Tracking Barriers to Health Care: Issues Affecting Individuals with Limited English Proficiency

A Pittsburgh Perspective

Issue Brief

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Executive Summary

This project was made possible through funding from the Children’s Health Insurance Program Reauthorization Act (CHIPRA). The Act authorized funding to help reduce the number of instances in which children lost health coverage through Medical Assistance or the Children’s Health Insurance Program (CHIP). Ultimately, the funding seeks to ensure that all uninsured children are not denied access to health insurance.

Through Consumer Health Coalition (CHC)’s enrollment efforts, it was discovered that language barriers are one reason that many children are losing coverage. As a result, CHC reached out to several of its partner organizations that also work with consumers with Limited English Proficiency (LEP). A group was formed and charged with identifying and tracking barriers experienced by LEP consumers.

As noted, all of the organizations work with LEP consumers, and as a result, possess firsthand knowledge of the barriers that exist for consumers who are trying to access public health insurance programs. Together, the group was able to identify several types of common barriers to care, not only in the health care setting, but also in other social service agencies. A tracking form was created and organizations were asked to document barriers as they happened.

When CHC began analyzing the barriers, trends were immediately identified. It was obvious to CHC that LEP consumers faced challenges receiving legally-required translation services when seeking medical care. This, in many cases, led to a lack of informed consent. It was also clear that their limited English caused delays and lapses in health insurance coverage.

This report outlines CHC’s process and findings. It also highlights several examples of barriers faced by clients of CHC and/or a partner agency. The evidence documented represents times when clients, or advocates working along with clients, faced clear barriers in client care, which triggered the need for assistance. In many cases, clients’ civil rights were violated (i.e. lack of informed consent and lack of interpretation services.) Under Title VI of the Civil Rights Act, all health care providers who receive federal funding must provide meaningful access to their programs for persons with limited English proficiency. This report is meant to serve as a public education tool and for use in advocacy efforts to address and eliminate barriers and to promote positive change.
Background

CHC assists many families with the application process for public health insurance programs. Due to the amount of paperwork required and the constant interaction with the caseworkers, Limited English Proficiency (LEP) consumers face many difficulties during the application process. Many of the consumers CHC encounters are Spanish-speaking and require additional assistance. To ease the process, CHC’s bilingual staff facilitates the application for the consumer. A number of its community partner organizations assist families who speak English as a second language, in addition to Spanish speakers. In fact, the 2005-2009 census data estimates that in Pittsburgh 29,460 people, or 9.9% of the population, speak a language other than English at home. This statistic shows that nearly 1 in 10 people may face a language barrier. Without the help of CHC, some LEP consumers face various barriers in obtaining and retaining insurance coverage.

All of CHC’s community partners were essential in contributing to this report. One such partner that assists women through their pregnancy has extensive contact with LEP consumers. Every woman receives prenatal care (generally 10-14 appointments over the span of the pregnancy, usually with the same provider). This includes: a minimum of one ultrasound, WIC service, labor and birth care, post-partum care, applying for public assistance, and newborn and pediatric care. Given the scope of services received, there are many opportunities for a woman and her family to experience miscommunications and misunderstandings with her health care providers.

CHC’s other community partners that also have face-to-face interactions with consumers were indispensible in contributing to this report. These interactions are important when assessing potential barriers because many times a consumer does not realize that they are being faced with a barrier. This is due to the fact that they simply do not understand what is happening. By having a staff member from a community partner present, these barriers, that might have otherwise gone unnoticed, were documented and included in our data.

Barriers Surveys

In addition to CHC witnessing barriers to accessing insurance, CHC’s community partners noticed language barriers were affecting access to quality medical care. As a result, a work group was formed to address barriers faced by LEP consumers. Initial meetings of the work group concluded that in order to bring attention to the issue, it would be necessary to develop a mechanism for recording occurrences of barriers. Once the barriers were recorded they could be tracked and analyzed, and a plan could be developed to correct the issues.

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1 U.S. Census Bureau, 2005-2009 American Community Survey
Immediately, the group drafted what was later named the “Tracking Barriers to Care” form. Through its discussions, the group identified a number of recurring problems/themes. These issues were included in the form (examples of the list can be found later in this report). Other information such as the date of occurrence, where the incident took place, the LEP speaker’s primary language, the barrier that occurred, and any anecdotal evidence were also included in the barrier form. To ensure the privacy of all consumers no identifying information was required in the barrier form.

Forms were distributed to work group members and their staffs, as well as other partner organizations that work with LEP consumers. Individuals working with the LEP consumer were asked to fill out a form every time a client experienced a barrier. All forms were then forwarded to CHC for compilation. The group began tracking barriers in March of 2010, and collected forms over a five-month period. CHC received barrier forms from a number of its partner organizations. During the five-month period, a total of 122 barriers were documented and returned. It should be noted that in some cases multiple barriers were encountered by one client in a given situation and therefore recorded on one form.

Note: The barrier forms were collected from a relatively small number of organizations that frequent a limited service area and number of providers. Also, the data was collected during a short time period; from March 2010 through August 2010. Although all community based organizations’ staff members were urged to document every case where a barrier was encountered, there is a strong possibility that some cases went undocumented. Despite the groups’ efforts to document every occasion when language barriers were an issue, it is unlikely that this occurred.

Tracking Process

The most common barriers experienced include:

1. Agency/Institution would not make appointment for client unless client provided a translator at their own expense or inconvenience;

2. No oral translation (blue translation phone, in-person agency-provided) provided upon request and/or no necessary written or visual materials (consent forms, registration forms, medical information, required video advisory, etc.) provided upon request;

3. Lack of informed consent (materials not available in native language, clear understandable information not given, questions not answered);

4. Personnel asked questions or made statements that could be construed as inappropriate during professional interaction (examples: Why don’t you speak English, continued questioning regarding Social Security Numbers);
5. Registration staff or financial counselors did not request Emergency Medical Assistance (Medicaid) application and/or hospital staff did not file Emergency Medical Assistance application;

6. County Assistance Office rejected application for Medical Assistance or other assistance and consumer does not understand why they were rejected;

7. CHIP provider rejected application and consumer does not understand why they were rejected; and

8. Telephone call or mail correspondence conducted in English after request for native language.

**Results**

Upon completion of the five month tracking, CHC compiled the barrier reports in order to analyze the data. CHC received barriers affecting LEP consumers speaking five different native languages: Spanish, Burmese, Arabic, Nepali, and Burundi. In addition, issues occurred at 20 different institutions across the City of Pittsburgh. The institutions included, but were not limited to hospitals, County Assistance Offices, physician offices, and dental offices.

In total 122 barriers were reported. The analysis showed that the two most common barriers were “lack of informed consent” and “lack of translation services”. These two barriers occurred 71 times, and represent 58% of the total barriers collected. In each of these instances medical care and/or insurance access were compromised as a result of the client’s lack of understanding due to the institutions failure to provide translation services despite the client’s request.

Beyond the two most prevalent barriers, other barriers reported also led to lapses in medical care and/or losses or denials of insurance coverage. For example, 17 times institutions would only see the client if they provided their own translation services, 11 times information was provided in English when requested in an alternative language, and 7 times consumers were subjected to inappropriate questioning such as “why don’t you speak English” and “why are you in the US without US identification”.

Also reported were instances in which County Assistance Offices rejected Medical Assistance applications and consumers were unable to understand why. The same was true for the Children’s Health Insurance Program - applications were rejected and consumers did not understand the reason. In the case of Emergency Medical Assistance, it was documented that completed applications returned to hospital staff were never submitted by the hospital.
Several actual situations are recounted below to further illustrate the variety of situations that led to lapses in care and coverage. All names and identifying information have been removed to protect the privacy of the individual and institution.

**Example One – Lapse in Insurance Coverage** - “Application for Medical Assistance for a child was rejected by the County Assistance Office. The notice stated income verifications were not returned. Staff member had sent verifications from the consumer with a note identifying the documents as income verification. The documents were disregarded by CAO because they were in Spanish. To assist the consumer, the community based organization staff member resent the original verifications with an English translation. Once received with the English translation, application was approved.”

**Example Two - Lapse in Quality Medical Care and Unnecessary Multiple Visits to Provider** - “Advance request [for translation services] was not necessary because the woman entered the hospital through the ER. No translation was offered by the hospital for the pregnant Spanish speaker. Hospital records reflected that the doctor didn't understand the woman's symptoms and were treating her for symptoms she didn't have. The woman ended up at a community based organization’s office with severe fever and urinary tract infection because she had been treated for dizziness, a symptom she never had. She ended up being sent back to ER for treatment where she had been three days before.”

**Example Three – Inability to Provide Proper Instructions** - The absence of translation services led to inappropriate solutions, such as using a family member or unqualified interpreters, to translate during a procedure.

“Woman was scheduled for a mammogram, requested an interpreter, but one was not provided. She ended up having her teenage son in the room to interpret during the procedure.”

**Example Four – Refusal to Provide Care** - “Three year old refugee needed to have teeth pulled at [dental institution]. Family was completely denied service, even after the community based organization’s staff member offered to locate and pay for a translator. The woman at [the dental institution] said they would not serve the family because of their ‘language problem.’ The family had Medical Assistance and the dental institution was a participating provider.

**Example Five – English Correspondence Despite Request for Native Language** – “Consumer received renewal papers in English and did not understand them. Only when I called her to remind her to complete the paperwork did she realize what they were for. She went directly to the Department of Public Welfare to have someone help her. Original application was in Spanish, renewal papers sent in English.” Five cases were documented to have affected consumers during the renewal process, and multiple other cases
were documented that affected billing, communication, and appointment scheduling.

Example Six – Errors in Medical Care - “Advance request for [translation services] was not necessary as man entered through ER. Spanish-speaker entered ER and was hospitalized for 3 days. Never once received phone or in-person translation. Upon looking up hospital records at PCP’s office, several errors had been made in the man’s chart, presumably because of lack of translation, including incorrect age, patient name, and description of accident.”

Federal and State Laws

Both federal and state laws prohibit national origin discrimination as it affects persons with limited English proficiency. Federal requirements derive from Title VI of the Civil Rights Act of 1964 ("Civil Rights Act"). The purpose of the Civil Rights Act is to ensure that federal money does not support activities that discriminate on the basis of race, color, or national origin.2

Under the Civil Rights Act, all health care providers who receive Federal financial assistance must provide meaningful access to their programs by persons with limited English proficiency. Federal financial assistance includes grants, training, use of equipment, donations of surplus property, and other assistance paid for completely or partially with federal funds (including payment for services provided to Medicare, Medicaid, and Children’s Health Insurance Program enrollees). Thus, in the health care context, this includes virtually all:

- Hospitals.
- Nursing homes.
- Home health agencies.
- Managed care organizations.
- Physicians.
- Other providers who receive Federal financial assistance from HHS, such as County Assistance Offices, WIC, etc.

Legal Obligation

Under the Civil Rights Act, there is an absolute obligation on covered providers to:

- Provide competent interpreter services free of charge.
- Offer oral and written translations of important documents.
- Notify LEP persons of their rights to interpretive services.

2 42 U.S.C. s. 2000d.
Importantly, in meeting its obligations, a health care provider may not require a person with limited English proficiency to provide his own interpreter and especially may not require the use of a family member. Providers receiving federal financial assistance from the Department of Health and Human Services (HHS) have also been reminded, via policy guidance, of their obligations under the Civil Rights Act.

Pennsylvania state law echoes these rules by requiring providers to post translated signs and provide translated materials when the “regular” patient population is non-English speaking and provide interpreters for non-English speaking patients.

Medical care providers and federal institutions are required to provide translation services to LEP consumers at no cost. As stated by the laws cited above, federal and state laws require health care providers to offer interpreters to individuals who do not speak English well. If a provider discriminates against individuals, the HHS Office for Civil Rights can initiate investigations or respond to complaints of discrimination.

**Conclusion**

Although the report’s findings are limited, CHC believes its findings reflect pervasive discrimination based on language and ethnicity. Though its sample size is small, CHC was able to document instances of poor medical care and access due to language and cultural barriers using the Tracking Barriers to Care Forms. The Tracking Barriers to Care Forms allowed CHC to identify the problems at the source. On behalf of these documented cases, as well as the countless others that go undocumented, this report was drafted to demonstrate the vital need for a non-discriminatory solution and the implementation of widespread positive change so that all persons, regardless of sex, ethnicity, race, or primary language are not denied services.

CHC will continue to work with organizations and institutions to bring attention to the problems that consumers have faced while seeking medical insurance and/or health care. By making organizations, institutions, and individual consumers aware of these problems, CHC hopes that procedures currently in place that have the potential to limit access to services will be corrected.
Appendix A

Appendix A shows the percentage-breakdown of barriers by type. Along with “lack of consent” and “no oral translation”, other barriers were experienced as well. Such examples include “County Assistance Office Rejection”. Consumers that fell into this category experienced problems understanding approval and rejection notices because of confusing wording and/or the letters were not sent in the consumer’s requested native language. In some cases, notices were not even received by the consumer. Another barrier that occurred included “inappropriate questioning”. In this case, workers at County Assistance Offices and other providers or their staff, were reported to have inappropriately questioned a client. Examples include stating that the family should not be “here”, “Why don’t you speak English?” and “Why are you in the U.S. without U.S. identifications?” Other barriers include: inability to reach a caseworker, voicemails being full, and applications taking longer than thirty days to process within the Department of Public Welfare.
Key

Treq- (Translation required) Agency/Institution would not make appointment for client unless client provided a translator at their own expense/inconvenience.

NOT- (No oral translation) No oral translation via phone or in-person interpreters provided upon request; and/or no necessary written or visual materials (consent forms, registration forms, medical information, required video advisory, etc.) provided upon request

LoC- (Lack of consent) Lack of informed consent (materials not available in native language, clear understandable information not given, questions not answered).

IQ- (Inappropriate questioning) Personnel asked questions or made statements that could be construed as inappropriate during professional interaction (examples: Why don’t you speak English, Continued questioning regarding SSN)

EMA- (Emergency Medical Assistance) Registration staff or financial counselors did not request Emergency Medical Assistance application and/or hospital staff did not file Emergency Medical Assistance application.

CAOrej- (CAO rejection) County Assistance Office rejected application for MA or other assistance and consumer does not understand why they were rejected.

CHIPrej- (CHIP rejection) CHIP provider rejected application and consumer does not understand why they were rejected.

Engcorr- (English correspondence) Telephone call or mail correspondence conducted in English after request for native language. Where did this occur.

O- (Other) Other situation or circumstance.
Barrier Complaints Received

N = 122