



REDUCING BARRIERS, **IMPROVING OUTCOMES:**

Using Federal Opportunities to Expand Health Care Access for Individuals with Limited English Proficiency

SUMMARY

The United States' health care system consistently fails people whose primary language is not English, frequently known as individuals with limited English proficiency (LEP). These breakdowns result in increases in both unnecessary care due to misdiagnoses and poor health outcomes. Luckily, there are clear and actionable policy interventions that Congress and federal agencies can take to address these health disparities. By increasing the quality of languages services, making them more available, and strengthening both provider and patient understanding of existing rights and tools, we can improve the health of millions of families in the U.S.

Introduction

There are more than 25 million people with limited English proficiency in the United States, defined as people who report speaking English less than "very well." Our health care system does not adequately serve the LEP community, which represents dozens of languages and dialects. This population ranges from newly arrived refugees to indigenous communities who have resided here for centuries. One in four people with LEP have no health insurance compared to 8% for those who speak English with proficiency. And in some areas of the country, 69% of the remaining uninsured population live in households where no one has English proficiency.

The Joint Commission, a leading health care accreditation body, notes, "language barriers significantly impact safe and effective health care." Healthy People 2030, the U.S. Department of Health and Human Services (HHS) strategic public health framework released in 2020, has <u>language communications</u> as a key objective in tackling the major causes of death and disease in the United States. The American Medical Association Journal of Ethics dedicated <u>an issue</u> to language and cultural barriers given the inability of doctors to provide adequate medical care without first addressing them. In spite of this, policymakers have yet to make significant progress in improving poor health outcomes and system costs caused by language access disparities.

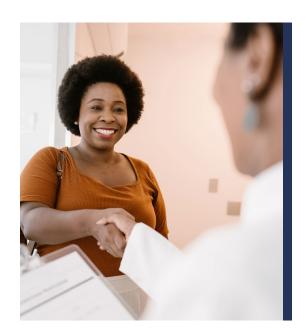
The current administration has committed to addressing language disparities. In Executive Order 14091, on racial equity and underserved communities, President Biden called for the federal government to "improve language access services to ensure that all communities can engage with agencies' respective civil rights offices." The resulting HHS Equity Action Plan commits to "address barriers to heath care and human services, such as those individuals with limited English proficiency face in obtaining information, services and/or benefits from HHS federally conducted and federally assisted programs." This paper describes how, by realizing civil rights and addressing the gaps raised by research and communities, Congress and HHS can achieve those goals.

This paper uses the term "limited English proficient" to refer to people who may need language services when accessing health care. While this term has been rightly criticized for being deficit focused, it is also the term used by many of NILC's community partners and within federal regulatory frameworks.

Research Demonstrates That Addressing Language Barriers Can Improve Health Outcomes

Decades of academic research have documented how a lack of or poor language access leads to worse health outcomes, creating a robust justification for policy interventions. There are points of failure for every interaction with a doctor, pharmacy, health insurer, public insurance agency, or hospital. For example:

- During the COVID-19 pandemic, individuals with LEP were three times more likely to test positive for the virus, and hospitalized patients were 35 percent more likely to suffer serious health outcomes compared with English speakers.
- Individuals with LEP receiving home health care are more likely to be readmitted to the hospital than those who speak English very well.



- Language barriers reduce patients' treatment adherence and chronic disease management. For example, patients with LEP make medication dosing errors twice as often.
- ▶ Individuals with LEP have worse outcomes for diseases like certain cancers and mastitis.
- ► Children with parents who are LEP are twice as likely to experience adverse medical events when hospitalized, potentially due to language barriers in communicating with their doctors.

Conversely, when language services are provided, health outcomes improve:

- ▶ While patients whose doctors do not speak their language are less likely to control their diabetes, their control improves when they switch to a linguistically matched doctor.
- An intervention in a hospital found that providing patients with LEP access to interpreters reduced their readmission rate. Similarly, a hospital system that targeted strategies to support patients with LEP during the pandemic found that gaps in health outcomes closed.
- Overall, the use of interpreters is associated with improved clinical care and outweighs associated costs.

Research also demonstrates that language services must be high quality and culturally appropriate:

- A review of Spanish language Medicaid applications found they were often written at too high a literacy level to be accessible by the target audience, making enrollment in coverage difficult.
- Attempts to use machine translation in place of professional translators have led to errors, such as when a Virginia Department of Health COVID-19 website told Spanish readers that the COVID-19 vaccine was "not necessary." The Massachusetts Board of Registration in Medicine has advised clinicians that the use of such tools can compromise patient safety.
- One in five staff members being used as interpreters in health care organizations lack sufficient skills to serve in that role while patients with LEP have expressed concerns about misinterpretation and confidentiality. Even when qualified, medical interpreters and health care providers report insufficient training in working with LEP patients. Highly trained interpreters are less likely than untrained staff to make errors in medical settings.

Surgery Misinterpretation

As shared by Sudarshan Pyakurel, Executive Director of Bhutanese Community of Central Ohio – In an Ohio Medical center in 2015, an older Bhutanese woman was being prepared for surgery. She had been provided an interpreter, but the interpreter spoke Nepali, which is distinctive from Bhutanese. When the interpreter relayed to her that she was being prepped for "surgery," the woman balked in fear and did not want to go forward with the procedure. The Nepali word for "surgery" meant "funeral" in her language.

Federal Laws, Regulations, and Guidelines Around the Provision of Health Care Language Services

In the last half century, federal language access policy has developed significantly through statutes, executive orders, regulations, federal agency interpretive guidance, and compliance activities. Over time, these policies have affirmed that access to language services is a civil right. However, confusion over legal obligations, lack of funding, and lack of enforcement mean that gaps in language access persist.

Title VI

The primary basis for language access rights is Title VI of the Civil Rights Act of 1964:

No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

Federal agencies and courts interpret Title VI's prohibition on national-origin-based discrimination to require access to language services. In 1974, the U.S. Supreme Court issued its seminal opinion in Lau v. Nichols, a class action brought by Chinese-speaking students, in which the court found that a school district's failure to provide language services denied plaintiffs a meaningful opportunity to participate in public education programs.

Alameda County Medical Center, Highland Campus (CA):

In a landmark language access complaint, in 1981, a network of health clinics and legal aid groups serving immigrant communities in Alameda County, CA filed a complaint with HHS OCR against Highland Hospital, which often relied on unqualified staff or family members of patients to step in to translate and interpret medical information. OCR investigated the complaint and mediated a settlement; the Medical Center agreed to train its staff, provide cards to patients indicating their primary language, update inlanguage signage, and contract with interpreter services. This settlement has served as a basis for other settlements in provision of health care to people with LEP.

However, individuals have often had to turn to federal and state administrative bodies to vindicate language access rights. The Supreme Court has repeatedly recognized that Title VI prohibits not just policies and practices that are intentionally discriminatory, but also actions which are neutral on their face but have a disproportionate effect on protected groups. However, in April 2001, the Court ruled in Alexander v. Sandoval - a lawsuit against the Alabama Department of Public Safety over its English-only drivers' license examination -that Title VI only provides individuals with a right to sue in federal court over intentional discrimination, not 'disparate impact' discrimination.

Cultural Competency is a Necessity

As shared by Regine Ndanga, LMSW of the Partnership for the Public Good in Buffalo, New York – A Congolese elder went to the doctor and was diagnosed with high blood pressure that required daily medication. The available interpreter did not explain this adequately to the man, who as a result, did not know what he had been diagnosed with and why the pills he had been given were important. He did not take them and was later hospitalized for his blood pressure. His family members ultimately explained his diagnosis and treatment plan in a culturally competent way so that he was able to understand how to manage his condition.

As a result, Sandoval significantly impaired the ability of impacted individuals to vindicate their rights to language access (and a host of other Title VI protections) in court and led to increased reliance on federal and state agencies to regulate and enforce language access protections.

Federal Language Access Regulations

Federal agencies have implemented regulations to enshrine Title VI protections. Since 2000, agency regulations have generally required recipients of federal financial assistance, as well as federal agencies, to take reasonable steps to provide language services for their programs and activities. Within the U.S. Department of Health and Human Services (HHS), the Office for Civil Rights (OCR) enforces language access protections through complaint investigations and compliance reviews. Yet, despite significant progress on a case-bycase basis, advocacy organizations continue to receive widespread reports of health care providers failing to provide individuals with LEP meaningful access to health programs and services as required by Title VI.

Executive Order 13166 and Federal Agency Guidelines

On August 11, 2000, President Clinton signed Executive Order 13166, "Improving Access to Services for Persons with Limited English Proficiency," directing each federal agency providing federal financial assistance to issue LEP guidance for funding recipients and develop language access plans for agency programs. HHS was the first to do so, providing a framework for funding recipients to develop language access plans tailored to their programs, activities, and LEP populations. This order has been renewed by the Bush, Obama, and Biden administrations, though to date, many federal agencies continue to provide only partial information and services in languages other than English, at best.

Mental Health Failure

As shared by Regine Ndanga, LMSW of the Partnership for the Public Good in Buffalo, New York – A Sudanese woman attended group therapy at an outpatient clinic but was not offered an interpreter in the sessions nor during follow-up conversations with a social worker. The social worker wrote out a treatment plan, including medicated interventions, but the woman never understood them and therefore did not try to reach the identified goals and took the medication inconsistently. As a result, there was no improvement in her mental health.



No In-Person Interpretation

As shared by an immigrant service organization in New York – An Arabic-speaking woman with cancer requested an in-person interpreter at her treatment sessions. While the nurse originally agreed to do so, the hospital administration later refused and would only provide a phone interpreter. The woman previously had poor experiences with a remote interpreter, who told her that chemotherapy pills were vitamin D and had been unable to describe a doctor's visual aid for bone marrow transplants. These experiences caused stress, confusion, and frustration. With help, the woman was able to navigate the hospital's bureaucracy and obtain in-person interpretation, but only through great time and effort.

Culturally and Linguistically Appropriate Standards (CLAS)

In 2000, the HHS Office of Minority Health (OMH) published <u>national standards</u> for the provision of culturally and linguistically appropriate health care. These standards include a set of 14 recommendations for adoption or adaptation by stakeholder organizations and agencies. They include many best practices for avoiding adverse health outcomes for people with LEP. The standards note that while they are not requirements, health care providers are obligated to comply with the language access requirements of Title VI.

Reimbursement for Language Services

While health care providers who receive federal funding are required to provide language services, financing remains a major barrier for patients to fully access these rights. Under the Children's Health Insurance Program Reauthorization Act of 2009, states have the option of claiming enhanced matching rates for language services provided through Medicaid. As of 2017, 15 states provide reimbursement to providers for these services. Yet Medicare does not

provide this type of reimbursement and many private insurers, including qualified health plans under the ACA (Affordable Care Act), expect providers to treat language services as an administrative expense. As a result, providers are disincentivized from proactively offering high quality language services to patients who need them.

Section 1557 and its Implementing Regulations

Section 1557 of the 2010 Affordable Care Act marked an important step towards ensuring lasting civil rights protections specific to health care settings by addressing the full scope of civil rights in health care. The law prohibited certain health programs or activities from engaging in discrimination on the grounds under Title VI, as well as Title XI, the Rehabilitation Act, and the Age Discrimination Act. Section 1557 prohibited discrimination based on a wide range of characteristics

Medical Bills Without Language Assistance

As shared by Edith Avila Olea with the Illinois Coalition for Immigrant and Refugee Rights -A Spanish-speaking immigrant went to the emergency room for an urgent medical condition but was unable to afford the thousands of dollars in bills. When speaking to the hospital staff about the costs, she asked for help understanding the situation in Spanish but was not provided an interpreter. She was only told to apply for Medicaid, which she did not think she was eligible for, and given no information about the hospital's charity program. In addition, all her discharge papers were in English, and she did not understand them. As a result of poor communication by the hospital staff, her bills were sent to collections.

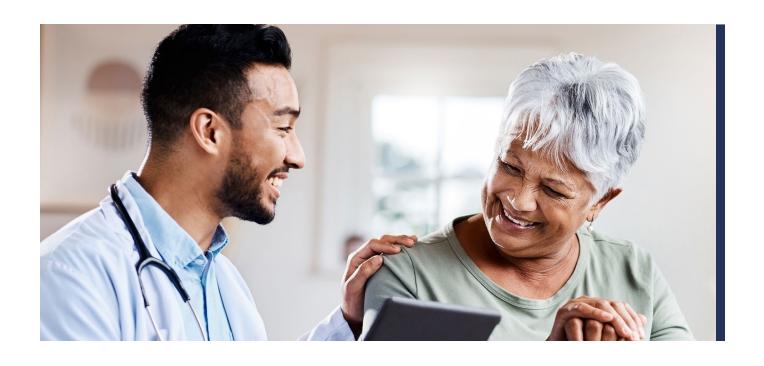
and covered any health programs and activities which receive federal financial assistance, including any hospitals that accept Medicare, doctors who receive Medicaid payments, health insurance marketplaces and issuers that participate in those marketplaces, and any health program that HHS itself administers. Although enforcement of most claims under Section 1557 fell to the HHS Office of Civil Rights and federal agencies, Section 1557 delegated authority to federal agencies to shape Section 1557 standards through rulemaking.

Section 1557 Regulations

Under Democrat and Republican administrations, HHS has issued three sets of regulations implementing Section 1557 and detailing the steps covered entities are required to take to ensure meaningful access: in 2016, 2020 and 2023. Under the first rule, under the Obama administration, HHS set standards requiring the use of qualified interpreters and translators when providing language services and prohibiting the use of family members in place of these professionals. These requirements remain in effect. It also required covered entities to post a notice of individuals' rights providing information about communication assistance for individuals with LEP. Covered entities

Unmet Special Needs

As conveyed through Gabriella Barbosa of the Children's Partnership - In California, a monolingual Spanish-speaking mother of three children with disabilities has been receiving services for her three special-needs children but has never been offered a trained interpreter by her children's doctor. Instead, they use untrained administrative staff who do not seem to understand or clearly explain what the doctor says. This has resulted in her not fully understanding her children's diagnoses, treatment and services related to cerebral palsy. For example, she was not provided an interpreter when her daughter's neurologist suspected she had sleep apnea. The doctor recommended for her daughter to have surgery to remove her tonsils to address this, but nobody ever explained how this would address her sleep apnea or why this was needed so she felt uncomfortable moving forward with the surgery. She also has never received written information about her children's diagnoses or medications in Spanish, despite having requested it from the neurologist. As a result, she feels that she cannot adequately care for her children's needs.





sending significant publications, such as notices relating to health coverage or bills, were required to include taglines in at least the top 15 languages spoken by LEP individuals statewide that indicate the availability of language assistance.

In 2020, the Trump administration issued a <u>final rule</u> repealing the notice and tagline requirements, as well as video remote interpreting standards, on the basis that the cost to covered entities outweighed the benefits. This action eliminated any specific requirements for how entities informed individuals with LEP about their access to language services. During the COVID-19 pandemic, after reports of failures to provide language access in public health outreach, the Trump administration also issued a bulletin reminding covered entities of their civil rights obligations.

In the fall of 2022, the Biden administration issued its own proposed rule interpreting Section 1557. The proposed rule, expected to be finalized in 2023, would expand the definition of LEP individual to include persons who may be competent in English for certain types of communication, but still be LEP for other purposes. It also:

- ▶ Requires covered entities to adopt a non-discrimination policy and language access procedures, including a staff training requirement and the appointment of a designated language access coordinator.
- ▶ Requires covered entities to include, in certain communications, a notice of availability in at least 15 languages on how to access language and disability communication services. These notices are similar to the taglines required under the 2016 rule.
- Addresses the use of automatic translation services, such as Google Translate, requiring that covered entities which use these machine translations have materials reviewed by a qualified human translator.

However, even strengthened civil rights regulations are useless if those who fail to receive meaningful access are unaware of their rights or if the civil rights office lacks the staffing to ensure compliance. In many cases, even HHS itself fails to comply with the spirit of these requirements due to inadequate resourcing, prioritization, and clarity.

RECOMMENDATIONS FOR FEDERAL POLICY MAKERS

Language barriers to accessing health care persist, often resulting in significant health disparities for individuals with LEP. Federal policy makers have a range of opportunities to step in to fill these gaps when private entities lack the resources or capacity to do so. The following recommendations outline ways Congress and HHS can begin to improve health outcomes for people with LEP. The recommendations address three areas: strengthening awareness of existing language access standards; improving the quality of language access services; and addressing gaps in the provision of services.



Strengthening the Availability of Language Access Services

CONGRESS

Provide Reimbursement for Language Services in Coverage Programs

- Recommendation: Require Medicare to reimburse providers for interpreter services in a clinical setting without any cost-sharing requirements for enrollees.
- Why? Currently, Medicare expects providers to treat interpreters as administrative expenses. While providers are expected to provide language services under civil rights law, requiring them to treat language access services as an additional clinical expense puts providers who treat high numbers of patients with LEP at a disadvantage due to the unreimbursed costs.

Dedicate Funding for Language Services in HHS Programming

Recommendation: Provide dedicated appropriations for HHS to regularly produce in-language written and video content and hire more multilingual staff. To support this work, develop an HHS staff corps of on-

- staff language service workers available to support HHS funded programs, drawing on the model of the Department of State's Office of Language Services.
- Why? There is no dedicated funding stream to ensure that HHS resources are available to individuals with LEP, resulting in low prioritization and inconsistent level of service. A dedicated funding stream would address budget conflicts between provision of inlanguage services and other important tasks.

Provide Language Access Funding for Safety Net Providers

- Create a stream of funding for provision of language services by federally qualified health centers and other entities that serve populations with higher rates of LEP. For example, the funding could be used to compensate multilingual staff, as envisioned by the Mental Health Workforce and Language Access Act.
- Why? Safety net providers are more likely to treat people with LEP, but lack the extra resources required to do so.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Strengthen Language Access in Medicaid

- Recommendation: Identify and address barriers to states taking up the Medicaid option to claim an enhanced match to address language services. For example, identify common questions or concerns and then address them in a State Health Officials letter encouraging states to utilize this option, while highlighting successful practices in states that have taken it up.
- Why? While approximately 10% of Medicaid recipients have LEP, for nearly 15 years, states have had the option to claim enhanced Medicaid funding for their own provision of language services or to develop arrangements so that providers can obtain these services. However, only a third of states have done so.

Require Applicants for Federal Funding to Demonstrate Their Plans for Language Access Compliance

Recommendation: Given that all recipients of federal funding must provide meaningful access to people with LEP under Title VI, require that all funding applications include the specific steps prospective grantees will take, including budgeted line items, for how they do so. When

- conducting compliance reviews, incorporate whether these steps were achieved.
- Why? HHS funds thousands of entities every year but cannot monitor all of them to ensure they are following Title VI requirements. Including compliance expectations as part of the funding review process will make expectations clearer for applicants, and the agency can better provide accountability for civil rights.

Fund Community Organizations Best Positioned to Serve People with LEP

- ▶ Recommendation: For federal grant programs likely to serve LEP communities, prioritize funding, such as assigning points during grant application reviews, for organizations that can demonstrate a consistent history of high-quality service provision for individuals with LEP and connection to communities with high numbers of multilingual individuals.
- Why? Organizations with deep ties to communities with high numbers of people with LEP are often at a disadvantage in competing for federal grants because they lack significant fundraising staff. Strengthening the competitiveness of grant applications from these organizations by recognizing their ability to work directly with impacted populations will better position them to receive funding.



Improving the Quality of Language Access Services

CONGRESS

Promote Best Practices for Health Information Technology Access

- Recommendation: Develop a federal taskforce to document best practices on accessibility for people with LEP in accessing telehealth or patient portal platforms, soliciting input from consumers, providers, and developers.
- Why? Many telehealth platforms do not allow for third party interpreters to participate in service delivery, such as joining virtual visits. In addition, access instructions tend to be only in English. Individuals with LEP are less likely to select telehealth options when available. A taskforce would help technology developers understand how to make their products more accessible while providing best practices for providers to reference when selecting venders.

Fund Community Review of Translated Material

- Recommendation: Create a new grant program within HHS to fund community-based organizations to review in-language materials produced by the agency or its contractors and grantees for cultural competency and appropriate literacy.
- Why? Community review is a best practice in translating materials, however current federal agency practices are inconsistent as to whether this occurs and when community groups are asked to review materials, they are usually not

compensated. Without community review, translated materials lack cultural competency and often must be re-translated for use within the targeted community to better reflect common terminology and literacy levels.

Ensure Coverage Agencies, Issuers and Providers Can Proactively Provide In-Language Communications

- Recommendation: Require federal health insurance programs to collect data on beneficiaries' primary written and spoken languages and share that data across health systems. This information should be collected and shared for all enrolled members of a household, while maintaining strong privacy standards. For beneficiaries utilizing programs run through private insurance, such as Medicare Advantage, Medicaid Managed Care, and Affordable Care Act Qualified Health Plans, primary language information should be shared with beneficiaries' insurance companies. Allow the company to similarly transmit this data to selected primary care providers.
- Why? The best practice of proactively providing information in individuals' primary language is not possible when agencies, issuers, and providers are not already aware of that language. Currently, applications for ACA and Medicaid coverage ask for the primary language of only the applicant, not others on the case, and do not share that information with providers.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Use Standardized Words for Translation

- Recommendation: Develop standardized glossaries in multiple languages to guide the translation of words and phrases commonly used across HHS programs, akin to those developed by the IRS.
- Why? Literal translations often fail to resonate with their intended audiences. Some words do not have a clear corollary in all languages. HHS should ensure consistency when complex health/medical terminology is translated into other languages/dialects. Having ready-to-use terms and phrases, vetted through native speakers, would also allow for faster and more consistent translations.

Further Define "Qualified" Language Service Providers

- Recommendation: Develop definitions of "qualified interpreter" and "qualified translator" for use in both internal HHS programs and among entities subject to Section 1557.
- Why? Current regulations require use of qualified professionals in ensuring meaningful access but lack consistent definitions and standards to help health care entities and

language service companies evaluate language service providers for quality and skills by providing a baseline comparison point. Patients have complained about poor experiences when working with language providers who seem unversed in a given language or in standard interpreting practices.

Ensure Agencywide Language Access Quality and Coordination

- Recommendation: Create an HHS Office of Language Access for the purposes of providing and coordinating language access services across all divisions, including ensuring compliance, contracting with language access companies, and providing trainings and best practices. Require each division within HHS to have a lead language access coordinator working in coordination with the office, following the model of New York state.
- Why? HHS lacks transparent standards and coordination for its own meaningful access compliance, beyond its language access plan, which is currently being updated. Divisions have multiple, duplicative contracts with language service providers and lack clear, consistent business practices for when and how to provide in-language communication.



Realize Existing Civil Rights Protections

CONGRESS

Create a Universal Language Access Symbol

- Recommendation: Authorize and fund the creation and dissemination of a universal symbol that indicates the availability of language access services, along with a campaign to work with health care and community stakeholders to implement the symbol.
- Why? When faced with information in English, such as a notice or bill, individuals with LEP need to understand how to access help in their language. A symbol would be a more streamlined and direct way of providing this information than existing methods. Taglines, which are required across different programs, are typically accessible in only 15 languages and are often missed, being appended at the end of notices. Providers and issuers have also expressed concerns about the costs of taglines. A symbol, which could be accompanied by a phone number or link to website via QR code and URL, if properly implemented, could be adopted in paper notices, web pages and physical locations. Australia has adopted its own version of a symbol for interpreter availability.

Adequately Fund the HHS Office For Civil Rights

- Recommendation: Increase appropriations to the HHS Office for Civil Rights to match its caseload so the agency can proactively enforce Title VI regulations and disseminate best practices to covered entities.
- Why? As pointed out in the HHS fiscal year 2024 budget request, OCR's budget has essentially remained flat in recent years while the number of complaints filed has increased by more than 50 percent. Individuals with LEP need a well-funded civil rights office for proactive enforcement and efficient resolution of complaints, while covered entities need more clarity and guidance than can be provided with current staffing levels.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Educate Health Entities About Their Civil Rights Obligations

- Recommendation: Develop an ongoing education campaign, with roundtables, webinars, and other forms of outreach, aimed at health entities covered by Title VI and Section 1557 to inform them of their responsibilities, and available resources, for serving patients with LEP.
- Why? Health care providers, especially smaller practices, may lack the resources necessary to fully understand and carry out their obligations under civil rights laws. HHS should make it as easy as possible, through education and resources, to comply with updated language access regulations.

Demonstrate the Consequences of Failing to Provide Language Services

- Recommendations: Regularly publish the results of all investigations and compliance reviews by OCR regarding language access, including unpublished administrative law judge decisions and settlements and compliance agreements. Publish an annual report on the number of language access complaints filed, by category, and the resolution or lack thereof. Adopt clear internal standards for how and when this information is provided.
- Why? Since civil rights regulations allow for variance depending on circumstances, covered entities and advocates lack full context to understand if a violation is occurring. By being able to understand how past complaints have been resolved, for example, advocates can refer to precedent in encouraging covered entities to provide services, without going through the process of filing a complaint.











