BRIEF IN-PATIENT FAMILY INTERVENTION IN MENTAL RETARDATION

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SUMMARY

A novel programme of intervention - brief inpatient family intervention - was formulated to impart the training skills to the parents of mentally retarded children to optimise the development of their retarded child. During the period of this study, 106 mentally retarded children with different socio-demographic backgrounds and degrees of handicap participated in this programme, with encouraging results. The individualised management plan, spread over 2 weeks of inpatient stay, included intensive counselling, training of the parents in techniques of multisensory stimulation, speech, motor, and self-help skills training, behaviour modification and medical management, as required. The programme could serve as a suitable model for professionals working with the mentally retarded, to implement with limited resources.

Introduction

The current emphasis in the management of mental retardation in India has been on early detection and non-institutional home care of the retarded person. The role of parents in such care cannot be overemphasised. This is especially so with regard to severely retarded children who are likely to require life-long supervision. Hence, it becomes imperative to detect mental retardation (MR) as early as possible, and impart the appropriate skills to the parents in bringing up and looking after their retarded children.

The vast body of research in the last 2 decades has demonstrated the beneficial effects of early detection and intervention with mentally retarded children (de Coriat et al. 1968, Brinkworth 1973, Clarke and Clarke 1974; Hayden and Haring 1977; Ludlow 1979; Cunningham 1979; Shearer and Shearer 1976; Sower 1978). Feasibility and practicability of training the parents in techniques of early intervention also has been well established (Shearer and Shearer 1976; Sower 1978). A small body of research from India concentrating on the issue of parental training has by and large reported favourable results (Padma Embar 1979; Singh and Kaushik 1982; Mehta and Ochaney 1984; Date 1986). The benefits of such early intervention are immense, both in terms of better emotional and adaptive adjustment of the family, and in helping the retarded child develop as normally as possible.

Since the time of their inception, the services for mentally retarded persons at the National Institute of Mental Health and Neurosciences (NIMHANS) have

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been organised with this philosophy in mind. The experience of the team with group parental counselling held every week for parents of mentally retarded persons has been quite satisfying (Padma Embar 1979). Encouraged by this, we launched the parental self-help group movement in 1980 (Narayanan 1985).

However, there was a subgroup of families with mentally retarded children attending the M.R. Clinic who, we felt, required a more intensive and systematic intervention for various reasons: very poor coping styles, extreme ignorance and negative attitudes, multiply handicapped child, severe behaviour disorder in the child, more than 1 mentally retarded child, long distance, etc. It was found difficult to handle such problems on out-patient basis. To overcome this constraint a brief, intensive, inpatient training programme for such families was started in April, 1985, at NIMHANS.

**Description of the programme:**

Model of brief inpatient family intervention for the families of the retarded children was developed at NIMHANS as an innovative approach in the management of mental retardation in April 1985 and has been functioning since then. The major objective of the programme has been to intensively train the parents and key family members in acquiring the appropriate skills to optimally bring up their handicapped child. The admission to the facility is generally restricted to families with a child who is (i) severely mentally retarded (IQ below 50) or (ii) child which multiple handicaps, i.e., sensory impairments, cerebral palsy, behaviour problems, autistic features in addition to mental retardation and (iii) families with poor coping skills and extreme negative attitudes. The average duration of stay is 2 weeks and facilities for the simultaneous admission 4 families are available.

The training is accomplished through a multi-disciplinary team comprising psychiatrist, clinical psychologist, psychiatric social worker, physiatrist, speech therapist and psychiatric nurse. The intervention has the following partly overlapping stages:

1. Stage of evaluation: on admission, a detailed evaluation is carried out involving a thorough clinical work-up, relevant investigations, and psychological testing, yielding information about the degree of retardation, probable cause, associated problems, and the parents' knowledge, attitudes, misconceptions, expectations, motivation and coping skills. Based on this information, an individually tailored plan of management is decided upon by the whole team with each member contributing from his/her specialised knowledge and skills in its implementation.

2. Stage of “Priming” the parents: After stage 1, parents/key trainers are counseled intensively about the nature, causes, and associated conditions of M.R., and the misconceptions, if any or cleared. Special attention is paid to sorting out emotional problems which may be present and to motivating them for training.

3. Stage of individualised parents training: Subsequent to priming, parents are trained intensively, the content focusing on sensory-motor stimulation, and development of motor, language self-help skills, behaviour modification techniques, and physiotherapy wherever each of these is applicable. Training is accomplished through instruction, discussion, demonstration, and in-vivo feed-back while the parents are exercis-
ing the newly acquired skills under the supervision of the team members. Targets are set for each child at the outset (based on evaluation) in the areas of gross and fine motor, adaptive, social and language skills. Again the focus is more on the parents learning the general principles of training while achieving a particular target during the stay, so that the newly acquired skills of training would generalise to home situation. A typical family would receive the inputs of up to 4 hours per day of professional time by one or other member of the team.

4. Stage of pre-discharge evaluation: This includes recording the changes perceived in the family (in terms of acquisition of new skills, reorientation towards the child, and motivation for training) and in the child (whether set targets were achieved or not).

Material and Methods

This study covers a period of approximately 1 year 4 months, from April, 1985 to August, 1986. During this period 106 children, along with their families, were admitted under this programme. They represent a heterogeneous group of mentally retarded children, selected for admission according to the criteria defined earlier, broadly indicating a particularly severe degree of handicap on the part of the child and/or the family. The present paper reports on only certain aspects of the training programme including the socio-demographic and clinical characteristics of families admitted during the study period, pre-post evaluation of the motivation, attainment of targets by the index children during the stay, and relationship between these variables. The data was collected retrospectively from the detailed case records maintained during admission. This data was pooled onto a structured format and analysed by computer.

To provide for objectivity while quantifying the change, only the actually observed gains recorded in the files, as reported by the case-worker were taken into account. Operational criteria were used to define each degree of improvement. Thus, in each specific developmental area, mild improvement denotes attainment of 1 target, moderate improvement 2 targets, and marked improvement 3 or more targets, during the period of stay. For the overall assessment of improvement, mild improvement represents achievement of 1 target in at least 2 of the specific areas, moderate improvement, 2 targets in at least 2 areas, and marked improvement, minimum 3 targets in at least 2 of the areas. Socio-economic status was assessed based on the parent’s education, occupation and income. Assessment of parents’ motivation, however, remains largely subjective, and hence, should be interpreted with caution.

Results

1. Socio-demographic Characteristics.

The 106 patients comprised of 69 (65.1%) males, and 37 (34.9%) females. Twenty-four (22.6%) were from an urban, 20 (18.9%), from semiurban, and 62 (58.5%), from rural, background. Sixteen (15.1%) belonged to upper, 41 (38.7%) to middle, and 49 (46.2%) to lower socio-economic class. Among the mothers and fathers, respectively, 38 (35.8%) and 13 (12.3%) were illiterate, 12 (11.3%) and 16 (15.1%) had primary school education, 18 (17%) and 12 (11.3%) had had high school education, 28 (26.4%) and 39 (36.8%) had passed SSLC, and 9 (8.5%) and 26 (24.5%) were college graduates and above. (Information regarding other
family members involved in training was not computed.

2. Clinical characteristics.

Nine (8.5%) of the children were below 1 year, 40 (37.7%) between 1 and 3 years, 25 (23.6%) between 3 and 5 years, 12 (11.3%) between 5 and 7 years, 6 (5.7%) between 7 and 9 years, and 14 (13.2%) over 9 years old. Nineteen (17.9%) had mild, 32 (30.2%), moderate, 36 (34%), severe, 13 (12.3%), profound, and 6 (5.7%), unspecified, MR.

In addition, 16 (15.1%) had impaired vision, 18 (17%) had impaired hearing, 22 (20.7%) had cerebral palsy, 15 (14.1%) had hyperkinesis, 8 (7.5%) had autistic features, 36 (34%) had epilepsy, 26 (24.5%) had behaviour disorder of a significant degree, and 1 (0.9%) had psychosis.

Forty-six (43.4%) children were born of consanguineous parents, and 31 (29.2%) had another family member affected. Aetiology could be determined in 44 (41.5%). Prenatal causative factors were thought to operate in 26 (24.5%), perinatal factors in 43 (40.6%), and postnatal factors in 10 (9.4%). In the rest, the aetiological factors remained undetermined. Twenty (18.9%) of the parents were judged to be very poorly motivated at the time of joining the programme. In the rest, motivation was either fair or good.

3. Management:

All the parents received intensive counselling during their period of stay regarding the nature of the disorder, the child's specific problems, importance of multisensory stimulation and/or training, futility of shopping for miracle cures and drugs to enhance intelligence, possibilities for rehabilitation and prognosis.

In addition, the children received other specific therapies depending on their requirements. Thus, 97 (91.5%) received speech therapy, 72 (67.9%) received occupational therapy/physiotherapy, and 24 (22.6%) received behaviour therapy (this includes only those who received behaviour therapy for specific and severe behaviour disorder; all parents were trained in the elements of behaviour modification techniques for training their child).

Thirty-five (33%) were treated, also, with drugs—29 (27.4%) for epilepsy, and 6 (5.4%) for other psychiatric or medical indications. Sixty-four (60.4%) parents received instruction in providing sensory–motor stimulation, and 72 (67.9%), in training in self-help skills. Genetic counselling was offered to 5 (4.7%) parents who requested it.

4. Outcome.

In terms of overall change, 91 (85.8%) of the children were found to have achieved at least small gains, 9 (8.5%) showed no change, while none worsened. For 6 (5.7%), sufficient data were not available, largely because of the family having had to curtail their stay for various reasons. The overall change was cross-correlated with the various socio-demographic characteristics of the families; however, none of these were found to be statistically significant. Table 1 presents the correlation between the child's age and overall change. The outcome in terms of specific areas of development, and parent's motivation is presented in Table 2. A correlation of the outcome and the degree of MR is presented in Table 3.

Discussion.

The most important trends to emerge from this study are: (i) most parents ex-
Table 1
Correlation between the age and the outcome

| Age in (years) | Below 1 | 1-3     | 3-5     | 5-7     | 7-9     | Above 9 |
|----------------|---------|---------|---------|---------|---------|---------|
| Outcome:       |         |         |         |         |         |         |
| No Change      | 0(0.0)  | 3(7.5)  | 3(12.0) | 1(8.3)  | 1(16.7) | 1(7.1)  |
| Mild*          | 6(66.7) | 28(70.0)| 10(40.0)| 9(75.0) | 0(0.0)  | 11(78.6)|
| Moderate*      | 2(22.2) | 8(20.9) | 7(28.0) | 2(16.7) | 2(33.3) | 2(14.3) |
| Marked*        | 1(11.1) | 1(2.5)  | 1(4.0)  | 0(0.0)  | 1(16.7) | 0(0.0)  |
| Inadequate data| 0(0.0)  | 0(0.0)  | 4(16.0) | 0(0.0)  | 2(33.3) | 0(0.0)  |
| Total          | 9(100)  | 40(100) | 25(100) | 12(100) | 6(100)  | 14(100) |

* Improvement
Figures in brackets indicate percentages.

Table 2
Changes in specific developmental areas and parents' motivation

|                      | Language | Motor | Self-help | Motivation |
|----------------------|----------|-------|-----------|------------|
| Outcome:             |          |       |           |            |
| No change            | 19(19.6) | 9(12.5)| 13(18.1)  | 4(4.0)     |
| Mild*                | 66(68.0) | 44(61.1)| 42(58.3)  | 18(17.8)   |
| Moderate*            | 9(9.3)   | 14(19.4)| 9(12.5)   | 36(35.6)   |
| Marked*              | 3(3.1)   | 5(7.0) | 8(11.1)   | 43(42.6)   |
| Total#               | 97(100)  | 72(100)| 72(100)   | 101(100)   |

* Improvement
# excludes cases for whom not applicable/inadequate data
Figures in brackets indicate percentages.

Table 3
Correlation between degree of mental retardation and outcome

| Degree of Mental Retardation | Mild | Moderate | Severe | Profound | unspecified |
|------------------------------|------|----------|--------|----------|-------------|
| Outcome:                     |      |          |        |          |             |
| No change                    | 2(10.5)| 3(9.4)  | 3(5.5) | 1(7.1)  | 1(16.7)     |
| Mild*                        | 9(47.4)| 7(36.8) | 6(33.3)| 6(66.7) | 5(41.7)     |
| Moderate*                    | 7(36.8)| 6(33.3)| 8(44.4)| 8(88.9) | 6(50.0)     |
| Marked*                      | 1(5.3) | 2(10.5)| 1(5.5) | 6(66.7) | 0(0.0)      |
| Inadequate data              | 0(0.0) | 5(25.6)| 1(5.5) | 4(44.4)| 0(0.0)      |
| Total                        | 19(100)| 32(100)| 36(100)| 13(100)| 7(100)      |

* Improvement
Figures in brackets indicate percentages.

There are very few published reports of parent training programmes in India as mentioned in introduction (Singh R, 1982; Kaushik, 1984; Mehta and Ochaney 1984; Date, 1986, Padma Embar 1979). Out of these only one is a distinctly inpatient based parent training project (Date, 1986). Intervention reported here shares several characteristics with the work of the Date. However, there are significant differences, in that (i) duration of inpatient stay is much shorter and (ii) focus is on training the family members rather than the child and targets for achievement experienced a favourable change in motivation to train their child, and (ii) most children had small gains in their skills during their participation in the programme. These findings could be taken to reflect the efficacy and utility of the approach in general. However, these changes were not significantly related to any of the socio-demographic or clinical variables, though there were some non-significant trends. Perhaps, a more objective and sensitive assessment would have brought out such differences. Also, more valid and reliable methods to assess the impact on the family are in order.
during the hospital stay are more in order to demonstrate to the family the principles and techniques in training and that the child can be trained with sustained effort.

The duration of in-patient stay has been kept short in order to cause as little disruption of the family life as possible, and to involve, if feasible, other signifcant members of the family (often sibs, grandparents, uncles and aunts, in additon to the parents) in the child's training, which would not be possible with a lengthier programme. Our experience sofar suggests that 2 weeks' inpatient training is sufficient to equip most parents with enough basic skills to continue the training at home under out-patient supervision.

The acid-test of this new approach lies in the durability of these changes, which can only be evaluated by the follow-up assessment of the families. Efforts in this direction are being made.

In conclusion, the authors are of the opinion that the present approach seems to fulfil the dual goals of better adjustment and coping for the parents, and "normalisation" for the mentally retarded child, and can be implemented with limited additional inputs in most set-ups.

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