

Effect of Play and Exposure on Development of Children with Intellectual Disabilities through Community Based Rehabilitation

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Abstract

This paper studies the effect of play and exposure on the development of children with intellectual disabilities through community Based Rehabilitation in the impoverished, tribal population of Madhya Pradesh state, India. In study, 23 children (male -13 & Female - 10) ranging from mild to profound disability, were selected from seven villages of Thikari block of Barwani district. Parents and community based rehabilitation workers (CBRWs) worked rigorously with these children for one year. Children were exposed to play and participation in household activities under the guidance of a professional therapist. The goal was to mainstream these children at play and in the home. Before starting intervention, both groups (CBRWs and parents) were provided training at Ashagram Trust Center. A Likert scale was applied pre and post intervention to record progress on the development of children. A standard test VSMS also administered on 10 randomly selected children to verify Likert scale progress. Obtained pre and post scores of Likert scale and VSMS test were analyzed in conclusion.

Keywords: Community Based Rehabilitation, Intellectual Disability, Mainstreaming, Play and Exposure.

Introduction

People with intellectual disabilities (formally known as mental retardation or mentally challenged) are perceived as a challenge to mainstream by Government due to distended characteristics and manifold needs. Recent rehabilitation models available are being tried out at many levels by different agencies to address the maximal needs of such individuals¹⁻³. The Institutional Based Rehabilitation (IBR) Model predominantly focuses on the medical and educational needs of such individuals. It's reach has extended no further than the urban communities. Usually IBR brings more quantitative than qualitative results. Other Community Based Rehabilitation (CBR) models are being applied⁴⁻⁶. Evaluation of a CBR in rural India) and are of great help in developing countries. Available research proves these are most suitable models to address the needs of children with intellectual disabilities in more humanitarian ways. CBR brings both quantitative and qualitative results. Application of CBR models is found to be cost effective and most acceptable by the communities. A CBR approach needs to be practiced more as more disabled people live in rural areas. In India, 21 million people suffer from some kind of disability. This is equivalent to 2.1% of the population. Among the total disabled in the country, 12.6 million are male and 9.3 million are female. The number of disabled is more concentrated in rural areas. As of the 2001 Census, rural occurrences totaled 76%, while urban disability rates are only 24%. In total males accounted for 59% while Females are at 41% (NSSO). In Madhya Pradesh we have 14,08,528 total disabled people. Out of this total, 115,257 are mentally disabled (Census 2001).

All children follow the same pattern of development whether they are disabled or not. Their growth and learning also occurs in same manner. Irrespective of impairment or disability, all children deserve and require the same kind of environmental stimulation for acquiring lifelong skills and abilities. In well-accepted theory the development in four major developmental areas i.e. motor; language, social and cognitive, progressed much better and healthier when children get adequate opportunities to explore and observe. Children with disabilities are victims of social attitudes. They are deprived from having equal access to developmental opportunities.

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Many children in especially poor rural areas do not get the freedom to enjoy a natural environment. Predetermined attitudes towards children with developmental impairments restrict their participation in family or community based occasions. They face many social obstacles due to a poor awareness level throughout rural communities. Misconceptions towards mentally disabled children are widespread in these communities. Such attitudes restrain them directly and indirectly from participating in various activities. Parents are not an exception to this behavior. They carry a double load in terms of managing presupposed attitudes and opinions that are formed due to a lack of understanding, not to say that these parents dislike their children. Parents want to give them the best platform on which to grow because parents expect best for them. But this does not always happen in the case of disabled children. Parents do not readily compensate for their slow cognitive development and learning abilities. Parent's decreased expectations affect their parenting style, which turns into a negative and discouraging environment for the children.

Since these children are developmentally delayed⁶, they are unable to acquire certain behaviors and skills at right age. They lag behind in communication, motor skill, and concept formation and socialization skills. Very often they pick up undesirable behaviors. Most commonly; thumb sucking, spitting, body rocking, crying, defiance, throwing objects, repeating words and stammering among others. Community members; including parents, misread these characteristics. They don't understand the reason promoting the behavior. This is typically viewed as a physical disease; thus, it is looked at from different angle. A number of people; including some parents, make false judgments about their disabled children. Sadly, some parents in rural communities fear that contact with disabled children will affect their non-disabled children, making them disabled by proximity. Initially parents seek help from medical professionals, who try everything possible to diagnose them. When these attempts don't yield any improvement in their condition they loose hope and patience. As time passes, parents feel helpless and frustrated. This frustration leads improper and disparate parenting. Children not involved in mainstream interaction are often ignored or overprotected. An unhealthy parenting style creates more barriers for disabled children. They are segregated and restricted from sharing a uniform atmosphere available for healthy children within families as well as in the overall community. As a result disabled children lose natural opportunities to grow and learn.

Play activities are essential to healthy development⁷ for children and adolescents. "Play is the work of the child" (Maria Montessori). Research shows that 75% of brain development occurs after birth. The activities engaged in by children both stimulate and influence the patterns

of connections made between the nerve cells. This process influences the development of fine and gross motor skills, language, socialization, personal awareness, emotional well-being, creativity, problem solving and learning ability. The most important role that play can have is to help children to be active, make choices and practice actions to mastery. They should have experience with a wide variety of content because each is important for the development of a complex and integrated brain. Play links sensory-motor, cognitive, and socio-emotional experiences, and provides an ideal setting for natural brain development.

Children learn by observing and participating in activities. Children without disability are usually encouraged to engage in household courses while kids with impairments are discouraged from everything. Due to sub average intellectual capacity, slow reaction and performance these children are unable to follow the pace of non-disabled children. They are very capable of learning many things at their speed if the instructions are provided in a graded manner. Communities at large do not understand this fact so they give little importance to these children. Comparisons between non-disabled and disabled happen all the time. That leads to emotion-based reactions in parents. Most parents end up making uninformed opinions about them. Most often they feel that these children can't learn or perform tasks correctly⁷⁻¹⁰. Resulting in the sidelining of these children from normal course. Parental focus shifts from disabled to non-disabled children. Non-disabled children receive more attention and disabled children; in turn, become isolated. Bonding between disabled children and parents grows weaker.

Objectives

- 1 To assess effect of play and exposure on children with Intellectual disabilities in parental views.
- 2 To assess impact of community-based rehabilitation in children with intellectual disabilities in rural poor tribal area.

Methods

Design and settings: This study was done in year 2005-2006 under a collaborative project "Empowerment of persons with disabilities through capacity building initiatives" (June 2005 to Dec 2007). This project was implemented by two organizations Ashagram Trust, Barwani (MP) and Concerned Action Now, Delhi (CAN) in 36 villages of Thikari block. Department of International Development (DFID) funded this project. DFID is a department comes under UK Ministry. Usually DIFD do not work or support to grassroots organization directly. Organization support and work through government system. But this was under it's a unique scheme Poorest Area Civil Society (PACS) through a New Delhi based

organization called "Development Alternatives" (DA). Researcher was the employee (May 1999 to July 2007) of Ashagram Trust who played crucial role in planning and implementing this project. More important study was not the part of project plan. The idea of such study came in researcher mind first. Then the other important persons at Ashagram Trust also supported it. Researcher was also a Project Director of this project.

All selected children were called in medical camps where researchers and highly trained therapists for mental retardation carried out diagnostic procedures with them. Therapist visited the rest of the children who could not be brought in to the camp by parents for diagnostic purpose. Diagnoses were made using three major diagnostic tests used in Mental Retardation. These are Gassels Developmental Drawing Test (GDT), Developmental Screening Test (DST) and Vineland Social Maturity Scale (VSMS). Their medical history and functional ability were also assessed (NIMH, Secuendrabad model). Orthopedic surgeon, ENT specialist and a Physician also examined these children for any other disability or medical condition.

Once diagnostic exercise was completed for all children therapist conducted home visits to every child in the selected group. Local CBRWs were also taken along. Therapist then carried out a detailed needs assessment. Usually it took on an average two and half hours with per client. Therapists then shared details of the progress of individual projects with parents. How does this empower and build capacity for people with disabilities? Specific steps and intervention envisaged for selected groups were shared elaborately. Attempts were made to address the whole family at a time but in 36% of instances only mothers and grandparents were available. Most of them have not shown enthusiasm to participate in the program but also none of them refused to participate. This whole exercise of need assessment was done in 11 visits by therapist over the period of one month.

Alongside parents, CBRWs received residential training at the Ashagram Trust Institute. This training was done in 5 rounds. Each round took three days, 15 days in total. Training had two basic components. First, a therapeutic component in which they learned different theories, concepts and skills applicable to children with intellectual disabilities and secondly, social components are learned including how to conduct meetings in the village, communicate with parents, school teachers and other stakeholders and also about to create awareness in the community. People and children at all levels are encouraged to create conducive atmosphere for such children to participate that includes important mainstreaming. After each round of theoretical training all trainees were sent on field. They were assigned

agendas to practice under the supervision of experienced supervisors of other CBR project areas. Later on; additional and specific to research, input was provided to select CBRWs who participated in study.

CBRWs contacted each parents and administered the questionnaire using the Likert rating scale. They were asked to rate their responses on 0 to 10 point scale on questions mentioned below. All questions were asked in their local languages (Nimari and Bhilali). The questionnaire comprised the following questions addressing all four major areas of development. (1.) How much you allow your child to participate in house hold activities? (2.) How much you communicate with your child daily? (3.) How much you socialize/ play with your child daily? (4.) How much you think your child shows appropriate behaviors? (5.) How much are you happy with the natural development/ progress occurring in your child. (6.) How much are you worried with his/her future?

Intervention in Family and Community: CBRWs were asked to make compulsory visits to each house at least once per week or more if possible. During visits they played with kids. Took them out and encouraged them to play with other children of the community. They also talked very frequently to other children to allow and involve disabled children in their play. Some disability sensitivity activities were done in the village and school level. Parents made it a point that all their children should play together involving their disabled siblings. Most of the families work in agriculture or as a manual laborer where they started taking their kids along in order to provide comprehensive life skill exposure. Grandmothers played a great role by involving these children in all household activities such as cleaning, sweeping, arranging beds, peeling, cutting vegetables, washing dishes, washing cloths, bringing water from hand pump, feeding livestock etc. Parents started taking subject children to the markets. These changes in the parent's behavior have created a very positive and conducive atmosphere in which children can grow and progress.

In initial months of study, parents were brought into the project for implementing organization and exposure. During these visits they were given some form of orientation on mental disability. They were also shown some useful videos demonstrating positive changes in children with mental disability through encouraging play and involvement in family and community activities. This exercise was aimed to educate and motivate parents, mostly. In project agenda it was also ensured that each child should be entitled to a disability certificate and a social security pension. Admitting children to Aaganwadis and primary schools did educational mainstreaming. After completion of one full year of intervention in study, another group of CBRWs was sent to each family to record

parental responses on a similar Likert scale questionnaire. This was done in order to minimize error and rule out subjectivity, which might have come if the same CBRWs were asked to administer it. In broader terms, overall attempts had been made to mainstream these children through exposure to play and by promoting active participation in all household activities following CBR principles.

Sample: The Community-based Rehabilitation project “Empowerment of persons with disabilities through capacity building initiatives” implemented in 36 villages (populations 41,629, census-2001). There were total 107 children with intellectual disabilities identified in preliminary survey done by CBRWs. Entire project area was divided into 11 smaller clusters comprising 3-4 villages in each. Out of these 11 clusters two clusters were selected randomly by picking up their names for this research. These two clusters had seven villages (Semalda Dev, Mehgoon Dev, Ranswa, Junapani, Uchawad, Bhmauri & Rangoon Dev) with 9,638 populations. Caste wise distribution is SC – 12.71 %, ST – 40.73% & other – 46.56 (census 2001). There were total 31 children with intellectual disabilities in selected sample. Out of them - 8 (25.80%) children those had borderline mental disabilities were excluded strategically from research because they were already seen in mainstream. And we found it unethical to bring their disability in notice. Rest all 23 (M - 13 & F- 10) had mild to profound disability was taken for study. These children’s age range is 0-5 years – 08 (34. 78 %), 05- 11 years - 09 (39.13 %) & years 10 onwards – 06 (26.08%) and diagnosis Mild – 07 (22.58 %), moderate – 11 (35.48%), Severe – 04 (12.90%) and profound - 01 (03.22%). It can be said that all selected children were known as disabled by community.

Measures: Parents together with CBRWs are given orientation and inputs to understand different plays those are crucial role players in development of children. These are **Motor Play**, which provides critical opportunities to develop both individual gross motor and fine muscles and strengthen overall integration of brain function. **Social Play** by which children learn social rules such as give and take, reciprocity, cooperation and sharing, **Constructive Play** that allow children to manipulate their environment to create things and to find out combination that work and don’t work. **Fantasy Play** in which children learn to abstract, to try out new roles and possible situations, and experiment with language and emotions and also through this they develop flexible thinking, stretch the imagination. And Games with rule to grow from an egocentric view of the word to an understanding of the importance of social contracts and rules. **Solitary Play**, that means playing alone by him / her only. **Parallel Play**

children play alongside with other kids without much interaction with each other. **Group Play** when children play in group by which learn social skills such as sharing and turn taking. **Task Analysis** that is most effective technique in training children with mental disability was exposed to whole group so that they can break down steps of all play & house hold activities in which child encouraged to participate. Training also covered various parenting styles such as **Authoritative, Permissive, and Rejecting/ neglecting** and **Democratic**. Focus was given to be **democratic** in parenting and rearing the children.

Results

Obtained finding on likert scale of all areas are mentioned below in table.

Items	Pre/Post	Mean	SD +	t-value	p-value
Participation	Pre	2.00	1.65	9.64	0.05
	Post	6.91	1.80		
Communication	Pre	2.04	1.42	6.11	0.05
	Post	5.43	2.25		
Socialization	Pre	2.56	1.64	5.03	0.05
	Post	5.43	2.19		
Appropriate Behaviour	Pre	2.26	1.32	5.25	0.05
	Post	5.08	2.21		
Natural Progress	Pre	1.43	1.03	5.53	0.05
	Post	4.17	2.14		
Worry Level	Pre	6.56	1.97	7.30	0.05
	Post	2.79	1.97		

Table 1: Scores on Likert-rating Scale (n= 23, males-13 & females-10). P < 0.05, DF- 44, t-value on one tail- 1.68, two tail – 2.01 & P < 0.005, DF- 44, t-value on one tail – 2.69 & two tail- 2.95, mean difference highly significant.

Verification of Results on Standard Test: In order to validate parent’s responses and verify whether the children really made progress the “Vineland Social Maturity Scale” (VSMS) was administered again on 10 randomly picked up children from the group. Score shows that there is a good progress on children’s development. Actually it was not planned earlier to use this test at the end of this study. Implementing organization was in plan to administer this test on few children of entire project area (36 villages) at the end of project (June 2005 to Dec.2007) to get the some idea of project outcomes.

VSMS has developed by US psychologist Edgar Arnold in 1936. In India its Indian version is being used for the making part diagnosis and measuring functioning level of different areas of persons with mental retardation. This measures eight category of behavior, self help general, self-help eating, self-help dressing, locomotion, occupation, communication, self-direction and socialization. It is also used very effectively in planning

for therapeutic intervention or Individualized instruction for persons with mental retardation. VSMS can be used from birth up to the age of 30 years. It consists of 117-item interview with a parent or other primary caregiver.

Test	Pre/Post	Mean	SD +	t-value	p-value
VSMS	Pre	42.1	11.25	2.13	0.05
	Post	52.2	9.90		

Table 2: VSMS pre & post scores (n= 10, females- 6 & males -4). P < 0.05, DF- 18, t-value on one tail- 1.73, two tails – 2.10. Mean difference is highly significant.

Referring table 1, obtained score on pre and post assessment on likert-rating scale analyzed to see significance of true mean difference by calculating t-value on P<0.05. Participation of children in all activities (Pre-Mean-2.00, SD-1.65, Post- Mean-6.91, SD-1.80) t-value is 9.64 on p<0.05 & p<0.005 (t-value 1.68) indicates that mean difference is very significant. Communication of children improved quantitative and qualitatively, has (pre-Mean-2.04, SD- 1.42, Post- Mean- 5.43, SD-2.25) has t-value 6.11 on both p<0.05 & higher shows mean difference is significant. Similarly Socialization aspects of all these children found better in all settings (pre – Mean – 2.56, SD-1.64, post- mean- 5.43, SD- 2.19) t-value is 5.03 on p<0.05 have high significant mean difference. Parents found that their children have acquired desired behaviors and showing Appropriate behavior in their settings (pre- mean 2.26, SD-1.32, post- mean- 5.08, SD- 2.21) t-value is 5.25 indicates that mean difference is highly significant on p<0.05 & p<0.005. Natural Progress considered overall development of children in parental views which has improved a lot since statistics also (pre-mean-1.43, SD-1.03, post- mean-4.17, SD-2.14) t-value is 5.53 on p<0.05, p<0.005 indicates very high significance of mean difference. Parents Worry level with children' future was very high in the beginning, which came down significantly by this whole exercise. They developed realistic picture and some hopes. On (Pre-mean 6.56, SD-1.97, post- mean- 2.79, SD- 1.97) t-value is 7.30 on p<0.05 & p<0.005 indicates that mean difference is significant. Thus statistics shows high level of improvement in all areas. Analysis on VSMS a standard psychological test the statistical scores (table-2) is (pre- mean 42.1, SD-11.25, post –mean 52.2, SD-09.90) t-value 2.13 on p<0.05 indicates that results are true.

Discussion

Analysis of result findings on likert scale strengthens the hypothesis that by providing adequate natural play opportunity and systematic inclusion in daily routine brings a great positive change in children with intellectual

disabilities. It also indicates that provided intervention improved child-parent, child-peer, child-community & parent-community relationship. It also increased awareness as well as build up hope and sense of pride among parents for their kids. Same time carried out intervention reduced inappropriate practices. More important dying hopes rejuvenated towards hope and success. Other than statistical findings, research team observed great integration and mainstreaming of these children in their communities by end this study. The outcomes of this study are very positive which proves that children exposed to natural play, household tasks and brought up in democratic parenting styles develop significantly. Post VSMS findings also indicate that there was significant development occurred in all children. Intervention also helped in reducing disability percentage in children and prevented them from acquiring secondary handicaps.

Limitations

In this kind of intervention community also play very significant role but here perceptions of community have not been assessed at any level from beginning to the end of this study. It would have been better to do this exercise in order to see its impact on other beneficiaries of this program such as community at large.

Conclusion

Obtained results strengthen the arguments that play and exposure provided under community-based rehabilitation model helps children with intellectual disabilities to enhance their development and reduce parental worries significantly. This study is supporting CBR, as a suitable approach of rehabilitation for persons with intellectual disabilities living in poor rural areas.

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