# An Epidemiological Study To Assess Health Needs Of Mentally Challenged Children Enrolled In Special School

**Dr. Aftab A. Siddiqui**

Assistant. Professor, Dept. of Community Medicine, Seth GS Medical College, Mumbai

**Dr. Sanjay Panchal**

Associate Professor, Dept. of Community Medicine, H.B.T. Medical College, Mumbai

**ABSTRACT** *Context: Presently there is no cure for mental retardation. So that asserting morbidity profile and health needs and health seeking behaviour, awareness and utilization of available welfare facilities becomes imperative. Aim & Objectives: To assess the socio-demographic profile and health status of mentally challenged children enrolled in special school & study the health seeking behaviour by their parents. Methodology: This is a cross sectional study carried out in 2 special schools on 64 children. Face to face interviews were carried out with pretested semi structured questionnaire after obtaining Informed consent. Results: Most common grade of Mental retardation (MR) was mild. 36% participants had Ophthalmic Morbidity. Mean age at diagnosis was 30.5 months. Most common felt need of the parents was the rehabilitation of their child after 18 years. 81% parents were using Welfare schemes for their child. Conclusion: The incidence of refractive errors, ENT problems was statistically significant*

## Introduction:

According to Persons with Disabilities (Equal opportunities, protection of rights and full participation) Act, 1995, enacted in India, mental retardation is defined as a condition of arrested or incomplete development of mind of a person which is specially characterized by subnormality of intelligence. [1] Some 5 to 15 % children of 3 to 15 years in both developing and developed countries suffer from mental handicaps. [2] Nearly 75% of the people diagnosed to have retardation fall in the category of mild mental retardation, while remaining 25% having an IQ of less than or equal to 50 are classified as moderately, severely or profoundly retarded. [2] From several small scale surveys in India, [3] it is generally believed that between 2-3% of population suffer from mental retardation (NIMH 2010). This implies that mentally retarded people in India could be anywhere near 26 million. [4] The majority of mentally retarded persons are below 15 years of age and prevalence of 15 to 30 per 1000 as per NSSO under the Dept. of Statistics, Govt. of India. [5]

Provision of education and employment for Persons with mental retardation, as a matter of need, and above all, as a matter of right, has had its recognition only in recent times in the form of shifting focus from residential schools towards interactive special schools after the enactment of Persons with Disabilities Act, 1995.

Consideration needs to be given to a wide range of handicaps involved, their diagnosis and assessment and the potential areas of interventions best suited to the problem in a given area. An understanding of the various preventable predisposing factors and their comparison with degree of mental retardation is needed in order to intervene effectively, together with an understanding of the range of services, both medical and psychosocial (welfare services) from parents point of view, that would offer practical opportunities for amelioration and rehabilitation. In the light of this, present institution based study was conducted to meet the felt needs. (The new term for mental retardation is differently abled, but for the purpose of study, the term mental retardation is used).

## Aim & Objectives:

1. To assess the socio-demographic profile of mentally challenged children enrolled in special school.
2. To assess the health status & specific needs of mentally challenged children enrolled in special school.
3. To study the health seeking behaviour by parents in the interest of their mentally challenged child.

## Material & Methods:

The present study is a cross sectional study, carried out in 2 special schools for mentally challenged in the particular ward of the metropolitan city which was in close vicinity of parent college, over 1 year period. A non-randomized sampling technique was used and a total of 70 children enrolled in both schools along with their parents were involved in the study. But 6 children never appeared for the interview due to chronic absentee. (Sample size – 64).

Those who satisfied the definition of mentally challenged and whose parents consented to take part in the study were included. Whereas those who did not give consent or left the study in between were excluded. The permission to conduct the study was obtained from the education department and respective schools. Orientation meetings were organized to elaborate the need and purpose of the study to the parents and the teachers.

Face to face in depth interviews were carried out with the help of pretested semi structured questionnaire in Marathi or Hindi. Informed consent was obtained prior to starting the interview. The information of each child i.e. Socio-demographic, economic etc was collected. A thorough history regarding the health status during pregnancy, neonatal history, initiation and progress of the health problems of their child was asked. Various predisposing factors were compared with the degree of mental retardation in these children.

Medical examination included general examination and assessment of nutritional status, systemic examination with test for vision, hearing and speech during school time in the presence of their parents and teachers. Assistance from an Ophthalmologist, ENT specialist and a Pediatrician was sought when necessary.

All responses were tabulated and Data analyzed using SPSS software version 20.0. Percentage analysis was done for Socio-Demographic factors. Statistical tools like mean, median, range, proportions and Chi Square test were used as appropriate.

## Results:
### A. Socio-Demographic Distribution:

**Table 1: Distribution of participants according to Gender:**

| School | Female | Male | Total |
|---|---|---|---|
| School A | 15 | 15 | 30 (46.9%) |
| School B | 15 | 19 | 34 (53.1%) |
| Total | 30 | 34 | 64 (100%) |

Male students (53%) were slightly higher than female students (47%). Male to female ratio was 1.1 to 1.

**Table 2: Distribution of participants according to age:**

| Age Group (in years) | Female | Male | Total |
|---|---|---|---|
| Upto 6 | 3 | 0 | 3 (4.7%) |
| 7 – 10 | 8 | 8 | 16 (25%) |
| 11 – 13 | 8 | 8 | 16 (25%) |
| 14 - 18 | 11 | 18 | 29 (45.3%) |
| Total | 30 | 34 | 64 (100%) |

Mean age of the participants was 12.33 years with SD 3.41. Maximum students were from 14 – 18 year age group i.e. 29 (45.3%).

**Table 3: Distribution of participants according to Grades of Mental Retardation:**

| Grades of MR | Female | Male | Total |
|---|---|---|---|
| Mild | 15 | 18 | 33 (51.6%) |
| Moderate | 9 | 11 | 20 (31.3%) |
| Severe | 3 | 4 | 7 (10.8%) |
| Profound | 3 | 1 | 4 (6.3%) |
| Total | 30 | 34 | 64 (100%) |

The most common grade of Mental retardation (MR) is mild (51.6%) followed by Moderate (31.3%), Severe (10.8%) and Profound (6.3%). Mean IQ was 49.02 with SD = 14.41 for further statistical purpose, Moderate, Severe and Profound grades are clubbed under one category: Serious Mental Retardation.

**Table 4: Distribution of participants according to Type of Family and Socio-Economic classification:**

| Type of Family | Mild MR | Serious MR | Socio-Economic class | Mild MR | Serious MR |
|---|---|---|---|---|---|
| Joint | 14 | 10 | Lower | 0 | 2 |
| Nuclear | 19 | 21 | Upper Lower | 27 | 24 |
| Total | 33 | 31 | Lower Middle | 4 | 3 |
| | | | Upper Middle | 2 | 2 |
| | | | Total | 33 | 31 |

Total 40 participants were from Nuclear families. Maximum cases belonged to Upper Lower Socio-Economic class (80%) according to Modified Kuppuswami Classification.

**Table 5: Distribution of participants according to H/o Consanguinity and Place of Delivery:**

| Type of Consanguinity | Mild MR | Serious MR | Place of Delivery | Mild MR | Serious MR |
|---|---|---|---|---|---|
| 1st Cousin | 8 | 9 | Home | 5 | 2 |
| Uncle-Niece | 1 | 0 | Hospital | 28 | 29 |
| More distant relation | 3 | 5 | Total | 33 | 31 |
| Total | 12 | 14 | | | |

Out of 64 participants, 26 (40.6%) were born of consanguineous marriage and of that close parental consanguinity was present in 17 cases. Total around 89% cases were delivered in Hospital.

**Table 6: Distribution of participants according to H/o problem during ANC period; INC Complications & Birth Order:**

| Problem during ANC | Mild MR | Serious MR | INC Complications | Mild MR | Serious MR | Birth Order | Mild MR | Serious MR |
|---|---|---|---|---|---|---|---|---|
| Yes | 8 | 5 | Yes | 13 | 17 | 1st | 15 | 8 |
| No | 25 | 26 | No | 20 | 14 | 2nd | 10 | 14 |
| Total | 33 | 31 | Total | 33 | 31 | 3rd | 7 | 5 |
| | | | | | | 4th | 1 | 2 |
| | | | | | | 5th | 0 | 2 |
| | | | | | | Total | 33 | 31 |

Around 20.3% had a history of problem during ANC Period. Approximately 47% had a history of intranatal complications. Birth order 2 has the highest incidence of MR i.e. around 37.5% followed by Birth order 1 i.e. 35.9%.

### B. Health Status
**Table 7: Distribution of participants according to Ophthalmic and ENT Morbidity:**

| Ophthalmic Morbidity | Mild MR | Serious MR | ENT Morbidity | Mild MR | Serious MR |
|---|---|---|---|---|---|
| Refractive Error | 6 | 10 | ASOM | 1 | 3 |
| Refractive Error & Nystagmus | 1 | 1 | CSOM | 0 | 4 |
| Squint | 1 | 4 | Reduced Hearing | 3 | 5 |
| No | 25 | 16 | No | 29 | 19 |
| Total | 33 | 31 | Total | 33 | 31 |

Around 36% participants had Ophthalmic Morbidity with refractive error having the maximum incidence i.e. 25%. The incidence of refractive errors was more in Serious MR group which was statistically significant (p = 0.04). 25% students had ear problems and it was statistically significant in Serious MR group (p = 0.01).

**Table 8: Distribution of participants according to Dental and Speech Defects and BMI grades:**

| Dental Decay | Mild MR | Serious MR | Defective Speech | Mild MR | Serious MR | BMI Grading | Mild MR | Serious MR |
|---|---|---|---|---|---|---|---|---|
| Yes | 6 | 20 | Yes | 7 | 7 | Severely Thin | 7 | 5 |
| No | 27 | 11 | No | 26 | 24 | Thin | 1 | 9 |
| Total | 33 | 31 | Total | 33 | 31 | Normal | 12 | 15 |
| | | | | | | Overweight | 6 | 2 |
| | | | | | | Obese | 7 | 0 |
| | | | | | | Total | 33 | 31 |

About 40% (26/64* 100) students had dental decay which was statistically significant in Serious MR group (p = 0.001).

Approximately 21% (14/64* 100) participants had some kind of speech defects. Mild and Serious MR group had more incidence of over nourishment and under nourishment respectively which was statistically significant (p = 0.007).

## C. Health Seeking Behaviour
**Table 9: Distribution of participants according to Age at the time of Diagnosis of MR and Time Lag in approaching the health Facility (Patient Delay):**

| Age at the time of Diagnosis (Months) | Mild MR | Serious MR | Time Lag in Approach (Months) | Mild MR | Serious MR |
|---|---|---|---|---|---|
| ANC | 0 | 1 | 0 – 1 | 16 | 17 |
| Birth – 1 | 4 | 5 | 1 – 3 | 3 | 1 |
| 1 – 12 | 8 | 6 | 3 – 6 | 9 | 6 |
| 12 – 24 | 5 | 6 | 6 – 12 | 5 | 5 |
| 24 – 48 | 8 | 6 | 12 – 24 | 0 | 2 |
| 48 – 72 | 7 | 5 | Total | 33 | 31 |
| Above 72 | 1 | 2 | | | |
| Total | 33 | 31 | | | |

Mean age at diagnosis is 30.5 months with SD = 27.14 months. In approximately more than 51% cases there was no patient delay followed by 23% cases having a delay of 3 – 6 months. The mean patient delay was 3.98 months with SD = 5.51 months.

**Table 10: Distribution of participants according to Time Lag between Health care approach for the first time & Diagnosis of MR and Visit to specialists:**

| Time Lag for Diagnosis (Months) | Mild MR | Serious MR | Visit to specialists* | Mild MR | Serious MR |
|---|---|---|---|---|---|
| 0 – 1 | 4 | 8 | Endocrinologist | 1 | 0 |
| 1 – 6 | 11 | 12 | Cardiologist | 1 | 2 |
| 6 – 12 | 13 | 4 | Neurologist | 7 | 9 |
| 12 – 24 | 3 | 4 | Orthopedics | 1 | 1 |
| 24 – 36 | 0 | 1 | Physiotherapist | 4 | 4 |
| 36 – 48 | 2 | 1 | Psychiatrist | 1 | 2 |
| Above 48 | 0 | 1 | Speech | 7 | 8 |
| Total | 33 | 31 | | | |

**\* Multiple Response**

Around 36% cases had delay upto 6 months. The mean delay was 10.45 months with SD = 13.24 months. Total 38 participants were receiving treatment from specialists and out of those 8 were receiving treatment from 2 different specialists. Most commonly visited specialists were Neurologists (42%) followed by Speech Therapists (39%).

## D. Rehabilitation
**Table 11: Distribution of participants according to Years of Special Schooling:**

| Years of Special Schooling | Mild MR | Serious MR |
|---|---|---|
| 1 | 7 | 5 |
| 2 | 0 | 5 |
| 3 | 3 | 7 |
| 4 | 7 | 2 |
| 5 | 5 | 5 |
| 6 | 2 | 2 |
| 7 | 1 | 2 |
| 8 | 3 | 1 |
| 9 | 2 | 1 |
| 10 | 2 | 1 |
| 12 | 1 | 0 |
| Total | 33 | 31 |

Mean years of schooling was 4.61 years.

**Table 12: Distribution of participants according to information got about Special School & Felt needs of Parents:**

| Information about School from | Frequency | Felt needs of Parents* | Frequency |
|---|---|---|---|
| Doctor & Hospital Staff | 5 | Rehabilitation after 18 yrs | 43 |
| Friends & Relatives | 4 | School bus service | 35 |
| Neighbour | 14 | Dedicated OPD hours | 31 |
| Normal School | 21 | Speech therapist at school | 28 |
| Self searched | 12 | Physiotherapist at school | 25 |
| Social Worker | 2 | Financial support | 22 |
| Special School Teacher | 6 | Helpline | 15 |
| Total | 64 | Counselor at school | 15 |
| | | Patient friendly referral services | 13 |

**\* Multiple Response**

Maximum parents got information about Special School from Normal School (32.8%) followed by neighbours (21.9%). Most common felt need of the parents was the rehabilitation of their child after 18 years followed by school bus service.

**Table 13: Distribution of participants according to Parental involvement in School Health checkup; Received referral services and Use of Welfare schemes:**

| Parental involvement | Mild MR | Serious MR | Received referral services | Mild MR | Serious MR | Use of Welfare schemes | Mild MR | Serious MR |
|---|---|---|---|---|---|---|---|---|
| Don't know | 15 | 10 | Yes | 7 | 4 | Yes | 29 | 23 |
| No | 4 | 2 | No | 26 | 27 | No | 4 | 8 |
| If required | 8 | 6 | Total | 33 | 31 | Total | 33 | 31 |
| Yes | 6 | 13 | | | | | | |
| Total | 33 | 31 | | | | | | |

Approximately 39% parents had no knowledge of parental involvement in school health check-up. Parental involvement was better in Serious MR Group. 17% participants received referral services till date. Approximately 81% parents were using Welfare schemes for their child.

## Discussion:
### A. Socio-Demographic Distribution:

Sunil Kumar Raina et al found that no notable sex difference was present. (6) Mudgil et al found preponderance of males over females (1.8:1) in the age group of 4 to 11 years. (7) Kumaraswamy reported that 38.7% had mild MR, 22.3% had moderate MR, 24.4% had severe MR while 14.6% had profound mental retardation (8) whereas most common grade in our study was mild Mental Retardation. Rai concluded that Mental Retardation was more common in lower socio-economic class. (9)

Joshua showed that 70% consanguinity was present. (10) Madhavan and Narayan found that 31.14% were born of

consanguineous marriages. (11) Sinclair (12) and Ramanujan et al (13) found positive family history in 8.3% and 7.4% respectively. Kumar and Nanda found that 1st borns have a higher occurrence of MR than later borns. (14)

### B. Health Status

Aitchison et al (15) and Jacobson (16) reported refractive errors to be 30% and 23% respectively. Parikshit Gogate et al reported that 45.3% had ocular morbidities. (17) Donoghue and Abbas found that 29% had ENT problems. (18)

Nazia Ameer et al found that intellectually disabled group had highest plaque scores and poor oral hygiene. (19) Bell and Bhate (20) and Rimmer et al (21) found obesity more common in Mentally retarded with prevalence ranging from 30% to 50%. Touger-Decker and Matheson found 66% children with MR to be overweight. (22)

### Summary & Conclusion:

This was a cross sectional study conducted in 2 special schools near the parent institute to study the health status of mentally challenged children and to study the health seeking behaviour of the parents in the interest of their differently abled child. Male to female ratio was 1.1 to 1. The most common grade of Mental retardation (MR) is mild (51.6%). Approximately 40% participants were born of consanguineous marriage. Birth order 2 has the highest incidence of MR i.e. around 37.5%.

Around 36% participants had Ophthalmic Morbidity with refractive error having the maximum incidence i.e. 25%. The incidence of refractive errors was more in Serious MR group which was statistically significant (p = 0.04). 25% students had ear problems and it was statistically significant in Serious MR group (p = 0.01). About 40% students had dental decay which was statistically significant in Serious MR group (p = 0.001). Mild and Serious MR group had more incidence of over nourishment and under nourishment which was statistically significant (p = 0.007).

Mean age at diagnosis is 30.5 months with SD = 27.14 months. The mean patient delay was 3.98 months with SD = 5.51 months. The mean delay in diagnosing MR from health care side was 10.45 months with SD = 13.24 months. Most common felt need of the parents was the rehabilitation of their child after 18 years. Parental involvement was better in Serious MR Group. 17% participants received referral services till date. Though all the parents had knowledge about welfare schemes, only 81% parents were using Welfare schemes for their child.

### Recommendations:

1. Specific day should be designated only for the mentally challenged children at tertiary care hospital.

2. School health check-up should be more frequently like quarterly and not yearly as in the current scenario.

3. Special health screening camps by specialists should be arranged at the school with reference to treatment of Dental caries, Ophthalmic, ENT morbidities.

4. Parental involvement in School health check-up should be increased by informing the dates to them in advance.

5. Part-time Speech Therapist, Physiotherapist, Clinical Psychologists should be appointed by municipal authorities for special schools.

6. Assessment of undernourished children should be done and special nutritive care should be provided to them.

7. Assessment of over-nourished children should be done for endocrine causes and specific measures should be provided like hormonal support.

8. Preventive approach

As there is no treatment available for mental retardation, prevention is the best approach. Pre-conception Genetic Counselling should be compulsorily done in close consanguineous marriages and history of mental retardation in the family.

Knowledge regarding normal developmental milestones should be imparted to the mother during ANC period.

In Well Baby Clinics, parents should be educated about the Red flag signs of mental retardation and when to approach the health facility.

IMNCI program should include component of management of mentally challenged children.

9. Current helpline (104 Toll free Medical Advice Service of State Government and 108 Toll free Helpline of Municipal Corporation) should be upgraded for needs of parental guidance with regards to mental retardation.

10. Parental participation should be increased and they should be assisted in procuring all Govt. documents which will facilitate availment of concession and schemes for mentally challenged.

### Bibliography:

1. The Persons with Disabilities (Equal opportunities, protection of rights and full participation) Act, 1995, http://www.disabilityindia.org/pwdacts.cf cited on 12.12.2013.

2. CBR Manual: Concept and Extent of Disability in India.

3. Rehabilitation Council of India: Disability Development in India, 2005, New Delhi.

4. WHO and AFMC's Textbook of Public Health and Community Medicine. Page no. 569. Cited on 26.12.2013.

5. Mental Retardation - Rehabilitation Council of India. http://www.rehabcouncil.nic.in/w ritereaddata/mr.pdf cited on 28.12.2013.

6. Sunil Kumar Raina: Prevalence of Mental Retardation among children in RS Pura town of Jammu and Kashmir. Ann Indian Acad Neurol. 2012 Jan-Mar; 15 (1): 23-26.

7. Mudgil A, Singh SB, Srivastava JR: An etiological and psychological study of MR children. Indian Pediatrics. 19 (8): 689-93, 1982.

8. Kumaraswamy N: A profile of mentally retarded persons seen in child guidance clinic of a teaching hospital. Indian Journal of Clinical Psychology. 18 (2): 45-48, 1991.

9. Rai GC: A study of discrimination, generalization of DL of mentally retarded. Journal of Personality and Clinical studies. 4 (1): 11-15, 1988.

10. Joshua GE: Mental Retardation in children. An etiological study of 303 cases. Indian Pediatrics. 11(1): 47-51, 1974.

11. Madhavan T, Narayan J: Consanguinity and MR. Journal of Ment. Def. Research. 35 (3): 240-46, 1991.

12. Sinclair S: Etiological factors in MR. A study of 470 cases. Indian Pediatrics. 9 (7): 391-96, 1972.

13. Ramanujan BK, David S: A clinical study of 100 cases of mentally retarded children seen in clinic for the mentally retarded. Indian Pediatrics. 6 (3): 118-31, 1969.

14. Kumar R, Nanda S: Rate of MR as a function of birth orders and Maternal age. Indian Journal of Maternal Health and Disability. 1 (1): 15-17, 1996.

15. Aitchison C, Easty DL, Jancar J: Eye abnormalities in the mentally handicapped. J Ment Defic Res: 1990; 34: 41-48.

16.    Jacobson L: Ophthalmology in mentally retarded adults. Acta Ophthal-mologica. 1988; 66: 457-62.

17.    Parikshit Gogate: Ocular disorders in children with learning disabilities in special education schools of Pune. Indian J Ophthalmology 2011 May-June; 59 (3): 223-28.

18.    Donoghue EC, Abbas KA: The physical condition of severely subnormal children in hospital. Br J Clin Pract. 1972; 26: 9-13.

19.    Nazia Ameer et al: Oral Hygiene and periodontal status of teenagers with special needs in the district of Nalgonda, India. J Indian Soc Periodontal. 2012 Jul-Sep; 16 (3): 421-25.

20.    Bell AJ, Bhate MS: Prevalence of overweight and obesity in Down's syn-drome and other mentally handicapped adults living in the community. J Intell Disab Res. 1992; 36: 359-64.

21.    Rimmer JH: Obesity and overweight prevalence amongst adolescents with disabilities. www.cdc.gov/pcd/issues/2011/mar/10_0099.htm cited on 3.1.2014.

22.    Tougher-Dercker R, Matheson P: Obesity in Special Olympics – Year 2000 findings. Special Olympics in New Jersey, 2000 Summer Games. Wash-ington DC: Special Olympics, Inc. 2000.