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# Disability, Assistive Technologies and the 'Special' Needs of Children

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In this piece, Kim Fernandes draws our attention to the politics of assistive technologies for children with disabilities, to show how design processes and choices, starting from the framing of who is prioritized and served, can make a difference that pins down whether children with disabilities will be heard and understood or further stigmatized.

Amidst a slew of recent efforts directed at the early detection and subsequent prevention of childhood disabilities, assistive technologies have been frequently discussed as a solution aimed at eradicating the numerous barriers that disabled children face within inaccessible home and school environments. In particular, assistive technologies (AT) have been widely hailed for their role in “improving an individual’s functioning and independence to facilitate participation and to enhance overall well-being” (WHO). In line with the social model of disability, this phrasing gestures to the interactions between individuals with impairments and various disabling barriers in the built environment. At first glance, therefore, AT is often hailed for its presumed neutral, and is even thought to be widely beneficial. While there is no doubt that several kinds of assistive technologies (spectacles being perhaps the most widely cited example) have enhanced individual quality of life, the design of these technologies can also carry forward ableist notions of what a body should be and do. Within discourses around the importance of early childhood development, especially those that emphasize the prevention of childhood disabilities, the politics of assistive technologies have often been ignored – in particular, little attention has been paid to how these politics come to impact the lives of disabled children.

In this brief post, I draw on Langdon Winner’s foundational article, “Do Artifacts Have Politics?” to outline the framing through which I engage with the politics embedded in the design of AT. Writing forty years ago, Winner notes that “technical systems of various kinds are deeply interwoven in the conditions of modern politics,” as a result of which “what matters is not technology itself, but the social or economic system in which it is embedded” (1980, p. 122). As an entry point, this framing demonstrates how AT, - even when ostensibly designed with good intentions and the promise of changing the lives of ‘special’[1] children – is never neutral. Instead, thinking about artifacts as having politics enables us to interrogate more carefully who they are designed for, and who they come to be made accessible to. In this framing, I also draw upon Ashley Shew’s work on technableism i.e. what she clearly outlines as “the ableism in technological design and engineering environments” (2019). I extend Shew’s theoretical framing to my own multi-sited fieldwork in India. Although I do not discuss each of the various phases in the design of assistive technologies here, I draw upon data from ongoing fieldwork to examine how these assistive technologies – and the need for them – come to be conceptualized prior to design and forward three provocations for thinking about the work that AT does. In particular, I have paid attention to field environments that enable the design of AT, such as makeathons and incubators. Both formats have significant structural differences but are nonetheless focused on bringing together different stakeholders to think through and respond to a listed set of challenges through the design of a suitable technology.

During my fieldwork, I noticed that these challenges were ostensibly designed with the aim of increasing accessibility and eradicating the barriers that disabled children faced. However, despite the attempt to work past environmental barriers and

ensure that disabled children could live lives that resembled those of their normate<sup>[2]</sup> peers, I argue that these challenges were often framed in a manner that put the onus of defeating the ableism inherent within them on to disabled children who would use the technologies designed. For example, one challenge focused on the creation of solutions that “helped deaf children communicate better with their hearing parents”. Within this challenge, the difficulty outlined by experts (on behalf of disabled children who would be the end users of the assistive technologies being designed) was that hearing parents often could not communicate with their d/Deaf children, particularly since they “were apprehensive that if their child learns sign language, they will not be able to integrate well into the hearing world” (fieldnote quoted). Despite pointing out that this was a shortcoming on the part of the parents – particularly in “understanding the importance of a bilingual education” – the challenge was structured in a manner that focused solely on how the education and emotional development of disabled children was hampered due to the absence of sign language in their lives.

First, the ableism inherent in this framing is particularly apparent – while the reported apprehensions of parents are also common ones that I have heard elsewhere during my fieldwork, this challenge does not gesture toward a practical solution wherein the parents might be encouraged to learn sign language and to use AT to ensure that their d/Deaf children have the chance to learn it too. Instead, by prioritizing the needs of hearing parents and ultimately broader hearing-centric environments that remain unfriendly to d/Deaf people, the framing of this challenge suggests first that d/Deaf children are lacking in their attempt to learn what is seen as a societally appropriate means of communication. The challenge makes little mention of the possibility of learning sign language as the primary language for both parents and children, emphasizing instead the need for children to be part of a ‘bilingual’ environment while failing to consider that it may not be possible for all d/Deaf children to lip-read. Here, I argue further that the constraints of how the challenge has been framed are particularly relevant for the ways in which this framing comes to influence design choices – rather than noting the implicit, pervasive ableism in whose needs are prioritized and for what purpose, the challenge and the subsequent drive toward producing a technology-based solution (through either a makeathon or an incubator) reifies ableist hierarchies and preferences.

Additionally, through the framing in the challenge above, although the explicit purpose is to ensure that d/Deaf children have the same kinds of access and opportunities as their normate peers, the challenges make no attempt to normalize the needs of disabled children. Children with disabilities are painted as ‘special,’ having needs that make them different from their peers in ways that reinforce the stigmatizing idea of disability as extraordinary or abnormal. Instead, through the note that d/Deaf children need to be able to communicate with their parents, the challenge focuses particularly on how a medical diagnosis forms the basis for considerations of access and inclusion. Here, the emphasis is on how d/Deaf children need the kind of attention and consideration that their normate peers (implicitly) do not, thereby making d/Deaf children out to be ‘special’ children with ‘special’ needs. In doing so, the challenge also forwards a portrayal of language learning that is framed through the lens of (presumably hearing) adults. It is therefore unclear from this framing, for instance, whether any d/Deaf children had been involved in determining what challenges they faced in terms of communication, and how the barriers that they wrestled with might be removed. As has been widely discussed elsewhere, the paucity of sign language use proves to be a significant access barrier and a form of ableism that excludes d/Deaf people from several avenues.

Finally, environments like makeathons and incubators also raise the question of how a stakeholder comes to be defined, and how this definition is in turn influenced by considerations of expertise. Over the course of my fieldwork, several stakeholders have involved in framing challenges for the design of AT, including engineers, designers, educators of disabled children, disability rights experts, and on occasion caregivers of disabled children, researchers and policy makers. However, although these technologies were designed for disabled children, their input was rarely – if at all – centered in the

conceptualization and design processes. Amidst numerous discussions of expertise which were classified by type of disability, by time spent working in the disability sector, and by knowledge of the disability, there was no focus on how children might often be their own best advocates for their embodied experiences. The various experts involved in these processes were all adults who wanted children to have better lives, but the centering of adult voices ensured that the perspectives of children who would be using these technologies were hardly taken into consideration. Instead, children were widely seen solely as the pilot audience, on whom new technologies were tested amidst assumptions that disabled children and normate adult caregivers shared the same aims and needs.

Taken together, these three provocations around the design of AT point to larger questions about access and inclusion that are often left out of discussions on the transformative potential of AT. By working from the assumption that a technology will provide the solution to a particular challenge, less attention is paid to the crucial question of who perceives this issue as a challenge, and how their embodied experiences influence this perception. Interrogating the assumptions on which technologies are designed therefore also allows us to ask for whom they are being designed.

## References

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[1] A note on language use: In line with the current legal and political expectations around how to refer to disabled children, I use the terms disabled children and children with disabilities interchangeably throughout the article. However, in a number of educational settings in India, disabled children are often still incorrectly referred to as 'special' children, on account of their having 'special' needs which set them aside from normate children. In this article, I use 'special' very selectively to gesture to the politics embedded in the conceptualization and design of assistive technologies.

[2] Here, I use the term normate (rather than normal) from Rosemarie Garland-Thomson's scholarship, where she defines the normate body as "the corporeal incarnation of culture's collective, unmarked, normative characteristics" (1997, p. 8). Key among these characteristics is that of able-bodiedness as unmarked-ness – the disabled child's body is often marked by its perceived deviance.



Image description: A person with brown skin smiles at the camera, their hair over their left shoulder. They are wearing a blue t-shirt. Behind them is a grey wall.

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