

Issues related to disability in India: A focus group study

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ABSTRACT

Background. Systematic research into disability has been scarce, especially from India, even though an estimated 5% of the population may have significant disability due to physical disorders. Depression as a common psychiatric disorder affects about 3%–5% of the population. Thus, the impact of disability related to physical, mental and substance use disorders is enormous and it influences resource allocation and policy planning.

Methods. The issues relating to disability were addressed through a qualitative multicentred study. Focus groups were conducted at three sites in Chennai, Bangalore and Delhi on three themes: (i) parity, stigmatization and social participation; (ii) current practices and needs; and (iii) the General Disability Model as proposed by the World Health Organization. The focus groups were homogeneous and included members from six categories of participants: individuals with physical disability, individuals with mental disability, individuals with alcohol/drug-related disability, family members of mentally disabled persons, family members of physically disabled persons and health professionals. In all, 118 groups were conducted with a mean (SD) group size of 8.6 (1.6).

Results. Patients with mental and alcohol/drug-related disability were more discriminated against than those with physical disability. Awareness regarding the existing laws and social programmes was uniformly poor across the three centres. Stigmatization was a major reason for under-utilization of the meagre resources available. There was poor awareness of the Disability Act, 1996. The consumers felt more comfortable with the earlier terms of 'handicap' and 'impairment'.

Conclusions. The study has implications for policy planning, clinical decision-making and social behaviour. Awareness of the laws, facilities and programmes needs to be increased, especially regarding the Disability Act, 1996 among consumers as well as health professionals. More disability-friendly facilities are required.

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INTRODUCTION

It is becoming increasingly clear that diagnosis alone is not enough to predict outcome and care utilization in the health sector.

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For effective utilization of meagre health resources, especially in the developing world, additional indices of burden of disease and patterns of utilization need to be evaluated. The World Health Organization (WHO), in its constant endeavour to bring uniformity in technical language, has developed sequential editions of the International Classification of Diseases (ICDs) of which the tenth edition (ICD-10) is currently in use. In recognizing the above caveat, WHO has been developing an updated edition of the International Classification of Impairments, Disability and Handicaps (ICIDH) which attempts to redefine some of the basic terminology. The ICIDH-2¹ defines impairment as 'a loss of function or abnormality of body structure or of a physiological or psychological function'. The terms 'disability' and 'handicap' have been changed to 'activity limitation' and 'participation'. Activity limitation is defined as 'the nature and extent of functioning at the level of the person, which may be limited in nature, duration or quality'. Participation is defined as 'the nature and extent of a person's involvement in a life situation in relation to impairments, activities, health conditions and contextual factors which may be restricted in nature, duration and quality'. It is envisaged that the ICIDH and ICD classification for disability and diagnosis, respectively, would be used together to generate a better prediction of health care utilization, needs, outcomes and cost of health care services. This study, aimed at understanding disability in India, is part of the larger WHO study to assess disability in a cross-cultural perspective using various methods, including focus group discussion.

Focus groups are special group interview techniques that allow inferences to be made beyond the individual. They are important techniques to assess needs, interventions, programmes and models. They are based on discussion among participants on the concerned topics and there is no need to arrive at a consensus.² Focus group discussions were conducted to study the socio-cultural context of disability in India.

The issue of disability relates not only to the disease producing the disability that is almost identical globally but also to the attitudes, reaction and hindrances that are social in origin and hence likely to vary. The unique characteristics that cultural differences are likely to impart to the assessment and understanding of such characteristics must be retained. Focus groups, by being the means to elucidate such cultural variations, define the unique flavour and also fine-tune the assessment methods.

Physical disorders have long been recognized as a cause of disability all over the world. However, there is growing awareness of mental disorders being a major cause of disability. The Global Burden of Disease study³ estimates depression to be the fourth major cause of loss of disability-adjusted life years (DALYs) globally. The relationship of depression and burden has been emphasized in a global as well as Indian context in a recent editorial.⁴ Another study⁵ that assessed the family burden in 163 family members of 200 severely mentally ill persons about to be

discharged, found high levels of both objective and subjective burden. Other psychiatric disorders responsible are alcohol use, schizophrenia, bipolar affective disorders and obsessive compulsive disorder.⁶

The available literature regarding disability and burden from India supports the literature available from elsewhere. One study from Madras (now Chennai), using the Schedule for Assessment of Disability (SAPD),⁷ showed relatively stable deficit in the fourth to sixth year of illness, though there was much more disability in the acute stages.⁸ In this study, burden was especially more in members who dealt with disruptive behaviour. Other studies from India have compared family burden, dysfunction and subjective well-being of patients with schizophrenia and those with mood (affective) disorders.^{9,10} These studies showed that the burden was more on the family members of patients with schizophrenia. In a study on depression,¹¹ there was no correlation between dysfunction in the patients and social support. The limited available literature indicates more disability and dysfunction in major psychiatric disorders. Though reliable estimates of the extent of disabilities are not available, a report presented at a national seminar on rural rehabilitation at Nasrapur¹² put the figure of the handicapped at 3 to 9 million children. Current estimates suggest that the prevalence is about 5% and the total affected population is approximately 50 million. The issue of assessment and understanding disability thus assumes importance in the national as well as cross-cultural context.

Another issue that has an important relationship with the societal attitude to disability is the legal standpoint. In recognition of the growing global awareness, the Persons with Disability Act, 1996¹³ came into existence. However, it appears that awareness regarding this progressive Act is still limited.

This study, using qualitative methods, aimed to develop an understanding of disability from a socio-cultural cross-national perspective in groups of affected individuals, care-givers and health care professionals.

METHODS

The focus groups were conducted at the three study sites—All India Institute of Medical Sciences, New Delhi; National Institute of Mental Health and Neurosciences, Bangalore and Schizophrenia Research Foundation at Chennai. The aim was to discuss issues related to disability using a predetermined guide of logically laid questions on three themes in groups of affected individuals, family members and relatives of affected individuals, and health professionals. The themes were:

1. *Parity, stigmatization and social participation (PSSP)*. This theme explored the stigma attached to disability in a culture.
2. *Current practices and needs (CPN)*. This referred to the current practices and needs of people with disability and their care-givers.
3. *General Disability Model (GDM)*. The groups with this theme discussed the underlying model of disability as outlined in the ICIDH-2. The model that was subject to the group discussion proposed disability and functioning as outcomes of interactions between health conditions and contextual factors. This interaction was explained as complex and bi-directional, though no causal assumptions were implied. There are two types of contextual factors, viz. personal such as age, gender, coping styles, social background, education, etc. and social and environmental factors such as attitudes, architectural considerations, legal structures, etc.

Participants

The groups were homogeneous in constitution and the participants were from the following categories:

1. Mentally disabled group (MD)
2. Physically disabled group (PD)
3. Family members of mentally disabled (FMD)
4. Family members of physically disabled (FPD)
5. Health professionals (HP)
6. Individuals with alcohol and drug-related disability (AD)

Data recording and management

Two researchers (one coordinator and one rapporteur) conducted all the group discussions. The rapporteur took detailed notes of the discussions. These notes were compared at the end of the discussion and detailed records were compiled for each group. The focus groups at Chennai additionally used an observer as well as tape-recorded the focus group discussion, which were then used for completing the notes.

Ethical considerations

The participants were explained the aims of the discussion and their cooperation was solicited. They were informed that they might choose to not participate without any adverse effects on their treatment. A verbal consent was also taken. The participants were assured of confidentiality and anonymity.

Data analysis

Both descriptive and relational analyses were done for the data.¹ The descriptive analysis discussed the findings of the focus group by summarizing and providing the clearest possible understanding of the issues. Verbatim quotes were used wherever required to illustrate a point. Emergence of patterns by studying similarities was looked for. Accurate reporting was the main aim of the report.

In relational analysis, the range and depth of variation were focused on, to highlight differences between experts and lay persons and differences in social or economic groups.

RESULTS

Table I gives the details of the themes and the group membership at the three centres. There were 18 focus groups in all, of which 9 were conducted by the Chennai centre, 4 by the Bangalore centre and 5 by the Delhi centre. These focus groups included one group on GDM, 8 on PSSP and 9 on CPN at the three centres. There were 8 groups comprising individuals with disability, 7 groups with family members of affected individuals and 4 groups with health professionals. The size of the groups varied from 5 to 11 (mean [SD] 8.6 [1.6]).

In the group of mentally ill individuals which comprised predominantly of men, the age range was 20–51 years. The duration of illness varied from 3 months to 12 years and major psychiatric illnesses as well as drug and alcohol dependence were represented. The health professionals included psychiatrists, psychologists, social scientists and rehabilitation experts. About half of them were men. Family members included parents and siblings (women 60%, men 40%).

Parity, stigmatization and societal participation (PSSP)

In discussing *attitudes and behaviour* towards individuals with PD, MD and AD-related disorders, the participants at all the centres felt that the latter two were more stigmatized than the former. Amongst the latter two, subjects with AD-related disorders were

TABLE I. Details of themes and group membership at the three centres

Themes	Members	Number
<i>All India Institute of Medical Sciences (AIIMS), New Delhi</i>		
Parity, stigmatization and social participation (PSSP)	Mentally disabled	8
	Family members of mentally disabled	7
	Alcohol and drug	11
Current practices and needs (CPN)	Physically disabled	10
	Health professionals	10
<i>Schizophrenia Research Foundation (SCARF), Chennai</i>		
Parity, stigmatization and social participation (PSSP)	Mentally disabled	10
	Physically disabled	8
	Family members of mentally disabled	8
	Family members of physically disabled	8
Current practices and needs (CPN)	Mentally disabled	10
	Physically disabled	8
	Family members of mentally disabled	8
	Family members of physically disabled	8
	Health professionals	10
<i>National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore</i>		
General Disability Model (GDM)	Mentally disabled	15
Parity, stigmatization and social participation (PSSP)	Health professionals	10
	Health professionals	7
Current practices and needs (CPN)	Mentally disabled	10
	Mean (SD) group participation	8.6 (1.6)

more stigmatized than those with MD disorders. The Delhi centre looked further into the attitude of family members, workmates, neighbours, etc. It was felt by the participants that the family was generally supportive towards subjects with MD and AD-related disorders but with time, the attitude changed to neglect and even hate. Individuals with AD-related disorders were castigated by neighbours and workmates as a result of which they hid their problems. Children and spouses of those with AD and MD disorders were stigmatized and the marriage prospects of such individuals often suffer. The MD group felt that they were not understood properly in terms of their liabilities and assets. 'Others are not aware that we can do something because of our mental defect and that we can do something in spite of being ill.' The attitude also had something to do with the ability to get a job. A participant with MD said that, 'Getting a job and having some income is essential for others to accept us'.

Existing laws and social programmes. Awareness of existing laws and social programmes was poor among the participants at all the centres and in all the categories. The PD group and their family members were more aware than the MD group and their family members. The MD group were not aware of their legal status in the Chennai centre. The awareness regarding enactment of the Disability Act, 1996, was poor. Some knowledge about free treatment and other facilities was present but it was inadequate. Participants were not aware about tax relief, other financial benefits and equal opportunities for jobs. Participants from family members at the Bangalore centre also felt that despite knowledge of facilities, there was reluctance to use them because of the stigma. A relative commented: 'Law often acts against the interest of the mentally disabled especially drug abusers, whom it considers as criminals.'

Differences in attitude toward MD- and AD-related problems. At the Delhi centre, participants uniformly agreed that

individuals with AD- and MD-related disability are more stigmatized than those with PD. Between subjects with MD- and AD-related disorders, opinion was divided and each group claimed more stigma for itself. It also depended on the severity of the behavioural disturbance in the MD category; the more severe the behavioural disturbance, the more the stigmatization.

Equality of service and laws. Participants at the Delhi centre including individuals with MD- and AD-related disability and their family members felt that the laws were equal for both these groups and the PD group, but the services were much more for the latter. Facilities such as soft loans, concessional tickets, etc. were used for the PD group. Participants at the Bangalore centre voiced a similar opinion. 'We should form self-help groups ourselves. We are in no way seen at par with the physically disabled. We receive no sympathy,' commented one participant at the Chennai centre.

Changes in society. More free treatment facilities, specialized centres, improvement in existing centres, provision of jobs and other incentives such as financial assistance should be made available to individuals with AD- and MD-related disability. Individuals from the latter group, however, were of the opinion that the AD group should not be given any benefits, though individuals from the AD group did not feel so. The need to establish non-governmental and social organizations that participate actively was also expressed. The Chennai centre participants expressed the desire to establish a central trust that would cater to the needs of the disabled after their primary care-givers had died. Dissemination of correct scientific messages should be done by professionals to effect a change in the attitude of others. One of the participants remarked: 'Call us chemically imbalanced and not mentally ill', as this would make it equivalent to a disease such as diabetes mellitus and possibly help in reducing the stigma and also disseminate a scientifically correct message.

Current practices and needs (CPN)

Programmes available. Patients with PD and their family members at the Delhi centre had poor knowledge about the laws regarding disability. Even the 1996 Act had not been heard of by a majority of the patients. Awareness regarding governmental programmes was poor, though there was some knowledge of the facilities provided such as concessional tickets, preferential house allotments, telephone connections, etc. Availability of free appliances and treatment provided by the government was known to only a few. Professional care-givers were aware of these. Most of the members were not aware of private and non-governmental organization (NGO)-based programmes, though professionals were. At the Bangalore centre, the awareness of individuals was poor but professionals knew about the facilities at the governmental and non-governmental levels. However, knowledge about the existing laws was uniformly poor.

Process necessary to receive services. At all the centres professionals knew the procedure to follow for receipt of services. The cumbersome and often discouraging nature of the process was highlighted. The urban-rural inequality in distribution was disturbing. The individuals and their family members could also detail the process. However, the long wait and inequitable distribution were highlighted as drawbacks.

Responsibility of the government. The participants felt that free medical treatment, provision of aids and appliances, and other services should be made available by the government. Financial assistance to those who cannot work and incentives to work should be provided. The government should set up day-care and long-stay centres. The socio-economic status and the severity of disability should be the guiding principles for provision of services.

Responsibility of the family and community. There was unanimity that the family should be the primary care provider for individuals. The community and government should assist the family in carrying out its duties towards the disabled. The rapid change in community organization was, however, felt to hamper a clear definition of the community's role in taking care of disabled individuals.

Gaps between services provided and needed. Lack of awareness of treatment facilities, lack of follow up after treatment and differential quality of treatment facilities were some of the gaps, according to participants at the Chennai centre. Range, quality, geographical coverage, actual availability and user-friendliness of the services was recounted by the Delhi centre participants.

Changes necessary in society. Changes necessary for better management of individuals with disabilities included improving medical, rehabilitative and social facilities, making the physical environment more disabled-friendly and society more aware of the potential of disabled individuals, along with professional commitment and educational and vocational rehabilitation programmes.

General Disability Model (GDM)

Bangalore was the only centre to have conducted one group discussion on this theme. The responses to specific issues discussed were as follows:

1. Distinction between 'impairment and disability'. It was felt that there was an overlap between 'impairment and disability' and also that the two connote degrees of difficulty rather than distinct entities. 'Handicap' was felt to be a better term than 'participation' and 'disability' than 'activity'.
2. Suggestions regarding improvement included using 'disability' for 'activity' and illustrating factors as 'personal' and

'environmental' to improve clarity and presentation. Adequate explanation of 'personal' and 'environmental' factors with examples was felt to be necessary.

DISCUSSION

The use of qualitative research in exploring issues related to health has been emphasized in a recent review.¹⁴ For an area such as disability, which is in the initial stages of scientific investigation, these methods can provide valuable information that can lead to formulation of hypotheses to be tested by quantitative methods. However, the results of qualitative studies can also be directly utilized in policy planning.

Disability related to health conditions is being increasingly recognized as an important issue modifying the impact and outcome of these conditions. The implications of understanding disability are three-fold: in planning intervention at the individual level, in modifying the surroundings and in formulating appropriate health policies. The understanding of disability is, however, constrained by the limited scientific literature, especially for mental and drug abuse disorders.

This exploratory study addresses the issues of physical, mental and drug abuse disorder-related disability in India. Being a multicentric study, the findings are more generalizable. The uniform methodology at the three centres further adds to the strength of the study.

The attitude and behaviour towards individuals with disorders and disability revealed a generally less discriminatory attitude towards PD than MD- and AD-related disability at all the three centres. Between the latter two, i.e. MD- and AD-related disability, the distinction was not so firm. AD-related disorders were felt to be somewhat more discriminated against. For MD, attitudes vary according to the severity of the disturbance. The attitudes of family members towards MD have been studied earlier by various authors who have generally indicated the above in terms of increased critical comments, hostility, etc.¹⁵ Dissatisfaction, disappointment, frustration and anger are often expressed at the 'unsolvable' nature of the problem.¹⁶ Behavioural symptoms leading to marital discord between spouses as well as limited prospects of marriage due to the social stigma, have been reported in a previous study¹⁶ and in the present focus group discussions.

- Disability associated with mental and alcohol- and drug-related disorders is much more discriminated against than that with physical disorders. Between the former two, there is no clear distinction.
- There is general paucity of facilities and services for the disabled, in both governmental and non-governmental sectors. The available services are concentrated in urban areas.
- There is poor awareness regarding the law, facilities, programmes and utilization of available benefits.
- There is a considerable felt need for improvement in the facilities, services and opportunities for the disabled. The Persons with Disability Act, 1996 is a progressive step.
- The modified model of disability outlined in ICIDH-2 is too complex to be readily understood by the general public. There is a need to simplify the model for use outside medical specialty settings.

Stigmatization of individuals with AD-related disorders was an almost uniform phenomenon with all the study groups. It can partly be understood as substance abuse disorder is considered much more a 'social malady', with the individual bringing it on 'voluntarily' as against 'physical disorders', and 'mental disorders', which are beyond the individual's control.

The focus group discussions revealed limited awareness and poor knowledge of the services, existing laws, social programmes and change in society uniformly across the three centres. Governmental and non-governmental agencies need to play a more active role in the organization and delivery of services related to individuals with disability. Making the society more disability-friendly by implementing necessary changes were highlighted. The felt need of the participants was increasing awareness amongst caregivers, health professionals and disabled individuals about the services and benefits.

It was felt by participants that the proposed General Disability Model needs to be further simplified and elaborated with examples, especially of the 'personal' and 'environmental' factors. There is general difficulty in differentiating handicap, disability and impairment. The terms 'activity' and 'societal participation' which have been introduced to replace 'disability' and 'handicap' were difficult to comprehend and accept in the model. Overall, the model was felt to address the learned than the lay public. It is suggested that the model be made more appropriate to the public it addresses. A low level of awareness and confusion as to the definition of disability itself could be responsible for the participants' inability to understand the model.

These findings have implications at clinical as well as societal levels. At the former, there seems to be a discrepancy in the commonly used words to denote disability between clinicians and the lay public and other professionals. This is likely to impede accurate assessment. Therefore, it is important to adopt uniform and simple terminology. It is also important that clinicians and other health professionals develop adequate skills to identify disability early and intervene effectively to reduce burden.

At the societal level, the disparity in the attitude towards different disorders is apparent. The stigmatization related to alcohol and drug abuse is much more as compared to others. An effective education programme is needed to destigmatize the disability related to various disorders as well as increase awareness. Inclusion of disability-related issues in awareness programmes should also help in changing attitudes.

Policy implications are important, as India is a signatory to the proclamation on full participation and equality of people with

disabilities in the Asian and Pacific Region at the Economic and Social Commission for Asia and Pacific (ESCAP) meeting in Beijing in December 1992. In recognition of this, the Persons with Disability Act¹³ came into being in December 1995. The Act has been proclaimed to be a significant advance in issues relating to disability in India and has explicit provision for various situations. This study showed that there was a uniform difficulty in understanding the terminology and implications of the Act at all the three centres. It is important that the public and the affected population understand the tenets and import of this Act, so that the benefits available to them are utilized. It is thus emphasized that the government should educate the people about the Act and its benefits. A similar opinion has been voiced by Ali Baquer¹⁷ who says that the 'Government has not announced it as much as it should have', and that 'the awareness of the legislation is rather poor'. The impact of the legislation and consequent changes in the society should be assessed systematically in future studies.

REFERENCES

- 1 ICIDH-2: International Classification of Impairments, Activities and Participation. *A manual of dimensions of disablement and functioning. Beta-1 draft for field trials.* Geneva: World Health Organization, 1997.
- 2 Morgan DL. *Focus groups as qualitative research.* Beverly Hills: Sage Publications, 1989.
- 3 Murray CJ, Lopez AD. Global mortality, disability, and the contribution of risk factors. *Global Burden of Disease Study.* *Lancet* 1997;**349**:1436-42.
- 4 Saxena S, Dhawan A. Disability and burden of depressive disorders. *Natl Med J India* 1999;**12**:49-50.
- 5 Reinhard SC, Horwitz AV. Caregiver burden: Differentiating the content and consequences of family caregiving. *J Marriage Family* 1995;**57**:741-50.
- 6 Andrews G, Sanderson K, Beard J. Burden of disease: Methods of calculating disability from mental disorder. *Br J Psychiatr* 1998;**173**:123-31.
- 7 Thara R, Raj Kumar S, Valecha V. Schedule for the assessment of psychiatric disability: A modification of the DAS II. *Indian J Psychiatr* 1988;**30**:47-53.
- 8 Thara R, Raj Kumar S. Nature and cause of disability in schizophrenia. *Indian J Psychiatr* 1993;**35**:33-5.
- 9 Raychaudhuri J, Mondal D, Boral A, Bhattacharya D. Family burden among long term psychiatric patients. *Indian J Psychiatr* 1995;**37**:81-5.
- 10 Chakrabarti S, Lok Raj, Kulhara P, Avasthi A, Verma SK. Comparison of the extent and pattern of family burden in affective disorders and schizophrenia. *Indian J Psychiatr* 1995;**37**:105-12.
- 11 Chadda R. Social support and psycho-social dysfunction in depression. *Indian J Psychiatr* 1995;**37**:119-23.
- 12 Sethi BB. 1981—Year of the handicapped. *Indian J Psychiatr* 1980;**22**:127-8.
- 13 Persons with Disability Act. Ministry of Law, Justice and Company Affairs, Government of India, 1996.
- 14 Seeberg J. Qualitative research in health care: Fringe or frontier? *Natl Med J India* 1998;**11**:132-6.
- 15 Trivedi JK, Chaturvedi PK, Sethi BB, Saxena NK. A study of attitudes of key relatives in schizophrenic patients. *Indian J Psychiatr* 1983;**25**:264-8.
- 16 Suman C, Baldev S, Srinivasa Murthy R, Wig NN. Helping chronic schizophrenics and their families in the community: Initial observations. *Indian J Psychiatr* 1980;**22**:97-102.
- 17 Rights of the Disabled in India. *SPAN* 1998 Jan/Feb:22-3.