



PREVALENCE AND BARRIERS FACED BY CHILDREN WITH DEVELOPMENTAL DISABILITY LIVING IN URBAN SLUMS OF DELHI-A COMMUNITY STUDY

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ABSTRACT **Purpose:** This study aimed to evaluate prevalence of type of disability, and environmental barriers faced by PWD in urban slum of Delhi, India.
Method: A cluster sample of 1200 children, was done where age less than 18 years. In collected data, 295 disabled children were identified. Questionnaire filled which consisted of questions pertaining to the 7 components of environmental barriers faced by PWD: Accessibility, Accommodation, Resource availability, mobility, self care, interpersonal relationship and Social life.
Results: The disability related to vision stands high in order followed by intellectual and locomotion disability. The results showed that 60% faced problem in Accessibility, 58% of urban slum PWDs faced problems in accommodation, and most of them requires assistance from others. With respect to Resource availability 40% had lack of awareness about the health services. The participants did not face problems in interpersonal relationship (43%).
Conclusion: An understanding of the environmental barriers faced by PWD in urban slum can provide guidance in mapping policies and strengthening laws which would help to improve their QOL.

KEYWORDS : environmental barriers, urban slum, disability.

INTRODUCTION

Developmental disability cause individuals face difficulties in certain areas of life, especially in "language, mobility, learning, self-help, and independent living"(CDC,2013).The International Classification of Functioning, Disability and Health (ICF) provides a framework for disability that incorporates environmental factors, i.e. those factors that "make up the physical, social and attitudinal environment in which people live and conduct their lives"(WHO,2001).

Following the ICF, environmental factors can enhance participation or act as barriers and decrease participation, in the former case it increases functioning opportunities, or in latter case restrict participation (Schneider et al., 2003). Research on environmental barriers indicated that more environmental barriers are experienced in countries with fewer resources than in those with more resources (Cerniauskaite et al., 2011; Reinhardt et al., 2011); and in rural compared to urban areas within a country (Eide et al., 2008).

Wiman et al (2002), estimated 84.7% of PWD reported environmental barriers which include social isolation, trouble in obtaining resource information, accommodation, equality, transportation and attitude of the people towards them. The more the environmental barriers are reduced, the more a person with impairment will be able to participate in social, educational and vocational aspects of life (Chaves et al, 2004). Whiteneck and colleagues (2004) have categorised environmental barriers as Accessibility, Accommodation, Resource availability, Social support, and Equality. Accessibility is defined in terms of physical access and accessibility of transportation (Whiteneck et al, 2004). Accommodation is that aspect of the environment that either restricts or facilitates an individual's ability to participate in an activity. Resource availability is referred to as the availability and provision of services and resources necessary for a particular disability. Social support is defined as the attitudes that encourage community integration to flourish and may be provided by family and friends, employers and teachers, neighbours, peers and community members.

There are at present few studies which have specifically evaluated or quantified problems faced by disabled in urban slums of India. Therefore this study was undertaken, to evaluate the environmental barriers faced by PWD in urban slums of Delhi. A self reported questionnaire was used to quantify the environmental barriers as they affect the functioning of persons with disabilities. It should be noted that this tool does not measure environments and their characteristics objectively, but elicits a characterisation of the severity of perceived barriers to social participation as reported by the individual with disability.

METHOD

This was a cross-sectional community based study conducted between 2014 and 2016 in 6 urban slums of Delhi. Cluster sampling was done 200 sample were collected from each slum.

Inclusion criteria:

- 1) Children with age group less than 18 years
- 2) Children who are residing in urban slums of Delhi

Exclusion criteria:

- 1) Children and care giver who were not willing to participate.
- 2) Children not residing in urban slums of Delhi.

Prior permission to conduct the study was taken from the Institutional review committee of Amar Jyoti Institute of Physiotherapy, and informed consent was obtained from the parents and assent from children. Data were collected through self-report survey questionnaire. Questions were asked in a face to face format with respondents selecting the appropriate response option for each question. Data collection was carried out by teams of interviewers led by a supervisor. The questionnaire consists of 7 components – Accommodation, Accessibility, Mobility, self care, interpersonal behaviour, Community, Social, and civic life.

- Two questions assessed Accommodation (barriers due to design and layout of homes, school and community).
- One assessed Accessibility.
- Seven assessed mobility
- Five assessed self care.
- Two assessed Interpersonal Behaviour
- Three assessed community, social and civic life.

Each component consisted of 2 parts, namely the person is able to carry out the activity (Activity limitation) and severity of disability (Assistance required).

- Four question assessed usage of services-Resource availability (Medical rehabilitation, assistive devices, welfare and health services)

Each component consisted of a person is aware of the services, need services, received the services and improvement in condition.

Descriptive statistics was used to analyse results of the data regarding environmental barriers in all the components. Microsoft Excel was used to analyse and generate graphs and Tables.

RESULTS

The data was collected from 1200 samples out of which 1081 samples were analysed 119 were deleted as the complete information was not retrieved. From the collected data 786 children were normal children, 295 were disabled children (Table 1).

Table 1: Type of Disability

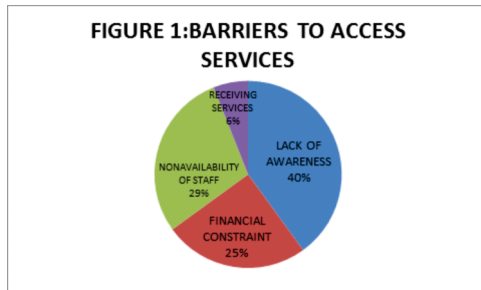
S.No	Type of Disability	Number	Percentage prevalence
1	In Seeing	99	33.56%
2	In Hearing	19	6.44%

3	Locomotion Disability	40	13.90%
4	Intellectual Disability	90	30.51%
5	Multiple Disability	41	13.56%
6	Others	6	2.03%

In accommodation, perceived barrier are 42% of children had their house accessible 58% of children had their house not accessible. The children who did not have accessibility to their house where carried to the house by the parents/care giver. Stairs were the most common access (36%) to the house in urban slum. Most of the children did not have accessibility to transportation and had to depend on others for transportation. The basic activity limitation in different component is shown in Table 2. More than 60% of the children were dependent on parent/care giver/ another person.

Table 2: Activity component limited in PWD.

S.No	Component	Activity limitation			
		No Difficulty	mild difficulty	moderate difficulty	severe Disability
1	Mobility	24%	29%	26%	21%
2	Selfcare	33%	31%	22%	14%
3	Interpersonal Behaviour	43%	20%	19%	18%
4	Community, social and civic life	26%	28%	30%	16%



It is inferred from the Figure 1, the resource availability is limited to the urban slum population. Only 6% of the children living in urban slums of Delhi were receiving Medical rehabilitation, Assistive device, Welfare and Health services. 40% of the people had lack of awareness about the services, 29% people reported non availability of staffs, 25% of the people had financial constraint because their jobs were daily wages as they had to wait for long time for availing the services they lose their earning. Secondly, more money is spent for transportation of the disabled persons.

DISCUSSION

The prevalence of vision related disability was found to be more followed by intellectual disability and locomotor disability. Hearing related disability was found to be the least type of disability. The self reported questionnaire is a comprehensive tool to assess environmental barriers faced by PWD. Analysis of the Accessibility issue among PWD revealed that the maximum percentage (60%) perceived barriers in transportation, and they need to be dependent on others. Since the study participants resided in urban slums of Delhi, it can be inferred that an integrated system of wheelchair /assistive device accessible vehicles for transportation is not available in this city. The results of this study was similar to Venter et al (2002), uneven road surfaces and unpaved or poorly maintained sidewalks have made it difficult for PWD to travel from one place to another.

Barriers faced by PWD in accommodation are due to Design and layout of their home, community and school. These children were also not going to school or denied admission in schools because of their disability. Their perceptions were based on the lack of railings and disabled-friendly toilets at home, and lack of lifts and ramps in their community. Most of the study participants were from lower socio-economic groups, and hence could probably not afford to make the changes and modifications necessary for their individual needs. Similar results found by White et al (1995) in which the lack of affordable, accessible housing was cited as the top concern among PWD. Due to increased awareness about the needs of PWD, many educational and corporate institutions have modified their environments by constructing ramps, railings and disabled-friendly

toilets however there are many schools which lack this facilities. The mobility in relation to bed and home based were better than mobility outside the house. Even though PWD were dependent in their self care activities because of the layout and space constraint in the toilet 67% of persons required some form of assistance. Interpersonal relationship did not have much difficulty however the social life of these peoples were affected. With all these shortfalls, the PWD were not able to participate fully in their community as well as perform their household activities (Hurd et al, 2009).

Under Resource availability, the barriers faced by PWD are due to Lack of awareness, non availability of staffs, more waiting time, financial constraint. Maximum number of persons with disability (40%) in this study perceived barriers due to lack of awareness. This situation can be dealt with growing number of NGOs and institutes for PWD give proper guidance and information to this population. So these type of NGO's and institute can establish centres in urban slum to create more awareness and assist these peoples.

Limitation: Did not found the prevalence of all 21 types of disability. Also which type of disability has what type of environmental barrier was not explored.

CONCLUSION

This study found that PWD face the maximum number of environmental barriers in the component of Accessibility and accommodation followed by resource availability, mobility, selfcare and social life. Fewer barriers in the fields of interpersonal relationship. These insights into the environmental barriers faced by PWD can provide guidelines for mapping policies and strengthening laws which would help to improve their quality of life.

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