

Social Life of a Person with Disability

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Abstract

The study aims to explore the influence of disability on the social lives of college going students. The study argues that having a healthy social life is a basic right for a person with disability (PwD), and the need to capture the nuances of social lives of PwDs. The study used an online survey constructed by the researcher. The survey explored whether being a person with disability impacted social lives of the participants, how this impact differed across different disabilities alongside their concerns as a person with disability. The participants were 15 college going students with disabilities. Five with vision, hearing, and physical disabilities respectively integrated in the mainstream education system. The study found that participants felt that their social lives were impacted by their disability wherein persons with the all three forms of disabilities reported dissatisfaction with their current social scenario. They reported limited social interaction leading to a sense of exclusion. Participants also expressed the need to be seen as more than their disability.

INTRODUCTION:

Disability is a complex and multidimensional condition, and not just limited to being unable to hear, speak, see, or walk. It impacts each and every aspect of a person's life. According to the World Health Organization "disability is an umbrella term, covering impairments, activity limitations, and participation restrictions". "*Impairment* is a problem in body function or structure while an *activity limitation* is a difficulty encountered by an individual in executing a task or action and a *participation restriction* is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives (Ministry of Statistics and Programme Implementation (2012)

Often impairment is seen as the inability to engage in certain activities, thus restricting participation. However, this impairment does not necessarily have to result in disabilities and restrictions. More often than not, restrictions are a result of social stigma and the perceptions about persons with disabilities. Lack

of infrastructure and supportive legislations may also contribute to this discrimination. Persons with disability (PwDs) require inclusive planning, places and products to bridge the gap between impairment and ability.

According to a recent World Health Organization report (2011), more than a billion people or about 15% of the world's population lives with some kind of disability, and this number is increasing rapidly on account of increasing population, medical advances and changes in life expectancy. PwDs are the largest minority in the world.

According to census 2011, 2.21% of Indians suffers from some kind of disability, i.e. about 21million people. This unfortunately is just the tip of the iceberg because collecting data on disability is difficult, wherein people are not comfortable with reporting disability, considering data on disability was collected for the first time only in 2001. Though estimates vary, according to a World Bank report (2007) there is growing evidence that PwDs comprise of, about 4-8% of the Indian population (40 to 80 million people).

There are various kinds of disabilities that individuals may have. Each disability impacts different aspects of an individual's life. A 1998 United Nations Development Programme (UNDP) study revealed that the global literacy rate for persons with disabilities is as low as 3%, being even lower (1%) among women. As per a study by India's National Centre for Promotion of Employment for Disabled People (1999), in spite of the "People with Disabilities" Act of 1995, which reserves for them 3 per cent of government jobs, of around 70 million people with disabilities in India, only 0.28% got employment in the private sector while 0.05% were employed in multinationals.

Hence, PwDs especially women are more vulnerable to social stigma and poverty. They are also more vulnerable to violence both from within the homes and in the society and are less likely to seek legal intervention. They share the disadvantages of all girls and women and are disproportionately victims of sexual violence and sexual harassment (Emmett & Alant (2006)).

Social aspects of living with disability

Not only are aspects such as education and employment affected, being disabled has various social implications as well. The various social aspects of living with disability are:

Acceptance: Disability has a devastating effect on the quality of life of PwDs. Negative social perceptions about PwDs extend to employment, educational attainment and marital and familial life (Hossain, Atkinson & Underwood, 2002). The negative impact of disability is greater for women and girl child. This lack of acceptance results in adverse effects such as social exclusion, lower self-esteem and confidence. It also impact the immediate family financially, socially and psychologically. (Emerson, 2003)

Assistance: Though people with disability face many problems, assistive aids can make their lives better. Assistance may range from developing proper infrastructure such as ramps to make buildings accessible for wheelchair users to providing proper hearing aids to a person with hearing impairment. Using aids helps persons with disabilities realize their true potential and be

accepted as able persons in society

Social perception and interaction: Acceptance and assistance play a major role in improving the social perception of PwDs. They help realize the capabilities of PwDs and focus on their abilities rather than disabilities. Though attitudes have been changing for the better in the past few years, research in India has consistently found substantial social marginalization of people with disabilities. Disability is often perceived as a punishment from God thus blaming the person for his/her disability (Rao, Sharmila & Rishita, 2002). This, in turn, increases hostility towards people with disability and hinders opportunities for healthy social interactions.

Additionally, efforts to improve lives of PwDs are directed towards providing basic healthcare, economic support and aid to cope with the disability. *But little is done to provide healthy social lives and improve the quality of life.*

Research on disability, even to this day, focuses on basic needs and medical care with recent emphasis on education and employment. Even the rights and provisions provided by the state such as the employment act (Rashtriya Bal Suraksha Yojna) emphasize more on health and issues related to dealing with the disability. This increases the focus on disability and what PwDs can and cannot do, reducing their worth to the activities they can and cannot perform.

There is limited work on how people's social lives are impacted by their disabilities. The rationale for this study stems from the need to understand the impact of disabilities on social lives of PwDs. The study focuses on the college going population, an age at which people seek social interactions as one of the source of self-identification and self-worth.

METHODOLOGY:

Objective of the study

The specific objectives of the study are:
To understand if being a PwD makes social interactions difficult

To explore how different disabilities impact social lives of people with different disabilities differently
 To understand the social determinants of disability
 To provide an argument to move beyond basic survival related rights for PwDs and look at healthy social lives as a basic right

Sample of the study

The study is a qualitative exploration of the social life of college students with disabilities. The sample of the study consisted of college going students in Delhi who are integrated into the common education system.

The specific disabilities that the research focused on are:

Physical Disability- It includes people with various types of physical disabilities including upper and/or lower limb disability, muscular dystrophy and problems in co-ordination. Disability in mobility can be present at birth or acquired with age. It could also be the impact of a disease or an accident. Participants in this category were born with physical disabilities.

Vision Disability- This includes a range of minor to major vision related disabilities that may be due to injury, medical conditions, or since birth. Participants in this category include both people who were born with the disabilities and those who acquired it due to non-injury related complications.

Hearing Disability- People suffering from hearing disabilities are those who are completely or partially deaf since birth or have become over a period of time. Participants in this category were born with hearing disabilities.

Method

The participants were contacted by the researcher and were requested to fill out an online survey created by the researcher. The survey explored the interests of the participants, focusing on whether their interests were impacted by their disabilities or

not. It also tried to gauge if social lives of the

participants were impacted by their disabilities, their level of comfort with non-disabled individuals, their opinions on provisions for a better life for PwDs and their general concerns as a PwD.

RESULTS AND DISCUSSION:

The responses of the participants showed a certain level of impact of their disability on their social lives. The themes arising out of their responses are discussed below-

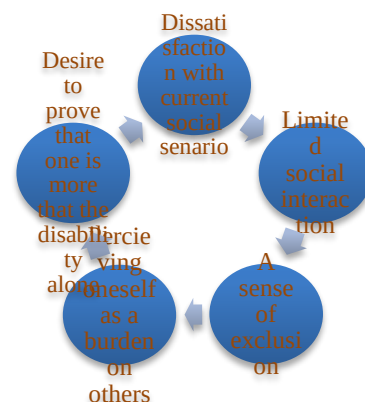


Figure 3.1: Majors themes of the study

Impact on interests of participants: Research shows that persons with visual disability, although shared the same interests as people without disability, were constrained in certain activities owing to their disability (Kjadka, Rayan, Margrain, Woodhouse, & Davies 2012). This trend was seen in the present research as well where participants felt restricted to engage in activities like going to the mall and meeting people for lunch/dinner. They preferred solitary activities like reading & using the Internet where their disability did not become a restriction. Further, research provides evidence that provision of opportunities for desirable leisure activities enable a better sense of self, experience power and control, and social justice (Cuthrell 2013). A similar impact was also seen on the interests of persons with physical disability.

Again, most of the participants preferred to read books and listen to music. Most of them felt restricted and mentioned limited instances of engaging in activities that required movement. Here it is important to understand that most of the restrictions felt by persons with physical disability can be addressed with proper infrastructure and aids. Research provides evidence that participation in individualized physical activities helps modify perceptions of the social self in terms of expanding social interactions and also initiating social activities (Blinde & McClung, 1997). The results in the case of persons with hearing impairment were found to be mixed. While some of them did mention going out for lunches and dinners, Again, most of the participants mentioned reading books, something that is not impacted by their disability.

Frequency of outings – Despite participants mostly doing things alone such as playing games and reading books, the frequency of their outings was interestingly moderate. The frequency generally ranged from twice to four times a month. The moderate frequency of outings may be a reflection of trying to include oneself in society. It clearly shows that persons with visual impairment are willing to socialize and interact with others as much as possible. This may stem from the fact that visually impaired in India all go to Nations Association for the Blind (NAB) for initial training and are well connected to each other. Additionally, most of the participants went out with friends. This further reflects their willingness to socialize. However, most research sites contradictory findings. Research shows that persons with visual disabilities preferred to interact with others with visual disabilities (Sacks, Wolfe, Tierney 1998). Research also provides evidence that adolescents with visual impairment less often had friends and dates with other young people, had difficulties with self-esteem, social skills, and loneliness, especially so among visually impaired girls. Just as in the case of non-disabled individuals, social interactions have been found to increase self-esteem among visually impaired as well (Komulainen, Aro, & Huurre, 1999).

Dissatisfaction with social life

The following key themes arise out of the responses of the participants when asked about their social lives

Level of satisfaction with current social scenario-

The participant's ratings of their social lives gave mixed results. While some participants were quite satisfied with their social lives others were not. However, it was interesting to find, that despite a high level of satisfaction with their social lives all the participants felt that their college lives were different as compared to that of their non-disabled counterparts. Persons with hearing disability are were found to be more satisfied with their social lives as compared to participants with other disabilities. They mentioned more outings with friends, majority of whom were non-disabled.

Sensitivity & difficulty in communication-

Communication barriers further make it difficult for PwDs to interact with others. There is a certain level of discomfort as others might be unsure about how to interact with PwDs- what to say/ what not to say. PwDs, especially people with hearing impairment, also find it hard to initiate conversations and talk to others. *This clearly depicts lack of opportunities to socialize and an implied exclusion from society.* Research has found that adolescents with visual impairments, especially those who were completely blind, had more difficulties in their relationships with friends (Haro & Hure 1998). The current study also reflects that persons with hearing impairment find it difficult to communicate and interact, especially in new surroundings. One of the participants stated that he felt uncomfortable during family gatherings because people do not try to include him in conversations because of his impairment.

The lack of social interaction also has adverse impacts on the self-confidence. Participants in the study reported the need to stop being shy and improve self-confidence.

Additionally, one participant mentioned that perceptions others have about him are really bad. Thus the two-way barrier of the perceptions between the disabled and non-disabled further aggravates the stigma, making social interactions more difficult.

Restrictions from parents- Parents tend to be more vigilant, protective and concerned about their children with disability because of the belief that

going out into the world may hurt their child. Further, parents of PwDs tend to give them the best of what they have knowing that PwDs have many limitations. However, this overindulgence may have negative impacts on the confidence as well as level of independence of PwDs.

Participants in the study also faced stricter curfews and restrictions on travel and recreation, ones that may be acceptable for a person without disabilities. Decisions about travel, recreation and outings are a matter of personal choice for people without disabilities. However, such decisions may be driven by the degree and severity of the disability for PwDs. Research has shown that PwDs engage in fewer activities outside their homes and engage in activities of lesser variety and tempo. (Brown & Gordon 1987). The whole idea of protection may become one of scrutiny for someone who wants to find his/her identity beyond that of being disabled.

A sense of exclusion: Often PwDs, especially physical disabilities tend to feel excluded from their social circles. Participants stated that they were not invited to outings or could not get to the venue because of inaccessible transport/ infrastructure. This may be due to the perception among the non-disabled that it would be difficult for disabled people to go out. This may be true, but this perception makes things worse because someone who might be able to go out is often not given the choice. How a disability impacts a person differs greatly. The individual should be given a chance to decide his or her limitations.

Perception of oneself as a burden on others_- PwDs may perceive themselves as a burden on others. This can be inferred from a statement made by one of the participants. She believed that others do not talk to her because they might have to help her. The idea that they have to ask for some kind of support or help may impact a disabled person's confidence in turn influencing their level of comfort during social interactions. This in turn may give peers/ non-disabled people the impression that the person does not want to interact or make the non-disabled people reluctant to interact themselves.

I am more than my disability: People tend to emphasize the activities that a PwD cannot engage in rather than numerous activities that they can do

despite their disability. PwDs are in no way looking for sympathy and pity. Participants reflect the importance of focusing on things that they can do. Highlighting this, a participant stated that, the focus is more on my inabilities rather than my abilities and that such a focus is detrimental to a person's self worth and confidence. Another participant stated that a disability is not a disability - it is just a missing part or function, one just needs to try and live like others without that part or function. One needs to emphasize on inclusivity and creating greater awareness about the rights of the disabled among the non-disabled population. This will make the non-disabled more aware and change their attitudes towards the disabled in society.

A sense of sufficiency – PwDs, just like everyone else, want to be independent and self-sufficient. However, more often than not people make it worse by showing pity and feeling bad for PwDs. Hence, there is a need to accept disability and be open to diversity. This is quite clear from a statement made by one of the participants "I strive to be a better person not only in terms of my disability but also in terms of overall development. I try and see things in a much positive vein." While another stated that he/she had no regrets about being disabled. Being self-sufficient also means being able to provide for oneself. Participants have expressed the desire to be employed. This clearly shows a desire to show the world that PwDs are not as different as they are made out to be and to be self-sufficient like everyone else.

Conclusion

The conclusions drawn from the study are as follows-

1. Improvements in infrastructure and aids to handle impairments and lead a productive life. Especially in a country like India most of the public places such as malls, restaurants even government offices lack the basic infrastructure for a persons with disabilities to find their way. The need of the hour is to develop the required infrastructure to make life better and more productive for PwDs.
2. Improvements in avenues for greater social interactions- Developing infrastructure and providing the required aids such as hearing or walking aids will also provide arenas for social interactions.

3. Research and policy attention needs to go beyond health and employment to deliberations on quality of life as a basic right for PwD. – Research and policy needs to be developed beyond just dealing with disability, keeping in mind that a good social life is also one of the basic rights of PwDs

Turning the attention to quality of life automatically ensures basic rights and moves the debate towards dignity, and equity in physical, social, and financial contribution.

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