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Awareness among Parents Regarding the Care for their Special Child in Rural and Urban India

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Abstract: **With the implementation of the persons with Disabilities Act (PWD), 1995 mental retardation has been recognized as a disability with an identity of its own. A survey was conducted in which 40 families were involved in the study. Results showed that the people living in urban areas are more aware of the care that has to be taken during pregnancy to avoid the birth of a mentally challenged child and they are also more aware of the later care that has to be taken of the special child.**

Keywords: **special child, mental retardation, parents, PWD Act.**

I. INTRODUCTION

Identification of persons with special needs and offering them care and management for their disabilities is not a new concept in India. The concept is being changed over time as a community participative culture. The status of disability in India, particularly in the provision of education and employment for persons with mental retardation, as a matter of right, has its recognition only in recent times, almost after the enactment of the Persons with Disabilities Act (PWD), 1995.

A. Changes as Per Time

Changes in attitudes towards persons with disabilities also came to about with city life. The administrative authorities began showing interest in providing formal education systems for persons with special needs, particularly for families which had taken up residences in the cities. Changes in life style of a persons with special needs were also noticed with their shifting from 'community inclusive settings' in which families rendered services to that of services provided in 'asylums', run by governmental or non-governmental agencies (Chennai, then Madras, Lunatic Asylum,1841). It was at Madras Lunatic Asylum, renamed the Institute of Mental Health, that persons with mental illness and those with mental retardation were segregated and given appropriate treatment.

B. Establishment of Special Schools

Article 41 of the Constitution of India (1950) embodied in its clause the 'Right to Free and Compulsory Education for All Children up to Age 14years'. In 1953, training teachers to teach persons with special needs was initiated in Mumbai by Mrs. Vakil. The Indian Education Commision,1964-66 made a clear mention of the presence of only 27 schools for persons with mental retardation in the entire country at that time. In 1971, special education to train persons with special needs, specially persons with mental retardation, was introduced in Chennai at the Bala Vihar Training School by Mrs. M. Clubwala Jadhav. In the same year, the Dilkush Special School was established in Mumbai initiating special teachers' training programs.

C. Mental Retardation

The AAMR (1992) definition of mental retardation, manifesting before age 18, refers to a substantial limitations in present functioning, characterized by significantly sub-average intellectual functioning which exists concurrently with

related limitations in two or more of the following adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.

In adopting this definition and the accompanying classification system, AAMR (1992) suggests the mild, moderate, severe and profound classification to be substituted with 'levels' of support needed by an individual. These terms may be summarized as below:

- Intermittent: support of high or low intensity is provided as and when needed. Characterized as episodic or short-term during life-span transitions.
- Limited: supports are provided consistently over time, but may not be extensive at any one time. Supports may require fewer staff members and lower expense than more intense levels of support.
- Extensive: supports characterized by regular involvement (daily) in at least some environment (work or home) and not limited (example: long term support and long term home living support).
- Pervasive: high intensity supports are provided constantly, across environments, and may be of life sustaining and intrusive nature. Pervasive supports typically involve a variety of staff members.

The AAMR 2002 definition reads 'mental retardation is a disability characterized by significant limitations, both in intellectual functioning and in adaptive behaviour, as expressed in conceptual, social, and practical adaptive skills, the disability originating before the age of 18.

D. Estimates in India

Most available data on the prevalence of mental retardation in the country is derived from the psychiatric morbidity surveys conducted by the mental health professionals in specific or circumscribed geographical areas or on target populations, such as rural-urban, industrial population and educational institutions. The prevalence rates of mental retardation, some from the school population, some from the general population, is reported from 1951 to 1994, in the range of 0.07 to 40 per 1000. The prevalence rates for mental retardation in the school population and the general population, rural and urban, based on psychiatric morbidity survey ranges from 0.1 to 140. The sample selected has been a skewed one.

The National Sample Survey Organisation (NSSO) under the Department of Statistics, Government of India conducts large scale survey for socio-economic planning and policy formulation. The first large scale attempt to collect information on the prevalence of developmental delays was in the 47th round of survey by NSSO. Data obtained from various sources indicate that the prevalence rate of mental retardation is about 20 per 1000 general population while the prevalence of developmental delays is about 30 per 1000 in the 14 year old population. In rural areas, the incidence of mental retardation is 3.1 % and in urban, it is 0.9%. The NIMH mentions that 2% of the general population is MR. Three quarters of them are with mild retardation and one-fourth are with severe retardation (Panda,1999). The Government of Tamil Nadu has initiated creation of a database on disabilities (2007) on the population with a door-to-door survey in all its districts.

E. Family with Children Having Special Needs

Parenthood is perceived as an expected, positive and rewarding aspect of life. Every parent wishes to have a healthy baby but some persons though not by choice are forced into a situation of having a child with disability. Parents having a child with mental retardation experience variety of stresses and strains. It is traumatic specially: when parents learn or suspect disability in the child. Parents get upset when they come to know the disability of the child which is followed by denial associated with sadness, fear, anxiety, anger, disappointment, hostability but some of them accept the reality as per time, start recognizing the fact by showing willingness to seek help and information. Parents also get impacted emotionally, physically, socially and financially. Siblings feel mentally pressurized, emotionally disturbed and socially stigmatized.

Presence of a child with mental retardation is unforeseen and new situation. Family members do not have alternatives to resolve the situation. The emerging crisis disorients them and lower their functional abilities. This is termed as 'stage of disorganization', which is a temporary phase till the confusion is sorted out. Through education, training, guidance and emotional support they can be helped to accept the problem in a realistic way and develop coping skills to improve and reach near normal level of performance.

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F. Role of Parents

Professionals, working in the field of disability, are increasingly realizing the necessity of involving parents, early enough in the habilitation programme. This is precisely for the reason that parental involvement not only helps in strengthening the families but also insures meaningful and important form of input to the school programme. The parents are important sub-group of consumers served by the school system. Therefore, special attention need to be given to such children who require services beyond those provided in the mainstream of education.

G. Factors Affecting Rehabilitation in Urban and Rural Settings

Urban Setting: nuclear family, family conflicts, social stigma, non-acceptance, rejection or over-protection, special school at distances, transportation problems, expensive services, unemployment, non awareness of services etc.

Rural Setting: joint family, ignorance-lack of awareness, traditional thinking, lack of trained personal, lack of facilities, non-availability of resources, poverty and illiteracy, misconceptions etc.

H. Urban and Rural Needs of Habilitation

Urban Needs: information about habilitation services, Decentralization of services: pre-school programmes, special schools, day care centres and centre forspastics, Counselling services, Need to transportation facilities, Need of centres for vocational training, job placement and follow up programmes, need for financial assistance for self employment, job reservations in public and private sector, need for residential institutions, need of medical, therapeutic and care services for severely and profoundly retarded persons in institutional setting or in hospitals, public awareness, advocacy and enforcement of laws for protection of rights and need of appropriate provisions for recreation etc.

Rural Needs: creation of public awareness, provision for prevention, early detection, intervention, and management, training programme for village level rehabilitation workers, counselling services, need of aganwadis and balwadies, home based programmes, training and rehabilitation facilities at community level, need for developing low cost aids and educational material, provision for reaction and leisure time activities etc.

II. LITERATURE REVIEW

A review of the literature reveals that only few local studies have been done in this field. The term ‘inclusive education’ is nowadays broadly conceptualised to include students from different backgrounds and with languages other than English, as well as students with disabilities (Ashman, 2002). Some parents prefer and advocate for inclusive placement, while others favour separate placement (Grove & Fisher, 1999). As the trend towards inclusion grows, one of the chief concerns of parents is the protection of support services for their child. Daniel and King (1997) found that parents were more concerned about the degree to which their child’s individual education plan (IEP) actually addressed the needs of their child when the child was being educated in an inclusive setting, as opposed to a segregated setting. It may be difficult for parents to find schools with personnel who are sufficiently knowledgeable about inclusive educational goals in order to provide appropriate services to their child (Grove & Fisher, 1999).

III. OBJECTIVE OF THE STUDY

To study the awareness level of parents regarding children with special needs residing in urban areas and parents residing in rural areas

IV. HYPOTHESIS

Parents residing in urban areas would be more aware about the symptoms and the care that has to be taken in case of a child with special needs than parents who are residing in rural areas

V. METHODOLOGY

A structured interview was conducted in which 36 questions were asked to the people who are residing in urban areas and the people who are residing in rural areas. Small sample size was taken. Total 40 families were included as a sample, 20 families from village and 20 families from town. Each family has a special child as their member. All the families are residing in Barrackpore, 24 parganas (north), Kolkata, West Bengal. The informants were the parents of the special child, either the mother or the father. A detailed case history of the child was taken from either of the parent. Along with the

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case history, educational qualification, monthly income and occupation of the parent was also noted down. The questions were decision making types, with answer 'yes or no'. For each 'yes' answer, 1point was given to the informant. Comparison between the two groups (village and town), was done on the basis of mean and standard deviation which was calculated, later on.

VI. RESULTS

Table 1 Shows The Raw Score Of The Families Residing In Urban Areas

Family no.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Raw Score	24	27	13	19	21	16	28	19	32	32	18	28	14	32	24	36	12	13	19	24

Table 2 Shows The Raw Score Of The Families Residing In Rural Areas

Family no.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Raw Score	24	27	13	19	21	16	28	19	32	32	18	28	14	32	24	36	12	13	19	24

Table 3 Shows The Mean And Standard Deviation Of The Two Groups (People Residing In Urban Areas And People Residing In Rural Areas)

	People Residing in Urban Areas	People Residing in Rural Areas
Mean	23	19
Standard Deviation	4.6368	4.3012

VII. DISCUSSION

A survey was conducted to check which population (the people residing in villages or the people residing in town area) is more aware of the care that has to be taken during pregnancy which could prevent the birth of a special child. After the survey was conducted it was noted that the people who are living in town or urban areas are more aware of the precautions that should be taken during pregnancy. This can be due to many factors, for example, education can be one of them. After taking a detailed case history from the parents, it was noted that the parents who are living in villages has education upto class 8^{th}. Whereas the parents who are living in urban areas have a minimum education upto graduation. Since the education level is higher, they are more aware of the biological facts regarding pregnancy and the care that needs to be taken during pregnancy. The basic care would help the pregnant lady to resolve the health issues in the three trimesters.

Also, media plays a great role in creating awareness. Media has a greater effect on the people living in urban areas as compared to the people living in villages. Parents are more aware of the care that needs to be taken if a special child is born. A special child needs special care. Special classrooms with multi sensory strategies to help the child in the learning process is required. Special educators need to be appointed to meet their social, personal, intellectual and vocational needs. Media has the power to influence greater number of people. Government has started many schemes to help children with special needs. But the results showed that the people residing in urban areas are more aware of the schemes that are launched by the government.

VIII. FUTURE RESEARCH SCOPE

In the census of India, 2001, an attempt has been made to assess the disability population in the country belonging to different categories. Unfortunately, no reliable information could be obtained from such data as regards mental retardation since it has been clubbed with mental illness, a term alien to mental retardation in its current conceptualization. We can help the families by providing education regarding the facts of mental handicap. Family members need to exchange and express their feelings with close ones. There is a need to establish a system or mental support group between the family

and rest of the society. Take an opportunity to speak or discuss in social, or public gathering to educate community members. Publish articles to share the thoughts and experiences of the persons with special needs or share the activities and efforts to others.

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