



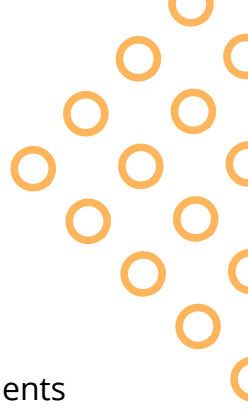
# Promoting Equitable Access to Language Services for Families of Children and Youth with Special Health Care Needs

## Environmental Scan Executive Summary

March 2024

# 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

## 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 experience 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 and translation services, especially for families who are new to the United States.





# 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

## 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 and 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.

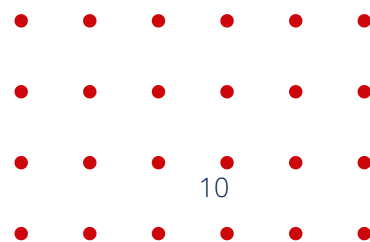
Because families may decline interpretation services for a variety of reasons, **providers should not assume that patients/ families understand a patient encounter**. This is particularly important for patients/ families with a low to medium level of English proficiency.

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/ caregivers and patients.



# Key Informant Interviews with Pediatric Providers

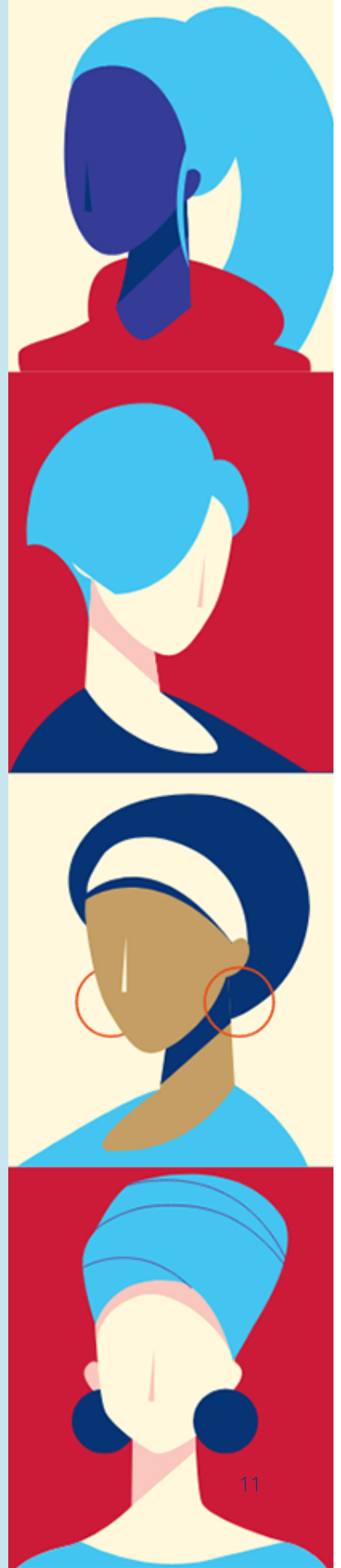
## Recommendations

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 Group

## 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."

# Medical Interpreter Focus Group

## 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 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.



# Acknowledgements

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## Project Advisory Committee

Parvaneh Alavi	Doris Moldonado Méndez
Christina Boothby	Jingwen Niu
Oanh Bui	Kristin Nordness
Aurora GrantWingate	Annie Peña
Lynda Kazairwe	Dana Summers
Giannina López	

## External Evaluator

Pamela Kelley, PhD  
*Kelley Analytics*

## Organizational Partners

American Academy of Pediatrics  
National Association of Community Health Workers  
Children's Hospital Association

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