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Disability Justice as Part of Structural Competency: Infra/structures of Deafness, Cochlear Implantation, and Re/habilitation in India

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Abstract

In 2014, the Indian state revised a key program providing aids and appliances to disabled people to also include cochlear implants for children living below the poverty line. The program is remarkable in its targeting of the poorest of the poor to provide them with expensive technology made by multinational corporations and its development of new surgery and rehabilitation infrastructures throughout India. Based on interviews and participant observation with key stakeholders, this paper argues that in focusing only on "a right to hearing" and on cochlear implants as a solution for deafness, health care practitioners ignore the complex work required to maintain cochlear implant infrastructures, as well as the advocacy work done by disability activists in India and internationally to transform existing political, economic, educational, and social structures. Since cochlear implants are the "gold standard" in intervening on hearing loss and increasing numbers of countries in the Global South have started state-funded cochlear implant programs, an exploration of India's program provides an opportunity to analyze both the importance of infrastructure and the need to combat ableism within structural competency frameworks. Disability justice is part of structural competency. Ultimately what is at stake is expanding health practitioners' ideas of what it means to maximize potential, particularly in the face of new technological interventions around disability.

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Introduction

In 2014, India's central government revised a key program providing goods and services to eligible disabled people, the Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP) scheme. Previously, the program provided a range of devices, including wheelchairs, crutches, hearing aids, and modified scooters. In its revision, for the first time, cochlear implants were included, specifically for children under the age of six and living below the poverty line. Cochlear implants are considered among the most successful neuroprosthetics and are increasingly a gold standard in the treatment of deafness.[1] In addition to cochlear implant surgery, the central government program provides cochlear implant mapping, two years of re/habilitation therapy, and two years of warranty for the external processor. On the surface, this program appears to be an ambitious and cutting-edge program, providing listening and spoken language to deaf children through the latest technology. On the surface too, such a program and intervention maximizes the independence and agency of deaf children, as government administrators, surgeons, audiologists, and speech and language therapists stressed to me. Such stakeholders often told me, "Deaf children have a right to hear" and "Deaf children must go for cochlear implants; they are the only option for making deaf children become normal."

However, while government administrators, together with multinational cochlear implant corporations, surgeons, and allied health professionals such as audiologists and speech and language therapists, desire to develop cochlear implant infrastructure, they often do not think beyond the medical and re/habilitative process of producing a sense of hearing. That is, such stakeholders stress the importance of "a right to hearing" but not the ongoing structural and maintenance work required to maintain hearing. They focus on a one-time surgery and technological fix and ignore that cochlear implants are not a one-time solution. In addition, in focusing on cochlear implantation as "the only option for deafness," program administrators and health professionals do not consider Indian Sign Language (ISL) or other linguistic possibilities as options, and they do not reflect on the disabling role of political, economic, educational, and social structures. Furthermore, they do not contribute to or support Indian disability activists' desires to create more accessible worlds and to combat ableism. Indeed, I learned that surgeons and allied health professionals rarely told families about ISL and that if they did, it was only mentioned as a "last resort," and often after a child had already experienced language deprivation.[2] (And note that professionals did not speak of language deprivation but rather auditory deprivation, continuing their focus on audition).

Cochlear implantation is a human rights issue in that for implantation to be successful, more than just a surgery is required; issues of differential access, varied motivations, and diverse and perhaps conflicting ideas of what it means to be a valuable and capable human being are in play. And as programs providing cochlear implants to children emerge in developing contexts and as cochlear implant companies see developing contexts as the next frontier of their work, the stakes are high.[3] Indeed, there is a paradox here: while disability is increasingly becoming normalized because of disability advocacy, there is also a simultaneous growth in so-called normalizing technologies such as cochlear implants. This paradox raises crucial questions in relation to structural competency and how health care practitioners understand the possibilities and limits of biotechnology in relation to the broader social, political, and economic context. Concerns about uneven access, the role of policies and structures, and the importance of focusing on the most marginalized people have long been at the heart of the disability justice movement.[4] In this paper, I argue that health and human rights scholars and practitioners must consider disability justice, specifically in relation to questions of economic access, infrastructure, and ableism, and that centering disability justice would strengthen a structural competency framework.

I draw from over 15 years of ethnographic research on deafness in India with ISL-speaking deaf people and with surgeons, speech and language pathologists, audiologists, families, government administrators, and educators. Focusing specifically on cochlear implantation between 2016 and 2022, I conducted participant observation and interviews in a wide range of settings, including hospital and clinic waiting rooms and consultation rooms, schools, government offices, family homes, and international cochlear implant conferences in Indian cities such as Delhi, Bangalore, Chennai, Mumbai, and Pune. My argument is that by focusing only on "a right to hearing" and on cochlear implants as a solution for deafness, health care practitioners ignore the complex work required to maintain cochlear implant infrastructures, as well as other kinds of structural transformations needed to create more just worlds for all people.[5] They disregard the structural advocacy work done by disability activists in India and internationally to transform existing structures. India signed and ratified the United Nations Convention on the Rights of Persons with Disabilities in 2008 and 2009, and this convention goes further than any other United Nations treaty in stressing the role of social, political, and economic rights in its attempts to build a more equitable and accessible world.[6] As the convention stresses, it is important to consider social and economic rights when thinking about disability and not just abstract ideas of civil and political rights. I build on work on structural competency frameworks to analyze structure in terms of both infrastructure and the ideological structures that devalue disability and non-normative embodiment.[7] Focusing only on one sense, neglecting maintenance, and failing to see disability rights as valuable are forms of structural violence.

To be clear, I do not have a normative or prescriptive argument regarding cochlear implants and recognize that they can be transformative for people. It is exactly because they can be "life changing" that there should be enabling structures and policies surrounding their provision. If the state is going to provide them, it must also provide children with the necessary infrastructure and support to succeed, in addition to recognizing the complex role of multinational corporations and the multiple interests of health professionals. Children who ultimately stop using implants because of breakage, obsolescence, or other reasons are often left worse off than before and are not given other options for communicating and engaging the world. My concern is ensuring that deaf children have access to language and to societies that allow them to maximize their potential, broadly defined, and not defined just as the ability to listen and speak.

What is a cochlear implant? Unlike a hearing aid, a cochlear implant bypasses many parts of the acoustic hearing system and electronically stimulates the auditory nerve to produce hearing. A cochlear implant has two main parts: a surgically implanted component (the internal part), in which the most significant element is the electrode array, and an external processor. The battery-operated processor is typically worn behind the ear and has a cable with a magnet in it that communicates with a receiver. The receiver transmits sound information to the electrode array. Each electrode stimulates a specific frequency range in the cochlea, which then stimulates auditory nerve fibers associated with that frequency. Adjusting to implant hearing takes time and work. Two to three weeks after the electrode array is inserted, an audiologist activates the external processor using proprietary software. The audiologist then adjusts the settings for each electrode and creates a range of hearing between a threshold level (the least amount of electrical stimulation possible) and a comfort level (the loudest sounds that the person can tolerate). This is called "mapping" the implant. The goal of mapping is to optimize the implanted person's access to sound by adjusting input to the specific electrodes. As the person becomes accustomed to the implant, the map needs to be adjusted, and typically the person will return to the audiologist frequently after the initial activation and mapping. Most people who receive implants can expect to have a stable map established within eight to eighteen months after activation. In addition, the external processor, much like a hearing aid, has cables, coils, magnets, microphone covers, and other breakable essential components.

Importantly, cochlear implants are manufactured by four multinational corporations: Cochlear in Australia, Med-El in Austria, Advanced Bionics in the United States, and Neurelec in France. Each company has patented its internal components, processors, devices such as coils and magnets, and spare parts. Except for Neurelec, the companies all have headquarters in India and employ Indian audiologists and speech and language therapists. These professionals aid the state in developing newborn hearing screening and cochlear implant infrastructures around the country; they also often conduct training for surgeons and re/habilitation workers in both government and private institutions, including in locations outside metro areas. In addition, they create branded re/habilitation materials to be used by therapists and families alike and provide help with troubleshooting devices. These professionals thus support the state, surgeons, re/habilitation professionals, and implant recipients and their families; the companies often do the work of developing infrastructure.

While there are efforts to develop an "indigenous Indian implant," spearheaded by the Indian Defense Research and Development Organization, currently Indian children and their families must negotiate complex dependencies on and with multinational corporations. This is the case because families need to maintain the cochlear implant processors—the processors require cables, coils, batteries, and microphone covers, among other things—and they also must upgrade from one processor to another if the model that the family has been given becomes obsolete. Processors become obsolete at different times in different geographic locations. In India currently, and in contrast to countries in the Global North, the main processor distributed through government programs does not have noise cancellation or speech-focusing technology and, as a result, Indian children utilizing the program are implanted behind wealthier Indian children who can afford the latest technologies on the private market, as well as children in the Global North who receive implants through public and private insurance programs.[8] This decision not to provide the latest technology is particularly problematic because deaf children work through degraded signals as it is.[9] And the lack of noise cancellation or speech focus is especially egregious in an Indian context in which schools, homes, and other everyday institutions are noisy. Strikingly, this processor was never available in the United States or Europe, and it is marketed and distributed exclusively in developing contexts, of which India is one. To be clear, multiple processors are available on the private market in India, and families with funds can purchase more expensive and newer processors. A singular focus on "a right to hearing" thus obscures political-economic hierarchies.

(Infra)structural competency and the neglected work of maintenance

According to Jonathan M. Metzl and Helena Hansen in their landmark work on structural competency, "structure implies the buildings, energy networks, water, sewage, food and waste distribution systems, highways, airline, train and road complexes, and electronic communications systems that are concomitantly local and global, and that function as central arteries in some locales and as sclerotic corollaries in others."[10] In this section, I discuss the work of building cochlear implant infrastructures and the role of national and multinational actors. I then foreground the importance of maintaining such infrastructure.

Much of the work on technology development and transfer in the realm of disability in the Global South focuses on accessibility, affordability, sustainability, and maintainability. In the international disability and development realm, there is a growing focus on the importance of assistive technology, which includes "hearing aids, wheelchairs, spectacles, prostheses and devices that support memory, among many others."[11] The Convention on the Rights of Persons with Disabilities advocates for state parties to ensure the provision of assistive technology for everyday life (article 20) and in rehabilitation (article 26). It also stresses that assistive technology can be a leveler in empowering people with disabilities and that nation-states should share technical and scientific research related to the development of such technology (article 32).[12] However, as John Borg, Stig Larsson, and Per-Olaf Östergren point out, despite this emphasis on the importance of assistive technology, "except for personal mobility, the [Convention on the Rights of Persons with Disabilities] seems not to give persons with disabilities the right—or legal support—to approach their government to demand necessary assistive technologies at affordable cost, which for many may be at no or very little cost."[13] In research on wheelchairs and other assistive aids in the Global South, scholars and practitioners have pointed to the importance of technology that is accessible and maintainable, and available to be repaired using locally sourced materials.[14] In India, the growing field of assistive technology focuses primarily on individualized technological solutions. Incubators and accelerators funded by the Indian government and corporations encourage the development of sustainable assistive technology, an individualized infrastructure.

The World Health Organization, in collaboration with national government agencies and nongovernmental organizations, has produced handbooks such as *Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings* (2008) and *Preferred Profile for Hearing-Aid Technology Suitable for Low- and Middle-Income Countries* (2019), which explicitly discuss sustainable design and maintenance. The World Health Organization, however, has not released any such guidelines for cochlear implants, although in its 2021 *World Report on Hearing*, it (vaguely) mentions the importance of sustainable cochlear implant programs. While a hearing aid is considered assistive technology, a cochlear implant processor is not. Yet the same issues of affordability, access, and maintainability exist for the external processor as for a hearing aid; batteries, coils, cables, microphone covers, and magnets, among other things, must all be maintained and often replaced.

India's ADIP scheme is also concerned with affordability and sustainability, and it has focused on manufacturing aids and appliances in India. The scheme began in 1981 with a stated goal to

> *assist the needy disabled persons in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances to promote physical, social, psychological rehabilitation of persons with disabilities by reducing the effects of disabilities and at the same time enhance their economic potential. Assistive devices are given to [persons with disabilities] with an aim to improve their independent functioning, and to arrest the extent of disability and occurrence of secondary disability.*[15]

The ADIP scheme's goal is thus to maximize individual functioning through the provision of individual devices and technologies.

In 2014, in response to negative perceptions and in a desire to technologically scale up under the ruling Bharatiya Janata Party's "Make in India" campaign, the ADIP scheme began including "modern" and "technologically complicated" devices such as electric tricycles, smart canes, and digital hearing aids. Also in 2014, following the establishment of state government cochlear implant programs in Kerala, Andhra Pradesh, and Tamil Nadu and in the Indian Armed Forces' health services, cochlear implants were added to the ADIP portfolio for prelingual deaf children five years of age and under (exceptions are made for children up to six years of age) and postlingual children under the age of twelve who lost their hearing after the age of four or five. To be eligible, children cannot have additional disabilities.

To receive a cochlear implant through the scheme, the child's family must have monthly income below Rs 15,000 (US$198). Partial inclusion in the scheme is possible for families with income below Rs 30,000 (US$396) a month. The government purchases cochlear implants from one of four major manufacturers through a competitive bidding process through which the contract is awarded to the lowest bidder that meets specification requirements. The cochlear implant is by far the most expensive device distributed through the ADIP scheme. The total package costs Rs 6 lakhs (US$7,934) and covers implantation, the external processor (which has a two-year warranty), batteries and replacement cables and coils, and two years of re/habilitation at an institute or provider enrolled in the program. By way of comparison, the second most expensive device under the scheme is an electric scooter that costs Rs 36,000 (US$476). According to ADIP guidelines, hearing aids for school-going children can cost up to Rs 12,000 (US$157), while hearing aids for everyone else are covered up to Rs 10,000 (US$132), a significantly smaller financial investment than that for a cochlear implant. The cochlear implant program is an ambitious flagship program that is often featured in the popular media in heartwarming stories about children who can now hear and speak thanks to the generosity of the state and the skilled work of surgeons.[16]

To learn how cochlear implants came to be included in the ADIP scheme, I interviewed a man I call Alok Sharma, a former joint secretary in the Ministry of Social Justice and Empowerment. Sharma is an Indian Administrative Service officer who is much respected by both the mainstream disability community and re/habilitation professionals for his ability to get things done. Sharma efficiently and energetically told me that the ADIP scheme was revised when the ministry realized that new technology was available and that the current level of funding per beneficiary was very low. The ministry sought out stakeholder participation, including input from the All India Institutes of Medical Sciences, the Ali Yavar Jung National Institute of Speech and Hearing Disorders, cochlear implant surgeons, cochlear implant distributors, and the Ministry of Health (there was no participation by signing deaf individuals or groups). Sharma continued: "And based on this stakeholder participation, we found out that if we do large-scale cochlear implants within the country, then the process of implementation of the cochlear implants will become popular, the cost of cochlear implants will come down—because it would get government supported." He also said that because of "a transparent process using web-based platforms and application portals," "large-scale" cochlear implantation is now happening in India. He summarized his work as follows:

> *We did three things. One, we brought down the prices of cochlear implants. We brought into India a culture of cochlear implants. We brought the culture of training the children, after the cochlear implants, with their parents. As well, we brought a culture of getting the doctors to do the surgery also. There are a large number of government hospitals which undertook the surgery. We empaneled the hospitals, we empaneled the doctors. All that also happened. So ultimately, it was an all-round process.*

As Sharma noted, private and public hospitals all over India have been empaneled (enrolled) in the program to perform cochlear implant surgery. Surgeons are mentored by more experienced surgeons who are sponsored by cochlear implant companies, the hospitals, or the state. Audiologists and speech and language therapists have also been empaneled.

Every application for an implant through the ADIP scheme is uploaded onto a central government site along with the required paperwork, such as audiograms, CT scan results, medical reports, disability certification, Aadhaar number, proof of income, and birth certificate. After someone is approved for a cochlear implant, he or she is placed on a waiting list, which—in the interest of transparency—is available for public viewing on the ADIP web portal. As implants are delivered by the contracted companies, the Ali Yavar Jung National Institute of Speech and Hearing Disorders slowly and incrementally sends them out to the empaneled surgeons and facilities. Families then receive notification that they are to report to a hospital for surgery; the surgery typically requires an overnight stay.

Approximately three weeks after surgery, families report to an audiology clinic for activation. Cochlear implant activation videos are ubiquitous on YouTube and other social media. In a typical video, the camera focuses on a small child as the child's implant is activated in a clinic. The child ostensibly hears or senses something, celebratory tears are shed, and the child is sent back out into the world—the child, the family, the implant, and the new sense of hearing. However, this is not all that happens when a cochlear implant is activated, or "switched on." At the time of activation, the family is given a large kit in a cardboard box, a duffel bag or backpack, or a hard-plastic box, depending on the manufacturer. The kit contains individually wrapped spare magnets, cables, batteries, battery chargers, microphone covers, small tools for cleaning the processor, and a thick instruction manual, among other things.

And this is where infrastructure breaks down: most of the Indian families I met received no information about implant components and the need for their care and maintenance practices before activation. While I observed audiologists discussing the external processor with prospective families during orientation sessions, I never saw a discussion of cables, coils, or even batteries. Families typically did not see these things until activation day. Some audiologists informed me that their practice was to activate the implant and then give the kit to the family. They would then send the family, lugging the kit, to lunch or tea "to process everything" and tell them to return to the clinic afterward. At that point, the audiologists would explain the care and maintenance processes and go through the objects in the kit with the family. Although these things are not included in the cochlear implant activation videos that circulate online, for the family, receiving the kit and learning about the different devices, cables, batteries, and spare parts and their maintenance is a significant part of activation.

On the importance of maintenance and repair, Stephen Graham and Nigel Thrift write, "It becomes increasingly difficult to define what the 'thing' is that is being maintained and repaired. Is it the thing itself, or the negotiated order that surrounds it, or some 'larger' entity?"[17] As Graham and Thrift stress, concerns about maintenance are not just concerns about particular devices, here cochlear implants; rather, they index larger issues within a structuring order that are political as much as they are personal.[18] Indeed, while the state argues that cochlear implant maintenance is a personal expense and responsibility, I see this individualizing of maintenance work as a political move that absolves the state of responsibility.

Arguing that scholars and laypersons alike are overly attentive to innovation and ignore maintenance, Andrew Russell and Lee Vinsel define maintenance as "all of the *work* that goes into preserving technical and physical orders."[19] With regard to maintenance and repair, scholars have analyzed the emergence of informal maintenance and repair workers who creatively tinker with and fix things—particularly mobile phones and televisions and stereos using recycled and repurposed parts.[20] In contrast to this body of literature on the important work of maintenance and repair, cochlear implants represent a hard limit to this discourse. While families and individuals can maintain external processors (albeit only for so long) through daily cleaning routines, they cannot repair these devices. "Spare parts" must come from cochlear implant corporations or licensed suppliers, and they are prohibitively expensive, with a cable or battery easily costing a half a month's salary or more for a low-wage worker.

Some state programs, notably those in Kerala and Tamil Nadu, provide lifelong maintenance support in their schemes, including free replacement parts, but the processes that families must go through to get replacements and repairs involve many bureaucratic steps and are often inconsistent. Government officials and other stakeholders know that people cannot afford maintenance or repairs, but it is easier to critique parents than it is to blame political-economic structures.[21] Indeed, a government audiologist once told me, "This scheme is exactly for people who cannot afford to maintain implants," while many surgeons told me vaguely "people will find a way to maintain the devices" after implantation. After implantation and a two-year period, families are on their own. Stories abound of children who have become "nonusers," or gone "off-ear," with the blame for their noncompliance placed squarely on the families for being lazy or careless, or for not saving up the money needed to maintain their children's implants. Indeed, during my research, surgeons and allied health professionals often told me that if families did not pay for anything, they would not value the devices, which was contradicted by what I saw in the field: parents who admonished their children not to play during school recess in order to avoid their devices breaking, parents who would not permit their children to go out in the rain for fear of water ruining devices, and parents who begged their children's teachers and schools to keep an eye on their child's processors. Such parents know that they will be blamed for device breakage or, more importantly, that they will struggle to afford repairs.

This analysis of the ADIP scheme points to the importance of both maintaining infrastructure and thinking about infrastructure across different scales. While the state has focused on developing a country-level cochlear implant infrastructure, it has neglected to think about the ways that this infrastructure is enacted in individual bodies and relationships and the complex work that families must do to maintain this infrastructure. "A right to hearing" might be replaced or at least augmented by a right to maintenance and repair or a right to a functioning device that does not cause families to need to make impossible decisions about whether to buy food or implant batteries.[22] Ultimately, families must engage with cochlear implant manufacturers themselves, which may have different motives and goals than the state. It is thus crucial that concerns about maintenance and repair—and who is responsible for such acts—become part of discussions about structural competency.

Ableism and structural competency

A singular focus on the right to hear also reflects assumptions about what it means to be a valuable human being. Metzl and Hansen note in their work on structural competency that "structure connotes assumptions embedded in language and attitude that serve as rhetorical social conduits for some groups of persons, and as barriers to others."[23] In this section, I focus on the need for an analysis of ableism, or beliefs and practices that devalue and discriminate against disabled people, as an essential part of structural competency. I then argue for the importance of political, economic, educational, and social work to create more enabling infrastructures; such work and infrastructures can serve to combat ableism.

Deaf communities around the world, including in India, have had strongly negative reactions to cochlear implants, and they have been called unethical and unnecessary. For example, Paddy Ladd writes that cochlear implantation is an example of "neocolonialism"; motivated by economic profit, it imposes scientific technology on and in deaf people.[24] Similarly, Harlan Lane argues that cochlear implants are a means of controlling, medicalizing, and disabling deaf people and that their use will lead to the "eliminat[ion] of Deaf culture, language, and people.[25] Such strong positions have increasingly become nuanced, with more sign-language-speaking deaf people in the Global North choosing to get implants as teenagers and adults while also remaining involved in deaf communities. In contrast, very few of the Indian surgeons, audiologists, and speech and language therapists whom I interviewed had any awareness of India's deaf communities, dense social networks, or cultural and sporting clubs.

Surgeons, audiologists, and speech and language therapists often stressed to me that they thought it was "very difficult" to be a deaf signing person in India, that few people knew ISL, and that there were few schools and employment sites available for signers. I also attended cochlear implant conferences in India where surgeons and re/habilitation professionals (dismissively) spoke of American Sign Language or just an unmarked "sign language," thus revealing that they were not aware of the existence of ISL, let alone state efforts to institutionalize ISL with and through the Indian Sign Language Research and Training Center. In observations of speech and language therapy sessions, I noted that therapists often spoke of "total communication" or "gesture" instead of ISL; they also never mentioned the possibility of ISL-based early intervention or education. In one remarkable exception, the chief orator at an Indian cochlear implant conference in 2019 was an experienced audiologist and speech and language pathologist who used her platform to stress the importance of ISL and to point out that both Indian disability laws and the Convention on the Rights of Persons with Disabilities mention sign language. She asked those present to stop ignoring ISL's existence and to educate themselves about it. The audience listened politely, and then subsequent presentations returned to the topics of surgical techniques and the importance of bilateral implantation.

Performing cochlear implant surgeries and working with cochlear implant recipients are considered prestigious and lucrative professions.[26] Cochlear implant surgeons have revered status, as they are seen as the people who make children hear, and their expertise is unquestioned.[27] However, and unfortunately, they often disparage other paths for deaf children and do not see the importance of educating themselves or families about the effects of language deprivation and the need to nurture and support multiple re/habilitative paths involving senses other than audition and modalities other than verbally speaking. For example, I interviewed a Delhi-based surgeon about someone whom he had implanted when the child was five. The child was 11 at the time of our interview and was not listening or speaking; his implant had also broken, and the family did not have funds to replace it. I asked the surgeon what he thought should be done and I wondered if the child should be referred to a sign language-based school. He told me that he did not support this idea because the child should learn to listen and speak. He was unaware of the family's financial struggles and the heavy burden they were experiencing. Indeed, in this case, the family's struggles affected not only the child's hearing but the mother's health. Since they had migrated from a rural area to Delhi and were living in a dense neighborhood, the mother had contracted tuberculosis and had to then avail herself of government tuberculosis programs.

Another example of a surgeon who refused to consider options other than speech: I met a surgeon who performed surgery on older children who did not become listeners or spoken language users; other surgeons, audiologists, and speech and language therapists had criticized his work. To restore his reputation, Praswant Bal created an app for mobile devices that allows deaf children to learn sounds (not language) by seeing immediate feedback on their production. Children using the app look at the screen and practice pronouncing "ma," "ta," "pa," and other sounds, and the app tells them if and when they are vocalizing these sounds properly. The app's brochure claims that in trials, "completely deaf and mute persons" have learned to utter eight sounds in a matter of weeks. Bal's project has been funded by the central government: it fulfills the state's desire for innovative and technological projects that utilize existing infrastructure and are "make in India." A state government was excited about the project and permitted a pilot in deaf schools in the state, in which the children used instruction time to practice uttering sounds. This brings up questions about privileging the production of sounds over learning language and subject content—perhaps in ISL. The surgeon was uninterested in ISL, insisting that it could not be used to communicate effectively in the world. He was also unconcerned about a deaf school using instructional time to teach sounds instead of language or academic content. He instead focused on feedback from parents who were ecstatic that their deaf children were uttering the sounds "Ma" and "Pa." This surgeon's endeavor articulates with points made in the previous section—the state's desire to create technical infrastructures and the valuing of such infrastructures above all else—and the ways that these desires often result in obfuscating other possibilities such as learning ISL and becoming a signer.

Health care practitioners must analyze their biases in relation to deafness and disability because such biases impact the kinds of choices families might have, as well as the current and future availability of enabling social and economic infrastructures. Disabled people consistently report their quality of life as being higher than what is expected or assumed by non-disabled people.[28] Disability studies scholars have often stressed the importance of a social model of disability in which social, political, and economic barriers to daily life and participation are the focus of remediation; cure comes from social fixes.[29] More recently, scholars have called for an explicitly political-relational model of disability that analyzes how disability is a political category created in relation to norms and structures.[30] What would happen, then, if health care practitioners saw and presented to parents ISL as a viable and valuable option? Why is cochlear implantation considered the only option and path available? Indeed, health professionals often possess a narrow definition of what it means to be "normal," and this points to the necessity of political, economic, and social work to create more enabling infrastructures.[31]

Disability justice as a key component of structural competency

Health and human rights scholars have stressed the need to focus on more than just civil and political rights; they argue for the importance of social and economic rights and emphasize that health care practitioners have a role to play, particularly in how they understand the role of the state and the impact of political-economic structures in creating health care inaccessibility.[32] Recently, disability justice scholars and activists have called for recognition of the ways that disability is an intersectional issue and of the relationships between disability, race, class, geographic location, gender, and capital, among other things. These scholars and activists have pointed to the importance of nuancing disability rights frameworks to address the workings of power and inequality.[33] Additionally and importantly, I argue that they provide a much-needed expansion of how scholars focusing on health and human rights have thought about access, infrastructure, and ability.

In *Ten Principles for Disability Justice*, Patty Berne and the Sins Invalid Collective call for an approach to disability that is anti-capitalist, sustainable, and rooted in the experiences and expertise of those most impacted by oppressive social and economic systems.[34] While Berne and Sins Invalid have proposed principles that emerge from their work in North America, I see deep resonances and the need for a structural competency approach to also engage with questions of disability justice, especially in relation to infrastructure and structure more broadly. Their principles point to the importance of critiquing intellectual property regimes that make cochlear implant maintenance and repair so costly, as well as the absence of deaf people involved in leadership and advisory positions within cochlear implant and re/habilitation infrastructures. The movement and the principles also emphasize the importance of focusing on intersectionality and multiple and often competing needs.

During the early days of the COVID-19 pandemic, for example, the father of a child who received a cochlear implant through the Indian central government program wondered why the government had not given them food or money instead of a costly device that the family cannot afford to maintain. The same father said that he and his family were just trying to stay alive. Such statements stress the importance of considering "the right to hearing" in relation to other rights.

In the case of cochlear implantation, health care practitioners must consider the complex dependencies that are created as the state implants young children and as families become dependent on multinational corporations for maintaining and repairing their implant processors. While health care practitioners might work with a family for a finite time, that family's relationship with cochlear implant manufacturers is for a lifetime. The relationship does not end after surgery or at the time that a child might attain so-called age-appropriate listening and speaking skills. This dependence is all the more fraught because families are often not aware of other options besides implantation. Beyond this physical infrastructure, ableism is a structure of thought that serves to limit possibilities for treatment, care, and ultimately all aspects of everyday life. Regardless of hearing status, all children have the right to maximize their potential. Health practitioners have a role in expanding how we might measure potential more broadly; potential does not just start and stop at hearing.

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