A STUDY OF PERSONS WITH SEVERE MENTAL RETARDATION AND MULTIPLE DISABILITIES

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SUMMARY

Service facilities for persons with severe mental retardation and multiple disabilities are meagre. The present study aims at analysing the problems of persons with severe mental retardation and multiple disabilities in terms of presenting complaints, previous consultations, aetiological factors and associated problems. Persons with severe mental retardation and multiple disabilities numbering 164 who sought services at NIMH over a period of 15 months were studied. They formed 22% of the total number of mentally retarded individuals registered during the period. The major presenting complaints were in the areas of self-help, language, epilepsy, motor problems and behaviour problems. Infection in brain, birth anoxia and trauma were major aetiological categories in addition to a large number forming unknown category. Suitable service delivery models are suggested for this population.

Persons with severe mental retardation and multiple disabilities form a highly heterogeneous group. They form a challenging group to the family and professionals because of the nature and complexity of their problems, need for adaptive equipment and nonavailability of adequate service facilities. Severe handicaps encompass a wide range of ages, functioning levels, additional handicaps and diagnostic categories which make it difficult to define this population. As noted by Van Etten et al. (1980) mental retardation constitutes the largest single characteristic among people within the severely handicapped population. Even though all severely handicapped persons are not mentally retarded, current limitations in technology often make the assessment of intellectual functioning extremely difficult across this population. Profound mental retardation actually designates a population of individuals who vary considerably in their behavioural functioning. The problem of the label ‘profound’ is not so much that it groups behaviourally diverse individuals in a more or less arbitrary manner (Haskett and Bell, 1978). Traditional diagnostic instruments like Vineland Social Maturity Scale and IQ tests designed for higher functioning individuals tap such few functions at the bottom end of intellectual spectrum that they are incapable of rendering precise developmental diagnoses. Precise definition of persons with profound mental retardation and the other disorders associated with them are therefore very difficult.

Because of the problems in nomenclature and operational definition, the prevalence figures vary from place to place. A change in trend in the placement of persons with profound mental retardation from institutions and convalescent hospitals to the community was noticed in the Western countries (Eyman and Miller, 1978). Systematic studies on the prevalence of severe and profound mental retardation and the available service facilities have not been conducted in India, probably due to the varied factors such as the unique characteristics of the condition, the nonviable economics, lack of trained manpower and the scattered nature of the population. With

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a view to collect information on the nature of this population the present study was undertaken.

Aims and Objectives

1. To analyse the persons with severe mental retardation and multiple disabilities in terms of age, sex, area of residence, presenting complaints, previous consultations, cause, additional disabilities and medical problems.

2. To analyse the nature of intervention suggested.

3. To recommend suitable service facilities.

Methodology

The data collected from the case files of persons with severe mental retardation at the National Institute for the Mentally Handicapped, Secunderabad over a period of 15 months formed the material for the study. The data was tabulated on the parameters of age, sex, area of residence, presenting complaints, aetiology, medical problems, additional handicaps and suggested management plan. Similar spreadsheet was used by Rhode et al. (1989) in displaying the information about the range of multiple disabilities experienced by individuals with mental retardation from handicap's register.

Results and Discussion

Out of 746 persons seen over a 15 months period, 164 (22%) were diagnosed as severely and profoundly retarded when assessed using developmental schedules and a social maturity scale. An analysis of the severity of retardation among the subjects revealed that 116 (70.7%) were severely retarded while 48 (29.3%) were profoundly retarded. Eyman and Miller (1978) in a demographic overview of severe and profound mental retardation quote figures of profound mental retardation at 0.5 per thousand and severe mental retardation at 0.8 per thousand population. Table-1 gives the details of age, sex distribution and residing locality of these persons. One hundred and sixteen were found to be male (70.7%) and 48 female (29.3%) giving a male to female ratio of 2.3 to 1. Sixty nine percent of the sample was below 13 years of age. Ninety five persons were from the twin cities of Hyderabad and Secunderabad whereas 69 were from far off places. The less number of persons seeking services from outside the twin cities may be due to the practical problems involved in bringing severely and profoundly retarded individuals from far off places.

The details on 28 different presenting complaints of the persons with severe and profound retardation as reported are given in table-2. Though no speech is perceived to be the major problem in the age group of 4 to 13 years, poor speech as a problem extends upto the age group of 18 years. Inability to look after self and absence of toilet control rank high as complaints which is understandable. Hurting others, seizures, running away, motor problems, laughing to self, disturbed sleep and hyperactivity are the other frequently encountered presenting complaints. As it is seen, identifying this group of mentally retarded individuals is relatively easy as the presenting complaints predominantly pertain to absence or deficit of essential skills necessary for daily living. The screening questionnaire on severe childhood disability included majority of these symptoms for easy identification (Belmont, 1984).

Though the subjects are predominantly of school going age (85.4% which excludes children below 3 years), complaints regarding scholastic performance has been reported only in 3.7% of cases. This was not perceived as a major problem as the subjects had deficits in daily living skills that required attention on priority.

Table-3 gives the details of the previous consultations which clearly shows allopathic consultation alone or in combination
### TABLE 1: AGE, SEX AND RESIDING LOCALITY OF THE SUBJECTS
(N = 164)

| Age in years | 0 – 3 | 4 – 8 | 9 – 13 | 14 – 18 | 19+ | Total |
|--------------|-------|-------|--------|---------|-----|-------|
| M            | 3     | 5     | 15     | 8       | 18  | 9     | 5     | 95 (57.9%) |
| F            | 9     | 16    | 7      | 6       | 9   | 5     |       |         |
| Local        |       |       |        |         |     |       |       |         |
| Non local    | 7     | 4     | 14     | 4       | 16  | 11    | 4     | 2       | 69 (42.1%) |

M = Male,  F = Female

### TABLE 2: PRESENTING COMPLAINTS AND AGE OF THE SUBJECTS

| Age in years | 0 – 3 | 4 – 8 | 9 – 13 | 14 – 18 | 19+ | Total | %   |
|--------------|-------|-------|--------|---------|-----|-------|-----|
| N            | 11    | 24    | 20     | 4       | 5   | 64    | 39.0 |
| N            | 2     | 12    | 22     | 12      | 10  | 58    | 35.3 |
| N            | 1     | 11    | 18     | 17      | 9   | 56    | 34.1 |
| N            | 2     | 23    | 20     | 1       | 3   | 49    | 29.8 |
| N            | 2     | 8     | 21     | 8       | 4   | 43    | 26.2 |
| N            | 7     | 11    | 18     | 5       | 4   | 35    | 21.3 |
| N            | 8     | 13    | 4      | 1       | 2   | 28    | 17.0 |
| N            | –     | 3     | 14     | 7       | 2   | 26    | 15.8 |
| N            | 11    | 8     | 5      | 1       | –   | 23    | 14.0 |
| N            | 4     | 12    | 4      | –       | 1   | 21    | 12.8 |
| N            | 5     | 7     | 3      | 4       | 1   | 20    | 12.1 |
| N            | 14    | 2     | –      | –       | –   | 16    | 9.7  |
| N            | –     | 4     | 6      | 3       | 3   | 16    | 9.7  |
| N            | 5     | 3     | 2      | 3       | 2   | 15    | 9.1  |
| N            | –     | 3     | 5      | 4       | 1   | 13    | 7.9  |

Complaints that were less than 13 (7.9%) included difficulty in chewing 12 (7.3%), lack of awareness of danger 11 (6.7%), temper tantrums 11 (6.7%), inability to indicate needs 10 (6.1%), inability to recognise anyone 8 (4.8%), eating non edibles 8 (4.8%), no/poor vision 9 (5.5%), no/poor hearing 7 (4.3%), excessive crying 7 (4.3%), poor memory 6 (3.7%), teeth grinding 6 (3.7%), poor in studies 5 (3.7%), masturbation 4 (2.4%), startling 4 (2.4%) and spitting 2 (1.2%).
with others is the choice of majority of the parents. This can be attributed to the fact that in the severely and profoundly retarded population, the associated medical problems are relatively higher. In addition, the discrepancies between the actual and expected performance of the individual that alert the parents to seek help is very obvious. This may also be a reason for the low number of those (7.3%) who did not seek any consultation. Faith healing and religious consultations also form a major mode of help sought which may be a cultural reflection.

Post infective states and birth anoxia contribute to more than one third of the sample as seen in Table 4. Mental retardation of all levels due to post infective states is reported to be 5.8% (NIMH, 1990) and 6.6% (Madhavan and Narayan, 1989) in two different studies. However the sample includes all levels of retardation in these studies. In the present study 22% of severe and profound retardation are found to be due to post infective states which ranks first among the aetiological factors. Birth anoxia is documented to be one of the major causes of mental retardation in India, the figures varying from 7 percent to 38 percent (Sethi and Lal, 1975). Three separate studies conducted at NIMH earlier reported percentages of 13.4, 7.2 and 26.4 of cases of mental retardation due to birth anoxia (Madhavan et al., 1986; Madhavan and Narayan, 1989; NIMH, 1990). The last of the three figures is from a multicentred pilot study on the aetiology of mental retardation conducted at three centres in the country. Though the present study falls in line with this fact, it should be noted that the diagnosis of birth anoxia is based on the retrospective information given by the parents/informants and may not be totally reliable. This may be a reason for the wide range of percentage in various studies.

| Diagnosis               | N  | %  |
|-------------------------|----|----|
| 1. Post infective states| 36 | 22.0|
| 2. Birth anoxia         | 24 | 14.6|
| 3. Post-traumatic       | 7  | 4.2 |
| 4. Metabolic            | 7  | 4.2 |
| 5. Down's syndrome      | 8  | 5.0 |
| 6. Mucopolysaccharidosis| 5  | 3.0 |
| 7. Unknown              | 64 | 39.0|
| 8. Others*              | 16 | 9.8 |

*Others: Microcephaly 3, Prematurity 3, Aminuricidemia 2, Degenerative 2, and one each of Turner's, Storage disorder, Tuberous Sclerosis, Vascular accident, Laurence Moon Biedl syndrome and arrested hydrocephaly.
Mentally retarded persons due to post infective states, birth anoxia and trauma were found to have more of associated problems like seizures, physical handicap, hyperactivity and psychosis as seen in Table-5. Persons under the category of unknown aetiology also had a high percentage of associated problems. This finding is close to that of Minnis et al. (1989) who in a study on the neuro-developmental state of profoundly handicapped children in a hospital found that all the children were tetraplegic, 40 percent were blind, 38 percent cortically deaf and 95 percent had bulbar palsy. However, their sample included not only mentally retarded persons but also others with profoundly handicapping conditions. The authors emphasise the management of associated problems.

### TABLE-5 DIAGNOSTIC CATEGORIES AND ASSOCIATED CONDITIONS

| Associated Conditions | Seizures | PH | VH | HH | Combined | Hyperactivity | Psychosis | No problems |
|-----------------------|----------|----|----|----|----------|--------------|-----------|-------------|
| 1. Post infective states | 12       | 9  | 1  | 1  | 3        | 5            | 3         | 6           |
| 2. Birth anoxia       | 7        | 4  | 2  |    | 2        | 3            | 1         | 12          |
| 3. Post traumatic      | 3        | 1  |    | 1  | 2        |              | 2         |             |
| 4. Metabolic          |          | 1  | 1  |    |          |              |           | 2           |
| 5. Down's syndrome    |          |    |    |    |          |              | 2         |             |
| 6. M. P. S.           | 1        | 1  |    |    | 2        |              |           |             |
| 7. Unknown            | 17       | 18 | 1  | 1  | 2        | 15           | 2         | 19          |

PH — Physical handicap, VH — Visual handicap, HH — Hearing handicap

### TABLE-6 MANAGEMENT PLAN AND THE AGE OF THE SUBJECTS

| Age in years | 0 – 5 | 4 – 8 | 9 – 13 | 14 – 18 | 19+ | Total |
|--------------|-------|-------|--------|---------|-----|-------|
| N            | 134   | 122   | 76     | 58      | 46  | 134   |
| %            | 81.1  | 74.4  | 46.3   | 35.4    | 28.0| 81.1  |

1. Training in self help skills | 5 | 43 | 48 | 23 | 15 | 134 | 81.1 |
2. Training in speech/communication | 20 | 33 | 37 | 19 | 15 | 122 | 74.4 |
3. Drugs-Fits, hyper activity psychosis | 6 | 25 | 26 | 8  | 11 | 76  | 46.3 |
4. Physiotherapy | 16 | 21 | 11 | 4  | 6  | 58  | 35.4 |
5. Beh. management | 9 | 25 | 7  | 5  | 4  | 46  | 28.0 |
6. Sensory stimulation | 19 | 8  | 3  | 4  | 13 | 27  | 16.5 |
7. Prevocational/domestic skill trg | 9 | 4  | 4  | 5  | 2  | 11  | 6.7  |
8. Referrals | 1 | 2  | 3  | 2  | 3  | 11  | 6.7  |
An analysis of the associated conditions (Table-5) shows that seizures form a major medical problem in 25% of those with severe and profound mental retardation. This finding concurs with an earlier study where occurrence of seizures was found to be on the increase with the increase in the severity of retardation (Madhavan and Narayan, 1989). Physical handicap (22%) and hyperactivity (15.2%) rank relatively higher among the other associated problems. Visual, hearing, and combination of sensory handicaps were noticed in eleven percent of cases. There were no associated problems in thirty-six percent of cases.

In severely and profoundly retarded individuals the major focus on training is needed in self-help skills, followed by communication skills, each forming 81.1% and 74.4% respectively, as seen in Table-6. As Sailor and Guess (1983) rightly pointed out, one form of functional retardation or delay associated with severely handicapped persons is in the realm of independent self care skills especially toilet training. As noted earlier in Table-2 lack of toilet control is the 4th major presenting complaint amounting to 30% of the cases having this problem. Drugs for fits, hyperactivity, and psychosis ranked third highest among management plan in the present study. The effect of drugs for fits is seen in an earlier study (Madhavan and Narayan, 1989) where seven out of ten mentally retarded children followed up longitudinally for progress in skills and control of fits through drugs, showed improvement in skills when fits were under control. Yousef (1985) reported that intense and frequent seizures, brain damage, related behaviour problems and attention deficits have all been impediments to learning in children with epilepsy. As motor problems are common among profoundly retarded individuals physiotherapy naturally ranks as the next highest need. It is understandable that sensory stimulation and prevocational skills do not rank high as they are age-based skill needs, as can be seen in the table.

The findings of this study throw light on the importance of prevention, early detection, and appropriate management. Preventive aspects need to be the primary focus as almost one-fourth of the mentally retarded population (22%) happen to fall under the category of severe and profound retardation. As the characteristics of this group of children are conspicuous in nature, they are easily identified and medical attention is sought as seen in the data. If the hospitals and private nursing homes equip themselves with early intervention facilities and programmes which can be easily implemented, management can start early in the life thus limiting the intensity of the disability. Short in-service training to a nurse or equivalent staff in early intervention programmes can facilitate such a set up. As the number of cases seeking help are higher from the local area of the service facility than the non-local areas, detection and training facilities through a home-based model can be adopted. This would reduce the problem of transport and manpower for training. Where special schools are available, admission to severely/profoundly retarded children are limited due to inability to provide individual attention required by them. As noted by Narayan (1988), under supervision, pairing a mildly retarded child with a severely retarded one in the classroom for certain of the skills, can assist to some extent in school-based training of the severely retarded children. The positive effect of peer tutoring for mentally retarded children is well documented (Allen, 1976; Gerber and Kauffman, 1981 and Krouse et al., 1981).

Though deinstitutionalisation and mainstreaming is the trend of the day, residential facilities cannot be totally ignored. Certain number of severely/profoundly retarded children who do not have access to the above mentioned facilities
require residential facilities. While planning for the severely and profoundly retarded individuals all these factors need to be considered and appropriate model of intervention should be chosen which is a step towards reducing their dependence.

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REFERENCES

Allen, V.L. (1976). Children as teachers: Theory and research on peer tutoring. New York: Academic Press.

Belmont, L. (1984). The International Pilot study of severe childhood disability. Final report: screening for severe mental retardation in developing countries. Bishop Beckers Institute, The Netherlands.

Eyman, R.K. and Miller, C. (1978). Introduction—A demographic overview of severe and profoundly mentally retarded in quality of life in severely and profoundly mentally retarded people: Research foundations for improvement. (Ed.) C. Edward Meyers, American Association on Mental Deficiency, Washington, p.p. in—xii.

Gerber, M. and Kaufman, J.N. (1981). Peer tutoring in academic settings. In: (Ed.) P. Strain, The utilization for classroom peers as behaviour change agents, New York: Plenum press.

Haskett, J. and Bell, J. (1978). Profound developmental retardation: Descriptive and theoretical utility of the Bayley Mental Scale. In: (Ed.) C. Edward Meyers, Quality of life in severely and profoundly mentally retarded people: Research Foundations for improvement, American Association on Mental Deficiency, Washington, p.p. 927.

Krouse, J.; Gerber, M.M. and Kaufman, J.M. (1981). Peer tutoring: procedures, promises and unresolved issues. Exceptional Education Quarterly, 1, 4, 10-115.

Madhavan, T.; Peraha, A.J. and Menon, D.K. (1988). Aetiology and associated medical factors: An analysis of 350 cases of mental retardation. Presented at the 39th annual conference of Indian Psychiatric Society, Jaipur, January 1988.

Madhavan, T. and Narayan, J. (1999). Epilepsy and Mental Retardation. Presented at the 10th International epilepsy congress, New Delhi, October 1999.

Minnis, R.A.; Wong, B.; Brown, J.K. and Fraser, W.I. (1989). Neurodevelopmental Study of Profoundly handicapped children in hospital care. Journal of Mental Deficiency Research, 33, 459-454.

Narayan, J. (1988). Facilities for children with Severe Mental Retardation, Souvenir International Workshop on Mental Deficiency, India, 8th August 1988, Cochin, p.p. 39-58.

National Institute for the Mentally Handicapped (1990). Report on the multicentered pilot study on the aetiology of mental retardation (unpublished data).

Rhode; J.; Fawcett, R.; Glover, G. and Nurey, A. (1989). A method of displaying assessment information about people with multiple handicaps as a disability profile. Journal of Mental Deficiency Research, 33, 95-98.

Sailor and Guess, D. (1983) Severely handicapped students an instructional design. Houghton Mifflin Co, Boston, p.p. 12.

Sethi, B.B. and Lal, N. (1975) Child Psychiatry (Indian scene). In: Mental Health in children, Vol.1., (Ed.) D.V. Siva Sankar, West bury, New York: PJD Publications.

Van Eten, G.V.; Arkel, C. and Van Eten, C. (1980). The severely and profoundly handicapped. St. Louis: The C.V. Mosby Co.

Young, J.M. (1985). Medical and educational aspects of epilepsy. A review. D.P.H. Journal, 8 (1), 3-15.