

Testimony for S.302
02/20/2014

Hello, my name is Christel Tonoki. I am from Williston, and I am a senior studying Public Health Sciences at the University of Vermont. I discovered the Alzheimer's Association through an internship course provided by my college.

Today I will be testifying in support of S.302 An act relating to public health outreach programs regarding dementia risk. I want to touch on how a lack of cultural relevance, health literacy, and patient provider care communication has shown up in Congolese communities in Vermont. My parents are from the Congo and came here about 22 years ago and had me. While they've worked hard to integrate fully into the language and culture, it wasn't always like this. In my younger years, I frequently found myself acting as a translator in settings like grocery stores, school meetings, and doctor appointments. While this might appear typical for immigrant children, my studies in public health have enlightened me to the burden it places on a child. It's essential to clarify that the issue isn't merely encountering individuals who don't speak English, but rather the lack of supportive systems and programs that could streamline these daily processes for them.

At a young age I had to explain to my mother to tell her physician how much pain she's feeling on a smiley face scale—now that I am 21 and immersed in the healthcare field, I often think of what it would be like for a child to have to explain to the doctor why her mother is displaying unusual and/or forgetful behavior.

This bill advocates for an **increase public understanding and awareness of:**
(i) the early warning signs of Alzheimer's disease and other types of dementia
It also pleads for uniform, consistent guidance in nonclinical terms with an emphasis on cultural relevancy and health literacy.

In this instance, this would be demonstrated by having a translator proficient in French or Lingala available, and by ensuring that healthcare services are provided with cultural sensitivity, considering the unique backgrounds and customs of my culture.

In an ideal scenario, the appointment would conclude with the physician and translator collaborating to communicate information about my mother's health in a manner that she can easily understand. Additionally, they would facilitate connections with networks of skilled volunteers or community health workers from the Congo, who could offer reliable guidance and support within their own communities.

Solely relying on newsletters, emails, or health campaigns isn't sufficient for effectively disseminating information. Simply having information available doesn't guarantee it will be absorbed. These communities require personalized, customized communication. Storytelling proves to be a powerful method for conveying messages, mirroring how my mother and many adults in our community impart lessons to the youth.

After attending my doctor appointments and undergoing tests, I anticipate receiving the results via the MyChart website. However, each time the results arrive, I find myself unable to comprehend them. Despite having excelled in my medical terminology course, I'm struck by the complexity of the information presented. Even after attempting to search online for clarification, I'm left with more questions than answers. Feeling frustrated and discouraged, I eventually chose to ignore the results, assuming that if there were any serious issues, I would receive a phone call. Unfortunately, this is a common experience for many patients. Providing easily understandable language is not only empowering and potentially life-saving for patients but also fosters a sense of self-autonomy, enabling individuals to understand their health status and make informed decisions about their care.

Data from the CDC shows the prevalence of Alzheimer's among Black Americans over 65 is notably higher than among their white counterparts, with diagnostic discrepancies further complicating the picture. This statistic hit home when my grandmother succumbed to dementia on August 14, 2023. As a student, it wasn't until this internship that I realized studying health sciences didn't necessarily encompass education in brain health or dementia. I vividly remember video calls where she struggled to recognize my mother or engaged in peculiar behavior. Just a week prior, she was her usual self, laughing and singing hymns. The sudden transformation baffled me, highlighting the urgent need for comprehensive education on brain health and dementia.

To endorse this bill is to advocate for equitable access to vital information on brain health, regardless of language or community background. Let us stand in solidarity with all Vermonters affected by Alzheimer's/dementia, striving for a healthcare system that serves everyone effectively. Thank you for your attention to this critical matter and for the opportunity to enhance healthcare delivery.