Role of NGOs in Identification Camps for Persons with Intellectual Disabilities in India

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ABSTRACT

Purpose: *Identification camps for persons with disabilities are conducted by both government and non-government organisations (NGOs) in India, as a viable option for mass screening. However, it has been noticed that identification of persons with intellectual disability is hindered by various factors and the percentage of people identified tends to vary, depending on the agencies carrying out screening and identification.*

Methods: *To validate this observation empirically, data collected from 33 identification camps was analysed post-facto.*

Results: *The results confirmed that more people with intellectual disabilities were diagnosed at camps organised by NGOs, than at the ones held by government agencies.*

Conclusions: *Qualitative analysis of contributory factors revealed certain salient features related to NGOs that contribute to more accurate identification of persons with intellectual disabilities in camps. This study highlights these factors, while drawing specific inferences for better identification and screening of persons with intellectual disabilities in the Indian context.*

Key words: *Identification camps, intellectual disabilities, NGOs*

INTRODUCTION

Estimates from the Census of India (2001) and National Sample Survey (NSSO, 2002) indicate that persons with 'mental' disabilities (including those with intellectual disabilities and those with psychosocial disabilities) comprise about 10% of the population with disabilities. However, a recent World Bank

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report (2007) projects higher estimates for all disabilities, including intellectual disabilities, and indicates that intellectual disabilities as well as mental illness are neglected or under-represented in large-scale surveys. Several methodological and sociological reasons are cited for lack of consistency in findings across studies (Roger & Singal, 2001; Mitra & Sambamoorthi, 2006). Yet, vital issues such as the percentage of people identified with reference to the estimated population, and the mechanisms in place for identification, are seldom discussed. Identification is an important step in assessment and programme planning, and along with preliminary screening, is cost-effective as compared to the assessment of each individual, especially from a developing country context.

In India, the means for identification of persons with disabilities include hospital or institute-based clinics, specialised educational and rehabilitation centres, and temporary camps. Most hospital or institute-based clinics are usually well-equipped with qualified personnel, assessment material and the support mechanisms necessary for authentic identification of people with disabilities, but they may not be available everywhere. Similarly, though educational and rehabilitation centres may have non-medical personnel who are trained to identify and manage disabilities, they may not be equipped with medical facilities. Camps, therefore, have advantages when compared to the other two establishments. If planned properly, they can be organised anywhere at reasonable cost, and can cater to larger groups than are possible in institute-based settings. Sometimes facilities for screening, identification, certification and extension of basic intervention services to people with disabilities are all arranged in a single camp. The problem with informal screening and identification is that identification of disabilities is usually based on manifest impairments, while intellectual disabilities, which do not have definite sensory-motor manifestations, are not properly identified. Consequently there are a high number of false positives, while people with intellectual disabilities are rarely identified for further intervention.

The purpose of this study was to examine the differences, if any, in the identification process of persons with intellectual disabilities by different agencies, the nature of the conditions among the false positive cases, and to make a qualitative analysis of potential factors responsible for the differences. This involved studying the concurrence between the initial identification by an external agency and the subsequent diagnosis of intellectual disability made by the authors as part of the multi-disciplinary team, at camps conducted by (a) the Government agencies (b) the NGOs, and (c) Government and NGOs in partnership.

METHODS

Research Design: This is a retrospective study, based on data the authors obtained after participating in various identification camps organised by government agencies and NGOs. Data was sourced from 33 identification, assessment and intervention camps held in the last five years in West Bengal state, and a few parts of the North East and Uttarakhand state.

Tools: A questionnaire was designed to re-code the retrospective data along the following parameters: the agency involved in initial screening or dissemination of information about the camps (e.g. Government or NGOs); the purpose of the camp; the number of people who attended the camp; the number of people whose intellectual disabilities were subsequently confirmed, as assessed by the present authors; the nature of conditions among those who were not confirmed as intellectual disability; and salient features of the approach adopted by different agencies in organising the camps.

Procedure of Assessment in Camps: The same method was followed for registration and assessment in all the camps. Accordingly, the authors maintained a register of demographic and clinical variables of the people who attended. After registration, each person's developmental history was obtained from the parents or guardians. This was followed by direct, individual assessments of development, adaptive behaviour and intelligence. While the same tools were used for the assessment of development (Bharatraj, 1977) and adaptive behaviour (Bharatraj, 1992) for everyone, the tests of intelligence were varied as per the abilities of the individual, which is an accepted practice. However, it was ensured that only standard intelligence scales such as Gessell's Drawing Test (Venkatesan, 2002), Seguin Form Board (Goel & Bhargava, 1990) and Binet-Kamat Test of Intelligence (Kamat, 1967) were used, either singly or in combination, based on their relevance and indications.

Statistical Analysis: Percentages and chi-square test were calculated manually.

RESULTS

Table 1 indicates that the camps conducted by NGOs recorded high percentages of concurrence between the identification made by the NGOs and subsequent assessment by the authors. In other words, the number of true positive cases of intellectual disability was significantly higher when NGOs were involved in initial identification.

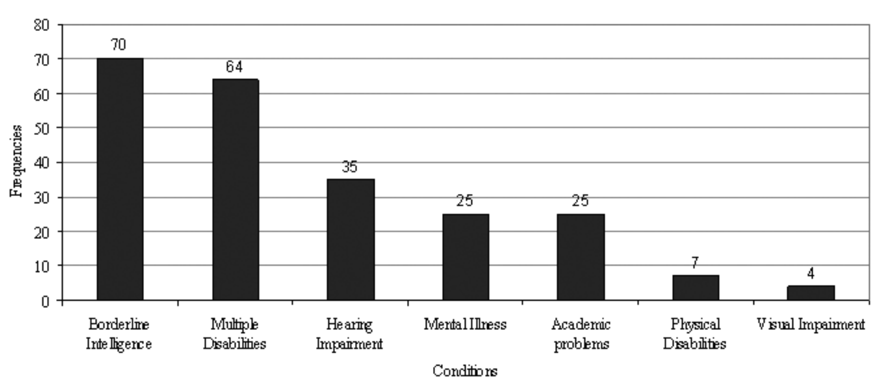
Table 1: True and false cases of intellectual disability among the cases referred for assessment by different agencies.

Agency	Total	True cases	False Cases	χ2 (df= 1)
NGO	1330	1145 (86%)	185 (14%)	692.93**
Government Agencies	87	51 (58.6%)	36 (41.4%)	2.59
Both the Government and NGOs	128	119 (93%)	9 (7%)	110**

p < .01

A separate analysis also indicates that where the NGOs were involved, the true positive cases of intellectual disability were upwards of 75%, and at times were 100%. Conversely, the percentage of concurrence was just above 50% at the camps conducted by the government agencies. Among the false positive cases of intellectual disability, the numbers were higher for those with borderline intelligence and multiple disabilities (Figure 1).

Figure 1: Distribution of the conditions among the false positive cases for mental retardation.



DISCUSSION

While the authenticity of estimates about the population of persons with disabilities is often debated, the question of how the estimated population is to be identified is largely ignored. Irrespective of acceptance or rejection of the estimates, there is a need to first address the process of identification and screening at grass-roots level, where one of the main problems is lack of proper understanding about disabilities (Kumar, 2009). This issue has more relevance where intellectual disabilities are concerned, because there may not be obvious sensory-motor signs which are helpful for preliminary screening. Consequently there is always the possibility of under - or over - representation. Within the identification process, the focus should ideally be on screening methods, keeping cost-effectiveness in mind. However, everyone may not need detailed assessment. From among the avenues available, community-based camps seem to be an economical, viable option for mass identification of people with disabilities. While both government agencies and NGOs are involved in organising these camps, field experience has suggested that they employ different methodology in mobilising people likely to possess intellectual disabilities.

In the present study, a consistent phenomenon was noted across several camps. When NGOs were involved in preliminary screening and identification of people for certification, either independently or in association with government agencies, there was a high probability that those people would receive a diagnosis of intellectual disability after assessment by authorised professionals. The factors working in favour of NGOs in screening persons with intellectual disabilities were as follows:

- The workforce, with only functional knowledge and no formal training, was well able to identify people with high probability of intellectual disabilities. Their hands-on experience in the field seemed to facilitate proper screening.
- NGOs, invariably based in the community, were familiar with families who had children with intellectual disabilities. Hence it was possible to inform them about identification camps through door-to-door contact, and to ensure that they reached the assessment camps.
- The NGOs passed on very specific information about what to expect from the identification camps. Otherwise, many people who are not in need of identification and certification turn up at these camps with different expectations.
- NGOs considered dates and venues that were compatible with local geographical, climatic and cultural conditions. Most of them could not afford to change the schedules, as this would delay their programmes and result in

various setbacks like economic loss and bad reputation. If the community lost faith in them, it would be difficult to operate at grass-roots level.

- Another potential reason for mass participation in the camps organised by the NGOs was that transport was arranged to and from the camp site, making commuting easy for the families and their children with disabilities. The people appreciated the fact that basic amenities were provided. Some parents expressed their satisfaction at not having to run around for food and water with their child, while awaiting their turn for assessment.
- Most of the NGOs followed methods to assure help and social benefits to the families at subsequent stages of certification. This approach might possibly have ensured active participation.
- Since the NGOs passed on information uniformly, people within the community were aware of all those who were going to attend the camps. Perhaps the parents were motivated to attend the camps due to a sense of togetherness.

However, discrepancies were also noted between the initial screening done by the NGO personnel and the assessment done later by the professionals, in the case of hearing impairment, cerebral palsy and mental illnesses. This indicates a need for more training to differentiate between these conditions and intellectual disabilities. In some instances the NGO personnel were aware that a few of the persons who were brought to the camp might not have intellectual disability, but still wanted detailed evaluation. In a few other cases, they wanted to extend social benefits available for people with disabilities to those in the borderline range of intelligence, because of the poor socio-economic status of the families. Another point was that unless they were professionally qualified, their expertise in screening very young children (i.e. below two years) and those with mental illnesses was very limited.

The government agencies showed specific features which might have contributed to the lower turn-out and higher number of false positive cases in the identification camps. They were:

- The information about the camps was not always disseminated at the grass-roots level; due to lack of information, some people who needed it, might not have turned up at the camps.
- The information was usually disseminated by those who were not professionals, or who did not have any hands-on experience of working

with children with intellectual disability. Unlike the NGOs, the government agencies - with the exception of medical establishments - did not have personnel with practical experience involved in the preliminary screening.

- Since government agencies conducted camps for persons with different disabilities, diverse groups would arrive at the camps. The mainly non-professional personnel directed the people, on the basis of manifest impairments, to different units at the site for further evaluation. Persons with intellectual disabilities were usually not recognised; if they had any additional sensory or locomotor impairment, they were sent to clinics dealing with those conditions. As a result, a significant number of people with intellectual disabilities lost the opportunity to reach the appropriate unit; this led to their being under-represented.
- Since the community was usually under the impression that camps organised by the government would offer cash or material incentives, the general population would report to the camps. Many people arrived with specific expectations of social benefits, and this contributed to false positive cases of intellectual disabilities.

Based on these findings, it appears that NGOs can be very useful in mass screening for intellectual disabilities within the communities. The role of NGOs, as a very important institutional mechanism to provide affordable services to complement the endeavours of the government, is widely recognised (Alur, 2001; World Bank, 2007; Singh, 2010). For the same reason, they can also be involved in screening and identification of disabilities, particularly intellectual disabilities.

It may be concluded that community-based NGOs have an advantage over government agencies, in terms of personnel who are familiar with the local families who have children with disabilities. In most cases the local NGO personnel know the children with intellectual disabilities better, and are in a position to motivate the families to attend identification and certification camps, by addressing issues related to suitability of venue, date, transportation, and follow-up services. Most importantly, they remain as a support for parents in dealing with their children with disabilities in the community.

ACKNOWLEDGEMENT

The work was carried out at the NIMH Regional Centre, Kolkata.

Part of this paper was presented at the 4th Congress of Rehabilitation Professionals, West Bengal, from 7th to 9th January, 2011.

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