

BRIEF REPORTS

**A STUDY OF KNOWLEDGE, ATTITUDES AND PRACTICES (KAP)
SURVEY OF FAMILIES TOWARD THEIR CHILDREN WITH
INTELLECTUAL DISABILITY IN BARWANI, INDIA**

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ABSTRACT

The purpose of this study was to conduct an assessment of knowledge, attitudes and practices related to intellectual disability among families with such children in Barwani, India. A total of 41 parents (tribal - 28 & non tribal – 13) from 43 villages covering 55,366 population of two blocks of Barwani district were interviewed in their own languages in order to understand their knowledge, attitudes and practices toward their children. A questionnaire with 15 items comprising of major rehabilitation components (medical, educational, economical, social and behavioral) was used for the study. Data were analyzed and the results are discussed based on responses of tribal versus non-tribal and male versus female. Implications for practice are presented.

INTRODUCTION

Intellectual disability or developmental disability first appears in children from birth to 18 years. Currently it is also been defined as an intellectual functioning level as measured by standard tests, that is well below average and with significant limitations in daily living life (1). Individuals with intellectual disability are trainable and educable. Severe to profound levels of disability need regular custodial services due to their very limited learning capacity. Often intellectual disability is associated with other kind of disabilities such as cerebral palsy, hearing impairment, visual impairment and so on. Families especially in rural areas of backward states do not have proper understanding of such disabilities so they are unable to offer appropriate support to their children and to access their rights. To understand the exact scenario of such a community a study of knowledge, attitudes and practices are useful for

planning community based interventions (2).

It is known that the triad of knowledge, attitudes and practices in combination governs all aspects of life in human societies, and all three pillars together make up the dynamic system of life itself (3). These three components can be defined thus: **Knowledge** is the capacity to acquire, retain and use information; a mixture of comprehension, experience, discernment and skill (3); **Attitudes** refer to inclinations to react in a certain way to certain situations; to see and interpret events according to certain predispositions; or to organise opinions into coherent and interrelated structures (3); and **Practices** mean the application of rules and knowledge that leads to action (3). Good practice is an art that is linked to the progress of knowledge and technology and is executed in an ethical manner.

This study measures knowledge, attitudes and practices of families of children with intellectual disability. Understanding the levels of knowledge, attitudes and practices will enable a more efficient process of awareness creation, as it will allow the programme to be tailored more appropriately to the needs of the community if applied through a community based rehabilitation project.

Worldwide professionals, policy makers are talking about community-based approaches for providing services to persons with disabilities (4). It has been understood that community based rehabilitation (CBR) is cost effective, has wider impact and is more acceptable by people (4). Today CBR has also been seen as an alternative sustainable approach of delivering services to people specifically when we have larger population living in rural areas where IBR (Institutional Based Rehabilitation) cannot reach all people. There has been a question whether it is effective and provides what it is supposed to provide. Many successful experiences have been documented that show that CBR is significantly better if it is properly designed and implemented effectively (5). It can be another alternative model besides the IBR to provide comprehensive rehabilitation services with major focus on awareness building, strengthening community institutions and more important empowering persons with disabilities, with less resource and infra- structure (6). Since a majority of disabled children live in rural areas (7) so it is necessary to focus and create replicable CBR models.

Location of the project

Barwani is among the most backward and poor districts in Madhya Pradesh state of India. Around 67 % of the population of this district is tribal. The district is well connected with adjoining cities by road but within the district, roads are very bad and people do not have proper transportation to reach to the town to avail any kind of services. The entire district is hilly and dry and had been drought stricken since the previous 5-6 years when this survey was done. Agriculture and labor work are the primary occupation of the large number of population in this district. Extreme poverty, lack of resources and poor health services are the main contributing factors towards disability in this region.

Ashagram Trust is a non-government organisation (NGO) started in 1983 doing community based rehabilitation in a few pockets of Barwani. The first author was the part of this organisation with core duties of a therapist and project administrator, including the design and getting project funding.

It was observed that awareness about intellectual disability is very low in this region compared to other areas of the state. People are not aware about the Persons with Disability Act (PDA) and its provisions. Most of the time intellectual disability was understood and treated as a mental illness. Because of this misunderstanding the misconceptions attached to mental illness also extended to intellectual disability. Even the government data counted such people as mentally ill. Due to low intellectual capacity and poor processing skills, people with intellectual disability are not able to understand the complicated social system and claim their rights like persons with other categories of disabilities. Thus, they remain hidden and unheard in society. Their presence is not acknowledged.

Objectives

Against this backdrop, the objectives of this study were two fold:

- To understand knowledge, attitudes and practices of families towards their children with intellectual disability.
- To prepare appropriate awareness material and project a strategy for a community based rehabilitation project.

METHOD

Development and validation of the instrument

The concept of this study was presented in a core meeting of the organisation, which comprised of disability professionals, doctors, and project administrators. Except for a few modifications and resistances there was a general agreement and approval from this core team. Later on, a broad strategy was planned out for implementation of this project. Responsibilities were assigned. The first author became the coordinator of this project and called a meeting of 44 community based rehabilitation workers (CBRWs) from three CBR projects of the trust. The detailed concept of the study was presented before them, which further sharpened the idea among those involved. CBRWs were asked to come up with questions around the theme in order to develop a questionnaire for the survey. A total of 38 questions came up from this exercise. However all questions were focused around 15 major themes. Thus with the consultative process 15 questions were selected and prepared in simple Hindi language. This questionnaire was once again presented to the core team for their inputs and suggestions. No major changes were made. This was the process of questionnaire validation.

Pilot testing of the questionnaire was done by administering it to four field workers. The questionnaire was administered in Hindi language for two and Nimari dialect on the other two candidates. The purpose of pilot testing was to ascertain if the questionnaire was easily understood, was completed in planned time, and was indeed appropriate.

Sampling

Two blocks of Barwani district were selected for this study because the organisation already had projects running in these blocks on different issues. The Thikari block has tribal and non-tribal communities while Pati block is comprised entirely of tribal communities. Some of the parents were interviewed at “rehabilitation diagnostic and consultation center for intellectual disability” situated in the campus of Ashagram Trust. These cases interviewed at this center had not received any kind of intervention from Ashagram Trust before. Government disability data / list of PWDs were collected for the two blocks. As per the government data there

were 42 cases in 45 villages of Thikari block, and 13 in 10 villages of Pati block. All cases of selected villages of Thikari block were taken for interviewing. Some strategic changes were made in sampling process whereby 12 villages were dropped from the list since they were not priority villages for the organization on other indicators. Some mistakes were found in the government data. Many persons mentioned actually did not have any disability. Thus a total 23 people from 33 Thikari villages (population - 46,972) and 6 people from 10 Pati villages (population – 8,369) mentioned in the government data were interviewed. In addition 12 cases were interviewed at the rehabilitation center at the Trust. Majority of these cases were from different blocks of Barwani including 3 cases of adjoining district. A total of 41 parents from two different communities (tribal= 28, non tribal = 13), gender (males = 24, females =17) were interviewed.

Training of surveyors

Six CBRWs of Thikari CBR project team, two MSW professionals and one worker of rehabilitation center (all employee of Ashagram Trust) were chosen for training. These workers had good exposure of doing surveys for organization in the past. A total of nine people (seven CBRWs and two MSWs) in two groups received one day training by the first author.

Participants were trained on concepts of intellectual disability, characteristics and features of identification. They were also trained minimally on “Gessalles Developmental Drawing Test” (GDT) for administration on the child before interviewing his/her parents/relatives in order to make sure that the selected child had intellectual disability and also to estimate the degree of disability (8). GDT is a standardized psychological test that is used in clinical settings by trained professionals in getting an estimated idea of the mental age of the child. This test is only applicable for children with adequate fine motor abilities.

Training was done through demonstration and use of role-play. In the role-play, participants administered the questionnaire on each other in Bhilali and Nimadi dialects. This helped them get more clarity and confidence.

RESULTS

Table 1 summarises the age range of the 41 children chosen for the study. The majority of the disabled children were in the ages 10-15 years. Table 2 summarises the level of disability

among the 41 children chosen for the study. The majority of the children had moderate degree of disability.

Table 1. Age range of children from Barwani district (n-41)

Age (yrs.)	M	F	%
0-5	03	02	12.2
5-10	09	04	31.7
10-15	07	09	39
15+	05	02	17

Table 2. Level of disability of children from Barwani district (n=41)

Degree*	M	F	%
Borderline MR	01	-	2.43
Mild MR	03	02	12.19
Moderate MR	16	03	68
Severe – Profound MR	04	03	17

*Some children had secondary disabilities but those were not taken into account

Table 3. Summary of responses between tribal and non tribal communities (n-41)

No	Items	Yes		No		Without Breakup	Chi- square (χ^2)	p -value
		T	N	T	NT			
1	Intellectual disability happens due to sin of previous life	22 (78.6%)	6 (46.2%)	6 (21.4%)	7 (53.8%)	-	4.30	0.037
2	<i>Jhadphook</i> (Faith healing) can make the child alright	16 (57.1%)	3 (23%)	11 (39.3%)	9 (69.2%)	2 (4.87%)	3.90	0.048
3	The person can manage their life by themselves	3 (10.8%)	3 (23%)	25 (89.3%)	9 (69.2%)	1 (2.43%)	1.34	0.246
4	Parents should allow kids to play with non-disabled children	13 (46.4%)	5 (38.5%)	15 (53.6%)	8 (61.5%)	-	0.22	0.632

5	The child benefit from School	16 (57.1%)	10 (77%)	12 (42.9%)	1 (7.7%)	2 (4.87%)	4.05	0.044
6	Appropriate training improves condition of the person	19 (67.9%)	11 (84.6%)	6 (21.4%)	2 (15.4%)	3 (7.31%)	0.38	0.53
7	The person can marry and enjoy her/his life	8 (28.6%)	4 (30.8%)	19 (67.9%)	8 (61.5%)	2 (4.87%)	0.05	0.81
8	The person can look after her/his property	4 (14.3%)	3 (23%)	24 (85.8%)	9 (69.2%)	1 (2.43%)	0.66	0.41
9	The child can learn new skills with stepwise training	13 (46.4%)	8 (61.5%)	14 (50%)	5 (38.5%)	1 (2.43%)	0.63	0.42
10	The child can be trained to speak	8 (28.6%)	9 (69.2%)	19 (67.9%)	4 (30.8%)	1 (2.43%)	5.63	0.017
11	The child has disability certificate	0 (0.0%)	2 (15.4%)	28 (100%)	11 (84.6%)	-	4.52	0.33
12	The child is involved in household activities	17 (60.7%)	4 (30.8%)	10 (35.7%)	10 (77%)	-	4.36	0.036

Responses of tribal and non-tribal parent on 12 items of questionnaire are presented in the Table 3. There is statistically significant difference between two groups largely on six themes: disability occurs due to sin, faith healing can cure, the child can benefit from school, can be train to speak, have disability certificate and involve in house hold activities. However both groups had similar responses on the remaining 6 items presented in this table: person can manage life independently, should be allowed to play with non disabled children, improves with appropriate training, can get married, look after their property, and learn new skills with stepwise training.

It is clear from Table 3 that 78.6% tribal parents believe their children became disabled due to their sin in previous birth while only 21.4% thought there were different reasons. In non-tribal population 46.2 % believed in the sin theory while rest 53.8% did not agree with this. Analysis using chi-square ($\chi^2 = 4.30$, $p = 0.037$) between tribal and non-tribal groups indicates significant difference in belief regarding previous lives sins and causation of disability. Approximately 57.1% tribal parents compared to 23% non-tribal parents think faith healing (*Jhad-phook*) can make their disabled children all right but 39.3% tribal and 69.2% non-tribal parents do not agree with it. Significant chi-square ($\chi^2 = 3.90$, $p = 0.048$) demonstrates difference in knowledge of both groups. Larger numbers of parents (tribal = 89.3% & non tribal = 69.2%) believes that people with intellectual disability cannot manage their lives independently. Only a few (tribal = 10.8% & non tribal = 23%) think it is possible. Chi-square ($\chi^2 = 1.34$, $p = 0.246$) was not significant. Approximately 46.4% tribal and 38.5% non tribal parents allow their children to play along with other children while the larger group (tribal = 53.6%, non tribal = 61.5%) of parents said no. Approximately 57.1% tribal and 77% non-tribal parents believe that children benefits from school, while 42.9% tribal and 7.7% non-tribal did not agree. There were statistically significant differences between tribal and non tribal parents ($\chi^2 = 4.05$, $p = 0.044$). Parents of both groups (tribal = 67.9%, non tribal = 84.6%) indicated that appropriate training improves condition of their children while 7.31% parents had no idea and a small percentage of parents (tribal = 21.4%, non tribal = 15.4%) did not think so. Majority of parents (tribal = 67.9%, non tribal = 61.5%) believed that the person cannot marry and enjoy their lives, 4.87% had no idea while approximately one third (tribal = 28.6% and non tribal = 30.8%) considered it to be possible. A smaller proportion of tribal (14.3%) and non-tribal (23%) parents believed that person with intellectual disability can

look after his/her property while a majority (tribal = 85.8%, non tribal = 69.2%) thought it was not possible. Parents (tribal = 46.4%, non tribal = 61.5%) trusted that a child with intellectual disability could learn new skills with stepwise training but rest of the parents (tribal = 50%, non tribal = 38.5%) did not agree. Among the tribal 28.6% and among non-tribal 69.2% parents believed that children could be trained to speak while rest did not agree. On this issue there was a significant difference between tribal and non-tribal ($\chi^2 = 5.63$, $p = 0.017$). All tribal (100%) and majority non tribal (84.6%) children did not have disability certificate ($\chi^2 = 4.52$, $p = 0.033$). Approximately 60.7% tribal and 30.8% non tribal parents involved their children in household activities while 35.7% tribal and 77% non tribal did not. There are significant differences between tribal and non tribal ($\chi^2 = 4.36$, $p = 0.036$).

Table 4. Summary of responses between male and female (n-41)

No	Items	Yes		No		Without Breakup	Chi- square (χ^2)	p -value
		M	F	M	F			
1	Intellectual disability happens due to sin of previous life	13 (54.2%)	4 (23.5%)	11 (45.8%)	12 (70.6%)	1 (2.43%)	3.34	0.067
2	Jhadphook (Faith healing) can make the child alright	7 (29.2%)	9 (53%)	16 (66.7%)	8 (47%)	1 (2.43%)	2.06	0.15
3	The person can manage their life by themselves	6 (25%)	2 (11.8%)	17 (70.8%)	15 (88.2%)	1 (2.43%)	1.25	0.26
4	Parents should allow kids to play with non-disabled children	10 (41.7%)	5 (29.4%)	14 (58.3%)	12 (70.6%)	-	0.64	0.422

5	The child benefits from School	18 (75%)	6 (35.3%)	5 (20.8%)	11 (64.7%)	1 (2.43%)	7.51	0.0061
6	Appropriate training improves condition of the person	20 (83.3%)	8 (47%)	3 (12.5%)	09 (53%)	01 (2.43%)	7.40	0.0064
7	The person can marry and enjoy her/his life	11 (45.9%)	3 (17.6%)	13 (54.2%)	14 (82.3%)	-	3.51	0.060
8	The person can look after her/his property	5 (20.8%)	0 (0.0%)	17 (70.8%)	16 (94.1%)	3 (7.31%)	4.18	0.040
9	The child can learn new skills with stepwise training	15 (62.5%)	6 (35.3%)	9 (37.5%)	11 (64.7%)	-	2.94	0.085
10	The child can be trained to speak	10 (41.7%)	5 (29.4%)	13 (54.2%)	12 (70.6%)	1 (2.43%)	0.82	0.36
11	The child has disability certificate	2 (8.3%)	0 (0.0%)	22 (91.7%)	17 (100%)	-	1.48	0.222
12	The child is involved in household activities	6 (25%)	15 (88.2%)	18 (75%)	2 (11.8%)	-	15.92	0.000065

Differences were observed in 8 items probably owing to gender role difference in the communities. The items were: intellectual disability is due to sin, faith healing can cure, they

may benefit from school, appropriate training improves condition, the person can get married and enjoy life, can look after own property, learn new skills with stepwise training and can be involved in house hold activities.

It is clear from Table 4, that 45.8% male and 70.6% female parents believed that sin of previous birth was not the reason of their condition and this difference was significant ($\chi^2 = 3.34, p = 0.067$). According to 66.7% male and 47% female, faith healing could not make their children all right however 29.2% male and 53% female parents thought it was possible. Majority of male (70.8%) and female (88.2%) parents believed that the children could not manage their lives independently. Due to several reasons majority parents (males = 58.3%, females = 70.6%) did not allow disabled children to play with others. A significant differences is observed between male (75%) and female (35.3%) parents regarding knowledge that MR children could benefit from school ($\chi^2 = 7.51, p = 0.0061$). A substantial number of males (83.3%), compared to females (47%) had awareness that appropriate training improved condition of the children ($\chi^2 = 7.40, p = 0.0064$). Approximately 54.2% male and 82.3% female thought that the person could not marry. A large majority (males = 70.8%, females = 94.1%) did not think that person with the could look after his/her property ($\chi^2 = 4.18, p = 0.040$). Slightly more males (62.5%) than females (35.5%) believed that the children could learn new things with stepwise training ($\chi^2 = 2.94, p = 0.085$). More than half of male (54.2%) and female (70.6%) parents thought that the child could not be trained to speak ($\chi^2 = 0.82, p = 0.36$).

Table 5. Comparisons of responses regarding life span (n-41)

(13) Life span of the child	Community /Gender	Normal	Abnormal	No Idea	χ^2 Normal vs. no idea	p-value
	T	8 (28.6%)	5 (17.8%)	15 (53.6%)	0.0081	0.98
	NT	4 (30.8%)	2 (15.4%)	7 (53.8%)		
	M	8 (33.3%)	4 (16.7%)	12 (50%)	0.47	0.49
	F	4 (23.5%)	3 (17.6%)	10 (58.8%)		

It is clear from Table 5 that only 28.6% tribal and 30.8% non tribal believed that the children could have normal life span. There were no significant differences between tribal and non tribal ($\chi^2 = 0.046$, $p = 0.83$). With regard to gender, 33.3% males and 23.5% females believed that the children could have normal life span. There were no significant differences between males and females ($\chi^2 = 0.172$, $p = 0.67$).

Table 6. Comparisons of responses on causes of intellectual disability (birth-related versus no idea) (n =41)

(14) What are the causes of intellectual Disability	Community/ Gender	Birth related cause	No Idea	(χ^2)	p-value
	T	10 (35.7%)	17 (60.7%)	2.12	0.144
	NT	8 (61.5%)	5 (38.5%)		
	M	13 (54.2%)	10 (41.7%)	2.90	0.088
	F	5 (29.4%)	12 (70.6%)		

It is evident from Table 6 that 35.7% tribal and 61.5% non tribal understood that the cause of disability of their children is related with birth (pre, peri and postnatal) ($\chi^2 = 2.12$, $p = 0.144$). With regard to gender differences 54.2% male and 29.4% female indicated that causes are related with birth ($\chi^2 = 2.90$, $p = 0.10$).

Table 7. Comparisons of responses on handling of behavior problems

(15) How do you manage behavior problems	Community/ Gender	Make him understand	Ignore	Punishment	Analysis chi-square	p-value
	T	20 (71.4%)	3 (10.7%)	5 (17.9%)	8.90	0.0028
	NT	4 (30.8%)	0 (0.0%)	9 (69.2%)		
	M	15 (62.5%)	5 (20.8%)	4 (16.7%)	6.21	0.0126
	F	6 (35.3%)	1 (5.9%)	10 (58.8%)		

From Table 7 it is evident there is a large difference between two groups in practice of managing behavior problems in disabled children. In tribal and non-tribal category 71.4% tribal and 30.8% non tribal tried to make their children understand while 10.7% tribal and 0% non tribal ignored, and rest (tribal=17.9%, non tribal = 69.2%) used punitive measures ($\chi^2 = 8.90$, $p = 0.0028$). Significant difference ($\chi^2 = 6.21$, $p = 0.0126$) was also observed between male and female. Approximately 62.5% males compared to 35.3% females made them understand while only 16.7% males compared to 58.8% females punished the children.

DISCUSSION

The purpose of this study was to conduct a survey of knowledge, attitudes, and practices of parents of children with intellectual disability. Data revealed that there is not much difference between tribal and non-tribal groups except in few areas. Both groups lack information and do not receive appropriate services from anywhere (10). Both groups have misconceptions and misperceptions. There is evidence of punitive practices towards their mentally disabled children in both groups though the tribal group shows more of these tendencies. In both communities, most families had shown great openness toward acquiring new skills and knowledge for handling their children with intellectual disability. However, tribal parents have shown a more humanitarian approach in handling behavior problems in children while non-tribal families seem demanding and “pushy” for desired behavior and use coercive treatment. Female children are more victimised due to gender inequity in non-tribal community. Tribal families involve their children more and do not show much discrimination while the other group restricts participation of their children in day-to-day life.

Largely, parents believe that birth of these children in their families has taken place only due to sins of their previous life and not because of poor nutrition, improper delivery, or other birth related problems. These findings also match with study done by Persha and colleagues (9). Parents are convinced that their offspring could be cured if they can remove the effects of “God’s punishment” by prayers. They pay money to faith healers and on conducting worship rituals. However, many of these faith healers use practices like beating, burning on stomach, and not giving food for days in the name of treatment. Burn marks were seen on many children who had epilepsy.

According to many parents, the community believes that the intellectual disability is contagious, and can infect other children (2). Children bully, tease (verbal abuse) and beat (physical abuse) intellectually disabled children, as was mentioned by many parents. Some of them especially in non-tribal community feel ashamed about the condition of their children and also not consider play as important for development in their lives. Another belief is that marriage cures the disability (11). Many respondents wanted their disabled children to get married as quickly as possible due to that belief.

Limitations

The study was conducted in 2006 and data was analyzed in 2009. Data analysis after a gap of three years could result in change in situation at the ground level. Further the data of two groups (tribal and non tribal) is small therefore it is not possible to generalise outcomes at larger level. The psychological test (GDT) only provided performance based mental age while administration of test measuring social adaptability might have given a clearer idea for interventional plans to mainstream these children.

Implications for practice

This study reveals that there is huge lack of awareness in the community at large regarding intellectual disability. Lack of proper practices and attitudes towards disabled children are also the result of poor awareness and knowledge about the disability. Attempts should be made to build awareness among parents on various aspects of mental disability ranging from their handling at home, education and rehabilitation at large. Community-based rehabilitation programmes must prepare and provide information in local language, preferably in pictorial form. Community-based rehabilitation programmes must provide multi sensorial training in the mother tongue and sensitise other stakeholders in the community through puppet shows, street plays, and group meetings. Agencies should make rigorous effort of ensuring legal rights in terms of acquiring disability certificate and legal guardianship under The National Trust Act of the government.

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