Language Access Services

All participants reported that their practice or institution has a method in place for identifying patient and family language access needs in advance of an office visit and informing the care team of language access needs through the patient's medical record.

Most participants reported that practice managers or administrative staff ask patients and families about language access needs during the patient intake process.

Most participants reported that their practice has very limited or no promotional materials to inform patients and families about the language access services offered in their practice.

Key Informant Interviews with Pediatric Providers

Positive Impacts and Successful Strategies

- Connecting families to interpreters helps families feel more empowered to ask questions and take ownership of decision-making conversations during the visit.
- Advocating for and hiring bilingual practice staff, who can play an important role in language access as part of overall practice management.
- For bilingual providers, providing their own interpretation services for patients/ families helps build rapport and supports family centered care, but can present a challenge if medical students, residents, and/ or fellows are also present who do not speak the language.
- Some in-person interpreters have been working in their communities for many years and are often seen as cultural ambassadors.
- Offering language access services for recent refugees provides support and culturally responsive care, particularly for families coming from countries impacted by war.
- Access to a patient and family's preferred language is an important component of health equity, particularly for communities that speak less common languages and may have faced decades of generational trauma associated with colonization and other forms of oppression.
- Using the teach-back method and body language helps to communicate with patients and families, especially when an interpreter is not available.
- For visits that will involve difficult discussions related to end-of-life care and advance care planning, it helps to meet with the interpreter before the visit to prepare the interpreter for discussing these sensitive topics.
- The use of iPads for language interpretation services has been a "complete gamechanger" in improving access to language access services.

Key Informant Interviews with Pediatric Providers

Conclusions

Providers have a basic understanding of language access but could benefit from **additional education on the language access rights of patients and families**. If providers have this additional information, they can be more prepared to share it with families and empower families to ask for language access services.

In-person interpretation services are often preferred by patients and families; however, these services may not always be readily accessible or available and have higher **fiscal implications** for institutions as compared to telehealth interpretation services.

Planning ahead for interpretation services (reserving an interpreter in advance, preparing an interpreter for complex conversations) **often improves the patient encounter** and can help ensure accessibility. This may be particularly important **as the level of medical complexity increases**, such as in the instance of end-of-life care conversations and advance care planning.

The way patients and families are asked about their need for language access services matters. Some families may choose not to disclose their language access needs in **fear of discrimination** and/ or other negative consequences in the medical setting.

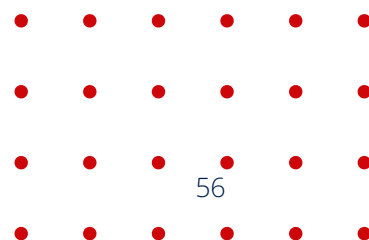
Because families may decline interpretation services for a variety of reasons, **providers should not assume that patients and families understand a patient encounter**. This is particularly important for patients and families with a low to medium level of English proficiency.

Communication **strategies such as teach-back** may need to be implemented during a visit to confirm understanding.

Extended family members (like grandparents) may also need language access services even if other caregivers do not.

Promotional materials in the practice waiting room are important to raise awareness about language access services.

Since the medical setting is just one component of the system of services for CYSHCN and their families, **language access throughout all CYSHCN system partners is critical** in supporting families and caregivers as well as patients.



Key Informant Interviews with Pediatric Providers

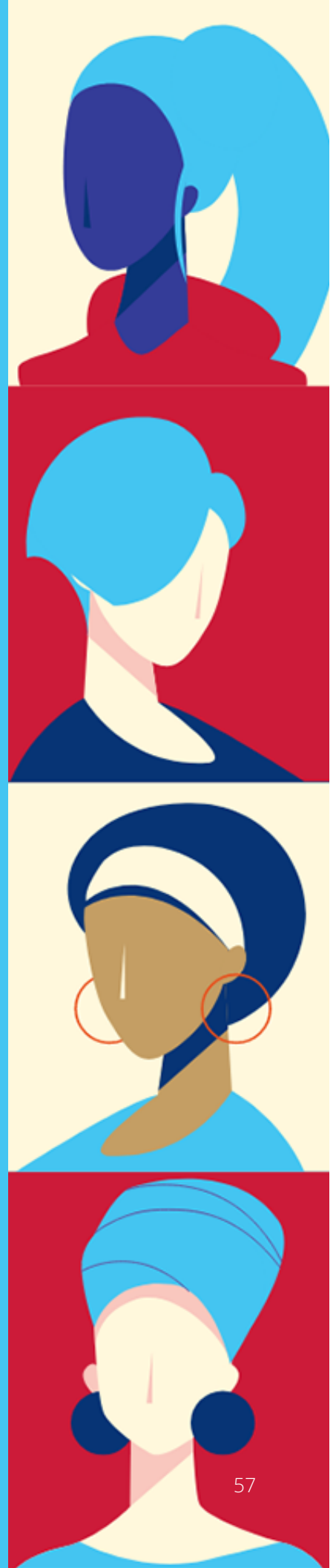
Recommendations

Educational offerings for providers focused on improving language access for CYSHCN and their families could include some of the following topic areas:

- Understanding patients' and families' language access rights.
- How to communicate and promote language access rights to patients and families, including how to ask about language preferences in culturally responsive ways.
- Strategies to prepare for visits with interpreters, in-person and through telehealth.
- How to support families who decline language access services.
- How to use communication skills, including primary palliative communication skills, with families and caregivers whose preferred language is not English.
- Strategies to connect families whose preferred language is not English to accessible community resources.

Limitations

While every effort was made to select providers from diverse backgrounds, a key limitation of this initiative was its small sample size of 5 providers and therefore potential lack of generalizability. Additional components of this project's environmental scan offer important insights to language access needs, barriers, challenges, and successes.



Medical Interpreter Focus Groups

The medical interpreter focus group was conducted in December 2023 by Family Voices and its partners. The purpose of the interpreter focus group was to identify the barriers or challenges experienced by families who cannot speak, understand, read, or write English while trying to use health services for their children and youth with special health care needs (CYSHCN) or for themselves.

Focus group findings will be used to inform program activities, training content, guidance documents, and educational resources to increase awareness, understanding, and use of language access services in health care settings for families whose preferred language is not English.

Methods

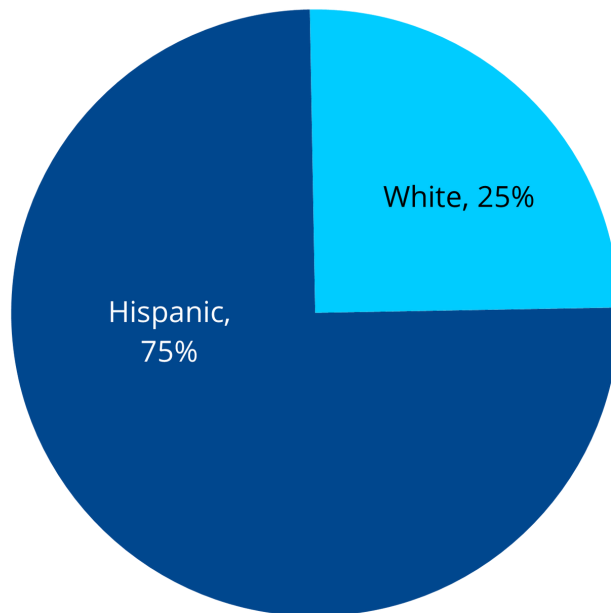
A one-hour, semi-structured focus group was conducted virtually (via Zoom) with four medical interpreters who work with families of CYSHCN. The Family Voices PEALS project team and the PEALS Project Advisory Committee (PAC) collaboratively developed a nine-question focus group discussion guide.

Focus group participants were recruited using a purposive sampling approach that involved targeted outreach through the translation/ interpretation services organization contracted by the project. In addition to the facilitator, a note taker was present to take notes on focus group discussion themes and key points. The note taker's notes were analyzed using qualitative techniques including thematic and content analysis.

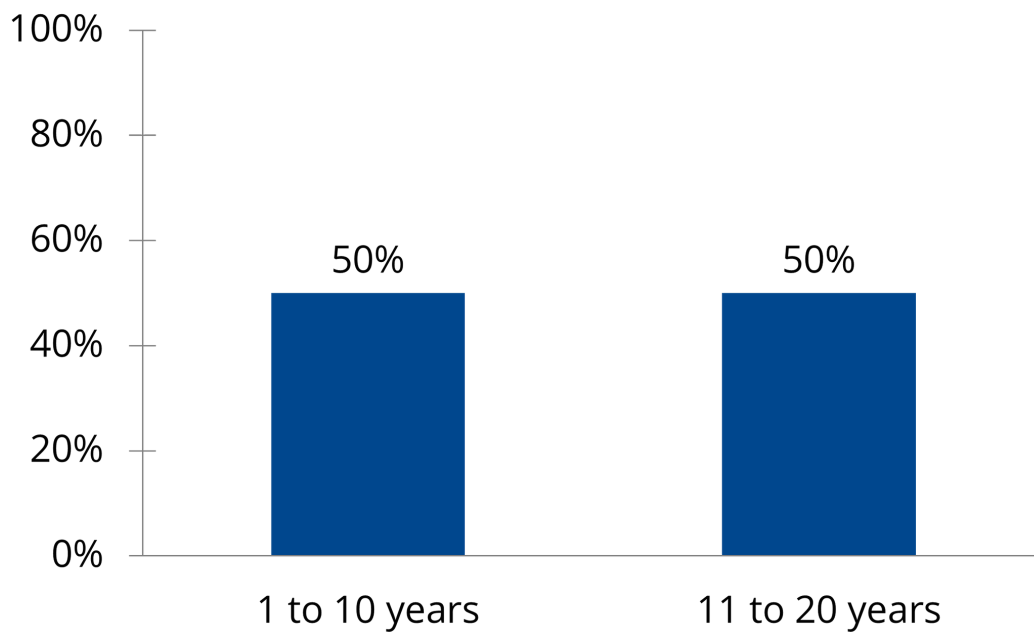
Medical Interpreter Focus Groups

Participant Characteristics

Race / Ethnicity



Years of Experience as a Medical Interpreter



Medical Interpreter Focus Group

Experiences with Providing Language Access Services



Interpreters use in-person interpretation more than other communication methods.

Participants reported that in-person interpretation is:

- Preferred by families, interpreters and providers over other communication methods (online video, phone, iPad)
- More effective, compared to other communication methods
- More accurate because it allows interpreters to see non-verbal communication and feelings
- More reliable because there are no technical issues (Wi-Fi issues, video visibility, etc.)



Interpreters enjoy helping people but are dissatisfied with the pay.

Participants' descriptions of being an interpreter:

- Interpreting is a job done for the service of people and the community, not for the pay; a good job for a "people person."
- Low pay
- No reimbursement for mileage
- Differences in pay for certain languages
- Appointments are often scheduled and/or cancelled at the last minute.
- Having multiple in-person appointments at the same practice is more cost effective in terms of time and scheduling.
- There are fewer budget constraints and more flexibility with business contracts compared to government organizations.

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Experiences with Providing Language Access Services

Barriers Faced by Medical Interpreters



Stigma; the belief that not speaking English is a weakness



Families who want to use a bilingual child or family member to interpret instead of a professional medical interpreter



Lack of stable internet connection



Privacy concerns: Interpreters and families may know each other, especially in smaller communities



Shortage of male interpreters to accommodate people who are more comfortable communicating with a male



Using face masks can make interpreting challenging

Participants' Successes



Participants reported they have noticed more Spanish speaking staff in hospital settings.



"Families **love** having in-person interpretation."

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Participants' Suggestions to Help Families Make Better Use of Interpretation Services



Increase **awareness of language access law** and families' right to interpretation and translation services.



Increase **interpreters' understanding of specific cultures and dialects**; adapt language to families' culture and dialect.



Increase **families' understanding of interpreter professional ethics** and boundaries, especially around:

- Keeping information confidential
- Building trusting relationships
- Not sharing personal opinions with families
- Not providing transportation to families

Participants' Suggestions to Improve Language Access in Hospitals and Other Provider Settings



- Increase interpreter availability.
- Hire more bilingual staff.
- Offer more provider training, especially on how to work with interpreters.
- Post reader-friendly signage about language access resources.
- Give medical interpreters as much information as possible before the appointment.

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Conclusions

Participants use in-person interpretation more than other communication methods, such as online video, phone, or iPad.

Participants reported that in-person interpretation is preferred by families, interpreters, and providers, and it is more effective, more accurate, and more reliable compared to other communication methods.

When describing their job as an interpreter, participants reported that they enjoy helping people but are dissatisfied with the low pay.

Key barriers faced by interpreters include:

- Stigma
- Families who want to use a bilingual child/family member instead of a professional interpreter
- Lack of a stable internet connection
- Privacy concerns

To help families make better use of interpretation services, participants suggested increasing:

- Awareness of language access law and families' right to interpretation and translation services
- Interpreters' understanding of specific cultures and dialects
- Families' understanding of interpreter professional ethics and boundaries

To improve language access in hospitals and other provider settings, participants suggested:

- Increasing interpreter availability
- Hiring more bilingual staff
- Offering more provider training
- Posting reader-friendly signage about language access resources
- Giving medical interpreters as much information as possible before the appointment



Medical Interpreter Focus Group Recommendations

- Identify strategies to **promote the use of in-person interpretation services** when possible.
- Plan **education and training opportunities** to increase and enhance interpreter understanding of specific cultures and dialects.
- Provide families with information and resources about **medical interpreter professional ethics and boundaries**, especially around keeping information confidential.
- Continue to **raise awareness of language access law** and families' right to interpretation and translation services.

