

FROM HOPING TO EXPECTING: Cochlear Implantation and Habilitation in India

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I am saying that the problem of our society is not a failure to integrate but of integrating too well, integrating in such a way that identicalness reigns, at least a rough identity, a socially constructed identity, an identity of which citizens can be convinced.

—Henri-Jacques Stiker, A History of Disability

In 2015, a prominent United States—based audiologist and Auditory Verbal Therapy (AVT) practitioner wrote on her blog about new hearing technologies such as cochlear implants: "It is not the same old deafness." More recently, I observed a well-known AVT therapist from the United States stating in a workshop: "In 2020, there is absolutely no reason why we cannot have listening and speaking outcomes in deaf children if this is what families want." With her statement, this therapist stressed that technology and therapeutic techniques had changed the landscape of deafness, as well as expectations of what deaf children can do and be(come). Increasingly, deaf children, specifically those who have cochlear implants and have undergone AVT, are listening and speaking, meeting developmental milestones, and mainstreamed in normative life; they have (near to) typical hearing in the sound booth, which translates to living a typical daily life beyond the clinic. With

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the view that deafness is malleable, and the expectations accompanying this malleability, a shift has occurred from the subjunctive to the imperative mood: families and other stakeholders such as the state, surgeons, audiologists, and therapists expect that many of these children will become "normal." Normal here means having typical listening and spoken-language abilities, meeting developmental milestones on target, and participating in mainstream life: here biomedical and social normativity are co-constitutive (Lloyd and Moreau 2011).

Surgeons, cochlear implant manufacturers, families, and speech and language therapists, among others, insist that with timely cochlear implant surgery and appropriate habilitation, deaf children can become typically hearing and that they can develop on par with or exceed their developmentally typical peers in terms $% \left(\frac{1}{2}\right) =\frac{1}{2}\left(\frac{1}{2}$ of their language and social skills. Indeed, they often stress that because of therapeutic interventions that focus on "proper" ways of interacting, such as dyadic turn-taking, asking and answering context-appropriate questions, and making polite conversation, these children often wind up ahead of their typically developing peers. As I heard repeatedly, cochlear implantation in coordination with AVT unleashes the potentiality of hearing brains and produces "wonderful outcomes." 5According to one line of thought, post-cochlear implantation, children are simply no longer deaf, if they ever were deaf before. As an Indian engineer developing an Indian-made cochlear implant told me: "The brain is intact and unimpaired, but there are connectivity problems. With an implant, deaf children do hear, and they hear normally in that the CI [cochlear implant] stimulates the auditory nerve." However, cochlear implanted hearing is not typical or normal hearing, and attempts to establish equivalence or similitude between deaf hearers and hearing hearers proves problematic (Lloyd and Bonventre 2020).

I conducted ethnographic research in the Indian cities of Delhi, Pune, Mumbai, and Chennai from 2016 to the present on pediatric cochlear implantation and habilitation. I interviewed families, surgeons, audiologists, and speech and language therapists and conducted participant observation in therapy sessions and conferences. I also reviewed archival materials and current texts on different therapeutic techniques and popular media articles. While the bulk of research took place in India, I also draw from interviews conducted with and workshops organized by international AVT experts and from participant observation at an Alexander Graham Bell Association symposium in the United States. Cochlear implantation and accompanying therapeutics are globalized with four major cochlear implant manufacturers located in Australia, the United States, Austria, and

France and AVT certification offered through the United States—based Alexander Graham Bell Academy.

India has long had educational programs focusing on teaching deaf and hearing-impaired children to listen and speak with the goal of producing normative communicative personhood. In the debate between oralism (using a spoken language) and manualism (using a sign language), oralists have loomed large since before the colonial period, and most of India's deaf schools are oral, at least on paper, with teachers and administrators communicating in spoken language while students struggle to receive an education (Friedner 2015). Indian audiologists repeatedly told me that previous generations of hearing technology were simply not up to the task of providing deaf and severely hearing-impaired children with auditory input. One audiologist I interviewed called older technology "a bullock cart trying to carry a heavy load." While audiologists and speech and language pathologists, specifically those working in government institutions with a wide range of deaf children and families, told me that in many cases they were able to achieve outcomes in which children learned to listen and speak, particularly through using lipreading, tactility, and really working ("forcing" is the verb used) whatever audition children had, these constituted modest results. Children often had difficult-to-understand "deaf accents," and they struggled to participate in everyday life through lipreading.8 Still, this was often acceptable, or functional, communicative personhood.

However, new and increasingly sophisticated technology and habilitation techniques have resulted in changed understandings and paradoxes in the current moment. At stake is no longer communicative personhood but the creation of a hearing brain and the removal of deafness, thus the achievement of normative sensory personhood. While during previous research between 2007 and 2015 with families with deaf children, I witnessed tensions around how learning and using sign language seemingly marked a child as visibly different and outside of normative trajectories (also see Das and Addlakha 2001 on negotiating normative life course trajectories with disabled children), I observed a different phenomenon from 2016 onward: families placed on well-trodden paths toward implantation and expectations for normative life trajectories.9 Doctors, audiologists, and speech and language therapists told such families that implants would make their children "normal," "almost normal," or "near to normal," and that implants were "the only option." Furthermore, families, particularly those with financial resources, managed to tap into international therapeutic and educational communities, such as the United States-based Alexander Graham Bell Association and the John Tracy Academy, and to receive consultations over web-based platforms with internationally acclaimed therapists in England and Australia, among other locations. Families without resources were also encouraged, sometimes ordered, to implant their children via state and central government programs and NGO and charitable funding, and to seek out therapy at government or free non-governmental organizations and charities.

My overarching argument in this essay is that cochlear implantation and the habilitation associated with it—because of the "successful outcomes" they produce—constrain possibilities for carving out new ways of being in the world. Expectations of activating potentiality through an increasingly sedimented process of implantation and therapeutic intervention contract other ways of conceptualizing potential—and ultimately what is considered normal. My research on deafness and cochlear implantation reveals that while disability might constitute a "new normal," at least in locations in the global North (Ginsburg and Rapp 2017), it is increasingly possible for children to become normal, in the sense of normative developmental trajectories. Early intervention, habilitation, and technological pathways focusing on listening and speaking are becoming more and more commonplace. Through these interventions, deaf children ostensibly become normatively sensing, setting up the scene, or rather the brain, for all other development.

While Rayna Rapp and Faye Ginsburg (2001, 537) argue that disability narratives and other forms of public representations of disability serve to "widen the space of possibility in which relationships can be imagined and resources claimed," we can also track the opposite effect in the circulation of discourses and representations of cochlear-implanted children who are labeled "success stories," and the idea that such success is possible and expectable. ¹⁰ In highlighting another process and set of logics through which disability appears and disappears (Titchkosky 2011; Zoanni 2019), I argue that while disability might increasingly constitute a new normal, this new normal also rubs up against expectations for a future without it, as well as increasingly narrow ideas of potential and personhood.

Parents from varied class backgrounds told me about inspirational popular and social media articles detailing the "magic" of cochlear implantation, articles remaining silent about other options such as Indian Sign Language (ISL). Surgeons, audiologists, and therapists also counseled parents to implant their children as "the only option." Deafness, the use of a sign language, or other possibilities for conceptualizing potential or becoming and being normal were simply not provided as options. Successful personhood, in these cases, remained contingent on a narrow definition of communicative, sensory, and social potentiality.

Potentiality is thus harnessed to one outcome: becoming a listening, speaking, and independent person who does not need to rely on family or others for help or support. That is, children are to become independent and empowered actors (Chaudhry 2015; see also Addlakha 2020, Ghosh and Banerjee 2017) who are not disabled. According to this logic, children must be capacitated and their potential activated; they require habilitation now to avoid needing care later.¹¹ The Indian state follows the same logic in its program that provides children living below the poverty line with cochlear implants: it justifies high levels of spending on a cochlear implant surgery, device, mapping, and therapy to create, through habilitation, an independent subject who contributes to the nation later. This imagined independent subject ostensibly would not need accommodations or modifications made to social, educational, and economic life. In what follows, I analyze the potentialities and desired outcomes attached to habilitation pathways, technologies, and people. I end by considering under-used and unused paths; following Sara Ahmed (2019), I argue for conceptualizing habilitation differently and choosing new paths, paths that might stretch and reconfigure how we think of personhood, potentiality, and the social more broadly.

REHABILITATION AND HABILITATION: Past, Present, Future

What are the specific stakes attached to the concepts of rehabilitation and habilitation in relation to potentiality? Much anthropological research exists on rehabilitation, which Henri-Jacques Stiker argued became a salient concept and practice during World War I (Stiker 1999, 121; also see Bloom 2020; MacLeish 2020; Mattingly 2010; Messinger 2010a,b; Wool 2015, 2020). According to Stiker (1999, 124), "Replacement, re-establishment of the prior substitution, compensation—all this now becomes possible language." Rehabilitation aims to repair, restore, and return to previous states and levels of functioning and exists to uphold social norms and "society such as it is" (Stiker 1999, 137). Rehabilitation focuses on the reintegration and reincorporation of the individual body into the national and social body. Seth D. Messinger (2010b) stresses that rehabilitation technologists often attend exclusively to the impaired or damaged body and ignore peoples' social worlds or the contexts in which they live (also see Wool 2020). In the realm of substance-abuse related rehabilitation, Jarrett Zigon (2011, 31) argues that rehabilitation involves self-transformation and is a process of working on oneself as a form of labor and "completely remaking one's moral personhood" (also see Carr 2011; Raikhel 2016). In this vein, a self or personhood must be reinvented or recreated, with limited potentiality to make new.

In contrast to rehabilitation, habilitation, as defined by the Oxford English Dictionary, refers to "the action of enabling or endowing with ability or fitness; capacitation, qualification." While rehabilitation seeks to minimize loss and restore functioning, habilitation focuses on potentiality and the maximization of potential, in other words, on capacitating children to become what they should become. As Laura Mauldin (2016, 63) writes: "While rehabilitation is the process of restoring what was lost, habilitation creates an ability that never was—or in the case of dealing with children, one that has yet to be developed." The concept of habilitation typically emerges in relation to work with and on children who are malleable and have potentiality. 12 As opposed to transformation, habilitation involves formation. If rehabilitation is about remaking or transforming, habilitation is about becoming, about working on a malleable not-yet bodymind. Habilitation also skirts close to cure (Clare 2017; Venkat 2016; Warren and Addison 2020), as well as to the potentiality of children to lose diagnoses. Habilitation might result in the impossibility of finding and claiming deaf and disability identity and community, which constitutes another kind of normal. But how do you lose something you never had?13

Habilitation depends on potentiality. Potentiality depends on malleability. As (some forms of) deafness are seen as malleable in ways that other impairments might not be, cochlear implantation offers a critical site for tracking habilitation discourses, ideas of potentiality, and possible futures that are produced and constrained. Karen-Sue Taussig et al. (2013, S7) suggest "that people appear to ascribe potentiality to those things they believe can be manipulated (or they desire to manipulate) and not to those perceived as being beyond human control (or seen as not in need of change)." They note that "in biomedical practices, potentiality indexes a gap between what might, could, or even should be" (Taussig et al. 2013, S5). Indeed, habilitation paths concern circumscribed expectations oriented toward outcomes that shore up the normal. In this case, the expected outcome is for a child to develop a hearing brain, like all other non-deaf children, and to listen and speak; anything other than such an outcome appears suboptimal. The imperative mood indeed.

As I discuss, AVT existed as a habilitative approach long before cochlear implants came onto the scene. However, internationally and in India, the approach has been catalyzed by increasingly prevalent newborn hearing screening, early intervention, and cochlear implantation. While India does not currently have universal newborn hearing screening, advocacy for it exists. (The World Health Organization's 2021 World Report on Hearing stresses the importance of developing

universal newborn screening.) An early screening and intervention program called Rashtriya Bal Swasthya Karyakram, which screens for disabilities, diseases, and developmental delays, launched in 2013. Increasing awareness exists about children's potentiality and the importance of habilitation in preventing or mitigating disability. In the case of deafness, habilitative potentiality is said to wane with age and surgeons, audiologists, and therapists stress the existence of a critical window of opportunity for developing a hearing brain and learning language. As children age, surgeons, audiologists, and therapists argue, families' expectations must be managed as possibilities for becoming normal decrease. At that point, the hope is that children can become near or adjacent to normality. Normal may be a receding horizon but it is still the horizon, one becoming more sharply etched as it is (re) produced.

TECHNOLOGICAL POTENTIALITIES

To be sure, other interventions besides cochlear implants have existed, and continue to exist, in India and elsewhere: there are hearing aids that range from one-size-fits-all body aids to programmable digital aids. There are also a range of therapeutic techniques that often involve multisensory approaches whereby therapists use tactile and visual methods. Tactile methods include blowing on feathers or having people touch therapists' and their own throats and lips to feel vibrations. Visual methods include lipreading, reading texts, and showing objects or pictures. Adults and older children often share memories of repeatedly and laboriously repeating sounds and words to practice saying them correctly. Increasingly, however, surgeons, audiologists, and therapists denigrate multisensory approaches or discuss them ambivalently as something to be utilized when unisensory, or solely auditory-based, approaches do not work. An older speech therapist commented that multisensory interventions and hearing aid technology have been backgrounded by the spectacular "noise" of cochlear implants.

As more children are implanted, therapists have fewer opportunities to learn about and use multisensory approaches. Students in bachelor's degree programs in audiology and speech and language pathology throughout India often enthusiastically shared their desire to work with implanted children. They considered working for a cochlear implant manufacturer post degree an exciting job opportunity, with perks such as high salaries and travel within India and abroad. Practicing therapists emphasized that "everyone wants to jump on the implant train." Parents have also jumped on the implant train: in interviews they expressed their desire to skip necessary hearing aid trials because they perceived the required three-month

trial, during which children receive minimal input, as a waste of time. ¹⁵ They felt cochlear implants offered more in terms of potentiality and future life possibilities.

Cochlear implants did not immediately gain popularity in India. In interviews with Indian surgeons, audiologists, and therapists, I learned that, in the late 1980s, the first Indian surgeon to conduct cochlear implantation operated on older prelingually deaf children. These children were ostensibly too old to be habilitated successfully, and they did not attain desired listening and spoken language outcomes. While these initial implanted people could hear, they could not speak well, and so cochlear implants were not deemed worth the expense (and they were very expensive on the private market). Those I interviewed in the field of cochlear implantation viewed this first surgeon as "irresponsible" in implanting less-than-optimal candidates who lacked potentiality, therefore setting back the field. Yet as implant technology progressed and cochlear implants became normalized in other countries, Indian otolaryngology surgeons slowly started performing surgeries, initially on adults, and after conducting a specific number of adult surgeries, the implant manufacturers approved them to implant small children.

The first cochlear implant surgery performed on a young child in India occurred in 1999 and after this, a handful of children received implants every year, initially middle- and upper-class children whose families could afford the expense.¹⁶ In 2011, the state of Andhra Pradesh started providing cochlear implants to children within the state, followed by Kerala. Other states and the Indian Armed Forces followed suit. In 2014, the central government began offering cochlear implants to children under the age of six living below the poverty line as part of its Assistance to Disabled Persons for Purchase / Fitting of Aids and Appliances (ADIP) scheme, and it also included two years of therapy as part of the program, in addition to device mapping and maintenance. (Note that stakeholders, from families to surgeons, feel that two years of therapy and follow-up maintenance do not suffice. They critique the state for valuing surgery and the implant device more than the habilitation process, thus misrecognizing the potentiality of the device and the therapeutic process.) These programs resulted from various stakeholders such as surgeons and device manufacturers providing "evidence" of cochlear implanted children's successes through videos of such children talking and engaged in activities of everyday life such as playing sports, excelling in mainstream academics, and participating in music and dance classes. Implanted children, they were quick to point out, were normal, just like everyone else.

An increased focus on therapeutics and the circulation of new expert discourses about deaf children's potentiality accompanied technology uptake. Co-

chlear implant corporations have employed Indian audiologists and therapists to provide trainings throughout the country, and they also fund international "expert" trainers from the United States, Australia, and European countries to visit Indian clinics. Select manufacturer-sponsored therapists also travel abroad to visit cochlear implant corporate headquarters and training centers. In addition, some upper-class mothers have decided to become therapists, pursuing training from international venues like the Alexander Graham Bell Association and seeking out international AVT mentors.

The importance of habilitation is increasingly foregrounded. As multiple therapists, and some surgeons told me: "Surgery is only 20 percent of the work; therapy is the rest." The device and the surgery, then, only have so much potential, and trainers stress AVT principles, which foreground the importance of early intervention and implantation. At stake is habilitation—building, cultivating, and maintaining a hearing brain.

AVT AS POTENTIALIZING NORMAL SENSING

Consider this United States-based story, discussed at length because it demonstrates what habilitation ideally does in terms of audiograms and daily practices. In November 1974, John Croft, the American father of a then nine-year-old deaf child named Rose, wrote a passionate essay titled "The Third Way," in which he argued that the contentious debate between oralism and manualism obscured the existence of a third category and movement, which he called "auralism" (Croft 1974, 1). Croft, a professor of education, argued that both oralism and manualism were imperfect because neither method could "teach an individual with only four senses how to compensate well enough to compete successfully in a world where others have five" (Croft 1974, 1; emphasis original). In contrast, auralist methods create "hearing-deaf" children who become "functionally mildly hard-of-hearing" through training their auditory sense (Croft 1974, 1). According to Croft, aural children can have conversations through walls, use the telephone, and hear their teachers regardless of where they sit in the classroom. They do not need to read lips during spelling tests and can watch television. Aural children experience "fivesensed normality" (Croft and Croft 1978, 1). What is required for "five-sensed normality" is a constant focus on audition, "until listening becomes as much a habit as looking, and feeling, and smelling, and tasting" (Croft 1974, 3; emphasis original).

The principles and methods for which Croft advocated are currently called Auditory Verbal Therapy (AVT), although at the time they were not gathered under

an approach or acronym. Doctors did not discover Rose's hearing loss until she was two years old. As a result of this purportedly late diagnosis, which occurred after she was already considered delayed in her language development, her visual sense had a two year "head start." To counteract this, Rose's family focused entirely on her auditory channel to ensure it did not remain "deficient" (Croft and Croft 1978, 2). When Rose was diagnosed, the doctor did not say that Rose could not hear. Rather, he claimed that Rose "does not appear to be using any hearing. Therefore, after providing proper amplification, we must begin immediately to teach her to listen" (Croft and Croft 1978, 2; emphasis original). Rose learned to listen through weekly therapy sessions and by working extensively with her mother. She wore her binaural hearing aids from morning to night. A broken hearing aid was quickly repaired or replaced; she never went three hours without a well-functioning hearing aid (Croft and Croft 1978, 3). Throughout her training, Rose's listening ability improved and her aided audiogram climbed up the chart. At the age of seven, Rose had reached the borderline of "normal hearing at some frequencies" (Croft 1977, 3; Croft and Croft 1978, 6). According to Croft, his daughter and others like her are "hearing-deaf children" that have been kept a secret (Croft 1977, 2). Croft was stressing the importance of habilitation.

Rose's therapist was an AVT pioneer before the method took this name. Known in different circles as the unisensory approach, acoupedics, auralism, the auditory approach, the acoustic method, natural language, and other names, the method stressed that most hearing-impaired children, even those profoundly deaf, have some residual auditory sense that can be capitalized on. In 1978, the International Committee on Auditory-Verbal Communication was formed as a section within the Alexander Graham Bell Association for the Deaf. In 1985, an AVT certification process started as practitioners wished to differentiate their methods from other approaches, such as the auditory-oral approach, which allows visual cues, and to have a credential that recognized AVT mastery. About 1,000 certified AVT therapists exist internationally, with most concentrated in countries in the global North, although the Alexander Graham Bell Academy, the certifying body, currently has a committee focused on diversity and barriers to uptake in the global South. Certification requires a degree in a deaf education or a re/habilitation-related field, mentorship by a current certified AVT professional (which potential AVT therapists might pay for), and an exam in either English or Spanish at a licensed testing center. After certification, therapists must abide by the following ten principles (Estabrooks et al. 2016, 4-8):

- Promote early diagnosis of hearing loss in newborns, infants, toddlers, and young children, followed by immediate audiologic management and auditory-verbal therapy.
- Recommend immediate assessment and use of appropriate, state-ofthe-art hearing technology to obtain maximum benefits of auditory stimulation.
- 3. Guide and coach parents to help their child use hearing as the primary sensory modality in developing listening and spoken language.
- Guide and coach parents to become the primary facilitators of their child's listening and spoken language development through active consistent participation in individualized auditory-verbal therapy.
- Guide and coach parents to create environments that support listening for the acquisition of spoken language throughout the child's daily activities.
- Guide and coach parents to help their child integrate listening and spoken language into all aspects of the child's life.
- 7. Guide and coach parents to use natural developmental patterns of audition, speech, language, cognition and communication.
- Guide and coach parents to help their child self-monitor spoken language through listening.
- Administer ongoing formal and informal diagnostic assessments to develop individualized auditory-verbal treatment plans, to monitor progress and to evaluate the effectiveness of the plans for the child and family.
- Promote education in regular schools with peers who have typical hearing and with appropriate services from early childhood onwards.

India currently has five certified AVT therapists with private practices who conduct training sessions with other therapists and consult with national institutions as well as cochlear implant manufacturers. These five certified therapists play an outsized role in therapeutic practice, and they and cochlear implant manufacturers have argued that AVT is the "gold standard" in terms of working with implanted children. As a result of their lobbying campaigns, NGOs, government institutes, and for-profit entities conduct AVT courses of various lengths, although they cannot provide certification. Uncertified therapists are not permitted to claim that they do AVT; as such, therapists might use auditory verbal principles under the umbrella of "auditory habilitation" or "auditory therapy."

As noted in the AVT principles, in addition to "state-of-the-art hearing technology," parents, typically mothers, must play a role in their children's habilitation. They are required to constantly talk to their children about everyday life. Mothers are to be rehabilitated in how they work and interact with their children. I observed in clinics as therapists coached mothers to engage in turn-taking, to ask questions, and above all, to narrate everyday life. Mothers, according to therapists, should talk as they cut vegetables, cleaned their houses, and went shopping at markets. Therapists admonished mothers not to engage in "emotional" acts such as cuddling their children. Instead, they are to talk to them. One therapist told me that it was acceptable for a child to sit on a mother's lap, but that the child needed to face outward, so that they could not read their mother's lips. Mothers talked about doing mehanat, hard work, to achieve listening and speaking results, and two common expressions were that "hard work brings sweet fruit" and "hard work brings colors." The sweet fruit and the colors referred to listening and speaking children. Habilitation was to take place in all aspects of daily life, to become habit. Note, then, that not only children have potentiality but also parents, or more specifically, mothers. There are multiple subjects of habilitation, all focused on the same goal.

Therapists overwhelmingly agree that AVT only works for children who are young and do not have additional disabilities: most therapists told me that they could not do AVT with children older than five, although they might utilize some AVT principles. As one Delhi-based AVT therapist matter-of-factly told me, a child over five "could not become an auditory person." During a presentation at an Indian cochlear implant industry conference in 2019, a corporate representative showed a PowerPoint slide that outlined the commonly accepted stakes: ages 0 to 3.5 were the maximum critical period; ages 4 to 7 were designated the open critical period; and ages 8 to 12 were considered the questionable critical period for learning language. These neatly delineated periods map onto the "hearing potential" of a child (Estabrooks et al. 2016, 10) and provide a roadmap of potentiality as a race against time, one in which plasticity is maximally, openly, and questionably present. At different ages, then, potentiality and habilitation possibilities are differentially available.

The age of implantation and beginning AVT matters because increasingly, experts regard deafness as a brain issue rather than an ear problem. They agree on the importance of early intervention, and the numbers usually cited are one-three-six: a child should have a hearing test by one month of age, a diagnosis by three months, and early intervention by six months.¹⁷ This is important because

deaf children are considered already behind at birth. An Indian cochlear implant surgeon told me that "[the] child is hearing mother's voice in the last three months of the pregnancy, in the third trimester. So a deaf child is already 12 weeks deaf by the time [the] child is born." As a result of the view that there is a race against time, younger and younger infants are receiving cochlear implants: the age of cochlear implantation approved by the United States Food and Drug Administration has just decreased from twelve to nine months.

During my research, audiologists, cochlear implant manufacturers, surgeons, and speech and language therapists stressed that deafness is a "neurological emergency" and insisted that families must "act now" to actualize potential and avoid harm and delays. However, being able to "act now" is often a class privilege. I observed that it often took families six months to a year to compile the necessary paperwork and medical tests to be eligible for the state schemes and then there were waiting lists. Families ineligible for government funding or those that decided to cobble together funding on their own also had to "run from pillar to post," in their words, for funding. The only families able to "act now" were upper class families with access to financial resources. Economic barriers create temporal constraints. Potentiality is beholden to capital.

As the AVT researchers and practitioners Carol Flexer and Ellen A. Rhoades (2016, 27) emphasize: "Identification of newborn hearing loss and other hearing differences should be considered a neurodevelopmental emergency." AVT experts stress that neuroplasticity is greatest in the first three years of life: "The younger the infant, the more neuro-plasticity the child has" (Flexer and Rhoades 2016, 30). If audition is not introduced and the brain does not stay wired for sound, "sensory deprivation" and subsequently cross-modal reorganization in favor of vision will take place (Flexer and Rhoades 2016, 30). Cross-modal reorganization will result in a reduction of "auditory neural capacity" (Flexer and Rhoades 2016, 30). Such a reduction means that the child will have less potential to become someone who uses listening and spoken language. While these discourses about the brain and the division of the senses originate in the United States and elsewhere in the global North, they have made their way to India via cochlear implant manufacturers and AVT therapists.¹⁹

CHANGING EXPECTATIONS

As a result of earlier hearing testing and intervention, more sophisticated technology, and discourses about hearing brains, a person previously considered a "success story" or "star case" perhaps no longer qualifies as such: families have

come to expect more of and for their children. These heightened expectations are, perhaps ironically, occurring at the same time that disability activism is growing in India and disability access, through initiatives such as the central government's Accessible India Campaign and the inclusion of Indian Sign Language interpreters at official speeches, is improving. (Expectations are growing in disability activist spaces as well.) While disability is ostensibly becoming more visible in public discourse and spaces, families, particularly those with means, have come to expect normalization and the loss of a diagnosis.

Families told me they did not use the category of *disability*, and they declined to utilize disability quotas for their children. Audiologists and speech and language pathologists similarly wondered if it was necessary or even fair for implanted children to utilize quotas in education and eventually in employment since, with implants, children were no longer deaf. In an interview, one audiologist rhetorically asked if implanted children should be compared with other deaf children or to hearing children. To be clear, when implanted children remove their external processor, they might not hear anything, since implantation typically results in the decimation of residual hearing. Losing or discarding the diagnosis of deafness, however, means that children are listening and speaking and meeting normative milestones, thus competing against and in relation to non-deaf children, rather than other deaf children, in their pursuit of selective education and employment. Importantly, habilitated implanted children can compete, and may even be ahead because of the intensive AVT training they have received.

Encounters across time and technology reveal the stakes of changing expectations, as well as communicative and sensory hierarchies. For example, Aruna, a mother of a deaf son, told me that after her son received his diagnosis of deafness in the early 2000s, she set out to learn as much as possible about different interventions, programs, and technologies in Delhi, where she was living, and elsewhere in India. She visited an NGO providing early intervention in Delhi, which other parents of a deaf child had started. She met their daughter, who is (was?) considered a star case; this girl used hearing aids and lipreading to communicate and had been mainstreamed into a regular school. Yet the girl's deaf accent and laborious lipreading practices left Aruna dismayed. She did not want her son to end up like this. Aruna decided to look elsewhere because she wanted her son to listen and speak more clearly; she had different ideas about his potentiality and she expected normative sensory personhood for him.

Aruna also visited an early intervention center in Chennai, where she felt disheartened by what she called the center's "anti-technology" focus. She said that

the center did not favor sophisticated digital hearing aids and that its administrators preferred children to use basic analog behind-the-ear hearing aids or the one-size-fits-all body hearing aid. When I met the founder and current principal of this center, they stressed that they obtained wonderful results with these (more) affordable devices and did not see the point of "bells and whistles." They were also concerned that foreign devices were heavily taxed, and more advanced devices were financially out of reach for most families with whom they worked. They did not approve of the government programs that did not pay for device maintenance or replacement after two years of implantation in most cases. This center focused on reading and writing to develop language and did not spend significant time on speech training; it had its own ideas of successful outcomes. Interestingly, both the Delhi-based NGO and the center in Chennai opposed cochlear implants, considering them unnecessary, expensive, and risky. In turn surgeons, audiologists, and speech and language therapists critiqued both centers for being out of date and for stifling deaf children's potential. In their view, these institutions were not thinking potential otherwise but were rather preventing children from becoming listening and speaking, two essential characteristics needed for success in the world; these children would never lose their diagnoses.

Aruna decided to implant her son and eventually became a certified auditory verbal therapist. ²⁰ Today, Aruna's son is a young adult; he attended an elite private school in Delhi, served as the captain of his school's Lincoln-Douglas Debate team, and played cricket. He told me that he is often held up as a role model for what other deaf children can become (and he and his mother have been featured in promotional videos for the cochlear implant corporation that manufactured his device). However, he knows (he does not hope; he *knows*) that in the future, other deaf children will accomplish more than he has. While he felt that being a role model created a lot of pressure, there was something melancholy and awkward about realizing that in the future, he would be found wanting in the name of progress. And indeed, children will be diagnosed earlier and receive earlier intervention. Implant technology is also evolving, with more flexible electrode arrays on the internal device and smarter noise reduction and nuanced speech-processing features on the external processors. Surgeons, audiologists, and speech and language therapists also increasingly encourage bilateral implants when families can afford it.

I talked with another mother who runs a parents' organization that provides early intervention, education, and support both for parents of deaf children and for deaf children themselves. Her child is now in her early thirties, a product of analog hearing aids and multisensory therapy approaches. She was diagnosed at the age of _

three, after doctors dismissed her mother's concerns about her not hearing. I asked this mother how she felt seeing infants now, who have access to early, and sometimes newborn, hearing screening and early intervention. She said that she took comfort in knowing that she did the best she could at that time. She felt that she had maximized her child's potential in working with what was available. While her daughter is now a young adult, the family is considering using their own funds to implant her, because surgeons and therapists consulted by the family think that she does retain some auditory potential that can be acted on. She would not, however, be a candidate for AVT. She was successfully habilitated as a child using her hearing aids, and conditions of possibility for further progress as a listener and speaker remained should she choose cochlear implantation.

There is both the metaphorical and empirical existence of the older child who was diagnosed late. What kind of potentiality does she have and what habilitation paths are productive? A late diagnosed child is considered always already behind and not on an ideal developmental trajectory.²¹ The benefit of implants for older deaf children and adults is often debated, although surgeons, cochlear implant manufacturers, and audiologists insist that implants always offer benefits, such as environmental noise. Yet what does environmental noise give someone in terms of potential? While government programs will not provide older children and adults with implants, there is an expanding private market as parents seek out possible benefits. Here, there is hope, though no expectations.

One afternoon during the summer of 2018, I visited Purnima, one of India's most respected AVT therapists, at her office. She was conducting a training for audiologists and speech and language pathologists from around India. On an easel and butcher paper were written questions and themes they had been discussing. I focused on one question: "Older children—is there hope?" Intrigued, I asked Purnima about this topic, and she replied that there was hope but that expectations needed to be managed. She believed an older child could benefit from an implant and achieve some auditory discrimination, such as the ability to distinguish traffic sounds. However, their actual listening and speaking ability might not improve. Some hearing, she stressed, was better than none.

Similarly, a clinician named Parvathi at a prestigious government hospital told me about an eight-year-old, recently implanted child with whom she was working. She told the family: "See, your child has already crossed the age of plasticity. Though he will learn language, that will only be functional language, what he needs immediately." Functionality becomes a way forward, although it is not ideal. I also observed Aruna, the mother and AVT therapist mentioned above, counsel a family

of a late-implanted child that they might consider vocational training so that their child could become "independent." The child had been implanted at five and was now eleven. He was not listening, although he could speak a bit. Aruna stressed that he could become functional through learning a trade (never mind that he was still a child). Aruna's comments about functionality demonstrate that she did not see this child as possessing potential. Functional here translated as the ability to do manual labor; it did not mean excelling at piano, getting admission to an elite college, or becoming a software engineer. More broadly in these clinical and therapeutic spaces, functionality means curtailed potentiality in the absence of aurality and a hearing brain. A functional person is never fully independent and never fully normal; they remain disabled. Functionality is thus a form of foreclosure.

Purnima, Parvathi, and Aruna "managed expectations" while at the same time orienting families to futures involving (limited or diminished) listening and spoken language opportunities. As a child aged, potentiality was a receding horizon, and children were seen as only capable of "basic" or "functional" communicative personhood through implants. This raises questions about other potential paths. What other kinds of habilitation might there be, perhaps involving ISL or a multisensory approach that includes a sign language, lipreading, and a focus on reading and writing, for example? Why are there not many paths for being deaf and hearing? The three therapists mentioned here would not consider other such paths to be habilitative, because they do not result in hearing brains, listening and speaking, and normative life trajectories.

NEW PATHS AND A POSSIBLE (RE)HABILITATION

Becoming normal is increasingly an expected process because of technological developments and the emergence and sedimentation of habilitation pathways. While rehabilitation is concerned with recuperation, retrieval, and recovery, habilitation is focused on potentiality and oriented toward activating normative notyet functioning. While there have always been deaf and hard-of-hearing "success stories" who succeed in mainstream life as a result of audiological and speech and language interventions, cochlear implantation and AVT have brought new expectations for deaf listeners and speakers, deaf "aural" people, into the mix. According to the logic utilized by cochlear implant advocates and health and therapeutic professionals, deaf children can have hearing brains, lose their diagnoses, and become normal if the right kinds of habilitation occur early enough.

How might habilitation—and ideas of potentiality more broadly—become more expansive? The key is to stretch how we think of communicative and sen-

sory personhood beyond hearing brains and listening and speaking. ISL-speaking deaf activists have advocated for this through promoting Indian Sign Language and deaf flourishing (De Clerck 2016). In 2020, an Indian Deaf activist created a video blog in which he signed the following and posted a transcript:

To Audiologists & Speech Pathologists: For your information, I have nothing against you for providing devices for Deaf people to try to hear. I, myself, am a hearing aid user. I strongly encourage you to advise parents of Deaf children to learn sign language so that they can communicate with their own child starting at an early age. This will establish a lifelong bond between the parents and child. Clarify the myths that learning sign language does not reduce or eliminate their ability to speak. For you being in this profession, you'll gain much more respect from the Deaf community if you become our allies in promoting sign language. You could spark this transformation for millions of parents who lose hope for their Deaf children due to being misinformed by your professionals.

I am struck by this leader's comments about parents losing hope because of hyped-up misinformation about technology's promise and the importance of listening and spoken language. I, too, have met numerous parents who spoke about ISL with gratitude and relief: even though it was their last option, it proved life-changing for their relationships with their deaf child and activated new forms of communicative relationality. This Deaf leader brings up the possibility of sparking a "transformation." I return to Zigon's (2011) definition of rehabilitation as self-transformation in thinking about this Deaf leader's statement: he is calling for the rehabilitation of audiologists, speech and language pathologists, families, and society at large. Rather than for a return or restoration, however, he is calling for something different, and, to his mind, better—the embrace of ISL and multiple paths. Here rehabilitation means being open to various possibilities of world-making and living (also see Wool 2020). Rehabilitation means reconceptualizing potential.

While professionals and families often dismiss ISL as a viable option because it is not widely used, I think about Ahmed's (2019) observation that embarking on one path serves as a means of limiting other (also potentially useful) options. "The more a path is used, the more a path is used" (Ahmed 2019, 41; emphasis mine). When one starts walking along a well-used path, it becomes easier to walk on it: the path seems commonsensical or natural, and one might feel encouraged and invited to

head off in that direction. As Ahmed notes (2019, 42): "The law of most paths: following a path makes a path easier to follow." Thus, multiple understandings of potentiality, habilitative paths, and ideas of normal are needed.

Cochlear implantation and the habilitation that accompanies it are premised on a commitment to activating potentiality; however, these processes also limit possibilities of communicating, sensing, relating, and understanding potential. Families come to expect, rather than hope for, normal listening and speaking, and hence normative life trajectories. They become oriented toward their child's normative successes and do not embark on other paths or stretch the social. In response, I think of the work of disability studies scholars and activists who argue that disability has introduced new possibilities and paths for (re)imagining and creating social interactions, familial and caring relations, arts, literature, and the built environment, among other things (Autistic Self Advocacy Network 2012; Bauman and Murray 2014; Hamraie 2017; Hendren 2020; Kafer 2013; Piepzna-Samarasinha 2018; Wong 2020). These works argue for (the making of) a more capacious social that is inclusive of disability and nonnormative life more broadly; they see and enact potential otherwise and, in the process, they perform prefigurative politics.

How might we reach families and children to foreground multiple paths for being deaf, disabled, and normal? It seems to me that one answer lies in expanding how we think of role models and star cases. Recently, I interacted, first on social media and then in conversations, with three Indian cochlear-implanted adults in their twenties, considered to be "star cases" by the manufacturer that made their devices, their surgeons, and speech and language therapists. They are considered exceptional because of their listening and speaking abilities and educational achievements. Yet these young adults have come to embrace the category of disability, are learning sign language, and are playing around with categories and modalities: they are deaf and hearing and speaking and signing. They also speak out about what they call the ableism permeating cochlear implant corporate advertising, and they are reinventing what it means to be a role model. In doing so, they point to the heavy labor involved in meeting and exceeding expectations as an implanted young person. They critique normative interventions such as cochlear implants while also utilizing them. They think potentiality otherwise and refuse narrow expectations through foregrounding discussions of access and calling for a more capacious social. 22 Disability activism and biotechnology might coexist more easily if individual habilitation were accompanied by society's rehabilitation. Such rehabilitation would involve embracing an expansive conceptualization of potential, an open-ended approach to habilitation, and an acceptance of multiple outcomes as normal.

ABSTRACT

While scholars have attended to disability as a new normal that is increasingly present as a category and experience in public spheres, this essay argues that technologies such as cochlear implants and accompanying therapeutics make it possible for children to "become normal." Parents come to expect, rather than hope, that interventions will work. An analysis of habilitating children with cochlear implants in India—and habilitation as a process and practice in general—foregrounds the ways that potentiality attaches to certain kinds of devices, therapeutic methods, and people because of the presumed existence of malleability. Habilitation in the case of cochlear implants means developing a hearing brain and becoming a listening and speaking person. Potentiality and ideal habilitative trajectories wane with age and families must negotiate expectations in relation to sharply etched ideas of what is normal. This essay stresses that just as scholars have critically attended to rehabilitation, habilitation too is an important process of activating what is perceived to be latent and has future-oriented stakes. [habilitation; rehabilitation; deafness; potentiality; cochlear implants; India]

सारांश

शोधकर्ताओं ने विकलांगता की खोज सार्वजनिक क्षेत्रों में तेजी से फैलता हुआ एक वर्ग एवं " नये साधारण " अनुभव के रूप में की हैं ।इस निबंध में यह तर्क दिया है कि " कॉक्लियर इम्प्लांट " जैसी टेकनोलोजि और उसके सहयोगी उपचारात्मक तंत्र बच्चों के नॉर्मल बनने की संभावना निर्माण करते हैं। माता-पिता आशा करने की बजाय अपेक्षा करने लगते हैं कि इस प्रकार के हस्तक्षेप सफल होंगे। भारत में " कॉक्लियर इम्प्लांट " का उपयोग करने वाले बच्चों के हॅबिलिटिशन एवं आम हाबिलिटिशन की प्रक्रिया और कार्यप्रणाली का विश्लेषण क्षमता विस्तार के उन विविध मागों को सामने लाता है , जो संस्कारक्षम प्रभाव का अस्तित्व मानने से , विशिष्ट प्रकार के उपकरण , उपचारात्मक तंत्र , मानव संसाधन के साथ जुड़े हुए हैं।

" कॉक्लियर इम्प्लांट " के संदर्भ में हॅबलिटिशन का मतलब श्रवणक्षम दिमाग विकसित करना एवं सुनने और बोलने वाली व्यक्ती बनाना । क्षमता विस्तार और हॅबलिटिशन के आदर्श मार्ग उम्र के साथ धीरे-धीरे घटते हैं परिवार वालों ने इस बात को ध्यान में रखते हुए "नॉर्मल" की संकल्पना के बारे में अपनी धारणा तय करनी चाहिए ।

इस नबिंध में यह बात अधोरेखित की है: शोधकर्ताओं ने रिहेंबिलिटिशन संकल्पना को गंभीरता से परखा हैं। हॅबिलिटिशन एक ऐसी प्रक्रिया है जो , हम जिसे कथित रूप में अव्यक्त समझते हैं उसे सक्रिय करता है और इसका भविष्य में महत्वपूर्ण योगदान हैं । [कीवर्ड: हॅबिलिटिशन, रिहॅबिलिटिशन, कॉक्लियर इम्पलांट, विकलांगता, संभावना]

NOTES

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- 1. For information about and a description of a cochlear implant, which includes a surgically implanted electrode array and external processor that sends signals to the electrode array, see https://www.nidcd.nih.gov/health/cochlear-implants.
- See https://hearinghealthmatters.org/hearingandkids/2015/its-not-the-same-old-deafness-2/
- 3. Statement made September 2020, online workshop.
- 4. At the same time, however, neuroscience research exists on the so-called degraded signals that people with cochlear implants work with and through, the increased cognitive load carried, and fatigue experienced by people with cochlear implants. Cochlear implant manufacturers, audiologists, and speech and language therapists often downplay or ignore this research. See Bess and Hornsby 2014; Moore and Shannon 2009; Pals et al. 2013, 2020; Pisoni et al. 2008.
- 5. I use *potentiality* and *potential* interchangeably, although I see potentiality as the quality of having potential; there is no potential without potentiality.
- 6. I use pseudonyms for all named participants and in some cases I have changed participants' gender to further protect their anonymity. I have also changed John Croft's daughter's name in my discussion of Dr. Croft's and his wife's work with their daughter.
- 7. The Alexander Graham Bell Association for the Deaf and Hard of Hearing is headquartered in Washington, D.C. Its mission is "working globally to ensure that people who are deaf and hard of hearing can learn to hear and talk" (https://www.agbell.org/). It became an explicitly international organization in 2019.
- 8. I write "particularly those in government institutions" because private therapists often carefully screened and chose families with whom they worked: they wanted the families and children with the most potential (and the most resources).
- 9. See Mauldin (2016, 28) on the "anticipatory structures" in place to guide families toward cochlear implantation and the scripts they follow.
- 10. Also see Landsman (1998, 87) on how families reorient to having a disabled child and, in the process, create new narratives for themselves about their children's qualities, personalities, and potential. In an Indian context, Vaidya (2016) has written in a similar vein about parenting an autistic child.
- 11. In an Indian context, much research on disability tends to focus on questions of care, specifically how families care for and manage the integration of their disabled children within families, neighborhoods, and across the life course more generally (Addlakha 2020; Das and Addlakha 2001; Ghosh and Banerjee 2017).
- 12. Children play particularly liminal and ambiguous roles in disability movements predicated upon the concept of "nothing about us without us" (Groce 1996; Carey et al. 2020). Who speaks for children and who decides what potential is and what children can become?
- 13. In deaf signing worlds, learning to sign is also seen as habilitation in that through learning sign language, deaf people become members of deaf sociality. Thank you to Brad Weiss for pointing this out. Currently in India, employees at the Indian Sign Language Research and Training Center are fighting for the creation of an early intervention program through which parents and infants/small children will learn sign language.
- 14. As deaf people often stress, the frame of hearing loss does not capture deaf peoples' experiences, especially for people born without hearing. Such people have not experienced "loss" of a sense, although they may experience loss of a social sense depending on context (Bauman and Murray 2014).
- Audiologists, speech and language therapists, and families routinely criticized government-distributed hearing aids as low quality.

- 16. In an interview with this family, the mother told me that she faced familial pressure to not have her child be the first case, or "the guinea pig," but she felt that she needed to do everything possible for her child.
- 17. See https://www.asha.org/Articles/Early-Hearing-Detection-and-Intervention/.
- 18. This is what Mauldin (2016) calls "precarious plasticity."
- 19. Note that what therapists told families changed according to their perceptions of families' class and education levels. Some therapists simply told families that their child had a "hearing problem" and needed a "machine." However, I observed therapists in government institutions instructing families about neuroplasticity and the importance of the brain.
- 20. I met quite a few mothers who became therapists; they were activating their own potentiality as well. Another mother named Namitha told me that her life dramatically changed after she had her son, learned that he was deaf at six months, and implanted him (too late, she said ruefully) at the age of four. She had a degree in chemistry that she had never used because she had married soon after graduating. She was formerly a housewife but now has become a different person with a new career. She has her own AVT practice on the ground floor of her house and sees six to seven children a day. It is easy to dismiss Aruna and Namitha as upper-class (they are) women rendered malleable by access to resources and time to devote to studying AVT. Yet this reductive view ignores the ways that these women become different kinds of people in terms of their life and career trajectories and develop new forms of expertise. While malleability—or plasticity—is expected in and from implanted children, it is also expected of mothers.
- 21. These discourses around lateness have resonance with postcolonial scholarship on teleologies of progress (Chakrabarty 2000). However, instead of sitting in the "waiting room," these children are sitting in the clinic or at home without any intervention, according to professionals (who have a particular view of intervention)—and then they arrive at the waiting room. And note that the "late implanted child" occupies a particularly vexed position in cochlear implant and neuroscience research (Fitzpatrick et al. 2015; Holt and Svirsky 2008), as does the "later signer" in sign language and neuroscience research (Hall 2017; Mayberry and Eichen 1991).
- 22. Also see writings, films, and public speeches by Chella Man, a deaf implanted signing and speaking artist and performer: https://chellaman.com/

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