**To:** Mayor’s Office for People with Disabilities

**From:** Daniela Arias Rodriguez

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**Re:** Federal and State Mandate to Improve Health Literacy in Deaf Population using American Sign Language.

**Statement Issue:** In the United States, roughly 100,000 to 1 millions of people communicate essentially through American Sign Language (ASL) (Barnett et al, 2011). Just like any other minority group, individuals of the sign language community faces health care inequality in which language and communication barriers are common factors. Deaf communities tend to have low health literacy due to inaccessible information that is normally available to hearing persons (Pollard, 1998 as cited in Barnett et al, 2011). The lack of health resources and poor professional training with ASL patients make more difficult to address the low health literacy in the deaf community. As the National Association of Deaf (NAD) describes “Healthcare is routinely inaccessible to deaf people due to communication and linguistic barriers.” Low health literacy has been linked to poor adherence to treatment, appointment follow-up and provider’s recommendation.

**Background**

* **Deaf community has insufficient knowledge about common health problems.** Deaf communities of United States, Brazil and Swaziland have scarce knowledge and understanding of the propagation of HIV (Bisol et al, 2008 as cited in Kuenburg, 2015). Moreover, in a sample of 203 deaf adults, 60% couldn’t identify symptoms of stroke, and just 49% of deaf participants were able to identify symptoms of heart attack as compared to the US population in which 90% is able to name these symptoms (Margellos-Anast, Estarziau, & Kaufman, 2006 as cited in Kuenburg, 2015).
* **Public messages are not suitable for the deaf community**. The communication and language barriers of the deaf communities restrict them from mass media messages and critical health information (Barnett et al, 1999 as cited McKee et al, 2011)
* **Deaf community has low English competency.** The reading English level of an ASL individual is at or below 6th grade. (Allen et al 1986 as cited in Kuenburg, 2015). Because of their hearing incapability and language differences, deaf ASL users have difficulties comprehending written English (Allen et al, 1986 as cited in McKee, 2015).
* **Deaf individuals tend to have lower health literacy than hearing population**. Based on study of 166 deaf participants, 48% have poor health literacy and were 6.9 times more likely to have low health literacy than hearing participants in the study. (McKee, 2015)

**Policy Option**

* The establishment and funding of community programs intended to educate deaf population on health education matters at federal or state level. These community programs should be imparted by competent and qualified ASL staff knowledgeable in health issues. In this community programs, health issues related to HIV, cardiovascular disease, diabetes, family health and hereditary conditions, preventive medicine, alcohol, substance abuse and mental health should be addressed. Information sessions and video-base workshops in ASL should be an integral part of this health education initiative. Another important component should be “prevention week” in which providers and health professionals qualified in ASL impart preventive care.
* **Advantage:** The deaf community would be informed and knowledgeable of health issues affecting their community and the general population. Improving their health awareness would also increase their health literacy; consequently, they would be more prone to maintain treatment adherence, follow their provider’s advice, navigate effectively the health care system and share critical symptoms with their providers. By improving health literacy in the deaf community, health disparities in this population can be potentially reduced. Moreover, these community programs can collect health data for the Center for Disease Control and Prevention (CDC) and the Department of Health and Human Services (HHS), since data related to the health of deaf population is lacking.
* **Disadvantage:**  Health community programs would add more expenses to the current health care expenditure or would reduce the fund predestined to other federal or state agencies. This increase in health care expenditure could be reflected in others federal organizations not related to health management and delivery. Moreover, unequal geographic distribution of deaf population could affect the establishment of these community programs in certain neighborhoods over others.
* Public health facilities receiving federal or state fund would be require to incorporate ASL written instructions in critical health forms. This policy would also require public health facilities to have accessible written and visual (video) health related material directed to deaf and hard hearing population in waiting areas, information desk, provider’s office and facilities’ corridors. This policy could be implemented at the state level.
* **Advantage:** Deaf and hard hearing patients would have access to common health issues and prevention in their prefer language which commonly is ASL. Deaf individuals will have first -hand experience and autonomy to read, fill-out and sign hospital and health documents and forms. This initiative will help deaf population to become familiar with common processes in the health care system.
* **Disadvantage:** Incorporating new health form with ASL instructions in hospitals and health facilities would be costly as well as monitoring that these public health facilities follow the regulations. This could be a financial and logistic barriers for the Department of Health and Human Services which is responsible for enforcing health regulations. Even though ASL is mostly the prefer language by the deaf community, differences in ASL competencies might exist across the deaf population. This could interfere with the effectiveness of the ASL written form and health material.
* Establishment of a deaf patient navigation system in hospital and health care facilities at the state or federal level. Through this system, deaf and hard of hearing patients can get personalized assistance that focus on prevention, diagnosis, understanding the health care system and its processes. Interpreters should be an important component of the navigation system.
* **Advantage:** By implementing a patient navigation system for deaf population, their awareness to preventive measures, diagnose and treatment can be improved. They would have the tools to effectively navigate the health care system and become familiar with health resources and their right as patients. This initiative can encourage deaf patients to actively participate in their care and health care decisions. Previous success was obtained with the navigation system established in Harlem Hospital Center of New York City in an attempt to improve cancer diagnose and treatment in individuals with low SES (Freeman, 2011).
* **Disadvantage:** Funds to establish and maintain the program can be costly. Despite the efforts of the Americans with Disabilities Act (ADA) to decrease health disparities, it is an area lacking of resources. Financing ASL interpreters is still a barrier (Barnett 2011). Therefore, financial resources could be an obstacle to recruit ASL staff and interpreters for the deaf navigation system.

**Policy recommendation**

Considering the low health literacy of the deaf community in common health topics, the community program that addresses directly their poor health literacy and provide preventive services seems the most effective policy option. Although, this policy option would require an generous financial investment to maintain the facility, pay medical and non-medical staff, ASL facilitators and among other administrative cost. If these community centers are strategically placed in neighborhoods with average to high deaf population, their health and health literacy can be greatly improved. Despite the considerable financial burden, it is the policy option that could best address the low health literacy in the deaf community.

**Sources**

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