

Visually Impaired Person's Experiences of Social Inclusion

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Abstract

The study was undertaken to bring forth unheard voices, understanding and perceptions of social inclusion and a socially inclusive milieu among Young Adults with Visual Impairment (YAVI). Twenty YAVI in the age range of 18 to 35 years were part of the study. This included both men and women selected through purposive and snowball sampling. The tools included in-depth interviews and a detailed self-constructed checklist. Findings revealed that a socially inclusive milieu for YAVI include inclusive institutional arrangements, availability of assistive devices, visually-impaired friendly commute, guaranteeing of rights, decreased neglect and more connection with others, change in attitudes and behaviours of people towards them. The participants in the study shared that they needed reservations and opportunities, in education and employment. They see themselves as participating in the social, political life around them.

Keywords: *Visual impairment, social inclusion, young adults, lived experiences*

Introduction

Social inclusion can be summarised as a process by which efforts are made to ensure equal opportunities for all so that everyone can achieve their full potential in life. It is a multi-dimensional process aimed at creating conditions which enable full and active participation of every member of the society in all aspects of life including civic, social, economic and political activities as well as participation in decision making processes. From 'physical inclusion' of an individual with disability, we have now shifted to 'social inclusion'. This shift makes persons with disabilities independent, develops into a positive sense of self, improves interactions and provisions of specific support services, hence bringing them out from the verge of marginalisation to mainstream society. This shift can also help in thinking about cultural, social, economic and environmental contexts. Promoting social inclusion of persons with disabilities should be viewed as a long-term investment for sustainable development (UNDP, 2012). The encouragement of social interaction is reflective of an interrelationship between existing people with disabilities and people without disabilities residing over the world. The broad and universal 2030 policy agenda for

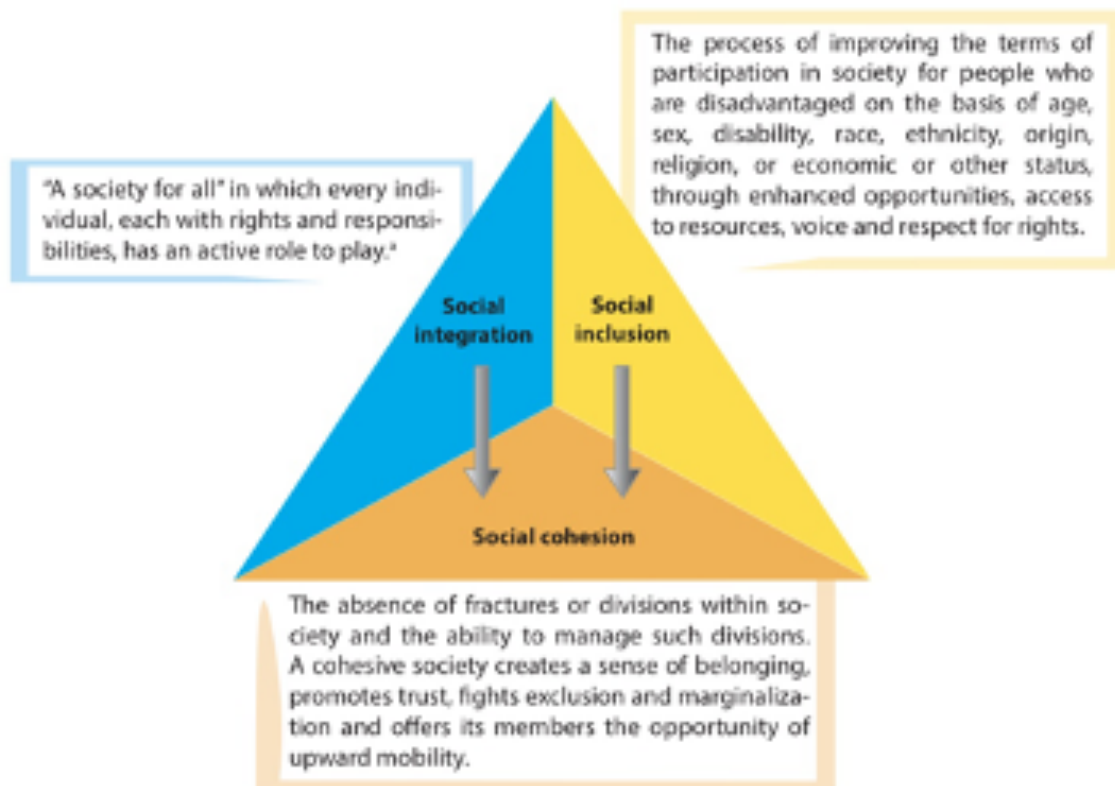
Sustainable Development Goals (SDGs) adopted at the United Nations Summit in New York, September 2015 aims to achieve and transform their approach to inclusive and people-centred thus 'leaving no one behind'. This aim 'Leaving No One Behind' builds on the Millennium Development Goals (2018) and aims to complete what could not be achieved through them. The inclusion of people with disabilities is increasingly being prioritised in development programs and national agendas (UN Flagship report on Disability and Development, 2018, p.41).

Social inclusion for people with disability means-

- Sense of belongingness
- Acceptance in their communities for who they are
- Valued for their particular social roles
- Being active participants in their community
- Involvement in activities based on their own preferences
- Social relationships based on their own choices

Social inclusion, social cohesion and social integration are one of the same kinds representing a vision for a 'society for all', in which participation of persons with disabilities in all spheres of life is emphasised (UN Flagship Report in Disability and Development, 2018).

Figure 1



Social integration, social inclusion and social cohesion

Source: Based on Easterly (2006), Hulse and Stone (2007), Organisation for Economic Cooperation and Development (2011*), United Nations (2010). *Report of the World Summit for Social Development, Copenhagen, 6-12 March 1995, para. 66.

A variety of factors in socialisation can act as either facilitators or barriers to the concept of social inclusion. These are personal abilities and skills, self-advocacy, commute, support from others, education, opportunities available, attitudes and behaviours of others, environment (home, school, college, workspace), quality and accessibility of services and facilities, rights and responsibilities, social roles and value *and* recreation and leisure. This can be experienced in the society such as home, school, college, community, participation (day-to-day activities and specific ones) and living accommodations. These can be experienced at infrastructural,

interpersonal and personal levels. A research conducted by UN Support to Social Inclusion in Albania Programme (2015), concluded several themes based on the interview responses of persons with disabilities. These are changing realities, lack of physical access and adaptability, poor access to information and knowledge, poor access to rehabilitation services, exorbitant and

unpredictable treatment costs, family vulnerabilities, neighbourhood effects, poor law enforcement, lack of political voice, preferential treatment and collective action and change, which seem to hinder the process of social inclusion.

A child with a disability is often regarded and treated as 'different' with associated factors such as impairment, background, language to name a few. As a consequence, they are often excluded from the society and local communities. Wadegaonkar & Uplane (2017) highlight that the educational needs of a child with disability and other children have no difference. Both of them are working towards one common goal: social inclusion. Inclusive ideologies and practices facilitate social engagement of individuals with disabilities, for the benefit of the individual, their communities and of the society.

For generation of opportunities and favorable experiences, there must be various support systems such as family, education, workplace

and social support system in the lives of individuals with visual impairment through which they can perceive their importance (Kumari, 2011). Moreover, it can easily be put that individuals with disabilities need to be in tandem with institutions and services so as to promote the whole concept of social inclusion. Research undertaken by UNRISD (United Nations Research Institute for Social Development) indicates that social policies with a focus on solidarity, reciprocity and practices on universal rights-based entitlements are likely to lead to long lasting social inclusion. World Conference on Special Needs Education: Access and Quality (Salamanca, Spain 1994) and the World Education Forum (Dakar, Senegal 2000) reiterated the need for social inclusion. Including people with disabilities requires transforming behaviours and attitudes towards them, adopting practices that work in their favour, giving them chances of association with organizations and the outside world. This enables them to participate equally and contribute to society.

Inclusive education means all learners including with or without disabilities are able to learn together in ordinary preschool, school or community provisions and educational settings with appropriate support services (Kumar & Kumar, 2007). Unnikrishnan (2010) explains the idea of inclusion as incorporating various skills which will benefit the children with disabilities together with children without disabilities thus preparing them for adult life experiences. Social inclusion in the school stresses upon social and emotional aspects of the school setting (Plaskett, cited in Roe, 2008; p. 57). Inclusion involves minimising and trying to overcome, thus increasing participation (Ainscow, Booth, & Dyson, 2006, p.18).

Johnson (1994) notes that inclusive education forms an integral part of the overall education system in regular schools having a support system that is individual-specific and flexible for children with special needs.

However, research in the area of education of individuals with visually impairment reveals that there are lacunae in the accessing and availability of these services which are 'promised to be available' at school and college levels. The social and emotional integration of individuals with disability is fraught with tensions. Jessup et al. (2018) finds that participants describe peer exclusion or rejection

as the most hurtful experience in their school lives. Further, they have smaller friendship networks and struggle to be considered useless, helpless, and unable to be self sufficient, hence, neglected and stigmatised by people (Kumari, 2011).

Method

The research was designed to study the understanding and idea of a socially inclusive milieu among YAVI. The aim was to gain an insight into their day-to-day experiences vis-à-vis their notions of social inclusion. The sample for the study consisted of twenty young adults with visual impairment in the age range of 18 to 35 years. In all fourteen men and six women were part of the study who were selected through purposive sampling through non-government organisations located in New Delhi. The sample was snowballed. The tools used for data collection were:

- An in-depth unstructured interview schedule was developed and used to collect information related to their understanding of social inclusion and their day-to-day experiences. The broad sub-heads were: understanding of social inclusion, relationships (family, friends, peers and marriage), recreational and Leisure time activities, education and employment and participation in social/political/cultural/economic activities. Also, this tool was helpful in bringing out personal experiences of young adults with visual impairments.
- A self-constructed checklist was used to explore perceptions of a socially inclusive milieu among young adults with visual impairment. It included a set of activities divided under different sub heads such as self-advocacy skills, orientation and mobility skills, physical environment, communication, participation and support.

Both the tools (in depth unstructured interview schedule and self constructed checklist) were translated in Hindi to take care of the language criteria based on the locale of the research study in mind. The data was analysed based on the objectives of the study by identifying common themes. Individual responses were quoted in between text. The research study also took into consideration their lived experiences vis-à-vis notions of social inclusion. The responses obtained from young adults with visual

impairment were analysed to understand their idea of a socially inclusive milieu.

Research findings and discussion

Demographics of YAVI

The research was conducted on twenty YAVI in the age range of 18-35 years presently staying in the national capital of the country India, Delhi. Of these, fourteen were men/boys and six women/girls. The regions of India from where they hail are well depicted in the table below.

Table 1

Distribution of participants across regions

Region participants belonged to	YAVI (Males)	YAVI (Females)
Bihar	4	2
Uttar Pradesh	3	1
Delhi	2	2
Madhya Pradesh	2	1
Jharkhand	2	-
Rajasthan	1	-

Out of 20 YAVI, 11 were blind by birth and nine (9) had vision loss at different periods of their lifespan, reasons for which are indicative in the pie chart mentioned.

Figure 2

Causes of vision loss

Note. This figure demonstrates various causes of vision loss as expressed by the participants of the study, who experienced vision loss later in their lives.

Notions of social inclusion among YAVI

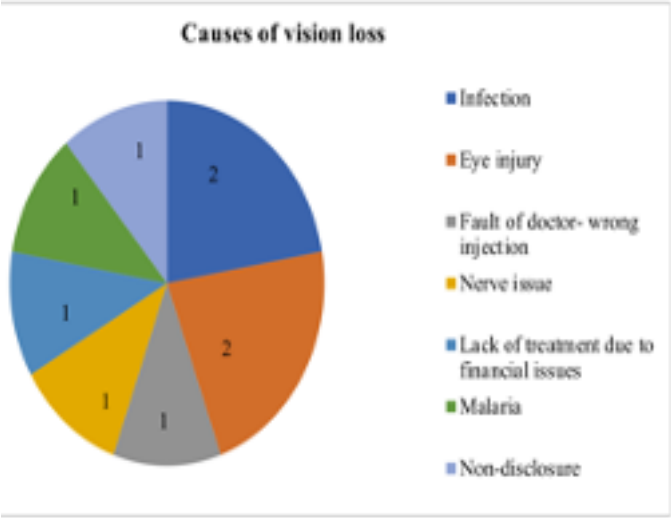
From the total sample of this study, fifteen YAVI were aware of the idea of social inclusion. Majority of the participants assumed the notion of “सामाजिक समावेश” or “social inclusion” as provisions and facilities for them through which they can lead a better life. They stressed on empathetic individuals in society at large and placed a high importance and emphasis on services like education and employment for them. They believed that if the services are available and accessible to them, then, they can also get a chance to prove their abilities. However, five YAVI did not know what ‘social inclusion’ or “सामाजिक समावेश” meant. Fifteen YAVI said a socially inclusive milieu would be

where they are counted as participants and contributors to the society. This was attributed to the fact that this will help them feel connected with the society. They felt the need for more special educators and specifically teachers who have visual impairment or are blind so that they can relate to them more. This understanding is in consonance with the conception of social inclusion which envisages creating conditions that enable full and active participation of every member in all spheres of life including civic, social, economic and political activities.

Understanding of rights and reservations

Eighteen YAVI were aware of the reservations, provisions and services they were entitled to, from the government such as the percentage in jobs, provision of pension and scholarships. They seemed to be optimistic of provisions and services that they were getting presently. They are willing to fight and raise their voice if needed for the issues that concern them such as a reserved railway compartment in trains. They had a fair understanding of what is happening around them regarding reservation in education and jobs, matters that especially concern them. This awareness signifies their coming forward in the society and making their voices heard.

Self-concept: Nine YAVI had an inclination towards music, three of them reported enjoying



with friends and going out, two towards dance, one YAVI was really keen towards robotics and mechanics, three were totally into using technology during their free time such as surfing on YouTube or listening to news. One of them was interested in teaching her peers, another would devote a lot of time to robotics, one wanted to open his own typing centre and

another wanted to run an academy for training peers for athletics. They portrayed talent that can help them grow in unique ways. This puts light on how similar they can be to their typically growing peers. Sixteen YAVI were well aware of what they wanted from their lives and they had already planned for years to come and were motivated to complete their studies and determined to attain a job. The reason for this inner strength, confidence and motivation was the support they got from their families and encouragement from mentors and peers. They valued their independence and wanted to fulfill their dreams and goals. One of the participants shared that she was thankful for her life and was happy in whatever way she was. This is a judgement of the self as well as an attitude towards self. Augestad (2017) argues that social support, friendship, independence in mobility, and parenting and teaching style as those promising aspects which help children with visual impairment to enhance their self-concept and self-esteem.

One of the respondents had encountered name calling and teasing in earlier classes and did not show any desire to re-join studies or any professional course. Such labelling and negative attitudes have proven to be barriers within the course of learning and acquisition of education, thus developing negative attitudes towards educational institutions, subjects, materials, teaching-learning methods and instructional strategies (Kapur, 2018). The societal attitudes also impact negatively upon the self-perception or self-concept of individuals with visual impairments (Hardman, Drew and Egan, 1987; Kirk & Gallagher, 1983; Kirankumar et al. 2016). Most YAVI seemed to neglect what other individuals think or comment about them and have shifted their focus to what they wanted to do for themselves in their lives although we cannot negate the impact of derogatory remarks/comments that they have gone through and its impact on their self. A major gender difference was noted in dealing with the discriminatory societal practices faced by them. Male YAVI expressed more bold and firm responses in handling negativity from people in the society whereas female participants were gentle in their response to negative comments.

Experiences in varied settings

Home: Thirteen YAVI lived in the hostel setup and five lived with their parents and two lived

with their partners. Two YAVI revealed remembering worries of their parents about their marriage and having their own family. However, they also said that they haven't heard their parents discussing such worries in front of them in the recent past. The setting surrounding an individual is a key aspect in ensuring a positive outlook towards life and holds up as an added asset if encouragement is perceived. The response of the participants does not indicate any familial pressure highlighting aspects of decision making in terms of education, lifestyle, adjustment, employment and marriage and their current home settings have proven to have a positive influence in their lives. They were pampered and cared for. Concerns of parents of YAVI vary across contexts including education of their child, seeing them getting married, wondering about support for the child and that they progress in life for their own betterment. Most YAVI assert their parents support them the most, in all circumstances, in all odds. Only two YAVI didn't have any support from their families facing rejection in earlier stages of their lives and were not aware of their families if they existed.

Parents of individuals who are blind by birth seem to adjust and accept the fact earlier than those who experienced vision loss later in life. The latter react in shock, take more time to accept and adjust to the change. Fifteen were totally dependent on their families financially and four of them worked full time so they took care of their finances by themselves. One of the participants worked part time at the reception desk in a neighbourhood typing centre. Of total, seventeen were able to make their decisions independently and three preferred getting their parent's opinions and guidance. They consider their parents knowledgeable and experienced thus showing signs of faith and trust in their parents.

Marriage and personal life: Two participants were married to visually impaired individuals, seven of them did not report having a partner at the time of the study, eight of them reported that they had not even thought about it as they wanted to focus on their studies at the moment. Also, fifteen preferred to have their partners as visually impaired individuals as they would have more understanding and cooperation amongst them. The respondents felt that with the visually impaired partners, the level of

relatability will be more and disparagement will be less.

Workspace: Out of twenty, four were employed at the reception query desk, in a government bank, as a coach for training individuals and as a music teacher at a school respectively. A large number of persons with disabilities are employed in the government sector due to prevailing reservations and concessions and provisions. Accessibility and desk jobs rather than field one were taken care of by them other than colleagues, facilities and provisions available to them at their workspace. They portrayed higher value towards their employment and a sense of responsibility and being empowered.

Community participation: Most of the participants mentioned that they participated in cultural celebrations like Ganesh Chaturthi, Saraswati Pooja, Louis Braille event and Kavi Sammelan.. They visited places of worship like mandir, gurudwara or churches. Although these festivals and celebrations were celebrated at home and their hostel setups, joy and euphoria that they received by taking part in functions was intense. One of the participants reported not having been allowed to attend any religious events or family functions back in her village by relatives as she was a ‘double trouble’: a girl, that too visually impaired. Being a girl and with a disability is simply a double disadvantage in a person’s life through the eyes of the society (Rangila, 2004).

Nine YAVI mentioned that they were not or had never been part of any society or club or group whereas eight acknowledged that they had been part of or are part of society or group or club. However, most of the time they took part in competitions were in schools or in their own hostel functions with visually impaired peers only. The acceptance rate was reported to be less among their sighted peers so they did not feel like participating with them. In addition, three respondents also added that they want to take part but in college events when any club or society is being formed or during any function, they are not welcomed or informed; if they still went they were not entertained well and they felt excluded.

Sixteen of them reported never taking part in any rallies or campaigns and four declared that they have been part of the rallies once or twice but not in any kind of campaigns. They seemed to be

very specific of the fact to take part in rallies that were directly related to them and their rights or benefits.

Eight of them reported not having a voter identification card yet. Twelve respondents reported that they regularly voted in every election. They sounded to be much aware of the parties in the elections and whom to support for their rights and benefits. Almost all participants stated no problems in monetary transactions. They reported that it was nearly effortless to perform money related tasks and newer technology has been a boon. However, one YAVI reported it was still tricky to identify new currency notes. All twenty YAVI deliberated in favour of technology and computers. Respondents told the positives of technology and how beneficial it proved for them and making use of it in every possible way.

Conclusion

“Alone we can do so little; together we can do so much”. This line by Helen Keller perfectly fits in for the notion of social inclusion. In context of the present research, majority of the participants responded positively about their ideas of social inclusion and ‘provisions’ for education and employment. They were enthusiastic about how their lives can move towards betterment with the availability of facilities and provisions. They wanted empathy rather than sympathy from people. In addition to this, discriminatory attitudes and behaviours of people can lead YAVIs to isolating themselves, however on the contrary, positive interactions can build up intimacy. This is in accordance with Erikson’s theory of psychosocial development, viz. the participants were at the stage of intimacy versus isolation (1958, 1963) (Santrock, 2014).

Social inclusion takes forward the idea of ‘social context’, not only as an individual and its activities but the society as a whole. So, it creates a need to unify them well into the society so that they feel a part of it and not some other excluded left behind individuals. It urges to further analyse both the individual and the social factors that pertain. Social inclusion can be linked to the individual’s development in relation to the environment he or she gets (Bronfenbrenner, 1979 as cited in Rosa and Tudge, 2013). Not only physical inclusion is necessary but also the ‘societal inclusion’. The person and environment share a dynamic

relationship, in which environment can include social networks, political and economic systems, services and policies. In the process of social inclusion, these environmental factors are needed to act as facilitators and not barriers.

However, the wider gaps between concessions enunciated by the government in the legal framework, plans and programs and the situational reality of the status of YAVI were also highlighted. For YAVIs some of the main features of a socially inclusive milieu included- better arrangements and provisions in institutions like more availability of disability-sensitive teachers and special educators, visually-impaired friendly commute, availability

of devices specific to visually impaired people such as walking sticks, eye wear, laptops, recorders and mobile phones in colleges, accessible provisions and services that are planned for them, opportunities which can be obtained easily, controlling the neglect and trying to change discriminatory attitudes and stereotypical behaviours they have to face from the society and an equal vision for them like any other normal individual. Moreover, indicators of societal accessibility were educational, employment and economic factors. There were major gaps in the concept of 'social inclusion' and the actual situation or ground realities visually impaired individuals come across during their span of life.

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