



## Disability, humility and professionalism

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### Abstract

“Doctor knows best” is something all of us have heard; but very rarely do we meet professionals who know best because they have personally experienced the ailment. Often, they know only about the *non-lived* aspect of a condition. This is a drawback for professionals who work with people who have disabilities that significantly influence how they experience the world. Only by acknowledging this vacuum in knowledge can professionals play a truly supporting role. Disability studies can fill the vacuum and can make the slogan - “Nothing about us without us” - become a reality in every sphere of life for people we care for.

**Keywords:** Disability; Empathy; Nothing about us without us; Social model of disability

On December 3, at a cultural program organized in connection with International Day of People with Disabilities, I was reminded of something that a parent once told me. She lamented that if at all her son had to be born with a disability why couldn't it have been something to do with the body rather than with the brain? It is quite likely that others feel the same - especially when they are parents of children with learning disabilities or Autism. Indeed, studies show that the attitude towards people with mental health conditions and learning disabilities is more negative than that towards people with

physical disabilities; Forlin (1995) found that educators were cautious about accepting a child with cognitive disability but were more accepting of children with physical disabilities.[1] Comparatively, this difference in the attitude of the public would differentially color the experience of bringing up a child with mental disability. In fact, mothers of children with cognitive disability reported a higher social burden than did those of children with physical handicaps.[2]

What happened at the cultural program that I attended made it blatantly clear that

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disability is aggravated, if not created, in the context of social circumstances. The cultural part of the program began with a talk by a postgraduate student of English literature who was born without any limbs. In his pep talk, which he began with a blunt question to the audience about whether they felt pity when they first saw him, he shared aspects of his life with amazing positivity - cracking jokes, playing selected bits of songs and videos on his laptop, as well as playing the keyboard.

The audience was composed of individuals with different disabilities including Deaf people, people with visual disability, and people with learning disability. While the individuals with learning disability enjoyed the talk - cheering the speaker on, responding to his questions, and grooving and clapping along with the songs - the people with visual disability and the Deaf people remained aloof. And understandably so, for while the latter could see the person on stage, they couldn't hear what he said; on the other hand, the former were not able to place what they heard in context as they couldn't see this young man, who had no limbs, moving around confidently on stage. It occurred to me then, that this was a live example of how disability was not in the mind or body of the person with the impairment but embedded in the minds and acts of society.

The social model of disability views disability as a socio-political construction - "disabled people live in a disabling world".[3] Historically, this model paved the way for a change in the perception of disability from a charity-based to a rights-based model; however, it is only one of the many models of disability. Being representations, models are not equated to truth.[4] None of the various models of disability that have been proposed over time can be treated as invalid but need to be seen as different perspectives that are evolving and are focusing on different aspects of the complex experience of disability.

A theme that began with the disability rights movement and that has endured is encapsulated in the motto, "Nothing about us

without us". I do not want to underestimate the ability of human beings to empathise - walk in another's shoes. In order to do that we have to be willing to listen to silence, see darkness, move in the wheelchair and experience turbulence in seeming calm. We also need someone to offer us their shoes. Luckily, many authors have been gracious, sharing their experience with disability and a disabling world, so that we can understand better.[5] Still, those of us who are able to wear others' shoes must realise that they are still someone else's shoes. The momentary experience of a new world does not make us understand that world the way someone who lives it does. Only the rightful owner knows where s(he) wants those shoes to go and how. Personally, after a few years of working with children with autism, it was only after I discovered Temple Grandin's "Emergence: Labeled Autistic" that I began to see beyond what I had learned from lectures and purely academic books.[6]

The program I witnessed on December 3 can be deemed a success in that it opened the eyes of the community, many of who have important roles in policy making, to the fact that "Oh! These kids can do so much!" However, in order to make an inclusive society a reality, people with disabilities should be given access to decision making. There is no denying that putting people with disability at the forefront of any program has great potential for success. In his book, "Neurotribes: The legacy of autism and the future of neurodiversity", Steve Silberman, describes the Autreat conference which is an annual event organised by Autism Network International, an autistic-run self help and advocacy organization for autistic people.[7] Unlike other academic conferences on autism, this conference is truly autism friendly - possibly because the event is planned, organised and managed by people with autism themselves. The 'interaction badge' used at Autreat is a perfect illustration of why, in order to create inclusive spaces, we need input from people with disabilities. The organisers are in a special position to realise how the chaotic and overwhelming atmosphere of a conference can make processing and producing speech a struggle

for even highly verbal autistic adults. The “ingeniously low tech solution” to this problem is to provide the attendees with red, yellow and green badges. The red badge means “Nobody should try to interact with me”; yellow means “Only people I already know should interact with me, not strangers”; and the green means “I want to interact but am having trouble initiating, so please initiate an interaction with me”. This simple procedure is starting to be employed to make many more spaces autism friendly.

To conclude, we see how desirable and pertinent it is for any program to have representation from people with disability and

their caregivers, and for them to be in lead positions. In order to bring full inclusion, persons with disabilities should also be included in programs other than disability specific programs.

Others, including professionals, need to understand how very important it is to stand beside and play a supportive role, ensuring that options are aplenty, and that those options are not compromised or forced. In this endeavour, standing beside is as important, if not more, than standing in front - lest you should block the way. After all, the scaffolding holds up the building till the building can - and so that the building can - stand on its own.

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