

# **ACCESSIBILITY OF MEDICAL DEVICES FOR DISABLED ASIAN AMERICANS**

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By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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After undergoing abdominal surgery, patients often experience postoperative pulmonary complications (PPC), which includes decreased lung compliance, alveolar collapse, and a compromised ability to reach maximal inspiration (Miskovic & Lumb, 2017). Recently, the COVID-19 pandemic made PPC more relevant than it has ever been before. The incentive spirometer is a plastic, handheld medical device that is typically used to lower the risk of developing PPC; studies have shown that this device decreases the occurrences of PPC that may occur during recovery (Westwood et al., 2007). Despite how crucial the incentive spirometer is in preventing PPC, patient adherence remains low. In a study conducted by Eltorai et al. (2018) regarding incentive spirometry adherence, respiratory therapists and nurses agreed that patient adherence improve (p. 534). Thus, the overall aim of the technical project is to redesign the incentive spirometer and integrate a ‘gamified’ component; as a result, patients would be more encouraged to use the device consistently, improving overall patient adherence. The teammates of the technical project are undergraduates Danna Du, Paul Miranda, Theodore Vu, and Shirley Zhang, and the technical advisor is Masahiro Morikawa, MD, MPH, the clinical director of UVA Family Medicine.

The STS Research paper is tightly coupled to the technical project of redesigning the incentive spirometer not only because both are related to medical technology, but because the problem discussed in this paper arises from the technical project. The world is designed for able-bodied people; individuals with disabilities are forced to adapt to the environment rather than the environment adapting for the people. In an article from *The New Yorker*, “When the World Isn’t Designed for Our Bodies,” staff writer Katy Waldman (2020) reviews and summarizes Sara Hendren’s book, *What Can a Body Do? How We Meet the Built World*. Hendren argues that, although disability is in part a result of the physical, it also is a manifestation of how the built

world accommodates those with disabilities and determines what a body can or cannot do. This theme can also be applied to the world of medical devices.

People with disabilities are not defined by their disability and should not be treated as such. While disability does not define an individual, it is nevertheless a natural and nuanced part of the human experience. Likewise, the Asian American population, though being greatly diverse, also shares complex views and experiences. As such the scope of this paper focuses the demographic to Asian Americans with disabilities, a group that is even more so unique in their experiences and treatment. This paper analyzes accessibility of medical devices for disabled Asian Americans, a group that has been and is still underrepresented in US-based research studies regarding disability and mental health (Hasnain et al., 2020). Due to this underrepresentation, the overall approach to this research is to break down the issue by studying first the experiences of people with disabilities, the experiences of Asian Americans, and factors affecting medical device accessibility. The research will be presented as an analytical paper employing Actor Network Theory to answer the question, what is the status and extent of medical device accessibility for disabled Asian Americans?

### **GENERAL DISABLED EXPERIENCE**

Disability does not imply a lack of ability or inability of an individual; however, society makes it seem so. Whether it be via physical architecture or public perception, the commonly held concept of disability is a result of both human and non-human factors that are often unrelated to individuals with those disabilities. Theresa Thompson states in her *Handbook of Communication and People with Disabilities* that “disability is socially constructed as a defining characteristic of an individual” (Braithwaite & Thompson, 2000, p. 10). Historically, the perception of people with disabilities in America had long been dominated by a sense of disdain

with an emphasis on excluding and going as far as eliminating people with disabilities from participation in society (Lucas, 2021).

As such it is important to consider the language and specific diction specifically in disability research papers, such as this one. For example, two main approaches to discussing disability involve either person-first language (PFL) or identity-first language (IFL). As the name implies, PFL mentions the person before referencing disability, thus using a phrase such as “person with a disability.” This type of word choice acknowledges respect for and humanity of the person with a disability. IFL portrays disability as an integral aspect of a person, using phrases such as “disabled person” or “paralyzed person” (Ladau, 2021). IFL goes beyond the diagnosis and describes disability as part of a person’s identity.

It is also worthwhile to acknowledge that each disabled individual has unique perspectives of disability. Nevertheless, terminology should avoid discounting or dehumanizing people with disabilities. For instance, labels such as “high functioning” and “low-functioning” are arbitrary terms used to gauge an individual’s communication methods and intellectual ability. Using such labels is harmful because in reality it describes “how society experiences the [disabled] person,” often denying support needed for individuals deemed “high functioning” while also denying people labeled “low functioning” autonomy (Williams, 2019, para. 10). Discussions and studies of disabilities and the experiences of disabled people often question what is normal functioning or normal abilities.

### **THE ASIAN AMERICAN EXPERIENCE IN HEALTHCARE**

The Asian American experience is one that is fraught with discrimination, questions and assumptions about one’s identity, and looming pressure to assimilate into American society. Such discrimination and xenophobia have been exacerbated since the beginning of the COVID-

19 pandemic (Le et al., 2020). Furthermore, Asian Americans are not a monolith, both in terms of ethnicity and personality. Even within the regions of Asia each country is highly unique in its culture and traditions. Nevertheless, Asian American rhetoric and research tend to ignore the rich ethnic diversity of Asian Americans, which is harmful as it can lead to the more nuanced experienced and struggles of Asian Americans being overlooked (Hasnain, 2020). As a result ironically, for the purposes of this paper, Asian Americans are referred to as one group. Further generalizations of Asian Americans manifest in what is called the “model minority” myth, which portrays Asian Americans as well-educated, hardworking, committed to family, and successfully integrated in society. Though positive on the surface, this concept is damaging in that it erases the diverse experiences of Asian ethnic groups and pits them against non-Asian American minorities (Joo et al., 2016). This myth also downplays the struggles they experience as a result of systemic racism and discrimination (Jin, 2021).

As such, the model minority myth detracts attention from healthcare disparities that Asian Americans experience. Xie et al. (2022) conducted a study observing factors that contribute to mammography screening disparities between non-Hispanic white and Asian American women from 2015-2016 (p. 248). The original purpose of the study was to investigate the fact that the Centers for Disease Control and Prevention (CDC) found that cancer was a leading cause of death for Asian Americans, which was not the case for non-Hispanic white Americans. It was proposed that this could be due to low mammography screening rates in Asian Americans and therefore sought to identify contributing factors. Results were consistent with other studies demonstrating significant differences between Asian American and non-Hispanic white women in receiving up-to-date mammograms (Xie et al., 2022). Contributing factors are complex, involving clinical, socioeconomic, and cultural aspects. It was found that an absence in

preventive health visits is one barrier for Asian American women, especially those who are foreign-born, as they tend to rely more on traditional methods and experience linguistic isolation when trying to study public health papers. Other factors included age, limited health knowledge, and socioeconomic status. Several barriers that Asian Americans face in healthcare result in inadequate healthcare as well as the underutilization of available healthcare services. Language barriers present a formidable obstacle for Asian American immigrants in healthcare, most notably elderly Asian Americans, who are most likely not proficient in English. Another barrier that persists is limited health literacy, which involves both reading health content and understanding what that content means to make healthcare decisions. This limited health literacy can lead to erroneous health assumptions and thus poor health outcomes (Kim & Keefe, 2010). As mentioned already, infrequent medical visits for preventive care, stemming from a lack of familiarity and distrust in Western medicine, is another healthcare barrier. Additionally, though unemployment rates among Asian Americans are low, many lack health insurance, thus impeding access to healthcare (Green, 2021).

### **THE BUILT WORLD OF MEDICAL DEVICE TECHNOLOGY**

In the same way that the built world forces the adaptation of the people, the design of medical devices also forces some disabled people to adapt. For example, glucose monitoring devices, whose results are displayed on a screen, cannot be read by those with impaired or no vision. This is especially relevant for individuals with diabetes who require this device in order to observe blood sugar levels and manage the disease. A common complication of diabetes is diabetic retinopathy, in which the back of the eye, the retina, is damaged (NHS). Without proper treatment, this condition can worsen and eventually lead to blindness; in fact, the CDC (n.d.) reported that “diabetes is the leading cause of new cases of blindness in adults” (para. 1).

Furthermore, medical diagnostic equipment remains largely inaccessible for people who experience difficulties with mobility. In an observational study conducted by Agaronnik et al. (2018) analyzing physician attitudes toward accessible medical diagnostic equipment, most physicians surveyed agreed that accurate physical examinations are crucial for everyone, including patients with disabilities (p. 2032). Though acknowledging the benefits of accessible equipment, most reported inconsistent use of such equipment despite having it. Barriers to using accessible equipment that physicians cited included mechanical, economic, and safety aspects. Others experienced more personal frustrations in having difficulty operating the equipment, while other concerns noted a lack in space and money for equipment and extra time used to see disabled patients. Some physicians even considered using accessible equipment as being the more difficult and inconvenient option, thus conducting examinations of patients in their wheelchair and possibly missing clinical findings (Agaronnik et al., 2019). Thus, concerns in using such equipment dealt with inherent characteristics of the equipment and consequences of adopting more accessible technology.

Why is it that currently there does not seem to be a movement to design medical devices to be more inclusive? Such complication can be illustrated in Figure 1 through the cultural, organizational, and technical aspects of medical device technology in Pacey's Triangle (Pacey, 1983). The interplay of these aspects, especially from the organizational aspects, complicates and hinders a collective movement for improving the accessibility of medical devices. The push and pull of differing perspectives of the urgency of improving medical device accessibility prevents progression in the issue. Given that medical devices are well designed, usable, and function as expected, patients typically trust that technology as a source of rehab despite being expensive to obtain access to it (Montague et al., 2010). Nevertheless, the overall design of some medical

devices is typically based on able-bodied people with little to no consideration of people with

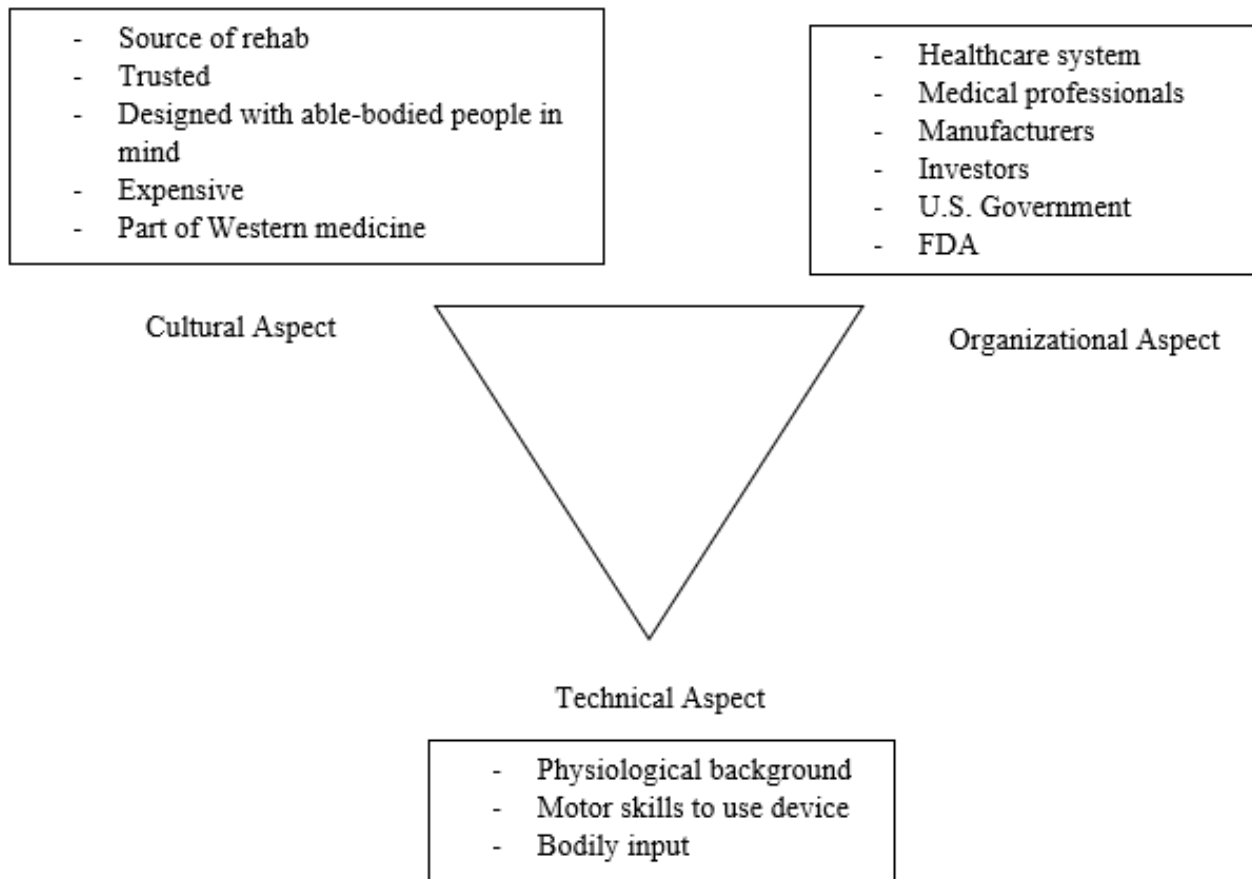


Figure 1: Medical Devices and Pacey’s Triangle. Several cultural, organizational, and technical factors are at play within the medical device industry. (Adapted by Talicurán (2021) from Pacey, 1983)

disabilities. The technical aspects, though inherently important for medical devices in general, do not significantly influence the level of their accessibility. The purpose of Pacey’s triangle is to demonstrate the general cultural, organizational, and technical aspects of medical devices.

## **DISABLED ASIAN AMERICANS AND MEDICAL DEVICES**

Asian Americans are among the fastest growing racial group in the United States, and included in that population are Asian Americans with disabilities; according to 2020 census data, 24 million people identified themselves as “Asian,” comprising 7.2% of the American population (Yam & Venkatraman, 2021). From 2000 to 2019, the Asian American population grew 81%,



compared to Hispanic and African Americans populations, which grew 70% and 20%, respectively (Budiman & Ruiz, 2021). The broad generalizations about Asian Americans, especially disabled Asian American, persist even within the healthcare industry. Studies have shown that Asian Americans are associated with a high prevalence of certain diseases and conditions such as stroke, diabetes, and tuberculosis (U.S. Department of Health and Human Services Office of Minority Health, 2021). This allows implicit bias in diagnosing Asian Americans who might have diseases or conditions uncommon to their community. For example, the doctors of Jennifer Lee, a Korean American, doubted she had Crohn's disease based on the generalization that Asian Americans typically are not diagnosed with the disease (Namkung, 2020). Furthermore, the stigma of being Asian American and earning a sense of belonging in Western society is exacerbated as a disabled Asian American (Lu, 2019).




Additional stigma surrounding having a disability can even stem from within the Asian American community itself. In both East Asia and Southeast Asia, there are two perceptions of disability, and compared to Western society, disability is a family concern. As such, the first perception or reaction to disability is embarrassment and the instinct to hide it from the rest of society; conversely, the second perception results in overprotective treatment of the individual with a disability, taking away their autonomy in participating in society (Braithwaite & Thompson, 2000). Further stigma and prejudice can be found outside the Asian American community as well. The COVID-19 pandemic brought along an increase in anti-Asian sentiments and violence (Lund et al., 2020). Thus, disabled Asian Americans must face both ableism and xenophobia, which provide more complex barriers to seeking adequate healthcare, whether it be subconsciously blaming disabled Asian Americans for the pandemic or neglecting to accommodate their accessibility needs.

In separately analyzing the disabled experience, the overall experience of Asian Americans in healthcare, and medical device accessibility, the paper extrapolates to determine the extent to which disabled Asian Americans can access medical device technology. This extrapolation can be visualized through the Actor Network Theory, a method developed by John Law, Michel Callon, and Bruno Latour analyzing social, material, and technical aspects of technology. The Actor Network Theory maps both the material and conceptual to illustrate sociotechnical relationships. Actors are people, organizations, or things, which are all treated equally and seen as having an equal amount of influence and agency, and the network refers to the overall relationships between actors, which can shift or change depending on context (Law & Callon, 1988). Figure 2 demonstrates the complex relationships between material and conceptual actors affecting accessibility of medical devices for disabled Asian Americans.

Approaches to addressing the lack of accessibility of medical devices for disabled Asian Americans involves addressing issues that disabled people face, considering the problems Asian Americans face in healthcare, and working to solve problems in medical device design. According to the CDC, six of the most common barriers to increasing inclusion are: attitudinal, communication, physical, programmatic, social, and transportation barriers (para. 3). Attitudinal barriers, involve able bodied individuals' personal perceptions of disability, such as stereotyping and holding prejudices against disabled people. Communication barriers are often encountered by individuals with sensory or cognitive disabilities, and transportation barriers and physical barriers typically prevent people experiencing mobility difficulties from independently traveling. Policy, programmatic, and social barriers are more structured obstacles that disabled people face trying to integrate into society (Centers for Disease Control and Prevention, 2020).

Nevertheless, there are policies whose purpose is to promote disabled people's

**Legend**

-  Users/institutions
-  Non-human actors
-  Concepts/ideas/metrics

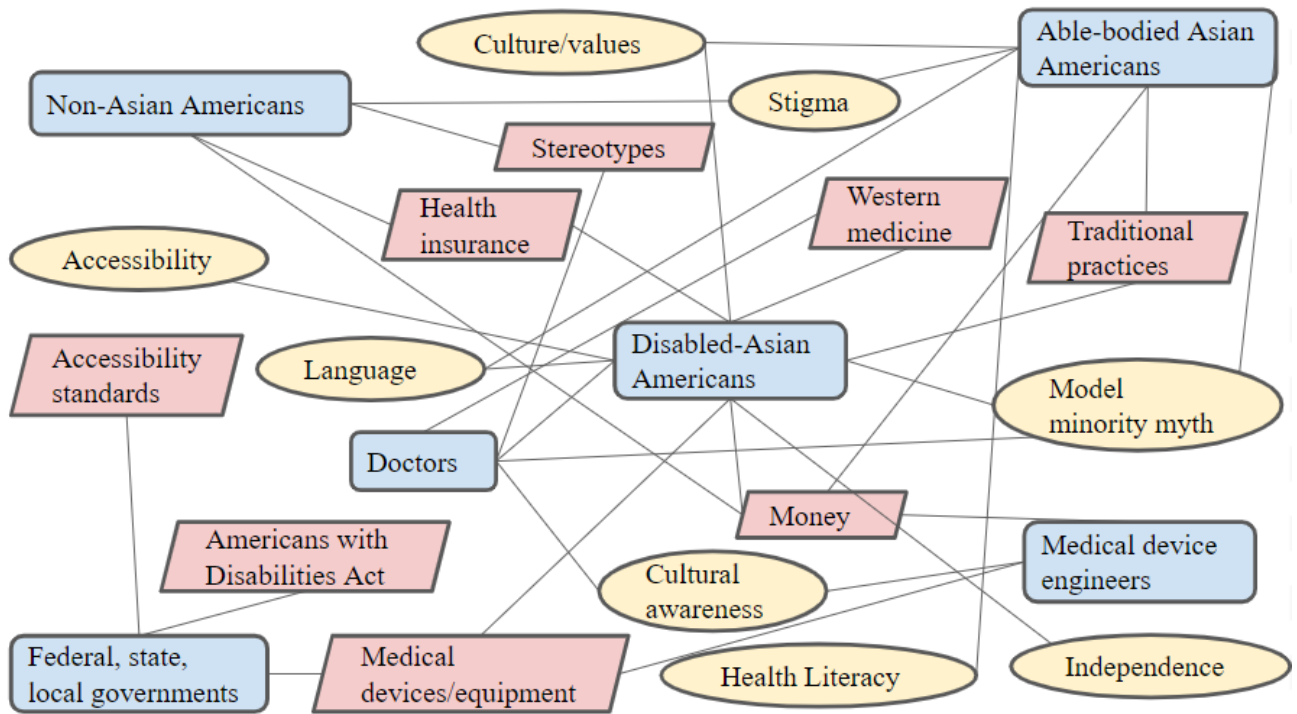


Figure 2: Actor Network demonstrating material and conceptual relationships actors affecting accessibility of medical devices for disabled Asian Americans (Adapted by Talicuran (2022) from Law & Callon, 1988)

independence. For example, the Americans with Disabilities Act of 1990 (ADA) is a federal civil rights law prohibiting discrimination against people with disabilities, and this extends to medical devices. The ADA includes providing accessibility to examination rooms for people in wheelchairs and in general making medical equipment accessible to ensure that a disability is not a barrier to receiving proper medical attention and treatment. Implementing and enforcing standards of accessibility are also crucial in designing accessible medical device technology. In 2007, the U.S. Access Board issued standards for Accessible Medical Diagnostic Equipment

including but not limited to examination tables and weight scales. These standards provided design criteria for accessible medical diagnostic equipment. Applying such standards would increase accessibility for patients with mobility difficulties while reducing risk of injury from transferring patients to examination equipment (Administration for Community Living, 2020).

Regarding disabled Asian American experiences in healthcare, those devising healthcare policies should be culturally aware and sensitive of Asian American culture to create relevant policies that would best meet the needs of Asian Americans. Doing so could help address the obstacles that Asian Americans face in accessing healthcare. Improving the Asian American experience in healthcare involves tackling multi-faceted issues, attitudes, and perspectives; nevertheless, it is not impossible.

Likewise, there are certainly avenues to improve accessibility of medical devices. One of which is to encourage genuine adherence to accessibility standards for medical diagnostic equipment and medical devices. Standards can be viewed as a necessary obstacle to overcome before marketing a device; as such, other methods and approaches must be devised so medical device engineers could adhere to not only the letter of standards but also the spirit of those guidelines. Furthermore, Jakob Nielsen's 10 usability heuristics outline general rules of thumb in identifying possible usability errors of a design (Nielsen, 2020). Universal design principles also ensure that a product is designed as inclusive as possible, allowing it to be used by as many people as possible, without any sort of adaptation to the original design (Abts & Butler, 2017). More focus on the human factors in medical device design such as usability would result in more easily usable and accessible devices.

## **PATIENT FOCUS AND CONSIDERATIONS**

The technical project aims to improve patient adherence by engaging the user with a

more gamified version of the currently existing design of the incentive spirometer. In doing so, the patients will be less at risk for developing PPC, ultimately decreasing adverse short term and long-term effects of PPC. The research paper broadens the perspective to study not only the incentive spirometer, but also medical devices as a whole and their inaccessibility to Asian Americans with disabilities.

The general experience for both individuals with disabilities and Asian Americans is marked by exclusion and pressure to prove one's societal worth. People with disabilities are forced to adapt to a world that is not built for them, which emphasizes their disability instead of accommodating their unique abilities. Asian Americans fight against being generalized and perceived as a monolith and "model minority." The intersection of these identities further emphasizes those unique struggles, especially in the realm of healthcare and medical devices. Due to the lack of research in the disabled Asian American with medical devices, this paper extrapolates from research on disabled Asian Americans and medical device accessibility.

Going forward, there must be more attention and research toward specifically studying and representing the experience of disabled Asian Americans and medical device accessibility. This research can be conducted by any group, ranging from the NIH to disability advocacy groups; however, specific measures must be taken to avoid the overgeneralization of Asian Americans in this research. It is easy to forget about the social aspects of medical device technology, especially the very people such technology is intended for: the patients, all patients. While focusing on safety and efficacy, medical device development often neglects the diversity of end users using the devices. This research paper attempts to break away from such thinking, revealing limitations of medical device technology that had been previously ignored.

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