



# Is it the arrogance of ableism or the meekness of the challenged?

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Received: 20-NOV-2025

Accepted: 23-JAN-2026

Published: 22-MAR-2026

Seat numbers 29, 30, and 31 were fellow passengers being verified by the train Ticket Collector (TC). During the first round the TC totally ignored me where I sat in seat number 33. His numbers must not have matched, because he arrived again for a second round and was a bit surprised to confirm that the allocated passenger was me. Even my co-passengers asked me, 'Are you travelling alone?' with a big question mark on their beautiful faces. Apparently, it was against their pre-conceived notions that a person with locomotor disability could travel alone.

This was Jaipur to Delhi, one of my first solo train journeys. I had been quite tense and hesitant initially. My confused thoughts added to the anxiety and my brain tried all possible permutations and combinations to convince me to cancel the trip. 'You have never travelled alone'; 'You have always had somebody accompany you'; 'You need somebody'; 'Will you be able to make it?'; 'What if something goes wrong?'

Was my lack of confidence innate, or was it a product of my adaptation to the reduced

expectations that society reserves for people like me? I have been struggling to find an answer, and I think it is the latter.

It is society that gives one a tag. The tag of being an "outlier" due to deviation from the standard or from the so-called "normal". The sympathy reflecting in the eyes of people who say, 'nature has been so unfair to you'; 'We feel so sorry for the family' is not helpful. The constant background noise and the discussion around our needs does not empower us: 'They will always need care, be dependent on someone'; 'what a life they'll have'; 'what a terrible future'; 'if only the condition had been detected earlier, something could have been done'; and so on.

For me, this learning came much later. I had enrolled to attend a conference to upskill my knowledge. I was full of enthusiasm, and the conference was well organised. Titled "Learning together towards responsible Healthcare using emerging tools and technology", it helped me understand many new concepts. One of the sessions focused on the application of advanced technology

Cite this article as: Halwai A. Is it the arrogance of ableism or the meekness of the challenged? RHIME. 2026;13:15-18.

to diagnose congenital disabilities with improved efficacy, which was followed by a statement from the presenter that “the burden on parents from bearing a disabled child can be reduced”. I was disappointed to hear that disability was indirectly being portrayed as burdensome and that technology was being touted as a means to avoid or eliminate this burden. While still trying to process this, I was reminded of my own life and I realised that this thinking is not just a one-off view but it reflects the views of society at large. Most people view disability as something to cure if it cannot be prevented.

Treatment which can reduce suffering and pain, and improve quality of life is welcome, but in the case of disability, things get complicated: propagating cure ideology for disability, or cure for the “burden” of it, undermines the existence of and devalues people living through these conditions. Eliminating or trying to cure disability can also be counterproductive. The urge to find a fix might not always prove beneficial. I remember when my parents decided to go ahead with surgery as a part of my treatment. A few days before the surgery they discovered that, for another child, a similar operation had resulted in paralysis and total dependency. The child’s life had been much better before the intervention, but the urge to cure the disability had worsened the quality of life.

Will individuals born with a disability ever feel accepted in a society which views disability as a burden? It makes me wonder whether I am a burden to society or if it is society that is burdening me. For example, the procedure to obtain a disability certificate is a nightmare for many. The processes to identify and grade disability result in undignified experiences. The reliance on 'disability' rather than the individual's capabilities forces the individual with disability to question their own existence.

Like every other individual, Persons with

Disabilities (PwD) also aspire to be independent in life. Dealing with the continuous noise of reduced expectations in the midst of societal norms of “you can do this but you cannot do that” - which sets limits on my ability - the only goal in life left to me is to try not to be a burden on anyone.

The negative narrative set by society is so burdensome in itself that it not only affects the individual but also the people around them, particularly their family. I remember when I was seven years old, my parents looked continuously for a cure. They took me to multiple hospitals across the state but came back disappointed every time. They worried enormously: 'My child is different. She needs to be cared for, looked after'; 'Who will take care once we are gone?'; 'Will she be able to go to college and get a job on her own?'; 'How will she survive?' I watched them being inconvenienced because of me. They struggled and neglected their own lives because of me. But I know now that the major struggle was not due to my disability but due to a lack of systems in place to accommodate the difference in me.

While barriers exist in multiple layers at an internal level, there are many at an external level too. 'The laboratory platform is much higher than your height, how will you manage to perform lab investigations?' was the doubt raised by a Vice Principal (VP) during an admission interview. 'I will use a stool-cum-table, Ma'am,' was my immediate answer. My father, who was sitting beside me, had a proud look on his face. Clearly, he admired my fighting spirit.

I now know that I shouldn't have had to fight for my rights. Instead of doubting my ability, the VP could have come up with a suggestion as to how I could use a stool/table to my advantage. That would not have shifted the burden on to me to adjust to prevailing conditions, but would have shown the willingness of the institution and the management to be all-inclusive.

After navigating structural barriers to gain an education, the hunt for employment began. I recollect that for one of the jobs I applied to, I met all the eligibility criteria, and cleared the telephonic and online interview rounds. All was going well until I was called to an in-person interaction with the employers. I could sense their troubled gazes as soon as I entered their presence. I was refused employment, and I couldn't help but think that it was not because I was underqualified or otherwise ineligible, but because I did not fit their so-called "normal individual" criteria.

The constant fear of rejection is not the end of it. When I did get employment, it did not guarantee that team members would treat me with dignity. When the discrimination began to affect me, even the desire to switch jobs and grow my career elsewhere was fraught with uncertainty. People would ask me: 'You got this job with such difficulty, and you want to leave?'; 'Will you be able to get another job, if you resign? Who will give you a job again?'

The challenges to gain and hold on to employment are real, but the main problem is not my disability, but others not being able to see the ability behind the disability. Why are people not ready to look beyond their veils of ignorance? How can they doubt our abilities without giving us a chance?

I have been fortunate to receive education from an institution which not only worked towards appreciating differences but also empowered individuals to hone the abilities they possessed. As a volunteer at The Xavier Resource Centre for the Visually Challenged (XRCVC), my Social Involvement program allowed me to observe first-hand that technology could be extremely productive in providing barrier-free access to education. Disability was never seen as a limitation in the Centre. That learning is why I found the conference experience so paradoxical: on the one hand, to witness how technology could empower

PwDs, and on the other, to listen to discussions on how it could be used to erase the disabled.

A renowned organization, XRCVC, has been successful in creating space for people with visual difficulties. Who could have ever imagined that a sport like cricket could be played by the blind using sound based techniques. The centre's efforts are evidence enough to prove that something appears to be a problem only because it is addressed as a problem to be fixed. Changing the lens through which disability is viewed can make a huge difference. It can give wings to someone's potential, like it did for me, empowering me to take my first solo train journey.

I wish that when I was younger, schools and colleges had understood the need to have disability-friendly sports activities. Had they encouraged social inclusion, it would have helped us all develop an inclusive mindset from childhood itself. Even now, they should be mandated to include teaching modules that inculcate inclusivity, solidarity, human respect and dignity, and respect for diversity.

If only institutions would invest in building appropriate infrastructure to facilitate employment instead of exhibiting resistance to change. I can imagine how empowering and enabling it would be if every organization became aware of the true meaning of reasonable accommodation. Once they understood and laid down the policies and processes to fulfill the requirements of such accommodation, I expect that efforts would not be limited to just railings and ramps, but would address needs at multiple levels.

How do we mitigate the inherent biases and bridge the gap between "them" and "us"? It will require inclusion at every level. Advisory boards that make policies around disability often do not include people with lived experience of disabilities. How will justice be

served by these boards and committees if they don't include the voices of people with disabilities?

Though disability can be challenging, it is not a burden in itself. The burden arises when the default system resists change, refusing to adapt in a way that can accommodate all people with all their unique differences. It is the arrogance of ableist societal structures

and mindsets that perpetuates social exclusion. Accepting differences is the most actionable solution to exclusion, yet seems to be difficult for many. Recognising and getting rid of our inherent biases and questioning our ableist mindset is one place to start. Shifting our attitude from “they cannot” to “how best can we accommodate them” can facilitate building spaces that value differences.

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**Acknowledgement:** with gratitude for the support and critical inputs provided by Dr Vina Vaswani, Director, Centre for Ethics, and Program Director, YU-FIC Masters in Research Ethics for India, Yenepoya deemed to be University, Mangalore.