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Sensitisation: Initiating the Paradigm Shift of Disability from Medical Model to Social Relational Model

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Abstract

Understanding disability as a social relational model where Persons with Disability (PwD) are considered for their strengths and impairments along with support from the environment, thus reducing the effect of disability in the interactions of the person, can lead to a paradigm shift. Deconstruction of stereotypes by changing the psychological perception of disability which we perceive currently as the medical model to the social relational model can be the key to inclusion of PwD in India. Related literature reveals that the research on disability inclusion in India is significantly less and calls for more studies. This research attempts to enumerate the experiences of a participant who is completely blind and map his disability and experiences to the social relational model. This research highlights the importance of sensitising the society on disability and the specific requirements of PwD and sensitising the PwD on the support from Government and the assistive technologies available.

Keywords: Persons with disability (PwD), Disability Inclusion, Awareness, Sensitising, Social Model, Medical Model, Social Relational Model

Introduction

The Rights of Persons with Disabilities Act (RPwD), 2016(Acts | Department of Empowerment of Persons with Disabilities | MSJE | Government of India, n.d.), states that "the

appropriate Government shall ensure that the Persons with Disability (PwD) enjoy the right to equality, life with dignity and respect for his or her own integrity equally with others". Accessible India Campaign (Accessible India Campaign | Department of Empowerment of Persons with Disabilities | MSJE | Government of India, n.d.) is an initiative by the Government of India where accessibility of infrastructure, transportation and ICT is being implemented. Despite these initiatives and regulations by the Government of India to promote disability inclusion, how a disabled person in India experiences life needs to be brought out. Related literature on disability inclusion (Suresh & Dyaram, 2020) reveals that despite 4-5 % of Indians being disabled, the research on disability inclusion is significantly less and calls for serious action in scholarly research in India. This emancipatory research tries to bring out the experiences of a PwD which may help the researchers to understand the struggles and complexities in fighting the roles prescribed by the society and living his life with dignity.

Literature Review

The way disability is understood in our society plays a vital role in setting the expectations and the mode of interactions with the PwD. The medical model (Brittain,2004) (Cameron, 2016) of disability defines disability as a deficiency or abnormality in the individual resulting from impairments in body functions or structures that need to be corrected. The other extreme is the social model, which views disability as a social than an individual construct and assumes social change is the solution (Barnes et al., 2002). The critique of the social model explains that it does not address impairment and does not serve the real practical needs of the PwD. Different perspectives of health as biological, individual, and social are integrated into

the ICF (International Classification of Functioning, Disability and Health (ICF), n.d.) model by WHO (World Health Organization (WHO), n.d.), but rather than a model, it is used for classifying and measuring disability.

The Norwegian philosopher Solveig Reindal proposed a social relational model (Reindal, 2008) that looks at the individual from two different contexts. He considers biological and physiological realities of the body and personal and social limitations due to reduced functioning, which is necessary for one context. The other one considered a sufficient condition is the material and cultural social barriers and the discriminating and restraining experience of social barriers (Kirkebaek, n.d.).

Understanding disability as a social relational model where PwDs are considered for their strengths and capabilities along with support from the environment, thus reducing the effect of disability in the interactions of the person, may lead to a paradigm shift. Deconstruction of stereotypes by changing the psychological perception of disability can be the key to inclusion of PwD in India. Related literature reveals that the research on disability inclusion in India is significantly less and calls for more studies (Suresh & Dyaram, 2020). This research attempts to enumerate the experiences of a participant who is completely blind and map his disability and experiences to the social relational model. The outcome of the research suggests the importance of sensitising the society on disability and the specific requirements of PwD and sensitising the PwD on the support from Government and the assistive technologies available.

In this research, the life experiences of the participant, referred to as Akash is narrated based on personal, relational, and structural dimensions by trying to connect them to the social

relational model. Akash is a man in his thirties, working as an IT specialist in a metropolitan city. He is a PwD with acquired vision impairment.

Research Methodology

The research design is based on exploratory and qualitative method using semi-structured interview as the tool. The experiences, as narrated by the participant, were interpreted, and constructed by the researcher. The researcher conducted the interview, and the content was recorded and transcribed with the participant's permission. The participant was informed about this research requirement, and informed consent was taken. He was also informed that he would be referred to as Akash, and his experiences would be narrated from his point of view and further analysed from the researcher's point of view. The paper was shared with him for confirmation of the narrated experiences.

The questions were based on disability, challenges, and complexities in his life, how he managed them and his social experiences. The interview was conducted by the researcher, which was further transcribed and thematically analysed. The following themes evolved from the interview transcript on analysis: Acceptance of the acquired disability, work, transport and infrastructure, international experience, and social experiences.

Acceptance of the disability

Akash had vision till his young adulthood and completed his schooling in regular schools. He lost vision in one eye because of glaucoma and started losing vision in the other eye by the age of eighteen. He went through the mental trauma of realising that he is losing vision and becoming fully blind by the age of twenty-five.

Akash narrates the experience as "I'm twenty-three and I just lost my sight, which was very extreme. My friends were in the college, they were roaming on their bikes there in the college. They're enjoying their life. Here I am sitting and sleeping in the house with one of my eyes blind. And then vision is getting poor day by day." His family and friends strongly supported him. He learned about computers being operated using screen readers and joined a computer course. That became the life saver and the most beautiful twist in his life. Initially, he had many difficulties, but he worked hard and cleared the course. In his words, "I asked my friends a lot of questions on how to do everything on computers and then after a couple of months, they used to come to me to clear their doubts". This course gave him much confidence in getting a job and moving forward.

Now, after so many years of acquiring the disability, he describes disability as "From my perspective disability is nothing but a limitation in certain body functions, it's as simple as that. I'm a person with vision impairment. So, I'm having restrictions in my vision. And whatever work I do, I'm doing it in a different way compared to how people with vision are doing."

Akash's transformation is evident from the way he describes his disability. His world changed when he accepted his disability and moved forward in his life by completing his studies and getting the job.

Work

After doing a higher degree course in computers, Akash was offered a job at an IT company and joined. Most of the employees were supportive, and he could upgrade his language and programming skills. He struggled initially but was able to work like any other

employee and received good performance ratings as well. Despite a high rating, he was offered significantly less increments which made him feel discriminated. He assigns this to the management's perception that being disabled, he will not go anywhere, so why to give an increment? He moved to another company for a better position and continues to work there. He appreciates the influence of assistive technologies in all areas of life, enabling him to live a life like any other person. He uses his phone, which talks back for most of his daily activities like communication, booking a cab, ordering food, and doing financial transactions to list a few. He uses his laptop with a screen reader for doing his official duties, which include reading, writing, preparing presentations, logging into calls and other domain-specific activities.

Akash is a tech savvy person and fulfils his work with the help of assistive technologies effectively. He extensively uses his phone to get his daily activities and uses screen reader of his computer for completing performing official activities. Being a person who travels on his own, he narrated his experiences on transport in India.

Transport and Infrastructure

He discussed his initial days of commute to office where he availed public transport. He used his mobile GPS to find his location during his commute. However, now the buses have GPS and even announce the next stop. But finding the bus stop and the bus to be boarded is still challenging. The buses do not have accessible doors for wheelchair users either. Seats are reserved for PwD, but most of the time, it may be occupied, and someone would help by providing a seat. People around help him in boarding the bus and getting down.

Things are better with local trains in his city where there are designated compartments for the disabled and tactile flooring to reach them at the railway station. Metros are far ahead

of this in terms of digital ticketing, tactile flooring, audio and video information and flasher at doors. Akash appreciates the Universal Design Principles followed for making the service accessible in metro trains and stations. He is unsure whether the metro stations are made accessible with ramps for wheelchair users. He also talked about air travel, where he books for assistance and gets support from the crew in the airport and on the flight.

Akash generally uses services from cab aggregators as they are accessible, but it is costly compared to public transport. Some cab aggregators even offer assistance for the disabled in some cities. He uses the app to book the cab and talks to the driver over the phone so that it is easier for the driver to locate him once it arrives. As per his calculation, only 20% of drivers cancel the ride once he reveals that he is blind. Akash understood from his experience that drivers who have at least once travelled with a passenger who is PwD are confident enough to accept the drive and interact with the passenger. He also started sensitising the drivers with whom he is riding on how a blind person can book a cab, pay the money and travel on his own so that the drivers can become confident on interacting with a PwD. He further discussed on the accessibility of the buildings where he resides.

Akash lives in a building with a ramp, but elevators are not accessible to him as they have touchscreens to select the floors and no audio mechanism to prompt each floor. He says that these are situations where he must compromise his independence and take help from others even if technology is available to solve these problems.

Akash was able to enjoy his independence where assistive technologies were available and he was able to use it. In some situations, even when assistive technologies are available

and he knows how to make use of it, he was not able to use it because of design issues and had to depend on or other people compromising his freedom.

International Experience

He mentioned that aircraft companies and airports offer to help people with disabilities while booking the travel itself. He got support at all the places, starting from the airport in India where he started his travel, by receiving him, collecting his luggage and all other assistance he asked for. He got assistance even on a bullet train that he travelled in the other country. Even when he booked hotels, he received a mail confirming his booking and a question on whether any special assistance was required. He even felt that people were more accommodating outside our country. He describes his travel experience in terms of transportation, infrastructure support and other digital mechanisms as highly accessible, inclusive, impressive, and connected. On a lighter note, the actual challenge in international travel was not his disability but the language, which he managed by using the translator app.

It is understood that, in the countries in which he travelled people were more open and the system had options to accommodate his requirements and most of the infrastructure was accessible which helped him to be as independent as possible.

Social Interactions

Akash explains that in most interactions with the public, fifty per cent of the people are welcoming and the other fifty per cent are ignorant. The ones who ignore him do not know how to interact, so they ignore him. He cited examples from various instances in his life.

Earlier, when cab aggregators offered shared rides, he used to book those as it was cheaper than booking a cab exclusively for him. He narrated one incident during one of the

rides, as a welcoming and supportive gesture, when Akash got into the cab's front seat, the person sitting in the back introduced himself and told him that he was travelling with his daughter. This gesture of the passenger who was riding in the same car by initiating a small conversation made him relaxed and feel inclusive. This was far better than the experience of bumping into the passenger who was sitting silently while he was entering.

He also narrated an experience at a famous coffee shop where he was supposed to wait for a friend. Akash went to the counter and asked to scan the menu card for him when the service person realised that he is blind and was not willing to accept his order. Akash interprets it as he may be worried about how this person will make the payment or whether he even has money, how he will eat the food and all such sort of doubts which prevented him from accepting the order. Later Akash managed to talk to the manager, who was able to sort this out. The only support Akash needed was getting the food served on his table.

He had experiences of people talking loudly to him, assuming that being blind, he could not hear as well. He talked about shopping experiences when he goes with a friend, and the questions regarding what Akash wants to purchase are directed to his friend, assuming that Akash cannot speak or comprehend. Most of the time, he was supported when asked for help, but instances were there when people ignored him as well. All these behaviours can be attributed to the lack of awareness of people on how to interact with a person with a disability.

Akash reflected on incidents that happened to him when he lost his eyesight and was stuck at home. The people around him tried to console him, saying that his family would look after him, feed him, etc., assuming that he would depend on someone throughout his life. He tags these as unethical and nonsense dialogues but tries to rationalise them, saying that those

people have seen only someone disabled selling artefacts at a railway station or operating a telephone booth.

He shared experiences with people who were curious to know about how he lived his life independently, how he manages to travel alone, how does he eat at hotels; how does he work and even how is he able to dress up himself.

Akash's experiences show that society was accommodating him when people are sensitised on disability and how to interact with PwD. People were not welcoming when they were not aware of the disability and thought the person with disability will be a burden for them and tried to avoid him so as to avoid problem.

Analysis and Discussion

Akash created his own identity to overcome marginalisation by virtue of his hard work, education, and employment by taking support from society and technology. He is living an independent and dignified life as compared to many others with a similar impairment. He handles things on his own whenever primarily possible or by using assistive technology and requests help only when neither is possible. This indicates that he lives his life independently, against the social assumption of being a "burden" and without "someone to take care and earn for him". His awareness on what all could be done by a person with vision impairment, making proper use of assistive technologies and awareness of job opportunities based on his skills transformed his life. It is evident that RPwD Act 2016 plays a very important role in bringing PwDs to regular work stream.

The social relational model based on Akash's life can be explained as follows. The first context is where the person is fully blind, and the limitation of vision affects his personal and social life. The second context is the inaccessibility of infrastructure/services, the discriminating experiences the person is going through because of the society. Analysing both contexts in connection with Akash's life experiences reveals that he was able to decrease the intensity of negative experiences generated by both by using his awareness and ability to use technology to lead a nearly independent life. He worked on the information that he will be able to operate computers with the help of screen readers and continued his studies with the help of technology. This helped him get employed and work using relevant assistive technologies. He reveals that because of his employment, he has an excellent position in society and is a role model to many others.

This paper discusses the experiences of an individual with complete blindness as a case while the researcher understands that each disability, and everyone's requirement and available support system will be unique. As per the narrative analysis, awareness of disability and understanding how to deal with it is the key for improving the lives of those with disabilities and enhancing the way the society views it. Creating awareness can help in changing the perception of society that disability is not some deficit of the individual and the person can be enabled in their own unique ways by providing accessible infrastructures and the means through which the society interacts with PwD.

Conclusion

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (Convention on the Rights of Persons with Disabilities and Optional Protocol UNITED NATIONS, n.d.) explains Awareness-raising under article 8 as "to raise awareness throughout society, including at the family level, regarding persons with disabilities, their capabilities and contributions to society, and to foster respect for their rights and dignity". As per the narrated experiences of Akash, all the negative experiences he faced from the society are mainly based on the ignorance of people on what disability means and how to deal with it. This could be effectively managed by sensitising the society on the same. There are two methods to sensitise the society; the first is to create accessible infrastructure, transport and accessible ICT solutions as initiated by Accessible India Campaign, where the disabled can come out to the public, and thus society gets an understanding by interacting with them. The second is to create awareness in society about disability and how to interact with and support PwD. This can be by including sensitisation programs as part of the formal curriculum for students and webinars, multimedia awareness programs etc for public. People who are disabled can be given proper directions on the assistive devices and the awareness on jobs that are available based on their strengths which helps them to lead a lesser dependent life.

Sensitisation of the disability and the requirements of the PwD changes society's attitude so that each PwD gets better experiences while interacting with society, thus building their confidence to move ahead in life. Sensitising PwD and their families/caregivers on what is available to support PwD as per government policy/infrastructure/assistive technology will help them redesign their lives accordingly to liberate themselves from the impairment and move forward to a dignified and independent life. This shifting of the paradigm of disability

from the medical model to the social relational model through sensitisation can help India to align with RPwD 2016 and thus create more positive experiences.

References

Accessible India Campaign | Department of Empowerment of Persons with Disabilities | MSJE | Government of India. (n.d.). Retrieved August 16, 2022, from https://disabilityaffairs.gov.in/content/page/accessible-india-campaign.php

Acts | Department of Empowerment of Persons with Disabilities | MSJE | Government of India. (n.d.). Retrieved August 17, 2022, from https://disabilityaffairs.gov.in/content/page/acts.php

Barnes, C. Oliver, M and Barton, L. (2002). Disability Studies Today, Cambridge, Polity, 1-17.

Brittain, I. (2004). Perceptions of disability and their impact upon involvement in sport for people with disabilities at all levels. Journal of Sport & Social Issues, 28, 429–452. doi:10.1177/0193723504268729

Cameron, C. (2014). The medical model. In C. Cameron (Ed.), Disability studies: A student's guide (pp. 99-101). SAGE Publications Ltd, https://dx.doi.org/10.4135/9781473957701.n31

Convention on the Rights of Persons with Disabilities and Optional Protocol UNITED NATIONS. (n.d.). Retrieved August 17, 2022, from https://disabilitiescommissionbahamas.org/assets/files/convoptprot-e.pdf

Kirkebaek, B. (n.d.). The invisible ones. Retrieved October 23, 2022, from

https://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2008/papers/kir

keb%C3%A6k2008.pdf

International Classification of Functioning, Disability and Health (ICF). (n.d.). Retrieved

October 23, 2022, from https://www.who.int/classifications/international-

classification-of-functioning-disability-and-health

Suresh, V., & Dyaram, L. (2020). Workplace disability inclusion in India: review and

directions. Management Research Review, 43(12). https://doi.org/10.1108/MRR-11-

2019-0479/FULL/PDF

Reindal, S.M. (2008). A social relational model of disability: a theoretical framework for

special needs education? European Journal of Special Needs Education, 23, 135 - 146.

World Health Organization (WHO). (n.d.). Retrieved October 23, 2022, from

https://www.who.int/