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Dear Readers

It is informed to all readers and subscribers that due to certain technical problems we could not bring out Volume 4, No. 1 (January to June, 2008) issue. Hence the combined issue of Volume 4, No. 1 and 2 (January to December, 2008) is being published.

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From Chairperson's Desk

I am glad to mention that the Journal of Rehabilitation Council of India (JRCI) is gaining more and more popularity with new dimensions of disabilities and other aspects related to it. The articles published in the last issue of the Journal (Vol. 3, No. 1 & 2) were appreciated very much by the readers.

This issue is a new volume which contains thought provoking research based articles. The issue opens with the article "Profile of Students Studying in Special Schools for the Deaf in North India" which highlights the achievements of students with deafness and also the problems faced by them in special schools. It also covers strategies used by special teachers to teach these children. The second article "Developmental Delay and Disabilities in High Risk Newborns – A Follow Up Study" deals with the implications of birth of high risk babies and associated problems. The authors have highlighted the need of disseminating information amongst the villagers and other end users about pre-matured babies and caution about the safeguards. The next article "A Comparative Study of Care Appraisal, Subjective Burden and Emotional Reactions among Caregivers and Care Recipients" is based on a research conducted by the authors and they have come out with certain implications that those working with care recipients display cognitive, neurological and other serious impairments. Care Givers may also help them to view the problems the recipients feel through a situational lens rather than dispositional characteristics.

The readers would find another useful article in this issue "Review of Practices in the Management of Attention Deficit/Hyperactivity Disorder (ADHD)" in which the authors have discussed various need based strategies to manage children with ADHD. The authors have suggested to undertake a longitudinal study to further refine the strategies for management of these children. Another useful article "Role of Social Workers in Community Based Rehabilitation (CBR) Services for the Disabled in India" highlights the need of professional social workers in CBR programmes.

It is for the first time this issue gives an opportunity to our readers to understand the problems faced by individuals with mental illness and their families in the article "The Role of Family, Society and Culture: A Collaborative Perspective on Management and Rehabilitation of Individuals with Mental Illness". The impact on family and the impact of culture on the individuals with mental illness are highlighted in the article.

Another very interesting article "Sensitivity of the Rehabilitation Professionals about the Appropriate Use of the Term Normal" appears in this issue which highlights the feelings of rehabilitation professionals about the use of the term 'normal' as it transmits wrong message to the public that disabled are abnormal people. Last but not the least, the article "Organizational Effectiveness of Disability Rehabilitation Organizations: Perception of Professionals and Managers" studies the perception of disability rehabilitation professionals and identifies four important components of organizational effectiveness.

I hope the readers will enjoy reading this issue and will benefit from the ideas contained therein in their professional work.

Maj. Gen. (Retd.) Ian Cardozo, AVSM, SM
Chairperson, Rehabilitation Council of India

From Chief Editor's Desk

I am pleased to inform our readers that the Conference organized by the Council in Chennai in February, 2009 on the implications of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) revealed that the people have now become very much aware about the significance of this Convention. The Conference was preceded by a series of meetings of Course Coordinators of various courses in which it was highlighted that the Council must include, wherever necessary, components of this landmark Convention in special education/rehabilitation courses. The Convention has outlined the need of making all aspects of life inclusive starting from family to the education and thereafter the work place and also the places of entertainment, transportation, religious functions and so on. The Council has initiated action in revising its curricula of various courses to fulfill this aim. UNCRPD also places emphasis on research and dissemination of information in the area of disability rehabilitation and special education for creation of a rights based society. It is in this perspective that the Council is bringing out this Journal which covers all aspects of rehabilitation and special education for the benefit of all stakeholders. It is desired that the readers/professionals would write articles on the implications of UNCRPD in the total rehabilitation of persons with disabilities. They are also expected to come out with concrete suggestions for the overall implementation of the provisions of this Convention.

At the end it is expected that the readers and other professionals would contribute many more articles based on their research experience so that this Journal may gain wide acceptance.

Dr. J.P. Singh
Chief Editor & Member Secretary
Rehabilitation Council of India

Profile of Students Studying in Special Schools for the Deaf in North India

Surinder P. K. Randhawa[1], **Renu Rastogi**[2], **S.C. Handa**[3]

Abstract

In the coming years, new educational policies, advancement in technology and better awareness will give more and more deaf children chance to be in schools. However, presently it is estimated that out of the 3-4.8 million deaf children in India only 1 in 10 go to school and most of them still study in special schools. Present study profiles the student population of 20 special schools for the deaf in North India. It was found that out of the total 3,168 students majority were male, had severe or profound hearing loss and belonged to mainly lower socio-economic strata and many of them traveled long distances to be at school. Age of the youngest child was still between 4 and 6 years and in the absence of universal new born screening, lack of early identification and early intervention facilities, there still was an educational gap of 3-7 years. The number of students at class X and XII was very low and the students' language and speech development remained poor even after years of schooling. Most students used non-verbal communication mode though teachers and students were not trained in sign language. Most students undergo pre-vocational or vocational training in school but that is usually not sufficient to get gainful employment on school leaving.

Introduction

School plays a major role in the habilitation process of a deaf child. Educational opportunities equip a deaf child with communication skills, academic knowledge and vocational skills along with contributing in his cognitive, social, emotional growth and personality development. India has a large school age deaf population but we lack exact data on how many

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of our deaf and hard of hearing children are there in mainstream schools or in special schools separately or together but it is estimated that available facilities do not cater to more than 1 in 10 children, though in coming years more and more deaf children should get opportunities to study. Allen (1992) while studying the sub-group differences in educational placement for the deaf and hard of hearing students noted that though there was a sharp drop in residential school attendance between 1979 and 1985 and an increase in local school attendance but that only a very small percentage (10%) of profoundly deaf students attended local schools. Another interesting finding of the office of Assessment and Demographics Studies of the Gallaudet Research Institute in its Annual Survey of Deaf and the Hard of Hearing Children and Youth (1997) revealed that in schools for the deaf nationwide, the number of deaf students born to hearing parents continued to decline.

It is important to profile the student population studying in all kinds of educational set ups. Profiling the age, gender, hearing loss, use of amplification devices, communication modes, educational and language achievements, parental profile, etc., would guide the instruction for better results and also help in formulation of future policies regarding deaf education which to say the least have not done justice with the deaf students till now who continue to pass out of schools either semi-illiterate or literally illiterate.

Randhawa et.al. (2007) profiled the principals and teachers of special schools for the deaf in North India. This paper profiles the students of those same 20 special schools for the deaf.

Results presented below are part of a larger status study of the special schools for the deaf done by the first author for her doctoral thesis.

Methodology

The data was collected from 20 special schools for the deaf of five states and one union territory of north India, which were personally visited by the researcher. The data was collected from the principals, teachers and parents on specially constructed questionnaires. School visits, discussions with the principals and teachers, students and classroom observations and video-taping of classroom teaching provided additional information.

Information about the students

The total number of students studying in 20 schools was found to be 3,168 with an average of 159 students per school. However, minimum number of students in a school was just 45 but the maximum number of students in a school was as high as 554 students.

Gender

Fig. 1 reveals that the number of boys studying in the special schools was much higher than the number of girl students. Out of the total 3,168 students as many as 1,981 (62.5%) were male and only 1,187 (37.5%) were female. Analysis of all the schools in India also showed a similar trend.

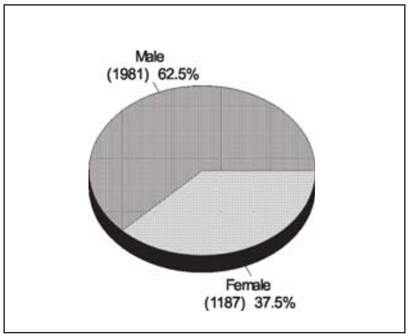
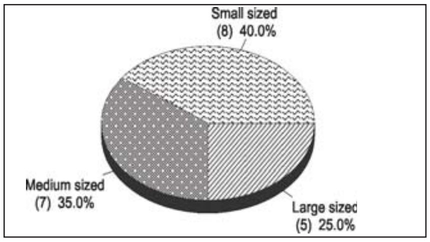


Fig. 1: Gender-wise distribution of students

The reasons for more number of boys than girls in the special schools are many. One reason is that Indian parents tend to send their male children more to school than their female children. Second reason is that the schools for the deaf are far and few, making it difficult for the girl students to travel long distances daily. Not all schools have hostels, and also many parents don't prefer to leave their daughters in the hostels. Many students including girls, however, were found to commute long distances to reach the special schools and in some cases one or both parents had shifted their residence to the town where the special school of their deaf child was located.

Size of the school

Based on the total number of students, the schools were divided into small, medium and large sized. Fig. 2 shows distribution of schools based on the size. Out of the five large sized schools, four schools had student population up to 250 only but one government school had as many as 554 students. However, majority schools for the deaf were small sized only.



Small sized – Less than 100 students
Medium sized – 100 - 200 students
Large sized – More than 200 students

Fig. 2 : Distribution of schools based on size (total student population)

Information about hostlers

Out of the 20 schools under study, 12 (60%) schools had hostel facility also. It was found that out of the total 3,168 students, 997 (31.47%) were living in the hostels. Average number of students living in a hostel comes out to be around 83; though the minimum number of hostlers was as few as 6 and maximum 146. In fact only 5 schools had more than 100 children in the hostels. The number of male students 660 (66.20%) in the hostels outnumbered the girls 337 (33.80%). Out of 12, 11 hostels were for both boys and girls, whereas one hostel facility was only for boys. In another school, hostel facility for the boys was till secondary level whereas for girls it was only till class VIII, resulting in sharp fall in the number of girl students at secondary level. The number of male hostlers ranged from 2 to 95 and female from 3 to 64. Lack of funds was reported as the main reason for not being able to build new hostel facility or expand the existing hostel capacity.

Class size

The ideal class size in a special school for the deaf should preferably be 6 students and not exceed 8-10 students. However in the study the average size of the class ranged between 4 to as many as 20 students. Fig. 3 shows that there were at least 5 (25%) schools where the average class size was 15 students. Again when asked about the minimum and maximum number of students in a class, it was found that even the minimum number ranged between 2 and 16 meaning that there was a school where the minimum number of students in a class was 16. Maximum number of students in a class also ranged between 7 and 27 students. Large class size can adversely affect the quality of teaching learning process.

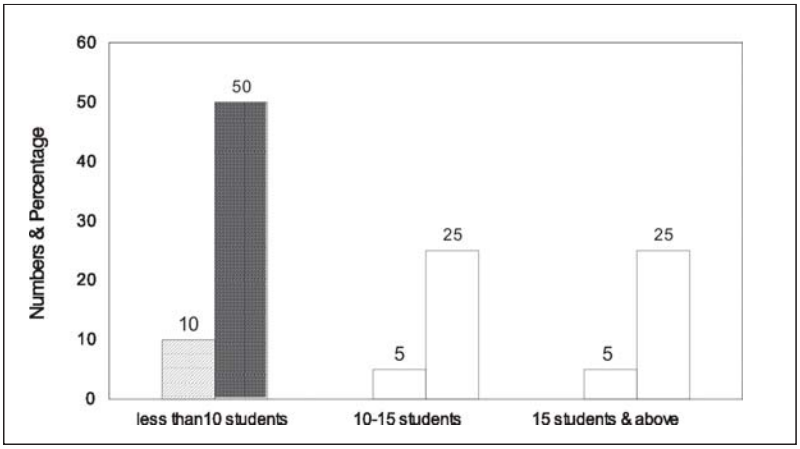
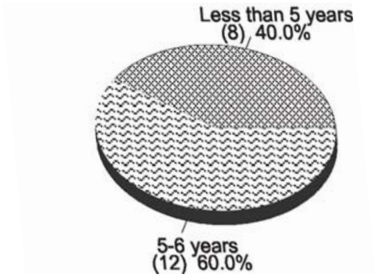


Fig. 3 : Distribution of schools based on average class size

Age of the students

The importance of early intervention in the form of special school services in the life of a deaf child is a well documented fact. When asked about the age of the youngest and the oldest child in the school, distribution as shown in Fig. 4 and Fig. 5 emerged.



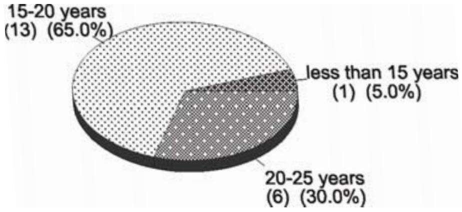


Fig. 4: Distribution of schools based on the age of the youngest child

Fig. 5 : Distribution of schools based on the age of the oldest child

Table 1 gives a descriptive analysis of the age factor of the deaf children. Further study of the analysis showed that a 14 years old child in class fifth and a 25 years old in class X showed an educational gap of 3 to 7 years. In many cases 18-20 year old children were found in class VIII. However all the principals admitted that with greater awareness, every year the age of the youngest child is decreasing and in the coming years the educational gap should decrease.

The only one school which had Parent Infant Programme (PIP) enrolled children less than 2 years, along with the parents who generally came twice or thrice per week but if the child was to be put in the hostel the minimum age for admission was 6 years. It was also found that majority schools (60%) admitted deaf children at any level though some schools preferred to admit the children only at the lowest level. However most of the time children of any age were admitted at any time of the year.

Distance travelled by students

As mentioned earlier, the special schools for the deaf are few and far between, so usually these schools cater to the needs of a large area. It was found that children travelled between 2 kms to as much as 90 kms (one way) to reach a special school. The schools which did not have hostel facility naturally had students travelling from far off places. Though 18 out of the 20 schools studied were located in urban areas, all these schools had students coming from the surrounding villages. In many cases where daily travelling was not possible, many parents (especially mothers) of young deaf children had shifted to the city area, so that their children could attend the school. The distribution of schools based on the maximum distance a child travelled to reach the school is shown in Fig. 6

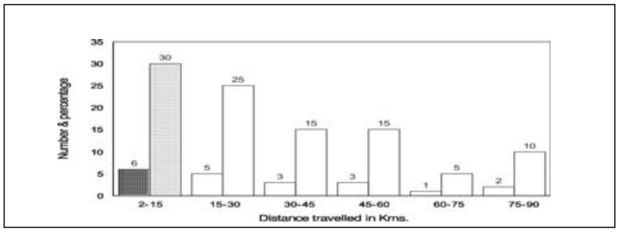


Fig. 6: Distribution of schools based on the maximum distance a child travelled to reach the school

Information related to classes

Teachers were asked to think of their first period in the school and give information about that particular class with an idea that in this way information about all the children in the school could be collected.

Class levels

Cross tabulation between the class level and the number of students studying in that class gave data about the number of students studying in each category of class level. Table 2 details the number of students in each category of 213 classes. (Seven teachers did not respond clearly about the number of students in their class of first period). As is obvious, almost 50% of the total students studied in classes I to V. The number of children studying in higher classes is found to be low as the number of dropouts after primary/middle level increases and secondly there were only eight schools offering secondary and only 2 schools offering senior secondary level education. Out of the total 17 classes at secondary level, it was found that as many as nine classes belonged to two schools and eight belonged to rest of six schools. In fact, there were a total of only five students studying in class XII in the two schools together.

Class profile

Descriptive analysis of 213 classes showed that mean size of the class was about 13 children, with few classes with a minimum of just one student in the class and on the maximum side there were as many as 30 students in a class. Gender-wise statistics show that though all the schools were co-educational, in certain classes there were no boys and in other classes there were no girls. Total number of students studying in 213 classes was found to be 2,703 out of which 1,714 (63.4%) were boys and 989 (36.6%) were girls.

Teachers teaching the same class or many different classes

It was found that there were only 60 (28.2%) teachers who taught to the same class throughout the day whereas majority of the teachers

153 (71.8%) taught to many different classes during the school hours.

Cross tabulation with the class level shown in Table 3 indicates that at middle and secondary level most teachers taught to more than one class.

Audiological information of the students

The principals of the schools under study were asked to write the approximate number of children falling in different categories of hearing loss. Table 4 gives the distribution of students into various categories of hearing loss. Only 120 children (3.78%) were reported to fall in the moderate to severe hearing loss category whereas 846 (26.70%) fell in the severe loss category. Maximum children, i.e., 2202 (69.52%) were reported to have profound hearing loss. It is clear from the above findings that the children with less than 55dB hearing loss did not study in the special schools for the deaf under study.

Teachers' knowledge about the hearing loss of their students

It was found that only 143 (65.0%) teachers knew about the hearing loss of their students. However, most of these teachers also could not properly categorize their students into various categories of hearing loss indicating that most teachers did not know the basic facts about their students.

Cross tabulation between the special education qualification and the knowledge of hearing loss of their students yielded that out of the 16 teachers who had not responded to this question, as many as 12 were untrained.

Availability of 'Aided Audiograms'

In most schools doing the audiometric assessment of the students was a routine activity of the school and 6 (30%) principals reported that their students had their hearing loss tested every six months and 8 (40%) schools got it done annually. However, it was found that in many cases the answers of the teachers and the principal of the same school did not match.

For maximum benefit from hearing aids it is necessary that aided audiometry (audiometry done with the hearing aids worn) which is done to check the utility of hearing aid may also be conducted periodically. Most principals however, did not understand the meaning of aided audiometry and filled some random figures to the question about aided audiograms. On personal enquiry it was found that most of the principals misunderstood the term aided audiograms. Out of the 12 (60%) principals responding their ignorance about aided audiograms, at least 4 had initially mentioned that all the students of the school had aided audiograms! It was further found that like principals, a large number of teachers, i.e., 84 (38.2%) also did not know what 'aided audiograms' were and majority of even those teachers who reported that aided audiograms for their deaf students were available, in fact did not know what they were. On further enquiry it was found that except for a very few students (who had got it done privately) the aided audiograms of most of the students were not available.

Similarily though 16 (80%) principals replied in negative about the availability of speech audiograms of their students, yet 4 (20%) replied that few students had undergone speech audiometry. However both principals and teachers did not have clear idea about speech audiometry also.

Individual hearing aids used by students

Information about the type of individual hearing aids used by the students was available for only 2,101 students as not all teachers answered this question. Table 5 reveals that as many as 715 (34.03%) students were reportedly did not have individual hearing aids and out of those who had; majority students, 972 (46.26%) had only one pseudo-naural body level hearing aid. Only 76 students were reported to have two body level hearing aids and only 87 students were reported to have two Behind The Ear (BTE) individual hearing aids. However further analysis showed that many of those students who had the hearing aids either did not use them regularly or their aids remained out of order for long periods. It was reported by both teachers as well as parents that in the absence of effective speech and auditory training curriculum at school, there was not much motivation for the students to wear their hearing aids especially the body worn, as they in many cases are mismatched with the audiogram of the child for the reason that majority of the deaf children receive body level hearing aids through the free distribution scheme of the government.

Working condition of the hearing aids

Only 76 (37.8%) teachers said that hearing aids were in good working condition most of the time and at least 15 (7.5%) teachers admitted that they were never in good working condition. Principals and teachers did show a concern that keeping the hearing aids in good working condition was a big problem. Majority of parents were reported not to be very cooperative and were too poor to get them repaired. Most principals reported the problem of lack of good hearing aid repair technicians also.

Though majority of the teachers (62.4%) reported that they checked the working of the hearing aids daily but there were 31 (15.3%) teachers who reported to never check the working condition of hearing aids of their students. From informal talks and first hand experience it was found that in most cases checking meant asking the students, "is there sound?" and many times even those students who did not have battery in their hearing aids or whose battery had run out or even whose aid was switched off also replied in affirmative and got away with it. It was hardly ever ensured if the aid was useful for speech development. Most parents in their interviews also admitted that child wore the aid to school to please the teachers but it did not really help him in hearing much or speech development; so he/she did not wear it at home. School visits, discussions and classroom observations of every school covered under study showed that most schools were faced with a situation where all the students did not have individual hearing aids, the ones who had mostly had one body level hearing aid which also did not work most of the time and unavailability of trained audiologist/speech therapists and very few working group hearing aids. Hence a scenario where no consistent auditory training program for speech development could be implemented. Auditory training hardly ever went beyond awareness and discrimination of few environmental sounds or names of class mates. Many teachers reported that in many cases, out of order hearing aids were not repaired for months.

Audiometric evaluation of the hearing aids

For the optimal use of hearing aids it is necessary to evaluate them for audiometric parameters but this facility was not available in any of the schools under study. However, it was found that that both principals and a large number of teachers did not know/did not understand the term audiometric evaluation of hearing aids.

Frequency of use of hearing aids at school and home

Fig. 7 shows that at least 30 (14.7%) teachers reported that most of the students never wore it even if they had a hearing aid, though 113 (55.1%) teachers reported that most of those students who had hearing aids wore them to school daily but just wearing a hearing aid does not help much. In many cases it was found that the child was wearing an aid without the battery or with broken wire. Though three schools followed 'Oral' communication policy and majority of other schools followed the policy of 'Total Communication' and claimed to put an emphasis on auditory inputs also, the real situation about the use of hearing aids however, was very different. Except for four schools under study, the teachers in other schools were quite indifferent to the use of hearing aids. Fig. 8 and Table 6 indicate that most teachers as well as parents agreed that most deaf children never or rarely wear/use their hearing aid at home. Parents in most cases reasoned that the hearing aid was not of much use so the child did not like to wear it.

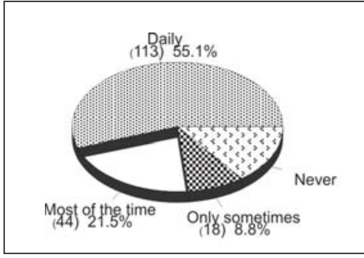


Fig. 7 : Frequency of use of hearing aid in the school by the students

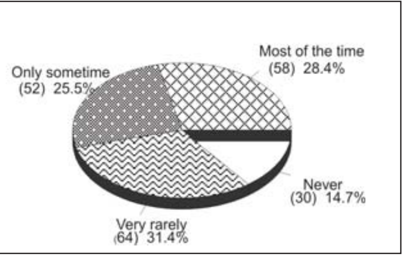


Fig. 8 : Frequency of use of hearing aid by the students at home (teachers'responses)

Speech intelligibility of students

Principals were asked to give an approximate number of students of their schools falling in different categories of speech intelligibility. Data analysis showed that 13 principals (65%) reported no child under 'very intelligible speech' category. Results presented in Table 7 further indicate that in rest of the seven schools only a total of 72 (2.27%) children were reported to have speech in this category. Better speech usually meant that those children had better audition and must have received early and better speech and auditory training either at school or home or at both the places. 243 (7.67%) students were reported to have 'intelligible speech' meaning just somewhat difficult to understand. Again 9 schools had no child falling in this category. 357 (11.26%) children were reported to have 'barely intelligible speech' and rest of the 2,153 students (67.96%) had either 'unintelligible' speech or they normally did not attempt to speak. Though the figures are only an approximate, yet, it is important to note that except for one school where sign language was recognized as the primary language, in rest of the 19 schools, spoken language was the key language. Principals did accept the fact that because of various reasons it was very difficult to develop intelligible speech in their deaf students. Most principals failing to recognize that sign language is the primary language of deaf children were apologetic about the fact that their students used gestures/signs.

Teachers were also asked to categorize the students of their first period into various categories of speech intelligibility as it will sound to lay persons. Since majority of the teachers did not categorize their students well, the number of children falling in each category could not be calculated. However, it was found that only four teachers (2.04%) reported to have children with 'very intelligible' speech in their classes and 74 (37.76%) more teachers reported to have children with 'intelligible' speech. Rest all teachers reported that most children of their class had 'unintelligible' speech or would not attempt to speak in front of laymen.

Speech pattern of the deaf students

Another important point noted after meeting the children was that most of the students whose speech was reported to be mostly good uttered isolated words instead of speaking in connected speech. Fig. 9 also endorses this fact. Most 144 (68.2%) teachers reported that majority of their students spoke only in 'broken words' and further 24 (11.4%) teachers responded that they spoke either in 'broken words or phrases'. Only 8 (3.8%) teachers reported that they had few students in class who spoke in full sentences. Again as many as 54.5% parents also reported that their deaf children spoke only in broken words. Another 40% reported that they spoke either in broken words or phrases. Only 5.5% parents reported that their children used full sentences and it was found that these children had less than profound hearing loss and had speech therapy from a younger age.

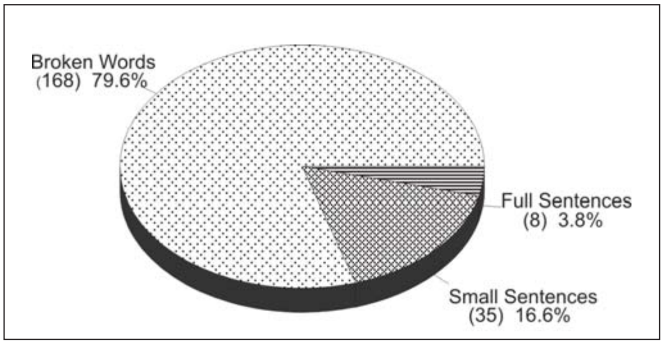


Fig. 9 : Distribution of teachers based on their assessment of speech pattern of their deaf students

Speech training of the deaf children

It was found that irrespective of the fact that whether the school had a speech therapist or not (only 50% schools had a speech therapist), in all except two schools, students on average got less than two hours in a week for individual or group speech/auditory training (Fig. 10). In majority schools, most of the time, the teachers, usually of the pre-primary classes, using mirror, did some repetitive drill exercises in the name of speech training. As mentioned earlier, auditory skills of majority of the students hardly ever went beyond recognition and discrimination of few environmental sounds and few words indicating that very few students used auditory inputs for speech development.

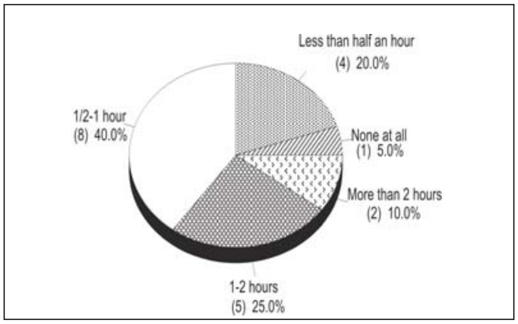


Fig. 10 : Weekly time given to children for individual/ group speech/auditory training

Teachers were asked that in a period of 40 minutes, how much time did they spend on auditory/speech training/correction of their students. Fig.11 shows that as many as 69 (33.7%) teachers claimed to devote 10-15 minutes and 54 (26.3%) teachers devoted 5-10 minutes. Cross tabulation between the time spent and class level showed that 42 teachers (20.5%) who spent 15-20 minutes were all teachers of pre-primary classes and 22 teachers (10.7%) who did not do any auditory training/speech correction were all teachers of higher classes. Though 9 schools reported to have speech software like VAGHMI or Speech Viewer, very few teachers made use of them and most of them reportedly relied on lip-reading and use of mirror for speech development and speech correction. Classroom observations showed certain teachers were overdoing the 'speech correction' work and were simply not allowing the students to communicate and in other classes especially of higher level it was being totally ignored. It was further noted that in many cases it was not the misarticulated utterance of the students which the teachers wanted to correct (spoken language communication of most students was very minimal) but a teacher initiated activity, whereby teacher introduced a new word and then repeatedly asked the students to articulate it. Many teachers admitted that many times it took up lot of precious time of the class and also turned out to be a futile exercise.

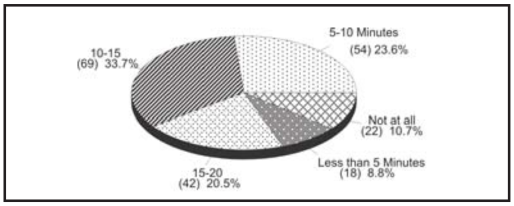


Fig. 11: Distribution of teachers based on the time devoted for auditory/ speech training or speech correction during a school period

Communication modes used in the school

Study of communication strategies used by the teachers and students comprised an important part of this present research. Considering its importance a separate paper is being prepared of the finding of this important aspect. However, this is to be mentioned that though out of 20 schools under study, 19 were following either 'Oral' or 'Total Communication' policy where key emphasis was on speech but out of 220 teachers as many as 211 (95.9%) reported to use gestures/signs with their students and 217 (98.6%) teachers said that their students used gestures/signs with them. Majority teachers reported that students used manual communication modes to communicate among themselves both inside and outside classroom. Data collected on 93 deaf students and ex-students (this study) revealed that major problems encountered by the deaf on account of their deafness were reported to be communication with the hearing counterparts, lack of higher education facilities and lack and difficulty in getting jobs. For school going deaf children the difficulty in understanding the school subjects was also directly related to the problem of communication.

Parental profile of the deaf students

Table 8 details the parental profile of deaf students. It shows that more than 98% students had both parents hearing, though globally the figures are considered to be 90 to 95%. Traditionally, in India deaf persons prefer to marry a normal hearing person (now there is change in the trend) and hence very few deaf children with both parents deaf are found, moreover, there is a high incidence of deafness acquired after birth. It is further noted that majority students (60%), belonged to low economic status parents whose monthly income was less than Rs. 5,000 per month. Only 6% students had parents whose monthly income was more than Rs. 10,000 per month. Similarly there were as many as 662 (24.35%) students whose both parents were illiterate and 1,539 students (56.63%) had parents who were just Xth or XIIth pass, only 517 students (19.02%) were reported to have one or both parents with college degree. Sridhar (1999) had also reported similar findings. The finding that majority of deaf students in the special schools for the deaf under study belong to low educational and low economic status families strongly suggest that irrespective of hearing loss, deaf children belonging to more affluent and more educated families were more likely to study in mainstream schools. Kluwin & Stinson (1993) also presented similar results.

Detailed interviews with 55 parents in the same study (Randhawa, 2005) showed that the average age of the father of a deaf student was 44 years whereas that of a mother was 37 years. It was also found that though there was no father who could not read or write there were at least 10% mothers who were totally illiterate. However, interestingly the number of undergraduate mothers (27.2%) was marginally higher than the number of undergraduate fathers (21.8%). The results had further indicated that there was an equal percentage of fathers who were in business and those who were doing some kind of service (45.1% each). However, more fathers than mothers had undergone professional vocational training which helped them to get a job.

School fee

Government and NGO run aided special schools for the deaf receive grant-in-aid from the government and are bound to provide free education to the students. Out of the 20 schools covered under the study, there were 17 such schools. However only 12 (60%) schools reported that they did not charge any fee, whereas 5 (25%) schools admitted that though there was no tuition fee, parents did pay between Rs. 50 and 500 to the school as development fee. Out of these five, four schools charged between Rs. 50 and 250, but one school charged as much as Rs. 500 from each student. 3 (15%) unaided schools reported that they had a differential fee system, meaning that children paid according to the parental financial condition and it ranged between no fee for few poor children to as much as Rs.1,000 per month for children of parents who could afford.

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Table 1: Descriptive analysis of the age factor of the deaf students

Average age of the youngest child	4.47 years
Range	2-6 years
Average age of the oldest child	18.75 years
Range	14-25 years

Table 2 : Distribution of students in different class levels

Class	*Number of classes*	*Number of students*	*Percentage*
Pre-nursery/nursery	17	183	6.78
KG Classes	46	618	22.87
Primary	98	1311	48.50
Middle/Junior high	36	407	15.05
Secondary/Senior Secondary	16	184	6.80
Total	*213*	*2703*	*100.00*

Table 3: Distribution of teachers based on teaching to single or more classes

Class	*Teach to more than one class*	*Teach to only one class*	*Total*
Pre-nursery/Nursery	11	6	17 (7.98%)
KG Classes	31	15	46 (21.59%)
Primary	62	35	97 (45.55%)
Middle	34	2	36 (36.90%)
Secondary & Sr. Sec.	15	2	17 (7.98%)
Total	*153* *(71.83%)*	*60* *(28.17%)*	*213* *(100%)*

Table 4: Distribution of students based on the degree of hearing loss

Hearing loss categories	*No. of students*	*Percentage*
Moderate to Severe Hearing Loss (56-70dB)	120	3.78
Severe Hearing Loss (71-90dB)	846	26.70
Profound Hearing Loss (above 90dB)	2202	69.52
Total	*3168*	*100.0*

Table 5: Type of Individual Hearing Aids used by students

Type of Hearing Aid	*No. of students*	*Percentage*
Two body worn	76	3.62
One body worn with 'V' or 'Y' cord	972	46.26
One body worn with 'S' cord	175	8.33
Two BTE	87	4.14
One BTE	76	3.62
No Hearing Aid	715	34.03
Total	*2101*	*100.00*

Table 6 : Distribution of children based on the usage of hearing aid at home (parents' responses)

Use of Hearing Aid at home	*No. of children*	*Percentage*
All the time (Excluding sleeping, bathing, outdoor play etc.)	1	1.8
Most of the time (More than 4-6 hours)	5	9.1
Between 2-4 hours	5	9.1
Between 1-2 hour	5	9.1
Less than 1 hour	1	1.8
Only rarely	22	40.0
Never	16	29.1
Total	*55*	*100.0*

Table 7: Distribution of students based on speech intelligibility

Speech Intelligibility	*No. of students*	*Percentage*
Very Intelligible Speech	72	2.27
Intelligible Speech	243	7.67
Barely Intelligible Speech	257	11.26
Unintelligible Speech	343	10.82
Would not ordinarily attempt to speak	2153	67.96
Total	*3168*	*100.00*

Table 8 : Parental profile of deaf students (as informed by teachers)

Parental characteristic		*No. of students*	*Percentage*
Hearing Status of Parents	Students with both parent deaf	6	0.22
	Students with one parent deaf	26	0.96
	Students with both parents hearing	2686	98.82
	Total	*2718*	*100.00*
Economic Status of Parents	Students with low income parents	1631	60.0
	Students with middle income parents	924	34.0
	Students with high income parents	163	6.0
	Total	*2718*	*100.0*
Educational Status of Parents	Students with lowly educated parents	662	24.35
	Students with average educated parents	1539	56.63
	Students with highly educated parents	517	19.02
	Total	*2718*	*100.00*

Developmental Delay and Disabilities in High Risk New Borns- A Follow Up Study

T.U. Sukumaran[1], P.V. Vijesh[2] and P.S. Sukumaran[3]

ABSTRACT

With medical and technological advancement in intensive neo natal care more and more preterm and at risk babies are born and have chance of surviving. Low birth weight and prematurity are factors that are associated with handicapping conditions later in life and have implication for Rehabilitation Services.

Assessment and follow up programmes for high risk new born babies are highly critical in this context. In a developing country like India, few studies are done in this field. In this study, 90 high risk new born babies who attended the out patient department of Institute of Child Health, Kottayam, Kerala State were followed up for one year period. The main tool used for the study was Trivandrum Developmental Screening Test and subjects were assessed at 1½, 3, 6, 9, 12 months intervals. The results showed that the prevalence of developmental delay and developmental disabilities were 14.4% and 15.6% respectively. Among different developmental disabilities, the prevalence of cerebral palsy was highest with 6.7%. Low birth weight was found to be a major factor among high risk new born babies. Neonatal asphyxia, prematurity and low birth weight were found to be major causes for developmental delay and disabilities in these high risk babies. Related variables such as age, weight, height, educational level and socio economic status of mothers were found to be non-significant

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among high risk new born babies with respect to the developmental of delay and disability. The study also emphasizes the need for early intervention of identified cases of high risk new born babies with developmental delay and disabilities.

Introduction

The neonatal care in India has improved considerably in the last decades. Babies who would not have survived 20 years ago are now surviving with all medical and technological advances in neonatal care. A baby born in less than 37-38 weeks of gestation – about 10% of the total term are considered premature. 90% of the babies weighing 1000 grams do survive. Extremely premature babies will be kept in ventilators as their lungs are capable of breathing effectively for themselves, often for about a month or more. Most premature babies will be kept in incubators to simulate the womb and to provide warmth.

But what lies beyond the survival for these babies? The main question is whether mortality is being converted into survival with disability and how best these babies can be followed up in hospital setting and in the community.

Different organizations working for the follow up services for high risk babies in India are facing a lot of challenges in their field. In a country where nearly 70% of deliveries takes place at home, the first hurdle is the identification of the baby as high risk either by a *Dai* or by Auxiliary Nurse Midwife. Another issue is the logistics of transport of this extremely sick baby to the hospital. The availability of adequate follow up services after the discharge is the next problem that has to be faced. Neonatal care is incomplete without adequate follow up programmes. So both these avenues, neonatal intensive care and follow up services have to be developed together.

Not all children with developmental disability have risk factors at birth. Most children with cerebral palsy, for example, are full term and have normal birth weight (Nelson et al., 1990). Many causes of developmental disability are unknown (Freeman, 1985). A system of tackling and monitoring high risk infants thus fails to identify a large number of infants who would benefit from early intervention service.

Generally, developmental outcome of pre-term infants has been reported primarily in terms of birth weight criteria. The incidence of major developmental disability varies from 5% to 10% for infants with birth weights below 1000 grams (Allen, 1992 and Aylword et al., 1989). Saigal et al., 1982 found that although survival improved dramatically with increasing birth weight, the incidence of neurologic handicap was not significantly different with respect to birth weight.

Although prematurity is a risk factor for developmental disability, 80% to 95% of pre-term infants are free of major disability (Escobar et al., 1991). Visual impairment occurs in 5% to 12% of pre-term infants with birth weight below 1000 grams, and hearing impairment occurs in 6% to 12%. The more subtle abnormalities of CNS dysfunction also appear to be common from 20% to 65% of school aged children with birth weights less than 1000 grams. (Nickel et al., 1982).

Studies which describe the prevalence of developmental delay and disability in high risk new borns in India is very less in number. This is due to the difficulties in monitoring the high risk new born babies for a period of one or two years and the lack of appropriate tools for identifying developmental delay and disability. A follow up study by Choudhary et al. (1996) showed that the prevalence of different disabilities in high risk newborns were in the following manner cerebral palsy 6.7%, seizure disorder 3.9%, hearing impairment 1.5%, cortical blindness 0.3% and mental retardation 5%. Now a days the situation has changed a lot with the availability of standardized scales for assessing developmental delay and disabilities developed in Indian culture. Such scales are available in almost all regional languages. Health care workers are working hard to make aware about the need of regular follow up programmes for high risk babies in order to detect the prevalence of developmental disability and the initiation of appropriate treatment strategies.

Methodology

It is a prospective study with 90 high risk new born babies who attended the out-patient department of Institute of Child Health (ICH), Kottayam, Kerala State, during the period of October 2000 to October 2001. 100 normal babies who attended the OPD of ICH were also evaluated periodically and included in the study as control group. The tools used for the study to assess the developmental delay and disability were, Trivandrum Developmental Screening Test (1991) for assessing developmental delay, Amiel Tiesion method (1986) for the assessment of muscle tone abnormality and other routine neurological and developmental examinations. The follow up assessment were done at 1½ 3, 6, 9 and 12 months after the initial assessment. To find out the cause for developmental disability and delay, investigations like ECG, CT Scan and metabolic screening were done in selected cases.

Limitation of the sample

An at risk mother is one who would give birth to pre-term baby. The factors could be having twins, triplets or even quadruplets, who has had previous pre-term births, who has uterine and cervical abnormalities, is over 35 years of age or under 18 years. A higher number of low birth weight and premature infants are born to girls under 15 years. However these may be aborted or they never reach hospitals. The sample was based on hospital admissions, there lies the bias of the findings.

Results

Analysis of data shows that the prevalence of developmental delay and developmental disabilities in high risk new born babies are 14.4% and 15.6% respectively.

Out of 14 (15.6%) high risk new born babies who were diagnosed as developmentally disabled, 6 had cerebral palsy (6.7%), 2 had hearing impairment (2.2%), one had visual impairment (1.1%), 5 had congenital malformations (5.6%) and 2 had seizure disorders (2.2%). Among the six cerebral palsy cases, 5 belonged to spastic quadriplegic type and one to atonic diplegic type. Three cases had multiple disability.

Analysis of causes for the birth of high risk new born babies, showed that very low birth weight (<1500g) is the commonest cause (51.1%), followed by prematurity (40%), septicaemia (27.7%), neonatal seizures (18.8%), neonatal asphyxia (15.5%) and hypoxic ischemic encephalopathy (HIE) (12.2%). Among the high risk babies, the prevalence of disability and delay was maximum with neonatal asphyxia. This was followed by neonatal seizures, HIE, low birth weight prematurity and hyperbilirubinemia.

Other selected variables such as maternal age, maternal weight, height, birth weight, birth order, gestational age, sex of the child, type of delivery, maternal educational level, socio economic status, etc. were found to be non-significant variables among high risk new born babies with respect to the developmental delay and disability*. All the babies in the control group were healthy and showed no signs of developmental delay and disabilities.

Table 1

Prevalence of Developmental Delay in High-risk New Born

Group	*Presence of Development Delay*		*Absence of Development Delay*		*Total*
	Number	%	Number	%	Number
Study	13	14.4	77	85.6	90
Control	0	0	100	100	100

'*'With reference to the sample.

Table 2

Prevalence of Developmental Disability in High Risk New Born

Group	*Presence of Development Delay*		*Absence of Development Delay*		*Total*
	Number	%	Number	%	Number
Study	14	15.6	76	84.4	90
Control	0	0	100	100	100

Table 3

Types of Disabilities in High Risk New Born

Types of Disability	*Number*	*Percentage*
Cerebral Palsy	6	6.7
Hearing Impairment	2	2.2
Visual Impairment	1	1.1
Congenital Malformation	5	5.6
Seizure Disorder	2	2.2

Table 4

Types of Cerebral Palsy

Types of Cerebral Palsy	*Number*	*Percentage*
Spastic Quadriplegia	5	5.6
Atonic Diplegia	1	1.1
Extra Pyramidal	-	-
Mixed Type	-	-

Table 5

Causes of High Risk Baby with respect to Development Delay & Disabilities

No.	*Causes*	*N*	*%*	*Developmental Delay*	*Disabilities*
1.	Low Birth Weight (LBW)	47	52.2	8(8.8%)	8(8.8%)
2.	Hyperbilirubinemia	46	51.1	5(5.5%)	4(4.4%)
3.	Prematurity	36	40	6(6.6%)	7(7.7%)
4.	Septicaemia	25	27.7	5(5.5%)	1(1.1%)
5.	Neonatal Seizures	17	18.8	4(4.4%)	4(4.4%)
6.	Neonatal Asphyxia	14	15.5	6(6.6%)	6(6.6%)
7.	HIE	11	12.2	2(2.2%)	3(3.3%)
8.	RDS	9	10	Nil	Nil
9.	ICH	6	6.6	Nil	1(1.1%)
10.	Meningitis	4	4.4	1(1.1%)	Nil
11.	Hypoglycemia	4	4.4	Nil	Nil
12.	MAS	2	2.2	Nil	Nil
13.	Congenital Infection	2	2.2	Nil	Nil
14.	Congenital Malformation	1	1.1	Nil	1

HIE – Hypoxic Ischemic Encephalopathy. ICH – Intra Cerebral Haemorrhage.

RDS - Respiratory Distress Syndrome. MAS – Meconium Aspiration Syndrome

Discussion

In this study 90 high risk new born babies born with various risk factors were followed up for a period of one year for assessing developmental delay and disability and this data was compared with 100 normal new borns. It is seen that the developmental delay (14.4%) and developmental disabilities (15.6%) are high in high risk new born babies when compared to control group. In a state like Kerala, where infant mortality rate is low (14/1000), the infant morbidity has increased. This may be due to the better survival of high risk new borns, better monitoring and management in neonatology departments. Since the prevalence of developmental delay and disability are high in high risk new born babies, all maternity hospitals should start high risk new born follow up clinic for the early identification and management of such cases.

All students of the normal nursery should be followed up periodically upto six years to detect the developmental delay and disability very early. All infants with developmental delay should undergo early intervention therapy to reduce the severity of their disability so that they can lead a fruitful life.

In this study 16 new born babies were identified as having developmental disability:- cerebral palsy (6), hearing impairment (2), visual impairment (1), congenital malformation (5), and seizure disorders (2) and were referred to corresponding disciplines for further follow up and treatment programmes.

On analysis of various factors for the development of high risk new born babies, it is apparent that most of the risk factors are preventable. Awareness and better monitoring during antenatal and prenatal period can certainly prevent hyperbilirubinemia, birth asphyxia, hypoxic ischemic encephalopathy, septicaemia, intrauterine growth retardation and prematurity.

This study has shown that there is no association between birth order, maternal age, weight, height, socio-economic status of mothers of newborn babies who presented the signs and symptoms of developmental delay and disability. So all pregnant mothers irrespective of age, height, weight, socio economic status, number of pregnancy, etc., should undergo routine antenatal check up and follow up programme.

There was no association between birth weight and gestational age among high risk new borns with respect to the presence of developmental delay and disability. This indicates that all high risk new borns have to be assessed periodically in high risk follow up clinics, irrespective of their birth weight and gestational age. Thus this study gives valuable information about the prevalence of different disabilities in high risk new borns and the need for periodic follow up programmes in these categories.

Implication for Policy Makers

Health and family care professionals should disseminate information among villagers about the risks of producing preterm infants and caution about the safeguards. Studies involving larger samples need to be undertaken to triangulate the findings of this present research. Monies to be allocated for neo natal care and research. Mobile neo natal units for rural areas will ensure that babies born premature stand a chance of survival.

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A Comparative Study of Care Appraisal, Subjective Burden and Emotional Reactions Among Caregivers and Care Recipients*

Dr. V. N. Yadav[1], **Dr. Surajmal**[2], **Dr. Savita Sheoran**[3]

ABSTRACT

The authors investigated the perception of exemplary care, subjective burden, problem solving ability and emotional reactions among hearing impaired (HI), orthopedically handicapped (OH), and their caregivers. A total of 100 participants participated in the study voluntarily. Among them 25 HI (age ranging from 50-70 years, recommended by audiologist), 25 OH due to accidents (age ranging from 20-45 years) and 50 were their respective caregivers from 25-40 years of age. These participants were administered exemplary care scale, perception of subjective burden and five items of emotional reactions. The t-analysis was insignificant for perception of problem solving ability. Caregivers reported higher scores on exemplary care, perception of subjective burden and emotional reaction measures. The findings were discussed in the light of existing literature. The implications, limitations of this study and suggestions for further researches were also discussed.

Introduction

All over the world care giving has been an integral part of every society. Care giving in the sense in which it is used here, refers to the

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assistance to needy that may be part time or later becomes an unremitting obligation (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch,1995). Care giving to the needy, helpless, orthopedically impaired, elders, sick and disabled people has been in existence from time immemorial. But the forms and methods of care have been varying from society to society, depending upon societal needs, attitudes, values, religious beliefs and the economical factors. The Indian traditional view of care is based on 'daya', 'dakshina', 'dheyeya', 'samya-bhaya', 'swadharma' and 'tyaga'. The crux of which is compassion, motivation, quality of humanism, self-discipline, self-sacrifice and the consideration for others. In modern times, most of the countries on the globe have adopted the concept of welfare state and trying to help needy individuals to meet their needs to make their life meaningful and to enhance their social adjustment so that they may contribute to the society.

The existing literature shows two major types of care, i.e., formal care and informal care. Formal care giving predominantly refers to assistance at institutional level by trained caregivers (Chan & Leathy,1999). However, it is limited in India only for persons suffering with autism, cerebral palsy, mental retardation and multiple disabilities. On the other hand, in practice, informal care refers to the assistance given by significant others (family or kin) at personal level in homes (Chen, & Lu, 2001). There exists a wide spread belief that usually frail elders, hearing impaired, sick and orthopedically handicapped are cared for in formal settings such as, rehabilitation centers, nursing homes, old age homes, community organizations, charity organizations, voluntary organizations, physiotherapy and occupational units (Dooley, Shaffer, Lance & Williamson,2007). However, on the other hand, the vast majority of the needy are cared informally at homes by spouses, adults, other family members, relatives or friends.

Undoubtedly, the informal care is more valuable, satisfying, rewarding and parsimonious than the costly and less loving formal care. Consistent with this reasoning, a plethora of studies indicate that most of the care recipients are reported to be satisfied with the quality of informal care they receive at home (Kasper, Shore & Penninx, 2000). In fact, many investigators claim to have found precisely different results, i.e., the conflicts between care recipients and their care givers (Ellott & Parker, 2007). Furthermore, according to Morrow – Howell, Proctor and Rozario (2001) professional care, providers often perceive informal care as inadequate or lower in quality. Indeed, conflicts and differences in perception of the quality of care among care recipients and their caregivers, often breed when care recipients feel disrespected (Clarke & Stephens, 1996), less competent (Martire, Stephens, Druley and Wojno, 2002) or more emotionally or physically strained and when caregivers feel care recipients' behavior as problematic, less respectful and more demanding. Fundamental attribution biases are well suited for such an explanation. Generally, people tend to focus on dispositions rather than situations when explaining other conduct or behaviour (Zuckerman,1979).

With this canvas of background it can be argued that care recipients and caregivers may differ in their perception of exemplary care (sufficient in a quantitative and qualitative sense, extending beyond the bonds of meeting basic needs). In a number of cases care giving can create strain and stress among caregivers which in-sequel may generate and perpetuate negative emotional feelings (Connell, Janevic & Gallant, 2001), feelings of subjective burden and reduction in problem solving ability. The aforesaid speculations are infrequently tested in previous studies.

Hence, special interest of the current study was to investigate the perception of exemplary care, subjective burden, emotional reactions and perception of problem solving ability among caregivers and care recipients. In view of the existing information it was presumed that caregivers and care recipients would differ on all the measures.

METHOD

Sample

The study included a total sample of 100 participants. Out of these 25 hearing impaired, 25 orthopedically handicapped (due to accidents) and 50 care givers of both the groups. The subjects in hearing impaired category were taken from District Rehabilitation Centre, Bhiwani on the basis of recommendation of audiologist, who were using hearing aids for more than one year. Their age range was 50-70 years. The subjects in the category of orthopedically handicapped were taken from physiotherapy unit of Ch. Bansi Lal General Hospital, Bhiwani. Their age range was from 20-45 years. The care givers were from their respective families whose age ranged from 25-40 years.

MEASURES

Exemplary Care Scale

The perception of exemplary care was assessed by using 11 items scale (Dooley, Shaffer, Lance & Williamson, 2007). Frequency of each item was assessed on a 4 point scale (1=never , 2=sometimes, 3=often, 4=always). Higher scores indicate exemplary care. Authors have reported adequate reliability and validity of the measure.

Emotional Reaction Measure

Negative affects which were used in the study are comprised of five items (e.g., Hostility, Irritability, Jittery, Scared and Upset). These were taken from Positive and Negative Affect Schedule by Watson and Clark (1991). This scale has respectable reliability and validity as reported by the authors. Responses were rated on a five point Likert- type scale anchoring the feelings of very slightly (1) to extremely (5). Higher scores indicate the high degree of emotional feelings.

Subjetive Burden Measure

The item was prepared for the purpose by the researcher, "How much do you perceive him (care recipient) as burden on you ?/ Do you (care recipient) feel burden on the care giver? "Responses were taken on Likert-type five point scale anchoring no burden (O) to heavy burden (4). Higher scores mean more burden.

Perception of Problem Solving Measure

The individual's perception of his problem solving ability was ascertained by single item measure "When I face a problem with regard to care giving/care receiving, I try to see it as a challenge or opportunity to solve the problem in some positive way". The item was selected from the Problem Solving Inventory by Heppner, 1988. Responses were taken on a five point scale anchored by strongly agree (5) to strongly disagree (1). Higher scores indicate better perception of problem solving ability.

PROCEDURE

First of all informal consent was obtained and information about demographic characteristics were collected from care givers and care recipients. Participants were ensured about anonymity and also encouraged for frank and true responses. They were further administered all the measures. The administration was done individually and orally with the trained assistant staff for recording the responses. The assessment was conducted at District Rehabilitation Centre and Ch. Bansi Lal General Hospital, Bhiwani. After completing all the measures participants were given warm thanks.

RESULTS AND DISCUSSION

The obtained scores on the measures were subjected to statistical analysis by using t-test. The t-ratio, however, could not attain the significance level for the perception of problem solving ability due to appraisal of care givers and care recipients ($p>.05$). The reason for this may be that perception of problem solving ability depends upon the internal or external resources of the person such as personal mastery, coping mechanisms, physical health, social support, income level, educational level, etc. Both the care givers and care receivers perceive their situation beyond their control. Thus, both have similar perception that resulted in the non-significance of the differences.

Table 1
Showing Means, Standard Deviations and t-values for caregivers and care recipients on various measures

Variables	*Care givers*		*Care recipients*		*t-values*	*Sig. level*
	Mean	*SD*	*Mean*	*SD*		
Problem Solving Ability	1.98	1.38	1.85	1.37	0.40	ns.
Appraisal of Care	30.15	9.11	25.92	10.05	1.98	P<.05
Perception of Subjective Burden	2.63	1.21	1.90	1.43	5.75	P<.01
Emotional Reactions						
(a) Hostility	3.48	1.21	2.63	1.38	2.93	P<.01
(b) Irritability	3.60	1.07	3.15	1.3	1.67	P<.05
(c) Jittery	3.65	1.04	3.00	1.52	2.24	P<.05
(d) Scared	3.63	1.24	3.10	1.37	1.78	P<.05
(e) Upset	3.60	1.07	3.00	1.41	2.07	P<.05

The analysis indicated significant differences for appraisal of exemplary care ($p<.05$), perception of subjective burden ($p<.01$) and on five items of emotional reactions, viz., hostility ($p<.05$), irritability ($p<.01$), jittery ($p<.05$), scared ($p<.05$) and upset ($p<.05$). It was observed that care givers supplied higher ratings for all these measures than the care recipients.

The tentative explanation for the obtained findings may be that care givers and care recipients have common complaints against each other, e.g., care recipients consider that care givers do not have enough time for them. Moreover, they neither use simple language and nor do they have respects for their feelings, wishes and opinions. On the other hand care givers complain that care receivers tend to ignore the instructions and do not take into consideration their familial and the other social responsibilities into account. Further care recipients also do not adopt changes in their life style which is the requirement of their prevailing physical disability. These complaints might have led the differences in their perception of care.

In case of emotional reactions and subjective burden the logical interpretation may be advanced in the sense that care recipients usually show more problem behaviour that accompanies dementia (e.g. agitation, suspicious thoughts) and they are less likely to exhibit a great deal of respect for the limitations, wishes, opinions and circumstances of the care givers.

This explanation finds ample support from findings of Dooley, Shaffer, Lance and Williamson, 2007. Therefore, care givers showed intense emotions as compared to care recipients. Care givers face many strains and stresses in the course of caring the disabled that would appraise as threatening to their coping resources. It has been generally observed that in realistic sense disability of a person affects the entire family and sometime family members are compelled to give up their professional careers. Moreover, care receiver's physical functioning, feelings of depression, pessimism and hopelessness instill the feelings of burden among care givers more than the care receivers. The present finding also corroborates with the earlier study by Harwood, Ownby, Burnett, Barker and Duara (2000) who have observed that lower care receivers physical functioning is the predictor of greater care giver's burden. Nevertheless, the results of the study suggest both the care givers and care receiver differ in their perception of care, subjective burden, emotional reactions and also it would be worthwhile to explore the underlying situational determinants rather than dispositional ones.

Implications

Present finding suggest that interventions focusing on disabled can be helpful for care givers. The major implication of the study is for those working with care recipients who display cognitive, neurological or other serious impairment. It may also help them to view these problems they feel through a situational lens rather than dispositional characteristics which may prevent care givers to blame the care recipients for such problems there by reducing their resentment, promoting the understanding and sensitivity that create higher quality care. The second intervention may be focused on ameliorating care givers appraisal of burden and negative emotions.

Limitations

The study is not free from limitations. The sample of the present study cannot be said to be representative of the population of care givers and care receivers as a whole. A large survey could insure a fuller more representative sample, which could make generalizability to the population as a whole safer in the Indian context.

Suggestions

Since, the study was concerned with the appraisal of care by care givers 'and receivers' experiences, future investigation should address the issue of reliability and validity of the measures by using more sophisticated and rigorous testing tools. Independent observational assessment would also be desirable. Future research should also assess the degree to which multiple care givers are involved in care giving. Since the study was a cross sectional one future investigation should involve longitudinal design or a long term programme. Future studies should also include other care receivers and care givers.

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Review of Practices in the Management of Attention Deficit/ Hyperactivity Disorder (ADHD)

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Abstract

Comparative treatment studies of attention deficit hyperactivity disorder are impeded by the paradigm perspectives, methodological quandaries, constricted and restricted focus, heterogeneity of children with ADHD, research design limitations or preferences, and treatment responsiveness. Comparisons are drawn among the five major treatment modalities for ADHD: stimulant treatments, primarily methylphenidate; behavioral treatment, including skill training, contingency management and parent training; cognitive behavioral or self regulation therapies; alternative therapies, such as yoga, music therapies, diet control, etc.; and the multimodal approach for the treatment of ADHD. The paper finally suggests more longitudinal research in the area of multimodal and other non-medical intervention methods (non-pharmaceutical-company sponsored area) to enhance their time and cost efficiency and to reduce their technicality and cumbersomeness.

Viewing the last decade, the detected prevalence of attention deficit/ hyperactivity disorder (ADHD) has increased and pharmacological methods of treatment have led the disorder to be a topic of media interest and controversy (Parr, Ward & Inman, 2003). ADHD affects 2% to 9% in school age children and 3% to 5% in adults (Biederman, 2005; Jindal, 2002). Although ADHD is one of the most frequently diagnosed and studied clinical disorders in child psychology (Barkley, 2006), very little is known about the efficacy of treatment for children and adolescents with this disorder (Olfson, Gameroff, Marcus & Jenson, 2003; Smith, Waschbusch,

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Willoughby and Evans, 2000; Trout, Lienemann, Reid & Epstein, 2007).

Investigation on the documented research reveals that the most widely studied, implemented and reported treatment for children and adolescents with ADHD continues to be **stimulant treatment** (ST), primarily methylphenidate (Ritalin) (Evans, Axelrod & Langberg, 2004). The vast majority of children diagnosed ADHD receive a course of medication that usually continues at least for several months and often throughout the school-age years (Chaddha, 2002). In a survey of primary care physicians, Wolraich et al. (1990) found that 88% of children considered hyperactive had received methylphenidate. Murray and Patel (2001) found that stimulant medications remain the mainstay of treatment in India and are highly effective in more than 75% of patients. According to Du Paul and Stoner (2003) approximately 1.5 million US children with ADHD are treated with psychostimulant medication. A survey study indicated that 4.3% of children (ages 4 to 17) took medications for ADHD in 2003; which was about 56% of the children who had a history of ADHD diagnosis (CDCP, 2005). In the year 2005, (Castle et al., 2007) 4.4% of children received one or more prescriptions and it was more common among older children (ages 10 to 19) than younger children (ages 0 to 9) and boys were 2.3 time more likely to use these medications than girls. Older boys (ages 10 to 19) showed the highest prevalence of use; 8.1% of in this range used ADHD medications during 2005. Improvement in the core symptoms of inattention, impulsivity, and hyperactivity are most noticeable as a result of stimulant treatment (Gorman et al., 2006).

Although **psycho-stimulant medication** has been widely used for many years, findings have suggested that as the sole treatment for ADHD, it is an inadequate form of intervention. Problems surrounding the use of high doses include adverse physiologic, cognitive, and social effects (Rhodes, Coghill & Matthews, 2006; Swanson & Kinsbourne, 1979; Trout, Lienemann, Reid & Epstein, 2007 and Volkow et al. 2001). The issue of community concern relating to the escalating use of stimulants in the management of ADHD symptoms, treatment acceptability, side effects, potential long term effects, danger and drug abuse dependency, and consumer and parental preference of non-pharmacological treatment, compels researchers to explore other treatment options. These limitations of psycho stimulant medication have led to the interest in **other therapies** in the treatment of ADHD. According to Rice and Richmond (1997), the most promising interventions are those that work with the whole family system and use medication in association with non-medical intervention. Non-medical interventions with ADHD include a variety of cognitive therapies, behavioral treatment procedures/techniques as well as complementary and alternative treatments such as dietary regulation/ modification, biofeedback, relaxation and meditation (Rhodes, Coghill & Matthews, 2006).

Behavioral treatment (BT), especially classroom contingency management and parent training, is the other major modality used with hyperactive children. A **wide range of behavioral approaches** are used to treat both the core problems (i.e., inattention, impulsivity and hyperactivity) and associated problems (i.e., aggression, academic underachievement, poor peer interaction) of children suffering from ADHD. As suggested by Gupta (2002) child with ADHD often required alternative educational and parenting methods. A behavior "management" approach in the management of ADHD children connotes the ability to plan ahead and prevent the need for responsive discipline. Behavior management is a framework within which specific techniques are employed to establish and maintain structure and consistency in the home and school environment. Thus the foundational concepts of behavior management are structure, routine, consistency, communication, clarity, and constructive consequences (Gupta, 2002).

Motor excess behaviors have been clearly linked to externalizing disorders, which are often comorbid with ADHD (Achenback & Edelbrock, 1978; Hinshaw, 1987). Tryon et al. (2006) reported the preliminary results of a study, using a device that combines a modern beeper and actigraphy technology for the purpose of measuring, monitoring and modifying motor excess in children with confirmed diagnosis of ADHD. Durston et al. (2007) observed that disruptive motor behaviors in children with ADHD were chiefly related to an impaired ability to predict temporal and contextual cues in the environment, thus the ability to alter motor behaviors according to the social demands is hindered. Although, Azrin, Ehle and Beaumont (2006) observed that motor behaviors can be reduced significantly if physical exercise is used as a reference to promote calmness.

Schulman, Suran, Stevens and Kupst (1979) demonstrated that classroom activity level can be reduced in hyperactive boys using activity feedback and positive reinforcement. In Taiwan, Li, Lin, Chang and Hung (2004) explored the temporal mechanism of attention deficit in children with ADHD and concluded that a training to control blinking (magnitude and time incidents) and thus closing gates of attention can reduce the various academic and attention related impairments in children with ADHD.

Data suggest that while behavioral therapy can reduce one of the main symptoms of ADHD-impulsivity (Kendall & Braswell, 1993) noted that it has not been successful in treating other symptoms of ADHD. Treatment outcomes are, at best, inconsistent. After a decade of careful investigation, behavioral therapies have not been shown to be helpful, either alone or as an enhancer of the effects of medication (MTA, 1999).

Cognitive–behavioral treatments (CBT) were launched as therapists started giving lesser importance to behavior therapies and started looking for something more than simply studying behaviors but lesser than the study of influence of unconscious mind. Young (2002) and Young, Brahmam, Gray and Rose (2007) found CBT a very useful intervention technique for young adolescents and adults with ADHD. CBT yielded significant improvement when given with as well as without medication to adolescents and adults with ADHD. Moore, Du Paul and White (2006) implemented self-management-procedures in school setting with students with ADHD in secondary school and found consistent results across the participants in enhancing attention span, better classroom behavior and improved academic performance.

At present, CBT is neither as pervasive nor as scientifically justified as either stimulant or behavioral treatments for ADHD in children (Stein, Zinter & Jensen, 2006). CBT approaches have, however, produced solid and growing enthusiasm for their use as adjuncts or even alternatives to more traditional pharmacologic and behavioral strategies (Whalen & Henker, 1991; and Dunn, Dalgleish, Lawrence & Ogilvie, 2007).

Slaich (2002) describes the role of **Occupational Therapy** in the treatment of ADHD. Attention span can be increased by vision therapy – which includes skills such as visual tracking, fixation, focus change, binocular fusion and visualization. Bole (2002) explains the use of **sensory integration** to overcome the learning problems of children. Numerous studies have reviewed the etiology of ADHD in parents and have tried to work out with **parent counseling and parent training**. It was observed that the children with ADHD tend to remain ADHD despite regular treatment (medicinal, therapeutic or both), partially because of the parental inefficiency on executive functions and inconsistency in their approach toward the management of behavior of children (Nigg et al., 2004).

Family therapy was found effective specially when parents were given 16 – 20 one hour sessions in three months of time duration with a focus to deal with the problem behaviors of children (Barkley, 2003). Madigan et al. (2007) suggested that unresolved maternal attachment representations, disrupted maternal behavior and disorganized attachment in infancy is linked to behavior problems in children.

Hook et al. (1999) examined if **parent tutoring** for reading problems is helpful for children with ADHD and pointed out that certain interventions may not be possible for parents to implement easily with children with behavior problems as the processes are cumbersome and too technical for parents to learn and implement.

Studies provided empirical evidence that childhood hyperactivity is a risk factor for psychosocial maladjustment in adolescence. Studies that have followed ADHD children for 4–14 years have reported a major risk for subsequent aggressive, antisocial and delinquent behaviors (Gerdes & Hoza, 2006). Treatment programmes have been developed to improve **social skills** of children with ADHD experiencing peer relationship difficulties; however often treatment gains are often small and infrequently generalize to naturalistic settings (Pelham et al., 1988). A study by Du Paul et al., 1998 describes the use of a **peer tutoring** program may be an important addition to other treatments for ADHD.

Arnold's (2001) review of alternative approaches to the management of ADHD noted that **meditation and yoga** was one of a number of promising strategies and warranted further systematic assessment. Reviews tend to present meditation and relaxation training methods conjointly (Canter, 2003; Chaan, 2002). According to results of the study undertaken by Harrison, Manocha and Rubia (2004); where parents and children took part in six-week program of twice a week, clinical sessions and regular meditation at home; there were significant improvements in children's ADHD behavior, self esteem and relationship quality.

Several other researchers studied the **combination of approaches and intervention** strategies. Strong believers in stimulants for ADHD Murray and Patel (2001) also advocated that a number of behavioral and psychosocial interventions can be used effectively as part of multimodal approach to address many ADHD & related problems. Reports suggest that a **multimodal treatment approach** is preferable to address many symptoms of ADHD and its associated problems for the children, the family, and the school.

Swanson (1992), views that the intervention is based primarily on two issues: to rely on medication for the children with ADHD and second is not to consider ADHD as a handicapping condition. The school based, multimodal intervention model described by him, has four components: a classroom behavior modification program; a small group training program; a medication assessment program and a parent training program

University of California, Irvine, Child Development Center, developed a **para professional model** program for the Irvine Unified School District (IUSD) to implement ADHD interventions on a school vide basis (Swanson, 1992). Based on experience in IUSD, the assignment of an extra aide to work with the targeted student with ADHD (as well as other students in the class room) was found to be a very cost efficient way of delivering effective educational intervention for students with ADHD who require extra help in the school setting (Swanson, 1992).

Multimodal treatment is a critical part of treatment for ADHD in children and adolescents. According to Du Paul and Stoner (2003) the scientific literature, the National Institute of Mental Health, US, and many professional organizations agree that behaviorally oriented psychosocial treatments — also called behavior therapy or behavior modification — and stimulant medication have a solid base of scientific evidence demonstrating their effectiveness. Treating children with ADHD often involves medical, educational and behavioral interventions. This comprehensive approach to treatment is called "multimodal" and consists of parent and child education about diagnosis and treatment, specific behavior management techniques, stimulant medication, and appropriate school programming and supports. The severity and type of ADHD may be factors in deciding which components are necessary. Treatment should be tailored to the unique needs of each child and family (Bramble & Cosgrove, 2002; Gerdes & Hoza, 2006).

The MTA results published in December 1999 (MTA, 1999) indicated that long-term combination treatments as well as medication-management alone are both significantly superior to intensive behavioral treatments and routine community treatments in reducing symptoms of ADHD. The MTA results also show that these differential benefits extend as long as 14 months. In other areas of functioning (specifically anxiety symptoms, academic performance, oppositionality, parent-child relations, and social skills), the combined treatment approach was consistently superior to routine community care, whereas the single treatments (medication only or behavioral treatment only) were not. In addition to the advantages provided by the combined treatment for several outcomes, this form of treatment allowed children to be successfully treated over the course of the study with somewhat lower doses of medication, compared to the medication only group. The study's overall results appear to be applicable and generalizable to a wide range of children and families in need of treatment services for ADHD.

The need for integrating treatment outcome research and **school-based mental health model** was pointed out in a review article by Rones and Hoagwood, 2000. They also noted that those school-based treatment programs that have been studied have focused primarily on youth in the primary grades (K-2) or youth diagnosed with mood disorders in high school. Treatment programs for youth in middle school with disruptive behavior disorders have not been reported (Rones & Hoagwood, 2000) or have produced minimal effects (Dupper & Krishef, 1993). School-based mental health models are specially suited to children with ADHD because of the levels of school dysfunction they exhibit. In addition there are many advantages believed to be inherent in this model of care related to effectiveness and generalization (Evan, 1999).

The Summer Treatment Program (STP) (Pelham & Hoza, 1996) is a multimodal treatment program, with in the school based mental health model, for children with ADHD. The STP operates as a summer camp for children with ADHD that provides intensive behavioral and pharmacological interventions. Research on the efficacy of a variety of interventions including medication, behavioral interventions, and educational interventions have come out of this program.

Evans, Axelrod and Langberg (2004), selected a school-based model to improve access to services. In the study, the effects of a set of behavioral and educational interventions provided in a middle-school based mental health program on the behavior and academic performance of seven students diagnosed with ADHD were studied. The treatments included educational, social skills and family interventions designed to target school functioning, peer relations, and family functioning. Large effect were found on measures of inattention and school functioning. Grades and measures of family functioning and peer relations yielded small to moderate effect.

Evans (1999) has reported that youth and their parents experience fewer and different obstacles to care when engaging in school-based services as opposed to clinic-based care. For example, many transportation and fiscal obstacles are encountered less frequently in school-based care than clinic-based care. On the other hand, there is a perception reported by some parents that the quality of care and adherence to standards of confidentiality are lower in a school than in a clinic (Evans, 1999). Given the pervasiveness and persistence of hyperactive behavior disorders, major amounts of public, professional, and scientific attention have been devoted to their treatment. For some years, the call has been out for definitive comparisons pitting pharmacologic against psychosocial therapies in order to identify the single superior approach or the optimal combination of treatment ingredients for the hyperactive child (Barkley, 2006). When the research done in this area is reviewed, some of the questions seem to be untenable and untestable and in fact divert energy from the fundamental issues of concern both to the clinical investigator and the practitioner. Certain methodological hurdles encountered in child therapy outcome studies can also be questioned. There are critical dimensions of therapeutic process and outcomes too as many of them are elusive or intangible, and must be considered in treatment evaluations. There is empirical literature to provide tentative comparisons of the modalities across these dimensions, concluding with a look at the implications of both the similarities and the differences that emerge (Whalen and Henker, 1991).

In **summary**, the tentative conclusion concerning applicability is that behavioral strategies, as typically used, are appropriate at the youngest ages but also tend to be the narrowest. Stimulant therapies have demonstrated efficacy in a refreshingly wide range of domains during childhood and may also be beneficial for adolescents and adults. However, ST has not yet proved sufficiently effective in some of the most problematic arenas (Reittman et al., 2001), notably academic achievement and peer status. Cognitive–behavioral modes also promise a broad horizontal range (Safreu et al., 2005; Spargue & Sleator, 1977) and, although they do not fit younger children, they are readily applicable to and even through adulthood. Unfortunately, they boast the poorest track record to date.

Cognitive therapies often create greater demands on the target children than on their significant others, requiring not only that they participate in and contribute to training sessions but also that they apply the tactics learned across settings and activities (Harborne, Wolpert & Clare, 2004). When one considers the fact that several BT components are often combined with CBT in the treatment of ADHD, the labor-intensiveness of these approaches becomes even more apparent. Stimulant treatment may be viewed as the least burdensome, requiring only that the child ingest a pill from one to three times a day. Even here, however, there are feasibility issues that require consideration. As with any other medication taken by children, parents need to manage regular visits to physician and pharmacist, ensure daily administration, and monitor side effects as well as behavior change. Moreover, given the abuse potential and street value of stimulant drugs, safeguards must be established, and stimulants may be contraindicated when siblings or parents have substance use disorders (Whalen and Henker, 1991). ST is clearly the most potentially stigmatizing treatment for hyperactive children. Most ADHD children dislike taking pills for academic or behavioral reasons and try to conceal the fact that they take medication (Sciutto & Eisenberg, 2007). Self esteem is often affected badly by the stimulants (Frankell, Cantwell, Myatt & Feinberg, 1999).

School based BT is easy in administration and is preferred, as there are trained professionals in the school, taking care of child's attention span, impulsivity and hyperactivity, taking care of child's academic achievement and peer/social relationships. Going to a psychiatrist is still a taboo (specially in India) and there is always a risk that any information about visiting a psychiatrist will further stigmatize a child and family already devalued and rejected by the peers, family friends and relatives (Humphrey, Storch & Gettken, 2007). School-based therapy where the child has to go to training room/resource room in this case was observed to be less stigmatizing provided the child is not supposed to be labeled as different or deviant or special needs student. Children with ADHD experience a double disadvantage, in the first place because of the nature of their problem and second because of exclusion from their peer group (Hennessey, Swords & Heary, 2008). Departures from the classroom for special sessions or in situ rehearsals of self-talk strategies should not be such unusual events that they spotlight the child as different from his classmates (National Institute of Health, 2000).

Conclusion

Despite the impressive track record established by stimulant therapies over the past two decades, this treatment has serious limitations. Not all children can be given these medications, nor do all who take them improve. As observed by Rhodes, Coghill and Matthews (2006), in the majority who appear to benefit, the changes may be short-lived or may persist only as long as the drug regimen continues. It is also quite common to observe positive changes in only a subset of the major problem domains. Moreover, physiological side effects may arise with stimulant treatment, and there are underlying concerns about chemical coping. For example in a study in UK (Rhodes, Coghill and Matthews, 2006), apart for positive effects such as enhanced performance on non-executive functioning, methylphenidate was also observed to slow down the response ability on relatively complex spatial recognition memory tasks.

It is not always evident that non-pharmacological alternatives come with a similar set of constraints, including dysfunctional messages, ethical dilemmas, and the problems of ineffectiveness with some children or some problem domains and circumscribed or short-term impact with others. The juxtaposition of successes and limitations that characterizes all therapeutic modalities for ADHD would seem to mandate further exploration of multimodal approaches. As a lifetime rather than an acute disorder, ADHD has a salient impact on key members of the child's social network, a network that, in turn, plays a pivotal role in shaping all future outcomes. The non-pharmacological treatments considered here teach problem-solving and coping skills not only to children with ADHD but also to those who interact with the children on a regular basis. Psychosocial approaches treat ADHD in its interpersonal context, recruiting the child's family and caretakers as partners and equipping the team with resources and skills for managing a challenging and persistent disorder. The profusion of problems called ADHD provides multiple avenues for efficacious action and a rich arena for testing therapeutic approaches and informing theories of developmental psychopathology.

Although much progress has been made in our understanding of the diagnosis and treatment of ADHD, much has yet to be researched for children and particularly for adolescents and adults. It is clear that the current diagnostic criteria, although valid for children, may need to be modified for adolescents and adults, to reflect the developmental changes that take place as children approach adulthood. How the subtypes change in the transition from childhood to adolescence and how the patterns of comorbidities change need to be identified more clearly. The recent pressure and incentives that the government has placed on the pharmaceutical industry have increased the number of pharmaceutical company-sponsored studies among adolescents. However, additional studies are required to clarify how and what non-medical interventions, unimodal or multimodal can be helpful for children and adults with ADHD along with their family members and caretakers including teachers. Better research is needed to examine the efficacy of non-medical treatment modalities in various settings and across the different age groups. Research is also needed to determine the long-term efficacy and cost efficiency of multimodal and other modalities of treatment, specially, BT, CBT and skill training procedures. Researchers must see that the non-medical interventions do not become too cumbersome, technical, time consuming and expensive for the family of children and adults with ADHD. Lastly, longitudinal studies examining the outcomes for adolescents and adults are required to identify more clearly the course of the disorder and the impact of treatment.

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Role of Social Workers in Community Based Rehabilitation (CBR) Services for the Disabled in India

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ABSTRACT

In this article an attempt has been made to holistically understand the concept of Community Based Rehabilitation (CBR) in the context of a developing country like India. It also strives to elaborate upon the basic features of CBR as evolved by the World Health Organization. It also sheds light on the process of implementation of CBR in the Indian context, and presents a critique of the same. Based on an examination of these components, the authors have made a case, thereby highlighting the need for involvement of professional social workers in the successful implementation of the CBR programme using Community organization and methods of Social Work. The participation of the community is vital since the programme involves the disabled, their families and community of which they are an integral part.

The emerging global scenario has seen a splurge in opportunities for the disabled worldwide out of which one of the important initiatives has been Community Based Rehabilitation (CBR) services for the disabled. The services have not only enabled in reaching out of various services to the disabled at the grass roots level, but also empowered them in the process. Rehabilitation of the disabled requires the professionals from all quarters, i.e., doctors, psychiatrists, physiotherapists, speech therapists, occupational therapists and social workers. Although the inputs from all the team members are of equal significance, yet, it is the professional social worker who needs to be more actively involved from the inception of rehabilitation services till the disabled themselves along with their family and community are ready to become active partners in the process of rehabilitation. It is

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the social worker, who ensures that suitable networking strategies are evolved with all professionals associated with rehabilitation process and also optimal utilization of resources is made use of by the disabled. Professional social workers are considered as instrumental in bringing the desired changes. They draw on an extensive knowledge base in order to meet the challenges of the work. The social worker is a link between various services, rehabilitation professionals and beneficiaries as the profession is concerned with influencing people and achieving desired changes with the help of specialized skills and use of appropriate values.

Understanding Community Based Rehabilitation

Community Based Rehabilitation (CBR) is one of the most effective alternative approaches for the comprehensive rehabilitation of persons with disabilities. However, as a concept it varies from place to place, depending on the setting. Unlike institution based approaches, there is no universal model of CBR which is applicable everywhere. Each programme of CBR has to evolve its own strategies and methods appropriate to the context in which it is based. Currently there are three main meanings attached to the notion of CBR. These are:

1. ***People Taking Care of Themselves:*** This is the 'real' CBR in which all the activities are undertaken by the disabled people, their family members and other community members for their own community of disabled persons. This includes general care, accommodating each others' needs, etc.
2. ***CBR as a Concept and an Ideology:*** CBR as a concept and an ideology promotes a decentralized approach to rehabilitation service-delivery, whereby it is assumed that the community members are willing and are able to mobilize local resources and provide appropriate services to the disabled persons.
3. ***Programmes, Projects, Organizations (mostly NGOs):*** Recognizing the human and material limitations of the disabled persons, their family members and other community members, a CBR programme tries to promote and facilitate rehabilitation by reaching out to the disabled persons and their families in their homes, and providing appropriate information and services to them.

The concept of CBR enlarges the concept of rehabilitation to include all of the services that exist for the disabled persons to develop their abilities.

The concept of CBR has also been given due importance in ICEVI-Asia Region Conferences held in Jakarta (1981), Ahmedabad (1995) and

New Delhi (2005). The Biwako Framework which aims to achieve an inclusive, barrier-free and right based society for the disabled in the new decade (2003-2012) has also emphasized on promoting the concept of community based rehabilitation involving the beneficiaries. The strategy desires that the governments, in collaboration with organizations of the disabled and civil society organizations should immediately develop national policies (if that has not yet been done) to promote community based approaches for the prevention of disability as also for rehabilitation and the empowerment of the disabled persons. Moreover, the CBR perspective should reflect a human rights approach and should be modeled on the independent living concept.

Basic features of CBR as evolved by the World Health Organisation

The WHO report suggested four basic features of CBR that are crucial and are needed to be addressed for the successful implementation of CBR programmes. These include:

1. ***Service delivery system:*** This system incorporates the way in which training or services are being provided by the CBR worker to the disabled person at the community level.
2. ***Technology transfer:*** This includes the technical skills that the local supervisor should possess in order to implement the programme.
3. ***Community involvement:*** This is one of the main ingredients in the implementation of CBR programme and it emphasizes that the training of the disabled persons should not only be the concern of the family trainer and CBR worker but also of the community in which the person lives.
4. ***Organization and management:*** People being the most essential component of any community based rehabilitation, the organization and management components play a significant role in ensuring an effective CBR programme. Management exists both on the horizontal level (local supervisor, family trainer, disabled person, community), and on the vertical level (referral structures from the town, province, district, national and international levels).

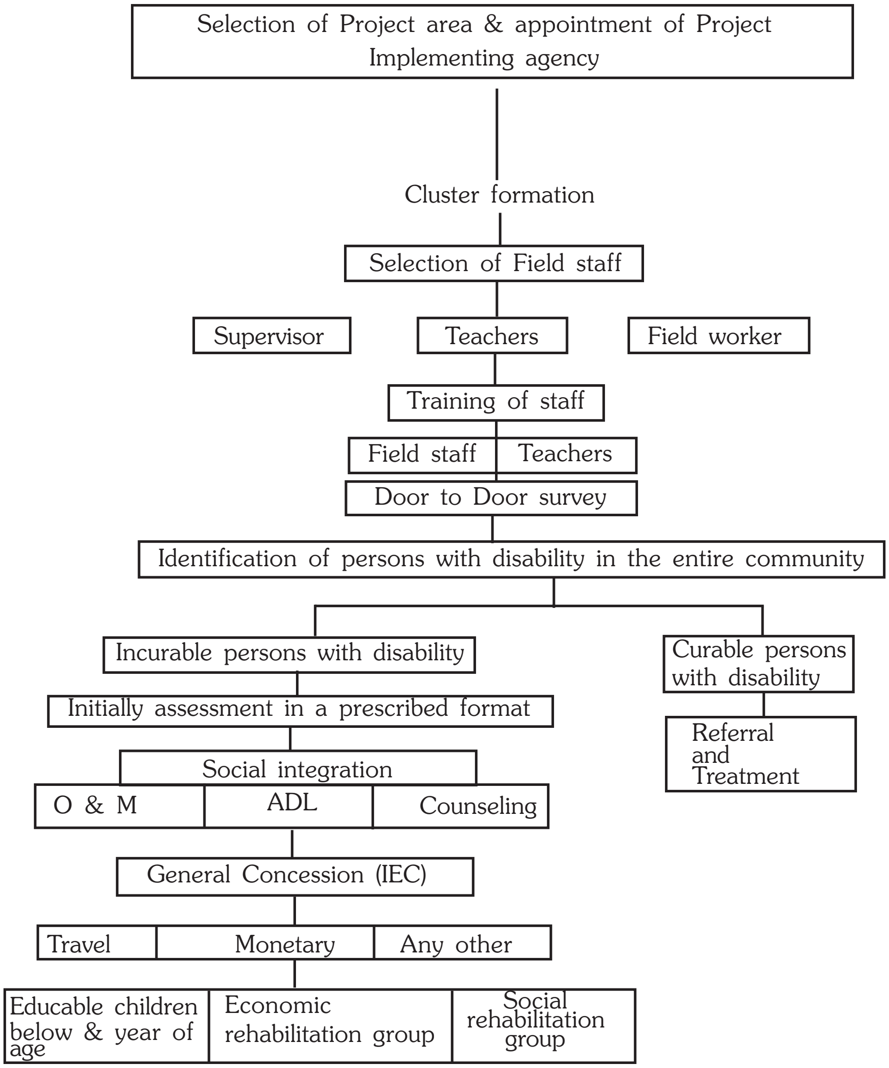
Implementation of Community Based Rehabilitation in India

In India, the CBR implementation process is a decentralized system functioning at the local level wherein the Project Implementing Agency is solely responsible for the effective implementation of the project, monitoring of the progress and handling accounts of the project. Here, the Project

Implementing Agency is completely independent to incorporate regional modifications and administer the project. To act as a guideline for these agencies, a standard CBR Process Chart has been evolved. This may however be modified depending upon the project specific like geographical terrain, socio-economic conditions of the project area, nature of the Project Implementing Agency, extent of availability of different services and such other factors (Chart I).

Chart I

CBR Process



As can be seen from the above, the most important stages in the CBR Process Chart include appointment of an appropriate agency, followed by the selection and training of field staff. A survey of the curable and incurable categories of people with disabilities is undertaken to chart out specific intervention plans for both the district categories. This is followed by taking all the necessary measures for mainstreaming those who are in the incurable category and taking all suitable measures needed for early intervention for the curable category of PWDs. This is followed by the active involvement of community. The management exists both at horizontal and vertical pooling in networking at all levels and making optimum use of available resources.

Implementation of Community Based Rehabilitation in India: A Critique

As is evident from the earlier section, Community Based Rehabilitation programmes are designed to be undertaken in the community on the setting in which the clientele group belong to or reside. It is unfortunate that in India these initiatives are being undertaken at the local level by non-professionals, or those who have almost no training and or are semi-trained.

Working with communities is a specialized task which requires planned and systematic work. For these professionals possessing a requisite knowledge and skill base to work with individuals, groups and the community as a whole are indispensable.

The experience of Community based Rehabilitation in India has shown that although the Government has embraced the programme, it has failed to recognize and acquire the 'Professionalism' needed for planning, implementing and evaluating the same effectively.

Presented below is a brief critique of the implementation of the Community Based Rehabilitation programmes in the Indian context:

1. The very thought with which the WHO recommended the programme and assumed that it is a part of 'Health for All' campaign and can be managed by non-professionals with limited training did not seem to be an appropriate proposition.
2. The medical professionals have dominated the scene of CBR owing to the significant role being played by them in prevention/ restoration (Joint Paper by ILO, UNESCO and WHO, 1994). This dominance has hindered the participation of the disabled persons in the entire process and it has turned out to be a service delivery mechanism by the so called 'experts' in the field of rehabilitation.

3. As no two communities are the same, a standardized model cannot be adopted for all communities. CBR is not only culture specific, it depends on the nature/extent of prevalence of specific disabilities as also the existing availability of support services for the mainstreaming of the disabled.
4. The less than adequate and late payment of remuneration to professionals has also acted as a leading hindrance to the spread of CBR. The highly educated and skilled workers do not prefer to go and work in communities, especially rural communities. Front line CBR work is a low profile job which fails to provide good social and economic status.
5. The CBR programmes have also been questioned on the ground of their cost effectiveness. Community Based Rehabilitation should ideally provide services for a larger number of people than is possible in an institutional setting. However, CBR has often failed to do so, mainly owing to inappropriate provisions by the funding organizations.
6. The organization and management of good CBR programmes is complex and difficult in countries where people often have no tradition of formal management and handling of funds.
7. Little quality research on CBR has been placed in the mainstream of scientific research. Only a few reports which mainly comprise of annual reports of international funding organizations are available.
8. Poor living conditions of most people with disabilities are also a contributing factor in their rehabilitation. The objective of individual CBR process therefore has to be very realistic, focusing on overall needs.
9. Majority of the disabled belong to some form of marginalized groups. They compete amongst themselves to avail of the provisions granted to everyone. The advantage given to one group is often viewed by the other as its loss. As a result many CBR practitioners in developing countries debate if it is worth spending their efforts to gain rights for the disabled persons rather than providing rehabilitation services which are non-existent.
10. Community participation has been emphasized as an important element in the CBR programme since the 1960s and early 1970s. It has been observed over a period of more than three decades that participation of community in general and the disabled in

particular has been limited to participation as beneficiaries' delivery rather than participation in design and management of services.

Need for Professional Social Worker in CBR

It has been recognized in the foregoing discussion that community involvement is a vital ingredient in the implementation of a CBR programme. It is not only the participation of the disabled which is important but the participation of the community is equally important as it is the community which needs to be prepared for the inclusion of the disabled persons in community processes. These initiatives if appropriately designed and managed can be effective vehicles in the quest for empowerment of the disabled persons.

The aim of the CBR programme is to provide rehabilitative services to the disabled in their home environment rather than trying to create a special environment for them. Thus, it is clear that the CBR programme is carried out in accordance to the needs of the disabled living in the community. It is very essential that the community has to be prepared to embrace the disabled and provide them opportunities for psychosocial and economic rehabilitation in their own setting.

The main emphasis in the CBR programme is on 'Community Organization', which is an important method of social work. Community Organization in context of Social Work implies a process by which the community identifies its needs or objectives, orders (or ranks) these needs or objectives, develops the confidence and will to work at these needs or objectives, finds the resources (internal and/or external) to deal with these needs or objectives, takes action in respect to them and in so doing extends and develops cooperative and collaborative attitudes and practices in the community.

The 'process' in community organization pertains to the conscious or unconscious, voluntary or involuntary movement from identification of a problem or objective to solution of the problem or attaining of the objectives in the community. The task of the professional worker in community organization is to help, initiate, nourish and develop this process. To do this, the worker uses certain methods and follows certain principles. Moreover, while working with the community the social worker is expected to play many roles simultaneously. These have been diagrammatically given in Chart II.

Chart II

Professional Social Worker

EXPERT	ENABLER	PLANNER	ACTIVIST	RESEARCHER	CHANGE AGENT

Professional Social Worker

In the performance of all the aforementioned roles, the professional worker facilitates the community to assume control and ownership of the community project or initiative and empowers the community people to take on further self help programmes based on cooperation and collaborative action.

It is our assertion that a professional social worker, trained in the art of working with communities and possessing the requisite expertise in the realm of rehabilitation and disability management can become the key person in planning and implementation of community based rehabilitation programmes. He will be expected to perform all of the above roles either sequentially or simultaneously, depending on the specific needs and specificities of the setting.

The primary role of the professional social worker in Community Based Rehabilitation is that of a guide who works in the community to achieve its goals. As a guide he has the responsibility of helping the community to choose the direction it wants to move in intelligently, and with due consideration of the many factors which he may be aware of because of his expert knowledge. Usually the prevalence of disability in the community goes unnoticed and unattended. This is either on account of the fact that it is concentrated amongst a few individuals or families or because of the fact that disability is often construed to be a manifestation of adverse fate (*kharab kismet*) or a 'punishment' of God (*Bure karam ka phal*). Therefore, the realization and acknowledgement of the existence of disability as an area of concern about which some action is possible, becomes the first requisite of any CBR initiative. It is here that the professional worker can guide and facilitate people to identify disability and to understand its nature causes and prevalence. He can then proceed to help people to rank disability prevention, management and rehabilitation as a priority area for community action.

The professional worker is also required to conscientise the community to the needs and problems of the disabled and creates the will and determination at the level of the community to respond to these needs and problems in an appropriate manner. In this particular task, the professional worker can take upon himself role of an *expert* who possesses specialized knowledge about the field of disability and rehabilitation and who transfers this knowledge to the community in a systematic and need based manner. His expert role is also called for in the process of identification of the clientele group of disabled persons in their categorization, based on the nature of their disability. Subsequently, a detailed assessment of their specific needs, problems and potentialities needs to be done.

Organizing the PWDs and their families to engage them in the process of rehabilitation is also a crucial role attributed to the professional worker. Here, he takes on the role of an *enabler* who facilities the organization process. He enables by awakening and focusing discontent about the existing situation. His task also entails helping the clientele group to verbalize its discontents. It needs to be mentioned here that, the worker should be skilled in dealing with negative expressions of feeling, which are often the precursors to more positive expressions. He should be able to help the clientele group to understand that many of the problems that they face individually are shared by all members. In other words, the professional worker plays a facilitative role in helping the members to probe their feelings, see the commonality of their feelings and nourish the hope that something can be collectively done about these. As consciousness about the common needs and problems begins to crystallize, the professional worker is expected to function in a way that his efforts support the efforts of the clientele group to come together and to organize, in order to deal with these issues in a more united manner. Another important component of his role has to be directed towards enabling clients to be realistic about their problems, otherwise they are likely to be quickly disappointed with the results.

Dealing with apathy and passivity will be an important challenge faced by professionals attempting to organize the clientele group and the community for Community Based Rehabilitation. Here the professional's skilled and patient approach of working with individuals and groups will be called for.

The professional worker also takes on the role of a *planner* in that he enables the community to plan its action/initiatives. The process will involve skills in identifying sources which can be harnessed for funding or for services to be provided to the disabled. In this context, the professional is expected to create an overall awareness of the various governmental and non-governmental schemes/programmes for the disabled, as also the concessions and other benefits available to them. Apart from this, he also brings the knowledge of the resource agencies providing differential services to the community consciousness. Identification and subsequent involvement of community level volunteers like *dais*, ANMs, PHC workers, anganwadi workers and others can be sought and these persons can be trained to become information repositories for CBR. This is an important role as most often there is a gross ignorance about existing benefits and services both among the disabled persons and their families, as also the community in general.

The planning skills of the professional are further called for when he facilitates the community and/or the clientele group to prepare a project proposal to respond to the priority needs and problems of the disabled in a scientific manner. Mobilization of requisite resources - both indigenous (by way of space, resources, materials and volunteers) and external (specialized services offered by agencies, financial resources, experts, etc.) also require skilled intervention of the professional. However, the sustainability of the programme should be ensured by the community. For this to happen, each component of programme planning must be handled by community, with the professional worker performing the role of a facilitator.

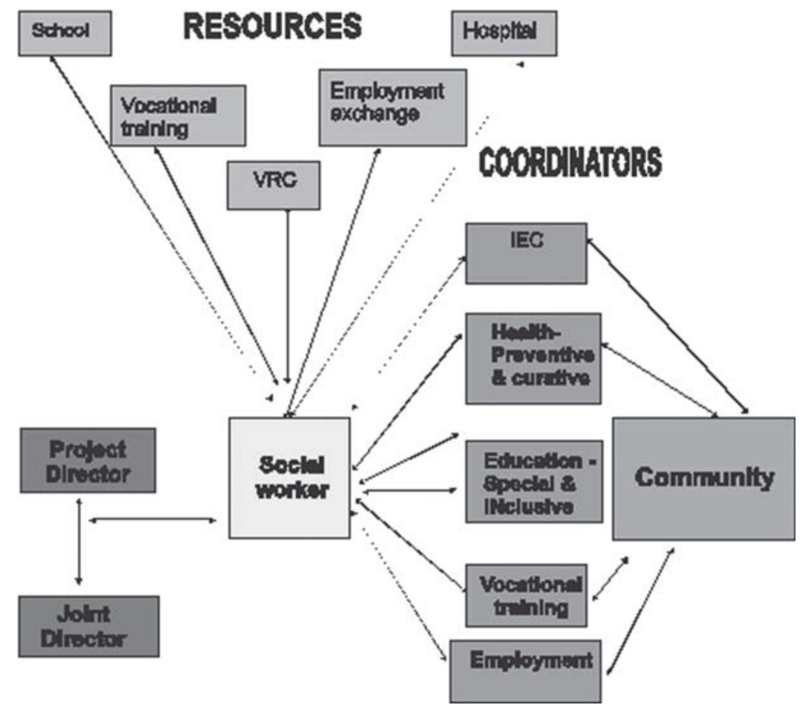
One option that the professional has with him is to plan for the initiation of new services and programmes, but this is not always a very feasible option, either from the perspective of the state/donors or from that of the clientele group. As the focus of any CBR initiative will be on community based and community oriented rehabilitation, efforts need to be directed towards using the existing services first and making them disabled friendly, disabled specific and inclusive. For example, the existing health care agencies could be encouraged to provide specialized health care to the disabled persons, as also design awareness programmes on the prevention of disability, the importance of rehabilitation and other relevant themes. Skill development initiatives being undertaken at the community level could be made accommodative to the needs of the disabled or specific training modules appropriate to the requirements of this special group could be initiated. Promoting integrated or inclusive education for children with disabilities may require special training to the providers of education or else referral of such children to special schools or ‘inclusive’ schools.

Inter community approach, which entails establishment of inter-community linkages for the provision of need based services to be set up in a group of contiguous communities can be adopted by the professional worker in order to make the CBR programme more cost effective and optimally utilizable. In doing so, the role of the professional takes on the essence of networking and collaboration, as he strives towards establishing networks and linkages with other groups and initiatives both within and outside the community.

Advocacy in pressing for the rights of the disabled through community participation also forms an important component of Community Based Rehabilitation. The professional worker thus works in the mould of an *activist* in invoking community sentiments and initiatives to press for better livelihood and employment options for the PWDs. Apart from this he is required to evolve networking with various governmental and non-governmental organizations, advocacy groups and support services existing in the area, which could then be utilized for the rehabilitation of the disabled.

It has been realized that community's acceptance and sensitivity to the disabled goes a long way in facilitating psycho-social and economic rehabilitation of this group. The professional is thereby expected to work with diverse community groups to facilitate an empathetic understanding of disability and the accordance of equal rights to the disabled persons. This is indeed a very important component of the CBR approach. The following model brings forth clearly the role of professional social workers in the process of implementation of CBR as an alternative approach. The same has been illustrated in Chart III.

Chart III



Thus, the above discussion clearly highlights the need for a trained professional well conversant with community organization and mobilization skills and also equipped with a sound knowledge base on Disability and Rehabilitation to act as the key functionary in Community Based Rehabilitation initiatives. He has the potential of becoming indispensable resource who can guide the disabled persons, their families and the community by working at their level and their pace.

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The Role of Family, Society and Culture: A Collaborative Perspective on Management and Rehabilitation of Individuals with Mental Illness*

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Abstract

In this review article an attempt has been made to highlight the present need to collaborate mental health services with the familial and socio-cultural resources for achieving the management and rehabilitative goals. Additionally, the article contends the bilateral implications of this relationship where the mental illness has an impact on the family and the society at large. The article continues by considering the extensive research that has been done in the area of community mental health and rehabilitation. The following discussion emphasizes the paradigm shift that has taken place with respect to families; formerly seen as etiological agents are now recognized as potentially important partner in the rehabilitative process. Furthermore, there is a focus on the issues prevalent in the Indian society that may act as barriers in the management process. The article also brings forth the cultural implications in the formation and manifestation of psychopathology and thus stresses on the need for culturally sensitive clinical care for the patients. In conclusion, the article calls attention to the pressing need to collaborate the family and socio-cultural assets in the prevention, treatment and rehabilitation of the mentally ill.

As is known, besides biological and individual psychology, factors like family, society and culture also play a significant role in the formation of

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an individual's psyche; thus, it becomes essential to understand how these factors relate to the concepts of mental health and illness and their relevance in achieving the rehabilitative goals. However, one cannot have a unidirectional approach for understanding this relationship. It is not only an individual who gets affected by these factors but even the mental illness has an impact on the family and on the society at large.

The Role of Family: A paradigm shift

The **role of family** in mental health and illness has gone through many changes. Previously viewed as a major cause of mental illness, today the family is seen as an important partner in rehabilitation process. In the past, families were incorrectly identified as etiological agents, literally causing serious mental illness. Mothers in particular, have borne the brunt of these assertions. Today, with the growing acceptance of biopsychosocial perspectives for understanding the etiology of mental illnesses has led to abandoning of purely psychogenic models and consequently, the use of terms like 'shizophrenogenic mother' (Pratt et al., 1999).

With the recent paradigm shift, families; formerly seen as dysfunctional, illness-causing systems; are now recognized as surprisingly **resilient and resourceful** with a potentially important role in treatment and rehabilitation. The availability of close relatives has been considered as the most important component of the primary social support system in India (Kapur, 1992). Despite the burden that a family member's illness might present, some individuals have reported discovering strengthened familial bonds, strong commitments, and a clearer identification of familial strengths and resources. Family members are finding they can make important contributions to the recovery process (Mannion, 1996). Today with very short hospital stays and deinstitutionalization a reality in many cases, families have reemerged as primary care providers (Pratt et al., 1999). Thus, involving family members in treatment as well as rehabilitation of mentally ill patients is the current approach (Chaddha et al., 2000).

Impact on Family and the Ill Member

Family members who believe that they have caused their relative to develop a psychiatric illness are subject to many additional stresses. They feel **guilty and stigmatized**, and as a result they may isolate themselves from friends and extended family members who may be important potential sources of help (Wolin et al., 1992). Lefley (1989) also reported that families fear, sometimes for good reason, that behavior of a relative with mental illness diminishes their reputation as individuals and as a family; jeopardizing their relationship with friends and neighbors. Because of this stigma, family members wish to distance themselves from their ill relative, but often feel guilt if they do so.

The construct of Expressed Emotions (EE), referred to as high levels of criticism, hostility, and emotional over-involvement, was put forth by the Camberwell group (Vaughn & Leff, 1976). Since then it has been demonstrated that patients suffering from schizophrenia, in contact with a relative having high expressed emotions, are more likely to relapse (Anderson et al., 1986; Parker & Hadzi-Pavlovic, 1990). This construct has also been validated in India (Wig et al., 1987 a & b). As noted by Chaddha (2007), maladaptive ways of functioning in the family and the expressed emotions are associated with increase in the perceived burden and affect care-giving. In general, authors concluded that relatives' being lower in EE was a major factor in explaining the better outcomes of patients in North India (Leff et al., 1987). Nevertheless, most family households with members who have mental illness do not have high EE environments (Lefley, 1989).

There is little question, however, that the burden of the families is extreme. For families, the impact of mental illness is manifold. Apart from the shared grief of unfulfilled life expectations there are various categorical sources of stress that affect family members of persons with major psychiatric disabilities. The stress on the family has been categorized into two broad areas: **objective** and **subjective burden.** The former is very tangible, such as the economic burden of high health care costs, the restrictive effects on carers' lives, disruption of household routines, carers' investment of time and energy in help-seeking, social isolation, and so on. Subjective burden includes less tangible, but no less real, such as emotional costs associated with each component of objective burden. This concept also encompasses, carers' mourning for the premorbid personality and for the failed aspirations of someone they love. Economic strain, isolation, burnout, and need for respite are common (Lefley, 2001). A number of studies in India and in the West have documented that the burden of caring for an ill relative is high and that families are in need of support (Fadden et al., 1987; Gautam & Najhawan, 1984; Gopinath & Chaturvedi, 1992; Mubarak Ali & Bhatti, 1988; Noh & Turner, 1987; Pai & Kapur, 1981; Rao et al., 1988, Roychaudhari et al., 1995).

Role of Family in the Management and Rehabilitative Process

Given the importance of the **family in the rehabilitation process**, a great deal of work has gone into studying how families can be assisted. Over the past two decades, sophisticated **psychosocial interventions** involving family members have been developed to assist in the rehabilitation of persons with serious and persistent mental illness (Dixon & Lehman, 1995). These methods have been studied empirically and rigorously evaluated, and they have been found to be effective. As it turns out, family interventions are one of the few psychiatric rehabilitation strategies whose effectiveness has been confirmed by research. In addition, families have been found capable of reducing relapse and promoting recovery among their relatives (Lehman & Steinwaches, 1998).

Mental Illness and Society

Perhaps the most important source of stress is society itself, ranging from the generalized social **stigma of mental illness** to inadequate funding for research and services. Studies on stigma and mental illness in the Indian setting have focused on locally important socio-cultural factors shaping stigma. There exists greater stigma and punitive attitude among rural Indians as compared to urban Indians (Jadhav et al., 2007). A few studies however, argue the opposite (Wig et al., 1980; Verghese et al., 1974; Kshama, et al., 1974) or report variable findings (Chatterjee et al., 2003; Raghuram et al., 1984). In all societies, political and economic forces affect the structure of mental health systems and the adequacy of services for the mentally ill. A society's legal decisions affect the rights of individuals who may be floridly psychotic to reject involuntary treatment, and the criminalization of mental illness through confinement of sufferers in jails rather than hospitals (Lamb & Weinberger, 1998).

Psychosocial Interventions for Alleviating Social Disability

Impairment in social functioning is almost characteristic of many chronic mental illnesses. Poor social competence contributes to the impoverished quality of life and social isolation experienced by many patients. It interferes with functioning within the family or in the work place. In addition, social disability has been found to be a potent predictor of symptom exacerbations and rehospitalizations (Gopinath & Rao, 1994). The most promising psychosocial intervention for alleviating social disability has been social skills training (SST) (Wallace et al., 1980), which is based on behavioural and learning principles and emphasizes modeling, role playing and social reinforcement. While social skills training is an effective strategy, the mental health professionals need to actively collaborate with the patient's family and social networks to facilitate the generalization of these skills to his natural environment.

In addition to individual and family focused approaches, the treatment and management of chronic mental illness demand effective development and utilization of environmental resources which encompasses a variety of community based care including day care and residential care. The term

day-care refer to ambulatory treatment programs that include psychiatric, psychosocial and prevocational treatment modalities designed for patients with severe mental illness. Such patients require a comprehensive and multidisciplinary treatment that is not provided in an outpatient and inpatient setting. These services usually provide the full range of medical and psychosocial treatments including family interventions. The **residential care** facilities also have an array of both individual and family based interventions depending on the individual patient and needs of the family. While the individual focus is on developing and maintaining adequate self-help skills for re-entering the community, the family is prepared to receive the patient, with an emphasis on psychoeducation and reduction of expressed emotions. The emphasis of these services is on **'normalisation'** that is not merely concerned with providing a social setting that offers a culturally valued means of living, but is also concerned with reducing the stigma (Gopinath & Rao, 1994). Thus, it is imperative that the mental health professionals collaborate actively with the non-governmental or voluntary sectors in the development of a network of community based services.

Social and Psychological Factors in Indian Society

The **social issues** focus on the adequacy of mental health services and barriers to treatment. Empirical evidences from Indian researches have identified various sociological and psychological factors restricting the scope of psychotherapy and counseling. The orientation and nature of current training of psychologists, the economic viability of seeking help for personal problems, our belief systems of *karma* and fate, interdependent cultural ethos, our concept of shame and family honor, gender stereotypes, and the dilemmas of change, are some of the factors that hinder individuals from seeking help from their social networks (Marwaha, 2003).

The Role of Culture

While the impact of family and society on an individual's mental health is unquestionable; at the same time, **cultural implications** cannot be overlooked. Conceptually, any behaviour is subject to cultural impact and is therefore, more or less related to culture. It is important clinically to investigate from a descriptive and phenomenological point of view how cultural factors relate to the formation and manifestation of psychopathology, the clinical picture, and the frequency of certain mental illnesses, particularly minor psychiatric disorders and closely related psychological problems, which are influenced predominantly by social and cultural factors (Mezzich et al., 1996). This may also include the study of culture – related specific psychiatric conditions that are heavily influenced by culture. Beyond theoretical investigation, it is currently the trend to emphasize the clinical application of cultural psychiatry, regarding evaluation, diagnosis, management, and treatment. The focus on culture is needed when a clinician is dealing not just with patients of minority or other ethnic backgrounds or from foreign countries but also with patients who are part of the majority population of their own society. Attention is needed not just on the ethnic-cultural background of the patient but equally on the therapist or caregiver. Cultural impact is manifested as a bilateral interaction between the therapist and the patient, rather than a unilateral influence. Every clinician is now expected to provide culturally sensitive, relevant, and effective clinical care and treatment for all of his patients (Tseng, 2003).

Clinical Applications of Cultural Psychiatry

In **cross-ethnic research** on mental health and illness, racial and ethnic differences have also been found in causal attribution, prognostic expectations, kinship roles of primary care givers, hospitalization and service utilization patterns and, in perceived psychological distress (Lefley, 1996). Cultural conceptions of mental illness include a disparate array of negative attributes, including dangerous and unpredictable, weakness and incompetence, and generalized attribution of "badness", thus leading to stigma. These conceptions are evidenced both in elements of mass culture, such as media, and in public attitudes concerning mental illness (Link et al., 1999). Link and colleagues (1989) have identified a mechanism through which **patients' attitude about stigma** may strongly affect their life circumstances. They further posit that psychiatric patient's experience culturally induced expectations of rejection that lead to negative consequences for self-esteem, job procurement, and the development of social networks. Once they expect rejection, interactions with others may be strained, and strategies aimed at minimizing feared rejection - such as withdrawing from social contacts – may impair their ability to function.

Conclusion

As a member of society, a person's behaviour; in addition to biological factors, individual psychology and personality; is also subject to the influence of one's family and socio-cultural dimensions. Thus a comprehensive system of care encompassing a variety of therapeutic approaches and the available familial and socio-cultural assets is needed to enable the mentally ill patient to function optimally and live in the community. As stressed by Gopinath and Rao (1994), the team work is also essential because not only does it reduce 'burn out' on the part of the care giver, but also reduces dependency on one therapist on the part of the patient. Psychosocial interventions have to be geared to the individual needs of the patient and family, and here, the socio-cultural diversity in India poses both a problem and a challenge. Thus an effective program for prevention, treatment and rehabilitation of persons with mental illness needs to be community based with its goal to decrease the psychiatric morbidity in the society where, in this context, family occupies an important position as it provides an excellent supportive environment.

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Sensitivity of the Re/Habilitation Professionals about the Appropriate Use of the Term 'Normal'

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Abstract

Use of labels during professional communication needs to be taken seriously not only because appropriate labels reflect updated knowledge and indicate desirable attitude but also because these send correct message to the others. One of the most commonly used label/term in the field of re/habilitation is 'normal'. It is noticed that the label 'normal' is undesirably used to mean 'non-impaired'. The aim of this study is to find out how sensitive the re/habilitation professionals are while using the label 'normal'. Re/habilitation professionals (special educators with degree, special educators with diploma and audiologists) were requested to identify and select one error for correction out of the planted five errors in a given leaflet. Result shows that labeling error is the least selected error indicating lowest sensitivity towards the use of the term 'normal'. Secondly, the sensitivity of the three types of professionals did not differ significantly. One can conclude that there is a scope for improvement in the re/habilitation field as far as the use of academic labels/terms is concerned. Since the lingua franca used by the professionals has far-reaching impact, heavily loaded terms like 'normal' is recommended to be used carefully.

Introduction

Shakespeare is famous for his immortal quote "what is in the name?" While Shakespeare finds labeling (or attaching name to an object) worthless, there are many linguists, sociologists and educators who are amazed by the strength of a 'name' (a label) not only in terms of carrying the load of meaning wonderfully and flexibly but also in terms of reflecting the attitude and personality of the user. Today, most of the linguists will not

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buy Shakespeare's argument - 'rose by any name would smell sweet'. The well-known Sapir - Whorf hypothesis holds that the language one speaks determines one's thinking about the world. According to them the labels we use, actually govern our sensory perception. Since words have meanings and since brains think using language, language and thought reflect each other. Even if the original Sapir Whorf hypothesis is criticized today, it is well accepted that language mediates thoughts (Lyons, 1987). Language frames thoughts in quantifiable and predictable ways. Hence, it is not surprising that language is considered the best indicator of attitudes and thoughts of the user. Labels are one of the most important parts of language and hence also are the best indicators of thought processes (Bennett, 2006).

Connecting this theory to the world of re/habilitation of persons with disabilities, least one could do is to introspect the lingua franca of the re/habilitations in terms of how updated and academically correct is the common use of terminology floating currently in the field. Present article reviews the use of just one of the most significant labels ('normal') by the re/habilitators working in the field of disability.

The academically correct terms to refer to individuals without disabilities (over and above the term 'person without disabilities' itself!) are 'non-disabled' and 'non-impaired'. With particular reference to children with hearing impairment, the term 'normal hearing children' is also used to indicate existence of no disability in hearing mechanism. However, the term 'normal hearing individual' (or more correctly individual with normal hearing) does not indicate the status of the other disabilities present in that individual and hence could prove partially correct. For example, in a statement - 'a child with normal hearing connects two words to make sentences at the age of 2 years'; the use of the term 'normal hearing' can be misleading since the statement does not hold good for children with mental challenges in spite of they being 'normal hearing'. Thus the use of the term 'children with normal hearing', though correct from audiology point of view, may work out to be inadequate. It unnecessarily hides the status of the other disabilities present or absent in that particular individual. In several developed countries, for example, the USA, the commonly used term referring to children without disabilities is 'typically developing children'. However, the conceptual boundaries of the term 'typically developing children' have some hazy areas. Firstly, this label includes Deaf children of Deaf parents and hence cannot be taken as synonymous to children without disabilities.

Secondly, this label may exclude institutionally raised children though having no disability. Hence, in Indian context, the terms to refer to individual without disabilities are:

1. Individual/child/person/student without disabilities. This term is not only academically correct but also goes well with the philosophy of 'individual first, disability later'. (Incidentally, the modification of the label from 'disabled child' to the 'child with disability', which is well accepted among the professionals; justifies the point put forward in the present study - labels used while communicating indicate attitude of the user and hence need to be taken seriously.)
2. Non-disabled individual/child/person/student.
3. Non-impaired individual/child/person/student.

The later two terms - though attitude wise less politically correct, are academically correct. These two terms fit better into the spontaneous sentence patterns used for communication than the first term.

Among these options of labels, which one is frequently chosen by the relhabilitators during the professional communication? Informal review of the lingua franca of laypersons, parents and individuals with disabilities themselves reports the use of the term 'normal' to refer to individuals without disabilities. More importantly, the rehabilitation professionals too use the term 'normal' to refer to anything to do with individuals without disabilities. One frequently gets to hear the labels 'normal child', 'normal parent', 'normal school', 'normal teacher', 'normal classroom', 'normal education', etc., not only during informal but also during significant professional discourse. Academically, the quality of normalcy can be attached to a capacity (or capacities) of the individual but it cannot be attached to the individual as a whole. Moreover, in terms of normalcy, there are only three possibilities: normal, subnormal and abnormal. If children without disabilities are termed to be normal, children with visual or hearing impairment automatically become either abnormal or subnormal. No professional intends to mean this.

Re/habilitation professionals obviously do have the required theoretical knowledge related to this but probably the use of terminology has more to do with linguistic habit formation - rather than serious consideration before using the term. Whether a particular term is used as an outcome of a serious thought or as a habit, it sends the incorrect message in the field if used inappropriately. The re/habilitators are considered leaders in disability management inspiring parents, community, para professionals and policy makers. It is needless to emphasize that the terminology used by them has to be academically and politically correct. It should reflect realistically desirable attitudes. At least, the labels like ‘normal’, which carry heavy loads of potential misinterpretation, should be used carefully.

Objective of the study

The aim of this study is to find out how sensitive the re/habilitation professionals are while using the label ‘normal’. In this study, re/habilitation professionals were asked to modify the language of an awareness leaflet about communicating with individuals with hearing losses. They were told that the content in the leaflet is to be released globally and hence needs to be perfect. This leaflet had five errors - planted intentionally. One of these was a labeling error whereby the label ‘normal’ was used incorrectly in place of the label 'the non-disabled’. The study intended to find out the sensitivity of the re/habilitation professionals towards the academically correct labeling by identifying the labeling error in that given leaflet. This sensitivity is measured in the present study in contrast with the sensitivity of the professionals towards four other linguistically relevant issues: capitalization, punctuation, spelling, and grammar.

The specific objectives of the survey therefore are:

1. To study the sensitivity of the three types of re/habilitators towards the incorrect use of the label ‘normal’ in comparison with their sensitivity towards the use of incorrect capitalization, punctuation, spelling and grammar.

   The three types of re/habilitation professionals are special teachers of students with hearing impairment having degree level professional qualification, special teachers of students with hearing impairment with diploma level professional qualification and the audiologists.

2. The second objective therefore is to see the difference among the sensitivity of the three types of rehabilitation professionals towards the incorrect use of the label ‘normal’.

Operational definitions

- **Sensitivity** in the present study is taken to mean the act of the participants of *identifying a particular error and selecting to correct it* over the other identified errors.
- **Labeling error** in the present study means use of the term ‘normal’ to refer to individuals without any disabilities.
- **Re/habilitation professionals** in the present study refer to those special educators (degree and diploma level) and the audiologists who participated in the survey.

Research design

The present research is a survey with convenient sampling. All re/habilitation professionals attending a seminar were requested to participate in the said survey. Out of all the professionals, 106 responded by returning the filled-in survey. Out of these 106 participants, 59 are special educators of students with hearing impairment and 47 are audiologists. Out of the 59 special educators, 30 hold diploma and 29 hold degree in special education. The inclusion criteria for the research participants consisted of relhabilitation qualification and adequate command over English.

Research tool

A researcher made awareness leaflet on communicating with individuals with hearing losses is used as the research tool. The content of the leaflet consisted of (deliberately made) five errors. These were of five types namely: Capitalization error, Punctuation error, Spelling error, Grammar error and labeling error.

The instructions given to the research participants were very clear. The participants were told that the distributed pamphlet was to be released internationally. They were therefore requested to read the content CAREFULLY and circle the points/words/phrases, which they think need correction. They were told, "There could be a few of such errors but please SELECT ANY ONE FOR CORRECTION that you may think is most important and hence need correction for sure."

The draft tool is validated by four experts for the concept, the content and the clarity of instructions.

Analysis and Discussion

As mentioned earlier, the researcher made tool consisted of five intentionally placed errors. The participants were asked to identify errors and select one - the most significant one - for correction. Following table shows the outcome of the responses of the 106 research participants. The numbers in the table indicate frequency occurrence of that particular error getting selected.

Participants' Category and Error Types Cross Tabulation

	Capitalization	Punctuation	Spelling	Grammar	Labeling	Total
Spl Educators	7	6	13	17	4	47
(deegree level)	6.6%	5.7%	12.3%	16.0%	3.8%	44.3%
Spl Educators	3	4	8	13	2	30
(dip. level)	2.8%	3.8%	7.5%	12.3%	1.9%	28.3%
Audiologists	2	3	7	12	5	29
	1.9%	2.8%	6.6%	11.3%	4.7%	27.4%
Total	*12*	*13*	*28*	*42*	*11*	*106*
	11.3%	*12.3%*	*26.4%*	*39.6%*	*10.4%*	*100%*

As per the first objective, the sensitivity of the participants in terms of frequency occurrence of selection of labeling errors by the participants as compared to frequency occurrence of the other four error types is to be studied.

It is needless to mention that the error, which got chosen least frequently by the three types of re/habilitators, is the labeling error. This simply means that the participants are least sensitive about the labeling error as compared to the other four types of errors.

On the basis of frequency occurrence of getting identified and getting selected, the grammatical errors have secured the first rank. All the three groups have selected to correct the grammatical errors more frequently over the other types of errors. Among the various parameters of language assessment like productivity, complexity, correctness, etc., correctness of language is highly valued (Huddar, 2001). Teachers are known to be sensitive towards grammar errors. It appears that the participants of the present study too, are more sensitive about grammatical errors than the labeling errors. Same holds good with spelling errors. Labeling errors are considered as petty as errors of punctuation or capitalization. It is not known whether the participants did not identify (or notice) the labeling error in the given leaflet or they did identify labeling errors but did not select it for correction over the other errors (the participants were asked to correct only one error). In both the cases, it indicates the insensitivity of the participants towards the labeling error. Not identifying labeling error by the participants can be interpreted as lack of awareness about the correct meaning of the term 'normal'. Identifying the error but not selecting it for correction can be interpreted to mean that the issue of labeling is too trivial for the participants. It appears that being correct is more essential than indicating correct attitude.

As per the second objective, the sensitivity of the three groups was to be compared. To fulfill the objective, Chi square analysis is carried out.

Chi-Square Test

Educators (Degree Level), Educators (Diploma Level) and Audiologists

	value	*df*	*Exact significance (2 sided)*	*Point Probability*
Pearson Chi square	3.428a	8	.914	.014

The frequency distribution of Special educators Degree Level, Special educators Diploma Level and Audiologist do not differ significantly as the Pearson Chi-Square = 3.428 has a p-value .914, which is >.05.

This means that the level of sensitivity of the special educators

(Degree Level), Special Educators (Diploma Level) and the Audiologists towards the use of the label 'normal' is similar. Among the special educators also, the level of sensitivity of degree level and the diploma level teachers is similar. This is important since all the three groups have undergone different training programs of different duration.

Conclusions and Recommendations

1. The sensitivity of the three types of relhabilitators towards the incorrect use of the label 'normal' is found to be comparatively low. This is in comparison with their sensitivity towards the use of incorrect capitalization, punctuation, spelling and grammar. Research participants are found to be more sensitive towards grammatical errors and spelling errors.

2. There exists no statistically significant difference among the three-relhabilitation professionals in terms of their sensitivity towards the incorrect use of the label 'normal'. A few recommendations related to further research into this area (of use of academic terms) are made here. Similar study involving random sampling and more extensive tool can be taken up. Finding out the use of terms by parents, community and more importantly by the persons with the disabilities themselves would also be informative. A document study of important policy statements like legislations, government GRs, manuals and guidelines, official websites, etc., can be undertaken to study the use of academic terms.

Pragmatic recommendation for the re/habilitation professionals about this issue of using terminology is: to use the labels carefully and as an outcome of 'seriously-thought-over' selection of one label over the other neighboring and competing labels rather than letting the tongue habits rule the lingua franca.

Overall, one can conclude that there remains a scope for improvement in the re/habilitation field as far as the use of academic labels/ terms is concerned. Labels like 'normal' if used inappropriately, go a long way in creating conceptual confusion. Labeling needs to be taken seriously not only because it reflects updated knowledge and indicate desirable attitude but also because it sends correct message to the others. Re/habilitators interact with policy makers and decision makers on one hand and parents, media and community on the other hand. The lingua franca used by them has far-reaching impact on both the sides. Use of technically updated, academically correct and politically appropriate terminology is an indicator of professional competence and hence best be taken seriously.

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Organizational Effectiveness of Disability Rehabilitation Organizations: Perception of Professionals and Managers

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ABSTRACT

Organizational effectiveness has been commonly defined as the extent to which an organization accomplishes its goals or mission. To achieve these goals, some critical organizational components needs to be given due consideration. Much research had been conducted to identify these organizational effectiveness components by considering the nature and scope of the organizations. In this study the efforts has been made to study the perception of disability rehabilitation professionals and/or managers about four important components of organizational effectiveness, i.e., Strategy & Leadership, Trust & Motivation, Capabilities & Ownership and Operational Effectiveness. The data was collected by using a five point rating scale developed by Metrus Group. The mean analysis of 50 responses, reveals that the Disability Rehabilitation professionals/managers associated with NGOs perceives their organizational effectiveness higher than the professionals associated with the corporate sector. This study also indicates that the representatives from international disability rehabilitation organizations feels their organizations are more effective in above domains than the local and national level rehabilitation organizations.

INTRODUCTION

Since organization and management science emerged in early 1900s in conjunction with the industrial revolution, an evolution has also occurred

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in the concepts related to nature and functions of organizations and also to the criteria for organizational effectiveness. These concepts have grown and evolved continuously in dynamic interaction with the organizations and institutions. Over the year these institutions became the companies, government agencies, and not-for-profit organizations as a part of today's global society. All organizations are composed of individuals operating within systems. From an organizational perspective the individuals, organizations, and systems constitute the principal units of analysis. For each unit of analysis, the attention can be focused internally (within the organization) or externally (on the external environment or on interactions with the external environment), though, the concepts about both the nature of the organization and its relationship with the external environment have undergone dramatic change over the course of the last 100 years.

Morgan (1997) vividly describes that there are numerous ways to conceptualize and model an organization, with profound consequences for criteria of effectiveness. These concepts typically deal with organizational form and structure on one hand and organizational functions and activities on other. How the organization is designed and how its functions are defined obviously have important implications on how processes and people are managed.

REVIEW OF ORGANIZATIONAL EFFECTIVENESS CONCEPTS

The organizational effectiveness theory began a dramatic evolution nearly 50 years ago with the merging of general systems theory concepts and then prevailing management theory (Ackoff, 1970; Churchman, 1971; Emery & Trist, 1965; Herbst, 1974). This combination signaled the start of a paradigm shift "a new way of viewing the world and relating to each other" comparable to a shift from "machine age to organic thinking" (McCann, 1991). Later principles originating with the Tavistock institute become crucial with the advent of "socio-technical systems" which often determined the interdependencies between organizational tasks within the groups or team (Herbst, 1974; Morgan, 1986; Trist et al., 1996). Later on the Systems theory has created an awareness of the organization's larger environment and the need for managing its complex and dynamic interdependencies. Many of the contingency models of this period, such as the "McKinsey 7-S" model, still provide powerful leverage for thinking about how to align all of the parts of the organization.

Similarly, the Organizational Development (OD) movement of the 1960s and 1970s critically depended on systems models for identifying the levels of intervention necessary to execute change (Argyris, 1964; Huse, 1975; Schein; 1978). Many intervention tactics and designs created by the OD movement are still in use (McCann & Gilkey, 1988). The special resources of the organization (Barney, 1991; Brown & Eisenhardt, 1998), its capacity for innovation (Edvinsson & Malone, 1997; Quinn et al., 1997), and stock of intellectual and human capital (Stewart, 1997) have all been intensely studied for their roles in promoting effectiveness. From the knowledge management perspective, effective organizations are those that promote individual and group learning through management practices and amplify the move of information through organization level systems, processes, and technologies (McCann & Buckner, 2004). In short the organization that achieved the closest fit or alignment between its larger environment, its overall strategy, and its organizational design would outperform its competitors, that is, be more effective.

John & Despina, 2005 quotes a research in which 700 CEOs from leading industrial and service companies representing both private and public enterprises were studied to identify the variables of organizational effectiveness. These variables as cited as requirements for organizational effectiveness are:

- Quality employees with a passion for their work and a level of satisfaction that leads to low employee turnover.
- Communication strategy with consistent and energizing messages.
- Clear practices, policies, and decisions.
- An environment accepting of change and innovation for new product development.
- Interdepartmental communication.
- Effective management of human resources – increased information sharing, extensive training, financial and non-financial rewards, appraisal and extensive feedback.
- Strategic choices about which markets to pursue and which opportunities to ignore but with flexibility to pursue experimentation.
- An ability to anticipate competitor reactions to strategic responses as well as anticipate employee responses.
- A strategy linked to organizational goals and reviews.

- All organizational levels participating in communicating core messages and communication flowing from top to bottom and bottom to top.
- Good external communication – from new releases, fact sheets, annual reports, supervision and leadership.
- Opportunities for employee advancement and growth.
- An emphasis on planning, training, and support.
- Adaptive organizational forms and structures.
- High levels of organizational trust – which minimize the potential for destructive conflict, unnecessary bureaucratic control, administrative expenditures, and expensive overhead.
- Consistency and congruency between words and actions.
- Effective Boards of Directors.
- Using information technology effectively.
- Integrating employees from different organizational units; particularly important in multinational organizations.
- An emphasis on ethics, the environment, and sustainability.
- Customer focus and ability to optimize customer value.
- Choosing the right partners and building trusting, durable relationships.
- Empowerment and delegation of real decision-making authority to those closest to the customers.
- Lean production and an emphasis on efficiency and efficient processes.
- Strong culture and mission.

More commonly and popularly identified features of organizational effectiveness have also been described by **Metrus Group** *(USA based industry leader in strategic performance measurement and organizational assessment).* According to Metrus Group following are the indicators for organizational effectiveness*:*

- Alignment with the Human Resource and operational systems.
- Working through high performance teams that deliver results.
- Developing critical skills and encouragement of their uses.
- Effective Communicate up, down, and across the organization.
- Motivating employees to reach beyond even the most ambitious goals.
- Measuring results continuously.

The comparison in Table 1 highlights the features of organizations stands apart from their competitors.

Table 1: Common Features of High and Low Organizational Effectiveness

High Organizational Effectiveness	*Low Organizational Effectiveness*
Effective communications • Formal • Informal • Lateral	Communications fuzzy or fragmented
Passion for results	Cynicism and distrust
Limited, focused initiatives	Initiative overload/fatigue
Reward for strategic and operational performance	Misaligned reward and incentive systems
Continuous, measurable positive short and long-term business results	Lackluster performance, iffy results

Source: http://www.metrus.com/issues/org-effect.html

High organizational effectiveness gives organizations the ability to react quickly, minimize costs, leverage employee talent, and outperform with competitors. Organizations are integrated — "organic" — entities consisting of four major categories:

1. Strategy and Leadership.
2. Trust and Motivation.
3. Capabilities and Ownership.
4. Operational Effectiveness.

STUDY FROM DISABILITY REHABILITATION SECTOR

The domain of organizational effectiveness identified by Metrus Group, i.e., Strategy & Leadership, Trust & Motivation, Capabilities & Ownership and Operational Effectiveness, contain systems, sub-systems, and drivers. For example, Capabilities and Ownership include: accountability, skill development and opportunities for skills use, and delegated decision making, among other elements. Strategy and Leadership include: vision, strategic communication, and alignment, among others. Each category and the related elements must be measurable so they can be improved upon. Each element above has specific drivers that influence performance on those elements. Understanding performance on each of these drivers, and how to leverage them is key to increasing organizational effectiveness, customer performance, and financial results. An attempt is made to study the organizational effectiveness of the organization rendering services to persons with all disabilities by keeping above parameters as domains for this study.

Data Collection Tool

In this study the response has been collected by using a five point rating scale developed by Metrus Group. This organizational effectiveness rating scale has 16 questions from four domains namely Strategy & Leadership (Q.No. 1,4,5,6), Trust & Motivation (Q.No. 3,7,11,14), Capabilities & Ownership (Q.No. 8,9,15,16) and Operational Effectiveness (Q.No. 2,10,12,13). Mail survey method was used to collect the response from 50 representatives belonging to different categories. These fifty (50) representatives/respondents/sample, belongs to different categories as mentioned in Table 2.

Table 2: Sample / Respondents Categories

N = 50

		Frequency	*Percent*
Operational Area of organization	Local or District level	14	28.0
	National level	28	56.0
	International level	8	16.0
Organization type	NGO's in Disabilty Area	10	20.0
	GO	20	40.0
	Corporate sector	4	8.0
	Foundations fully operated through corporate funds	16	32.0
Work Experience	0-2 years	2	4.0
	3-5 years	18	36.0
	6-10 years	20	40.0
	10 & above	10	20.0
Hierarchical Distribution	Top Level - Director, Head of Organization	10	20.0
	Middle Level - Section Heads	20	40.0
	Lower Level - Therapists	20	40.0

Data Analysis

The analysis of central tendency of distribution via mean in four domains (Strategy & Leadership, Trust & Motivation, Operational Effectiveness and Capabilities & Ownership) reveals findings as mentioned in Table 3.

Table 3 : Distribution of Mean, Domain Vs Category

N = 50

DOMAINS	QUESTIONS	Group	Level of Management			Organization Type				Operational Area			Work experience			
			TM	**MM**	**LM**	**NGO**	**GO**	**COP**	**CSR**	**Loc**	**Natnl**	**Intrnl**	**Exp 0-2**	**Exp 3-5**	**Exp 6-10**	***Exp 10+***
		Mean	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	**Mean**	***Mean***
Strategy & Leadership	**Q_NO._1**	**4.20**	**5.00**	**4.00**	**4.00**	**5.00**	**4.00**	**2.00**	**4.50**	**4.14**	**4.00**	**5.00**	**5.00**	**3.89**	**4.00**	***5.00***
	Q_NO._4	**4.56**	**5.00**	**3.90**	**5.00**	**5.00**	**5.00**	**1.00**	**4.63**	**3.86**	**5.00**	**4.25**	**5.00**	**3.78**	**5.00**	***5.00***
	Q_NO._5	**4.36**	**5.00**	**4.40**	**4.00**	**5.00**	**4.00**	**4.00**	**4.50**	**4.71**	**4.00**	**5.00**	**5.00**	**4.33**	**4.00**	***5.00***
	Q_NO._6	**4.68**	**5.00**	**4.20**	**5.00**	**5.00**	**5.00**	**1.00**	**5.00**	**3.86**	**5.00**	**5.00**	**5.00**	**4.11**	**5.00**	***5.00***
	Q_NO._2	**3.60**	**5.00**	**4.50**	**2.00**	**5.00**	**2.00**	**4.00**	**4.63**	**4.71**	**2.86**	**4.25**	**5.00**	**4.44**	**2.00**	***5.00***
Operational Effectiveness	**Q_NO._10**	**3.08**	**5.00**	**3.20**	**2.00**	**5.00**	**2.00**	**1.00**	**3.75**	**3.86**	**2.57**	**3.50**	**5.00**	**3.00**	**2.00**	***5.00***
	Q_NO._12	**2.80**	**5.00**	**3.50**	**1.00**	**5.00**	**1.00**	**1.00**	**4.13**	**3.86**	**1.86**	**4.25**	**5.00**	**3.33**	**1.00**	***5.00***
	Q_NO._13	**3.68**	**3.00**	**3.70**	**4.00**	**3.00**	**4.00**	**2.00**	**4.13**	**2.71**	**4.00**	**4.25**	**5.00**	**3.56**	**4.00**	***3.00***
Trust & Motivation	**Q_NO._3**	**2.72**	**4.00**	**1.80**	**3.00**	**4.00**	**3.00**	**1.00**	**2.00**	**3.14**	**2.71**	**2.00**	**5.00**	**1.44**	**3.00**	***4.00***
	Q_NO._7	**4.52**	**5.00**	**3.80**	**5.00**	**5.00**	**5.00**	**3.00**	**4.00**	**4.43**	**4.43**	**5.00**	**5.00**	**3.67**	**5.00**	***5.00***
	Q_NO._11	**4.36**	**5.00**	**4.40**	**4.00**	**5.00**	**4.00**	**4.00**	**4.50**	**4.71**	**4.00**	**5.00**	**5.00**	**4.33**	**4.00**	***5.00***
	Q_NO._14	**3.52**	**4.00**	**3.80**	**3.00**	**4.00**	**3.00**	**3.00**	**4.00**	**3.71**	**3.00**	**5.00**	**5.00**	**3.67**	**3.00**	***4.00***
Capabilities & Ownership	**Q_NO._8**	**3.84**	**5.00**	**3.10**	**4.00**	**5.00**	**4.00**	**1.00**	**3.63**	**3.86**	**3.71**	**4.25**	**5.00**	**2.89**	**4.00**	***5.00***
	Q_NO._9	**3.40**	**5.00**	**3.00**	**3.00**	**5.00**	**3.00**	**1.00**	**3.50**	**3.86**	**3.00**	**4.00**	**4.00**	**2.89**	**3.00**	***5.00***
	Q_NO._15	**4.28**	**5.00**	**4.20**	**4.00**	**5.00**	**4.00**	**3.00**	**4.50**	**4.43**	**4.00**	**5.00**	**5.00**	**4.11**	**4.00**	***5.00***
	Q_NO._16	**3.36**	**5.00**	**3.90**	**2.00**	**5.00**	**2.00**	**2.00**	**4.37**	**4.14**	**2.57**	**4.75**	**4.00**	**3.89**	**2.00**	***5.00***
	AVERAGE	***3.81***	***4.75***	***3.71***	***3.44***	***4.75***	***3.44***	***2.13***	***4.11***	***4.00***	***3.54***	***4.41***	***4.86***	***3.58***	***3.44***	***4.75***

A. In the domain of ***strategy and leadership***, the response analysis in different levels of hierarchical position (top level, middle level and lower level) illustrate that mean of respondents belonging to middle level is lowest, i.e., 4.13 while members belongs to top level is highest, i.e., 5.00 and the members belongs to lower level is 4.50. In the category of work experience of respondents suggest that the fresher (0-2 years) and highly experienced (more than 10 years) members have rated their organizational strategy and leadership as high as 5.00 while the respondents with 3-5 years experience and 6-10 years experience has rated their organizational strategy and leadership as 4.00 to 4.50. The respondents belonging to International organizations have rated their organizational strategy and leadership as 4.81 while the respondent belongs to the organizations operating at national level rated it as 4.50, the response from local level is 4.14. In the category of organizational type the respondents representing Non-Government Organizations (NGOs) have rated their strategy and leadership as high as 5.00, while the respondents from Corporate Social Responsibilities (CSR) organizations rated it as 4.66. The respondents from government organizations rating is 4.50 whereas the respondents from corporate sector where disability rehabilitation is being taken as a part of social service rated their group strategy and leadership as low as 2.00

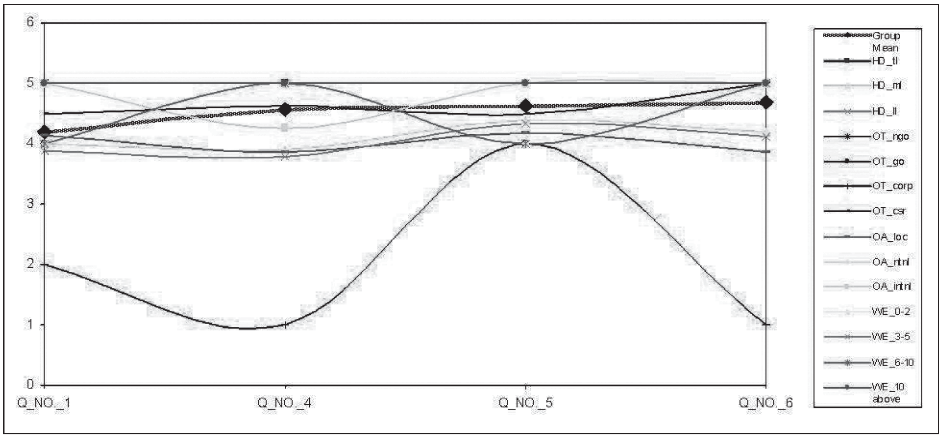

Exhibit 1 A: Mean: Strategy & Leadership

In this domain the comparison of mean in different categories as illustrated in Exhibit 1 A indicate that all the curves clustered near to high (4 & 5) except the response of corporate group in organizational type. This lower down curve indicate its significance by pointing out that the staff in these groups feels out of the loop. The organization may have high level goals, but staff needs to understand how their daily efforts ties into them. This common link might be missing in these corporate groups. In this case the leadership needs to be more visible and accessible and the organizations vision needs to be discussed and articulated in multiple forms by management.

B. In the domain ***Trust and Motivation***, the response of different hierarchical positions suggests that the group members belonging to middle level have rated their organizational trust and motivation as 3.45 while the members from top level rated it as 4.50 and the lower level as 3.75. In the category of work experience of respondents suggests that the fresher and highly experienced group rated their organizational trust and motivation as high as 5.00 and 4.50 respectively but the person with 3-5 years of experience and 6-10 years experience has rated it as 3.28 to 3.75 respectively. The respondents belongs to International organizations have rated their organizational trust and motivation as high as 4.25 while the representative belonging to national level organizations rated it as 3.54 and local level organizations as 4.00. In the category of organizational type the representatives form from NGOs have rated their organizational trust and motivation as 4.50, the representatives from CSR organizations rated it 3.63 and the respondents from Government organizations rated it as 3.75 while the representatives from corporate groups rated their organizational trust and motivation as 2.75.

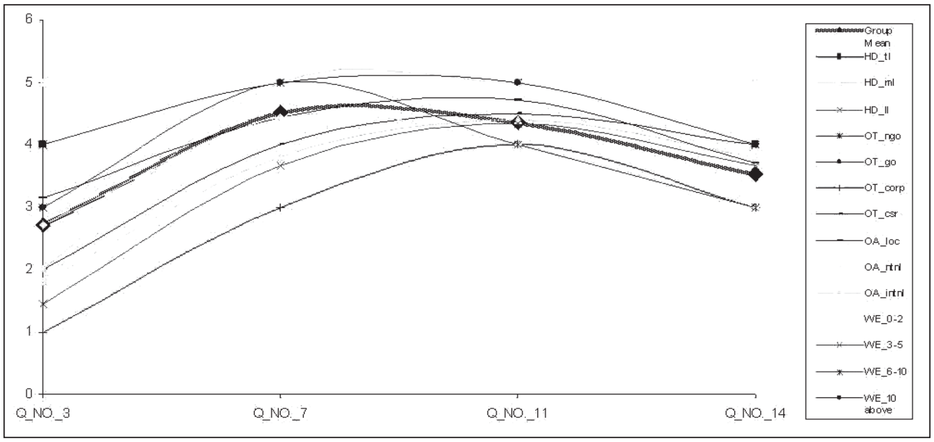

Exhibit 1 B: Mean: Trust & Motivation

The Exhibit 1 B represents the comparison of mean in different category. This indicated that almost all responses clustered between high, i.e., 4 & 5 and average, i.e., 2 & 3 except the response of corporate group in organizational type. This comparatively lower down curve indicate its significance by pointing out that there might be issues related to compensation or performance appraisal. This dissatisfaction might lead to cynicism and de-motivation very quickly. This also reflects that the team work and internal team issues may also be the point of concern. Reflection of this response suggests that the staff has lost some element of trust in management/leadership. Most commonly this develops from lack of follow through in stated plans and initiatives, a perceived lack of consistency in decision making, frequent shifts in direction due to management personnel changes.

C. In the domain of ***Operational Effectiveness***, in the category of respondents from different levels of hierarchical positions, the lower level employees has rated their operational effectiveness as 2.25 while the respondents from top level rated it as 4.50 and the middle level employee rated their operational effectiveness as 3.73. In the category of work experience the fresher and highly experienced group members rated the operational effectiveness as 5.00 and 4.50 respectively but the employees with 3-5 years experience and 6-10 years experience have rated it as 3.58 and as 2.25 respectively. The members belonging to International organizations have rated their operational effectiveness as 4.10 while the employees form national level organizations, i.e., 2.82 and local level organizations, i.e., 3.79. In the category of organizational type the representatives from NGOs have rated their operational effectiveness as 4.50 while the representatives from CSR organizations rated it as 4.16. The representative from Government organizations rated their operational effectiveness as 2.25 and the corporate representatives rated it as 2.00.

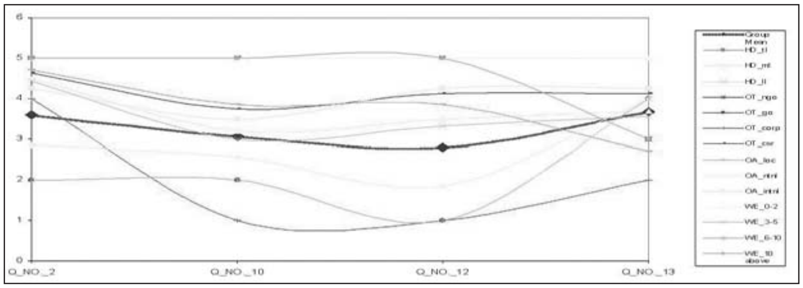

Exhibit 1 C: Mean: Operational Effectiveness

The comparison of mean among different categories as shown in Exhibit 1C points out that, all curves scattered between high, i.e., 5 to low i.e; 2. The lower down curves in the area of operational effectiveness corresponding to lower level workers, government and corporate, to some extent the organizational operating national wide and the respondent having 6-10 years of experience indicate the deficiency in formal communication channels. This suggests that people are getting important information from friends and associates. This is a dangerous situation because it promotes rumors and half truths. This also indicates that people do not trust other departments and there is a lack of synergy and shared performance results between areas. These organizations may not be experiencing quantum performance improvement, sustained incremental improvement, or break-through operational cost enhancements. This situation often stems from lack of adequate team structure, job insecurities, high-risk aversion or interpersonal issues.

D. In the domain of ***Capabilities & Ownership***, in the category of respondents from different levels of hierarchical positions, the lower level employees have rated their capabilities and ownership as 3.25 while top level employees have rated it as highest as 5.00 and the middle level employees have rated it as 3.55. In the category of work experience the members belongs to the group of fresher and highly experienced rated their capabilities and ownership as high as 4.50 and 5.00 respectively. The employees with 3-5 years experience and 6-10 years experience has rated capabilities and ownership as 3.45 to 3.25 respectively. The members belongs to International organizations have rated their organizational capabilities and ownership as high as 4.50 while the employees from national level organizations rated their capabilities as 3.32 and local level organizations as 4.08. In the category of organizational type the representative form NGOs have rated their organizational capabilities and ownership as high as 5.00; the representative from CSR organizations have rated it as 4.00 and the representative from Government organizations have rated their capabilities and ownership as 3.25 while the corporate groups' representatives rated it as low as 1.75.

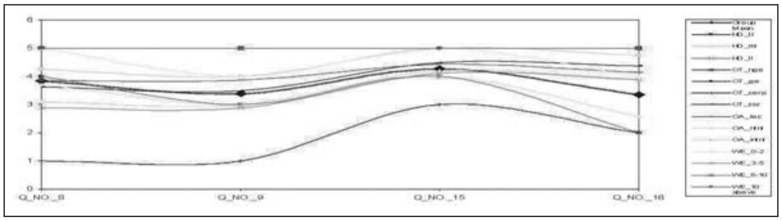

Exhibit 1 D: Mean: Capabilities & Ownership

Exhibit 1 D illustrates the comparison of the responses among all the variables identified by indicating that all curves scattered between high, i.e., 5 to low, i.e., 1. This lower down curve among the group from corporate indicate its significance by pointing out that there is no clear understanding in the organization about the key organizational capabilities. This undermines an employee's sense of contribution, belonging to the team and ownership of end results. The employees may feel an ambiguous sense of accountability since these accountabilities might be vague or non-existent and are not used as objective performance evaluators. The training and development offered by the organization either not timely, not high enough quality or not perceived as useful by staff.

DISSCUSSION

1. In the area of strategy and leadership, 94% respondents rated their strategy and leadership as high as 4 & 5 in five point rating scale. This indicates that their organizational groups have got good leadership and strategic thinking. Their challenge would be to ensure those strengths reside in the organization at large, and not just in one or two people. The 2% respondents rated that their group effectiveness in this area is average, i.e., between 2 & 3. This representation suggests that most of the time in these groups management might be making two big mistakes: (i) either they overestimate the organizations' leadership skill levels, and (ii) they do not clearly understand the concept of strategy. This also suggests that leadership in these groups might be respected but uninspiring and the strategy might be well written but not well implemented. The possible remedy could be in this situation to connect the leaders to vision, vision to expectations, expectations to staff, and staff to leaders. Self-reinforcing loop of strategy and leadership could also be created to emerge as a sustained leader in the field.

2. In the area of trust and motivation, 59% respondents feel their trust and motivation as high as 4 & 5 in five point rating scale. This indicates that their organizational groups have got good foundation of trust which supports motivating staff. Their challenge would be to maintain and grow in this area. Losses of trust can rapidly undermine an organizational performance. The 36% respondents rated that their group effectiveness in this area is average, i.e., between 2 & 3. This representation suggests that situation is not so critical but at the same time the organization is not charged up to take competitive hills. To reach the next level of performance, innovation and results the management need to grow enthusiasm and belief in the organization.

3. In the area of operational effectiveness, 56% respondents rated their operational effectiveness as high as 4 & 5 in five point rating scale. That indicates that their organizational groups have got good relatively efficient operational environment. Their challenge is to take that efficiency to the next level. The 20% respondents rated that their group effectiveness in this area is average, i.e., between 2 & 3. This representation suggests that their group has got some good process in place but certainly they have to improve their processes and efficiency by 10-30% with attendant cost saving as well.

4. In the area of capabilities and ownership, 64% respondents rated as high as 4 & 5 in five point rating scale. This indicates that their organizational groups have understood what makes them competitive and feel like they have a stake in the game. The 32% respondents rated that their group effectiveness in this area is average, i.e., between 2 & 3. This representation suggests that the group probably have grown slightly in degree over the past years or so. This is because people generally understand about the core capabilities but fail to make conscious leap to the impact that growth of their personal capabilities/skills can make on the organization. They are on board and want their organization to do well however they feel they are too small player to make a 'real' difference.

SUMMARY

In a nutshell, the perception of selected Indian rehabilitation professionals/Manager about organizational effectiveness revals that the organizations working for the disability rehabilitation are having very good strategic and leadership orientation. The analysis of the perceptions of the rehabilitation professionals/Manager also reveals that these organizations are having average Trust and Motivation followed by Capabilities and Ownership. Though the Operational Effectiveness is being rated as average but it stands last among all the four domains. This distribution might give the insight to the top managers/administrators to prioritize their organizational management related task by concentrating more on basic operations followed by developing capabilities and ownership among organization's human resources, developing trust and motivation among employees and maintaining the strategy and leadership of top management.

By referring the Metrus Group, following actions are recommended for organizations to move ahead:

(1) Identify the root causes of organizational ineffectiveness. What

are the primary contributing factors — processes, structures, systems capabilities and/or culture?

(2) Determine the leverage points for addressing the root causes. What are the impacts, benefits, pitfalls, and lasting changes that would result by eliminating these causes?

(3) Formulate a plan and make it logical, realistic and actionable. Be specific and include key results, resources, timelines, and milestones.

(4) Create buy-in and ownership of the plan.

(5) Implement and measure, implement and manage, implement and reward.

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Abbreviations

HD_tl	Hierarchical Distribution - top level
HD_ml	Hierarchical Distribution - middle level
HD_ll	Hierarchical Distribution - lower level
OT_ngo	Organizational Type – Non-government organizations
OT_go	Organizational Type – Government organizations
OT_corp	Organizational Type – Corporates
OT_csr	Organizational Type – Corporate Social Responsibility
OA_loc	Operational Area – Local level
OA_ntnl	Operational Area – National Level
OA_intnl	Operational Area – International level
WE_0-2	Work Experience – 0-2 years
WE_3-5	Work Experience – 3-5 years
WE_6-10	Work Experience – 6-10 years
WE_10 above	Work Experience – 10 and more

Annexuve 1

Organizational Effectiveness Scale Developed by Metrus Group

Sl. No.	*Items*	*Agreement*				
		Low				*High*
		1	2	3	4	5
1.	Major developments are communicated to me in a way that makes their impact on my work clear					
2.	Important information is rapidly disseminated through effective methods.					
3.	I understand how my incentive compensation is tied to my performance.					
4.	My division/unit/department have clear goals and objectives.					
5.	I have confidence in the leadership ability of senior management.					
6.	I have a clear idea of the organization's vision.					
7.	In my work group, people are valued for their contribution to the team.					
8.	I can list our key 2-4 strategic organizational capabilities.					
9.	People are held accountable for achieving high standards of job performance.					
10.	There is good teamwork and cooperation between work units and departments.					
11.	I am proud to say I work for this organization.					
12.	We have clearly documented work processes.					
13.	There is good teamwork and cooperation within my work unit.					
14.	I can count on top management to follow through and do what they say they will do.					
15.	I understand how my work contributes to the overall success of the organization.					
16.	There are sufficient opportunities for me to learn and grow professionally here.					

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