



FACTORS INFLUENCING SOCIAL PARTICIPATION OF PERSON WITH DISABILITIES

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ABSTRACT

This study was designed to analyze the factors associated with the participation Restriction of person with disabilities in all the four states viz. Uttar Pradesh (UP), Chhattisgarh (CG), Andhra Pradesh (AP) and Tamil Nadu (TN) during the period from December 2016 to August 2017. A Cross sectional study Design was incorporated in this study using the standardized Participation scale, along with socio-demographic variables were analyzed for a total of 379 persons with disabilities. Results indicated that the level of participation was graded into Two categories viz, No significant participation restrictions (NSPR) and Participation Restrictions (PR), and was cross tabulated with socio-demographic factors of each respondent. The findings from each state are compared with other states. The participation scale suggests the higher level of Participation restriction is seen in 82 (82%) in UP , 79 (79%) in CG, 56 (72.7%) in TN and less in AP 62 (60.8%). This study concludes that Participation restrictions in states are highly influenced by type of occupation, type of membership. Moderately influenced by Gender, Education and Disability classification and Less influenced by Income and Mobile phone. The variables such as Age, Marital status, Religion and Caste has no specific influence on participation restriction.

KEYWORDS: Person with disabilities, Participation scale, Socio demographic variables, States.

INTRODUCTION:

The first ever world report on disability, produced in 2011 jointly by the World Health Organization and the World Bank, notes that more than a billion people in the world today experience disability (WHO 2011). Persons with disabilities are described in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as those who have 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (United Nations 2006).

The (WHO,2001) International Classification of Functioning, Disability and Health (ICF) defines participation as involvement in a life situation and Participation Restrictions may occur in any life situation across nine areas of activity and participation i.e. learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, inter-personal interactions and relationships, major life areas and community, social and civic life.

In India, with more than 1.2 billion population, changing pattern of illness to more prevalent non communicable disorders is a area of concern (Srinath Reddy K et al, 2005; Kinra S et al 2010). Locomotor disability is the most prevalent type of disability in India (Patel S, 2009). Person with Movement and hearing disabilities have been found to be much higher among Indian men than Indian women, while rates of visual disabilities have been found to be higher among women than men (Das D, Agnihotri SB , 1999). The neurological disabilities predominantly affect multiple domains of day-to-day functioning such as mobility,

disturbance of cognition and behavior, causing pain, altered consciousness, bladder and bowel dysfunction, and difficulties in daily living tasks (Hewer RL, 1993)). In the new RPwD act 2016, 21 different types of disabilities were included and to be certified by a governmental medical authority for 40 per cent disability. Disability can lead to excessive poverty through participation restrictions, including exclusion from education, and barriers to get a decent job (Trani JF, Loeb M, 2012). Exclusion from income sources has also been shown to negatively impact on mental wellbeing and social inclusion (Waddell G, Burton AK, 2006).

Though it is evident disability is the reason for participation restrictions, evidence for other factors associated with participation restrictions in diverse socio-demographic and cultural groups is scanty.

Identifying individuals at risk and development of need based interventions to prevent participation restrictions would be a benefit to the persons with disabilities. The objective of the present research is to identify socio- demographic factors contributing towards participation restriction among person with disabilities in four states of India viz. Uttar Pradesh (UP), Chhattisgarh (CG), Andhra Pradesh (AP) and Tamil Nadu (TN).

METHODOLOGY

Study Design , Sample and Setting

A Cross sectional descriptive baseline study of CREATE project, approved by TLM Research ethical committee was carried out during December 2016 to August 2017 in four states with a total sample size of 379 ie. from Uttar Pradesh (100), Chhattisgarh (100), Andhra Pradesh (102) and Tamil Nadu (77), out of which 198 were males and 181 were females.

Study Tools

- Interview Schedule: Used to gather information of PWDs about the socio-economic and demographic variables viz. age, gender, marital status, education, occupation, income groups, membership, locality, caste and disability types as mentioned in their disability Certificates.
- Participation scale (Van Brakel WH et al, 2006): Is an interview based standardized scale of 18 items developed based on the terminology and conceptual framework of ICF, to measure level of social participation affected by stigma. This is an instrument validated through an exhaustive process of testing and retesting in a /multinational, multi- centric initiative. It measures the extent to which people participate in common social events.

Procedure

The participation scale (P-scale) was used in the vernacular languages of Tamil, Telugu and Hindi. Translation into vernacular languages was done based on the English scale and the translated versions are back translated to verify the intrinsic meaning that needs to be retained.

Interviews were conducted at the respondent's home environment after establishment of successful rapport by the interviewer.

Based on the P-scale scores of each respondent, the level of participation of 5 categories has been summarized in this study into 2 categories as follows:

1. No significant Participation Restriction(NSPR): Score (0-12) No Significant Restriction and Score (13-22) Mild Restriction.
2. Significant Participation Restriction (SPR): Score (23-32) Moderate Restriction, Score (33-52) Severe Restriction and Score (53-90) Extreme Restriction

The quantitative data collected from the four states were analyzed using SPSS 20 and association among different variables was tested using chi-square and other appropriate statistical tests.

Results

Prevalence of Participation Restriction and state: Analysis showed that, of the total sample majority (73.6%) face participation restrictions. which is maximum in UP (82%), followed by CG (79%), TN (72.7%) and least in AP (60.8%).

Table 1. Proportion(%) of persons with Disabilities (PWD) facing Participation Restrictions (PR) among different Demographic and Socio-economic categories and state

Demographic and Socio-economic variables		TN N=77	AP N=102	CG N=100	UP N=100	Total N=379
Proportion of PWDs with PR		56 (72.7)	62 (60.8)	79 (79)	82 (82)	279 (73.6)
Gender	Male	31 (77.5)	26 (52)	45 (72.6)	49 (80.3)	151 (70.9)
	Female	25 (67.6)	36 (69.2)	34 (89.5)	33 (84.6)	128 (77.1)
	P-value	0.235/NS	0.057/Sig	0.036/Sig	0.396/NS	0.106/NS
Age Groups	18 to 39 yrs	39 (81.2)	30 (55.6)	59 (80.8)	63 (77.8)	191 (74.6)
	40 to 59 yrs	16 (59.3)	27 (65.9)	19 (73.1)	17 (100)	79 (71.2)
	above60yrs	1 (50)	5 (71.4)	1 (100)	2 (100)	9 (75)
	P-value	0.093/NS	0.498/NS	0.618/NS	0.076/NS	0.785/NS
Marital Status	Married	30 (65.2)	38 (62.3)	42 (75)	40 (85.1)	150 (71.4)
	Un Married	23 (85.2)	19 (57.6)	36 (83.7)	40 (78.4)	118 (76.6)
	Sep/W/Div	3 (75)	5 (62.5)	1 (100)	2 (100)	11 (73.3)
	P-value	0.196/NS	0.900/NS	0.501/NS	0.553/NS	0.556/NS
Educational Status	Uneducated	12 (66.7)	31 (79.5)	17 (85)	30 (90.9)	90 (81.8)
	up to 9std	22 (73.3)	15 (65.2)	34 (82.9)	34 (89.5)	105 (79.5)
	10 to12 std	17 (70.8)	14 (43.8)	23 (74.2)	13 (65)	67 (62.6)
	Graduation+	5 (100)	2 (25)	5 (62.5)	5 (55.6)	17 (56.7)
	P-value	0.521/NS	0.003/Sig	0.465/NS	0.010/Sig	0.001/Sig
Occupation	Beggars	0	2 (50)	1 (100)	3 (100)	6 (75)
	Labour/Coolie	4 (66.7)	34 (75.6)	29 (78.4)	16 (66.7)	83 (74.1)
	Farming	19 (70.4)	0	6 (50)	23 (92)	48 (75)
	Buisness	5 (55.6)	1 914.3)	14 (70)	5 (83.3)	25 (59.5)
	Housewife	0	12 (63.2)	2 (100)	8 (88.9)	22 (73.3)
	DailyWage	0	3 (17.6)	2 (66.7)	0	5 (21.7)
	P/D/S	28 (80)	10 (100)	25 (100)	27 (90)	90 (90)
	P-value	0.483/NS	0.000/Sig	0.022/Sig	0.002/Sig	0.000/Sig
Income (INR)	No Income	6 (75)	0	1 (100)	20 (95.2)	27 (90)
	<1000	0	0	35 (97.2)	13 (76.5)	48 (90.6)
	<2500	27 (75)	28 (66.7)	5 (50)	26 (78.8)	86 (71.1)
	<5000	21 (70)	29 (56.9)	31 (75.6)	22 (81.5)	103 (69.1)
	<10000	2 (66.7)	5 (55.6)	7 (58.3)	1 (50)	15 (57.7)
	P-value	0.963/NS	0.594/NS	0.003/Sig	0.346/NS	0.002/Sig
Religion	Hindu	53 (72.6)	52 (61.2)	79 (79)	72 (83.7)	256 (74.4)
	Muslim	2 (66.7)			10 (71.4)	12 (70.6)
	Christian	1 (100)	10 (58.8)			11 (61.1)
	P-value	0.806/NS	0.531/NS	-	0.223/NS	0.440/NS
Caste	General/FC	0	1 (50)	8 (100)	5 (71.4)	14 (82.4)
	OBC/BC/MBC	34 (70.8)	39 (58.2)	53 (75.7)	38 (76)	164 (69.8)
	SC/ST	22 (75.9)	22 (66.7)	18 (81.8)	39 (90.7)	101 (79.5)

	P-value	0.418/NS	0.683/NS	0.261/NS	0.139/NS	0.094/NS
Type of Membership	CSO Member	24 (63.2)	60 (70.6)	70 (78.7)	77 (84.6)	231 (76.2)
	Champion	32 (82.1)	2 (11.8)	9 (81.8)	5 (55.6)	48 (63.2)
	P Value	0.054/Sig	0.000/Sig	0.583/NS	0.053/Sig	0.017/Sig
Possession of Mobile phone	Yes	50 (71.4)	41 (55.4)	53 (77.9)	55 (79.7)	199 (70.8)
	No	6 (85.7)	21 (75)	26 (81.2)	27 (87.1)	80 (81.6)
	P Value	0.380/NS	0.055/Sig	0.461/NS	0.277/NS	0.023/Sig
Note: P/D/S :Pensioners/Dependents/Students, NS: Not Significant, Sig: Statistically Significant						

Prevalence of Participation Restriction and Disability categories (Table 2):

Disability categories comparisons shows that proportion of those facing participation restrictions was significantly more among Visual Impairment in the states of CG (100%), AP (82.4%) and aggregate (89.5%) and not significant in TN and UP.

Table 2. Proportion (%) of persons with Disabilities (PWD) facing Participation Restrictions (PR) among different Disability categories and state

Disability categories	TN N=77	AP N=102	CG N=100	UP N=100	Total N=379
Locomotor Disability	38 (71.7)	29 (70.7)	59 (80.8)	69 (79.3)	195 (76.8)
Orthopaedic Handicapped	10 (76.9)	16 (43.2)	4 (44.4)	3 (100)	33 (53.2)
Visual Impairment	1 (50)	14 (82.4)	11 (100)	8 (100)	34 (89.5)
Hearing Impairment	1 (33.3)	2 (50)	3 (75)	0	6 (54.5)
Mentally retarded	6 (100)	1 (33.3)	2 (66.7)	2 (100)	11 (78.6)
Total	56 (72.7)	62 (60.8)	79 (79)	82 (82)	279 (73.6)
Chi Square(X^2)	5.262	10.939	9.862	3.280	21.730
P Value	0.261	0.027	0.043	0.350	0.000
Remarks	NS	Sig**	Sig**	NS	Sig**

DISCUSSION

Variables of maximum influence (in 3 states):

Occupation: Participation restrictions are influenced by Occupation on aggregate and also in the states of AP, CG and UP. The findings are same as Trani JF and Loeb M (2012) found that disability will cause more poverty through restricted participation, which includes exclusion from education, and barriers to participate in regular work. Exclusion from income generation opportunities has also been shown to negatively affect mental wellbeing and social inclusion (Waddell G, Burton AK, 2006)

The World Bank report (2009) on disability in India states that persons with disabilities have significantly lower employment rates as compared to the others. According to a 2002 National Survey, employment rate of persons with disabilities was found to be Thirty seven percent, whereas it was sixty percent for the general population.

Type of membership: Participation Restrictions are also influenced by membership in the states of TN, AP, UP and total sample.

Variables of average influence (in 2 states):

Gender and Education: Gender showed association with participation restrictions in the states of AP and CG but not on aggregate, while education is associated in AP, UP and on aggregate. This can be supported by findings of Wim et al (2012) that women were more affected by unemployment, which can be seen in the overall status of employment in a society such as Indonesia, as a result of poor education.

Persons with disabilities have less education and children with disabilities have very high dropout rates in comparison with their peers.

Disability Classification: Disability classification is related to participation restrictions in two states in AP, CG and total sample. This finding is supported by Maria LL and Jan L (2008) that Thirty five percent has perceived 1–6 severe issues with participation. Most participation restrictions were reported in the areas of Family role, Autonomy, Work and education. Hahn H (1985) reports that, Disabled persons mostly face discrimination and attitudinal constraints, which influence their independence and participation in society.

Variables of least influence (one state):

Income: Income exhibited association in one state of CG and total sample. The finding is supported by Dev NK (2017) Study that exclusion of persons with disabilities in the development process has many implications, as stigma of the visible disability can lead to loss of income and extra expenses required for their maintenance. This leads to loss of education opportunities and social exclusion of their family members.

Usage of Mobile: Usage of mobile phone is found to be associated with the level of Participation Restrictions in the states of AP and on total sample.

Variables of no influence: Variables of no influence on Participation restrictions include Age, Marital status, Religion and Caste.

Reeder GD and Pryor JB (2008) found that person with disability are mostly affected with social stigma which leads to a cycle of poverty via unemployment, social exclusion and poor mental wellbeing. World Bank report (2009) says that depending upon the type of disability, Locations, gender, category and regions, substantial variations were found in socio-economic Developments, stigma, and access to services for disability in India. The other challenges are attitudes of the family and community members which can further change their impairments into disabilities. All these factors contribute towards the participation restriction among the person with disabilities in four states.

CONCLUSION

The study concludes that Participation restrictions are highly influenced by type of occupation and type of membership in most of the states. The Variables such as Gender, Education and Disability category moderately affect the participation restrictions in some states. Income and usage of mobile phone least affect the participation restrictions in some states. The variables such as Age, Marital status, Religion and Caste have no specific affect on participation restriction. No findings are common in all the four states which highlight the cultural diversity of influencing factors and suggest a need for independent understanding of the needs of the each state. This analysis emphasizes the importance of an insight about the each state and planning of state-specific interventions to be effective on Person with Disabilities.

LIMITATION OF THE STUDY

This is a cross section study and involves an interview method to gather the information about the participant's response in 4 different states. Qualitative methods like Focus group discussions and In-depth interview can add more value to the contribution was not employed due to regional language constraints.

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REFERENCES:

1. Das, D., Agnihotri, S.B. (1999). Physical disability: Is there a Gender Dimension? *Economic and political weekly* 33(52): 3333–3335.
2. Dev Nandan Kumar (2017). Empowerment of persons with disabilities through institutional based rehabilitation services. *Asian journal of science and technology*. 08; 09, pp.5851-5856,
3. Hahn, H. (1985). Disability policy and the problem of discrimination. *American Behavioral Scientist*, 28(3), 293–318.
4. Hower, R.L. (1993). The epidemiology of disabling neurological conditions. In: Greenwood R, Barnes MP, McMillan RM, Ward CD, editors. *Neurological Rehabilitation*. New York: Churchill Livingstone. pp. 3–12.
5. Kinra, S., Bowen, L.J., Lyngdoh, T., Prabhakaran, D., Reddy, K.S., Ramakrishnan, L.(2010). Sociodemographic patterning of non-communicable disease risk factors in rural India: A cross sectional study. *BMJ*. 341:c4974.
6. Maria Larsson Lund., Jan Lexell. (2008). Perceived Participation In Life Situations In Persons With Late Effects Of Polio. *J Rehabil Med*, 40: 659–664
7. Patel, S. (2009). An Empirical Study of Causes of Disability in India. *Internet Journal of Epidemiology* 6(2).
8. Reeder, G.D., Pryor, J.B. (2008). Dual psychological processes underlying public stigma and the implications for reducing stigma. *Mens Sana Monogr*, 6: 175-186.
9. Srinath, Reddy, K., Shah, B., Varghese, C., Ramadoss, A. (2005). Responding to the threat of chronic diseases in India. *Lancet*, 366:1744–9.
10. The Rights of Person with Disabilities act. (2016). New Delhi: Ministry of Law and Justice, in the Gazette of India. Extraordinary, Part II- Section 1
11. The World Bank (2009). *People with disabilities in India: From commitments to outcomes*.
12. Trani, J.F., Loeb, M. (2012). Poverty and disability: A vicious circle? Evidence from Afghanistan and Zambia. *Journal of International Development*, 24:S19–S52.
13. UNCRPD.(2006). *United Nations Convention on the Rights of Persons with Disabilities*.
14. United Nations.(2006) *Convention of the Rights of Persons with Disabilities and Optional Protocol*. New York: United Nations.
15. Van, Brakel, W.H., Anderson, A.M., Mutatkar, R.K., Bakirtzief, Z., Nicholls, P.G., Raju, M.S., Pattanayak, R.K.(2006). The participation scale: measuring a key concept in public health. *Disabil. Rehabil*, 28(4):193-203.
16. Waddell, G., Burton, A.K.(2006). *Is work good for your health and well-being?: The Stationery Office*.
17. Wim, H. van, Brakel., Benyamin, S., Hernani, D., Kerstin, B., Laksmi, K., Rita, Y., Indra, K., Muhammad, K., Kadek, I. K., Annelies, W.S. (2012). Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Glob Health Action*, 5: 18394
18. World Health Organization. (2001). *The International classification of functioning, Disability and health- ICF*. Geneva.
19. World Health Organization. (2006). *Neurological Disorders: Public Health Challenges*. Geneva: World Health Organization.
20. World Health Organization. (2011). *World Report on Disability*. Geneva: World Health Organization.

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