

# Deafness in India and the Indian-American Community

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## ABSTRACT

This paper seeks to detail the experiences of the Deaf Indian community and the Deaf Indian-American community through different lenses such as cultural identity, public policy, and access to opportunities. It argues that social stigma in India is what directly results in the suppression of the Deaf community by the Indian government via policies that circumvent overarching anti-discrimination legislation. In the United States, Deaf Indians face racism from within the Deaf community as they are alienized and misrepresented. They are also ostracized from hearing Indian populations as they are not included in cultural traditions due to language barriers. As a result, the paper argues that the experience of the Deaf Indian needs to be analyzed from multiple axes of oppression such as race minority status, hearing status, socioeconomic status, etc. It operates under a framework of intersectionality while including critical literature from Critical Race Theory and disability studies.

## Introduction

Deafness is often viewed as a condition that applies to our society's idea of an otherwise "normal" person, which is why despite a lengthy and deep history of Deaf culture within the Black community, Black deaf people are often overlooked by hearing society and white Deaf society as well. (Waller 2021) This same concept can be extended to a large portion of other marginalized groups; whether that be other people of color, queer people, or disabled people. Despite being a country of over one billion people, the idea that Deaf Indian people even exist may be abnormal for others to hear. As the population of India and the Indian-American community continue to grow, it becomes important to understand the experiences of the Deaf sectors of these communities. Similar to the nature of the hearing population, the Deaf community in India faces vastly different experiences than that of the Indian-American. The Deaf experience in both of these scenarios can be observed in many different circumstances, including, but not limited to: cultural ideology, government policy, education, and job opportunities. Thus, this paper seeks to explore the similarities and differences in the Indian and Indian-American Deaf community in these aspects in order to first, increase dialogue on a community with very little literature, second, provide a critique on the actions that dominant hearing societies take towards Deaf communities, and finally, look to the future of progress for Deaf Indians.

## Critical Literature

### Crip Theory

The first theory that is explored arises from Robert McRuer's *Crip Theory: Cultural Signs of Queerness and Disability*. Colloquially known as "crip theory", it originates from an intersection of queer theory and disability studies and the author's understanding of similar experiences of queer and disabled people and their ostracization from mainstream society. The word "crip" derives from the derogatory term "cripple" to describe disabled people through a sense of pity and condescension. The theory reclaims the term, using it as one of pride in order to represent the pride disabled people should have in their disabled identities rather than shame. Crip theory argues that society centers itself around

the able-bodied person -- what defines a normal working day, how much time is normal to conduct a task, what mechanisms are necessary to complete a task, etc. are all dependent on that of an able-bodied person. Disabled people require resources that are different from an able-bodied person in order to achieve a specific task, a term which later became known as “crip time”. As a result, disabled people are sidelined into being given accommodations rather than having resources available upfront. In many cases, resources specific for disabled people may not be given (due to the nature of our able-bodied society), so disabled people are forced to sacrifice their own goals simply due to the fact that there are barriers present that are not in their control. Allison Kafer’s *Feminist, Queer, Crip* determines that disabled people are erased from the past due to marginalization and flawed misrepresentation, and are removed from the future by severely limiting their ability to succeed. As a result, disability studies advocate for societies that center around the disabled person by having “accommodations” be an inherent norm. This analysis can be extended to the Deaf community as Deaf people are often marginalized from the rest of society, and their own needs are seen as a secondary accommodation rather than something that should be simply present.

## DesiCrit

DesiCrit (short for Desi Critical Race Theory) originates from Vinay Harpalani’s *Desi Crit: Theorizing the Racial Ambiguity of South Asian Americans*, which argues that South Asians are racially ambiguous in a polarized white vs. black society and are racialized to fit either “white” or “black” in order to fit the narrative of a white supremacist society. The term *desi* is derived from the Sanskrit word देश (pronounced *desa*) which means “of the land”. It refers specifically to people of the countries of India, Pakistan, and Bangladesh, but Harpalani’s work extends to the experiences of other South Asians. (Nepal, Bhutan, Afghanistan, Sri Lanka, and the Maldives) DesiCrit bases its argumentation on other critical works like LatCrit (for Latines), AsianCrit (for East Asians), and TribalCrit (for Indigenous nations). All of these stem from an overarching Critical Race Theory (CRT), which formed due to the work of Black authors critiquing the Black experience in white supremacist America. CRT uses themes like “reclaiming the narrative”, systemic racism, essentialism, intersectionality, and storytelling (especially in TribalCrit). DesiCrit is essential for understanding the experiences of the Indian-American Deaf community as their Indian identity creates a unique experience that distinguishes them from the experiences of other Deaf communities in America.

## Intersectionality

Intersectionality, coined by Kimberlé Williams Crenshaw in *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, is a framework that analyzes a person’s identities in relation to each other rather than independently. Crenshaw’s analysis focuses on that of the Black woman who carries identities of a Black person and a woman, but whose experiences cannot be compared to either individually. A Black woman faces oppression from both Black men and nonblack women, so arguing that a Black woman’s experiences are simply that of a Black man and a nonblack woman combined is at best, ignorant, and at worst, deeply insensitive to the oppression they face. Intersectionality allows us to view these experiences not as separate axes of oppression, but rather, interlocking systems which enforce one another to create the unique experience of a person. Intersectionality is also not limited to systems of oppression: it is also necessary to explore layers of privilege a person might have. For example, white women have the unique ability to harm Black men via creating the narrative of stereotypical white, pure, innocent femininity against the Black, hypersexual, violent masculinity -- a narrative popularized through the infamous racist film “Birth of a Nation”. White women and Black men both have one axis of oppression and one axis of privilege, so without an intersectionality framework, the argument that white women are equal to Black men despite the centuries of racist oppression would still be made. Understanding intersectionality is important when discussing the experiences of Deaf Indians who undergo multiple axes of oppression.

## India's Deaf Community

Approximately 63 million Indians (6.3%) experience hearing loss (Varshney 2016), making it a significant portion of South Asia's Deaf community which represents over one-fourth of the world's Deaf people (WHO 2012). As a result, Deaf Indians are very important when it comes to advocacy. However, despite their large numbers, Deaf Indians are consistently marginalized by both Indian society and the government.

### Narratives

#### *Jhoti Prajapati*

Jhoti Prajapati was three years old when she was classified deaf by doctors. Her mother Rima immediately sought to get Jhoti into a school for the Deaf, of which there are only 388 schools in India. Originally rejected due to being too late in the admissions cycle, Prajapati was accepted the next year and gained access to learning sign language and being educated in an environment that was more suitable to her, something only 5% hard of hearing children get access to in India. Jhoti, now 19 in 2021, is part of a family that prides itself on breaking down stigmas Indian society has towards Deafness along with her younger sister Aarti who is also Deaf.



**Figure 1.** Family Portrait of mother Rima Prajapati and daughters Jhoti, Aarti, and Sangeeta via NPR

#### *Rupmani Chhetri*

Rupmani Chhetri was born Deaf to a poor hearing family in Nepal who could not afford to send her to school. Chhetri, like many Deaf children, formed her own personal sign language, and was berated and looked down upon by her peers for using it. After moving to Delhi at the age of 22, Chhetri connected with a centralized Deaf community that finally gave her a space to learn formal sign language and grow with others like her. Today, Chhetri is the first Deaf South Asian woman working with the UN and knows over five sign languages (International Sign, British Sign, Indian Sign, American Sign, Ukrainian Sign), and works to support the Deaf communities in the places she grew up in.



**Figure 2.** Rupmani Chhetri, Deaf advocate and volunteer for the United Nations in Ukraine

## Cultural Ideology

The mistreatment of Deaf Indians can overarchingly be attributed to Indian society's perspective on Deafness. Social stigma isolates and oppresses Deaf Indians and leads to other results like public policy and education that seek to enforce this system of oppression.

### *Deafness is a Curse*

Deafness is viewed as inherently negative in mainstream Indian society. Children who are Deaf are separated and labeled as less intelligent and needy of pity (Mishra 2021). As a result, Deafness is undesirable in hearing families and creates a social stigma against Deaf people. One viewpoint in India is that it stems from a mistake on part of the Deaf person or those related to the Deaf person. Examples include negative karma from a past life, an angered family spirit, or poor hygiene/injury. One mother describes her thought process towards having a Deaf child:

When I was pregnant, I had a cold. The *vaidya* [traditional Indian healer] gave me herbs to take. He told me that, after taking the herbs, I was not to take a bath the next day. But the next morning, I was feeling fine, so I took a bath. I think that is what caused my son to be deaf. (Trans., Prakash Dehta)

Consequently, Deafness can be seen as a display of poor behavior on behalf of the family as outsiders may think that the person made a mistake in order to incur Deafness. As a result, Deafness becomes an indicator of social status -- not a good one.

### *Stigmas Around Sign Language*

India's culture is deeply entrenched in oralism or the practice of forcing Deaf people to communicate through speech and lipreading over sign language. This is due to the deep social stigma that exists in India towards signing. In fact, Varsha Gathoo, director of the Department of Education, National Institute of Speech and Hearing Disabilities, argues that sign language is actually stigmatized more than Deafness. This is because sign language not only gives a visual indicator of Deafness, it also shows a family's failure at "properly raising" a Deaf child. Deaf people who engage in oralism are able to "pass" as hearing as they do not need additional resources that may signal that they are Deaf: they

can read lips, preventing the need for a hearing aid, and they can speak, preventing the use of alternative technology that would signal to other people that they are not “normal”. Using sign is a clear visual indicator to the rest of society that you are openly Deaf; this reflects back onto the Indian family as allowing a “curse” to exist. As Indian families seek to look perfect for status (Grace and Sarah, 2021), sign language can be one thing that causes that status to plummet.

### *Poverty and Deafness*

Deafness may also be stigmatized due to its link to poverty. Deaf people in India tend to have lower literacy rates since standard education in India does not accommodate the needs of its Deaf students and forces them to learn orally, which is not sustainable nor effective for many Deaf people. Lower literacy rates lead to lower job opportunities for Deaf Indians, which leaves them in cyclical poverty. Many Deaf Indians tend to work menial labor jobs with low wages. As a result, several Deaf Indians live below the poverty line. Poverty is looked down upon, so disability and Deafness, which have strong links to poverty, are looked down upon as well.

### Public Policy

#### *Disability Legislation*

India’s first legislation regarding disabled people was the Persons with Disability Act of 1995 (PDA) which defined various types of disabilities and mandated that disabled people should be guaranteed equal opportunities in education and employment. It defined “hearing impairment” as “a person who has a minimum of 60dBHL of hearing impairment in the better ear in speech conversation frequencies”. In 2007, India signed the United Nations Convention on the Rights of Person with Disabilities (UNCRPD) which argued that disability forms from an impairment with societal barriers, so disability isn’t inherently wrong in and of itself, rather, society needs to adapt around disability. India then had to reevaluate its laws towards disabilities, thus passing the Rights for Persons with Disabilities Act of 2016 (RPwD) which provided an enumerated list of rights: equality, property, home, family, reproductive rights, etc. It also placed a burden on the Indian government to be the ones to enforce the anti-discrimination clause in the legislation. Finally, RPwD expanded the definition of disability to include other chronic illnesses like sickle cell disease as well as neurodivergent conditions like autism. The treatment of Deaf people is intrinsically linked to its country’s disability policies: as a largely modernizing nation, India has anti-discrimination legislation to protect the opportunities of Deaf people.

#### *Diagnosis Barriers*

Much of this disability legislation cannot apply to a significant portion of the Indian Deaf community due to the fact that a lot of Deaf children are simply unable to get diagnosed. Deaf children in low-income countries are often identified late or never at all due to the lack of universal screening (Merugumala et. al. 2017). In poorer communities in Hyderabad, India, many Deaf children were unable to get the resources they needed due to the fact that their deafness wasn’t identified, funds were not given to local centers, or they were unable to travel to receive a diagnosis. Diagnosis is the most significant barrier to any form of healthcare legislation, and it is especially crucial for disability legislation. When you are unable to be legally classified as disabled, you have no grounds to receive the treatment that may be critical for you. As a result, Merugumala concludes that wider screening programs need to be implemented, especially in rural India, in order to promote access to the correct services for Deaf individuals.

### Education

Finally, Deaf Indians are prevented from achieving through educational barriers. Though the Indian government cannot legally restrict Deaf Indians from having equal educational opportunities through RPwD, other federal practices essentially have the same effect in a more sinister, hidden way.

### *Indian Sign Language*

Though India has a Deaf population of approximately 1.3 million (Petcosky-Kulkarni), Indian Sign Language (ISL) is still not recognized as an official language under the Indian Constitution. Vaibhav Kothari, a Deaf businessman, argues that as India seeks to preserve ancient languages such as Sanskrit, equal measures should be taken to acknowledge growth in the present and future like ISL. Leaving ISL unofficial has devastating consequences. It's no surprise that the majority of schools for the Deaf in India practice oral languages as opposed to ISL (Petcosky-Kulkarni), despite the fact that ISL is a fully developed language with a sophisticated lexicon. This is why out of the 5 million students with hearing loss in India in 2011, only 5% had access to basic education, and only 1% had access to quality education (Niazi 2021). Thus, even if Deaf Indians cannot legally be segregated from mainstream education and have opportunities restricted, by forming barriers to educational opportunities that could be vital to their growth, they face the same consequences regardless.

### *Progress*

Despite the undoubtedly large pushback, the Indian Deaf community has experienced from the greater society as well as the government, they have made countless strides forward when it comes to advocacy for themselves.

### *Education*

Though Deaf students do face discrimination in schools, the work of Deaf advocates like Centum-Gro Initiative alleviates these disparities and makes education created by Deaf people, for Deaf people available at schools. One individual describes how after taking a Deaf empowerment course, she felt proud to be Deaf for the first time. As more people begin to advocate for the introduction of ISL in schools for the Deaf, Deaf students across India feel empowered and appreciated.

### *Public Policy*

Deaf advocacy groups have also made countless strides when it comes to legislation, especially at the federal level. Alongside the World Federation of the Deaf (WFD), the Indian Deaf community has focused their advocacy on autonomizing the Indian Sign Language Research and Training Centre (ISLRTC), changing the terminology in India's Rights of Persons with Disabilities Bill, and the right to drive for Deaf people. These efforts have been largely successful, as the ISLRTC is now led by Deaf organizations within India who want to nationalize ISL, and the Indian government has agreed to use terms like "Deaf" and "Hard of Hearing" instead of "hearing impaired" in future and current legislation. Policy advocates like these further inspire young Deaf Indians to mobilize and represent themselves, showcasing the immense progress the Indian Deaf community has made over the years.

## **Indian-American Deaf Community**

According to the 2020 Census, there are currently 4.4 million Indian-Americans (labeled Asian Indians) in America. There is, however, a lack of data on the number of Deaf Indian-Americans. In the words of Deaf bioinformaticist

Sagar Kothari, “while there are many hearing ABCDs [American-born confused *desi*] in the USA, I think there are very few Deaf ABCDs out there...” As the Indian-American population continues to grow, so will the Deaf Indian-American community. However, even though there is very limited data on Deaf Indian-Americans, their experiences have still been documented.

## Treatment from Indians

The first overarching experience of the Deaf Indian-American community is that from hearing Indian-Americans.

### *Immigration*

Many Deaf people of color struggle with their identities as both a Deaf person and a person of color. This is especially true for Deaf Indian-Americans due to the intrinsic link all Indian-Americans have with the immigrant experience. Immigrants often feel isolated and alienated in a new country, which leads them to seek out other immigrants with a shared cultural experience (Recupero et. al. 2018). Thus, ethnic identity becomes incredibly important for immigrants and the children of immigrants as they struggle to find a place in a society in which they have almost nothing in common with others. Karthik Sethuraman, IT Specialist in Washington D.C., states that he sees himself as an immigrant first and a Deaf person second. Therefore, the immigrant experience is integral to the experience of all Indian-Americans, including Deaf Indian-Americans.

### *Cultural Preservation*

A value very important to the Indian-American community is to preserve Indian culture. Even as immigration to the USA increases, Indian families pass on traditions like religious festivals, food, clothing, and language. Language is integral to cultural identity (NSW DoE 2000) as it fosters a group connection and allows members of a community to share values and beliefs. Many hearing families are confused as to how to effectively communicate with their Deaf children, leading them to treat Deaf members of the family with disdain as sign language doesn't fit in with the hearing cultural identity's language. Caroline Goon of the Office of Equity, Diversity, and Inclusion of the National Institutes of Health reflects on her friend Julie's words: “Our Asian-American community did not seem to know how to talk about disabilities. They did not know how to interact with us, communicate with us, learn about us, or make us feel like an integrated part of the community. It was not because they were intentionally excluding us but seemed, they were not sure how to get close or even ask questions.” Thus, Deafness can be seen as potentially harmful to the cohesion of the cultural identity, leading to anti-Deaf sentiment from hearing members of the ethnic group.

## Treatment in the Deaf Community

The second experience is that from the larger Deaf community, white people in particular.

### *White Default*

The Deaf community has had a long history of racism. Deaf clubs used to reject memberships to Black Deaf people, one facet of a larger systemic racism issue within the community (Anderson and Bowe 1972). According to a study by the National Technical Institute for the Deaf at the Rochester Institute of Technology, a majority of Deaf people of color identify as their race first over their Deafness (Foster and Kinuthia n.d.). A Black respondent asserts: “No it doesn't matter if you are Black deaf or just Black hearing. Being a Black person, period, is difficult...”. Deafness is often seen as a white condition, as Sethuraman furthers, “I feel that Deaf culture is really more like ‘white Deaf

culture'. It's about their beliefs, their rights, their way. They really aren't concerned about people like us, people of color. It's more like they ignore us [...] So I don't feel that I'm part of the Gallaudet Deaf culture." Gallaudet University has a 45% white population and a 6.3% Asian population (Gallaudet 2014), so the average South Asian Gallaudet student may not feel welcome in an overwhelmingly white environment.

### *Interpreters*

Reflective of the demographics of the Deaf community, around 88% of ASL interpreters identify as white (RID 2017). This means that they are often unprepared for the cultural identities of nonwhite families, who are neglected as a result. From a study conducted by Cheryl Gallon at St. Catherine University, a Southeast American responder reports repeated assumptions that she and her family are immigrants and have poor language skills (Gallon 2018), which is a form of microaggression known as alienation. Additionally, white interpreters misunderstood her parents' desire for her to achieve success via the American Dream as unrealistic expectations that deserve pity. These experiences are also echoed in the lives of Indian-Americans who are treated as a foreign other in America and whose family lives can be misconstrued as strict or abusive.

### Progress

Deaf Indian-Americans work at the forefront of change for the Deaf community in both America and in India. Kavita Pipalia, the President of the California Association of the Deaf, has recently focused her efforts on organizing stories related to the experiences of Deaf BIPOC (Black Indigenous People of Color) in response to misinformation spread during Covid-19. Through her presentation on #DeafWoke, a program run by Antoine Hunter meant to make news related to #BlackLivesMatter, education, social justice, arts for Deaf, DeafBlind, DeafDisabled, Hard of Hearing, and Black Hearing communities, Pipalia describes her experiences as a Deaf Indian woman and her advocacy efforts. Pipalia also worked with other Black and Indian Deaf women to form the core team in deciding Kamala Harris's name sign. Finally, she is a co-founder of KODAWest, a non-profit organization that targets Deaf adults with hearing children.

### Conclusions

The Indian Deaf community faces barriers to success due to social stigmas present in Indian society towards Deafness and sign language that results in discriminatory public policies and educational movements. Deaf Indian-Americans, growing in number, experience racism from within the Deaf community and anti-Deaf sentiment from Indians, all the while coping with understanding their identities as immigrants, South Asian, and Deaf. Whether in India or in America, all Deaf people are forced to advocate for themselves in societies that prioritize the hearing person's needs over their own; making it all the more necessary for us to create future policies that center Deaf people and seek to remove barriers to access opportunities. Because as Deaf educator Smita Kothari exclaims,

“We can do everything except hear.”

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